

New York's Experience: People with I/DD and COVID-19

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Our Collective Experience

- March 7, 2020- State of emergency declared in NYS
- March 15 – ICF Visitors Restrictions
- March 16 – School closure
- March 17 – Day Program closure
- March 18 – IRA Visitor Restrictions
- March 20 – 50% in-person nonessential workforce reduction
- March 21 – 75% in-person nonessential workforce reduction
- March 22 – 100% in-person nonessential workforce reduction
- March 24 – Suspension of Home Visitation and Community Outings

Our Collective Experience

- March 31 – 10-point NY on Pause Plan, Return-to-Work guidance
- April 1 – Temporary Emergency Respite guidance
- April 6 – Quarantine and Isolation Directives
- April 8- Approval of Appendix K Waiver
- April 12 – Employee Facemask directive
- April 17 – Full-state Facemask directive
- April 24 – EO authorizes OpCert revocation if not following COVID protocols
- May 14 – Phase 1 reopening begins regionally
- May 29 – Phase 2 reopening begins regionally



Our Collective Experience

- June 13 – Phase 3 reopening begins regionally
- June 25 – Travel Advisory begins
- July 10 – Phase 4 reopening
- July 15 – Day Services reopening/Community Outings resume
- August 15- Appendix K Waiver Revision
- August 21- Local Assistance Payment Withhold (20%)
- October 1, 2020- Funding reductions implemented (retainer and therapy days, removal of the occupancy factor)
- October 26- Cluster Zone Strategy Implemented

Our Collective Experience

- December 11- Residents and Staff of OPWDD Included in Phase 1 of Vaccination
- December 12- EUA of Pfizer vaccine approved
- December 21- Week 2 of vaccination program begins (people in OPWDD residences and their staff included)
- December 22- EUA of Moderna vaccine approved



How this Project Started

- **New York Disability Advocates (NYDA) collaboration**
 - Recognized the magnitude of the virus early on
 - Became apparent that we were going to need to pay attention to the data and not rely on State/Federal government to share data – Self sufficiency with our data
 - Collaboration of various provider association staff with different strengths
- **Goals of the project**
 - Track the overall impact of the virus in terms of individuals served as well as staff
 - Geographic disparities
 - Ensure access to PPE
 - Advocacy for our providers
 - Understand your limitations, most data elements limited to certified residences

What Were We Looking to Measure

- Started collecting data statewide on March 30th but April 9th was our first usable data point
- 34 straight weeks with 67 consistent responders each week and about 100 agencies responding each week
- 45-50% of NYS OPWDD certified residential capacity each week
- Some of the data points we have collected include:
 - Certified capacity and number of employees to establish an “n”
 - Confirmed cases – staff and individuals
 - Deaths – staff and individuals
 - Quarantined individuals and staff to measure quarantine ratio and disruption to staffing patterns
 - Antibody testing
 - Hospitalizations – Early on this was a key metric

