

A photograph of a diverse group of healthcare professionals in a bright, modern hospital setting. In the foreground, a young woman with curly hair, wearing blue scrubs and a stethoscope, smiles warmly at the camera with her arms crossed. In the background, other staff members in blue scrubs are engaged in conversation near large windows.

Nurse's Health & Well-Being

This newsletter is full of information relevant to nurses who support people with intellectual disability/autism (ID/A).

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HCQU CARES



Introduction

“Now more than ever, we need to support and recognize nurses for their steadfast commitment to meeting the needs of patients and their communities every day. We encourage you to promote nurses’ health and well-being and honor them in any way you can” (American Nurses Association, n.d.).

Nurses who support people with intellectual disability/autism (ID/A) excel in many ways, from their commitment to advocacy, communication, and person-centered care that they continuously provide to individuals with (ID/A) (Jaques et al., 2018), to their leadership skills within the field of nursing that influence the practice, research, and education of ID/A nursing. The result is a profound impact on the care of individuals with ID/A. Effective leadership in the field of ID/A nursing is an integral part in bridging the “relationships between the field of ID/A nursing and the entire nursing profession.” (Auberry, 2018).

ID/A nursing requires sensitivity to the needs of individuals with ID/A “across the lifespan and in all settings”, and respect for and appreciation of differences. Nurses in this field support individuals with ID/A to actualize their full potential to be “active, engaged citizens, so that others can benefit from their talents and abilities” (American Nurses Association, 2019). Indeed, these nurses are uniquely positioned to be innovators in best practice standards and in fostering autonomy, self-advocacy, and inclusion for every person they support.

This newsletter explores ways to appreciate, support, and recognize the vital work of nurses in the ID/A

community and offers resources and self-care information specific to nurses. In addition, it presents information about the medical marijuana program, including the qualification requirements and the process for obtaining a medical marijuana card. Lastly, this newsletter shares suggestions for helping self-advocates transition into the community as pandemic restrictions are lifted, offering discussion on community guidelines and post-vaccination activities.

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With Deep Gratitude to All ODP Nurses

When we are young and contemplating what our lives will be like, we imagine all that is possible and all that brings a smile to our face and in our hearts. For many of us who chose nursing as a career, the excitement we feel is driven by our desire to be helpful, caring, and loving. For some, it is exploring their curiosity of science, wanting to improve our world through innovation in healthcare and enabling a higher quality of life for others. It is not often, however, we dream of our careers in the field of supporting people with disabilities, particularly those with intellectual disabilities. Yet, this is the career we find ourselves in, and it is here where we are able to achieve our professional goals and enjoy the satisfaction of serving.

Nursing overall is not an easy career. Your nursing career has not been easy. It is not glamorous or pretty. It can be stressful, frustrating, and exhausting. You engage with individuals and families when they are most vulnerable and it is then you must be your strongest. You are frequently asked to give what you must dig deep to find and, ironically, you come out feeling stronger for it. You are often the only person giving a caring touch. You provide excellence in care and advocacy.



Most people who do not understand what nurses experience in the day to day caring for individuals with varying degrees of physical and mental health challenges cannot really appreciate what it takes to do the job and love the job. Wiping drool, changing briefs, cleaning wounds, applying dressings, and suctioning mucous are not activities that would excite most people to go to work. Every day with your professionalism and expertise, you demonstrate your channeled passion for nursing care and your depth of compassion - every time you do these tasks and more. Particularly in this pandemic time, nurses have taken the challenges posed and raised the level of care and quality of healthcare for the individuals you serve.

In my more than 50-year nursing career, I have had the incredible opportunity to work in many different healthcare settings all over the world. My career path afforded the opportunity for me to serve in academic-research hospitals, pediatric rehabilitation hospitals, African mission hospitals, and non-profit organizations. Each experience allowed me to see the dynamics of nurses passionately caring for the sick and vulnerable. And as I find myself at the end of my career, it is clear, the best of my career has been my last nursing role here, with you.

Thank you for your passion. Thank you for compassionately caring. Thank you for your teaching. Thank you for advocating for those who cannot advocate for themselves. Thank you for your pursuit of quality health service. Thank you for the strength you bring to your job and your profession! I am deeply grateful to all of you for your efforts and am proud to be your colleague. With heartfelt gratitude, please accept my appreciation for your dedication to the individuals and families we serve.

