

Healthcare Access and COVID-19 – Frequently Asked Questions

The Down Syndrome Association of Minnesota has pulled together the following information to shed light on some of the most common questions and concerns we are hearing related to COVID-19, specifically as it relates to access to healthcare. This document contains information about individual's rights, hospital visitor policies, best practices related to adults under guardianship, and up-to-date information from national organizations.

Information Clarifying Individual's Rights and Access to Care

We strive to provide up-to-date, accurate information about COVID-19 and disability rights. We have been following the news regarding state disaster preparedness plans—specifically those that explicitly or implicitly put people with intellectual disabilities at a lower priority than others to receive lifesaving treatment if resources are scarce. Over the last 2 weeks, there have been official complaints against Washington, Alabama, Tennessee, and Kansas filed with the U.S. Department of Health & Human Services Office of Civil Rights (“HHS-OCR”).

On March 28, 2020 the HHS-OCR issued a guidance document making clear that disability rights laws apply to rationing decisions. “HHS is committed to leaving no one behind during an emergency, and this guidance is designed to help health care providers meet that goal,” said Roger Severino, OCR Director. “Persons with disabilities, with limited English skills, or needing religious accommodations should not be put at the end of the line for health services during emergencies. Our civil rights laws protect the equal dignity of every human life from ruthless utilitarianism,” Severino added. The full **HHS-OCR bulletin** can be found here:

<https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf>

Information about **Minnesota's plan and Crisis Standards of Care** can be found here:

<https://www.health.state.mn.us/communities/ep/surge/crisis/index.html>

On March 25, 2020 a coalition of Minnesota's leading disability organizations issued whitepaper entitled “**Upholding the Rights of People with Disabilities During the Coronavirus Pandemic.**” The document serves as a framework for elected officials, state agencies, services providers and others as they navigate this current public health crisis. Access that document here: <https://ici.umn.edu/news/upholding-the-rights-of-people-with-disabilities-during-the-coronavirus-pandemic>

Summary of Hospital Access and Visitors Policies – Pediatric Patients (Under 18)

Overall, all hospitals are applying stricter visitor guideline during this public health crisis. We understand that information on some websites is not always clear and potentially being kept from a loved one causes heightened anxiety. The following is a summary of hospital visiting policies for pediatric patients for the major health systems in Minnesota and bordering communities in Wisconsin, North Dakota, and South Dakota. It is fair to assume that all hospitals require visitors to be healthy/symptom-free, even if it is not spelled out in their policy.

Allina (includes Abbott Northwestern, WestHealth, Buffalo, Cambridge Medical Center, District One, Mercy, Mercy – Unity Campus, New Ulm Medical Center, Owatonna, Regina, River Falls, St. Francis Regional Medical Center, United)

- One parent/guardian per patient will be allowed in the room.
- The parent/guardian may stay overnight in accordance with usual policy.
- Cannot have flu-like symptoms, including a cough, fever or respiratory concern

CentraCare (includes Long Prairie, Melrose, Monticello, Paynesville, Sauk Centre, St. Cloud)

- Parents of a minor child or legal guardian of an adult with cognitive or developmental disabilities
- Each patient is limited to one healthy visitor at a time.
- All visitors will be screened for signs, symptoms and fever.
- Visitors who stay from one day to the next must be rescreened daily.

Children's Minnesota

- Two consistent legal guardians may be at the bedside during a patient's stay.
- If there is only one legal guardian, they may designate one other consistent adult to fulfill this role during the patient's stay.

- Visiting adults must be well and will be screened for wellness every day.
- No other visitors will be permitted anywhere in the hospital, including siblings.

Essential Health (includes St. Mary's – Superior, St. Mary's – Detroit Lakes, St. Mary's – Duluth, Ada, Deer River, Duluth, Fargo, Fosston, Graceville, Aurora, Sandstone, St. Joseph's Medical Center, Virginia)

- One person allowed to accompany children.
- Two parents are permitted for neonatal intensive care.
- Anyone accompanying a patient is required to be healthy.
- Anyone accompanying a patient is required to be at least 18 years old.

HealthPartners/Park Nicollet (including Regions, Methodist, Hutchinson, Lakeview, St. Francis Regional Medical Center, Amery/WI, Hudson/WI, Westfields – New Richmond/WI)

- Parents or Legal Guardians are permitted.
- All visitors will be screened for COVID-19 symptoms.
- If you are sick, you will not be allowed to visit patients.

Gillette Children's

- Two immediate family members or caregivers per patient per 24 hour period.
- No visitors under 18
- Visitors who have a cough, shortness of breath, or fever within the last 72 hours will not be permitted.
- People who have travelled internationally in the last 14 days will not be permitted.

Hennepin Health/HCMC

- One well parent or guardian at a time.

