



## **DD Community Forum**

The next DD Community Forum will be held  
via Zoom on

**Monday, November 16th**  
**3:00 PM - 4:30 PM**

Go to this link to register:

<http://www.tinyurl.com/NovDDCommunityForum>

If you need help to register call 877-532-5543.

You can also watch the forum at [Facebook.com/AdvocatesinActionRI](https://www.facebook.com/AdvocatesinActionRI)



### **Community Forum Agenda**

- Welcome- Acting Director Kevin Savage
  - Introduction of Team: Heather Mincey, Brenda Duhamel, Tracey Cunningham, Anne LeClerc, Susan Hayward
- Acting Director Savage's Report
- Updates
  - COVID response
  - SLA Support
  - START
  - Coordination of Efforts for Medicaid Application
  - EVV
  - Employment
  - SIS Update
  - Consent Decree
  - Conflict-Free Case Management
- Community Questions

### **New Guidance on Visitation Issued**

BHDDH has issued an updated guidance on visitation at congregate care sites. Please see the full guidance attached at the end of this bulletin.

## Rhode Island Mask Guidance Updated

### Wear the Right Mask



Any time you are near people who don't live with you, wear a mask. It protects you and anyone near you from COVID-19. Your mask should fit snugly but comfortably over your nose, mouth, and chin without any gaps.

Tips to know if you have a good mask: hold it up to the light (the less transparent the better); or try to blow out a candle (this shouldn't be possible with a high quality mask).

### COVID-19 Toolkit For DSPs: Resources to help DSPs take care of themselves during the crisis <https://nadsp.org/covid-19resources/>

With the coronavirus (COVID-19) global pandemic, there is a constant barrage of information being shared. Things are changing almost hourly across the country. The National Alliance for Direct Support Professionals (NADSP) is committed to sharing resources for Direct Support Professionals. Given this global crisis, Direct Support Professionals are still working to provide supports. As Direct Support Professionals are on the front lines, NADSP has created a tool kit with self care information and additional resources for individuals. [View the toolkit here.](#)

To assist the people they support, DSPs must also take care of their own needs, health, and wellness. Incorporating self-care practices into their everyday lives helps DSPs in their work and other life areas. [This issue of Frontline Initiative highlights](#) how this helps them continue in the field and improve professionally.



## **Governor Announces New Initiatives Aimed at Rebuilding Rhode Island's Support Systems**

Early in the pandemic, Rhode Island had to close many group-based activities like childcare centers, senior centers, support groups, and adult day programs. Today, although many of these services have reopened under enhanced safety guidelines, these programs are still struggling with limited staff and resources. **Rhode Island is investing \$3 million in stimulus funding to expand home and community-based services for individuals living with intellectual and developmental disabilities.**

We also know that this pandemic has inflicted unparalleled stress on our most vulnerable populations and those who take care of them. That's why we're going to invest in better mental health supports for both caregivers and teachers. **The Rhode Island Parent Information Network will begin providing online caregiver workshops for those across the state who care for family members.** These workshops will provide tools and supports to caregivers to cope with the stress and anxiety that often comes with caring for a loved one. **Workshops begin November 17th and you can register now by visiting the Rhode Island Parent Information Network website at [www.ripin.org/chn](http://www.ripin.org/chn) [r20.rs6.net] or calling 401-432-7217.**

Finally, Rhode Island is taking steps to address two rising tragedies in Rhode Island. The first is a concerning trend in fatal overdoses. COVID-19 has increased isolation and has disconnected some Rhode Islanders from the help they need. **Resources are being provided for local providers to offer home-delivered harm reduction services and provide the overdose reversal medicine, naloxone, that can save the life of someone experiencing an overdose.** If you or someone you know needs help with a substance use disorder, go to [PreventOverdoseRI.org/COVID-19](http://PreventOverdoseRI.org/COVID-19) [r20.rs6.net] for a list of local resources to keep you, your family, and loved ones safe.

Rhode Island is also seeing a significant increase in domestic violence-related calls to the statewide helpline over the past few months. **Non-profit organizations whose primary mission is to serve survivors of intimate partner violence, sexual assault and human trafficking, as well as their children will receive \$1 million in grants.** These funds will be used to increase assistance services for survivors, including counseling and advocacy. If you are experiencing violence, you are not alone. Call the Rhode Island statewide helpline for 24-hour support at **800-494-8100**.



