



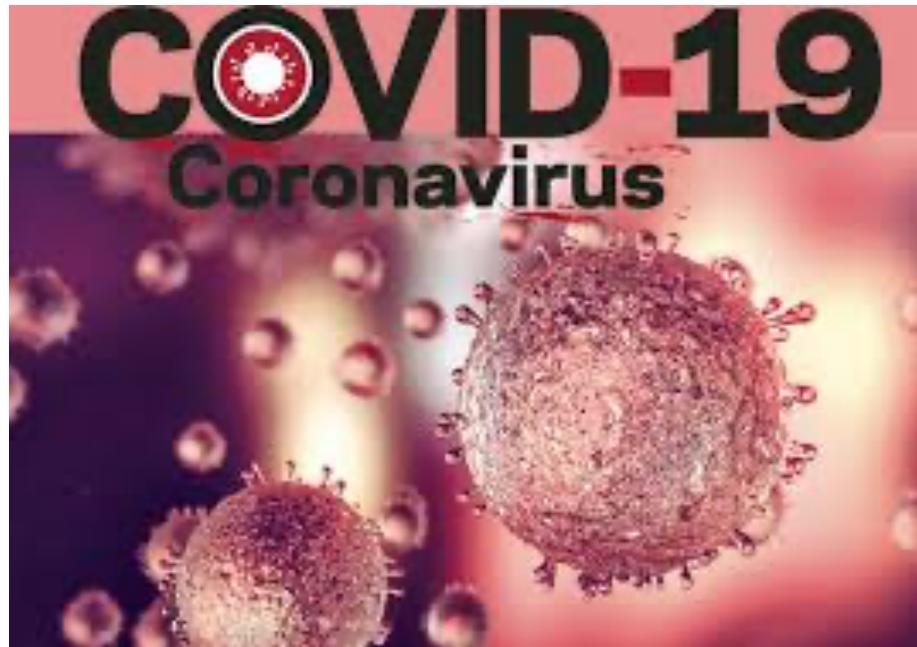
NDAC Briefing on COVID-19

April 2, 2020

NDAC
National Down Syndrome
Advocacy Coalition

Agenda

- Welcome
- Summary of COVID-19 Bills Passed So Far
- Asks for 4th COVID-19 Bill
- Discriminatory rationing of health care
- US Dept of Education resources on distance learning



COVID-19 Bills Passed So Far

- Coronavirus Preparedness and Response Supplemental Appropriations Act – became law March 6, 2020 [COVID-19 #1]
 - \$8 billion in emergency funding for existing health & human services spending
- Families First Coronavirus Response Act – became law March 19 [COVID-19 #2]
 - Paid sick leave (for parents whose kids under 18 are home from school)
 - Unemployment benefits
 - Insurance coverage of COVID-19 testing
 - Nutrition assistance
 - 6.1% federal Medicaid match rate increase (FMAP)

COVID-19 #3: CARES ACT – March 28, 2020

- Cash payments – “Recovery Rebates”
 - Earning less than \$75,000 = \$1200 for each individual, \$500 for each child
 - SSI recipients still eligible but need to file a tax return
 - Do NOT count towards asset or income limitations
- Extra unemployment benefits
 - Extended to part-time and gig workers
- Medicaid
 - \$100 billion in grants to states for crisis response
 - Hospital bill passed – allows state Medicaid programs to pay for direct support professionals to assist disabled people in hospital
 - Extension of Money Follows the Person through November 30, 2020

COVID-19 #3 (cont'd)

- Housing benefits - more than \$7 billion for HUD programs, temporary protection against eviction & foreclosure
- Education
 - Grants to states - \$13.5 billion for general & special education
 - Loan relief for college students
- Small business loans* (**now includes nonprofits who accept Medicaid dollars*)
- Nutrition – expands \$ for school meals, SNAP and community food banks
- Voting – funding to states to assist with voting and mail-in ballots

More on Recovery Rebates in CARES Act

- \$1200 for individuals; \$2400 married couples; \$500 per child
 - Payment gradually reduced for incomes up to \$99,000 (\$198,000 married)
- Most people are eligible, even people who do not usually file taxes
 - Caveat is that EVERYONE will need to file a tax return (even if don't owe \$)
 - Advocates are trying to change the filing requirement by appealing to Treasury, SSA, VA, media, Congress
- Not eligible: undocumented, lack Social Security numbers, file with Individual Taxpayer Identification Number, adult dependents
- Payments do NOT count toward asset or income limitations for 12 months from receipt
- More info: http://thearc.org/wp-content/uploads/2020/03/Recovery-Rebates-Fact-Sheet_3-27-20.pdf

COVID-19 #4 Asks

HCBS FUNDING IS THE #1 ASK!

