Volume 7 | Issue 2
March 2021

Delaware Journal of Public Health

A publication of the Delaware Academy of Medicine / Delaware Public Health Association

2020 American Public Health Association – Affiliate of the Year

Diversability:

Thriving with Intellectual and Developmental Disability

DELAWARE ACADEMY *of* MEDICINE
DPHA
DELAWARE PUBLIC HEALTH ASSOCIATION
www.delamed.org | www.delawarepha.org

APHA
AMERICAN PUBLIC HEALTH ASSOCIATION
For science. For action. For health.

Delaware Journal of
Public Health

March 2021
Volume 7 | Issue 2

A publication of the Delaware Academy of Medicine / Delaware Public Health Association

Delaware Academy of Medicine

Board of Directors:

OFFICERS
Omar A. Khan, M.D., M.H.S.
President

S. John Swanson, M.D.
President Elect

Lynn Jones
Secretary

David M. Bercaw, M.D.
Treasurer

Daniel J. Meara, M.D., D.M.D.
Immediate Past President

Timothy E. Gibbs, M.P.H.
Executive Director, Ex-officio

DIRECTORS
Stephen C. Eppes, M.D.
Eric T. Johnson, M.D.
Joseph F. Kestner, Jr., M.D.
Professor Rita Landgraf
Brian W. Little, M.D., Ph.D.
Arun V. Malhotra, M.D.
John P. Piper, M.D.

EMERITUS
Robert B. Flinn, M.D.
Barry S. Kayne, D.D.S.

Delaware Public Health Association

Advisory Council:
Omar Khan, M.D., M.H.S.
President

Timothy E. Gibbs, M.P.H.
Executive Director

Louis E. Bartoshesky, M.D., M.P.H.
Gerard Gallucci, M.D., M.H.S.
Richard E. Killingsworth, M.P.H.
Erin K. Knight, Ph.D., M.P.H.
Melissa K. Melby, Ph.D.
Mia A. Papas, Ph.D.
Karyl T. Rattay, M.D., M.S.
William J. Swiatek, M.A., A.I.C.P.

Delaware Journal of Public Health

Timothy E. Gibbs, M.P.H.
Publisher

Omar Khan, M.D., M.H.S.
Editor-in-Chief

S. John Swanson, III, M.D., F.A.C.S.
Charmaine Wright, M.D., M.S.H.P.
Guest Editors

Liz Healy, M.P.H.
Managing Editor

Kate Smith, M.D., M.P.H.
Copy Editor

Suzanne Fields
Image Director

ISSN 2639-6378

COVER

The term Diversability is currently a movement as the preferred term to replace the word "disability and disabilities". The word "disabilities" is said to be associated with the past and people's negative experiences with institutions. The term Diversability however embraces the uniqueness and potential in every human being, disabled or non-disabled.

The Delaware Journal of Public Health (DJPH), first published in 2015, is the official journal of the Delaware Academy of Medicine / Delaware Public Health Association (Academy/DPHA).

Submissions: Contributions of original unpublished research, social science analysis, scholarly essays, critical commentaries, departments, and letters to the editor are welcome. Questions? Write ehealy@delamed.org or call Liz Healy at **302-733-3989**.

Advertising: Please write to ehealy@delamed.org or call **302-733-3989** for other advertising opportunities. Ask about special exhibit packages and sponsorships. Acceptance of advertising by the Journal does not imply endorsement of products.

Copyright © 2021 by the Delaware Academy of Medicine / Delaware Public Health Association. Opinions expressed by authors of articles summarized, quoted, or published in full in this journal represent only the opinions of the authors and do not necessarily reflect the official policy of the Delaware Public Health Association or the institution with which the author(s) is (are) affiliated, unless so specified.

Any report, article, or paper prepared by employees of the U.S. government as part of their official duties is, under Copyright Act, a "work of United States Government" for which copyright protection under Title 17 of the U.S. Code is not available. However, the journal format is copyrighted and pages June not be photocopied, except in limited quantities, or posted online, without permission of the Academy/ DPHA. Copying done for other than personal or internal reference use-such as copying for general distribution, for advertising or promotional purposes, for creating new collective works, or for resale- without the expressed permission of the Academy/DPHA is prohibited. Requests for special permission should be sent to ehealy@delamed.org.

DELAWARE ACADEMY *of* MEDICINE

DPHA
DELAWARE PUBLIC HEALTH ASSOCIATION

An affiliated association of
APHA
AMERICAN PUBLIC HEALTH ASSOCIATION
For science. For action. For health

IN THIS ISSUE

A goal of this publication is to make things visible, and further, to explain them in a manner both scientific and accessible. To that end, we always include a lexicon of terms for the reader, as well as relevant resources for additional information and action. As we make things visible, we deepen our understanding and appreciation for the nuance of situations and solutions. At the heart of it, this is the core of public health.

In past issues we have helped to make more visible the lives of those living with substance use, those within the LGBTQ community, and this past fall, those who have lived the Black/African American experience. In this issue, we make visible another group – those with Intellectual and Developmental Disabilities (IDD). As you will read in this issue, there are two major "tsunamis" facing us: our aging demographic and its unique public health challenges, and – the one many are not as aware of – the growing population of those with IDD.

Why is this second tsunami occurring? According to the Centers for Disease Control and Prevention (CDC), one factor is much better early diagnosis of specifics types of developmental disability.[1] It is further theorized that many children who would have failed to thrive in the past now can, due to medical advances. Finally, there are the social determinants of health, coupled with a growing population. The odds and the risk factors of the different factors compound each other, and the population of those with IDD increases.

We have one overarching goal for this issue: to encourage everyone to think of people with IDD as differently-abled; as full members of our community who deserve our compassion, our respect, and our support. Our guest editors for this issue are the President-Elect of the Delaware Academy of Medicine / Delaware Public Health Association – S. John Swanson, III, M.D. (himself a parent of an adult with IDD), and Charmaine Wright, M.D., M.P.H., Director of the Center for Special Health Care Needs at ChristianaCare.

As always, we welcome your feedback, which you can provide at www.djph.org. In closing, we acknowledge the "elephant in the room:" we have now lived with, suffered and died from the COVID-19 pandemic for one full year. With vaccines approved from three pharmaceutical giants, there is more hope for the future with every dose given. We encourage you to do your part when the time comes, and get a vaccinated for yourself, for your loved ones, and for your community. Until then, mask up, wash your hands, and stay well!

REFERENCES

1. Centers for Disease Control and Prevention. (2019). Increase in developmental disabilities among children in the United States. Retrieved from: https://www.cdc.gov/ncbddd/developmentaldisabilities/features/increase-in-developmental-disabilities.html

Omar A. Khan, M.D., M.H.S.
President

Timothy E. Gibbs, M.P.H.
Executive Director

doi: 10.32481/djph.2021.03.001

Guest Editors

S. John Swanson, III, M.D., F.A.C.S.

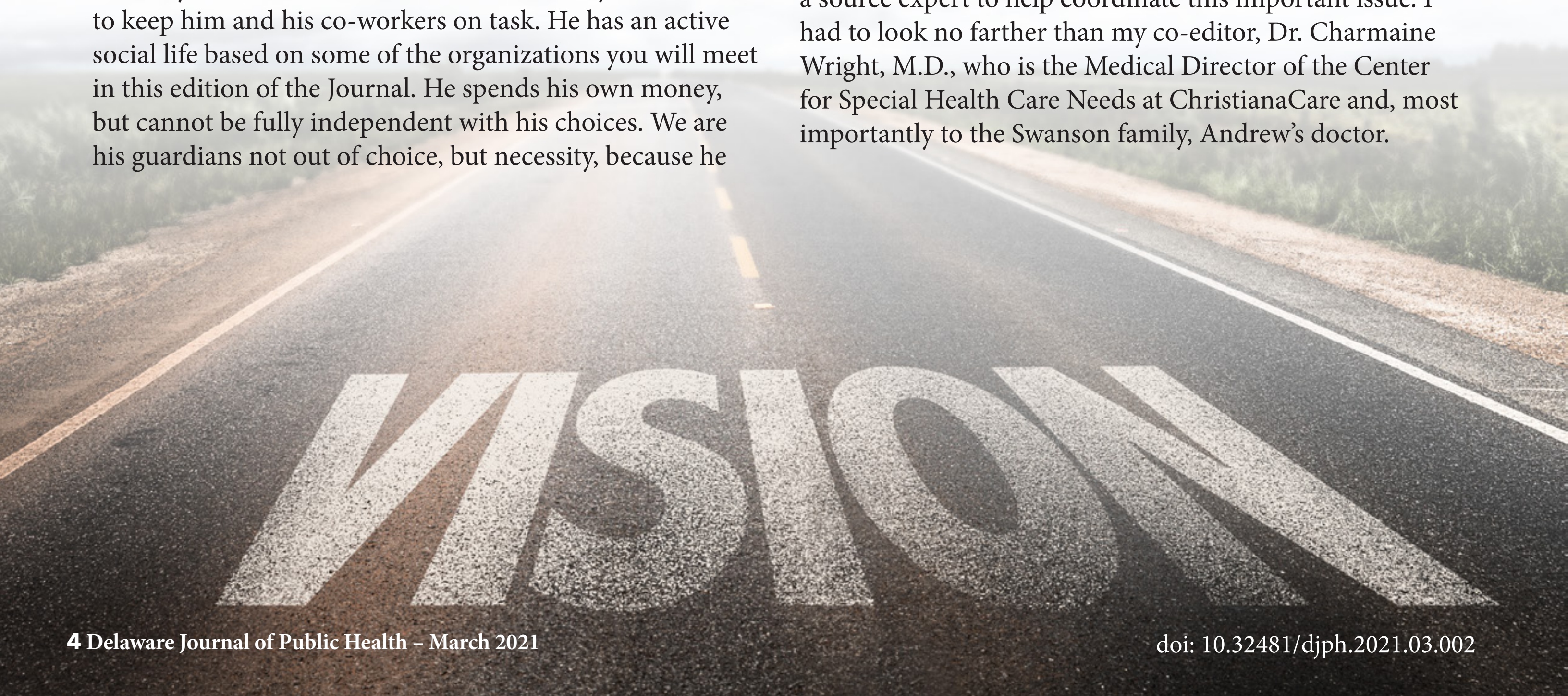
Surgical Director & Chief of Transplantation Surgery,
Kidney Transplant Program, ChristianaCare;
President-Elect, Delaware Academy of Medicine/
Delaware Public Health Association

Welcome to this edition of the Delaware Journal of Public Health, focusing on health issues of persons with Intellectual and Developmental Disabilities (IDD). I am the father of Andrew, a 32-year-old autistic man. Autism is one of many IDD, and is now apparently seen in 1 in 64 births. He has an identical twin brother who is not autistic. Andrew was diagnosed at age two when he lost speech and was not meeting normal milestones like his brother. Following initial disappointment and realization of a new normal with his diagnosis, my wife and I, like many parents in this position, began to look for a path forward. We were extremely fortunate in that he had an early diagnosis, and was enrolled in an excellent autism program through the public school system in Maryland by age three. The early intervention allowed him to learn to control disruptive behaviors, and to regain his ability to speak, which improved his ability to navigate his world. Had we been in Delaware during these early years, the same excellent programs would have been available here as well.

We moved to Delaware when Andrew was 18, and here he was afforded the services available to him and all citizens with disabilities through the public school system until age 21. At this time, his programing focused on his transition to work and life as an adult. With the assistance of a caring and gifted teacher who discerned which of his diverse abilities would help him gain meaningful employment, Andrew found a job. This job was not created for him, but instead one that matched his unique skills. He functions skillfully at work, but with the assistance of a job coach to keep him and his co-workers on task. He has an active social life based on some of the organizations you will meet in this edition of the Journal. He spends his own money, but cannot be fully independent with his choices. We are his guardians not out of choice, but necessity, because he needs protections legally and financially. We advocate for him because, though he conquered his loss of physical speech, he remains relatively voiceless in the events of his life. He frequently joins his mother in advocacy efforts, and one time had the opportunity to testify at the Joint Finance Committee in Dover. Wearing his hospital scrubs, Andrew handed out his W-2 to members of the committee to prove himself gainfully employed and a tax payer! You will find in this edition the many groups that serve and advocate for the population with IDD and have helped Andrew lead a full life.

I am also the incoming president of the Delaware Academy of Medicine/Delaware Public Health Association. Having seen the benefits of meaningful employment, stable housing, available health care and a positive social life in my son's overall well-being and health, I have chosen to focus my platform on these public health determinants, and advocate for the generalization of these opportunities to all persons like Andrew.

I was thrilled when I approached the editorial team about an issue to highlight the public health issues of this population and everyone was very enthusiastic to proceed. My vision for the edition was one of a guide to providers on what options they have to recommend and offer their patients with IDD and their caregivers to promote best health and life options. I think you will agree that mission has been completed. But as my wife and I often say, it takes a village to raise an Andrew, and I knew that we needed a source expert to help coordinate this important issue. I had to look no farther than my co-editor, Dr. Charmaine Wright, M.D., who is the Medical Director of the Center for Special Health Care Needs at ChristianaCare and, most importantly to the Swanson family, Andrew's doctor.



doi: 10.32481/djph.2021.03.002

Charmaine Wright, M.D., M.S.H.P.

