



# Unfair and Unequal: The effects of COVID-19 on people with IDD

February 22, 2021

BRANDEIS UNIVERSITY

The Heller School  
FOR SOCIAL POLICY AND MANAGEMENT

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The Lurie Institute  
*for* Disability Policy

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# Community Living Policy Center

- Aims to advance policies and practices that promote community living outcomes for individuals with disabilities of all ages through research and knowledge translation.
- The CLPC received support from the National Institute for Disability, Independent Living, and Rehabilitation Research (NIDILRR) within the Administration for Community Living, U.S. Department of Health and Human Services (Grant # 90RTCP0004). The contents of this webinar do not necessarily represent the policy of NIDILRR, ACL, or HHS, and you should not assume endorsement by the Federal Government.



# Community Living Policy Center Partners

- Lurie Institute for Disability Policy at Brandeis University
- University of California, San Francisco (UCSF)
- Association of University Centers on Disabilities (AUCD)
- Autistic Self Advocacy Network (ASAN)
- Disability Rights Education & Defense Fund (DREDF)
- Disability Policy Consortium (DPC)
- Centene Corporation
- ADvancing States
- Mike Oxford, Topeka Independent Living Resource Center
- Henry Claypool, National Policy Expert
- Disability and Aging Collaborative
- Angel Miles, Access Living



# Webinar Logistics

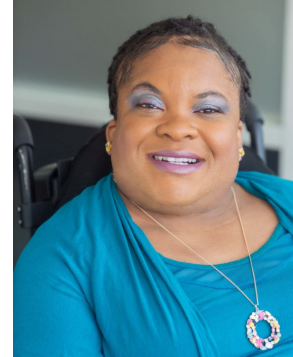
- The power point and archived recording will be available on the Community Living Policy Center website:
  - [www.communitylivingpolicy.org](http://www.communitylivingpolicy.org)
- Webinar is being live captioned
- Time for questions following speakers
  - Submit questions via the Chat function



# Presenters



**Scott Landes**  
Syracuse University



**Angel Miles**  
Access Living



**Julia Bascom**  
Autistic Self Advocacy  
Network



**Nicole LeBlanc**  
Human Services  
Research Institute



# COVID-19 Outcomes Among People with Intellectual and Developmental Disabilities

Scott D. Landes



# Cause for Concern: Early Evidence

- Risks for severe outcomes

- Severe spread in congregate settings such as nursing homes

*People with intellectual and developmental disabilities are more likely to live in group settings and receive in-person, close support*

- Older adults, those with co-occurring conditions, and populations experiencing health disparities

*People with intellectual and developmental disabilities are a health disparities population, experience structural barriers to healthcare, are at risk for medical rationing, and have higher rates of co-occurring conditions*

- Initial results

- TriNetX data – higher case-fatality rates at younger ages, <74y

Turk, M., Landes, S., Formica, M. & Goss, K. (2020). Intellectual and developmental disability and COVID-19 case-fatality trends: TriNetX analysis. *Disability and Health Journal*, 13, 100942.

Sabatello, M., Blankmayer-Burke, T., McDonald, K., & Appelbaum, P. (2020). Disability, ethics and health care in the Covid-19 pandemic. *American Journal of Public Health*, 110, 1523- 1527.