- Pass the Coronavirus Relief for Seniors and People with Disabilities Act (H.R. 6305/S. 3544) or another similar vehicle
 - Emergency funding for HCBS - \$20 billion
 - Ensure people with disabilities & the elderly have healthy food programs in their homes (school lunches & Meals on Wheels)
 - Cover the cost of COVID-19 treatment for those with incomes below \$19,000
 - Increase funding for nursing home surveys to prevent the spread of COVID-19
- HCBS funding will be flexible and states will have some discretion
- Could be used for things like increased pay and overtime for Direct Support Professionals (DSPs), Personal Care Attendances and Home Health Workers to support people with disabilities in their homes and communities

COVID-19 #4 Asks (cont'd)

- **Paid/Sick Leave**
 - Ensure paid sick days and paid leave provisions include caregivers who can't work because they are caring for an adult with a disability or aging family member whose program has closed or care worker is sick.
 - As passed, the Families First Act gives the HHS, Labor, and Treasury Secretaries the authority to specify any “**substantially similar condition**” under which employees are eligible for paid sick leave
 - Department of Labor is accepting comments about this until APRIL 10 - submit at <https://ffcra.ideascale.com/>
 - *NDSC will send out an Action Alert with model comments for you!*
- **Direct Support Professionals**
 - Define them as “Essential Workers”
 - Access to Personal Protective Equipment (PPE) and childcare supports
- **Healthcare**
 - Pay for COVID-19 treatment for low income people, not just free testing
 - 90-day refills for Rx and medical supplies (note that the CARES Act included this only for Medicare recipients - not Medicaid, CHIP or private insurance)

COVID-19 #4 Asks (Cont'd)

- **Protect the rights of people with disabilities**
 - No rationing of care based on disability
 - Pass the REAAIDI for Disasters Act to protect PwD during all phases of disaster preparation, response, recovery & mitigation.
 - Do not allow weakening of ADA for businesses or building of new facilities
 - Additional funding to states for accessible voting
- **Increased funding for Social Security & SSI**
- **School/Education**
 - Get more funding for IDEA implementation
 - Ensure that any legislation to support access to virtual education and other supports are inclusive of the unique needs of people with disabilities, including requirements under the Individuals with Disabilities Education Act.

Discriminatory Rationing of Healthcare

- Ventilator shortages will force medical providers to make difficult decisions
- Inherent biases about quality of life and contributions to society by disabled people always come into play
 - We saw this before the COVID-19 pandemic with organ transplant decisions
- Some hospitals are developing rationing plans and saying it is “ok” to deprioritize people with disabilities
 - This is NOT OK. This is ILLEGAL!

Rationing of Care Based on Disability is ILLEGAL

- Violates the Americans with Disabilities Act (ADA), Section 504 of the Rehabilitation Act and Section 1557 of the Affordable Care Act
- Also, there are many state laws on the books that protect people with disabilities from this sort of discrimination
- New guidance from Office of Civil Rights (HHS) affirming that it is ILLEGAL: <https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf>
 - “These laws, like other civil rights statutes OCR enforces, remain in effect. As such, persons with disabilities should not be denied medical care on the basis of stereotypes, assessments of quality of life, or judgments about a person’s relative “worth” based on the presence or absence of disabilities. Decisions by covered entities concerning whether an individual is a candidate for treatment should be based on an individualized assessment of the patient based on the best available objective medical evidence.”

What exactly is ILLEGAL?

- To deny or limit care to disabled people because of their disability;
- To deny or limit care based on the fact that a disabled person may have a lower likelihood of survival or require more intensive care;
- To rely on Quality of Life judgments when deciding whether to deny or limit COVID-19 treatment; and
- To deny or limit treatment to a person with a disability because they may require reasonable accommodations.

See Legal Brief by Disability Rights Education & Defense Fund:

<https://dredf.org/wp-content/uploads/2020/03/DREDF-Policy-Statement-on-COVID-19-and-Medical-Rationing-3-25-2020.pdf>

Advocacy and Enforcement Efforts

- Legal complaints with Office of Civil Rights (OCR) of Health & Human Services have been filed in 4 states so far: WA, AL, KS, TN
 - Complaints based on hospital plans that condoned discrimination
 - Alabama – “people with severe or profound mental retardation would be considered unlikely candidates for ventilator support”
 - Kansas – Ok to remove ventilators from patients with “advanced untreatable neuromuscular disease”
 - Washington – prioritize people with better “baseline functional status”
 - More info about OCR complaints: <https://medicaid.publicrep.org/feature/covid-19/>
- Letters to HHS resulted in positive guidance
 - <https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf>
- Social Media & Traditional Media (OpEds, etc)
- Letters from Governor ([PA](#))
- Letter from State Dept of Health ([CA](#))

What can you do to prevent this discrimination?