Medical Director, Center for Special Health Care Needs, ChristianaCare; Medical Educator, Health Services Researcher, Mary Campbell Center

It is such an honor to be a part of this special journal. We hope it serves as both teacher and guide. We hope you join in the awareness and appreciation of our fellow Delawareans with diverse abilities. You will find a discussion on the diagnosis of Intellectual and Developmental Disability and tips on building a medical home for individuals with this diagnosis. You will find important messages on employment, recreation, and sexuality – on those things which bring dignity and fulfillment to a well-lived life for any human. We get the opportunity to amplify the voices of those individuals and families for whom the pandemic has challenged the shaky patchwork of usual medical, financial, and behavioral supports. With a higher prevalence of adults with cognitive diverse abilities living in Delaware than in our surrounding states, you can be a part of the solution to improving life for all our residents, one person at a time. You can also join in the pride of so many things done just right, as showcased within these pages. Special thanks to my patients and their families who teach me about grace and the beauty of diversity every single day.

doi: 10.32481/djph.2021.03.003

Q. What does the term "Diversibility" mean?

A. The term Diversability is currently a movement as the preferred term to replace the word "disability and disabilities". The word "disabilities" is said to be associated with the past and people's negative experiences with institutions. The term Diversability however embraces the uniqueness and potential in every human being, disabled or non-disabled.

- Diversabilities refer to physical, cognitive, developmental, learning, and/or neurological differences, or diversity, in ability levels.
- Diversability events promote an atmosphere where individuals are comfortable discussing and exploring questions about accessibility, equality, and inclusion for people with disabilities.

Retrieved from: https://www.disabled-world.com/definitions/diversability.php

Intellectual Developmental Disabilities: Definitions, Diagnosis, and Delivery of Care

Louis E. Bartoshesky, M.D., M.P.H., F.A.C.M.G.
Professor of Pediatrics Sidney Kimmel Medical College, Thomas Jefferson University

Charmaine Wright, M.D., M.S.H.P.
Medical Director, Center for Special Health Care Needs, ChristianaCare; Adjunct Assistant Professor of Medicine and Pediatrics, University of Pennsylvania

INTRODUCTION

Intellectual developmental disability (IDD) is a developmental condition characterized by significant deficiencies in intellectual functioning and adaptive behavior. Some definitions specify an onset before age 22. Other definitions[1–3] stress the specific areas of disability: reasoning, planning, judgment, abstract thinking and experiential learning.[4] In the absence of a specific biomarker (IQ alone having been appropriately discarded along with the outdated term mental retardation), the determination or diagnosis of IDD is established on "clinical grounds." "Clinical" implies a sophisticated and comprehensive evaluation, not simply one person's impression. It includes an evaluator with a degree of clinical training and expertise capable of a thorough review and analysis.[1] Similarly, a comprehensive clinical care team ensures health for the individual throughout life.

FREQUENCY

It is difficult to report a specific prevalence of IDD, because of clinical heterogeneity of the condition, variations of age of subjects in reported studies, and variations in methods of diagnosis/determination. A recent CDC report quotes a prevalence of adults with cognitive disability in Delaware as 14%, while other sources quote figures in the 1 to 3% range.[3,5,6] In any case, the prevalence is substantial and of public health importance.

COMORBIDITIES

Frequently, individuals with IDD have accompanying comorbidities, such as autism spectrum disorder, seizure disorder, attention deficit disorder, anxiety, cerebral palsy, vision disorders, hearing loss, and depression. In other cases, there may be extensive physical and developmental features outside of the nervous system consistent with a syndromic IDD such as Down Syndrome.

CAUSES

A precise determination of cause in an affected person is often not determined.[1,5] However, consideration of causes can be important to families and in estimating prognosis. A useful approach is to consider possible causes related to environment and others to genetics with an acknowledgment that there is also a third category: "unknown" or, optimistically, "to be determined" or "multifactorial."[3]

Environmental causes can be prenatal, perinatal and postnatal. Examples of prenatal causes include poor maternal health, maternal infection with organisms known to be teratogenic (e.g. rubella, cytomegalovirus, varicella, Zika, toxoplasmosis); high dose of radiation; maternal use of drugs/medications such as anti-metabolites, warfarin, anticonvulsants, isotretinoin, tobacco, alcohol and others.

Possible perinatal causes or risk factors include low birth weight, prematurity, complications of labor and delivery, neonatal asphyxia, perinatal infections, newborn multiple congenital anomalies, infant infections such as Herpes, meningitis, neonatal sepsis and structural brain anomalies (microcephaly, hydrocephalus, schizencephaly) as well as other major congenital anomalies such as diaphragmatic hernia or complex congenital cardiac anomalies.

Potential postnatal environmental causes of IDD include serious infections, meningitis, acknowledged environmental toxins, traumatic brain injury and adult onset of degenerative nervous system disorders (e.g Parkinson's, Alzheimer's, Huntington's, and many others).

There are numerous genetic causes of IDD. Genetic disorders include variations of chromosome number (e.g. Down Syndrome), relatively large duplications or deletions of parts of a chromosome (e.g. Cri du Chat Syndrome, due to the deletion of part of the short arm of chromosome number 5), and single gene disorders. Single gene disorders include (but are not limited to) inborn errors of metabolism (e,g. PKU), lysosomal storage disorders, peroxisomal disorders, fatty acid oxidation disorders, disorders of energy metabolism (mitochondrial disorders) and a number of syndromes with multiple congenital anomalies including the central nervous system.[6,7]

The Online Mendelian Inheritance in Man (OMIM)[8] is a comprehensive, authoritative compendium of human genes and disorders related to mutations. Recently OMIM reported that about 1091 genetic loci have identified mutations which may be associated with an intellectual developmental disorder.[8]

EVALUATION

Determining a specific cause of an intellectual, developmental disability can assist a family in working with an affected individual. A specific determination might result in better understanding of how an IDD occurred and an idea of whether progression is likely to occur. Specific determination is not likely, at this time, to suggest specific interventions, but could help families and individuals understand risks to the individual, and likelihood of presentation in other family members. Genetic counselling is a useful tool to navigate risks to other and future family members.

In a diagnostic setting, medical history is important with specific attention to pre- and perinatal history, as well as a family history, including a three generation family pedigree taking into account history of early death, infertility, and consanguinity. A physical exam could be helpful in identifying minor congenital variants that could assist in determining a genetic disorder. For example, detecting minor variants in extremities could assist in identifying a chromosome disorder, or detecting certain subtle skin variants could suggest tuberous sclerosis complex.

Appropriate blood and urine studies – such as measurement of amino acids, organic acids, fatty acids, and lactate/pyruvate ratios – may lead to an identification of an underlying inborn

doi: 10.32481/djph.2021.03.004

error of metabolism. These are most often part of a pediatric developmental/genetic evaluation, though in recent years, late-onset inborn errors of metabolism have been proven to be more common than thought previously.

Karyotyping ("routine" chromosome analysis) has been available for decades and has been valuable in confirming certain clinically suspected syndromes - most notably Down Syndrome (in most cases due to Trisomy 21), but also confirming other trisomies such as Trisomy 13 and Trisomy 18 - as well as detecting relatively large chromosome deletions. Routine karyotype may be adequate in identifying variants in a suspected sex chromosome anomaly. As part of the evaluation of a person with congenital anomalies and/or IDD, newer technologies have replaced karyotype except in situations noted above.

Chromosome microarray (CMA) in its simplest explanation is a technology in which parts of an individual's DNA are compared to a standard.[9] There are other similar technologies involving single nucleotide variants with similar sensitivities. These technologies can identify copy number variants (CNV) in a subject with resolution to as few as 60,000 nucleotides. This means the technology can reliably detect disorders characterized by small deletions or duplications, including some relatively well known syndromes: Williams, DiGeorge, Smith Magenis, 1p36 deletion and others. It may also detect other deletions and/or duplications that could explain the IDD.[9] Occasionally the technique will detect a deletion or duplication not previously known to be pathogenic. These are known as variants of uncertain significance, or VUS. Parental studies could be helpful in interpretation of VUS if one of the unaffected parents has the same CNV. Though sometimes it can be confusing to interpret VUS, in a study of hundreds of persons with IDD, CMA resulted in up to 25% of selected persons having a diagnosis made.[9]

Many single gene disorders can be confirmed by specific mutation analysis. For example, if there is a clinical suspicion of Fragile X syndrome this can be confirmed at a number of available laboratories. In this situation, the lab looks specifically for mutations at the Fragile X locus. No other genes are studied.

Recently, nucleic acid sequencing technologies (so called next generation sequencing) have become clinically available. These allow for relatively prompt determination of the number and sequence of part of the DNA in a patient's genome. Genes are made up of exons and introns. The exons are the parts of the gene that code for a specific protein. The next generation sequencing can be set up to study all (or almost all) of the exons known as the exome. The technology (called whole exome sequencing, WES) is relatively expensive, though often comparable to the cost associated with step by step evaluations.[10] Generating substantial amounts of information, WES can reliably detect singe gene variants throughout the exome.[10–14] Fifteen to forty percent of persons with IDD who have WES will have a detectable mutation and a molecular diagnosis or determination made.

The next technology step, whole genome sequencing (WGS), is currently clinically available in some situations and will be generally available soon. This form of next generation sequencing "looks" at the entire (or almost entire) genome and can reliably deject single gene variants in exons AND introns. These new technologies at times can require complex interpretations. WGS can identify mutations in genes that were not being studied, so called Secondary Results. Appropriate responses to VUS or Secondary Results of sequencing are under investigation with particular attention to ethical issues.

CONCLUSION

New genetic technologies contributing to the understanding of the etiology of IDD are becoming available to persons with IDD and their families. This availability is expected to be beneficial for those individuals and families who wish to pursue a specific diagnosis with the guidance of a genetic counselor, and for the health care providers caring for the individual and his or her family throughout a lifetime.

COMPANION PEARL

Whether or not the specific etiology of IDD is known, an appropriate clinical team should be comprehensive and multidisciplinary, and based in collaborative primary and specialty care. Health disparities between adults with IDD and the general population result for a variety of reasons: fragmented access to primary and preventive care,[15] social and medical stigma,[16] and marginalization.[17] So, too, can there be increased morbidity from the associated conditions, with an all-cause mortality almost three times higher than in the general population.[18] Black race, Latinx ethnicity, low income status, and female gender accentuate the disparity.[19]

To empower adults with IDD, their caregivers, and their clinical teams, the goals of effective health care engagement follow:

1. Get specific! If genetic testing is warranted, pursue the diagnosis to better direct care. Searching for a genetic cause can be helpful, but not necessary. If a particular genetic syndrome is known, visit foundation websites and refer to guidelines of care that are syndrome-specific. The most common congenital etiologies of IDD are Down Syndrome, Fragile X Syndrome, and fetal alcohol syndrome (FAS). All three disorders have strong advocacy organizations and frequently updated guidelines for diagnosis and care accessible by secondary data sources like Uptodate or Medscape. For these and less known congenital causes, additional use of a research database like Pubmed or Medline can also direct care and demonstrate clinical experts familiar with the disorder who may be willing to collaborate.
2. Routine health care should include age-appropriate cancer screening, infection screening, immunizations, and periodic dental evaluation. For those in congregate living arrangements like group homes or facilities, evaluations should include screening for infectious diseases like tuberculosis. Frequent evaluation of common problems will focus on brain disorders (mental illness, seizure disorder), bowel complaints (from oral hygiene to dysphagia and constipation), and behaviors (both adaptive and maladaptive). On demand health services may be insufficient in those who have difficulty with communication, so routine health examinations at least every six months are advised.
3. Address sexuality and the need for birth control and infection screening among adults with IDD. Address the possibility of abuse. Those with IDD are at increased risk of experiencing interpersonal violence of all forms.[20]
4. Communicate! Encourage addressing the patient first and frequently during clinical encounters no matter how the particular individual communicates. Additional bidirectional communication is necessary among clinical team and both

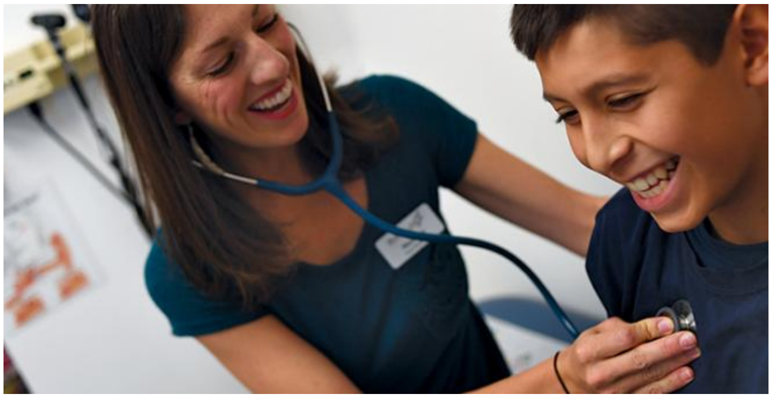
local and family caregivers who may be in different geographic locations and varying proximity to the patient. Provide written communication accessible by all. Clarify whether the patient speaks for him or herself and if not, who does. Sometimes there is a need to establish supported decision making or guardianship, especially when a patient is anticipated to need a procedure. This process can take time and money. The guardian may be a relative or state-appointed official.