Celebrating you and your contributions this National Nurses Week,

Beverly Farinelli, RN, BSN, MHA, NEA-BC

Department of Human Services

Office of Developmental Programs

Bureau of Community Services

Division of Program Administration



Tips on Wellness and Self Care for Nurses

Nurses use their professional skills to assess a situation, analyze the need, and implement care. Whether in their professional or personal lives, nurses utilize these principles to help those around them, balancing professional responsibilities and personal obligations. It is important for nurses to enlist a holistic, positive approach toward their health and wellbeing. Assess your need to take time for yourself, as a happier, healthier you benefits others; consider (analyze) activities to make this possible; and implement the “5 R’s” – Rest, Relax, Restore, Rejuvenate, and Reward.

Rest

The Merriam-Webster Dictionary (n.d.) defines rest as “a bodily state characterized by minimal functional and metabolic activities: freedom from activity or labor”. It is a critical component of a healthy lifestyle. Nurses often have hectic, unconventional schedules that make getting rest difficult at times. Working different shifts, weekends, and holidays can be exhausting.

Sleep, the simplest form of rest, is essential. To help maximize sleep, try these tips:

- Keep a simple and stable sleep/wake pattern.
- Avoid eating a heavy meal and drinking alcohol,

caffeine, or large quantities of fluids before going to sleep.

- Avoid naps.
- Exercise, but not before bedtime.
- Keep a consistent amount of sleep/wake time. Consistent sleep is healthier than fragmented sleep.
- Make sure your bedroom/sleep area is comfortable and inviting to sleep. An area that is clean, quiet, cool, and clutter free is often a preferred sleep environment.

(USCF Health, n.d.)

Relax

Relaxing is often easier said than done. Have you ever arrived at home and wondered whether you forgot to finish a task, complete charting, or pass pertinent information regarding a patient to the next shift? Nursing is a 24 hour-a-day/365 days a year industry, and there is always something that needs to be done. However, this does not mean that nurses must let their work interrupt their personal time. Consider the following tips:

- Separate work and personal time. For emotional and psychological wellness, nurses must try to keep work stress separate from home life. Below

are links to helpful articles related to nurse burnout and compassion fatigue, two very real conditions.

- » Overcoming Burnout and Compassion Fatigue with Self Care
<https://www.aapacn.org/blog/overcoming-burnout-and-compassion-fatigue-with-self-care-2>

(AANAC & Roam, 2019)

- » How Nurses Can Protect Themselves as They Work to Save Others
<https://online.nursing.georgetown.edu/blog/trauma-compassion-fatigue-in-nurses/>
(Nursing @Georgetown, 2018)

- » Nurse Burnout Is Real: 7 Risk Factors And The Top 3 Symptoms
<https://nurse.org/articles/risks-for-nurse-burnout-symptoms/>
(LeVeck, 2018)

- » Coping with Compassion Fatigue as a Healthcare Professional
<https://www.chamberlain.edu/blog/coping-with-compassion-fatigue-as-a-healthcare-professional>
(Britt, 2020)

- Days off from work are yours to use. Manage your time in a positive way to improve your wellbeing.
- Learn to perform deep breathing. “Breathing exercises are a good way to relax, reduce tension, and relieve stress” (Michigan Medicine University of Michigan, 2020). Belly breathing is an easy and efficient deep breathing technique that can be done virtually anywhere, any time.
 - » To begin, find a comfortable position.
 - » Place one hand flat on your chest and one flat on your stomach.
 - » Slowly, take a deep breath through your nose. The hand on your stomach should elevate, and the hand on your chest should remain still.
 - » Now exhale slowly through your mouth, using pursed lips. The hand on your stomach should return to resting position. To ensure exhale completion, give a gentle push with the hand on your stomach.
 - » Repeat 3 to 10 times to feel the effects of this relaxation technique.