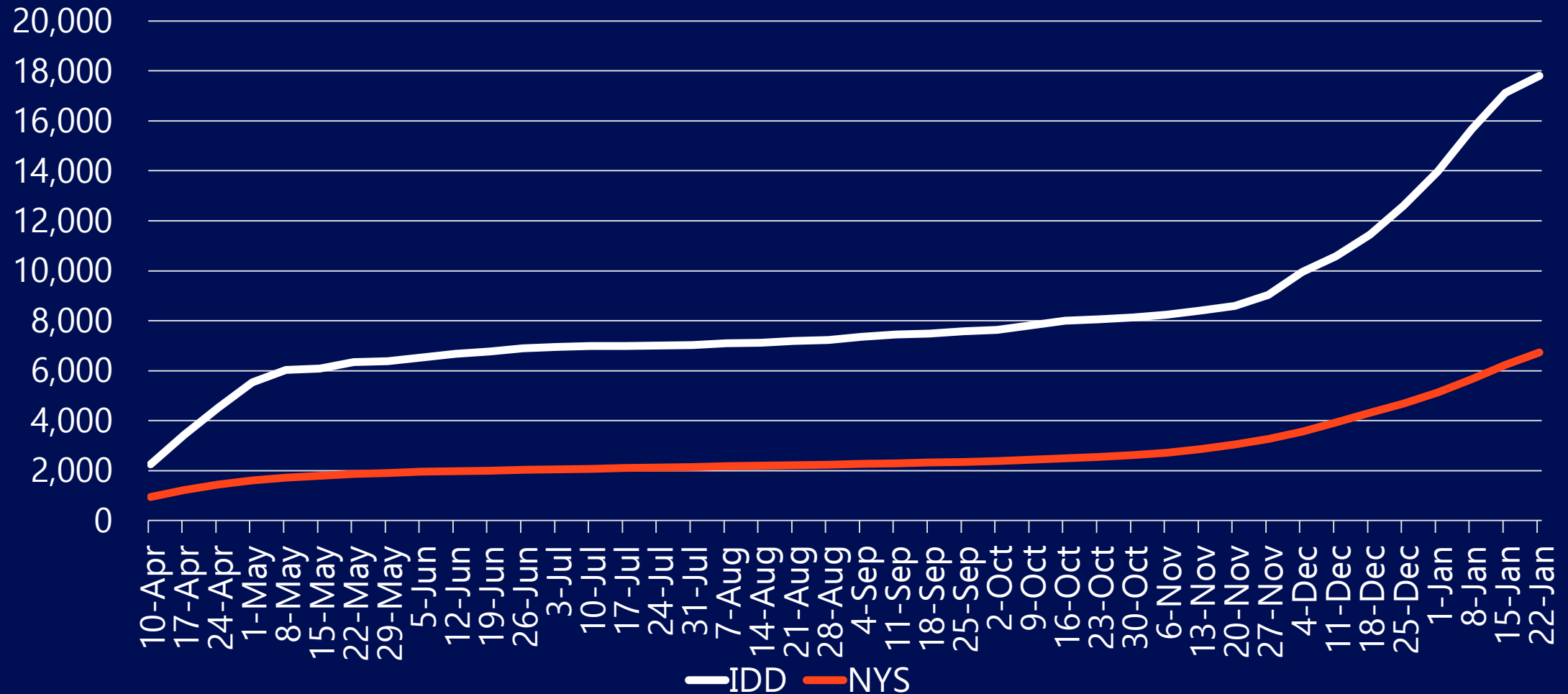
# Study 1: New York Disability Advocates (NYDA) Data

- Group homes in New York state for people with intellectual and developmental disabilities (IDD)
- 67 providers
- Geographic diversity
- Cohort study, N=13,042
- ~35% of NY state residential capacity
- Early April through ...

Landes, S., Turk, M., Formica, M., McDonald, K. & Stevens, D. (2020). COVID-19 outcomes among people with intellectual and developmental disability living in residential group homes in New York State. *Disability and Health Journal*, 13, 100969.