M Health Fairview (includes Fairview Range, Grand Itasca, Bethesda, Lakes Medical Center, Northland Medical Center, Ridges, Southdale, St. John's, St. Joseph's, East Bank, Masonic Children's, Woodwinds)

- One visitor age 18 or older.
- Individuals who are sick or have known exposure to COVID-29 are not allowed to visit.
- All visitors to our hospitals and clinics will be screened for symptoms and COVID-19 risk at each visit.

Mayo

- One visitor for pediatric patients.

North Memorial Health Hospital & Maple Grove Hospital

- One healthy parent or legal guardian at a time.
- A healthy individual is defined as someone who does not have a fever, cough, or other respiratory symptoms.
- Someone who has been directly exposed to an individual with COVID-19 is not allowed to visit for 14 days since last exposure.

Sanford Health (includes Aberdeen/SD, Bismarck/ND, Canby, Fargo/ND, South University – Fargo/ND, Thief River Falls, Tracy, Vermillion, Westbrook, Wheaton, Winner, Worthington)

- One per-determined visitor per day.

Hospital Access and Advice Regarding Adults with Down Syndrome

We reached out individually to all of the hospital systems included above. Not all systems immediately responded, but of those that did, ALL stated that **pediatric visitor rules should also apply to adults under guardianship**. In addition, in cases where the patient needs physical assistance, the visitor or guardian attending with the patient needs to be able to provide that assistance.

We reached out to Attorney Joseph P. Kukla of [Thiel, Anderson & Kukla PLLP](#) for his advice on how guardians should prepare if their loved one requires medical care. His advice is as follows:

- A guardian should **have their Letters of Guardianship document available and ready to present** if their adult child/ward/protected person requires medical attention.
 - o The Letters of Guardianship document is the shorthand version of the court order appointing the guardian(s). For reference, this the document usually requested by the county case manager, by schools or day program providers, and by the Social Security Administration when requiring proof of the guardian's authority.
 - o A primary care doctor may already have a copy of the Letters on file, but the guardians should not count on that information being available to other healthcare providers.
- If it is a situation where you are **able to set up an appointment in advance**, the guardian should make it clear to the healthcare provider that they are a court-appointed guardian with the authority to make healthcare decisions and review medical records, and then **either deliver a copy of the Letters ahead of time or bring the document to the appointment**.
- If it is an **emergency or urgent care matter**, the guardian should **bring the document with them** and thus should take care to make sure it is readily available and easily accessible—just as you would take care to have your insurance information available in that situation.
- **With guardianship, a doctor MUST consult with the guardian in ALL circumstances**. However, if proof of guardianship is not established, a healthcare provider must defer to HIPAA authority and the individual's right to privacy in medical matters.
 - o Even if a disability is physically obvious, every adult is presumed to be able to make medical decisions for themselves and healthcare providers will protect that legal right even if the parents (or also the spouse of a protected person) are present and arguing otherwise.
 - o Therefore, providing the Letters of Guardianship either ahead of time or physically at the medical facility will allow the healthcare providers and their staff to work with the guardian efficiently and without concern about their legal authority to review private records and make critical decisions.

Additional Resources from our National Partners

- **Comprehensive Q&A document** was collaboratively produced by the Down Syndrome Medical Interest Group-USA, LuMind IDSC, NDSS, NDSC, and Global Down Syndrome Foundation
 - o Expanded version: <https://www.ndscenter.org/wp-content/uploads/COVID19-DS-QA-EXP-03-27-20.pdf>
 - o Abbreviated version: <https://www.ndscenter.org/wp-content/uploads/COVID19-DS-QA-ABBR-03-27-20.pdf>
- **LuMind IDSC**: <https://www.lumindidsc.org/coronavirus-and-down-syndrome/>
- **NDSS**: https://www.ndss.org/wp-content/uploads/2020/03/Coronavirus_Fact_Sheet_-1.pdf
- **NDSC**: <https://www.ndscenter.org/programs-resources/covid-19-resources/>
- **Global Down Syndrome Foundation**: <https://www.globaldownsyndrome.org/covid-19/>
- **MassGeneral Down Syndrome Clinic**: <https://us18.campaign-archive.com/home/?u=091e3808ad727b47f62136992&id=4808ab3761>
- **Adult Down Syndrome Center**: <https://adsresources.advocatehealth.com/resources/?category=COVID-19>
- **Easy-to-Read Information for Self-Advocates**: <https://selfadvocacyinfo.org/wp-content/uploads/2020/03/Plain-Language-Information-on-Coronavirus.pdf>

Questions & Contact Information

If you have any questions about the information in this document or additional resources the Down Syndrome Association of Minnesota can provide, a list of the best contacts for most areas are listed below.