- Stay home, be extra vigilant
- Get pediatrician or other trusted doctor involved as your advocate
- Call the Office of Civil Rights 1-800-368-1019 or email OCRMail@hhs.gov
- Report incidents to your state's P&A organization (www.ndrn.org) and your states Center for Independent Living (CIL) (www.ilru.org)
- Report incident to NDSC, heather@ndsccenter.org
- Print HHS guidance and bring with you to hospital (or take photos with phone)
- Advocate in your state for Governor or State Department of Health to issue strong statements condemning medical rationing discrimination.

CARES Act K-12 Education

- \$13.5 billion in dedicated aid for K-12 schools, as well as billions more for childcare and nutrition services.
- This stabilization funding will be distributed to districts for all students, including those with disabilities, based on the states Title I aid-no specific earmark for IDEA funding.
- ESSA waivers are much more limited in scope and duration than in original bill, but more expansive than current law.
- No waiver authority for IDEA as was in original bill.
- However, within 30 days of the bill becoming law, Secretary DeVos must report to Congress if she thinks any additional waivers are necessary from IDEA, as well as ESSA, the Rehabilitation Act, and the Carl D. Perkins Career and Technical Education Act, in order to provide schools with "limited flexibility."
- Summary of CARES Act for k-12 (without IDEA info) <https://all4ed.org/wp-content/uploads/2020/03/CARES-Act-SummaryFINAL.pdf>

US Department of Education Resources

- COVID-19 resource page <https://www.ed.gov/coronavirus>
- OSERS fact sheet on providing services to SWDs
<https://www2.ed.gov/policy/speced/guid/idea/memosdcltrs/qa-covid-19-03-12-2020.pdf>
- OSERS supplemental fact sheet
<https://www2.ed.gov/about/offices/list/ocr/frontpage/faq/rr/policyguidance/Supple%20Fact%20Sheet%203.21.20%20FINAL.pdf>

US Department of Education Resources (cont'd)

- OCR webinar
https://www.youtube.com/watch?utm_content=&utm_medium=email&utm_name=&utm_source=govdelivery&utm_term=&v=DCMLk4cES6A
- OCR Fact sheet <https://www2.ed.gov/about/offices/list/ocr/docs/ocr-coronavirus-fact-sheet.pdf>
- Also OSERS is saying there is information regarding the IDEA and best practices and alternate models for providing special education and related services, including through distance instruction from Technical Assistance Centers. For Part C of IDEA (birth -age 3), there is the Early Childhood Technical Assistance Center <https://ectacenter.org/>. For Part B of IDEA (3-21+), there is the National Center for Systemic Improvement <https://ncsi.wested.org/>.

Message from US Department of Education

- Civil rights and website accessibility rules must be followed
- Federal law mandates that students with disabilities have an equal opportunity to participate in everything schools provide, including online learning, but assures districts they will have flexibility in reaching that goal.
- FAPE may include, as appropriate, special education and related services provided through distance instruction provided virtually, online, or telephonically.
- A few examples are provided, but flexibility is given to figure out what works for individual students.
- The OSERS supplemental fact sheet provides a list of regulations related to timelines under IDEA; emphasizes importance of parents and districts coming to consensus on flexibility.

Statement from NASDSE, COPAA, NDRN and Parent Centers

- [http://www.nasdse.org/docs/Joint COVID-19 Statement NASDSE NDRN COPAA National Place.pdf](http://www.nasdse.org/docs/Joint_COVID-19_Statement_NASDSE_NDRN_COPAA_National_Place.pdf)
- Provides a unified statement that all the rights for students with disabilities under IDEA must remain in effect despite school closures in response to the COVID-19 outbreak
- Calls on Congress to increase funding for educational services and for the organizations with the statutory responsibility to assist families of, students with disabilities, such as the Parent Centers and Protection and Advocacy Network
- Emphasizes that this is a time for community good will, maintaining trust and for educators and parents to work together to design and implement effective programs for students with disabilities.
- Provides some examples of promising practices.
- Also COPAA put out a FAQ on implementing IDEA
https://cdn.ymaws.com/www.copaa.org/resource/resmgr/docs/2020_docs/faq_final-3-31-2020.pdf

NDSC Position

- Supports NASDSE, COPAA, NDRN, Parent Center Statement
- Signed onto a CCD Education Taskforce Letter calling for NO WAIVERS to IDEA rights
- Doing our own analysis as to what Dept. of Ed. can and cannot do via guidance
- Working on position statement and Action Alert for next week