- » Propping your feet, closing your eyes, listening to relaxing sounds/music can add to the positive effects of this technique.
- Find activities that calm you, help you relax, and put your mind at ease. Some suggested activities include:
 - » Music
 - » Yoga
 - » Meditation
 - » Bubble bath
 - » Dance
 - » Stretch
 - » Doodle/color a picture
 - » Engage in a productive activity you enjoy, e.g., knitting, baking, cleaning, etc.*(Dolgoff, 2020)*

Restore

Nurses are very knowledgeable regarding the signs and symptoms associated with dehydration and vitamin deficiencies. Educating patients in the proper way to achieve their optimal health goals through hydration and nutrition is essential in most discharge planning. However, nurses can use this information for themselves to ensure that they restore the vital nutrients they need daily.

- **Hydrate.** Drinking water is one of the most essential ways to maintain wellness! Proper hydration is important to “regulate body temperature, keep joints lubricated, prevent infections, deliver nutrients to cells, and keep organs functioning properly. Being well-hydrated also improves sleep quality, cognition, and mood.” (Harvard T.H. Chan School of Public Health, n.d.)



Depending on gender, body size, and activity level, about 2.7 to 3.7 liters is an optimal amount of water to consume daily. If this seems like a lot, try some of the tips below. Remember to avoid drinks that contain artificial sweeteners, caffeine, and alcohol, as these can work against hydration (Mayo Clinic, 2018).

- » Flavor water naturally with oranges, lemons, berries, cucumbers, watermelon, or flavorful herbs.
- » Document how much water you drink each day. Tracking the amount you drink may help you achieve your daily goal.
- » Make it convenient – prefill water bottles for easy access and convenience.
- » Make hydration part of a daily routine; drink a glass first thing in the morning, before each meal, and/or after brushing your teeth.
- » Mix it up. While many favorite beverages consumed may not fit into the hydration definition, there are many options that do. Find a favorite alternative to plain water and utilize it. Consuming fruits and vegetables can add to daily water intake. For example, melons and citrus fruits have high water content.

(Mayo Clinic, 2018)

- **Nourish.** Nurses are notorious for skipping meals and grabbing unhealthy snacks while working. Below are some tips to improve your eating habits.

- » Make a shopping list to plan meals and snacks throughout the week. Bring meals and snacks to work. Avoid vending machines and fast food by prepackaging meals and snacks at home. Grab and go options are much healthier and more

economical if they come from your own kitchen.

- » Find healthy, convenient foods that vary on the food pyramid. Be aware of hidden sugars and additives. Look for foods that might increase energy, such as eggs, chicken, oatmeal, nuts, and berries.

(Simson, Rachel MS. RD. CDN. 2018)

- **Self-advocate.** Take care of your mental and emotional health by recognizing when you are taking on too much; learn to say no when you are overburdened. If something is not necessary and you feel it will increase your stress level, say no. In addition, be aware of the physical signs of stress, such as an increased heart rate, faster breathing, nausea, and muscle tension. Know your body's stress response, and allow yourself to say no.

(Cleveland Clinic, 2021)

Rejuvenate

Get outside; take a deep breath, feel the sun on your skin, enjoy the sights and sounds around you. Spending time outside improves your mental health, encourages time to refocus, and encourages physical activity.

- Exercise can take many forms, both indoor and outdoor. Intensity can vary according to your level of ability and stamina. The American Heart Association recommends healthy adults participate in 150 minutes of intense activity a week (or 75 minutes of vigorous activity) and strength training twice a week (2018). Below is a list of suggested activities that count as exercise. If you do at least one of these activities for 30 minutes, 5 times a week, you have achieved the goal!

Intense Activity		Vigorous Activity
Brisk walk	Gardening	Aerobic dancing
Swimming	Bike riding	Jump rope
Hiking	Dancing	Hiking with heavy backpack
Tennis (doubles)		Tennis (singles)

(AHA, 2018)

Add strength training 2 times a week, and you are on your way to physical fitness. You can incorporate strength training in your daily routine as well – do squats while brushing your teeth, use free weights or resistance bands while watching your favorite show, or stretch and do planks while you read a book.

Reward

Reward yourself, without guilt, for the wonderful person you are. Make a list of things that make you great. Don't be modest; you do amazing things every day. Aside from being a nurse, you may also be a spouse, parent, child, grandchild, sibling, and friend. Every day you do something in at least one of those roles to help someone other than yourself. Take credit for making dinner, bringing in the mail, washing laundry, and bringing a smile to someone's face.

