THE OHIO STATE UNIVERSITY
NISONGER CENTER

WEBINAR

JOIN US and REGISTER TODAY!

NISONGER INSTITUTE 2021

Scarcity of Medical Resources: Racial and Disability Equity

Kara Ayers, PhD
David Ellsworth, MPH, CHES
Ryan Nash, MD, MA
D'Arcee Charington Neal, MA
Kerstin Sjoberg, JD

moderated by: Susan M. Havercamp, PhD, FAAIDD

www.go.osu.edu/ni2021

May 21st
10am - 11:30 am
via Zoom!

- This webinar is being recorded; you must consent to view once the recording starts.
- Presentation materials are available from the event webpage: https://go.osu.edu/ni2021
- For Zoom support, contact: Darlene.Byler@osumc.edu
- For questions regarding certificate of attendance, please contact: tamara.hager@osumc.edu

Disability Rights: how the ADA protects access to medical care

Disability Rights OHIO

We have the legal right of way.

Ryan R. Nash, MD, MA, FACP, FAAHPM
Director, The Ohio State University Center for Bioethics
Director and Associate Professor with Tenure, Division of Bioethics
Department of Biomedical Education and Anatomy
The Ohio State University College of Medicine

THE OHIO STATE UNIVERSITY NISONGER CENTER

Who is DRO

Disability Rights OHIO

- Disability Rights Ohio (DRO) is a non-profit corporation with a Board primarily consisting of people with disabilities and family members of people with disabilities
- Ohio's designated Protection and Advocacy System and Client Assistance Program

Kerstin Sjoberg, JD
Executive Director, Disability Rights Ohio

THE OHIO STATE UNIVERSITY NISONGER CENTER

Our Mission and Vision

Disability Rights OHIO

- To advocate for the human, civil and legal rights of people with disabilities in Ohio.
- We envision a society in which people with disabilities are full and equal members, with the rights and opportunities of all, and free from discrimination

Americans with Disabilities Act (ADA)

- Purpose: to ensure equal access by removing external and societal barriers that prevent individuals with disabilities from engaging in the same programs and activities as all other individuals

What is Prohibited?

- Exclude from participation in a program or offered services
  - Including medical care
- Afford an opportunity that is not equal to that afforded to others

Discrimination Prohibited by ADA

- Unlike other civil rights laws, went beyond intentional or invidious discrimination
  - E.g., "I don't like you because you have a disability and am going to exclude you from my program/building/workplace."
- It includes the failure to remove societal barriers that prevent equal access to individuals with disabilities

Applied to Scarcity of Medical Resources

- require that decisions concerning whether an individual is a candidate for treatment should be based on individualized assessments of the person, using current objective medical evidence, and not based on generalized assumptions about a person's disability

ADA Coverage

- Title II:
  - State and local governments
    - E.g., state and local health departments
- Title III
  - Public accommodations (private businesses open to the public)
    - E.g., hospitals and other medical providers

Applied to Scarcity of Medical Resources

- prohibit treatment allocation decisions from being made based on misguided assumptions that people with disabilities experience a lower quality of life, or that their lives are not worth living

Applied to Scarcity of Medical Resources

- prohibit treatment allocation decisions from being made based on the perception that
  - a person with a disability has a lower prospect of long-term survival, or
  - a person's disability will require the use of greater treatment resources

Ohio Guidance

- Examples:
  - Making decisions based upon individualized clinical assessment, the best objective medical evidence, the patient's ability to respond to treatment, and short-term survivability from COVID-19
  - Not relying on projections of "long-term survivability" or maximization of "life-years"

OCR Guidance

- Confirms that civil rights laws prohibiting discrimination remain in effect even as dealing with the exigencies of the pandemic
- Issued March 28, 2020 (available at: https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf)

Ohio Guidance

- Examples, cont.:
  - Not penalizing people with disabilities or older adults who may require more use of treatment resources or greater time to recover than others
  - Making crisis standards of care and scarce resource allocation protocols transparent and accessible, including having an appeals process