What NDSC is Doing in Education Area

- We played a key role in ensuring that broad IDEA waiver authority was not included in the CARES Act.
- We are researching how much flexibility already exists under the law and can be provided via guidance as opposed to waivers.
- We will advocate that any flexibility must be limited in duration and scope, as well as include the protection of civil rights.
- We are advocating for additional federal funding specifically earmarked for IDEA in next bill.
- Planning joint webinar with COPAA for Thursday April 9

What Advocates Can do

- If the district is making policies that are concerning to you, find out whether they are in alignment with state policies.
- Keep records on what your child is getting and not getting and the impact on his/her education for discussions later on compensatory education.
- Share information you find on resources and best practices that your district/classroom teachers may not have seen.
- Advocate with your district regarding how the COVID stimulus stabilization funds will be spent so that students with disabilities are included.
- Take a deep breath and know that you (and likely your child's teachers) are adapting as quickly as possible to a difficult situation.

Postsecondary Education

- Reports from PSE programs are varied – range from online learning to very little
- Think College: Teaching & Learning Online: Strategies for Supporting Students with ID
[https://sites.google.com/umb.edu/thinkcollege-
teachingonline/home?authuser=0&utm_content=buffer4134b&utm_
medium=social&utm_source=facebook.com&utm_campaign=buffer](https://sites.google.com/umb.edu/thinkcollege-teachingonline/home?authuser=0&utm_content=buffer4134b&utm_medium=social&utm_source=facebook.com&utm_campaign=buffer)
- *What's going on with Higher Education Act reauthorization?????*

Some Online Learning Resources

- NCLD resources

<https://ncld.org/news/policy-and-advocacy/two-new-resources-to-support-students-with-disabilities-during-the-covid-19-crisis>

- AEM webinars http://aem.cast.org/about/events/2020/03/supporting-accessibility-in-distance-education.html?utm_source=CAST+Newsletter&utm_campaign=093f2ac65a-EMAIL_CAMPAIGN_2018_07_18_02_58_COPY_01&utm_medium=email&utm_term=0_7396dac1a2-093f2ac65a-55680037&fbclid=IwAR0ifgRjvEMy3DN6FgMlt7ek_32VXuTdbmAxmqwG7HDroHmlHnTUFsOtQ8

Some Online Learning Resources (cont'd)

- Center on Online Learning and Students with Disabilities
http://www.centerononlinelearning.res.ku.edu/?utm_source=LPI%20Master%20List&utm_campaign=5efefb01f7-LPIMC_COVID-19-Resources%20200319&utm_medium=email&utm_term=0_7e60dfa1d8-5efefb01f7-42305035
- Distance Learning for Special Education
<https://sites.google.com/view/distance-learning-specialed/home?fbclid=IwAR2vOS9UgJHpTMm1RJ2Tm9pIn033RK3srceurfUQgmILb7DtsHz3feKJHVM>

NDSC COVID-19 Resources

- NDSC COVID-19 Resource Library: <https://www.ndsccenter.org/programs-resources/covid-19-resources/>
- Collaborative Q&A COVID-19 and Down Syndrome document (both abbreviated and extended versions) <https://www.ndsccenter.org/programs-resources/covid-19-resources/>
- Adjusting to online learning: NDSC 3-part Online Learning Series, Preparing Yourself, Your Family, and Your Home for Online Learning; The ABCs of K-12 Online Learning for Students With Disabilities; and Practical Tips and Tools for Online Learning. <https://www.ndsccenter.org/outreach-education/parent-webinars/>

More NDSC COVID-19 Resources

- Podcasts with NDSC President and UPMC Down Syndrome Center Director, Dr. Kishore Vellody, and his colleague Dr. Andrew Nowalk, Clinical Director, Division of Infectious Diseases, UPMC Children's Hospital of Pittsburgh: Part 1 <https://podcasts.apple.com/us/podcast/down-syndrome-center-of-western-pennsylvania-podcast/id602494060>, Part 2 <http://directory.libsyn.com/episode/index/id/13784516>
- Music Therapy Partnership with The George Center: Offering FREE music therapy sessions throughout this period of social distancing, with new sessions each week for all age groups including young children, teens, young adults, and older adults. <https://www.ndsccenter.org/programs-resources/covid-19-resources/support-services/>
- NDSC webinars on various topics, including care rationing and educational rights

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- *Read our monthly Newsline e-newsletter*
- *NDAC Facebook Group*
- *Action Alerts*
 - <https://www.ndsccenter.org/political-advocacy/take-action-stay-informed/>
- *Facebook*
 - <https://www.facebook.com/dsadvocates/>
- *Twitter*
 - *@NDSCPpolicy*

THANK YOU AND
STAY SAFE!

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