



Self-Directed Hiring During COVID-19 Update

We apologize for any confusion caused by the different messages in the April 17th email and bulletin regarding self-directed hiring, and for the changing messages around hiring staff. Ongoing discussion has revealed more complexity to this issue than initially thought.

The correct information is that during the COVID-19 pandemic, people who self-direct can hire any qualified adult, including family members and parents, with the exception of legal guardians. The Department is conducting further legal review to determine if the individuals who have a legal guardian(s) can hire their legal guardian as an employee.

All self-directed staff must be able to pass a background check. Typically, a background check must be completed before hire. Due to COVID, a variance is in place for the requirement of a background check. The variance requires the background checks to be done within 60 days of the end of the State of Emergency. Fiscal Intermediaries have been given guidance on performing background assessments in lieu of background checks during the State of Emergency.

Supports During Hospital Stay

Many families have asked about the ability to have supports stay with their loved one if hospitalized. How hospitals and families can work together to safely support a family member with I/DD is under discussion. Please see the attached letter from Disability Rights RI on this issue.

We suggest calling the hospital directly with concerns or call the RI Dept of Health (RIDOH) COVID-19 Hotline at (401) 222-8022 or 211 after hours; or email RIDOH.COVID19Questions@health.ri.gov or visit their website at <https://health.ri.gov/covid/>. If restrictions are in place, we encourage families to put together concise information about their loved one for the hospital staff in advance.

Stimulus Check Update

Information from the House Ways and Means Committee states that, like other tax credits, the stimulus payments do **not** count as income or resources for means-tested programs. So receiving a rebate will not interfere with someone's eligibility for SSI, SNAP, Medicaid, ACA premium credits, TANF, housing assistance, or other income-related federal programs. These rebates do not affect receipt of state or federal unemployment compensation.

As a reminder, SSI recipients will automatically receive stimulus checks of \$1200. These funds will not count as income and will not be counted as assets for the first twelve months for SSI and Medicaid eligibility. However, adults who are claimed as dependents by others are not eligible for stimulus checks.

Check In and Speak Up: **Survey for Individuals with I/DD**

Advocates in Action (AinA) designed a questionnaire with a team of Self-Advocates who receive services through the RI DD System, but any Rhode Islander who has a developmental disability is welcome to answer the questions. The roll out was delayed slightly, but it's up and available now!

AinA will use your answers to figure out how to help during these challenging and uncertain times. They also plan to share the results with the RI Division of Developmental Disabilities and other allies. The combined results of what everyone gives for answers can help guide the people who are developing Rhode Island's emergency response to the pandemic for the DD Community. In other words, you can help make sure that they hear from individuals as they work on policies and make some important decisions in the days and weeks ahead.

You can find the questionnaire at <https://www.advocatesinaction.org/oksurvey.php>

Virtual Social Engagement Opportunity from Best Buddies

Social engagement is difficult for many during this COVID-19 crisis. Best Buddies has extended an invitation for people to join their e-buddies program.

e-Buddies promotes social inclusion online for people with intellectual and developmental disabilities. In e-Buddies, people with and without intellectual and developmental disabilities, such as autism and Down syndrome, come together online to form friendships and a community that celebrates their diversity of character and abilities. Anyone can be in e-Buddies! e-Buddies is great for students and adults with and without disabilities.

Here is a link for more information on how to join: <https://www.bestbuddies.org/what-we-do/ebuddies/>

Do you have the supplies you need?

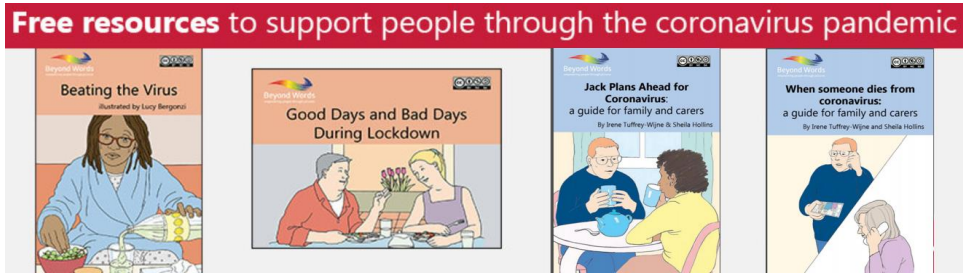
If you receive DD services, are medically compromised and are having a hard time getting PPE supplies, please let us know. Call your social caseworker at (401) 462-3421 or email BHDDH.AskDD@bhddh.ri.gov with the subject line: PPE Supplies and tell us what you need.

