

RIGHTS REVIEW



**Newsletter of the DDS Human Rights Advisory Committee
and the DDS Office of Human Rights**

The COVID-19 Edition

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A Thank You to Our Frontline Heroes!

In this edition of Rights Review, we will read about some of the advocates and service providers who stepped up to support others through the COVID-19 pandemic. During these unprecedented times, state guidelines were enforced to protect the general public from the deadly Coronavirus. These guidelines limited our access to the community and restricted our ability to engage in some of our favorite activities. They also limited our ability to interact with our loved ones face-to-face.

DDS services and supports had to be adapted to meet the needs of people who were grossly-impacted by the limitations and restrictions. While providers scrambled to adapt to the changes and develop new and innovative ways to provide supports, the goal remained to ensure people who received DDS services got the best services possible and received the necessary supports to connect with others, engage in meaningful activities and stay safe.

To our true heroes, the essential employees who have worked tirelessly, risking their lives and sacrificing their own needs to keep others safe: **WE THANK YOU!**



“A hero is an ordinary individual who finds strength to persevere and endure in spite of overwhelming obstacles.”

- Christopher Reeve



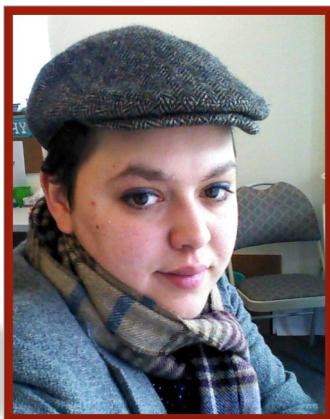
If you would like to submit an article or advertise an event in the Rights Review, contact:

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5 questions with...



West Regional Self-Advocacy Coordinator

Ness Bellini

1. How did you come to be a self-advocacy advisor?

After graduating college, I knew that I wanted to do something fulfilling. I wanted a helping profession. It made sense, because both of my parents were in helping professions. My mother worked in special education. After working with youth groups through the Americorps and the United Arc of Turners Falls, I came across the self-advocacy position. It looked interesting and felt like a good fit, because of my passion for social justice. It wasn't just about providing support. It was an opportunity to be a part of a movement to affect social change.

2. What impact do you think self-advocacy has had on people with disabilities?

I think about the self-advocacy movement as a whole and how much progress has been made in general. Groups used to meet in institutions to fight for change. There's a member of our group who was living at Belchertown State School. He told me about a time when he and some of the other residents noticed that they were getting instant coffee that didn't taste great, while the staff got coffee made in a coffee maker. The group got together to discuss the issue and to advocate for change. Self-advocacy can be as simple as that, or as complex as fighting to change the name of the Department of Mental Retardation (DMR) to the Department of Developmental Services (DDS).

Although the group I advise is not striving to make big legal changes right now, we are making an impact on folks who attend. Self-advocacy is important, because through relationships members come to understand their value and that they're valuable.



Ness with Cassandra, a member of one the West Region Self-Advocacy groups

3. What are some of the current barriers to self-advocacy that members are experiencing due to the COVID-19 pandemic?

Not everyone has access to technology or the skills needed to access our meetings now that they're virtual. We've lost some members. We've also gained members. We've actually had new members join who had never been in a self-advocacy group before, because they didn't have transportation to get to the meetings. Now that meetings are virtual, they can join.

4. What is your impression of the ways in which supporters and advocates of people who receive DDS services responded during the COVID-19 pandemic?

At the height of the pandemic, the agency I work for, the Western MA Training Consortium, adopted a model for staff to live on site for a full week so there would be less people in and out of the houses. Residential staff sacrificed time with their families and shifted their lives around to protect the individuals we support. People stepped up in other ways, too. The Berkshire self-advocacy group continued its monthly "Chance to Dance," but moved it online where members danced together over Zoom. To see the variety of events that went virtual and allowed individuals to maintain connections was really cool.



Ness with Brian, a member of the West Region Self-Advocacy group

5. What inspires and motivates you to advocate for others?

My favorite author, Leah Lakshmi Piepzna-Samarasinha, wrote a book called Care Work: Dreaming Disability Justice, which inspires me to ask, "what impact am I making?" I also have a tattoo on my arm that reads: "To love yourself is an everyday war against the system." It's a reminder that systems sometimes make us feel bad about ourselves. A really powerful thing you can do when faced with an oppressive system is to decide to live your life based on what you think of yourself and not what others think of you.