Ohio Guidance

- Guidance for crisis standards of care in hospital settings
- Incorporated several key factors that are effective in preventing policies that ration scarce resources in a manner that discriminates against people with disabilities

Kara Ayers, PhD
Associate Director, University of Cincinnati UCEDD
Director, Center for Dignity in Healthcare for People with Disabilities

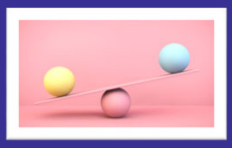
The Ohio State University Nisonger Center

Scarcity of Medical Resources: Racial and Disability Equity

Cincinnati Children's | University of Cincinnati | UCCEDD/LEND | Center for Dignity in Healthcare for People with Disabilities

Healthcare inequities

- are unjust differences in health between persons of different groups.
- are preventable
- are avoidable



Disclosures

I am a salaried faculty member of Cincinnati Children's Hospital Medical Center. The majority of my work is funded by the Administration in Community Living under HHS (HHS-2017-ACL-AOD-DDUC-0195). I am also funded as the Principal Investigator for a Project of National Significance (90DNHC0001). Lastly, I am a member of the PCORI Board of Governors. I do not foresee a conflict of interest with these roles and what I share today.

Cincinnati Children's | University of Cincinnati | UCCEDD/LEND | Center for Dignity in Healthcare for People with Disabilities

Kara Ayers, PhD

- Professor/Research
- Associate Director of University of Cincinnati UCEDD
- Director of the Center for Dignity in Healthcare for People with Disabilities

Cincinnati Children's | University of Cincinnati | Center for Dignity in Healthcare for People with Disabilities

Center for Dignity in Healthcare for People with Disabilities

Founded to address healthcare inequities faced by people with disabilities in:

- prenatal diagnosis
- mental health and suicide prevention
- aging and end-of-life care
- organ transplantation

CENTER FOR DIGNITY IN HEALTHCARE FOR PEOPLE WITH DISABILITIES

Inequities in COVID-19 response:

- failure to mitigate risks in congregate care settings
- inaccessible testing and vaccination sites
- inequitable treatment when hospitalized
- complicated vaccine roll-out

Scarce Medical Resources

Organs | Specialized knowledge in disability | Hospital space/beds | Medications and Vaccines

What does NOT predict health disparities

CENTER FOR DIGNITY IN HEALTHCARE FOR PEOPLE WITH DISABILITIES

Scarce Medical Resources

Time | Accessibility | Equipment | Transportation

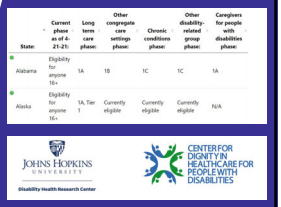
Absolute scarcity

vs.

Relative Scarcity

Bias in organ transplantation has resulted in media coverage and policy change.

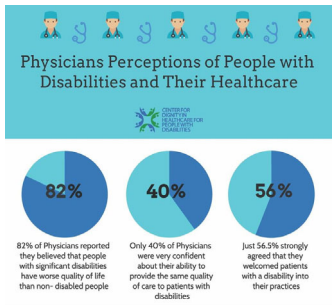
Vaccine priority groups didn't consistently align with research and highlighted disability data problem.



State:	Current phase as of 4-21-21:	Long term care phase:	Other congregate care settings phase:	Chronic conditions phase:	Other disability-related group phase:	Caregivers for people with disabilities phase:
Alabama	Eligibility for anyone 16+	1A	1B	1C	1C	1A
Alaska	Eligibility for anyone 16+	1A, Tier 1	Currently eligible	Currently eligible	Currently eligible	N/A

JOHNS HOPKINS UNIVERSITY
Disability Health Research Center

CENTER FOR DIGNITY IN HEALTHCARE FOR PEOPLE WITH DISABILITIES



Resource allocation relies on explicit and implicit judgement.

SCIENCE + DATA + POLICY
FOR MORE EQUITABLE ALLOCATION OF SCARCE RESOURCES

Research indicates that healthcare providers deny explicit bias but hold implicit bias.