We will be developing a list in case we are able to secure some supplies for individuals, and so we can help inform the discussion about ongoing needs.

Please note the intent of this is to track the needs of people who are medically compromised, in need for PPE and having difficulty obtaining supplies.

Books Beyond Words

<https://booksbeyondwords.co.uk/>



Beyond Words provides books and training to support people who find pictures easier to understand than words. Whether supporting somebody with a learning disability or communication difficulty, their resources empower people through pictures. Other books are available for purchase, but they are providing free books related to COVID for download.

- **Beating the Virus** A short wordless story that will help people to understand what to do if you have Coronavirus and how to keep yourself and those who you care about safe. The story also shows how to safely help others who may be self-isolating.
- **Good Days and Bad Days During Lockdown** A wordless booklet with scenes looking at what makes a 'good day' and what makes a 'bad day'. Scenes address social distancing, lockdown, mental health and daily routines.
- **Jack Plans Ahead for Coronavirus** An illustrated resource on end of life care planning in the context of coronavirus. Aimed at family and carers.
- **When Someone Dies from Coronavirus** A guide for family and carers

Autism Society of America Facebook Live COVID-19 Series

The Autism Society of America launched a Facebook Live series dedicated to providing relevant, COVID-19 information for the autism community. The weekly broadcast will feature an expert discussing topics like mental health, federal emergency funding, and continuing education at home. They are also co-hosting a second Facebook Live series where experts will discuss ongoing challenges for caretakers during the COVID-19 crisis.

Tune in to weekly episodes, with two chances to engage with experts, or watch at your convenience by accessing past episodes on their website: <https://www.autism-society.org/facebook-live-coronavirus-information-series/>

Silver Linings

This is a section we're adding to highlight some of the good things going on in the midst of all the difficulties right now. If you have anything you'd like to share, please send it to BHDDH.AskDD@bhddh.ri.gov with the subject: Silver Linings.

As social distancing measures mean individuals stay home, a **mobile DJ team** is bringing a little fun to group homes. Watch the video from Channel 10: <https://turnto10.com/news/coronavirus/show-us-something-good/a-mobile-dj-is-taking-dance-parties-to-group-homes>

Providing Direct Support during the COVID-19 Pandemic

Direct Support Professionals Survey, April 2020

The National Alliance of Direct Support Professionals (NADSP) in partnership with the Institute on Community Integration at the University of Minnesota has developed a survey for Direct Support Professionals (DSPs) to understand the impact of the COVID-19 pandemic on this workforce and identify the most effective ways to protect DSPs and the people they support.

The results of this survey will be shared widely with policymakers, services providers, direct support professionals, families, and stakeholders. Information from this survey can prove useful to state systems as they construct plans for recovery and future disaster planning. Answers will be anonymous.

The survey is at: https://umn.qualtrics.com/jfe/form/SV_9SsdU9SzTobvsLr

Survey for Adults with Disabilities on

Healthcare and Healthcare Access

The American Association on Health and Disability (AAHD) is conducting a confidential, real-time online assessment of the impact of the coronavirus pandemic on healthcare and healthcare access among adults with a range of disabilities. AAHD developed the COVID-19 & Disability Survey to collect and analyze that data. We are asking our colleagues to share the survey broadly amongst your constituents. Please use this link:

www.surveymonkey.com/r/COVID-19-Disability_r20.rs6.net

The survey is open until May 1, 2020 at 11:59pm ET.

Other AAHD Resources

AAHD has created 60-second videos you can watch on YouTube. www.youtube.com_r20.rs6.net

- **COVID-19: Who's at Risk for Complications?**
- **COVID-19 & Disability: Social Distancing**
- **COVID-19 & Disability - Precautions for People in Wheelchairs**

AAHD has also developed a resource list for people with disabilities. To review the comprehensive list of resources, please visit the AAHD website: www.aahd.us/covid-19/

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 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

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

Center for Disease Control COVID-19 Information

Website 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

RI Parent Information Network (RIPIN)

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

Call Center (401) 270-0101 or email 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 the Division, you can sign up on our website. From the main BHDDH page at 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 the Division

The department is working on a reduced workforce and therefore calls should not be placed directly to your social caseworker. DDD has put 24-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 below. 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.

AM **M T W Th F** **PM**

401-462-3421

8:30 AM → → → → → **4:00 PM**

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

PM **M T W Th F** **PM**

401-265-7461

4:00 PM → → → → → **10:00 PM**

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

AM **SAT SUN** **PM**

401-265-7461

8:30 AM → → → → → **10:00 PM**

ON WEEKENDS FOR:

- **VITAL**, Non-Medical Support Needs

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

Send general questions to the
AskDD email address. Please
do not email critical issues.
BHDDH.AskDD@bhddh.ri.gov

911

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

For medical or
healthcare related
emergencies, call
your Primary Care

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!