Make time for things that make you happy. Take a bath, read a book, watch a movie, visit a friend or family member, order your favorite take-out food, eat dessert, have a spa day, call someone on the phone, laugh... Don't feel guilty for doing things to take care of you.

(AANAC & Roam, 2019)

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Resources for the ANA Initiative: EXCEL-LEAD-INNOVATE

The resources listed below are designed to assist the professional nurse to **Excel-Lead-Innovate**, the theme for this year's celebration of nurses. Many of these resources provide population specific tools and information to enhance nursing care of individuals with ID/A. There are also resources for your personal and professional development.

ANA Enterprise is an organization resulting from three separate nursing organizations – American Nurses Association, American Nurses Credentialing Center, and American Nurses Foundation – partnering as one to provide nurses with current information. ANA Enterprise offers many resources for nurses at <https://www.nursingworld.org/ana-enterprise/>. In addition, it created the [Year of the Nurse 2021](#) website to offer methods for improving nursing skills. Items of interest on this website include:

- [To Be a Nurse](#) – stories submitted by nurses from around the world, divided into four chapters: Leading By Example, Our Inspiration, On The Front Lines, and Recognizing Nurses
- [Flo's Corner](#) – to celebrate the 200th anniversary of Florence Nightingale's birthday
- [Everything You Need for a Successful Celebration](#) – a resource toolkit designed to support nursing engagement throughout the year

HAPPY APP

American Nurses Association (ANA) suggests an app called [HAPPY](#). This app allows you to find comfort, support, and methods for self-care. "As a nurse, you know *empathy, listening and connecting* make all the difference. You also know even nurses need the same support, especially during this pandemic." (HAPPY, n.d.). You can try the app free for 30 days and your first telephone call for support/conversation is free as well.

ONLINE EDUCATION FOR NURSES TO SUPPORT WELL-BEING

Capella University has joined with ANA to offer online education about staying emotionally healthy in uncertain times, trusting teams, and supporting your well-being and resilience in the workplace for nurses. Visit the website and you can take a short course on demand at: <https://anayearofthenurse.org/honoring-the-importance-of-self-care/>.

The ANA has posted information on the nurses scope of practice at https://www.nursingworld.org/practice-policy/scope-of-practice/?_ga=2.58128938.1212060386.1615581360-1003650441.1615481858. It explores the *who, what, where, when, and why* of nursing. The page contains a link titled [Coalition for Patients' Rights](#),



an organization to ensure that the growing needs of the American health care system can be met, and that people everywhere have access to the quality health care providers of their choice. The patient resources page of that site provides a template for writing a letter to a healthcare insurance provider. The template is free and can be used when appealing the denial of *any* service, such as an occupational therapist for a sensory assessment, the need for assistive devices, or ongoing healthcare. The site suggests questions to ask when going to a new physician. Some of the questions might be useful when trying to find a physician suited to an individual's likes/dislikes or preparing an individual for an appointment.

Resources specific to the population with ID/A are:

Myers, R. MD and Myers, S. Ph. D. (2017). Individuals with Intellectual Disabilities and Aggression, Self-Injury, and/or Failure to Thrive. North Star Press.

Dr. Myers has been treating people with ID/A in private practice called, "The Community Circle," for many years. She has much information to offer based on many years of experience and training. The book shares valuable knowledge about every aspect of care: physical and mental health, advocacy, medication, and specific diagnostic syndromes and mental health diagnoses as related to people with ID/A.

Chicoine, B. MD and McGuire, D. MD. (2010). The Guide to Good Health for Teens and Adults with Down syndrome.

This easy-to-use book teaches about the common and uncommon knowledge about people with Down syndrome. It provides specific information about how someone with Down syndrome may display behaviors differently than others when being treated for an ear infection or GERD.

The Developmental Disabilities Nurses Association (DDNA) (<https://ddna.org/>)

The DDNA "serves to educate, empower, and advocate for nurses practicing in the specialty of developmental disability nursing" (DDNA.org, 2019). They offer members webinars, online educational opportunities, and networking.

Pennsylvania Developmental Disabilities Nurses Network (PADDNN) (www.paddnn.nursingnetwork.com)

This professional organization is a PA state network that addresses the needs of nurses working with people with ID/A. Networking is beneficial, so membership is encouraged.