5. Implement **e**thical care. Establishing goals of care in patients with IDD is no different that establishing goals of care in the general population. The diagnosis of IDD alone does not signify the type of procedures an individual may have nor resuscitation status. Understanding the patient's and family's wishes, in addition to the nature of terminal illnesses and likelihood of resuscitation success, should guide shared decision making. Check biases to ensure appropriate care delivery unfettered by discrimination.

REFERENCES

1. Tasse, M. (2019, Sep). Defining Intellectual Disability American Psychological Association Spotlight on Disability Newsletter
2. National Health Interview Survey; NHIS. (n.d.). http://cdc.gov.CBDD/Delaware
3. Centers for Disease Control and Prevention. (2021, Feb 5). National Center on Birth Defects and Developmental Disabilities.
4. Schalock, R. (2021). Intellectual Disability: Definition and Classification. Retrieved from: https://www.aaidd.org/intellectual-disability/definition
5. Karam, S. M., Riegel, M., Segal, S. L., Félix, T. M., Barros, A. J. D., Santos, I. S., . . . Black, M. (2015, June). Genetic causes of intellectual disability in a birth cohort: A population-based study. *American Journal of Medical Genetics. Part A*, *167*(6), 1204–1214. https://doi.org/10.1002/ajmg.a.37011
6. Korf, B. R., Rimoin, D. L., & Pyeritz, R. E. (2019). Ch. 3: Nature and Frequency of Genetic Disease. In Principles and Practice of Medical Genetics, 7th Ed. Elevesier: Boston. 48-51.
7. Havercamp, S. M., Scandlin, D., & Roth, M. (2004, July-August). Health disparities among adults with developmental disabilities, adults with other disabilities, and adults not reporting disability in North Carolina. *Public Health Rep*, *119*(4), 418–426. https://doi.org/10.1016/j.phr.2004.05.006
8. Online Mendelian Inheritance in Man. (n.d.). Retrieved from: https:// NGRI.www.nlm.ncb.gov
9. Miller, D. T., Adam, M. P., Aradhya, S., Biesecker, L. G., Brothman, A. R., Carter, N. P., . . . Ledbetter, D. H. (2010, May 14). Consensus statement: Chromosomal microarray is a first-tier clinical diagnostic test for individuals with developmental disabilities or congenital anomalies. *American Journal of Human Genetics*, *86*(5), 749–764. https://doi.org/10.1016/j.ajhg.2010.04.006
10. de Ligt, J., Willemsen, M. H., van Bon, B. W. M., Kleefstra, T., Yntema, H. G., Kroes, T., . . . Vissers, L. E. L. M. (2012, November 15). Diagnostic exome sequencing in persons with severe intellectual disability. *The New England Journal of Medicine*, *367*(20), 1921–1929. https://doi.org/10.1056/NEJMoa1206524
11. Trujillano, D., Bertoli-Avella, A. M., Kumar Kandaswamy, K., Weiss, M. E. R., Köster, J., Marais, A., . . . Abou Jamra, R. (2017, February). Clinical exome sequencing: Results from 2819 samples reflecting 1000 families. *Eur J Hum Genet*, *25*(2), 176–182. https://doi.org/10.1038/ejhg.2016.146
12. Wang, W., Corominas, R., & Lin, G. N. (2019, April 3). De novo mutations from whole exome sequencing in neurodevelopmental and psychiatric disorders: From discovery to application. *Frontiers in Genetics*, *10*, 258. https://doi.org/10.3389/fgene.2019.00258
13. Monroe, G. R., Frederix, G. W., Savelberg, S. M. C., de Vries, T. I., Duran, K. J., van der Smagt, J. J., . . . van Haaften, G. (2016, September). Effectiveness of whole-exome sequencing and costs of the traditional diagnostic trajectory in children with intellectual disability. *Genet Med*, *18*(9), 949–956. https://doi.org/10.1038/gim.2015.200
14. Stojanovic, J. R., Miletic, A., Peterlin, B., Maver, A., Mijovic, M., Borlja, N., . . . Cuturilo, G. (2020, February). Diagnostic and clinical utility of whole exome sequencing in children with moderate and severe global developmental delay / intellectual disability. *Journal of Child Neurology*, *35*(2), 116–131. https://doi.org/10.1177/0883073819879835
15. Zerbo, Q., Qian, Y., Ray, T., Sidney, S., Rich, S., Massolo, M., & Croen, L. (2019, March). Health care service utilization and cost among adults with autism spectrum disorders in a U.S. integrated health care system. *Autism in Adulthood: Challenges and Management*, *1*(1), 27–36. https://doi.org/10.1089/aut.2018.0004
16. Nicolaidis, C., Raymaker, D. M., Ashkenazy, E., McDonald, K. E., Dern, S., Baggs, A. E., . . . Boisclair, W. C. (2015, October). "Respect the way I need to communicate with you": Healthcare experiences of adults on the autism spectrum. *Autism*, *19*(7), 824–831. https://doi.org/10.1177/1362361315576221
17. Hotez, E., Hotez, P. J., Rosenau, K. A., & Kuo, A. A. (2021, February 5). Prioritizing COVID-19 vaccinations for individuals with intellectual and developmental disabilities. *EClinicalMedicine*, *100749*, 100749. https://doi.org/10.1016/j.eclinm.2021.100749
18. Tyrer, F., Smith, L. K., & McGrother, C. W. (2007, July). Mortality in adults with moderate to profound intellectual disability: A population-based study. *J Intellect Disabil Res*, *51*(7), 520–527. https://doi.org/10.1111/j.1365-2788.2006.00918.x
19. Magaña, S., Parish, S., Morales, M. A., Li, H., & Fujiura, G. (2016, June). Racial and ethnic health disparities among people with intellectual and developmental disabilities. *Intellectual and Developmental Disabilities*, *54*(3), 161–172. https://doi.org/10.1352/1934-9556-54.3.161
20. Hughes, K., Bellis, M. A., Jones, L., Wood, S., Bates, G., Eckley, L., . . . Officer, A. (2012, April 28). Prevalence and risk of violence against adults with disabilities: A systematic review and meta-analysis of observational studies. *Lancet*, *379*(9826), 1621–1629. https://doi.org/10.1016/S0140-6736(11)61851-5

The NATION'S HEALTH
A PUBLICATION OF THE AMERICAN PUBLIC HEALTH ASSOCIATION



New US leadership may bring brighter public health outlook

Health advocates hopeful for change

The Nation's Health

Vol. 51, Issue 1 February/
March 2021

Table of Contents Table of Contents (PDF)

Index by author

Complete Issue (PDF)

HIGHLIGHTS

Public health messaging vital for COVID-19 vaccine uptake: Leaders partnering on communications

With new COVID-19 cases daily, the pressure is on to persuade Americans to get immunized. Public health messengers are working to meet that goal, but are facing steep challenges.

Healthy People spotlights key objectives for improving health of US

A new set of 23 high-priority Healthy People 2030 objectives, called Leading Health Indicators, helps public health workers focus their community health work.

New national asthma guides call for mitigating indoor allergens

National guidelines for diagnosis, managing and treating asthma have received their first update in more than a decade.

New WHO guidelines encourage increase in physical activity

Millions of deaths could be avoided each year if people around the world became more active, according to new WHO guidelines.

Public health education shifts in wake of accreditation changes

Many schools have revamped their curricula, with a goal of graduating students ready to practice on day one.

Public health extras: February/March 2021

New findings on gun violence, Medicaid expansion, worker safety and more

Disability as a Determinant of Health: Lessons from the Pandemic

Elizabeth Ashford
Research Assistant, HELP-MLP; Widener University Delaware Law School
Michael Atkins
Research Fellow, Lurie Institute for Disability Policy, Brandeis University
Marissa Band, J.D., M.P.A.P.
Managing Attorney, Disabilities Law Program, Community Legal Aid Society, Inc.
David P. Donohue, M.D., F.A.C.P.
Chief Medical Officer, Progressive Health of Delaware
Robert L. Hayman, Jr., J.D., L.L.M.
Emeritus Professor of Law, Widener University Delaware Law School
Shannon Mace, J.D., M.P.H.
Director of Operations, HELP-MLP
Maija Woodruff
Research Assistant, HELP-MLP; Franklin & Marshall College

INTRODUCTION

The COVID-19 pandemic brought infections with coronavirus, hospitalizations from the illness, long-term disorders still not fully catalogued or understood, and in many cases–almost 1200 in Delaware–death. And for Delawareans with disabilities, it brought these things in grotesquely disproportionate numbers.

But it brought more, too; more ways to harm our health. The virus, and our necessary responses to it, closed businesses and schools and government offices; disrupted programs and services and routines; stole jobs, savings, and security; left us confused, anxious, and, too often, alone. These things, too, it did with a particular vengeance to disabled people.

What follows is a brief attempt to describe some of the ways the pandemic has challenged us: some of the ways it has visited its harms unequally, the ways in which–beyond COVID–the pandemic has been distinctively harmful to the health of disabled Delawareans. The hard data suggests that Delawareans with disabilities are especially vulnerable to such harms. Qualitative data–including the voices of Delawareans–suggests they have suffered those harms, are enduring them still, and that the challenges remain ours to meet.

HEALTH CARE SERVICES

From the outset, the pandemic caused substantial disruptions of support services for people with disabilities, as resources were diverted, programs suspended, and care providers were excluded from contact or themselves became ill. Substantially similar issues were reported for educational services. Combined with the economic impacts of the pandemic, the result for many Americans with disabilities has been increased need, new barriers, and greater isolation.

The health consequences of these changes can be substantial, and quite directly so when it is health care services that are disrupted. The evidence to date is largely self-reported, through interviews and surveys: it consistently shows that the COVID-19 pandemic has substantially exacerbated existing health inequities, as well as created new ones. In a survey of roughly 2500 adults with disabilities by the American Association on Health & Disability, for example, nearly one-fourth of the respondents (23%) reported that they had lost critical care services as a result of the pandemic, while over half (56%) reported a disruption of regular health care services.[1]

Wendy Strauss is the Executive Director of the Governor's Advisory Council for Exceptional Citizens (GACEC), the review board for policies, procedures and practices related to the delivery of services for all residents with exceptionalities or disabilities in Delaware, and the advisory panel for agencies providing educational services through the Individuals with Disabilities Education Act (IDEA).

> *For those with a disability, it's been really difficult to access any kind of health care. I know for myself, telemedicine can be problematic; for individuals with disabilities, it has to be heart-wrenching and difficult.*
>
> *And for individuals with disabilities that live in the community, home health care has been especially difficult. There's already a shortage of nurses and direct support personnel, and with the pandemic has come a greater shortage. So sometimes families might go for days without having a nurse coming in to do the home health care that they need. And the lack of nursing in home health care has really hit those individuals and their families hard.*
>
> *Keep in mind that nurses that do home health care, they haven't gotten a pay raise in quite a few years, and now they're working harder, and working in really hard conditions, too. And then you have individuals getting sick with COVID, whether it's in the family or whether it's the nurse direct service providers themselves that are getting sick.*
>
> *What can we do? I think it's really important that we make sure that our society, our community, our doctors and healthcare providers, and our legislators, do what is appropriate to ensure that our families get the services that they need. We also need to ensure that our children get the services that they need. That means, for a start, that nurses are paid adequately, so we have enough of them to go into the homes, to provide the care that's needed, to keep our constituents safe, and in their community, versus being in institutions.*
>
> *It's a matter of respect for the people that need care. And we have a very bad habit sometimes of being disrespectful, of treating people as though they are "less than," especially people with disabilities.*

doi: 10.32481/djph.2021.03.005

Access to Care

Home care, in private homes and group homes, has been substantially disrupted, as the already short supply of nurses and direct support personnel was diverted to emergency care, or was prevented from providing in-home assistance by social distancing mandates, the lack of personal protective equipment, or by infection. In a survey of 556 Developmental Disabilities (DD) nurses early in the pandemic, the top expressed concern was obtaining an adequate supply of personal protective equipment (PPE) and sanitizers. It is not an abstract concern: in Delaware, among the direct support personnel providing services to Delawareans with IDD in group homes, 350 have tested positive throughout the pandemic (as of January 31) and at least five have died. "The pandemic," the national survey concluded, "has left DD nurses feeling stressed, fearful, depressed, and burned out, and simultaneously wishing they could do more to help."[2]

Care outside the home has been problematic for a variety of reasons. Evidence suggests that roughly 70 percent of people with disabilities limit their regular travel because of their disabilities; 15 percent of the people with travel-limiting disabilities–a total of 3.6 million Americans–do not leave their homes at all.[3] And travel takes longer for people with disabilities, even after controlling for transportation mode.[4]

All of which has been made worse by the pandemic, when safe transportation–from public or private services, or from friends or relatives–may be harder to come by. Some Delawareans with disabilities avoid travel due to increased anxiety brought on by the pandemic; others avoid leaving home because their disabilities make them more vulnerable to severe COVID outcomes. Those Delawareans with disabilities who do not self-manage their transportation rely on caseworkers, peer specialists, and others to give them rides to medical and other healthcare appointments, as well as to help with logistics to make those appointments. If those supports and services are not available and accessible, then people with disabilities–who otherwise use health care more often than people without disabilities–simply miss out on the care they need. And because people with disabilities are more likely to be out of the labor force, or if they were employed, to have lost their job during the pandemic, paying for the transportation is often not an option.