VIA EMAIL TO: nicole.alexanderscott@health.ri.gov

April 14, 2020

Director Nicole Alexander-Scott, MD, MPH
Rhode Island Department of Health
3 Capitol Hill
Providence, RI 02908

RE: Hospital Visitation Policies for Individuals with Disabilities

Dear Director Alexander-Scott:

I write on behalf of Disability Rights Rhode Island (DRRI), the federally mandated designated Protection and Advocacy (P&A) agency for Rhode Island.¹ As the P&A, we are concerned about those Rhode Islanders with disabilities who may need assistance to access hospital services during the COVID-19 crisis. DRRI urges the Department of Health to adopt a statewide policy on hospital visitors for the duration of this crisis that includes exceptions for people with disabilities who may require a support or other assistance during emergency room visits and hospitalizations.

Rhode Island Department of Health regulations guarantee visitation rights during inpatient health care services in a hospital. These regulations permit a person in a health care setting to designate up to five (5) individuals whom the person deems to be considered as an immediate family member (including those whom have no legal relationship to the patient by blood or marriage) to be granted visitation while receiving inpatient care. See, 216-RICR-40-10-4. At the present time, Rhode Island hospitals are developing their own visitor policies, some of which exclude guardians and caregivers of people with disabilities from participation in their care. During this COVID-19 pandemic, it is important to remember that individuals with disabilities retain their rights to be free from discrimination and may need communication and behavioral supports in hospital settings as reasonable accommodations. These rights are guaranteed under federal and state law, including the Americans with Disabilities Act (ADA), Section 504 of the Rehabilitation Act, Section 1557 of the Affordable Care Act (ACA), as well as the Rhode Island Civil Rights of People with Disabilities Act.

¹ P&A agencies are created pursuant to federal laws designed to protect individuals with mental health, developmental and other disabilities, including the Protection and Advocacy for Individuals with Mental Illness Act (PAIMI) 42 U.S.C. § 10801 et seq., the Developmental Disabilities Assistance and Bill of Rights Act, 42 U.S.C. § 15041 et seq., and the Protection and Advocacy of Individual Rights Act, 29 U.S.C. § 794e.

To assist the Department in addressing the needs of these vulnerable individuals, DRRI reviewed several policies from various states hospitals. We propose that Rhode Island immediately issue a directive stating that hospitals that bar visitors must include an exception for patients for whom a support person has been determined to be essential to the care of the patient, including patients who have altered mental status, communication barriers, or behavioral concerns including those with intellectual and/or developmental disabilities (I/DD) and patients with cognitive impairments including dementia.

We suggest the directive include language to reflect this need, and at least permit the designation of two support people to ease the burden on any one individual support person, while still permitting only one support person to be present at a time. This approach would be consisted with New York's approach. See,

https://opwdd.ny.gov/system/files/documents/2020/04/doh_covid19_hospitalvisitation_4.10.20.pdf

We at DRRI want to thank you for the tireless work of the Department of Health, as well as all state agencies during the COVID-19 pandemic. Please do not hesitate to contact me if you have questions regarding this matter or would like additional information including suggested language for the directive.

Sincerely,

/s/ Morna A. Murray

Morna A. Murray, J.D.
Executive Director

cc: Honorable Gina M. Raimondo, Governor
Kathryn Power, Director, RI Dept. of Behavioral Healthcare, Developmental Disabilities and Hospitals

drri.org

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☎: 401-831-3150
☎: 401-831-5335

☎: 401-274-5568
☎: 800-733-5332



Communication**FIRST**

Because communication is a human right.

COVID-19 Communication Rights Toolkit **with Printable Patient Accommodations Request Form** (United States)

Patients with the coronavirus who need communication tools and supports due to speech-related disabilities face greater risks of discrimination and isolation during this pandemic. **Your legal and civil rights to access your communication supports do not go away during an emergency, in quarantine, or in the hospital!** But, for safety reasons, your family members and others who help you communicate may not be allowed to join you in the hospital. And you may face other barriers to communicating your needs and desires while you are being treated.

This toolkit: (1) explains your communication rights; (2) provides tips on advocating for them, and (3) has an accommodation request form you can bring to the hospital.

What are your communication rights in health care settings?