Building Healthy Inclusive Communities through the National Center on Health, Physical Activity and Disability (NCHPAD) (<https://www.nchpad.org>)

NCHPAD provides informative articles and videos regarding aging and disability. There is a myriad of topics available for education, and the information is free. Topics include physical activity, health promotion, and serving persons with sensory and cognitive disabilities, among others. Some of the video topics are useful for educating new support staff or updating well-seasoned support staff; examples are wheelchair maintenance, community health inclusion, exercising at home, and nutrition.

Vanderbilt Kennedy Center (<https://vkc.vumc.org/vkc/services/educators/>)

Vanderbilt Kennedy Center offers necessary information as it relates to the individual with ID/A, including

- » Healthcare for Adults with Intellectual and Developmental Disabilities: a toolkit for primary care providers and video-based trainings for professionals.
- » Tip sheets: one page, easy-to-print sheets that can be downloaded at no cost. Topics include: trauma, autism spectrum disorder, Charge syndrome, Down syndrome, Fragile X syndrome, hearing loss, supporting a healthy brain, and many more.

National Task Group on Intellectual Disabilities and Dementia Practices (<https://www.the-ntg.org>)

This site presents best practices when caring for people with ID/A who have dementia. The Early Detection and Screening tool (EDSD) can be found here at this link: (<https://www.the-ntg.org/ntg-edsd>) This tool looks at functional changes, rather than cognitive changes in people with ID/A. This approach recognizes the existing cognitive impairment in people with ID, making the results of the testing more reliable and relevant to the person's situation.

American Nurses Association position statement, "Nurse's Role in Providing Ethically and Developmentally Appropriate Care to People with Intellectual and Developmental Disabilities." This document outlines duties and responsibilities of the nurse in caring for people with an intellectual disability, and can be found at this link: <https://www.nursingworld.org/~4ab16d/globalassets/practiceandpolicy/nursing-excellence/ana-position-statements/social-causes-and-health-care/nurses-role-in-providing-ethically-and-developmentally-appropriate-care-to-people-with-intellectual-and-developmental-disabilities.pdf>

Unique

Provides up-to-date guides on genetic deletion syndromes. The website is: <https://www.rarechromo.org/disorder-guides/>. If an individual has had genetic testing that identified a chromosomal deletion, these guides can be very useful. The newsletter is an interesting read. It provides the documentation of lifetime effects of those with intellectual/developmental disabilities.

Intellectual Disability and Health

<http://www.intellectualdisability.info/physical-health>
The information is from the University of Hertfordshire. They have many articles on physical health, such as palliative care, epilepsy, the immune system and Down syndrome, visual and hearing impairments, obesity and exercise.

Resources such as those listed above can help nurses to excel, lead, innovate, improve leadership skills and provide quality care to people with ID/A.



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Tuberculosis Skin Test Compliance and COVID-19 Vaccination

According to the Centers for Disease Control and Prevention (CDC), it is not recommended to have a two-step tuberculosis (TB) skin test administered within 4 weeks of receiving a two-dose COVID-19 vaccine. At the same time, it is not recommended to delay TB testing due to vaccination administration when license and policy compliance is needed.

The Pennsylvania Department of Human Services (DHS), in coordination with the CDC, is conscious of the compliance difficulties regarding mandates for Tuberculin Skin Test (TST) and/or communicable diseases and individuals receiving COVID-19 vaccinations. The Governor of Pennsylvania has authorized a temporary suspension of the timeline for the compliance of TST provisions per specific sections of 55 PA Codes (listed in table A at the end of the article) in accordance with the disaster declaration. This suspension is only in effect until the Governor's Disaster Declaration expires. To maintain compliance with TST requirements for the effected sections of 55 Pa. Codes, the following must be observed:

- Individuals must discuss their pending TST with their physician in conjunction with the COVID-19 vaccination.

- Provide documentation of vaccination for COVID-19. This will include date of vaccine administration or written documentation noting the need to defer the TST by a physician.
- Complete TST as close to compliance time as possible following recommendation regarding COVID-19 vaccination.