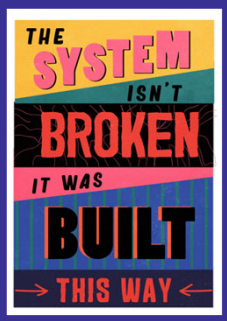
ALGORITHMS MUST BE

- transparent
- scrutinized for bias
- informed by diverse data

CENTER FOR DIGNITY IN HEALTHCARE FOR PEOPLE WITH DISABILITIES

BEST PRACTICES FOR EQUITABLE ALLOCATION OF SCARCE RESOURCES

- Direct involvement of disability advocates and advocates from other marginalized groups
- Options for provider involvement with oversight
- Financial investment to proactively prevent scarcity
- Policy reform to address scarcity



TWITTER
@ThinkEquitable
@DrKaraAyers

FACEBOOK
@ThinkEquitable

WEBSITE
www.centerfordignity.com

CENTER FOR DIGNITY IN HEALTHCARE FOR PEOPLE WITH DISABILITIES

Cincinnati Children's

University of CINCINNATI

UCCEDD/LEND

ADVOCACY ACTION STEPS

REPRESENTATION
Advisory committees and ethics committees must have representation from people who understand disability beyond a medical outcome.

BETTER DATA COLLECTION
States and the federal government must collect and share data that better describes people with disabilities and their health outcomes.

EQUITABLE CARE IN HOSPITAL
The era of rationing of care has not ended and didn't start with the pandemic.

ANTI-ABLEIST TRAINING
Given the known and dangerous existence of ableism, it is critical that anti-ableist training and policies address it.

References and Further Reading

Emanuel, E., Schmidt, H., & Steinmetz, A. (Eds.). (2018). Rationing and resource allocation in healthcare: Essential readings. Oxford University Press.

Iezzoni, L. I., Rao, S. R., Ressalam, J., Bolcic-Jankovic, D., Agaronnik, N. D., Donelan, K., ... & Campbell, E. G. (2021). Physicians' Perceptions Of People With Disability And Their Health Care: Study reports the results of a survey of physicians' perceptions of people with disability. Health Affairs, 40(2), 297-306.

Ongoing and expanded opportunities to work towards health equity

References and Further Reading

Kaushal, A. (2020, November 17). Health Care AI Systems Are Biased. Scientific American. https://www.scientificamerican.com/article/health-care-ai-systems-are-biased/.

Ari Ne'eman, Michael Ashley Stein, Zackary D. Berger, Doron Dorfman; The Treatment of Disability Under Crisis Standards of Care: An Empirical and Normative Analysis of Change Over Time During COVID-19. J Health Polit Policy Law 2021; 9156005. doi: https://doi.org/10.1215/03616878-9156005

VanPuymbrouck, L., Friedman, C., & Feldner, H. (2020). Explicit and implicit disability attitudes of healthcare providers. Rehabilitation psychology, 65(2), 101.

D'Arcee Charington Neal, MA
PhD Student, The Ohio State University
English/Disability Studies
EGO Social Chair 20-21
Sweetland Digital Rhetoric Scholar

THE OHIO STATE UNIVERSITY
NISONGER CENTER

THE FUNDAMENTAL ISSUE OF MISTRUST

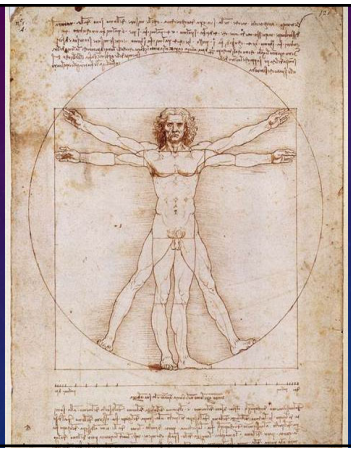
THIS COMES ABOUT AS A RESULT OF REAL HISTORIES AND IMAGINED SYSTEMS OF BELIEFS WHICH ARE BUILT FROM REAL WORLD FACTS. CHIEF AMONG THEM, IS THE REALIZATION THAT MUCH OF THE DISABILITY REPRESENTATION IN AMERICA IS WHITE.