Opportunity for Collaboration

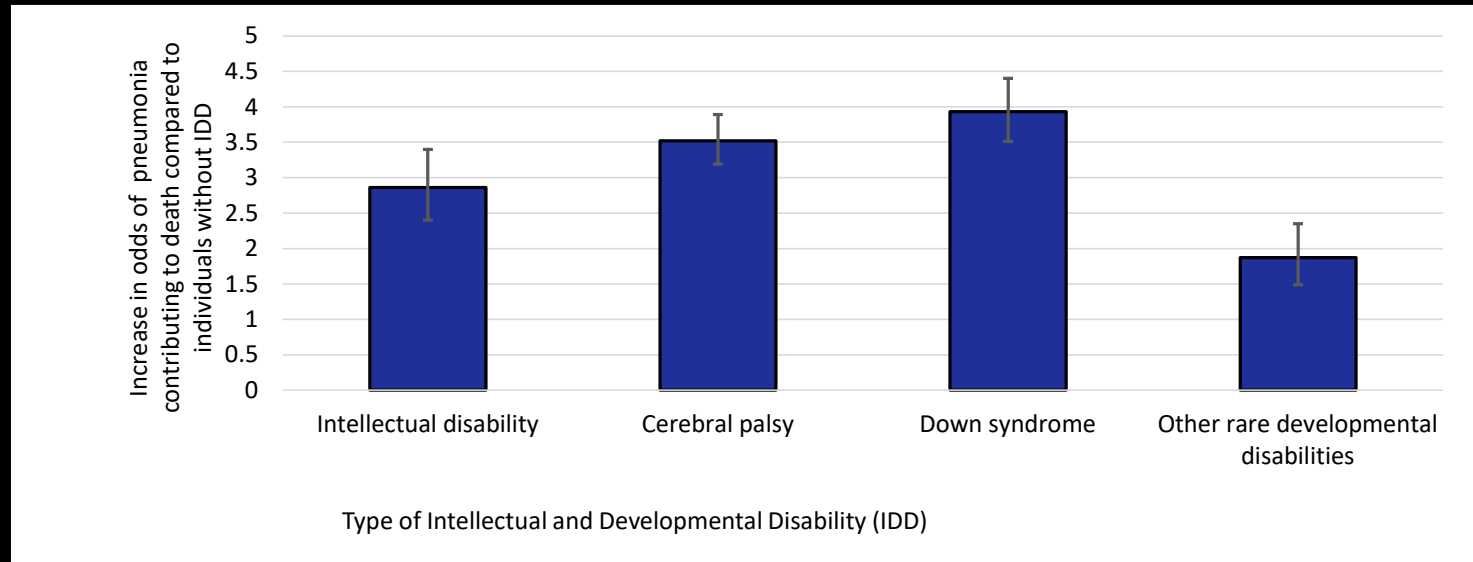
- Remember what it was like in the Spring – We needed to know more about the virus and how it affected people.
- Opportunity to work with researchers from Syracuse University who had experience doing research on how pulmonary diseases impacted individuals with I/DD.
- We were put in touch with Scott Landes – Associate Professor of Sociology at Syracuse University who had done some interesting research in the past that seemed to align with the data we were collecting.
- Mutually beneficial relationship, we had the data source but we needed more expertise in these types of research projects with large data sets.

Cause for Concern

- Early national/international data noted older age and comorbidities as risks for severe outcomes with COVID-19
- Severe spread in congregate settings such as nursing homes
- Minimal/no data about COVID-19 outcomes among people with IDD
 - NYT reporting
 - NYS and other state regulations related to people with disability
 - Reports of discriminatory triage

Early Lerner Center Reports

- Vulnerable health population
- People with disability, especially with IDD, have high prevalence for those comorbid conditions
- Disproportionate percentage of population with IDD live in congregate settings



TriNetX Analysis



TriNetX Analysis

- Real-time EMR data through TriNetX COVID-19 Research Network platform, through May 14, 2020
- Positive COVID-19 diagnosis: physician, test result (1/20/2020); exclusion other viral, suspected exposure
- ICD10 diagnosis codes IDD (ID, CP, DS, other)
- Analysis: trends in comorbidities, number of cases, number of deaths, case-fatality rate among people with and without IDD
- Total Eligible Sample: N=30,282 (IDD=474, No IDD=29,808)

People with IDD:

- Fewer at older age (8 vs. 15%)
- Higher rate comorbidities associated with poorer COVID-19 outcomes

Chronic Conditions	Age 0-17 (n)		Age 18-74 (n)		Age ≥75 (n)	
	IDD (125)	No IDD (791)	IDD (311)	No IDD (24,456)	IDD (38)	No IDD (4,561)
Respiratory	90%	71%	89%	68%	92%	73%
Endo/Nutri/Met	56%	20%	84%	43%	95%	61%
Circulatory	45%	10%	69%	36%	95%	68%

- Overall case-fatality rates similar, with IDD (5.1%) and without IDD (5.4%)
- Differences by age notable

AGE	IDD	No IDD
Case Fatality Rate % (95%CI)		
All	5.1 (3.4, 7.4)	5.4 (5.2, 5.7)
0-17 years	1.6 (0.4, 5.6)	0.1 (0.0, 0.7)
18-74 years	4.5 (2.7, 7.4)	2.7 (2.5, 3.0)
≥75 years	21.1 (11.1, 36.3)	20.7 (19.5, 21.9)