Due to the requirement of certain licensed facilities to administer TB test within a specific timeline, the following guidelines may be followed:

- The TST or Interferon-Gamma Release Assays (IGRA) blood test may be performed before or at the same time as the COVID-19 vaccination. TST and IGRA are not vaccines and, therefore, do not need to adhere to guidelines for time separation for vaccines.
- Do not delay administration of COVID-19 vaccine to correlate TB testing directives and/or policies when administrative policies direct testing for TB due to employment or possible exposure to tuberculosis. When testing for tuberculosis is performed within four weeks of administration of the COVID-19 vaccine, a false negative cannot be ruled out.

Sections of 55 Pa. Code effected by limited suspension of TST provisions			
OCDEL regulations 55 Pa. Code:	§3270.151(c)(2)	OMHSAS regulations 55 Pa. Code:	§5310.14(e)(1)
	§3280.151(c)(2)		§5320.41(1)
	§3290.151(c)(2)		ODP regulations 55 Pa. Code:
OCYF regulations 55 Pa. Code:	§3680.22(b)(5)	§2380.113(c)(2)	
	§3700.62(b)	§6400.141(c)(6)	
	§3800.151	§6400.151(c)(2)	
	§3800.152		§6500.121(c)(6)
OLTL regulations 55 Pa. Code	§2800.141(a)(11)		§6500.125(c)(2)

Table A

- A follow-up retest may be performed once the four-week window following administration of the COVID-19 vaccine has passed. Boosting must be taken into consideration if the initial test was the TST and the repeat test result is positive. Individuals who present with diagnostic findings or symptoms that may indicate active tuberculosis should receive a medical evaluation, such as a chest x-ray or sputum culture.

(PA Dept of Human Services, 2021)

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To view the entire report from the Pennsylvania Department of Human Services, follow the link below:

<https://www.dhs.pa.gov/coronavirus/Pages/Guidance-for-Tuberculin-Skin-Testing-and-COVID-19-Vaccinations.aspx>



On the Horizon: Medical Marijuana

Medical marijuana is used in the treatment of many conditions, including nausea, pain, muscle stiffness, spasticity, and loss of appetite (Penn Medicine 2020). In Pennsylvania, the use of medical marijuana was approved as a means to treat specific conditions and symptoms when other treatments are less effective or cause adverse side effects. For example, it has been shown to improve the quality of life for patients with cancer and multiple sclerosis (Penn Medicine, 2020).

Pennsylvania's Medical Marijuana Act was signed into law in April 2016 by Governor Tom Wolf. As a result, the Pennsylvania Department of Health (PA DOH) has implemented the Medical Marijuana Program, which provides patients with serious medical conditions access to medical marijuana while protecting patient care and safety (PA DOH, 2021b). The program makes medical marijuana available to Pennsylvania residents being treated by a certified healthcare practitioner for at least one of the following serious medical conditions:

- Amyotrophic lateral sclerosis (ALS)
- Anxiety disorders
- Autism
- Cancer
- Crohn's disease
- Central nervous system/spinal cord damage
- Epilepsy/Seizure disorders

- Glaucoma
- HIV/AIDS
- Irritable Bowel Syndrome (IBS)
- Multiple Sclerosis (MS)
- Neurodegenerative disorders such as Huntington's disease and Parkinson's disease
- Opioid use disorders
- Post-Traumatic Stress Disorder (PTSD)
- Severe chronic or intractable pain
- Sickle Cell anemia
- Spasticity/dyskinetic movements
- Terminal illness
- Tourette Syndrome

(PA DOH, 2021a)

Currently, medical marijuana is not covered under insurance, and the cost can vary depending on the dispensary and the quantity purchased. The forms of medical marijuana currently available include pills, oils, topicals, vaporized/nebulized (inhaled), tincture, and liquid (PA DOH 2021a). The Pennsylvania Department of Human Services Medical Assistance Bulletin, issued January 2, 2020, contains information about storage, use, and administration of medical marijuana by facilities licensed by the Department of Health and Department of Human Services in Pennsylvania. The Pennsylvania Medical Marijuana

Act can be found at <https://www.dhs.pa.gov/docs/Publications/Documents/FORMS%20AND%20PUBS%20MAP/012003.pdf>

(Pennsylvania Department of Human Services, 2020).