THIS LEADS TO MISUNDERSTANDING, MISINFORMATION, AND LACK F AGENCY OVER BLACK DISABLED NARRATIVES WHICH OFTEN ARE NOT ACCURATE IN THEIR DEPICTIONS OR ASSESSMENT.

(MIS)TRUST/ DIRECTION

HOW THE HISTORY OF BODIES HAS AFFECTED BLACK DISABILITY RESPONSE IN COVID-19

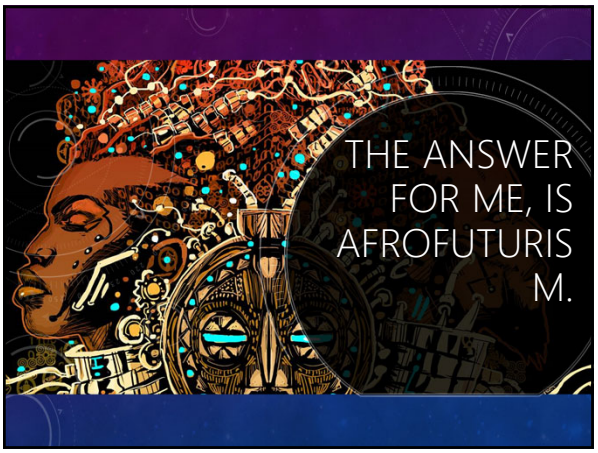
D' ARCEE CHARINGTON NEAL
PHD STUDENT, ENGLISH/DISABILITY STUDIES
THE OHIO STATE UNIVERSITY



DANIEL KALUUYA IN "WILL YOU TAKE IT?" AN SNL SKIT SPOOFING ANTI-VAXXERS IN THE BLACK COMMUNITY

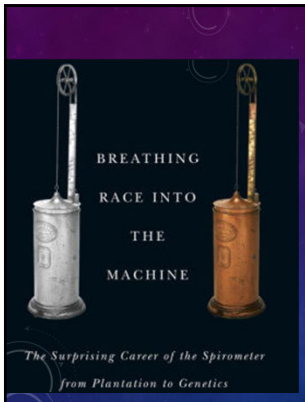
"Vitruvian Man simultaneously displays the elegance of our body and the deep-seated imperfections and old-fashioned workarounds that we inherited from our ancestors…but in selecting his model for human perfection, Leonardo also managed to depict how our perfect bodies, upon closer inspection, are never so perfect after all."

-Laura Cruthers



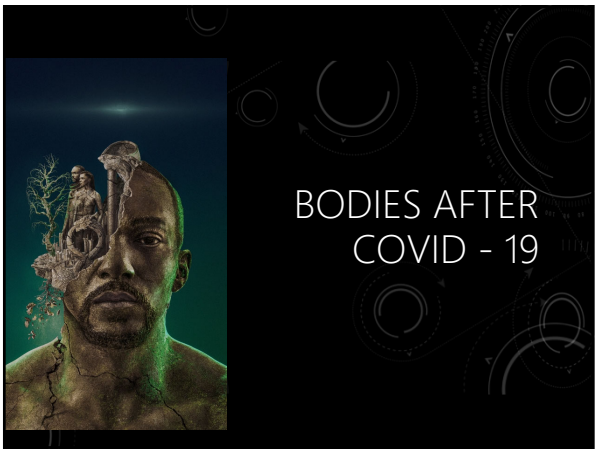
HOW DID WE GET HERE?