The Importance of Publishing COVID-Related Research from NYDA Perspective

- Research findings lead to press
- This administration especially, reacts to press
- Use that press to drive change in the system

- What headlines did the data show
 - Individuals with I/DD were 3.4 times as likely to contract COVID-19 as compared to the general population
 - Nearly twice as likely to die from COVID-19 once contracted

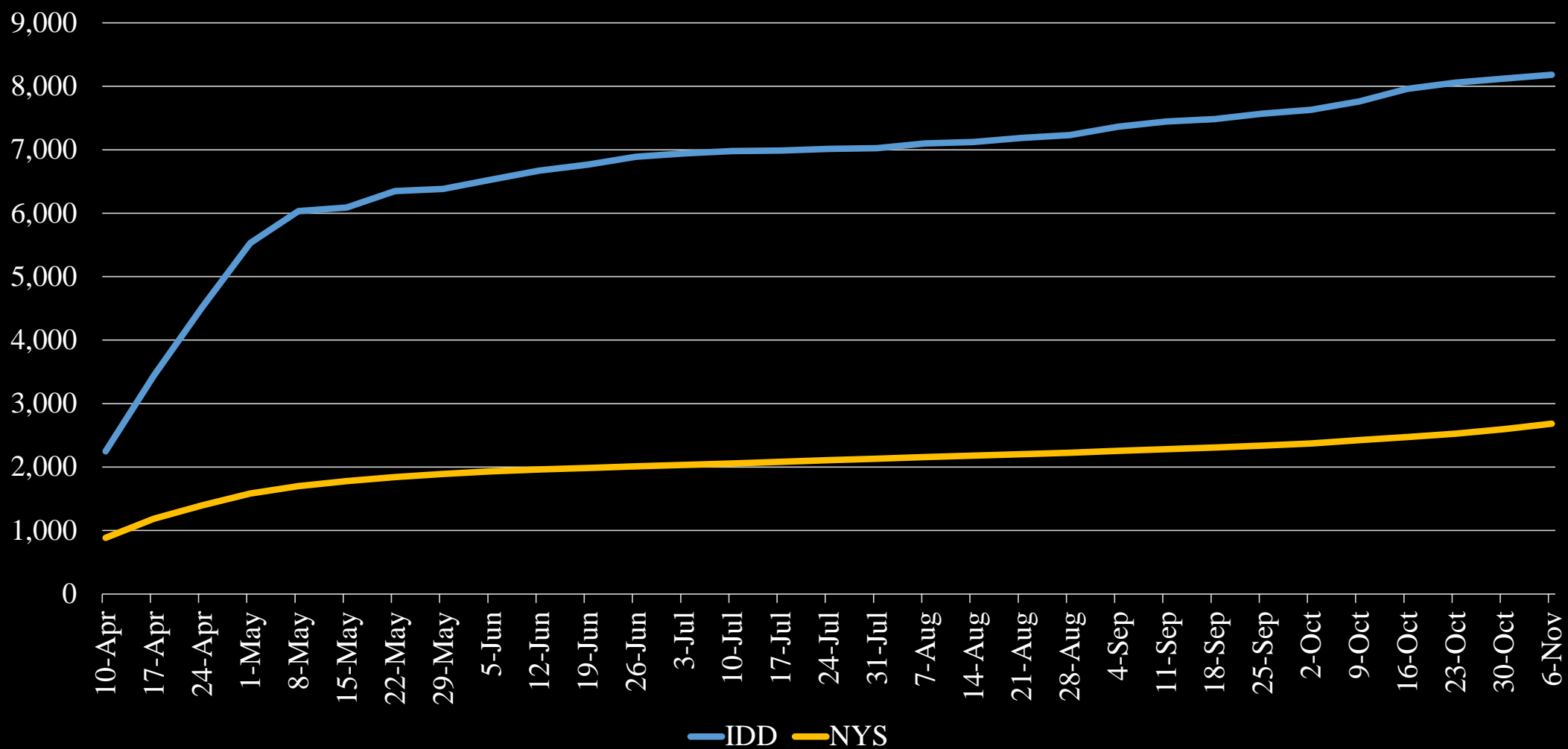
- People with IDD have not historically been granted the same priority for health care afforded to the general population.