Telemedicine, meanwhile, presents its own challenges, as it requires broadband access, technological skills, and accessible platforms–platforms, for example, that interface properly with video relay service or ASL interpreters. And something else can be lost in the transition from in- person care. "In some ways," notes Cory Nourie, Director of Community Services for the Delaware Division of Developmental Disabilities Services (DDDS), "telemedicine has helped because people can access care." At the same time, she notes that it's also difficult for people with IDD to maybe understand and utilize telemedicine the way somebody who doesn't have IDD uses it. For some individuals who are part of our system, they have a rapport with their provider, and the provider knows the secret way to convince the person to open their mouth, to let them look inside: they remember "when I tickle your neck, you're going to open up and show me your tongue." And through telemedicine, you can't establish or maintain that rapport; it just doesn't work the same way through a screen.

Access to Support Persons

At the outset of the pandemic, Delawareans with disabilities who were hospitalized were often denied access to caregiver support persons. As a result, people with significant disabilities who needed a support person–who required support from a family member, personal care assistant, or trained disability service provider in order to communicate with their care team or make healthcare decisions–were effectively denied access to services.

In May, however, Division of Public Health Director, Dr. Karyl Rattay issued a new guidance on hospital visitation policies. That guidance, amended in September, noted that "hospitals are permitted to restrict visitors during a pandemic or infectious disease outbreak," but declared that, for patients with intellectual or developmental disabilities, or cognitive impairments, the Division of Public Health "does not consider support persons to be Visitors." Advocates praised the decision, noting that the new visitation policies were crucial to ensuring that Delawareans with disabilities have equal access to medical care, and are consistent with the mandates of federal anti- discrimination law.

WEALTH DETERMINANTS OF HEALTH

Poverty correlates

Poverty is significantly correlated with disability in Delaware: in 2018, the poverty rate of working-age people without disabilities in Delaware was 9.7 percent; the poverty rate of working-age people *with* disabilities in Delaware was nearly triple that, at 28.6 percent. And wealth and poverty impact health in many ways.

COVID comorbidities, for example, are significantly correlated with poverty. Nationally, socio-economic status is strongly associated both with chronic kidney disease and with end stage renal disease progression[5]; with risk of diabetes[6]; with an increased risk of hypertension[7]; and with COPD.[8] The Behavioral Risk Factor Surveillance System (BRFSS) confirms these trends for Delaware: each morbidity is much more prevalent among low-income Delawareans. Meanwhile, general health and immunity boosters–nutrition, rest, and exercise–are unequally distributed based on wealth: according to the 2018 American Community Survey (ACS), just 5.4% of households with an income-to-poverty ratio of 1.85 or greater are food insecure, but for households with a ratio under that, the percentage soars to 29.1%. And, according to the BRFSS, low-income Delawareans are less likely to get adequate sleep and exercise.

Unsurprisingly, poverty compounds the disadvantages experienced by people with disabilities during the pandemic. Participants in a web-based survey of 5,378 people living with Parkinson disease reported that during the pandemic they had experienced "disruptions in health care, social engagement and exercise, as well as a worsening of motor and non-motor symptoms." And the impacts were worse for respondents with lower household incomes: they were less likely to attend telemedicine appointments, had greater difficulties obtaining medications and were less likely to find alternative means of exercise than participants with a higher household income.[9]

Job loss

People with disabilities have long been excluded from the workforce. In 2018, the labor force participation rate for working-age people without disabilities in Delaware was 80.0 percent; the rate for working-age people *with* disabilities in DE was 37.7 percent.[10] And that was before the pandemic.

Nationally, the labor force participation rate for working-age people without disabilities decreased from 77.4 percent in January 2020 to 75.5 percent in January 2021; for working-age people without disabilities, the labor force participation rate also decreased, and by roughly the same proportion, but from 33.6 percent in January 2020 to 32.8 percent in January 2021.[11] Meanwhile, for those in the labor force, according to the Current Population Survey, from February 2020 to September 2020, the total number of employed persons with a disability declined by approximately 670,000–from 5.92 million in February to 5.29 million in September, a 10.6 percent decline in employment.[12] And in addition to the job losses occasioned by business closures, caregivers of people with disabilities have lost employment because they cannot secure enough nursing coverage for a dependent family member with disability, to allow the caregiver to work outside the home.

Homelessness

Homelessness is a massive problem anytime, but it is of special concern in a pandemic: homelessness leaves people very vulnerable to infection, and makes it very difficult to contain the spread. Indeed, the Centers for Disease Control and Prevention (CDC) has issued a "declaration determining that the evictions of tenants could be detrimental to public health control measures to slow the spread" of the virus.[13]

And homelessness is a distinctive problem both of, and for, people with disabilities. It is, first of all, especially difficult for people with disabilities to manage their disabilities when experiencing homelessness. Consider the challenges in testing and responding to fluctuating glucose levels, and hygienically utilizing injectable insulin, for a homeless individual with diabetes. Or imagine trying to follow a prescribed medication regimen when the medication requires refrigeration. And consider the challenges for homeless people with mental illnesses: estimates are that least 25 percent of homeless people are seriously mentally ill, and that 45 percent have some mental illness,[14] and there is an unhealthy synergy between mental illness and homelessness, as homelessness may contribute to psychiatric vulnerability.[15]

The risk of homelessness is also greater for people with disabilities. Even before the pandemic, there was not enough supportive housing for people with disabilities: there are waiting lists for many different types of subsidized housing, as well as housing designed to support people with disabilities, like neighborhood and group homes. And without subsidies, people with disabilities–who are disproportionately poor, who are disproportionately excluded from work, and who may have special housing needs–are especially vulnerable in the housing marketplace. The pandemic has only heightened their economic vulnerability. While the eviction moratorium provides temporary security, rents still accrue, and when the moratorium is lifted, a crisis awaits.

DISRUPTION, ISOLATION, AND STRESS

In addition to the direct impact the SARS-CoV-2 infection has on health, the COVID-19 pandemic and subsequent policy responses have resulted in unprecedented disruptions to daily life activities, access to health care and supportive services, and social connection. The nearly inevitable result is increased stress among people with disabilities.[16,17]

American respondents to the COVID-19 Disability Rights Monitor reported loss of access to personal assistance, assistive technologies, rehabilitation services, therapies and development interventions, and more.[18] That, alas, is consistent with the Delaware experience. Delawareans with disabilities have lost access to a wide range of programs and services,

Maria Olivere is the mother of a twelve-year old student in the Brandywine School District. Her daughter, Francesca, AKA Franki, who has Down syndrome, was learning online in the spring and during Extended School Year in the summer, and is now back in the classroom part-time in a hybrid format. Before the pandemic, Ms. Olivere notes, Franki was making real progress with her social skills.

> *Franki had to learn social skills. We worked very hard on it. She was learning to take turns. She was learning to be a friend. She was learning to say hi. With the pandemic, all of that went away. Now we are back to, maybe not square one, but close.*
>
> *And it's not just school that is affected. She loves to go shopping. I don't know why, because I hate shopping. She keeps asking me, she signs, to go shopping and I'm like, "we can't go shopping." So it's been a year since she's been really anywhere, in a group of people to talk to, and that's just going to further inhibit her. So the socialization that we worked so hard for, just kind of goes away.*
>
> *We've fought so hard for inclusion and acceptance in our communities. And now we are once again forced to segregate our children. And I realize we all are, not just the special needs community, but it impacts our children differently and they really don't understand. They think they are being punished, that they did something wrong.*
>
> *It truly takes a village, and somehow the village is working in a lot of ways: I don't know how it's working, but it is working. The new normal is different than our old normal, so it's not getting back on track. We can't think of it that way. It's figuring out the new track. It's figuring out the new path, figuring out how we're going to navigate all of this going forward.*
>
> *And we need to keep this in mind: there are different levels and there are different abilities for all of us. To compare kids, even within the special needs community, does no good to anybody. So I don't compare her to her peers in our community, or to other kids at school. Because she is Franki. She is her own little person and she's doing things her own little way. And comparing only keeps you from appreciating the little things that do come along that can bring so much joy, that you may miss otherwise. Because after all, comparison is the thief of joy.*

Franki Olivere

either because they have become remote, or because they have closed altogether. These include recreational and group programs, a major social outlet for many participants, as well as day programs designed to develop independent living or vocational skills. In all cases, the loss of the programs means that the relevant skills–cognitive, communication, social–will not be enhanced, but may in fact be diminished. And at least as worrisome, the loss of the programs means a disruption of routine, a severing of connections, and, perhaps, a lost sense of progress, of independence, and of belonging.

The same, of course, may be happening in the schools. In a survey of more than 1,000 parents of Delaware school children, 61% of parents of students with disabilities reported that changes to their routine were "very disruptive" to their children, 50% higher than the figure for parents of students without disabilities.[19] Remote learning presents the same technological challenges as telemedicine, compounded by the need to maintain a connection–internet and interpersonal–with a child, and for hours at a time. And some learning may nearly impossible: it may be hard, after, to secure all the benefits of inclusion, while isolated at home.

The cumulative emotional impact of service disruptions–disruptions of health care services, social services, educational services–is undoubtedly substantial, both for the people with disabilities who participate in them, and the families who have come to rely on them. At the very least, the disruptions have contributed to the already overwhelming stress caused by the pandemic.

The detrimental effects of acute and chronic stress have been extensively documented in existing research.[20] Exposure to a variety of different types of trauma and social stressors over time has been shown to activate a complex stress response system that can result in structural and functional changes and impairments across numerous body systems and the exacerbation of existing vulnerabilities.[21] Impacts of chronic stress can include impaired or disrupted brain function (e.g., memory, cognition, learning, and mental illness),[22,23] immune response,[24,25] cardiovascular functioning,[26,27] and gastrointestinal functioning,[28,29] among others.[30] Furthermore, the harmful consequences of chronic stress and trauma can be intergenerational, resulting in poor birth outcomes and increased risk of mental and physical health conditions across the lifespan.[31–33]

During the COVID-19 pandemic, a wide-range of interrelated social and structural stressors, also commonly identified as harmful health determinants, have been experienced by people with disabilities and people with chronic disease. Using transportation during the pandemic as only one example, the myriad factors leading to increased stress become clear: a qualitative study in the San Francisco Bay Area revealed that people with disabilities had so many transportation concerns, they often simply abandoned the effort, resulting in less health care, and also greater social exclusion.[34]

Meanwhile, a separate study found that people who perceive themselves to be highly vulnerable to COVID-19–a group that is not limited to, but almost certainly includes, people with disabilities–reported more COVID-19 worries, higher social isolation, and higher traumatic stress than people who perceived themselves less vulnerable to COVID-19.[35]

While the true impacts of the increased stressors experienced by people with disabilities and chronic illness during the pandemic are yet to be known, an early example of one alarming consequence that may be related to increased stress and social isolation is the increase in overdose death rates in Delaware and nationwide.[36] In June 2020 compared to June 2019, there was a nearly 20 percent increase in overdose death in Delaware.[37]

Emmanuel Jenkins is a member of the State Council for Persons with Disabilities, and of the Employment First Oversight Commission, was a Community Resource Officer for the Delaware Developmental Disabilities Council, and is the Founder and CEO of We Stand 4 Something, a non-profit organization that helps individuals with disabilities accomplish their goals. Like many Delawareans, with and without disabilities, Mr. Jenkins has been affected by COVID-19 in more ways than one.

> *Whether you use a wheelchair or not, or have any form of disability, you have to learn how to adapt, because this world is not set up for people like us. People with disabilities have always known how to adapt. We just needed the rest of the world to catch up with us. It's the same with the isolation. People with disabilities have always dealt with social isolation. And now, for the first time in my 37 years of living, the world is getting a glimpse of what I feel.*
>
> *So things are harder now. For example, for people with disabilities, community-based services have always been at a disadvantage, because there is a lack of resources. We could add resources, if personal care attendants got paid more than $10.75 an hour. People say, "well, that's the job they chose." You know why they might've chose that job? Because they have a heart, they have a mind, they have a need, and they have a desire to serve people.*
>
> *And when we talk about community-based services, there are great things. You become part of the community, you're not only affecting your life, you're affecting people's lives that you come around, you're connecting them. That's what community based is all about: building relationships, connecting with people, being involved. And as long as we don't have the resources, that is always going to be a struggle.*
>
> *And it's hard without supports. As a parent with a disability during the pandemic, it's like a magic show and I am the juggler. There are so many new roles now. You have to be the guidance counselor; you have to be the principal; you have to be the cleaner; you have to be the psychologist; you have to be there at the table. So now you have to juggle all of these things. And my son has probably been getting away with murder, because he knows I'm working, and I cannot go running into his room every couple of minutes, because he's just going to hear my chair coming down the hall.*
>
> *Overall, I think, the pandemic has shown people they need to take a moment, stop, and breathe. Because the ability to be free can be gone at any moment. And this pandemic, you know, unfortunately there's not a vaccine for the side effects.*

DDDS's Cory Nourie offers this:

> *"We have no idea the long-term consequences of isolation, of loneliness, of depression, of lack of connectedness to other people. I think there's going to be long-term consequences that we haven't even thought about yet, from how this all plays out when it's eventually over–both for the general population at large, but also specifically for DDDS service recipients. It's just really hard for people who oftentimes have a harder time understanding information as it's presented to them, to now go back into a place where they haven't gone to their job or seeing their friends for 10 months."*

CONCLUSION

It seems that some of the lessons to be learned from the pandemic, are lessons that many Delawareans with disabilities learned long ago. That inclusion is better than exclusion, because isolation is hard. That we need one another, to lift us up sometimes, to move us forward sometimes, and at all times, to respect us. That we are at the mercy of one another, and we can hurt–and be hurt–not only by malicious action, but by stubborn indifference and neglect. That we can make our world adapt when we are moved to, but we have to know, and we have to care. That our civil rights require protection, as Harry Truman once said, not only from the government, but by the government, because "equal protection" is an affirmative duty. That the things we take for granted–the people, the places, our abilities, our every breath–are in fact precious and fragile, and can be stolen in an instant.