[Assumed bodily perfection (via white European) - whiteness + disabling bodily proportions (via craniology, facial comparison)]/survival of the fittest + European supremacy - internalized slavery (via drapetomania) = black (disabled) other



LUNDY BRAUN' S "BREATHING RACE" CHRONICLES THE SPIROMETER FROM THE CIVIL WAR, TO THE MODERN AGE ELECTRONICALLY CONTROLLED BY RACE-DEFINED ALGORITHMS

David Ellsworth, MPH, CHES
Health Services Policy Specialist
Ohio Disability and Health Program




History of Emergency Preparedness and People with Disabilities and Underserved Communities

Public Health During a Pandemic

Analysis of COVID-19 Response and Recovery for People with Disabilities

David Ellsworth MPH, CHES

05/21/2021

2021 Nisonger Institute

Barriers to short-term planning

- Most planning exercises tend to assume a short-term emergency
- Even biological exercises are usually short

My Background

- Public Health
- Emergency Preparedness
- LEND Trainee
- Ohio Disability and Health Program
- Office of Health Equity at Ohio Department of Health
- Small disclaimer – Does not represent the position of ODH

So what happened?

- Under-funding
- Power dynamics
- Scarce resources
- Hospitals Over-filled
- Needed to pivot

Luckily, there are advocacy organizations

THE PARTNERSHIP FOR INCLUSIVE DISASTER STRATEGIES

The Partnership actively engages with a community of local, national and global disability rights, emergency management and public health leaders and allies committed to equal access and whole community inclusion before, during, and after disasters. Our partners have a strong track record of protecting and advancing the rights of people with disabilities (26% of the U.S. population) and over one billion people with disabilities across the globe.

Our founding organization, Portlight Strategies (which led humanitarian response and relief initiatives to meet the needs of disaster-impacted disabled communities for over 20 years) formally established The Partnership in 2016 to focus on disability-inclusive emergency management, community organizing, policy, advocacy and training.

https://disasterstrategies.org/

TABLE 7-1
Implications of the Care Capacity Continuum for Resources

	Low Risk, Low Impact	Moderate Risk, Moderate Impact	High Risk, High Impact
Space	• Expand hours and use procedural spaces for out-of-hospital care (e.g., surgery and procedure center recovery areas) (Chung et al., 2011; Scarfone et al., 2011) • Use postanesthesia care areas for inpatient capacity	• Use operative spaces for inpatient care • Use alternate care sites to divert outpatients (e.g., "flu centers") (Cruz et al., 2010) or provide basic nonambulatory care (hospital overflow)	• Use cot-based care in flat-space areas • Make major changes to admission criteria (e.g., no admission for cardiac rule-outs if no electrocardiogram [ECG] changes and normal troponin)
Staff	• Change documentation requirements • Delegate nonclinical duties (e.g., meal serving) to administrative or other staff	• Change staffing patterns, hours, or supervision • Change frequency of clinical assessments (e.g., vital signs based on clinical changes)	• Provide just-in-time training to staff to allow them to provide lower-impact interventions and overall patient care (e.g., inhaler administration, change of burn dressings) so specialty staff can concentrate on higher-impact interventions (e.g., ventilator management, burn debridements)
Supplies	• Implement conservation strategies (e.g., restrict oxygen use to those that have hypoxia) • Recommend substitute medication classes where possible	• Adapt medications or supplies to the incident (e.g., use of BiPAP or selected anesthesia machines as ventilators) • Reuse otherwise disposable products that can easily be cleaned or disinfected (e.g., cervical collars, tourniquets)	• Reuse products that require high-level disinfection or sterilization (e.g., central lines, ventilator circuits) • Reallocate medications or supplies to those who will derive the greatest benefit and/or make the least demand on resources (duration of use or amount used for outcome)