New York Disability Advocates COVID-19 Survey of Providers

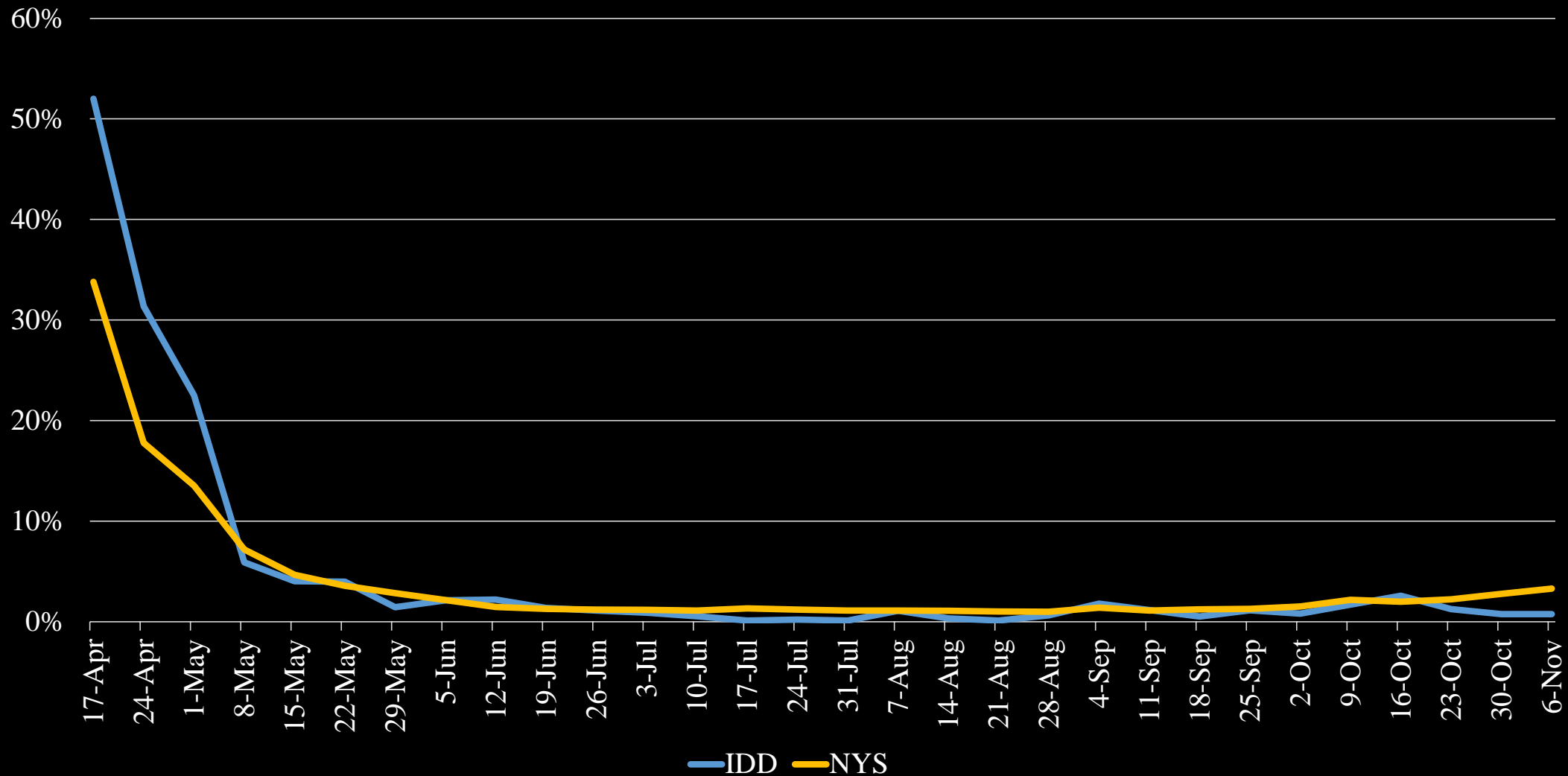


- New York State
- IDD residential group homes
- N=13,200
- 67 providers
- ~35% those served in residential group homes in NYS
- Early April through . . .