There are other lessons, we are sure, and we can't be certain of any of these. But we hope we are learning, and we are grateful to all the people–with and without disabilities–who have tried to teach us, throughout the pandemic, through their compassion and devotion.

"Nonetheless," Albert Camus wrote, about another plague, the tale we tell "could not be one of a final victory. It could be only the record of what had had to be done, and what assuredly would have to be done again in the never ending fight against terror and its relentless onslaughts, despite their personal afflictions, by all who, while unable to be saints but refusing to bow down to pestilences, strive their utmost to be healers."

REFERENCES

1. Drum, C., Oberg, A., Cooper, K., & Carlin, R. (2020). COVID-19 & adults with disabilities: health and health care access online survey summary report. *American Association on Health & Disability*. Retrieved from: https://aahd.us/wp-content/uploads/2020/09/COVID-19_DCRM_Comparative_Analysis_Version_9_508.pdf
2. Desroches, M. L., Ailey, S., Fisher, K., & Stych, J. (2021, January). Impact of COVID-19: Nursing challenges to meeting the care needs of people with developmental disabilities. *Disability and Health Journal*, *14*(1), 101015. https://doi.org/10.1016/j.dhjo.2020.101015
3. U.S. Department of Transportation Statistics. (2018). Travel patterns of American adults with disabilities. Retrieved from: https://www.bts.gov/topics/passenger-travel/travel-patterns-american-adults-disabilities
4. Chen, K. L., Brozen, M., Rollman, J. E., Ward, T., Norris, K., Gregory, K. D., & Zimmerman, F. J. (2020). Transportation access to health care during the COVID-19 pandemic: Trends and implications for significant patient populations and health care needs. UCLA: Institute of Transportation Studies. Retrieved from: https://escholarship.org/uc/item/22b3b1rc
5. Nicholas, S. B., Kalantar-Zadeh, K., & Norris, K. C. (2015, January). Socioeconomic disparities in chronic kidney disease. *Advances in Chronic Kidney Disease*, *22*(1), 6–15. https://doi.org/10.1053/j.ackd.2014.07.002
6. Robbins, J. M., Vaccarino, V., Zhang, H., & Kasl, S. V. (2005, June). Socioeconomic status and diagnosed diabetes incidence. *Diabetes Research and Clinical Practice*, *68*(3), 230–236. https://doi.org/10.1016/j.diabres.2004.09.007
7. Cuevas, A. G., Williams, D. R., & Albert, M. A. (2017, May). Psychosocial factors and hypertension: A review of the literature. *Cardiology Clinics*, *35*(2), 223–230. https://doi.org/10.1016/j.ccl.2016.12.004
8. Gershon, A. S., Dolmage, T. E., Stephenson, A., & Jackson, B. (2012, June). Chronic obstructive pulmonary disease and socioeconomic status: A systematic review. *COPD*, *9*(3), 216–226. https://doi.org/10.3109/15412555.2011.648030
9. Brown, E. G., Chahine, L. M., Goldman, S. M., Korell, M., Mann, E., Kinel, D. R., . . . Tanner, C. M. (2020). The effect of the COVID-19 pandemic on people with Parkinson's disease. *Journal of Parkinson's Disease*, *10*(4), 1365–1377. https://doi.org/10.3233/JPD-202249
10. Cornell University. (2018). Disability status report Delaware. Retrieved from: http://www.disabilitystatistics.org/StatusReports/2018-PDF/2018-StatusReport_DE.pdf
11. Filanoski, K. (2021). nTIDE January 2021 jobs report: Recovery stalls for people with disabilities, National Trends in Disability Employment (nTIDE). Kessler Foundation and the University of New Hampshire. Retrieved from: https://researchondisability.org/epm-rrtc/epm-news/2021/02/05/ntide-january-2021
12. Employment for Persons with a Disability (2020). Analysis of trends during the COVID-19 pandemic office of disability employment policy. Retrieved from: https://www.dol.gov/sites/dolgov/files/OASP/evaluation/pdf/ODEP_Employment-for-PWD-AnalysisofTrendsDuringCOVID_Feb-Sept.pdf
13. Centers for Disease Control and Prevention. (2020). Temporary halt in residential evictions to prevent the further spread of COVID-19: a notice by the Centers for Disease Control and prevention, 85 FR 55292. Retrieved from: https://www.cdc.gov/coronavirus/2019-ncov/covid-eviction-declaration.html
14. U.S. Department of Housing and Urban Development. (2015). Annual homelessness assessment report: part 1: point-in-time estimates of homelessness in the U.S. Retrieved from: https://www.hudexchange.info/resources/documents/2015-AHAR-Part-1.pdf
15. Castellow, J., Kloos, B., & Townley, G. (2015, August). Previous homelessness as a risk factor for recovery from serious mental illness. *Community Mental Health Journal*, *51*(6), 674–684. https://doi.org/10.1007/s10597-014-9805-9

16. Lebrasseur, A., Fortin-Bédard, N., Lettre, J., Bussières, E. L., Best, K., Boucher, N., . . . Routhier, F. (2021, January). Impact of COVID-19 on people with physical disabilities: A rapid review. *Disability and Health Journal*, *14*(1), 101014. https://doi.org/10.1016/j.dhjo.2020.101014

17. Douglas, M., Katikireddi, S. V., Taulbut, M., McKee, M., & McCartney, G. (2020, April 27). Mitigating the wider health effects of covid-19 pandemic response. *BMJ (Clinical Research Ed.)*, *369*, m1557. https://doi.org/10.1136/bmj.m1557

18. Disability Rights Monitor. (2020). COVID-19 Disability Rights Monitor Report. Retrieved from: https://covid-drm.org/en/statements/covid-19-disability-rights-monitor-report-highlights-catastrophic-global-failure-to-protect-the-rights-of-persons-with-disabilities

19. Amis, M. (2020). Delaware parents on COVID-19: Remote learning has been stressful and worries about return to classrooms. *Rodel.* Retrieved from: https://rodelde.org/delaware-parents-on-covid-19-remote-learning-has-been-stressful-and-worries-about-return-to-classrooms/

20. McEwen, B. S., & Gianaros, P. J. (2010, February). Central role of the brain in stress and adaptation: Links to socioeconomic status, health, and disease. *Annals of the New York Academy of Sciences*, *1186*, 190–222. https://doi.org/10.1111/j.1749-6632.2009.05331.x

21. Meier, H. C. S., Hussein, M., Needham, B., Barber, S., Lin, J., Seeman, T., & Diez Roux, A. (2019, September). Cellular response to chronic psychosocial stress: Ten-year longitudinal changes in telomere length in the Multi-Ethnic Study of Atherosclerosis. *Psychoneuroendocrinology*, *107*, 70–81. https://doi.org/10.1016/j.psyneuen.2019.04.018

22. Lupien, S. J., McEwen, B. S., Gunnar, M. R., & Heim, C. (2009, June). Effects of stress throughout the lifespan on the brain, behaviour and cognition. *Nature Reviews. Neuroscience*, *10*(6), 434–445. https://doi.org/10.1038/nrn2639

23. Marin, M. F., Lord, C., Andrews, J., Juster, R. P., Sindi, S., Arsenault-Lapierre, G., . . . Lupien, S. J. (2011, November). Chronic stress, cognitive functioning and mental health. *Neurobiology of Learning and Memory*, *96*(4), 583–595. https://doi.org/10.1016/j.nlm.2011.02.016

24. Kemeny, M. E., & Schedlowski, M. (2007, November). Understanding the interaction between psychosocial stress and immune-related diseases: A stepwise progression. *Brain, Behavior, and Immunity*, *21*(8), 1009–1018. https://doi.org/10.1016/j.bbi.2007.07.010

25. Powell, N. D., Tarr, A. J., & Sheridan, J. F. (2013, March). Psychosocial stress and inflammation in cancer. *Brain, Behavior, and Immunity*, *30*(Suppl), S41–S47. https://doi.org/10.1016/j.bbi.2012.06.015

26. Rozanski, A., Blumenthal, J. A., & Kaplan, J. (1999, April 27). Impact of psychological factors on the pathogenesis of cardiovascular disease and implications for therapy. *Circulation*, *99*(16), 2192–2217. https://doi.org/10.1161/01.CIR.99.16.2192

27. Kario, K., McEwen, B. S., & Pickering, T. G. (2003, May). Disasters and the heart: A review of the effects of earthquake-induced stress on cardiovascular disease. *Hypertens Res*, *26*(5), 355–367. https://doi.org/10.1291/hypres.26.355

28. Mönnikes, H., Tebbe, J. J., Hildebrandt, M., Arck, P., Osmanoglou, E., Rose, M., . . . Heymann-Mönnikes, I. (2001). Role of stress in functional gastrointestinal disorders. Evidence for stress-induced alterations in gastrointestinal motility and sensitivity. *Digestive Diseases (Basel, Switzerland)*, *19*(3), 201–211. https://doi.org/10.1159/000050681

29. Konturek, P. C., Brzozowski, T., & Konturek, S. J. (2011, December). Stress and the gut: Pathophysiology, clinical consequences, diagnostic approach and treatment options. *J Physiol Pharmacol*, *62*(6), 591–599.

30. Yaribeygi, H., Panahi, Y., Sahraei, H., Johnston, T. P., & Sahebkar, A. (2017, July 21). The impact of stress on body function: A review. *EXCLI Journal*, *16*, 1057–1072. https://doi.org/10.17179/excli2017-480

31. Su, Q., Zhang, H., Zhang, Y., Zhang, H., Ding, D., Zeng, J., . . . Li, H. (2015, December). Maternal stress in gestation: Birth outcomes and stress-related hormone response of the neonates. *Pediatrics and Neonatology*, *56*(6), 376–381. https://doi.org/10.1016/j.pedneo.2015.02.002

32. Bowers, M. E., & Yehuda, R. (2016, January). Intergenerational transmission of stress in humans. *Neuropsychopharmacology*, *41*(1), 232–244. https://doi.org/10.1038/npp.2015.247

33. Walters, K. L., Mohammed, S. A., Evans-Campbell, T., Beltrán, R. E., Chae, D. H., & Duran, B. (2011, April). Bodies don't just tell stories, they tell histories: Embodiment of historical trauma among American Indians and Alaska Natives. *Du Bois Rev*, *8*(1), 179–189. https://doi.org/10.1017/S1742058X1100018X

34. Cochran, A. L. (2020). Impacts of COVID-19 on access to transportation for people with disabilities. *Transportation Research Interdisciplinary Perspectives*, *8*, 100263. https://doi.org/10.1016/j.trip.2020.100263

35. Boyraz, G., Legros, D. N., & Tigershtrom, A. (2020, December). COVID-19 and traumatic stress: The role of perceived vulnerability, COVID-19-related worries, and social isolation. *Journal of Anxiety Disorders*, *76*, 102307. https://doi.org/10.1016/j.janxdis.2020.102307

36. Taylor, S., Paluszek, M. M., Rachor, G. S., McKay, D., & Asmundson, G. J. G. (2021, March). Substance use and abuse, COVID-19-related distress, and disregard for social distancing: A network analysis. *Addictive Behaviors*, *114*, 106754. https://doi.org/10.1016/j.addbeh.2020.106754

37. Ahmad, F. B., Rossen, L. M., & Sutton, P. (2021). Provisional drug overdose death counts. National Center for Health Statistics. https://www.cdc.gov/nchs/nvss/vsrr/drugoverdose-data.htm

The DPH Bulletin

From the Delaware Division of Public Health ***February 2021***

DHMIC awards grants to improve outcomes for black mothers and infants

The Delaware Healthy Mother and Infant Consortium (DHMIC) awarded more than $145,500 in grants to four local organizations to help reduce the wide variance in poor birth outcomes between black women and white women and to save infant and maternal lives. The DHMIC awarded the Parent Information Center for its Doula Program, the Rose Hill Community Center for its Stress Relief Program, the Metropolitan Wilmington Urban League for its Doula Training Program, and the Breastfeeding Coalition of Delaware for breastfeeding support.

"Every Delawarean has a role to play in decreasing the black infant and maternal mortality rate, and our community knows best how to connect with and empower women to be healthy to improve outcomes for moms and babies," said Dr. David Paul, DHMIC co-chair. "The consortium has undertaken an aggressive initiative to examine the social determinants of health by taking a life-course approach to both understanding and addressing the disparities that have led to the rise in lack maternal and infant mortality in Delaware."

According to the 2018 Delaware Vital Statistics Annual Report published by the Delaware Department of Health and Social Services, Division of Public Health (DPH), significant disparities existed between non-Hispanic black and non-Hispanic white infant mortality rates for 2014-2018. In 2014-2018:

- Delaware's infant mortality rate was 7.3 infant deaths per 1,000 live births.
- The non-Hispanic black rate (12.2 infant deaths per 1,000 live births) was nearly three times that of the non-Hispanic white rate (4.5 infant deaths per 1,000 live births).
- The Hispanic infant mortality rate (8.4 infant deaths per 1,000 live births) was 1.5 times higher than the non-Hispanic white infant mortality rate.