## Resources from the Mental Health and Developmental Disabilities National Training Center

<https://www.mhddcenter.org/>

The combination of an intellectual or developmental disability with a mental health concern, referred to as dual diagnosis, can be very difficult to identify, treat, and regulate symptoms. For someone who experiences a developmental disability, maintaining their mental health can be even more of a challenge than for others because symptoms manifest differently across individuals. Not only is it a challenge for individuals who experience dual diagnosis to keep up with their mental well-being, but mental health professionals are not always equipped to assist these individuals with their unique experiences. While these professionals have many resources in their tool belts for helping others achieve and maintain mental health, there is a lack of information to help them serve people who experience developmental disabilities and mental health concerns.

The **Mental Health and Developmental Disabilities National Training Center (MHDD-NTC)** was established by the University Centers for Excellence in Developmental Disabilities (UCEDDs) in three states – Alaska, Kentucky, and Utah – in order to help with this problem across the United States. Their website (<https://www.mhddcenter.org/>) is a hub that brings together mental health professionals, individuals experiencing dual diagnosis, and their support networks to access resources, trainings, and information that will improve awareness and understanding of mental health and intellectual and developmental disability.

Some of the resources available include:

- Online training modules to learn about the experiences of people with developmental disabilities and mental health concerns, with offerings geared to providers and clinicians as well as individual, families, and support staff
- Links to trainings by other partners have been vetted to ensure they meet the mission and values of the MHDD National Training Center
- Resources specific for diverse cultural and rural populations
- Blog posts include current research, first-hand experiences, helpful resources, and more
- Monthly podcast with self-advocates, professionals, and others
- Digital storytelling series highlights the lived experience of individuals with mental health conditions and developmental disabilities, with selections in English and Spanish



## News from RIPIN



### **Community Health Network**

*Your link to evidence-based health and wellness classes*

For more information and a complete listing of classes, visit [www.ripin.org/chn](http://www.ripin.org/chn) [[r20.rs6.net](http://r20.rs6.net)].

### **World Diabetes Day**

On November 14, people across the globe will celebrate World Diabetes Day 2020 (WDD). And we'll be celebrating right here in Rhode Island, with our first-ever **virtual** RIWDD. There are many ways you can get involved and support this important day — and take steps toward a healthier you. The RIWDD will be a full day of helpful, eye-opening, and inspirational online presentations, discussions, questions-and-answer sessions, and much more. You can join for the whole day, or choose the topics that most interest you.

**Saturday, November 14th**  
**9:00 AM - 5:00 PM**

[See Full Schedule and Register \[\[r20.rs6.net\]\(http://r20.rs6.net\)\]](#)

### **Powerful Tools for Caregivers**

This workshop allows caregivers to develop a wealth of self-care tools to reduce personal stress, change negative self-talk, communicate their needs to family members and healthcare or service providers, communicate more effectively in challenging situations, recognize the messages in their emotions, deal with difficult feelings, and make tough caregiving decisions.

**Multiple Class Offerings Beginning in November.**  
**Sign up for the day and time that's right for you!**

[View Full Schedule for Powerful Tools for Caregivers \[\[r20.rs6.net\]\(http://r20.rs6.net\)\]](#)

### **Tools for Healthy Living**

This research-based program teaches people to manage symptoms of chronic diseases, fatigue, pain, stress, sleep and emotional challenges such as depression, anger, fear, and frustration. Learn how to manage health better, make decisions, communicate with your healthcare providers and find reliable health information. Participants create action plans each week to move them along in reaching their goals.

**Mondays at 1:00 PM**  
**Beginning November 9<sup>th</sup>**

[Register for Tools for Healthy Living \[\[r20.rs6.net\]\(http://r20.rs6.net\)\]](#)



### **Need Help? Have Questions?**

**Call RIPIN: 401-270-0101**

RIPIN is a 501(c)3 nonprofit that uses a peer support model to help thousands people every year navigate healthcare, special education, and disability support systems in Rhode Island. Combining firsthand experience with expert training, RIPIN peer professionals are uniquely equipped to help families and individuals access the services and information they need to thrive. Learn more at [www.ripin.org](http://www.ripin.org) [[r20.rs6.net](http://r20.rs6.net)].

inform

support

educate

advocate

empower



## Silver Linings

### **Guggenheim's Audio Guide Brings the Art Museum To Listeners' 'Mind's Eye'**

Heard on NPR's [Morning Edition](#). Heidi Glenn adapted this story for the Web.