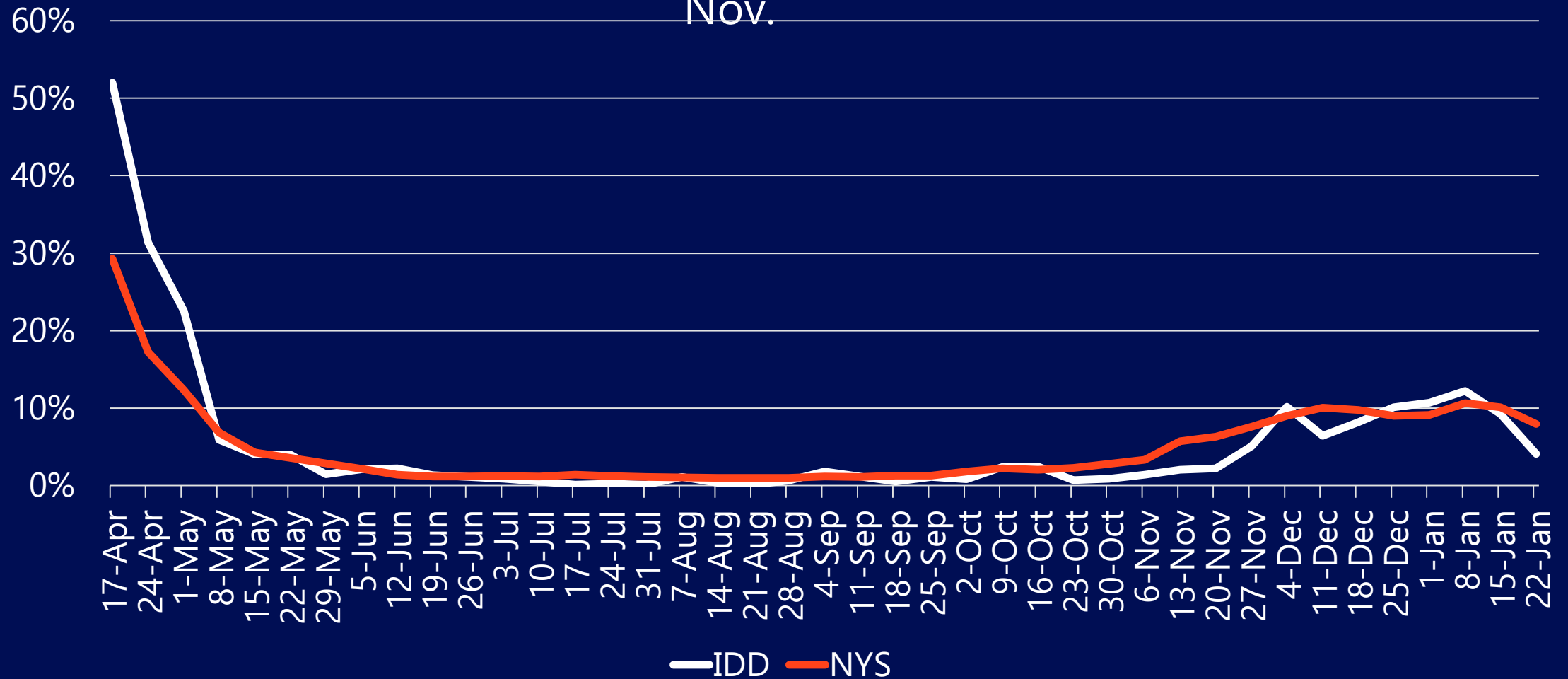
## Case rate per 100,000

Case rates increased for people with IDD and NYS over time.