For more information, visit DEThrives.com.

World Spay Day is February 23

The Delaware Office of Animal Welfare's Spay & Neuter Program provides low-cost spay and neuter services to cats and dogs of income-eligible applicants. Those who are eligible may have up to two pets spayed or neutered every fiscal year for $20 each.

Helen Knott, 85, of New Castle, at left; and David Lim, 72, of Wilmington, right, received were immunized at a COVID-19 vaccination event held at the Chase Center in Wilmington.
Photos by Jeff Winslow.

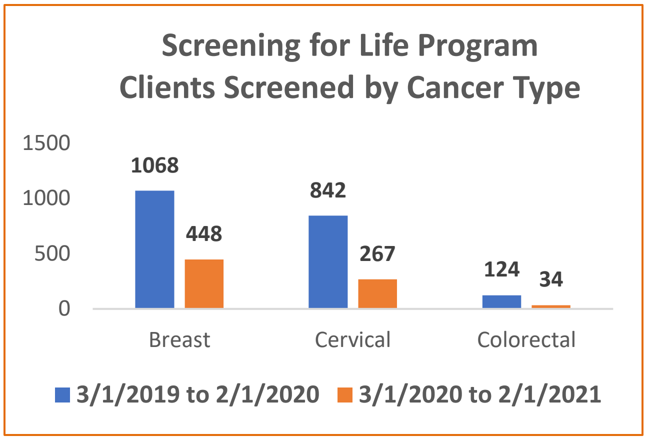
Reaching vulnerable, underserved 65+ Delawareans is a State priority

Delawareans age 65+ are currently eligible for COVID-19 vaccination. To reach the 65+ population and underserved communities, the State recently partnered with community organizations and held indoor vaccination events in conjunction with Curative, Vault Health, Delaware Technical Community College, Salesianum School, and Wilmington Housing Authority, and is coordinating with hospital systems, specialty care providers, and enrolled pharmacies serving underserved communities to reach vulnerable Delawareans.

"Our goal remains the same: we're working to vaccinate as many Delawareans as possible, as quickly as possible," said Governor John Carney. "We also need to make sure we're distributing the vaccine equitably and reaching especially those Delaware seniors who are less mobile and don't have access to a computer or smartphone. These additional efforts by the Division of Public Health and their partners will expand access to the COVID-19 vaccine among those populations, so we can reach all of our neighbors with this life-saving vaccine."

Request a vaccination appointment at vaccinerequest.delaware.gov or call DPH's Coronavirus Vaccination Call Center at 1-833-643-1715. Learn about Delaware's COVID-19 vaccination program at de.gov/covidvaccine. Send questions regarding testing, symptoms, and health-related guidance to DPHcall@delaware.gov.

DELAWARE HEALTH AND SOCIAL SERVICES
Division of Public Health



Source: Delaware Department of Health and Social Services, Division of Public Health, Screening for Life program, 2021.

COVID-19 causes dramatic decline in cancer screenings

An estimated 40.9 percent of U.S. adults avoided medical care during the pandemic because of COVID-19 concerns, according to the Centers for Disease Control and Prevention. Of those, 12 percent avoided urgent or emergency care and 31.5 percent avoided routine care (MMWR, September 2020).

The American Cancer Society reported that one consequence of the COVID-19 pandemic was a "substantial decline" in cancer screenings.

The Division of Public Health's Screening for Life Program (SFL) reports that COVID-19 disruptions have significantly impacted cancer screening and prevention efforts because providers have limited availability and capacity for cancer screening, and that makes scheduling in-person office visits extremely difficult.

The number of SFL screenings decreased 61 percent between the periods of March 1, 2019 to February 1, 2020 and March 1, 2020 to February 1, 2021. Among SFL clients, by cancer type between the same periods of time, there was a 58 percent decrease in the number of breast cancer screenings performed; a 68 percent decrease in the number of cervical cancer screenings performed; and a 73 percent decrease in the number of colorectal cancer screenings performed.

SFL suggests not delaying recommended screenings because early detection improves outcomes. Contact your medical provider or the SFL program to schedule your screenings. Visit SFL at https://www.dhss.delaware.gov/dhss/dph/dpc/sfl.html.

Delawareans can sign up for affordable health insurance until May 15

President Joe Biden signed an executive order on January 28 that created a three-month special enrollment period to give Americans affected by the coronavirus pandemic greater access to health insurance, including those who lost their job or their coverage as part of the fallout from the pandemic.

Delawareans in need of affordable health insurance can sign up for coverage from February 15 to May 15 on HealthCare.gov, the federal online Health Insurance Marketplace created by the Affordable Care Act.

"This special enrollment period provides a great opportunity for Delawareans who are looking for high-quality, affordable health insurance, especially those impacted by the pandemic," said Delaware Department of Health and Social Services Secretary Molly Magarik. "Despite the success of the Health Insurance Marketplace since it opened eight years ago, many state residents still lack insurance, and some might remain unaware that they can access comprehensive care – and, in many cases, get financial help to afford it – through HealthCare.gov."

The special enrollment period is available to all marketplace-eligible individuals who are submitting a new application or updating an existing application. You can enroll in marketplace coverage at www.HealthCare.gov or www.CuidadodeSalud.gov or by calling 1-800-318-2596 (TTY: 1-855-889-4325). For more information, go to www.ChooseHealthDE.com.

HealthCare.gov

Delawareans who want free help enrolling in coverage can make appointments with trained specialists at Westside Family Healthcare. Virtual and phone appointments are encouraged; in-person appointments are limited and must be made in advance. Assistance is available in any language and for all Delaware residents. Call 302-472-8655 in New Castle County, 302-678-2205 in Kent/Sussex counties or email enrollment@westsidehealth.org.

State-licensed insurance agents and brokers are also available to help individuals re-enroll and to help employers update their coverage, at no extra charge. See a list at ChooseHealthDE.com.

Project SEARCH

Takashi Rhoulac, M.Ed
Instructor/Program Coordinator, Project SEARCH

Project SEARCH is a unique, one-year, work-preparation program that takes place entirely at the workplace.[1,2] This innovative, business-led model features total workplace immersion, which facilitates a seamless combination of classroom instruction, career exploration, and worksite-based training and support. The goal for each program participant is competitive employment. Real-life work experience combined with training in employability and independent living skills help youths with intellectual and developmental disabilities (IDD) make successful transitions from school to productive adult life. Moreover, the goal is to achieve employment in jobs that go beyond the traditional limits often imposed on people with IDD. That is, Project SEARCH prepares program participants for real, rewarding jobs that are complex and systematic; aligned with the interests and skills of the individual; important to the operation of the company; and in integrated settings where employees with IDD can work alongside colleagues with and without disabilities, report to the same management structure, and receive the same employee benefits as their peers.

Project SEARCH ChristianaCare is a collaboration between the Red Clay Consolidated School District (RCCSD), ChristianaCare, Division of Vocation Rehabilitation (DVR), Delaware Department of Education, Community Integrated Services, and Autism Delaware, which started in 2011. Interns attend Project SEARCH for a full academic year (August – June) and follow the RCCSD calendar. Breakfast and lunch are provided by the RCCSD. Interns are responsible for their own transportation each day and may utilize Paratransit, DART Fixed Route or family members. The program can accommodate up to twelve program participants a year and is open to all students in New Castle County, Delaware. Eligible program participants are 18 to 21 years old, who have either just completed their high school academic requirements and earned a diploma the spring before entering the program, or who are in their last year of eligibility in an 18 – 21 transition program. Program participants apply in the winter and spring of the year they will enter the program. The Project SEARCH recruitment team facilitates the selection process that includes a student application, skills assessment, tour, and interview.

The team, which consists of a special education instructor/program coordinator, paraprofessional, and skills trainers, work to meet the educational and training needs of the students over the course of the year. Interns undergo a specially designed vocational assessment. The assessment explores skills that relate to the individual internships as well as basic job skills. The specific job skills will vary depending on the internship assigned; however, certain core skills, such as filing, computer skills, telephone use, and the ability to follow instructions and solve problems, are important in nearly any business setting. To become oriented to the ChristianaCare facilities and culture, the interns participate in "way-finding" exercises; review the employee code of conduct; hear presentations by representatives of ChristianaCare on the mission and core values of the business and how the interns contribute; learn about and practice communication protocols in use at the business; and complete any mandatory employee education, such as safety and confidentiality training.

After an initial orientation period, the interns' day consists of a one-hour morning classroom session where they participate in activities designed to enhance employability and independent living skills. Classroom activities are designed around eight major focus areas: team building, workplace safety, technology, self-advocacy, maintaining employment, financial literacy, health and wellness, and preparing for employment. The curriculum is flexible so that, as the year goes on and the instructor gets to know the interns better, the instructor customizes the curriculum to accommodate the specific needs and interests of the interns and the business as they arise. This flexibility helps to ensure a meaningful and successful experience for program participants, as well as responsiveness to the business.

The rest of the day is devoted to learning specific, relevant, and transferable job skills in an internship. Interns rotate through three different worksite internships at ChristianaCare over the course of the year. These include touring the potential internship sites, creating a resume and cover letter, and practicing interviewing skills. Throughout the week, the interns participate in 20 hours at their internship to learn work skills, as well as social and communication skills. As they experience the culture and learn to function with support and guidance, they utilize classroom time at the end of the day to review their work and experiences, discuss different options, and plan for the next day.

Starting in the second half of the school year, the emphasis shifts to refining skills, finalizing the career goal, and carrying out an individualized job search. The employment specialist from the supported employment agency takes the lead in the job search for a given intern, but all the members of an intern's team are involved. Job development is based on the intern's experiences, strengths, preferences, and skills.

Worldwide, there are over 600 Project SEARCH High School Transition program sites, with the majority in the United States. On average, each site serves eight individuals in a program year. Overall, Project SEARCH serves over 4800 young people with IDD every year. The number of program sites continues to grow each year, with a corresponding increase in the number of young people with disabilities served.

For more information, please email:
projectsearch@redclay.k12.de.us

REFERENCES:

1. Daston, M. M., Riehle, J. E., & Rutkowski, S. (2012). High school transition that works: Lessons learned from Project SEARCH. Baltimore, MD: Brookes.
2. Rutkowski, S., Daston, M., Van Kuiken, D., & Riehle, E. (2006). Project SEARCH: A demand-side model of high school transition. *Journal of Vocational Rehabilitation*, *25*, 85–96.

doi: 10.32481/djph.2021.03.006

EVELYN R. HAYES INNOVATIONS IN HEALTHCARE SYMPOSIUM - VIRTUAL

The Silver Linings of COVID-19 in Education, Practice & Research

Tuesday, April 13th 10:00 am- 3:00 pm
Location: VIRTUAL- register to receive link
Free & Open to the Public

David W. Willis, MD, FAAP

Senior Fellow, Center for the Study of Social Policy

"Building Back Better": Connecting the Medical Home and Community to advance the well being of our next generation of children.

The triple crises within our nation – the COVID epidemic, the economic collapse, and the racial justice reckoning – have laid bare the chasms of our social safety net, our racist infrastructures, and deepening impacts of poverty for young families, their children, and their communities. Yet, simultaneously, we have witnessed the mobilization of supports within neighborhoods and communities, the expansion of social connections, the discovery of the power of relationships and the power of hope and resiliency. And as the Biden-Harris American Recovery Act becomes a reality, we are witnessing unprecedented policy initiatives and leadership opportunities that "build back better" from the best knowledge of early childhood development and required community contexts. The development of new initiatives for the promotion, prevention, early intervention, and recovery for the next generation of our nation's children leans heavily on both child health system transformation in coordination with early childhood systems and community recovery. This Keynote will discuss the "silver linings" post COVID of current breakthroughs for child health and communities from new policy initiatives that expand a new emphasis on two-generational, early relational health and a relational workforce expansion for community rebuilding, advancing health equity and next generation wellbeing.

TO REGISTER: udel.edu/007974

UNIVERSITY OF DELAW
HEALTH SCIENCES

Delaware INBRE
Delaware's Biomedical Research Catalyst

Person First Language

Mary M. Stephens, M.D., M.P.H.
Associate Professor, Department of Family and Community Medicine, Sidney Kimmel Medical College, Thomas Jefferson University
Medical Director, Jefferson Continuing Care Program
Clinical Leader, Down syndrome program, Christiana Care
Diplomate, Specialty Board in Developmental Medicine

Our personal journey in the importance of person first language began with the birth of our daughter Callie in 2011. I quickly learned how seeing someone as a person first – and not a diagnosis – as a mother, would influence how I cared for my patients in the future. That was not on my mind, however, when I heard the doctor announce after 29 hours of labor, *"It's a girl. . ."* and our Callie was placed onto my chest. I took a deep breath and thought, *"We made it!"*

The joy and exhilaration I felt hearing that first cry and cradling my child for the first time was indescribable. I counted her fingers and kissed her nose. Soon she was off to the warmer. As we texted friends and family with our news, I noticed many people in scrubs surrounding Callie.