For art and architecture lovers who can't make it to the recently reopened Guggenheim Museum in New York City, there's an audio listening guide that can transport you there.

It's called [Mind's Eye: A Sensory Guide to the Guggenheim New York](#) and it's a compilation of what the museum calls "quintessential New York voices" describing the stunning architecture of Frank Lloyd Wright's iconic building. Each of the 10 tracks in the guide describes a sensory aspect of the museum; for example, actor Maggie Gyllenhaal describes touching the thick, pitted paint layers coating the museum walls.

Karen Bergman, access programs associate at the Guggenheim Museum, calls *Mind's Eye* a meditative experience. "I remember in one listening session, someone said that hearing these tracks really made them homesick for the museum," she says. "It really does bring people directly there."

It's a vivid escape for those of us stuck inside during the pandemic. But the *Mind's Eye* audio guide is designed for the blind and low-vision community.

"I've felt left out. I feel left out in almost every space that I go into," says actor Marilee Talkington, one of the guide's narrators who is also legally blind. "That's just part of moving through the world as a blind, low-vision person, as a disabled person. I mean, our physical architecture of the world excludes us."

But when Talkington listens to the audio tour of the Guggenheim Museum, she says she's immersed in a space she can vividly imagine.

"I feel that I'm able to access what most people visually access," she says. "This sensory guide I feel is for us — it's for my community. But it's actually for everybody."

In addition to the new *Mind's Eye* sensory guide, a range of digital programming including virtual talks, architectural and gallery tours, art classes for adults and families, and free teaching materials continue to be presented on the Guggenheim's website through [Guggenheim at Large](#) to extend access and offer experiences for audiences in any location.



## **Athlete With Down Syndrome Makes History as First to Finish an Iron Man Race—And Gifts the Medal to His Mom**

<https://www.goodnewsnetwork.org/triathlete-chris-nikic-finishes-iron-man-race/>



Clocking in at 16 hours; 46 minutes; nine seconds (just 14 minutes shy of the 17-hour cutoff time), triathlete Chris Nikic didn't finish with the fastest time when he recently completed his first Iron Man race—but he did set a new world record.

This past Saturday, after swimming 2.4 miles, the 21-year-old Floridian cycled 112 miles, and then ran a 26.2-mile marathon to become the first competitor with Down Syndrome to successfully cross the finish line in the 42-year history of the Iron Man Race.

“You have shattered barriers while proving without a doubt that anything is possible,” tweeted the official Ironman Triathlon Organization. “We are beyond inspired, and your accomplishment is a defining moment in Ironman history that can never be taken away from you.”

For his awe-inspiring efforts, Nikic also earned himself a place in the Guinness Book of World Records as the first person with Down Syndrome to become an official Iron Man.

Being the first person with Down's Syndrome is a great feeling,” Nikic told TODAY, prior to the event. “I can prove to kids that if I can do it, they can do it, too.”

Nikic's father, Nik, hopes that parents of other children with Down's Syndrome who see what his son has achieved will be inspired. “We want them to realize earlier that their child is a blessing, and they can live an amazing life,” he told TODAY.

As important as taking on the physical and mental challenges of an Iron Man were to Nikic, he had other compelling reasons for entering the competition. He might not have been carrying a banner, but the message he took across the finish line with him was clear.

“To Chris, this race was more than just a finish line and celebration of victory,” his dad told the BBC. “Ironman has served as his platform to become one step closer to his goal of living a life of inclusion, normalcy, and leadership. It's about being an example to other kids and families that face similar barriers, proving no dream or goal is too high... If Chris can do an Ironman, he can do anything.”

Nikic trained between four to six hours a day to prepare for the grueling event, and that training paid off. Even after suffering a fall from his bike during the second leg of the race, he called on his inner reserve of strength to get back up, keep going, and get the job done.