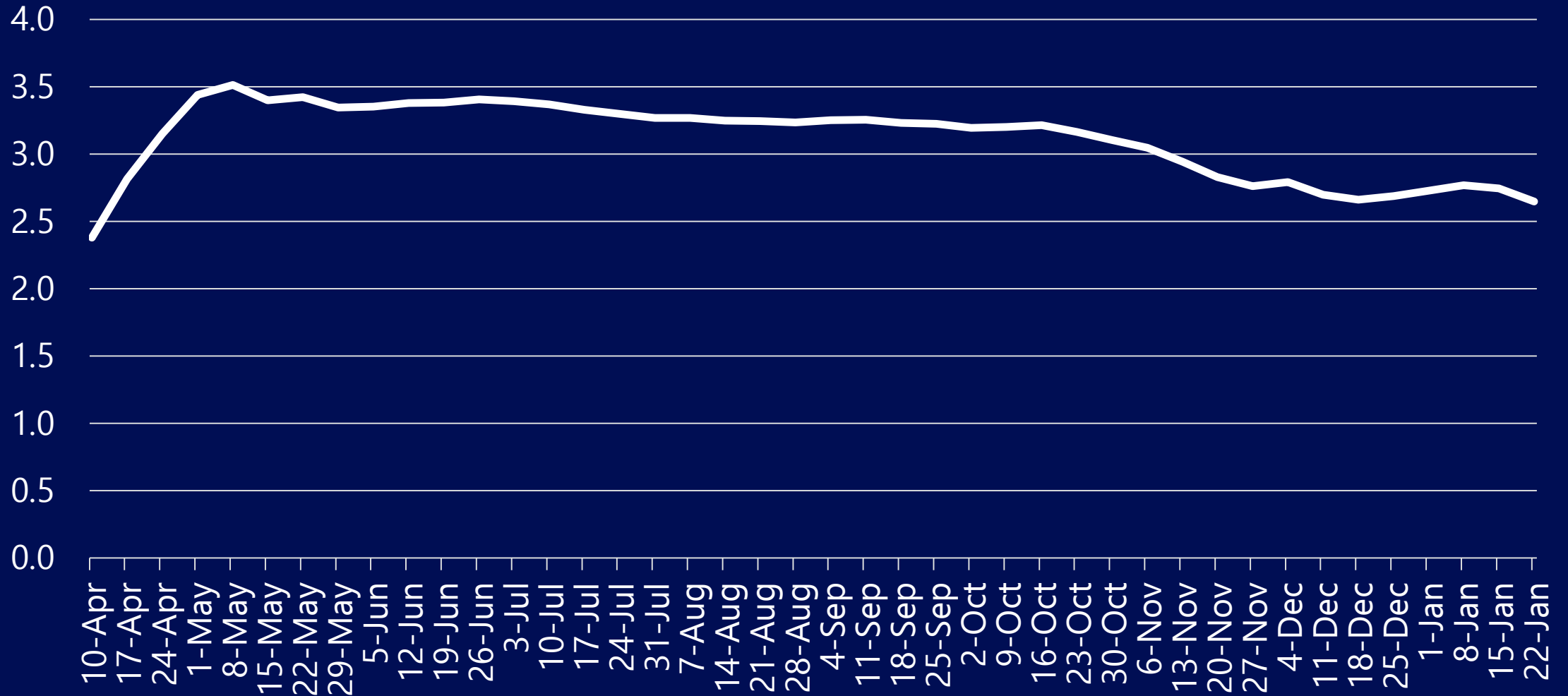
## Case growth rate

Case growth rate decreased for people with IDD and NYS from April 17 through May 8, was stable through late Oct, then rose starting mid-Nov.