> *"Tom, something's wrong," I said. "Go find out. . . "*
>
> *"I think your baby has Down syndrome," said the nurse practitioner who came to my bedside.*
>
> *"But she can't," I said, "she just can't. Our genetic testing was so good!"*
>
> *"I'll have some of the doctors upstairs look at her to see what they think," she said in response to my disbelief.*
>
> *"No, please get us Dr. B; I don't want a bunch of people looking at my baby."*

After the initial flood of tears, Dr. B soon arrived, despite the snow and the end of the day. Both my husband and I had worked with him professionally and, while we respected his skills as a geneticist, we also trusted his straightforward approach. All I could remember learning in medical school about Down syndrome was the risks of leukemia and congenital heart disease, so naturally I couldn't wait for him to tell us the initial assessment was wrong … but he did not.

> *"Our baby is beautiful and perfect and the test said she didn't have Down syndrome, and I can't see it when I look at her," I sputtered. "What kind of doctor am I?,"*

More tears, more tissues, and a gentle but firm discussion about the limitations of screening. A plan for definitive diagnosis and follow up quickly came together.

> *"I'll be back here tomorrow. Here's my beeper. You call if you need anything. Please remember – All of our kids come with their own special challenges and joys. Your expectations for Callie may be different than you thought, but she will also bring you unexpected joys and blessings!"*

After Dr. B left there was more adventure as within the hour the nurse thought Callie looked a "little yellow."

> *"She can't be jaundiced," I thought, "that's a really bad differential diagnosis in the first few hours of life and it's already been a really long day."*

The hospitalist came in to discuss the next steps as the bili lights went up and the CBC came back with platelets of 30,000.

> *"We'll watch her closely here – this may all be related to her Down syndrome."*

Suddenly Down syndrome seemed like a good thing, and much better than sepsis and the rest of the differential. Still, as Callie slept in only her little diaper and bili light goggles, and my husband snored in the next bed, I cried myself to sleep under the lights. I cried because I was tired, because I was scared, because I was sad, and then because I was sad that I was sad.

The next two days passed in a haze. My eyelids were a quarter inch thick from the tears and IV fluids. Good news and more visits from Dr. B and our OB as the bilirubin came down and the ECHO showed no major anomalies. Despite being two family doctors used to being on the other side of the stethoscope, we especially needed and welcomed the visits from our team as they took care of us and Callie. The call came from Dr. B five days later confirming her diagnosis. Callie was quickly started in an early intervention program and our learning journey about Down syndrome began in earnest. Dr. B and new friends we made who also loved people with Down syndrome helped us realize quickly Callie was first and foremost a beautiful baby who had quickly stolen our hearts.

At the age of six months, Callie's journey took a twist. A seemingly straightforward case of the croup turned into a six month journey of trips to the ER, prolonged hospitalizations and earned her the nickname "Darth Vader" from the sound of her breathing! With a respiratory rate frequently hitting the 60's, we struggled to find out what was wrong with her. We hit our first hard stop when one doctor told us, *"Well, you know she has Down syndrome."*

Yep, got that with her karyotype, but that didn't seem quite right as a cause for respiratory distress. The dismissal in the doctor's comments was painful, and led us to seek care elsewhere to have the chance to really figure out what was wrong with Callie.

Months later, as she was sleeping off the anesthesia the day before her first birthday after undergoing an esophagogastroduodenoscopy (EGD), bronchoscopy and having a pH probe placed, another physician walked in to do her preoperative consultation a little late.

> *"You know, she really doesn't need any scopes, she just needs a Nissen. All these kids with Down syndrome just have GERD."*

I remained speechless until he exited, seemingly unaware that she had already had the procedures that showed no signs of GERD (Gastroesophageal Reflux Disease) but significant broncho- and tracheomalacia. She was already significantly better than she had been in a while with the introduction of thickened feeds for

doi: 10.32481/djph.2021.03.007

dysphagia, so arguably perhaps she didn't need the procedures - although they ironically led to her being weaned off all her meds for GERD which was a victory! What we experienced and observed in Callie's care seemed to relate to how she was viewed, treated and talked about. Those who could see past her diagnosis of Down syndrome and not limit her possibilities or their differential diagnosis because of it, stepped in, figured it out and advocated for her.

Fast forward ten years, and Callie is now double digits and in the fourth grade in an inclusive education setting (albeit virtually as we contend with COVID-19). Individuals with Down syndrome are at high risk for complications due to multiple factors, that likely include immunodeficiency, low muscle tone and multiple co-morbidities. This fall, we celebrated the fifth anniversary of the Christiana Care Teen and Adult Down syndrome program in the Center for Special Healthcare Needs. I am proud to have co-founded the program with Callie's geneticist Lou Bartoshesky, Dr. B, who started us on our journey with Callie reminding us about joy and great expectations. Our mission there is to improve the health and well-being of individuals with Down syndrome. I'm otherwise at Jefferson full time where, in a mid-career twist, I have re-focused my clinical work inspired by Callie and motivated by the health disparities individuals with intellectual and developmental disabilities contend with. I lead a primary care medical home for individuals with intellectual and developmental disabilities, and other complex childhood-onset conditions. I also have the opportunity to teach, work with learners at all levels clinically, and advocate.

Jefferson was awarded a one-year competitive grant by the National Curriculum Initiative in Developmental Medicine (NCIDM) last year. We're striving to develop a future workforce with enhanced skills to optimize care for patients with intellectual and developmental disabilities (IDD). All third-year medical students during their family medicine rotation now learn about the care of patients with IDD, as a result of program development supported by funding through the NCIDM. As we focus on healthy equity and health disparities at Jeff, it is important to know that there is no formal requirement to teach medical students about the care of patients with IDD. Jefferson is now one of the ten percent of medical schools in the country to take this step! While good news and a start, the fact that this education is so rare is a little hard to believe in 2021. I remain hopeful that, among other things, this educational focus will prevent others from facing the obstacles to care and wellness we encountered from some on our journey with Callie.

All my didactics start with three things: a picture of Callie on my disclosure slide because she started me on this transformative career journey (and her smile really warms up the audience), defining and discussing the importance of person first language, and general language guidelines that influence the tone and substance of care.

Callie is a child with Down syndrome and not a Down syndrome child. Person first or people first language (PFL), is placing the person before their diagnosis. PFL is more than just disability etiquette, although individuals and caregivers will likely appreciate your word choice. It's a powerful term that may help us as clinicians think about bias and avoid diagnostic overshadowing. While clinicians do need to think about conditions associated with Down syndrome when caring for someone with Down syndrome, you need to think about the patient holistically and without blinders, and compare the individual to their own baseline, like we do with someone with congestive heart failure. As this issue of the journal has undoubtedly illustrated, people with disabilities – especially those with IDD – face huge health disparities and premature death. Using PFL is about serious medicine and thoughtful differential diagnosis that makes a difference in the lives of our patients and those we love, and may help us reduce health disparities. Like every good rule in medicine, there are always exceptions and many in the autistics, individuals on the autism spectrum, prefer the use of identity first language. As we've been taught from our first communication class in medical school, center your care and put the patient first by asking the patient how they want to be addressed.

After introducing Callie and PFL, I move on to the next slide about language, and talk about Special Olympics. For those of you not familiar with Special Olympics, it is an international organization with a prominent place in the Delaware community. It is the largest sports organization in the world for individuals with IDD, and both children and adults compete. In Delaware, athletes with and without intellectual disabilities play unified sports to have fun, get fit and to get to know each other as individuals. In 2009, Special Olympics launched the "Spread the Word to End the Word" campaign based on the "audacious" belief that "the world would be better if all people were valued, respected, embraced, and included in our schools, workplaces, and communities." By focusing on the word "retard(ed)," a starting point was found to begin a discussion and move away from a term that is exclusionary and hurtful. We know that the environment of care is critical to patient outcomes (and Press Ganey scores), and we should do our part and choose a word other than the "R" word when things don't go our way with the Electronic Health Record or scheduling. If it comes up in the lunchroom, think about tools used in our bias and diversity training, like saying something - even if all you can think of is "ouch." It is also way past time to change the documentation in our medical records to use the descriptor intellectual disability, and not mental retardation. In 2010, Rosa's Law (in honor of a young girl with Down syndrome) was signed by President Barack Obama and mandated the use of the term *intellectual disability* in place of *mental retardation* in federal statutes. Nick Marcellino, Rosa's brother, was quoted as saying at the time: "*What you call people is how you treat them. If we change the words, maybe it will be the start of a new attitude towards people with disabilities.*"

ACKNOWLEDGEMENTS

I would like to thank my husband, Dr. Tom Stephens, for his thoughtful edits to this manuscript even if he doesn't believe that skee ball is a sport! Special thanks to Dr. Charmaine Wright for not only the skee ball tip, but her extraordinary leadership at The Center for Special Healthcare Needs at Christiana Care and her invitation to contribute to this important discussion. It goes without saying, thank you to Dr. Lou Bartoshesky for his patient teaching, advocacy and partnership. Finally to James Dyksen from Academic Support Services at Jefferson, for his edits and thoughtful contributions to this essay as all of us need someone to help us on our journeys.

Access to Employment as Access to Health: Revisiting the Better Bottom Line

An interview with former Governor Jack Markel and former Secretary Rita Landgraf

Jody A. Roberts
Director, External Relations & Strategic Partnerships,
Office of the Director, Division of Developmental Disabilities Services,
Delaware Department of Health and Social Services

In 2012, then-Governor Jack Markell was selected to serve as Chair of the National Governor's Association. During this one year tenure, each Chair selects an initiative to focus on with his or her fellow governors. Governor Markell's initiative for 2012-2013, A Better Bottom Line: Employing People with Disabilities, focused on the often-overlooked gap – and untapped resource – in employment and economic plans: how to promote the hiring of more individuals with disabilities.

Coming as this did just as the country began to emerge from one of the most challenging economic periods in U.S. history, a focus on expanding employment opportunities for individuals with disabilities may have seemed an odd choice. But, as the resulting "Blueprint" highlights, a focus on expanding access to employment for individuals in this population helps to address multiple issues facing the State, the economy, and individuals with disabilities simultaneously. First, making disability employment part of a state workforce development plan and strategy helps to broaden opportunities across the workforce as accommodations are made to traditional workplace settings that make them universally more accessible (and safer), while spurring growth in entrepreneurial opportunities that can expand traditional economic sectors in a state. Second, a diversified workforce is a diversified economy, which generates innovation and resilience through the establishment of a more inclusive economy. Finally, supporting individuals with disabilities to access meaningful employment helps include them in the communities they live in, and encourages each individual to discover and tap into the unique resources they can share with all of us.

A key result of this work in Delaware was the establishment of the Pathways to Employment program administered by the Division of Developmental Disabilities Services within the Department of Health and Social Services. Building this program within DHSS helps to remind us that access to employment is not only a workforce issue, but also a key factor in the health of an individual. An individual active, involved, and engaged in their community is a healthier individual overall.

Once again, we find ourselves in the midst of an economic crisis that has disproportionately impacted some sectors of our economy – and some populations – harder than others. As we begin to imagine what an equitable recovery could look like, it may be worth pausing to think about how we might address recovery in ways that continue to expand opportunities for those still struggling to be included in the workforce.

To examine the history and legacy of *A Better Bottom Line*, I invited former-Governor Markell, and former-Secretary Rita Landgraf, to discuss the initiative. What follows is a lightly edited transcript of that conversation.

Why was this topic chosen?

Governor Jack Markell: About 20 years ago Rita [Landgraf] and Micki Edelsohn took me to an MBNA facility near Newark [Delaware] where MBNA employed a lot of people with disabilities. I met a 25-year-old man with a cognitive disability. He had a job making T-shirts and was very excited about this opportunity. He told me all about the job, and when I asked him what he did before he got the job, he told me that he had sat at home for six years, watching TV with his parents. And a light bulb went off in my head about the profound improvement in his quality of life because he was able now to have a purpose, every day, a reason to get up, a reason to get dressed, a reason to go to work and spend time with other people, earn a paycheck. I thought about the impact on the quality of life of his parents that they didn't have to stay at home with him watching him make bad choices about diet and watching him get depressed and everything else. I thought to myself at the time that this is such a huge issue and there are so many people who have a loved one with some kind of disability and if I ever had an opportunity to work on an issue on a bigger stage that I would want to choose this issue.

This is long before I was governor, but it was always in the back of my mind. I took office in 2009. The economy was a mess, and I wanted to be Vthe jobs Governor, but I made very clear from the beginning that I wanted to be the jobs Governor for everybody. And that included people with disabilities. I was fortunate that Rita was Secretary of the Department of Health and Social Services. She was so widely respected around the state by all of the advocates because she had been an advocate for people with disabilities for many years, and so they trusted her. She knew this issue inside and out, and so we were a team. So, when I was elected Governor, we started working on it.


Govener Jack Markell

When it became clear that I was going to be the Chair of the National Governors Association, I said to Rita that I wanted to make this my issue. There are no particular perks for serving as the National Governors Association Chair, but you do get to choose an issue for all the Governors to focus on for the year that you're the Chair, and so I decided to make this that area of focus.

doi: 10.32481/djph.2021.03.008

What did you hope to accomplish?

JM: I wanted to move the needle. There are so many people with disabilities who just want to have a shot, to have somebody give them a chance to show what they can do, and that's what I wanted to accomplish. When I started to talk with some of my advisors about choosing this topic as my area of focus as NGA chair, some of them said, well that's a mistake; you really ought to be choosing an issue like education reform or small businesses, some big issue that's going to be sexier, going to be of more interest to the press. And I said, that's not why I'm doing this. I just I know there are so many families out there for whom this is a major issue.