West Region Self-Advocacy meetings are held monthly. For more information contact:

Ness Bellini: NBellini@wmtcinfo.org





Provider Spotlight

Sunshine Village Continues to Shine

Submitted by: Gina Kos

Sunshine Village, a CARF accredited organization, was established in 1967 and has been successfully achieving its mission of improving the lives of people with developmental disabilities, including people on the autism spectrum for more than 53 years. Staying true to its founders' dream of a place where "everyone shines," the organization continues to work hard – even during the COVID pandemic – to deliver on the promise of a great day, every day!



The organization offers an array of innovative Life Engagement and Community Integration day services within sites located in Three Rivers, Agawam and Chicopee. In addition to supporting people to obtain and maintain their own jobs in local industry, the agency also operates a commercial cleaning company under a SourceAmerica contract that employs an integrated workforce and provides maintenance to all buildings and hangars at the Westover Air Reserve Base.

With the onset of the emergency closure due to COVID-19, Sunshine Village developed an interactive and engaging Virtual and Remote Services (VARS) plan that included a diverse number of activities focusing on wellness, personal growth and professional development. Virtual activities included: small group communication sessions through Zoom; fun programmatic and therapeutic videos featuring staff members and client leaders available through the agency's website, including videos in Spanish; as well as "Watch Parties" and "LiveCasting" on Facebook. For clients who did not have their own equipment, Sunshine Village provided Chrome Books and technical assistance. The most recent improvement to VARS is the addition of services being provided not only during the day, but also in the evening and on weekends.

Other VARS activities included: "Great Days Activity Packets" provided weekly to people through the agency's website and through the US Mail; "Message Express" allowing clients to send notes to their favorite staff; "Food and Fun Packages" and "Great Day Bags" delivered directly to people's homes through the "Ring and Run" program; "Stones for Hope" and "Care Cards" as part of the Home Volunteer Opportunities; "Wave Parades" and monthly personalized greeting cards mailed to people to help stay connected; "Great Outdoors Program" featuring Drive-In Bingo, CAR-A-Oke, Friday Fun Days, Wonderful Wednesdays and CBDS Adventure Camp to allow people to participate in outdoor programs; weekly telephonic services from the agency's nursing, therapeutic and case management personnel; and hosting private Facebook pages for program specific communication.



Sunshine Village began reopening its programs in early August and is currently operating six programs. Like all other day programs, capacity within all buildings has been diminished drastically with the strict adherence to mandates. Each client has their own personal storage container, and we use imaginative ways to remind people about social distancing, mask-wearing and proper respiratory etiquette.

The agency created and implemented a comprehensive COVID-19 CONTROL PLAN to ensure the highest levels of safety during the reopening process and operations during the pandemic. This plan has been revised several times since its creation and is posted on the agency’s website so that it is accessible to all stakeholders. All sites have been fully stocked with approved cleaning supplies – and new equipment like Victory Sprayers are being used regularly.

Sunshine Village continued its Positive Behavior Supports (PBS) program throughout the closure and reopening phases – hosting its PBS officers with virtual meetings and ensuring that the monthly PBS Educational Campaign topics were continued through the various VARS elements. For several months, a weekly “Great Day Activity Packet” featured PBS themes.

To encourage 30 minutes of both physical and mental excursion each day during the height of the stay-at-home order, the organization also created “CoastBusters: Moving Across America.” This self-directed wellness challenge encouraged people to “travel from coast to coast, getting fit and exploring American landmarks as well as the smallest rural towns and biggest busy cities along the way.

The pandemic isn’t over – and neither is Sunshine Village’s commitment to ensuring that people who want to attend a program – can (although some are not yet able to due to mandated restrictions) and that for those who are not able to attend a program or are unwilling to at this time, can engage with their trusted support staff and friends in fun and easy ways using a host of technologies (Zoom and Facebook) as well as “old school” communication (telephones and the US Mail!)



From Executive Producers:
President Barack Obama and Michelle Obama...



No one at Camp Jened could've imagined that those summers in the woods together would be the beginnings of a revolution.

Crip Camp tells the story of a group of teens who met at a summer camp for adolescents with disabilities. They went on to become nationally-known activists for disability rights, fighting for accessibility and equality, and changing societal views of people with disabilities.



Available now on
[Netflix](#) and [Youtube](#)

Learn more about the activists featured in the film.



Judy Heumann

www.fordfoundation.org/ideas/equals-change-blog/posts/confronting-shame-and-accepting-my-disability-with-judy-heumann/



James Lebrecht

<https://variety.com/2020/artisans/production/crip-camp-directors-netflix-1203546354/>

Events and Learning Opportunities

Eating Concerns in the Developmentally Disabled Population

January 22, 2021

10:00am-12:00pm

When you are working with those with Developmental Disabilities, eating concerns become far more complex. Sensory processing disorders and differences require special considerations. This presentation will provide the resources you need at your fingertips to ensure your clients get what they need in a way that feels good to them.