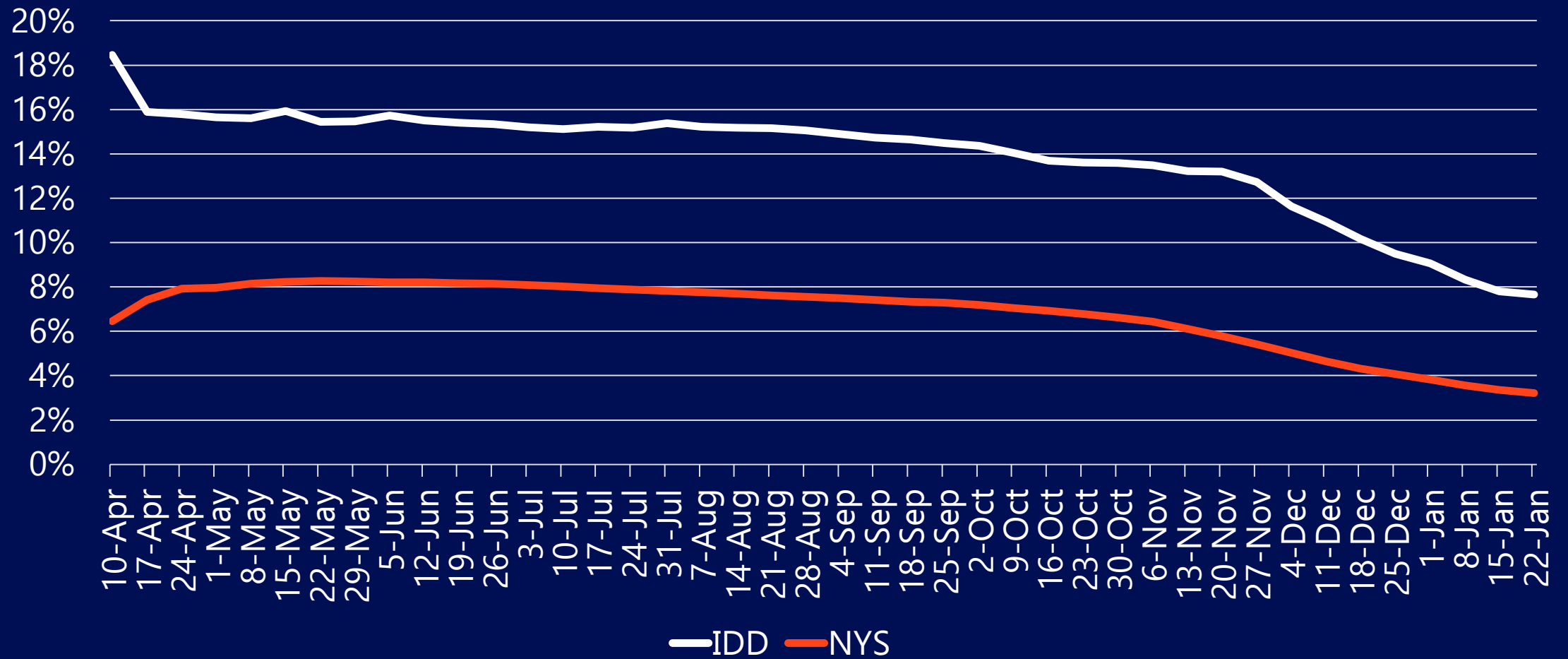
## Case rate relative risk

The disparity in case rate peaked at 3.5x higher on May 8, then gradually decreased to 2.4x higher on January 22.



Case-fatality rates decreased for people with  
IDD and NYS over time.

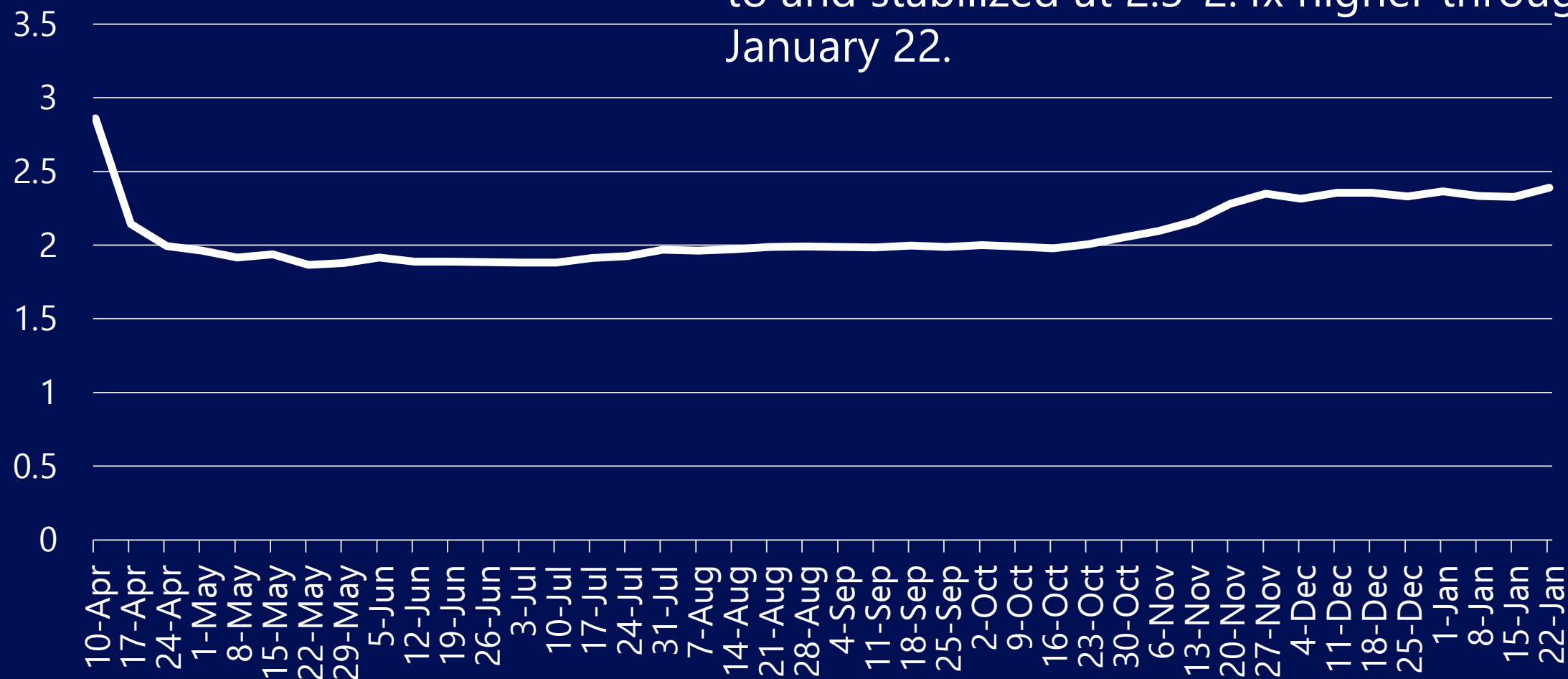
## Case-fatality rate





## Case-fatality relative risk

The disparity in case-fatality rate was 2.9x higher on April 10, decreased and was stable at 1.9-2.1x higher from April 17-Nov 6, rose to and stabilized at 2.3-2.4x higher through January 22.