There were some issues…

OHIO GUIDELINES FOR ALLOCATION OF SCARCE MEDICAL RESOURCES V.10
March 26th

Glasgow Coma Scoring Criteria

Criteria	Adults and Children	Infants and Young Toddlers	Score	Criteria Score
Best Eye Response (4 possible points)	No eye opening	No eye opening	1	
	Eye opens in pain	Eye opens in pain	2	
	Eye opens to verbal command	Eye opens to speech	3	
	Eyes open spontaneously	Eyes open spontaneously	4	
Best Vebal Response (5 possible points)	No verbal response	No verbal response	1	
	Incomprehensible sounds	Infant moans in pain	2	
	Inappropriate words	Infant cries in pain	3	
	Confused	Infant is irritable and continually cries	4	
	Oriented	Infant coos to babbles (normal activity)	5	
Best Motor Respons	No motor response	No motor response	1	
	Extension to pain	Extension to pain	2	
	Flexion to pain	Abnormal flexion to pain	3	
	Withdraws from pain	Withdraws from pain	4	
	Localizes to pain	Withdraws from touch	5	
	Obeys commands	Moves spontaneously or purposefully	6	
		Total Score (add 3 sub-scores; ranges 3 to 15):		

B. CSC Exclusion Criteria (for patients 18 years and older)

EXCLUSION CRITERIA

1. **Identify patients who are NOT CANDIDATES for critical care intervention**
2. Patients, in general, are **excluded from consideration** for critical care intervention when:
   a) There is a low probability of survival despite intensive care
   b) They require resources that cannot be provided; and
   c) Their underlying illness has a poor prognosis with a high likelihood of death
3. **The patients is EXCLUDED from admission or transfer for critical care treatment if ANY of the following is present:** (Refer to Appendix B Triage Tools and Tables)
   a) **SOFA score equal to or greater than 11**
   b) **Cardiac arrest** unwitnessed and/or recurrent arrest unresponsive to standard measures (defibrillation and pacing)
   c) **Severe trauma** with Trauma injury Severity Score & predicted mortality of >90%
   d) **Severe burns** with predicted mortality of >90%
   e) ~~**Severe and irreversible neurologic event** or condition with persistent coma or vegetative state and Glasgow Coma Score (GCS) <5~~
   f) ~~**Severe baseline cognitive impairment** unable to meet basic needs or care for oneself to any extent~~
   g) ~~**Advanced untreatable neuromuscular disease** requiring chronic ventilator support~~
   h)e) **Incurable metastatic malignant disease**
   i)f) **Advanced and irreversible immune-compromised condition**
   j)g) Known and/or previously documented **end-stage organ failure** meeting the following criteria:
      - Heart (NYHA class III or IV heart failure)
      - Lungs (End stage COPD, Cystic Fibrosis, Pulmonary Fibrosis or End state Pulmonary HPT
      - Liver (Child-Pugh score equal or greater than 7)

   k)h) **Known severe dementia** medically treated and requiring assistance with ADL's.
   l)i) **Patient preference to be excluded**

Dave Ellsworth Ellsworth March 30, 2020
These overtly discriminate against people with disabilities and would make many people with a developmental disability ineligible for critical care. My team and I recommend that bullet points e, f, and g be removed from this section. Several other states have faced complaints for including similar clauses in their guidance.
Reply Resolve

Not Ideal

The New York Health Association Functional Classification System

NYHA Classes	
Class	**Patient Symptoms**
Class I (Mild)	No limitation of physical activity. Ordinary physical activity does not cause undue fatigue, palpitations, or dyspnea.
Class II (Mild)	Slight limitation of physical activity. Comfortable at rest, but ordinary physical activity results in fatigue, palpitations or dyspnea.
Class III (Moderate)	Marked limitation of physical activity. Comfortable at rest, but less than ordinary activity causes fatigue, palpitations, or dyspnea.
Class IV (Severe)	Unable to carry out physical activity without discomfort. Symptoms of cardiac insufficiency at rest. If any physical activity is undertaken, discomfort is increased.

We had some stuff to say

Addition of the following language on page 9 under Ethical Considerations:

The US Department of Health and Human Services Office of Civil Rights (OCR) enforces the Americans with Disabilities Act, Section 504 of the Rehabilitation Act, the Age Discrimination Act, and Section 1557 of the Affordable Care Act which prohibits discrimination in HHS funded health programs or activities. As such, persons with disabilities should not be denied medical care on the basis of stereotypes, quality of life, or judgments about a person's relative "worth" based on the presence or absence of disabilities or age. Decisions by covered entities concerning whether an individual is a candidate for treatment should be guided by an individualized assessment of the patient and his or her circumstances, based on the best available objective medical evidence.