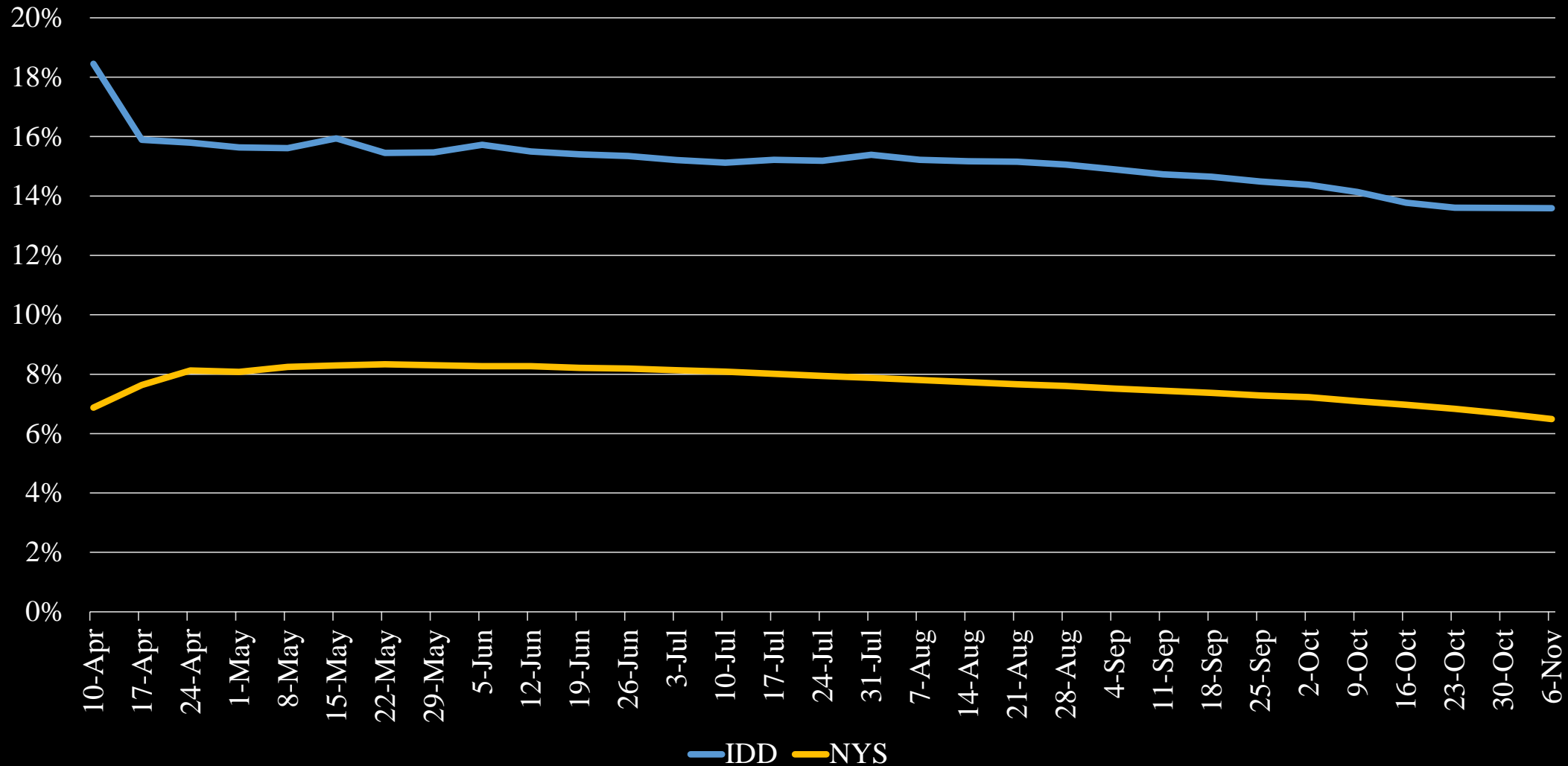
Case rate per 100,000



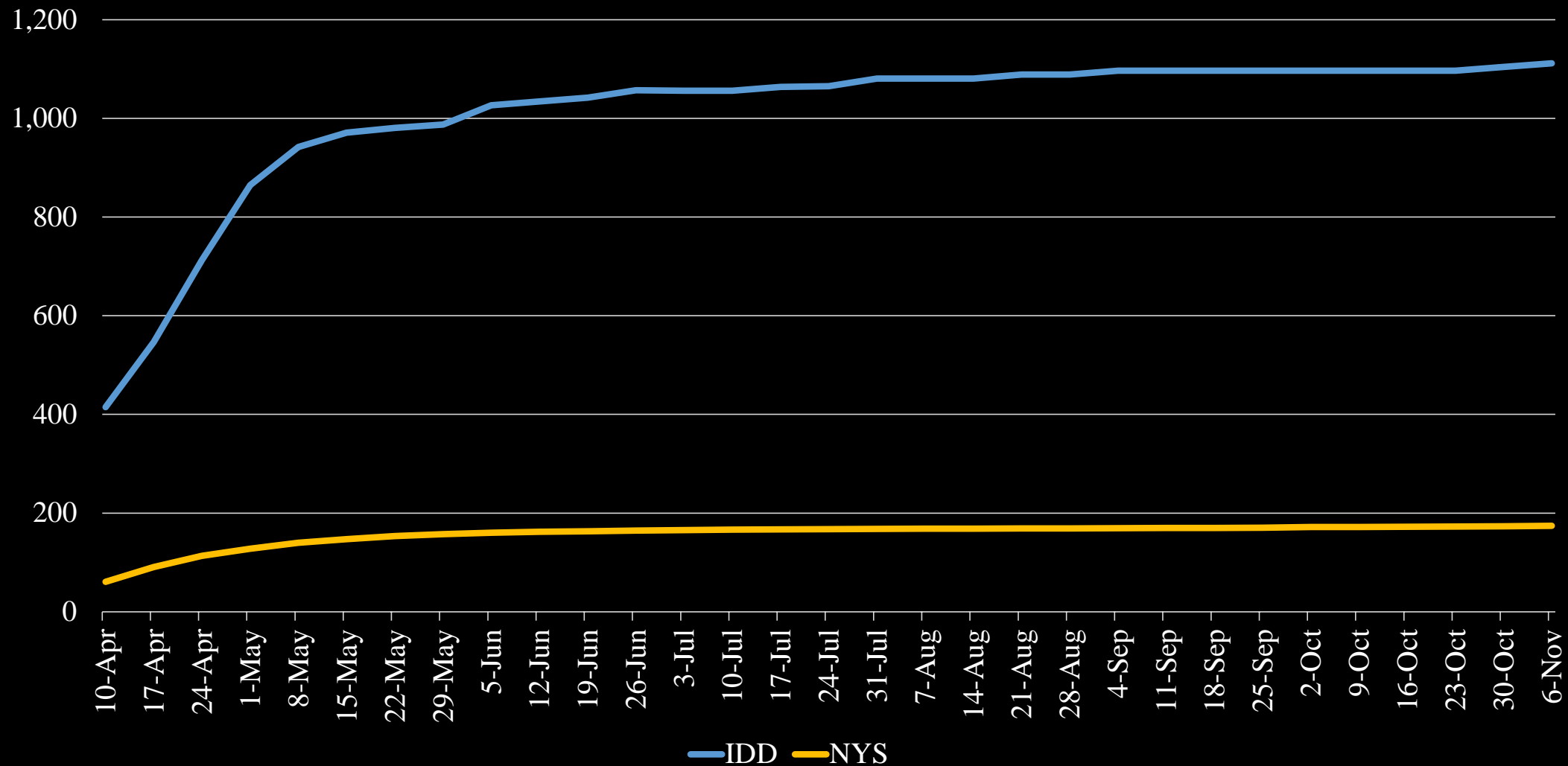
Case growth rate



Case-fatality rate



Mortality rate per 100,000



Reasons Providers Were Successful in Containing the Virus

1. Ability to quarantine

- Respite and quarantine facilities for known/suspected positives
- Difference from other congregate facilities
- Repurposing of day program space

2. Access to PPE

- Once PPE became widely available there was a direct correlation to decrease in case rate