# Summary

- Case rates and case-fatality rates are higher for people with intellectual and developmental disabilities.
- Case-fatality rates:
  - On average, 1.8 to 3.0 times higher
  - Vary by: geographic location, size of residence, receipt of nursing care
- Grey literature (often using specific medical conditions) and studies in other countries confirm these trends

# Final thoughts

- Data allows us to identify disparities and monitor their correction
- Need high-quality, actionable data
  - Subpopulations and intersectionality
  - Risk factors, barrier, facilitators
  - Disease, treatment, recovery, mortality, vaccinations, ...
- Ongoing concerns with data collection and reporting



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# Hello!

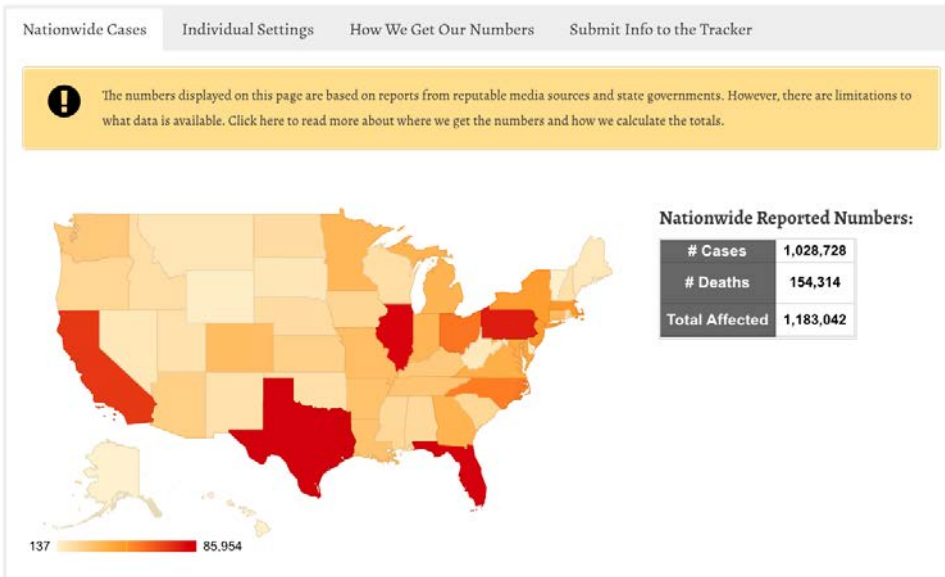
Julia Bascom

Autistic Self Advocacy Network (ASAN)

[autisticadvocacy.org](https://autisticadvocacy.org)



# ASAN's COVID-19 tracker



# ASAN's COVID-19 tracker

- People with disabilities in institutional settings have consistently represented around or over 40% of deaths due to COVID-19 over the past year.
- That percentage decreased to around  $\frac{1}{3}$  due to the December surge and increase in deaths in the general population.
- These numbers include people over the age of 65 in nursing facilities, who by definition are also people with disabilities.



## ASAN's COVID-19 tracker: data difficulties

- Lack of federal standards for data reporting
- Inconsistent data on institutions other than nursing homes
- Some states count staff and resident data simultaneously

Regardless, the overarching trend shows what we already knew prior to the pandemic: institutional settings are deadly, and uniquely vulnerable to infection and death due to the inherent characteristics of these settings.



# Medical rationing

Disability rights advocates have filed OCR complaints in 12 states regarding medical rationing.

<https://www.centerforpublicrep.org/covid-19-medical-rationing/>

# Supporters in hospitals

- Hospitals have enacted restrictive visitor policies due to the pandemic.
- But some people with disabilities, especially people with developmental or mental health disabilities, dementia, or communication disabilities, need a familiar support person with them in order to access medical care.
- The ADA and the Rehab Act protect this right. Hospital visitor policies must reflect this.
- <https://communicationfirst.org/covid-19/covid-19-guidance/>

# Accessible information

**Why Should I Get the COVID-19 Vaccine?**

  The vaccine keeps you safe from COVID-19.

