



UPDATED 5.5.2020

The resources included here are to provide information relating to individuals with Down syndrome living in North Dakota. Many organizations across the country are pulling together resource documents for their specific populations. We will continue to update this document and change the date above as we add resources. If you have questions or want more information, please contact Roxane Romanick, our Executive Director, at 701.391.7421 or email at info@designergenesnd.com.

SERVICE DELIVERY IN NORTH DAKOTA

- [North Dakota Department of Human Services COVID-19 Resources](#)
 - Among other documents, several Child Care Guidance Documents are listed under provider resources.
- [Division of Developmental Disabilities FAQ for Providers](#)
- [FAQ for ND Early Intervention Infant Development Providers](#)

DOWN SYNDROME SPECIFIC INFORMATION

- [Work Considerations for Individuals with Down Syndrome](#)
- [Travel Considerations for Individuals with Down Syndrome](#)
- [Health Considerations and Information relating to COVID-19 for Individuals with Down Syndrome](#)

- [Boston Mass Down Syndrome Program Updates/Activities for Individuals with Down syndrome](#)
- [Gigi's Playhouse Fargo Online Programs](#)
- [Karen Gaffney Asks About COVID-19](#)

FINANCIAL BENEFITS

- [Information relating CARES Coronavirus Bill Cash Benefits and Means-Tested Program](#)
- [The ARC of the United States Statement on 2020 CARES Act Recover Rebates](#)
- [Social Security Administration Statement regarding SSI Recipients and Stimulus Payments](#)

CIVIL RIGHTS

Designer Genes has closely monitoring both state and federal policy/procedure regarding crisis response planning, especially those for individuals with intellectual/developmental disabilities. Several states have encountered lawsuits from various disability advocacy groups with official complaints about discriminating policies, such as health care rationing decisions. On March 28, 2020 the federal Office of Civil Rights for Health and Human Services issued this statement: <https://nddac.org/wp-content/uploads/2020/04/COVID-19-Standard-of-Care-Document.pdf>

While North Dakota has kept hospitalizations to a minimum, the North Dakota Disability Advocacy Consortium, a coalition of North Dakota's leading disability organizations, including Designer Genes has continued to put the rights issues in front of the Governor, the Department of Health and the Department of Human Services. The correspondence can be found at: <https://nddac.org/wp-content/uploads/2020/04/COVID-19-Standard-of-Care-Document.pdf>

If you feel like your loved one's rights are being violated and you live in North Dakota, contact Protection and Advocacy at 701.328.2950 or 800.472.2670.

Guardianship Guidance for Adults with Down Syndrome – credits to the Down Syndrome Association of Minnesota:

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.
- 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.
- 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.
- 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.
- 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.

RESOURCES EXPLAINING COVID-19 AND SELF-CARE TO INDIVIDUALS WITH COGNITIVE DISABILITIES

- [National Down Syndrome Congress on explaining what COVID-19 is, healthy hand washing, hygiene, and eating](#)

Social Story Options

- [Printable Book on What is COVID](#)
- [Video on What is COVID](#)
- [Video On Wearing Masks](#)
- [Printable Book on Wearing Masks](#)

OTHER HELPFUL RESOURCES

- [Family Voices of North Dakota](#)
- [Sample Medical Emergency Form](#)
- [Emergency Name Badge Template](#)

Financial Assistance Funds

- [North Dakota Council on Developmental Disabilities COVID-19 Grant Program](#)
- [Global Down Syndrome Foundation Individual Grants](#)
- Designer Genes HOPE Funds – Contact Roxane at 701-391-7421 or info@designergenesnd.com.

EDUCATION

- [North Dakota Department of Public Instruction COVID-19 Parent FAQ for parents who have children on IEP's](#)
- [Boston Mass Tips on E-Learning and Students with Down Syndrome](#)
- [Federal Office of Special Education Q & A relating to providing services for students with disabilities during the COVID-19 emergency](#)
- [Early Childhood Technical Assistance \(national technical assistance center for Early Intervention and Early Childhood Special Education\) has a number of federal policy documents located at their site](#)
- [Tips for Virtually Educating Students with Disabilities](#)
- [NDSC's Parent Webinar Series: Preparing for Online Learning](#)
- [National Center for Learning Disabilities – Four Actions to Improve your Child's Experience with Online Learning](#)
- [North Dakota Department of Public Instruction Guidance on Extended School Year and Compensatory Services](#)