If you are a patient in a hospital or other health care setting, you still have communication and other civil rights under Titles II and III of the Americans with Disabilities Act (ADA), Section 504 of the Rehabilitation Act, and Section 1557 of the Affordable Care Act (ACA)—**even during a pandemic**. Hospitals and other health care facilities must meet your communication needs at all times. They also have an ethical duty to try to obtain your informed consent before treating or withholding treatment.

- **Communication supports:** Health care facilities are required to provide supports and services to ensure effective and clear communication 24 hours a day for patients who have hearing, vision, and/or speech impairments. The communication preferences of the patient should take priority.
- **Other reasonable steps:** Hospitals must provide other reasonable modifications and aids to give a patient with a disability equal opportunity to benefit from treatment.
- **No discrimination in treatment:** Hospitals cannot discriminate, exclude, or treat patients differently because of their disability. Treatment decisions must be based on individual needs and not on generalized assumptions about a person's disability or their quality of life. Care and treatment cannot be denied



Communication**FIRST**

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or lowered in priority based on a person's pre-existing disability or an assumption that the person has a lower prospect of survival due to the disability. A person with a disability who has COVID-19 cannot be excluded from treatment just based on their disability or inability to communicate.

How can you protect your communication rights at a hospital?

- Complete the attached **one-page form** with your individual needs and preferences as soon as possible. If you need to be treated, bring **two copies** (laminated, if possible). If you don't have access to a printer, send a copy to your health care provider and ask them to print it out.
 - While you are healthy, it is a good idea to prepare a **communication kit** with a range of tools you might need when you are sick during a long hospital stay, and may not have access to your regular communication support people. Include instructions for hospital staff.
- Tell the hospital **registration clerk and nursing staff** that you are requesting communication accommodations and hand or send them your form.
 - Also be sure to bring your communication kit, including all devices, chargers, and communication boards you might need. Keep them close.
- **If staff refuse to provide access to your communication supports:**
 - The hospital should have a webpage about disability discrimination and communication access rights that you can point to.
 - Contact the hospital's Patient Relations office or Civil Rights Coordinator.
 - Consider filing a grievance with the hospital's Civil Rights Coordinator. Request assistance from Patient Relations if needed.
 - If necessary, file a complaint with the U.S. Department of Health and Human Services, Office for Civil Rights, electronically at www.ocrportal.hhs.gov/ocr/portal/lobby.jsf.
- **For legal assistance and referral**, you can contact the Protection and Advocacy office in your state: <https://www.ndrn.org/about/ndrn-member-agencies/>



Communication**FIRST**

Because communication is a human right.

Legal References and Links

- **Americans with Disabilities Act** applies to public and private hospitals
 - Statute: [42 U.S.C. §§ 12101 et seq.](#)
 - Title II Regulations (publicly run health care facilities): [28 C.F.R. § 35.130](#) (prohibits disability discrimination); [28 C.F.R. § 35.160](#) (requirement to provide communication supports)
 - Title III Regulations (private health care facilities): [28 C.F.R. § 36.302](#) (disability-related modifications must be made); [28 C.F.R. § 36.303](#) (communication supports required)
- **Section 504 of the Rehabilitation Act** covers health care facilities that accept federal financial assistance, including Medicare and Medicaid
 - Statute: [29 U.S.C. § 794](#)
 - Regulations: [45 C.F.R. § 84.4](#) (prohibits disability discrimination), [45 C.F.R. § 84.52](#) (requires health care facilities to provide communication supports); [28 C.F.R. § 41.51](#) (must provide aids, benefits, and services to people with disabilities at a level affords equal opportunity to obtain the same result, to gain the same benefit, or to reach the same level of achievement as that provided to others)
- **Section 1557 of the Affordable Care Act** prohibits disability discrimination in certain health programs or activities; requires covered entities to ensure programs, services, activities and facilities are accessible
 - Statute: [42 U.S.C. § 18116](#)
 - Regulations: [45 C.F.R. § 92.101\(a\)\(1\)](#); [45 C.F.R. § 92.205](#)

Additional Resources

- **Communication Tools to Facilitate Communication Between Patients and Providers During COVID-19:** [PPC Taskforce](#)
- **“Health Passport”** (general fillable 4-page form): [My Health Passport](#)
- **Medical Order for Life-Sustaining Treatment** (gives patients more control over end-of-life care, including extraordinary measures and CPR): [National POLST Form](#); [California POLST Form](#) (in 13 languages)
- **Legal Resources on Medical Rationing on Basis of Disability:** [DREDF Memo](#)