Presenter: Monika Ostroff, LICSW, CEDS-S is the Executive Director of the Multi-Service Eating Disorders Association, Inc (MEDA).

For more information and to register, visit:
www.ddslearning.com



**The Assistive Technology Conference
of New England presents:**

**Tele-engagement for Individuals
Using AAC Webinar**

**January 18, 2021
2:00pm—5:00pm**

Understanding how to support an individual's engagement in a variety of ways is essential when establishing and implementing online services. This presentation describes ways to promote tele-engagement in the context of tele-AAC service delivery to individuals with complex communication needs.

Fees apply.

For more information:

<https://www.assistivetechconference.com/2020-presentations/>

Phone: (800) 916-8324

Email: techaccess@techaccess-ri.org

“YOUR IDEAS COUNT!”

It's the 22nd-Annual

**Massachusetts Advocates Standing Strong
(MASS)**

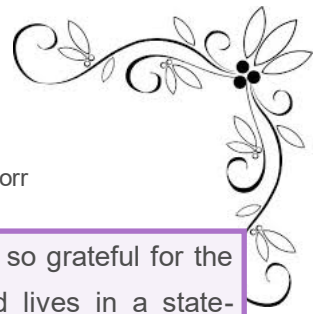
Self-Advocacy Conference

Want to present a workshop at our first online conference in February?

We are looking for self-advocates interested in presenting a recorded workshop either on their own or with other self-advocates. There is no right or wrong idea for a workshop. It just needs to be a topic that you think is informative and educational.

Think outside of the box and go for it!

For more information or to submit an application, email: info@ma-advocates.org



A GRATEFUL MOM

By: Ann Dorr

Allow me to share my pandemic story, because I am so grateful for the care my son received. My Jeff is 38 years old and lives in a state-operated home in Amherst with three other gentlemen. COVID-19 entered the home in March 2020 when one of Jeff's housemates presented with symptoms, tested positive and was quarantined in his bedroom. Soon, many staff and a second housemate also tested positive. This man's only symptom was a slightly high fever, that might not have been caught if the staff were not as vigilant about checking everyone, both staff and individuals, for temperatures and other symptoms. Eventually, my son tested positive. We were lucky; he showed no symptoms, but to be safe for everyone, he needed to be quarantined as well. The only space left was his bedroom.

A staff person, who planned many fun adventures and vacations for my son, had already caught the virus, been quarantined at home and returned to work with the blessing of her town's health department. She volunteered to take Jeff to her house while he recovered, and negotiated with the residential program to make it happen the same day we got the test results. With the approval of the DDS area office, Jeff left for her house that afternoon. Thank goodness for FaceTime. While this staff person texted me every day to confirm that Jeff still showed no symptoms, it was such a relief to be able to talk with my son and see for myself that he was fine.



My son, Jeff, greeting me for the first time since the start of the pandemic

I am so grateful that this person stepped up to help Jeff and that the program and area office were flexible enough to agree to the plan. What could have been a traumatic experience became a vacation for Jeff. Really, Jeff did not want to come back to the house!

To promote a smooth transition, I provided food for a welcome home party. All of Jeff's favorites; pizza, salad, soda, and Pepperidge Farm cookies were delivered to Jeff's house. Sadly, we lost the 90-year-old gentleman. Everyone else recovered.

Thanks to the hard work by the staff, one of the individuals never even got sick. After almost three months, I was able to see my Jeff in person. We wore masks and remained outside of the home, but at least we got to visit. Jeff is a hugger, so instead of saying, "sorry, we can't hug," I brought a grocery bag full of treats and surprises to distract him. It worked! I am grateful our pandemic story has a happy ending.

My best wishes to all who are part of the DDS family, with the hope that we have learned to cope with the virus and that the worst is over.

Hogan's Heroes

When I think of the word “champion” I think of an advocate, a person who is willing to make sacrifices for others or a cause. If we look around at all the staff at the Hogan Regional Center in Danvers, I see many examples of true champions for the people who live here. We were hit hard by the COVID-19 outbreak. It was a new disease that did not act like any virus we had experienced before. Whoever heard of being sick with a virus and being able to spread it to others while never having any symptoms at all? Guidance from health authorities was frequently changing as they learned about this new virus. We struggled to keep up as did everyone else. But through it all, staff here remained focused on one goal—to do whatever we could to keep the people who live at Hogan safe.