“Goal set and achieved,” Nikic posted to the delight of social media posse, including 33,000 new Instagram followers. “Time to set a new and bigger goal for 2021.”

One of Nikic's biggest fans, all-time tennis great Billie Jean King, tweeted the perfect response: “No limits. No boundaries. Keep dreaming big and going for it, Chris!”

With hopes of competing in the 2022 Special Olympics scheduled on his home turf in Orlando, it looks as if Chris Nikic has plenty of big dreams yet to come true.

As for that medal he won for completing one of the world's most grueling triathlons? He gifted it to his loving mom.

## If you are experiencing a mental health crisis, BH Link is here for you

BH Link's mission is to ensure all Rhode Islanders experiencing mental health and substance use crises receive the appropriate services they need as quickly as possible in an environment that supports their recovery. Call 911 if there is risk of immediate danger. Visit the BH Link website at [www.bhlink.org](http://www.bhlink.org) or for confidential support and to get connected to care:

CALL (401) 414-LINK (5465)

If under 18 CALL: (855) KID(543)-LINK(5465)

Visit the 24-HOUR/7-DAY TRIAGE CENTER at 975 Waterman Avenue, East Providence, RI

## Stay Informed with Information on COVID-19

### Rhode Island Department of Health COVID-19 Resources

Hotline (401) 222-8022 or 211 after hours;

Email [RIDOH.COVID19Questions@health.ri.gov](mailto:RIDOH.COVID19Questions@health.ri.gov)

Website <https://health.ri.gov/covid/>

### Center for Disease Control COVID-19 Information

Website [cdc.gov/coronavirus](https://cdc.gov/coronavirus)

Videos <https://www.cdc.gov/coronavirus/2019-ncov/communication/videos.html>

*Includes a link to ASL videos*

### BHDDH Information on COVID-19's Impact on DD Services and the DD Community

Website [bhddh.ri.gov/COVID](http://bhddh.ri.gov/COVID)

### RI Parent Information Network (RIPIN)

Website <https://ripin.org/covid-19-resources/>

Call Center (401) 270-0101 or email [callcenter@ripin.org](mailto:callcenter@ripin.org)

### Advocates in Action – for videos and easy to read materials

Website <https://www.advocatesinaction.org/>

*Website offers BrowseAloud, which will read the website to you*

## Sign Up for Our Email List

If you aren't receiving email updates and newsletters from BHDDH, you can sign up on our website. From the main BHDDH page at [bhddh.ri.gov](http://bhddh.ri.gov), select **What's New**, then go to bottom and click on **DD Community Newsletter**. The link to sign up for the BHDDH Newsletter is directly below the title, as shown in the picture at right.



DD Community Newsletter  
SIGN UP FOR THE BHDDH NEWSLETTER

## Contacting DD Staff

DDD has put extended hour phone coverage in place with a central business hour phone number and an on-call number for nights and weekends.

If you have a vital need, please call the numbers on the next page. If you have any general questions or concerns, please email them if you can, in order to try to leave the phone lines free for those who need to call. We will do our best to address your questions directly or through future newsletters.



**401-462-3421**

**WEEKDAYS DURING BUSINESS HOURS FOR:**

- VITAL, NON-MEDICAL SUPPORT NEEDS
- QUESTIONS ABOUT YOUR DD SERVICES

During business hours (Monday-Friday 8:30-4:00), for questions or support  
**(401) 462-3421**  
 Para español, llame  
**(401) 462-3014**

**401-265-7461**

**AFTER HOURS ON WEEKDAYS FOR:**

- VITAL, NON-MEDICAL SUPPORT NEEDS

For emerging or imminent care related questions, Mon - Fri 4pm-10pm and weekends 8:30am-10pm  
**(401) 265-7461**

**401-265-7461**

**ON WEEKENDS FOR:**

- VITAL, NON-MEDICAL SUPPORT NEEDS

Send general questions to the AskDD email address. Please do not email critical issues.  
[BHDDH.AskDD@bhddh.ri.gov](mailto:BHDDH.AskDD@bhddh.ri.gov)