New/Expectant Parents	If you are, or know, a new or expectant parent looking for resources, our new and expectant parent support line is open and staffed by a live person 365 days a year.	Call or text 651-231-8932, 365 days a year.
Financial Assistance Program Inquiries	Financial Assistance Program has been extended to all DSAMN families facing financial hardship.	Sarah Curfman , Executive Director: sarah@dsamn.org or 651-603-0720, press 3
General Program Questions	Including our parent groups, general support resources, or connecting directly with another parent for mentorship and support.	Tracy Hafeman , Program Manager: tracy@dsamn.org or 651-603-0720, press 1
Bike Camp Questions	Including questions about session confirmation, a new registration, and other general information.	Amanda Woll , Bike Camp Coordinator: amanda@dsamn.org
Referrals and Resource Connections	If you or a family member are looking for a medical provider or community resource referral.	Sarah Curfman , Executive Director: sarah@dsamn.org or 651-603-0720, press 3
Medical Provider Resource Requests	If you are a medical provider looking to replenish your brochures, including materials for new parents.	New requests: https://www.dsamn.org/providers/ Status of materials you have already requested: dsamn@dsamn.org .
New or Existing Memberships Questions	Membership is free and open to anyone with a passion and connection to our mission.	To join: https://www.dsamn.org/support-us/membership-2/ To update: https://www.dsamn.org/support-us/membership-2/current-member-update/
Sponsorship and Events Questions	Questions about an upcoming event or postponed event, or have any questions about donations or sponsorship.	Sarah Curfman , Executive Director: sarah@dsamn.org or 651-603-0720, press 3
Donation Inquiries	Including general donations, recurring donations, and donations directly to our Financial Assistance Program.	Annie Hines , Office Manager: annie@dsamn.org or 651-603-0720, press 2.
Finance and Operations Questions	Including donation/tax receipts, other recently completed financial transaction, or registration assistance.	Annie Hines , Office Manager: annie@dsamn.org or 651-603-0720, press 2.
Additional Questions, Comments, or Concerns		Sarah Curfman , Executive Director: sarah@dsamn.org or 651-603-0720, press 3

About The Down Syndrome Association of Minnesota

The Down Syndrome Association of Minnesota is a statewide nonprofit organization with the mission to empower individuals and families, create community, and celebrate the abilities of people with Down syndrome. We do this by providing support, assistance, and opportunity to individuals with Down syndrome and their families. Our vision is for all people with Down syndrome to achieve their fullest potential in an accepting and inclusive society. We are the leading source of information and support for individuals, families, and providers across the state of Minnesota.

Our organization is committed to providing support, assistance and opportunity to individuals with Down syndrome and their families. We support residents of Minnesota as well as communities in neighboring states. Membership is free and open to anyone with an interest or passion for empowering, connecting, and celebrating individuals with Down syndrome.

OUR PROGRAMS & SERVICES

We provide programs and services across three main focus areas—information & outreach, individual & family support, and advocacy & awareness.

Information & Outreach

- Publications for new and expectant parents, medical professionals, and the broader community to better understand Down syndrome.
- Annual Statewide Learning Conference for parents, caregivers, and individuals with Down syndrome.
- Additional conferences, webinars, and educational programming for individuals with Down syndrome, their parents, grandparents, and caregivers.
- Back-to-school workshops and resource fairs for parents and educators.
- Medical outreach to healthcare providers to educate and support the dissemination of up-to-date and accurate information about Down syndrome.
- Employment outreach to potential employers, government agencies and partner organizations to educate and support hiring individuals with Down syndrome.

Individual & Family Support

- Support 365 days a year through our new and expectant parent hotline.
- In-person parent support groups in communities across the state.
- Specialty support groups including Adult Matters, Dual Diagnosis, Somali Moms, Spanish-Speaking Family and Grandparent groups.
- Parent to Parent Connection matching new or expectant parents through one-on-one conversations and mentorship with parents who have experienced their same feelings, struggles, and celebrations.
- Networking opportunities for families through our quarterly New Parent Breakfasts, bi-annual First Birthday Bashes, Summer Celebrations in 6 communities, and Fall Family Celebration Pancake Breakfast.
- Collaborative programming with local and national nonprofit partners.

Advocacy & Awareness

- Disability Day @ The Capital in partnership with other disability organizations.
- Annual Step Up for Down Syndrome Walk and Family Festival which attracts more than 5,000 individuals from across the state to connect and celebrate the abilities of individuals with Down syndrome.
- World Down Syndrome Day Celebration, a free family event offered in partnership with the Mall of America to celebrate the abilities of people with Down syndrome.
- Collaboration with state and federal disability organizations including NDSS, NDSC, the Global Down Syndrome Foundation, the Arc Minnesota, PACER center and others to advocate for the rights of people with Down syndrome.
- Ongoing advocacy and awareness efforts with government offices and agencies whose actions and policies affect our members.

To learn more go to www.dsamn.org or follow us on Facebook (@DSAMN) and Instagram (Down Syndrome Association-MN) for up to date information about events, community stories, and programs.