Obtaining a medical marijuana card

A patient must register to participate in Pennsylvania's Medical Marijuana Program. The first step is to register as an individual or caregiver on Pennsylvania's Medical Marijuana site at www.medicalmarijuana.pa.gov. There is a link for both the patient and the caregiver. Helpful tips for successful registration include:

- Have a valid Pennsylvania driver's license or Pennsylvania state-issued ID
- Ensure the entry of information matches driver's license or state-issued ID exactly
- Type in all CAPS
- Do not use spaces between the numbers from driver's license or state-issued ID
- Do not use punctuation in address

(PA DOH, 2021a)

The second step is to obtain the patient certification from a healthcare practitioner approved by the program. A list of participating healthcare providers can be found at www.medicalmarijuana.pa.gov, under the "browse physicians" tab. Following patient certification, an email is generated prompting payment for the medical marijuana card. The individual and/or caregiver will need to log into the site as a returning user, using the username and password created in the initial registration, and click on the "make a payment" tab. The medical marijuana card costs \$50.00. Individuals participating in government programs such as Medicaid, CHIP, SNAP, and WIC may be eligible for a discounted card. Approximately 7-14 days after payment, the medical marijuana card should arrive in the mail. Upon receipt, the patient can purchase medical marijuana at any dispensary in Pennsylvania (PA DOH, 2021a). Individuals under the age of 18 years must have a caregiver register and pick up the medical marijuana

for them. A person with intellectual disability/autism (ID/A) who requires assistance may elect up to two caregivers to pick up the medical marijuana. Caregivers must be over 21 years old and register with the Department of Health to pick up medical marijuana (PA DOH, 2021a).

The Food and Drug Administration (FDA) has not approved medical marijuana yet. It continues to be classified as a Schedule I controlled substance by the Drug Enforcement Agency (DEA) (Penn Medicine, 2020). The FDA has approved a cannabis-derived drug, Epidiolex (cannabidiol) for treatment of seizures in Lennox-Gastaut syndrome and Dravet syndrome in individuals 2 years of age and older (FDA, 2020). The FDA has also approved three synthetic cannabis-related drugs including Marinol (dronabinol), Syndros (dronabinol), and Cesamet (nabilone) for use related to nausea associated with cancer chemotherapy and anorexia related to weight loss in individuals with AIDS. These medications are available by prescription from a healthcare provider (FDA 2020).

References:

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- Penn Medicine. (2020). Medical Marijuana. Retrieved on March 18, 2021 from <https://www.pennmedicine.org/for-patients-and-visitors/patient-information/medical-marijuana-therapy/medical-marijuana-therapy>
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Resources for Teaching Self-Advocates

Nurses working in the ID/A field are positioned to lead educational efforts for self-advocates. There are various tools to assist self-advocates (SAs) to learn about self-care, everyday tasks, and interests. Nurses can use these tools to educate SAs and empower them to learn more about their health. The following list includes tools and resources to help individuals learn and understand according to their needs.

Rehearsal Guides from the Kepro HCQU

<https://hcqu.kepro.com/resources/rehearsal-guides>

The Kepro HCQU's Rehearsal Guides contain pictures, concrete ideas, and clear, brief instructions caregivers may use to prepare an individual for what can be expected in specific situations. Rehearsal guides are:

- Beneficial when supporting people with ID/A who may be anxious about situations like doctors' appointments, hospitalizations, and medical procedures.
- An opportunity for caregivers to help the person learn about a specific situation related to what is needed, why it is needed, and what to expect.
- Most effective when presented using a person-centered plan. For example, they can assist with discussion of specific areas of concern with individuals.
- Intended for use prior to the event. Most

people with ID/A will benefit from seeing the information repeatedly, even on the day of the event.

Kepro HCQU, 2019

ASERT

<https://paautism.org>

"ASERT (Autism Services, Education, Resources and Training) is a partnership of medical centers, centers of autism research and services, universities, and other providers involved in the treatment and care of individuals of all ages with autism and their families. ASERT was developed to bring together resources locally, regionally, and statewide" (ASERT, n.d.). The key initiatives of ASERT are to:

- "Support the autism community throughout PA
- Educate individuals with autism and their families, professionals, and community members
- Measure data, needs, and change
- Connect local, regional, and statewide resources
- Build resources, programs, and initiative projects"

(ASERT, n.d.)