3. Day service closure

- March 18th through July 21st

4. Day service reopening – Gradual and Different

- Not the same as pre-pandemic, most providers delivering services in IRA

5. Proactive quarantine and staying out of the community

- At the cost of personal liberties

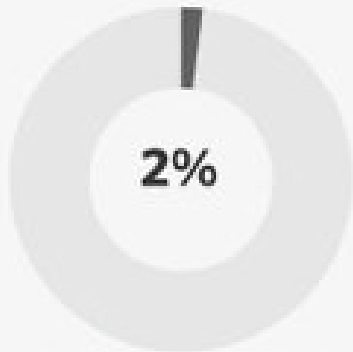
California Department of Developmental Disabilities Services data

- Type of residence
 - Californians not receiving IDD services (N=39,157,583)
 - Californians receiving IDD services
 - Own or family home (N=315,650)
 - CCF, 4-16 resident (N=23,722)
 - ICF/DD-H, 4-15 residents (N=3,739)
 - ICF/DD-Nursing, 4-15 residents (N=2,163)
 - ICF-DD, 15 + residents (N=557)
 - SNF, 80+ residents (N=1,031)

**Californians
not receiving
IDD services**

2,085

COVID-19 cases per
100,000 people

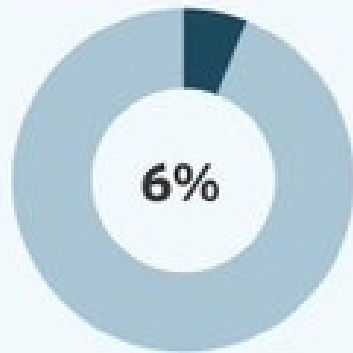


of COVID-19 cases resulted in death

**Californians
receiving IDD
services**

831

COVID-19 cases per 100,000 people



of COVID-19 cases resulted in death

Own home
or family home



residents
based on size
of family



15 COVID-19 deaths per 100,000 people

Community Care
Facility



Group home,
usually 4 - 16
residents



97

Intermediate Care
Facility-Habilitative



Group home,
4 - 15
residents



348

Intermediate Care
Facility-Nursing



Group home,
usually 4 - 16
residents



693

Intermediate Care
Facility



Health care
facility, 15+
residents



898

Skilled Nursing
Facility



In-patient
medical facility,
80+ residents



5,626

New York State Vaccination Program

- As we move toward the next phase in the natural progression of this virus it will be just as important to collect data on vaccination rates
 - Similar in scope to the day services reopening data collection
 - Reopening data – What that data illustrated and how it was used
- Our data can/will be used for:
 - Advocacy
 - Vaccine education and reinforcement (i.e. x% of people in our system statewide have received the vaccine)
 - Part of the larger story in this journey

NYDA Vaccination Data Collection

- Simplicity is key – Providers already providing data through Redcap
 1. Vaccination refusal rates
 2. Track vaccination efforts regionally
 3. Measure vaccine efficacy
- We need to collect the data so that we can have access and use it for our advocacy.
- Example – 1A vs 1B – Quick succession to 1B and the need to prove that 1A should still be prioritized

Compendium of Journals & Articles

From our Research

- Research
 - COVID-19 in Group Homes in NYS – June 2020
 - COVID-19 Trends Among Adults with Intellectual and Developmental Disabilities (IDD) Living in Residential Group Homes in New York State through July 10, 2020 – September 2020
 - FAIR Health – Risk Factors for COVID-19 Mortality Among Privately Insured Patients - Cited our research as part of their White Paper
- Press
 - New York Times: Developmental Disabilities Heighten Risk of Covid Death – November 2020
 - Harvard Political Review: A Crisis Decades in the Making: Disability Housing Policy and COVID-19
 - Disability Scoop: People With Developmental Disabilities More Likely To Die From COVID-19 – June 2020
 - Letter from Senators Warren, Murray, Hasan to President Trump calling for improved data sharing – Cited Scott's research
- Other – University of Michigan Data Repository



Next Steps

- Next research article or journal
- Look back and analyze the complete data set from the beginning
- <https://www.nap.edu/catalog/25917/framework-for-equitable-allocation-of-covid-19-vaccine>
- <https://beta.regulations.gov/search?filter=CDC-2020-0121>

Questions