Additional Guidance

- DRO
- DODD
- Ethical Considerations – Nisonger Center

Let's change that

Give resources to those who have the highest chance of survival **based on an individual assessment of the patient and his or her circumstance, based on the best objective medical evidence.**

- **Removed the following language:**
  - **Severe and irreversible neurologic event** or condition with persistent coma or vegetative state and Glasgow Coma Score (GCS) <5
  - **Severe baseline cognitive impairment** unable to meet basic needs or care for oneself to any extent
  - **Advanced untreatable neuromuscular disease** requiring chronic ventilator support

Outbreak Response

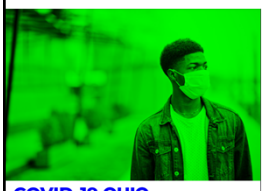

The Columbus Dispatch

60% of Ohio coronavirus deaths have occurred in long-term care facilities

- https://coronavirus.ohio.gov/wps/portal/gov/covid-19/dashboards/long-term-care-facilities/cases

Time for reinforcements

- Other Rising Issues
  - Inaccessible COVID testing
  - Patients being denied caregiver support
  - Outbreaks in nursing homes and congregate living centers
- Disability Rights Ohio
- OSU Center for Bioethics


COVID-19 OHIO MINORITY HEALTH STRIKE FORCE BLUEPRINT

MORE THAN A MASK

■ 9. Consider internal reviews as a tool to address racism and other discrimination in health care.

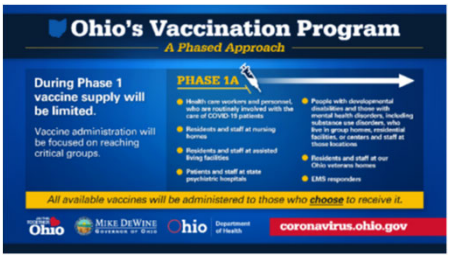
State government leadership should work with, and consider requiring, all health care organizations, including hospitals, behavioral health providers, long-term care facilities, and others, to collect complete and accurate patient demographic data (i.e., race, ethnicity, language, disability) through electronic medical records to track differences in outcomes among their patient populations and develop a plan to mitigate any disparities, including performing internal reviews of the provider organization's policies and practices.

■ 15. Ensure K-12 chronic absenteeism reduction efforts meet the needs of children of color.

State government leadership should tailor efforts to decrease K-12 chronic absenteeism and increase graduation rates to meet the needs of students of color and students with disabilities and consider providing support to local school districts to ensure that future online learning successfully engages all Ohio families.

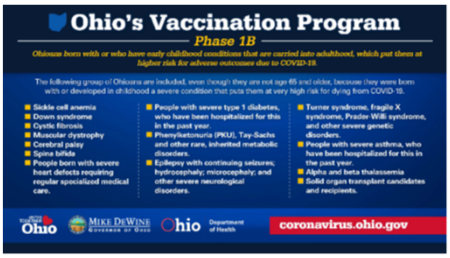
■ 23. Review the number of Ohioans in congregate settings.

State agencies should review the use of congregate settings to reduce unnecessary use (nursing homes, residential care facilities for people with disabilities, group homes, and correctional facilities) and consider policy changes that allow people to receive the supports or treatment they need at home and/or for justice to be served in the community.



New Strategies

- Disability Advisory Committee to inform ODH work
- Minority Vaccination Task Force
- Interest from FEMA in Ohio's response and recovery efforts



Questions?

The Ohio State University Nisonger Center

Current barriers

- Vaccine hesitancy
- Low rate of vaccine uptake among long-term care staff and Caregivers
- Inaccessible information
- Caregiver shortage
- Reaching people with disabilities at home
- Disruption in routine

Thank you for joining us!

We value your feedback! Please take a moment to complete this brief survey; you can scan this QR code using your smartphone/tablet camera or barcode app; or click the link provided in the chat!

The Ohio State University Nisonger Center