Social Stories™

<https://carolgraysocialstories.com/social-stories>

“Social Stories™ are a social learning tool that support the safe and meaningful exchange of information between parents, professionals and people with autism of all ages. The people who develop Social Stories™ are referred to as Authors, and they work on behalf of a child, adolescent, or adult with autism, the Audience” (Gray, Carol, n.d.). Social Stories™ are:

- Short in length, using pictures and words.
- Illustrations and descriptions of tasks or social skills in short, easy steps.
- Used to create positive learning experiences for individuals with ID/A to better understand what happens and is expected in certain situations.
- Helpful for relieving anxiety and creating opportunities for increased independence.
- Beneficial for people with developmental disabilities, attention or auditory processing deficits, or other learning disabilities.

(Bethesda, n.d.)

AID in PA

<https://aidinpa.org>

AID in PA (Autism and Intellectual Disabilities in Pennsylvania) provides resources designed for individuals with ID/A, parents, caregivers, professionals, and communities across Pennsylvania. The following groups work together to provide these resources under the Pennsylvania Office of Developmental Programs (ODP): ASERT [and its subsidiary teams #ASDNext (*an ASERT website to connect teens and adults with autism to resources,*

information, and others in the community) and Philly Autism Project], Health Care Quality Units across the state, and Temple University's Department of Disabilities and Resources. AID in PA provides:

- Information about the COVID-19 pandemic.
- Guidance and support related to challenges people with ID/A encounter, such healthy sexuality and trauma support/recovery.
- Resources and videos designed for self-advocates, caregivers, professionals, and the community.

(AID in PA, n.d.)

Autistic Self-Advocacy Network

<https://autisticadvocacy.org>

This network is run by and for people with autism and disabilities. It provides learning resources and videos (via YouTube) on the Disability Rights Movement for people with autism in the community (Autistic Self-Advocacy Network, n.d.).

References

AID in PA. (n.d.). About Us. Retrieved March 23, 2021 from <https://aidinpa.org/about/>

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Autistic Services, Education, Resources and Training (ASERT) (n.d.). About Us. Retrieved March 23, 2021 from <https://paautism.org/about-us/>

Bethesda (n.d.). Social Stories for People with Disabilities. Retrieved March 23, 2021 from <https://bethesdalc.org/blog/social-stories-for-people-with-disabilities/#.YHmLlehKjIU>

Gray, Carol (n.d.). What is a Social Story? Retrieved March 23, 2021 from <https://carolgraysocialstories.com/social-stories/what-is-it>

Kepro HCQU (2019, February). Training: Rehearsal Guides for Caregivers

Supporting Self-advocates to Transition Back into the Community

Now that many people are being vaccinated and COVID-19 restrictions are decreasing, individuals with ID/A are beginning to transition back into their communities to resume former activities. However, everyday community activities look different than they did in the past; returning to these activities may require a period of adjustment. Transitioning into this new environment may cause stress, anxiety, and fear along with feelings of happiness and relief for individuals. Resources for assisting and supporting self-advocates and educating caregivers during this transitional phase are listed below. They include guides to help self-advocates and caregivers determine readiness to transition back into the community, social stories and rehearsal guides for self-advocates, and CDC recommendations for those who are vaccinated. In addition, there is a video resource that offers a first-hand account from an individual with ID/A recounting how she felt about COVID-19 restrictions and what it meant to her to be able to resume some of her former activities.

AADMD's "Sharing the Stories of COVID-19 & People with IDD"

- » [Helen's Story](https://www.ourcovid19stories.org/)
<https://www.ourcovid19stories.org/>

AID in PA

- » [Your Roadmap Back into the Community – Parents and Caregivers](#)
- » [Your Roadmap and Guide Back into the Community – Self-Advocates](#)
- » [Help Transition Back into the Community \(video\)](#)

ASERT

- » [Talking About Going into the Community](#)
- » [Going Back into the Community Social Story – Self-Advocates](#)

Autism Society

- » [Going Back to Work Guide – Self-Advocates](#)
- » [COVID-19 Individual Transition Guide](#)

Centers for Disease Control and Prevention

- » [When You've Been Fully Vaccinated](#)
- » [Interim Public Health Recommendations for Fully Vaccinated People](#)
- » [Coping with Stress](#)

Kepro SW PA HCQU

- » [Transitioning into the Community after a Pandemic Rehearsal Guide for Self-Advocates](#)



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