My Communication Rights and Accommodation Needs

Patient Name: _____ Date: _____

Emergency Contact: _____ Tel: _____

I am capable of communicating my needs and preferences by (e.g., using my eyes/index finger to point to the picture cards/letterboard/number choices in the communication kit I brought with me; the X app on my iPad, which needs to be charged and within my reach at all times; handwriting; modified ASL; having my communication support person present at all times; having my emergency contact read my lips or revoice my speech by video call):

I have a communication disability and request the following reasonable accommodations under the Americans with Disabilities Act, Section 504 of the Rehabilitation Act of 1973, and Section 1557 of the Affordable Care Act while I am under your care:

1. Please keep a copy of this document visible at the top of my chart.
2. Please keep a copy of this document posted in a prominent, visible place near me at all times while I am in the hospital.
3. Please communicate with me using clear, plain language what the options are, the risks and benefits of each, and what the proposed course of action is.
4. **I need the communication-related accommodations listed above to communicate effectively and to provide informed consent.**
5. If I am able to communicate using my requested accommodations, please ask my opinion about everything.
6. If you have any trouble providing my requested communication supports, please make a video call to my emergency contact who can help.
7. If I am unable to communicate at any time and do not have a trusted communication support person present, my emergency contact should be contacted by video before any decision about or change to my care is made.
8. Unless I communicate otherwise, I do not consent to any decision to withhold treatment just because I have an underlying disability, or based on the assumption that my life is not as valuable as a nondisabled person, or that I will suffer less if I do not receive treatment.

Disability Rights

RHODE ISLAND

The Designated Protection and Advocacy System for Rhode Island

An Update from DRRI on COVID-19



Alert! New Date and Big Changes for RI's Presidential Preference Primary

COVID-19 is impacting EVERYTHING these days – including elections.

Please note that RI's Presidential Preference Primary will now take place on **June 2, 2020**, and will be conducted as a predominantly mail ballot primary.

This means that **the State will mail Applications for Mail Ballot to every registered voter** so that voters can vote by mail instead of voting in person at the polls.

You must return your Mail Ballot Application in order to receive a Ballot by mail. The postage will be pre-paid by the State.

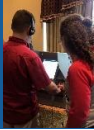
There will be a limited number of polling places open on June 2, 2020, with accessible voting systems.

All voters who are able to vote by mail are encouraged to do so.

The Presidential Preference Primary is when party voters (Democrat and Republican) chose the candidate they wish to represent their party in the November General Election and voters choose delegates to the presidential nominating convention.

Under Rhode Island law,

- Registered Democrat voters can only vote in the Democrat primary
- Registered Republican voters can only vote in the Republican primary
- Unaffiliated voters can choose which primary they would like to vote in



Things to do so that you can vote in the June 2nd Presidential Preference Primary Election:

- **Register to vote by May 3, 2020.** If you are unsure whether you are registered to vote, you can call Disability Rights RI at 401-831-3150, the Secretary of State's Elections office at 401-222-2340, or you may check online at [https://vote.sos.ri.gov/\[r20.rs6.net\]](https://vote.sos.ri.gov/[r20.rs6.net]).
- **Make sure that your current mailing address is the address where you are registered to vote.** If you need to update your registration to correct your address, you must do so by **May 3, 2020**.
- Review a sample ballot when you check your voter registration status at [https://vote.sos.ri.gov/\[r20.rs6.net\]](https://vote.sos.ri.gov/[r20.rs6.net]).
- When you receive your ballot, mark it and return it according to the instructions. **Your completed ballot must be received by the close of polls on June 2, 2020.** Allow ample time for your ballot to travel via mail.
- During the emergency mail ballot period from May 19 to June 1, you may be able to vote at your City or Town Hall. If you plan to vote in person during the emergency mail ballot period or on June 2, contact your local voting office called the "board of canvassers" to find out where and when you can vote. Contact information for your local board of canvassers can be found here [https://elections.ri.gov/canvassers/\[r20.rs6.net\]](https://elections.ri.gov/canvassers/[r20.rs6.net]). Any voter who applies for a mail ballot and then attempts to vote in person will be required to vote a provisional ballot.

**KEEP CALM
AND
VOTE BY MAIL**

If you have questions or concerns about the Presidential Preference Primary, your voting rights and any other disability-related legal concerns during this crisis, please contact us at:

Disability Rights Rhode Island
401-831-3150
contact@drri.org

Our answering service is available 24/7 and if you do not reach us during business hours, a member of our staff will return your call within 24 hours.

www.drri.org [\[r20.rs6.net\]](https://vote.sos.ri.gov/[r20.rs6.net])
(401) 831-3150



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