As we look back over the past several months we can reflect on so many selfless acts on the part of staff who did whatever they could to help stop the spread of the deadly virus here on our campus. One example was the group of trusty seamstresses and helpers who made masks for all the staff and residents who would wear them. With the help of outside groups, they were able to make enough masks for every single staff. In fact, they made enough to ensure that each staff had 2 masks so they could alternate and always have a clean one available. All of this was done during the evenings and on weekends after putting in a full week of work at Hogan. They paid for most of the materials themselves. We wore those masks until the guidance changed and we were issued recommended protective equipment.

Another example was the amount of time people dedicated to staffing shifts and providing care. You would see the managers of Hogan who worked a crazy amount of hours each week, plus holidays and weekends to help manage the spread of the virus and ensure that our residents always had familiar staff with them. At the end of these long days, they would still ask me if there was anything else that needed to be done.

Testing would prove critical in identifying who was COVID-positive and needed to isolate. Isolating sick individuals meant staffing overall became extremely tight. It required a significant amount of effort to fill shifts. Many people worked overtime. The clinical staff worked directly with our residents, even if it was outside of their usual job duties. So many people extended themselves to keep life as normal as possible for the over 100 people who call Hogan home. Other champions are the people who still today work well outside of their job duties to help make testing happen as often as it needs to.

The staff at Hogan are more than just champions, they are real heroes. A hero to me is someone who does their job even if it puts them in personal danger. If you think back to the beginning of the pandemic when it was so new, there were no treatments and the risk of serious illness and even death was real. People were scared to be around it. I could hear it in people's voices and I could see it in their eyes just how frightened they were. But even at the height of the pandemic, when still very little was known about the virus that was taking so many lives day after day, it was our medical staff, nurses and direct support staff who came forward and did their jobs as few could. Without hesitation, they provided loving care to people who had contracted the virus. They supported those who were sick and at their time of greatest need even if though it meant they could contract the virus, too.

Families were not able to visit their loved ones. The staff did what they could to fill the voids felt by the residents who could not see their family members. They did this although it posed a significant risk to their own personal well-being and possibly that of their families and loved ones. They did it because they cared that much for the people who live at Hogan.

To me, they will always be Hogan's true Heroes.

Paula Potvin, Facility Director



Ask Nate...

Nate Hoover

Human Rights Specialist, Southeast Region

Do COVID-19 restrictions violate our human rights?

Soon after the start of the COVID-19 pandemic, public-safety restrictions on visitation, community access and gatherings were implemented, and it was no surprise when the Office of Human Rights began to receive complaints, questions and concerns related to human rights, freedom of choice and self-determination. In order to stop the spread of the virus and save lives, limitations were placed on many of our rights, including our rights to access the community and associate with others. With these restrictions in place some of us were not able to go to work or day programs. We could not have loved ones visit us, go shopping or eat at our favorite restaurants. Although these limitations were necessary, because of the risk posed by the virus and its potential for harm, many people who receive DDS services had difficulty adjusting to the protocols and guidelines developed to stop the spread of the virus and felt that their rights were being violated.

In the Office of Human Rights, we refer to a four-step tool known as the Human Rights Framework when addressing complaints and concerns about restrictions, limitations and other rights-infringements. We begin by asking if there is a **compelling reason** to implement a restriction that might infringe upon a person's rights. The risk posed by COVID-19 was compelling enough to warrant limitations on our rights to community integration and association. With respect to people who receive DDS services, an important consideration was that many resided in communal settings, which further added to the need to limit social interactions and community activities.

The second step of the framework looks to see that the intervention or combination of interventions chosen to address the concern are the **least-restrictive** possible. Step three of the framework aims to **mitigate or balance out the restriction** identified, by teaching the person the skills necessary to cope with the restriction and in most cases, to eliminate the restriction altogether. Coping is one of the most important skills we can all practice during this pandemic. As supporters, we have a responsibility to assist those people we support to maximize their skills around coping. Another thing that we can do here in this step is to look for creative ways to offset some of the restrictions that are in place. To offset the restrictions on community access and association, one of the biggest workarounds that folks have utilized since the pandemic started are virtual programs like Zoom, which allow us to video call with each other. Human rights officers and advocates all over the state have done creative things to support people. Sharing these ideas with each other is a valuable exercise and we welcome Human Rights Officers, Coordinators and advocates to connect, virtually of course, to collaborate. If you are interested in hearing more about this, check in with your regional Human Rights Specialist about "Human Rights Networking" meetings.

The last step of the human rights framework is **due process**, which ensures that the person for whom the restriction is in place and/or their guardian is aware of the restriction and its necessity, and that they have had the opportunity to ask questions, request modifications, express grievances and/or refuse the intervention or service. ISP teams and the human rights systems within provider agencies are places wherein deep conversation about the best supports for residents and day program members can occur and where a better a balance may be struck.