  Once you get the vaccine, you probably won't get sick from COVID-19.

 This is a good thing!

 COVID-19 can make people very sick.

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# Informed consent

Accessible information is critical in order for people with IDD to give informed consent to the vaccine.

If an individual is hesitant to receive the vaccine once they have accessible information, supporters can use principles of supported decision making, person-centered, and trauma-informed approaches

# COVID19 IMPACT ON I/DD COMMUNITY

Nicole LeBlanc



# **Introduction**

**Hello Everyone, My name is Nicole LeBlanc. I am on the autism spectrum. I live in Silver Spring MD.**

**I am a seasoned policy wonk in the areas of employment, health disparities, public benefits, person-centered planning. I currently serve as the PAL Group coordinator for the National Center on Advancing Person-Centered Practices.**



# My Personal Experience

- Medication side effects
- Doctors Not listening and acting Passive-Aggressive
- Misdiagnosis spent 27yrs with Epilepsy label when seizures were actually PNES
- ER Visits
- Alternative Medicine Not covered by insurance!

# **COVID19 Impact on Disability Community**

- **COVID19 has exposed massive gaps in our system of support for people with developmental disabilities.**
- **A majority of people with developmental disabilities & seniors are at high risk of dying or having negative outcomes if they catch COVID19 compared to general population.**
- **Living in segregated settings is linked to a higher risk of getting COVID19 compared to living on our own or in a smaller setting with 1:1 support.**
- **COVID19 pandemic has shined a bright light on the massive amounts of ableism and racism in our society and systems. Rationing care and putting health vs disabled against each other when it comes to dealing with patients with COVID.**



# **Post Pandemic World Policy change Ideas**

- 1. HCBS must become a mandatory benefit.**
- 2. People DD declared a Medically Under-Served Population**
- 3. 1:1 support in community becomes the norm.**
- 4. Telehealth becomes part of menu of HealthCare**
- 5. Doctor House Calls make a come back, to meet needs of vulnerable or under-served groups.**
- 6. Increase / Invest in access to High-Speed Internet especially in rural areas**
- 7. Develop a Long-Term Care Buy In Program to expand HCBS support especially to adults with ASD who don't have I/DD.**

# **Post Pandemic World Policy change Ideas-Person Centeredness**

- **Self Directed Services is expanded more**
- **Close Segregated Settings and move towards 100% Community based supports!**
- **Massive Invest in Affordable Housing build in walkable areas and on public transit.**
- **Allow SNAP to cover delivery of groceries and buy food online nationwide**
- **Expand Social Security Disability**
- **Close Digital Divide by working with Tech Giants and other partners to Get Tech devices to all low income, people with disabilities.**
- **Invest in High Speed Internet**
- **Develop Supportive Apt programs.**
- **Use Tech. to support independent Living.**
- **Focus on helping the disability community get Work From Home jobs.**

# COVID19 Dignity of Risk

- People need to be able to make choices.
- Overprotection might seem kind, but it might smother a person.
- Letting people try things that may seem risky or scary for parents or professionals.
- It allows people to “get out of their comfort zone” to try new things—for example, moving to a new city or state.
- Being able to make choices and live the consequences of choices promotes self-determination and high expectations.

# Virtual World-Accessibility

- COVID19 has moved all our mtg from face to face to 100% online.
- The pandemic has shined a light on the need to close the digital divide so that people with disabilities can have easy access to tech devices that allow us to attend online meetings and everyday business.
- Many of us are low income and live in poverty. This makes covering the cost of computers etc difficult. Now is the time for us to work with government and private sector to get them to invest \$\$\$ into closing the digital divide.
- All mtg. platforms that businesses use must have call in numbers and meeting agendas sent out in advance.
- Slowing down and Not speaking too fast is essential for active involvement of PWD.
- Now is also a perfect time for all government agencies and business to commit to making websites fully accessible and allowing us to do all our business online.



# CONTACT INFO

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# Thank You For Attending

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@CLPolicy

- **Website**

[www.communitylivingpolicy.org](http://www.communitylivingpolicy.org)