**E-MAIL THE DIVISION**

**BHDDH.AskDD@BHDDH.RI.GOV**

**HELP US KEEP THE PHONE LINES OPEN FOR THOSE WHO ARE CALLING WITH A VITAL NEED!**

**WHEN POSSIBLE, PLEASE SEND AN E-MAIL FOR:**

- NON-CRITICAL CONCERNS about Your Services and Supports
- GENERAL QUESTIONS about Your Services or the RI DD System

**FOR MEDICAL EMERGENCIES CALL 911 RIGHT AWAY. DON'T WAIT!**

For medical or healthcare related emergencies, call your Primary Care Physician or 911

**CONTACT YOUR DOCTOR**

**CALL FOR:**

- ROUTINE Healthcare Questions
- NON-EMERGENCY Medical Care

**FOLLOW YOUR DOCTOR'S ADVICE**  
**DON'T go to their office unless they tell you to!**



## Congregate Care Visitation Guidance

Updated November 13, 2020

Effective November 16, 2020

Kathryn Power, Director of Behavioral Healthcare, Developmental Disabilities, and Hospitals (BHDDH) is strongly recommending that all congregate care residences increase visitor restrictions. This recommendation is made in response to the increasing number of individuals diagnosed with COVID-19 globally, and in Rhode Island, at the onset of the influenza respiratory illness season.

### Background

In August 2020, BHDDH issued guidance specific to licensed congregate care settings and requested that facilities develop a **facility-specific visitation plan** in order to safely ease visitor restrictions. This relaxed visitor guidance balanced the importance of visitation with the need to protect residents, patients, staff, providers, and visitors. These plans addressed scheduling of visits, screening for COVID-19 symptoms, practicing social distancing, hand hygiene, wearing a cloth face covering or facemask (both residents and visitors) for the duration of their visit, physical location of the visit, cleaning and disinfecting, communication, and when to pause visitation.

On September 17, 2020, The Centers for Medicare and Medicaid Services released guidance, affirming the importance of visitation, while noting that visitation may still be restricted due to the COVID-19 county positivity rate in the county where the facility is located, the facility's COVID-19 status, a resident's COVID-19 status, visitor symptoms, lack of adherence to proper infection control practices, or other relevant factors related to the COVID-19 Public Health Emergency.

Unfortunately, in the last few weeks, COVID-19 cases and hospitalizations have been increasing, prompting Director Power to issue the **strong recommendation that all BHDDH licensed congregate care facilities institute a "NO VISITATION" policy.**

**Continued adherence to all safety measures and cooperation with surveillance testing whenever possible remains critically important.**

### **No visitation unless required under federal guidance, or in certain other circumstances.**

- Visitation is suspended unless required under federal guidance (*See September 17 CMS Guidance*); or in certain other limited clinical circumstances, including compassionate care.
- Compassionate Care visits are allowed only under certain circumstances according to the core principles of COVID-19 infection prevention, the facility visitation plan, and federal guidance. Even under these circumstances, anyone who meets the conditions listed above is prohibited from visiting, in addition to those who are younger than 18.

### **Compassionate Care Visits**

Compassionate care visits should be allowed at all levels of visitor restrictions. This includes, *but is not limited to*, end-of-life situations.

### **Alternatives to In-Person Visitation**

Regardless of the phase, *facilities must have a process in place, at all times, to facilitate remote communications between a resident and a virtual visitor* (e.g. video call applications on cell phones or tablets).



# National Center on Advancing Person-Centered Practices and Systems

## Person-Centered Supports for People with Dementia

### Living in the Community

November 30, 2:00-3:30pm Eastern

To register: [https://zoom.us/webinar/register/WN\\_BgqVFpxrSEKx4wE8zg87kg](https://zoom.us/webinar/register/WN_BgqVFpxrSEKx4wE8zg87kg)

Panelists will discuss their personal and professional experiences with dementia, along with individual, community, and system level approaches to make supports for people with dementia more person-centered. Participants will learn about the definition of person-centered thinking, planning, and practice, and will hear the panelists answer questions such as: What do person-centered dementia supports look like to you? What are community approaches to support people living with dementia in a person-centered way?



**Rev. Dr. Cynthia Huling Hummel**, of Elmira, NY is a fierce advocate and a voice for those living with the dementia. Cynthia served on the National Council on Alzheimer's Research, Care and Services representing the 5.8 million Americans living with dementia. She has been an Alzheimer's research participant for 10 years. Cynthia currently serves as an advisor to several local, national and international organizations. An artist and author, she also sings in a country band. She will be moderating the discussion.