As always when considering human rights, it is important to remember our responsibility to balance a person's rights to make choices and exercise self-determination with the responsibility to protect their health and safety. We must consider the vulnerability of the people we support and help them to understand why limitations and restrictions are necessary. Most importantly, we must help them to understand our roles in protecting their rights and helping them to stay safe. They should see us as allies and know that we are all in this together.

Fly Like an Eagle Scout

By: Becky Christie



William Mance achieved his goal to become an Eagle Scout - the highest rank within the Boy Scouts of America. The Eagle Scout rank can be achieved by a member, also known as a “scout,” who has earned a minimum of 21 merit badges, is dedicated to serving their community and possesses the attitude, commitment and spirit of a leader. The scout must also complete a community service project.

After earning his badges and proving he had what it took to become an Eagle Scout, William got to work on his service project. William chose to create a memorial garden at the Creative Living home in Andover. In order to complete this project, William engaged in numerous fundraising efforts throughout the local Andover community. Creative Living, Inc. made the first a donation, which was followed by donations and assistance from a host of local businesses and community members. Holt & Bugbee, a local lumber manufacturer, provided the wood for the project. Mahoney’s Garden Center offered a significant discount on the plants. Lowe’s provided the sand, mulch and bedding along with nuts and bolts for assembly. Spinner’s Pizza provided food for William and his crew.

William called on members of his scout troop and friends to help with the project. The team received landscaping tips and woodwork advice from people like Mr. Barton, the father of an Eagle Scout who enjoyed spending time at Creative Living. William’s family was tremendously supportive of the garden project from the start, offering encouragement and guidance any time it was needed.



Now complete, the memorial garden is a much needed outdoor retreat for many. If you visit, then you’re likely to find William tending to the garden. You may even find him sitting on the bench, admiring his creation, lost in thought his journey to become an Eagle Scout. Congratulations, William!





Top Tips

...for Coping with Social Distancing

By: Tekla Harris

Social-distancing, albeit a necessary and life-saving measure to stop the spread of the Coronavirus, has been an unexpected lifestyle change for all of us. According to the Centers for Disease Control, social-distancing means “keeping space between yourself and other people outside of your home.” To prevent the spread of the virus, practicing social-distancing means staying at least 6-feet away from others, not gathering in groups and avoiding large crowds.

By now, many of us have adapted to the changes. We are utilizing alternative modes of communication to connect with our families, friends, colleagues and others. We are juggling our work lives and our household responsibilities. We are prioritizing essential activities and choosing to engage in only those activities that pose little to no threat to our health and safety.

For some of us, staying home has been a positive change, allowing us to spend more time with loved ones, and leading us to discover new and meaningful ways to spend our leisure time. For others, staying home has been an unwelcomed burden that has led to increased feelings of loneliness, stress and anxiety.

As advocates, it is important for us to see the impact social-distancing has had on those we care about. We should recognize and celebrate the positive experiences, but we should also take note of the challenges and struggles some people have endured.

We must help others to see that social-distancing does not mean our social lives end. In fact, social-distancing presents an opportunity to learn new things about ourselves and to discover talents, hobbies, meaningful activities we enjoy.

Here are some of the ways you can support others to adjust to the changes brought on by the pandemic:

- Help someone to participate in a virtual support group or regional self-advocacy meeting.
- Teach someone to open a social media account or use a virtual platform to video chat with family and friends.
- Recommend books or audiobooks the person might enjoy.
- Help the person start a book club or magazine club - read a book or an article and discuss it with friends.
- If the home phone is a shared one, then facilitate a house meeting so that housemates are able to discuss and create a telephone or computer schedule to ensure equal access and fairness to everyone in the home.
- Help the person to host a game night.
- Schedule weekly activities so that the person has something to look forward to.
- Keep an activity calendar posted in a common area as a reminder of what's to come.
- Organize a painting activity.
- Support the person to join an online workout class or use an app to complete a workout.
- Recommend a new meal and support the person to prepare it.
- Help the person to redecorate a room in their home.

As supporters of people with disabilities, we should help those experiencing difficulty with social-distancing to maintain contact with their loved ones, minimize the disruption to their lives and develop coping skills and strategies to deal with stressors associated with isolation. Social-distancing forces us to spend time alone, which could be detrimental to our emotional wellbeing, but with compassion, kindness and creativity, we can help others to see how solitude can actually lead to self-reflection, and how social-distancing can lead to self-discovery.

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