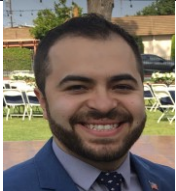
**Brian Van Buren** is an Alzheimer's advocate and public speaker, a Board Member of the Western Carolina Chapter of the Alzheimer's Association, and an Advisory Council Member for the Dementia Action Alliance. After his early onset Alzheimer's diagnosis in 2015, he reimagined himself as an advocate. Being an Afro-American man, he felt he needed to give a face to the disease. He also feels a need to address marginalized populations such as the LGBTQ community.



**Diana Blackwelder**, MS Systems Engineering, Black Belt Six Sigma Process Improvement was diagnosed with Young Onset Alzheimer's Disease in 2017. She successfully lives alone, provides care for her two pet cats, travels internationally and advocates for the betterment of lives of those living with multiple cognitive disabilities caused by dementia. Diana serves on the Board of Directors for Dementia Alliance International, is a volunteer researcher at University of Maryland, is a National Alzheimer's Association Early Stage Advisor Alumni and consults to the Smithsonian and US Botanical Garden Access Programs for people living with dementia.



**Cameron J. Camp**, Ph.D., originally developed the adaptation of the Montessori method as an intervention for persons with dementia. He is a noted psychologist specializing in applied research in gerontology, and currently serves as Director of Research and Development for the Center for Applied Research in Dementia. He gives workshops internationally on cognitive and behavioral interventions to reduce challenging behaviors and increase the level of functioning and quality of life of persons with dementia.



**Elias Rodriguez** is a Registered Nurse of 8 years, and works as the Community Life Director at Rowntree Gardens Senior Living Community. His passion for comfort and best practice has made him an advocate for quality care. As an ambitious and motivated leader, he spends his days seeking the highest quality of life of employees and residents in the community.

NCAPPS is an initiative from the Administration for Community Living and the Centers for Medicare & Medicaid Services to help States, Tribes, and Territories to implement person-centered practices. NCAPPS webinars are open to the public, and are geared toward human services administrators, providers, and people who use long-term services and supports. All NCAPPS webinars will be recorded and archived at <https://ncapps.acl.gov>.

# Working While Disabled—Work Incentives Overview

**Registration Now Open!**  
**Work Incentive sessions for SSI and SSDI Beneficiaries**

## **SSI Sessions:**

November 20th, 12-1 pm

December 9th, 12-1 pm

## **SSDI Sessions:**

November 21st, 9:30-10:30 am

December 16th, 12-1 pm

*Sessions will be offered on Zoom with subtitles in English.*



**REGISTER ONLINE at <https://bit.ly/2KkUCVQ>**

The Sherlock Center provides Work Incentive Information and Benefits Counseling services to SSI and SSDI beneficiaries and those that support them (family, guardian, rep payee, professionals). These sessions will be of value to anyone looking for a basic introduction to disability-related work incentives and/or has related questions. Along with providing an overview of basic SSI or SSDI and related information, these sessions provide an opportunity for you to ask questions about the following topics:

- Ticket to Work
- SSI or SSDI Work Incentives
- Resources about Work Incentive Information
- Access to Benefits Counseling
- Working and Impact on Health Insurance Medicaid/Medicare
- Other questions related to benefits and working

Upon registration please share your questions.

NOTE: These sessions will not address how to apply for SSI or SSDI benefits.

**TIP:** Unsure if you receive SSI or SSDI? You can confirm which benefit you have at <https://www.ssa.gov/myaccount/>

**Presented by Certified Work Incentives Counselors:**

SSI Session: Laura Elderkin, SSDI Session: Jeanne Fay

**REGISTRATION IS LIMITED!** Advance registration is required. After registering, you will receive a confirmation email containing information about joining the session. You can access the session by computer, mobile device or listen using a cell or landline phone.

**Accommodation requests or registration questions:** Contact Elaine Sollecito at [esollecito@ric.edu](mailto:esollecito@ric.edu).

**Session questions:** Contact Vicki Ferrara at [vferrara@ric.edu](mailto:vferrara@ric.edu).