When I presented this to the other governors the reaction was, over time, really, really, positive. At first, I think some of them thought this must be some kind of niche issue; that I must have somebody in my family with a disability, which I don't. But, as we got into the initiative, we began to travel. We took a trip to Seattle where we met at Microsoft and had presentations from some of their people focused on employment with disabilities; we went to Pittsburgh and visited Highmark and heard similar presentations.

Then some of the other Governors got involved. The other governors were amazing. The Governor of South Dakota at the time, a guy named Dennis Daugaard, said he wanted to be involved. He spoke at one of our conferences, and he talked about growing up with two parents who were deaf in South Dakota. He just talked about those stories, and it was just so emotional, and you could hear a pin drop.

Some of the governors who were most enthusiastic would not have been, frankly, ones I would have expected. Scott Walker, the very conservative Republican Governor of Wisconsin - he and I didn't agree on a lot - but he really embraced this. He talked about it in at least one of his State of the State speeches.

Secretary Rita Landgraf: He made it a big name. He named you and this work in his State of the State.

JM: Terry Branstad, the Republican Governor of Iowa who went on to become the Ambassador to China also became a champion. So Republicans and Democrats alike joined in. One of the things I feel very fortunate about was that very early on, I had the opportunity to meet with U.S. Senator Tom Harkin from Iowa. He was still in the Senate at the time. And, of course, if you think of any elected official over the last 30 years who was really a champion for the disability community, it was him. He really embraced what I was doing and did what he could to help me. He brought me to meetings of CEOs as well as other political officials.

With Rita's guidance, we pulled together a group of advocates from across the country who could advise our work. And they did a great job and helped us to come to a number of findings. But, basically, the main point was this: when we talk about and focus on the ability, rather than the disability, it's amazing what we can accomplish together.

RL: Senator Harkin, of course, was the author of the ADA [Americans with Disabilities Act] and his engagement was largely due to his brother Frank, who was deaf, and the impact these experiences had on Senator Harkin. Frank was only given three options to investigate for employment, as he was coming into the employment arena, and he didn't like any of them. You know how we do this with people with disabilities: food, filth, flowers used to be the saying. And that rang true for Frank.

Tony Coelho, Congressman from California also, on the House side, was a champion of the ADA. I bring that up because Tony Coelho now lives in Rehoboth.


Professor Rita Landgraf

Regarding Senator Harkin, I believe it would be fair to say he took us to the next level in terms of engagement nationally when our journey and his collided. Governor Markel's work with the Governors and Senator Harkin's with our Congress and policymakers together really worked to open things up.

JM: We had a big gathering in Delaware toward the end of our efforts: Senator Harkin came up, and Cathy McMorris Rodgers, a Republican Congressional leader from Washington State came up, and Judy Woodruff came up to moderate the event. It has an amazing effect to hear Senator Harkin tell a story about his brother, as Rita said. He was pushed into these different jobs he didn't want to do, and he ended up getting a job in a factory that made components of aircraft, and it was a very loud factory; but, of course, it didn't really bother him and it turns out that he ended up making components that went into the aircraft that Senator Harkin, I believe, flew in while he served in the military. It was very, very powerful.

RL: You also had Walgreens at the table.

JM: Yes. When Senator Harkin brought me to this original meeting, it was at a Walgreens facility near Hartford, Connecticut. Walgreens has been a very good employer for people with disabilities, starting in the warehouses, and then extending after that to their stores. Pete Sessions, a Republican, very conservative Republican member of Congress, had twins, one of whom was super intellectually gifted and the other one has an intellectual disability. And he said, look, I just want both of my kids to go as far as their potential will take them. Isn't that what we all want?

Why should those with disabilities be part of a State's workforce plan? Or, why did this even need to be said?

JM: Maybe it shouldn't need to be said, but it does need to be said: we're just so much stronger when we recognize that everybody brings something different to the workforce. I think that's incredibly important, including people with neuro abilities that are non-traditional. One of the things we had to do during this journey is we had to listen to employers.

Every business that I know of competes on the basis of talent, and talent comes in every shape and size. You as an employer have a responsibility to your shareholders to tap into talent, wherever it comes from. As Governor, I had the same two conversations virtually every day: one was with employers who said they can't find people with the relevant skills; and the other was with job seekers who said, all I want is for somebody to give me a shot. As long as that discrepancy existed, my job was to do everything I could, so that the people who didn't have the skills could develop the skills they needed so they can satisfy the employers' need for people with the right skills.

What was the response from the business community?

JM: The response from the business community is ongoing. The reason I was invited to this meeting at the Walgreens facility was because they invited CEOs from other big businesses. As you can imagine, Walgreen has warehouses all over the country, and they chose to have them pilot significant employment of people with disabilities in two of them: one in Connecticut and another one down in South Carolina. Walgreens measures everything when it comes to the performance of their facilities, and what they found was that those two warehouses outperformed their other warehouses. When you take the time to figure out how to embrace and integrate a diverse workforce into your broader workforce, you can have real success, and that is exactly what they found. So, I think the response from the business community has been positive.

One specific example related to Delaware is The Precisionists. Maybe ten years ago now, I read an article in The New York Times, a blog entry about a guy in Denmark [Thorkil Sonne], who was on the fast track in the IT industry. He had a son with autism. The more he learned about autism, the more concerned he got about his son's future. He decided to leave his fast track employment and to dedicate his life to creating tech jobs for people with disabilities. So, I read about him, and I called Rita and I said, take a look at this and give the guy a call. She did and we agreed we ought to invite him to Delaware.

Basically, we agreed that if he came to Delaware, that we would fill up my conference room - probably 15 seats - with employers in the tech industry so that he could explain his vision and to see if anybody would bite. So we did exactly that.

Ernie Dianastasis was one of the people who attended. Ernie, he's probably in his early 60s now, but for a couple of decades had run the regional operation of a company called CAI, which is a big technology employer. He was very good at his job, really successful, and he was there that day when the guy from Denmark, Thorkil Sonne, came and explained his vision.

Ernie was intrigued; without me even knowing it, he flew to Denmark to do his own due diligence. And Ernie came back and said, this is for real and we are going to integrate this into CAI. So we said to Thorkil, now you've got to move to Delaware because this is going to be something. So Thorkil and his wife and their youngest son, Lars, the one with autism, moved to Delaware. And they probably lived here, what do you think, Rita, five years?

RL: Yes

JM: So, they got this going and, in fact, the New York Times Magazine did a big story, I think it was maybe the cover story, on him about seven or eight years ago. They had probably 40 or 50 employees in Delaware, and then Ernie decided to start his own business, whose entire focus is on creating employment opportunities for people with cognitive disabilities, mainly for individuals with autism, in the tech industry. They're based in Delaware, but they have offices in Nashville, they have offices in Phoenix, and they're doing work for clients in Ohio. It's been really just amazing.

So, when you think, what has the business response been? It's amazing. And they're in this business not out of charity. They have to be at a very high quality and at a competitive cost, and that's what they do. If it's charity, it's not going to be sustainable, because you know businesses need to succeed; they need to make a profit. It's not to say they won't be charitable, but it won't be sustainable if it's only charity.

This became one of our key findings. Historically, divisions of vocational rehabilitation would go to an employer and essentially say, please do us a favor and find jobs for these five people. We need to change the orientation; and the new orientation is: I'm part of the Department of Labor and one of my responsibilities is to figure out how we can add the most value to our employers, so that you as an employer can be successful. So my job is to know your business well enough to understand the kinds of skills that you are looking for, and to bring you people who embody those skills and talents. Some of the talent may be traditionally abled, some of them may be differently abled. That's the way we're thinking about our role now.

How do we rethink youth engagement and the importance of training for employment opportunities as early as possible?

JM: One of our findings is that far too many young people with disabilities, historically, have been led down a path where there's an expectation of a lifetime on public support. And the earlier that we can change that expectation, the earlier that we can give people a sense of the possibilities of being integrated into the workforce, the more successful we're going to be.

We've got some fantastic employers who have really embraced this and it makes a massive difference. I mean, imagine if you're a teenager, you know 14, 15, 16 years old, you get to go into the workforce, while you're in school, you get to learn what the expectations are, as you work with other people, you have to show up, you have to do the job well, you have to follow through. The difference between that and somebody who's maybe 23 and has never, never had that exposure when they were a teenager is massive. Figuring out ways to work with young people in the schools as a bridge to the community is really, really important.

RL: That finding translated back into Delaware when we created the Pathways to Employment, that starts at age 14, and which is housed at DDDS [Division of Developmental Disabilities Services].

What are the obstacles to trying to get some of that set up? Realistically, what were your expectations in terms of what would have to be done to make something like this work?

JM: I do think it was mainly a mindset; this is one of those areas where people think, well, this isn't how we've done it before; so anytime you're talking about change, going from one way to a different way, it takes a while. And so celebrating the small successes, celebrating the early successes, giving people a sense of what's possible; that's why I say this is going to evolve over time.

RL: I'll say the public policy around it was also coming together. At this same time, Delaware was becoming an "Employment First" state. As the governor said, traditionally people were following this path that wasn't leading to any career. So, to put in place a policy that says we're going to be an employment first state was great, but then we had to ask, what does that mean in practice; how do we look at the system and really retrofit our system so that it will reinforce employment first? And, then, how do we start inserting that into the education process?

How did you create public private partnerships to maximize resources and opportunities?

JM: I was fortunate that governors have the ability to convene different stakeholders. I don't know that we really understood at the beginning exactly how these meetings should play out, so I think you learn as you go. So, for example, I mentioned this thing between Ernie Dianastasis and Thorkil Sonne. They took it upon themselves. The State of Delaware was an early client of this project. That was very helpful, because it let them get going, and then build up a little bit, and then recruit private sector clients.

Separately, the University of Delaware got involved. Rita, what was that program where you had young students involved?

RL: Disability Mentoring Day; it's a program where you bring employers in, as well as the students with intellectual disabilities that are looking at career opportunities, and you match them up for a day. We did it all throughout the state.

JM: A key question is, how do you make these efforts sustainable? You build and maintain demand from employers because they recognize that this is good for them and for the community. For parents and the young people themselves, you provide many opportunities. The more people see what is possible, you're more likely to have it ongoing.

RL: I think the Governor's absolutely right; when it comes from the top, then people really will all come to the table. There was a momentum that was created. Even when we were hiring within State government, there was a positive momentum.

When you think about who has the highest rate of unemployment, individuals with disabilities always came up to the top overall as a population. As the Governor said, a lot of that had to do with the fact that people did not think of this issue from a talent pool perspective.

How was the report and the project greeted by other states?

JM: Very well, a lot of endorsement, a lot of changes in policy. What you aim for is for this to be just embedded in the work of the State, so that it continues on, and no longer has to be a special initiative. Some of the groups who look on from the outside have followed the numbers, and we're seeing some very good improvements in terms of employment of people with disabilities.

Our efforts are probably one contributing factor. It was one of the reasons I chose this initiative. You know, people are so skeptical about government being able to work, people are so skeptical because of the partisan split, on virtually every issue. This was an issue that I was very confident there should be no partisan split because disabilities respect no boundary; they don't respect race, they don't respect geographic boundary or anything else. So I was really struck when I was going around the country how many people came up to me to say, "I'm so glad you're doing this because I have a daughter…, I have a son…, I have a nephew…, I have a niece…" whatever it is, "and it's about time people really took this issue on." So, I was very pleased by the response from other states.

What barriers were identified that were not previously obvious or visible?

JM: I think I mentioned a couple of them already, specifically around the way that the Division of Vocational Rehabilitation interacts with employers. I think that was a pretty important insight: that they needed to move away from thinking about it as asking for a favor, charity, to really try to integrate their efforts with a broader approach of being a value added service to the employers. Also, this idea of helping young people migrate to an expectation of a lifetime of employment as opposed to a lifetime of public support.

RL: And I think if you look at the report, it's not necessarily time limited. I believe the Governor really wanted to focus on: How do we build a toolkit? And how do we listen first? And then figure out how to match those things up. Because, sometimes in the system we get so ingrained in the system that we're not listening to, for example, what is business saying to us relative to searching for a talent pool? So, by having the Governor convene people around that topic, he was able to really provide that opportunity for the system. To hear, for example, what does the market look for, what did they want? It's not that they don't want to hire people. So I know that it was very important to be able to create some type of a toolkit that would address, systemically, what we needed to do to change. And I would say that *The Better Bottom Line* also added intel for when the Workforce Investment Opportunity Act was being created and passed because, again, that was through the efforts of Senator Harkin.

The Governor was really connecting all these dots because sometimes states would say, "well, that's federal policy, and that hampers us here stateside to really advance competitive integrated employment."

And as you know, that work continues. It was kind of laying a little quiet under the Trump Administration, but now it is starting to return under the Biden Administration. I think that work lives on because it was setting a tone. And as that evolution continues, when all those things start coming together, I believe we're going to get momentum around this issue once again.

What new partnerships emerged from this work?

JM: Well, certainly the work that The Precisionists is doing, and that's just one I know about. I think, though, that these examples are very tangible, these are not theoretical partnerships. These are real people, you know, with autism being employed in communities where they never had that chance before.

RL: I think another area that really started gaining traction, and is gaining more today, is the alignment between all of these things like the Employment First states, and their initiatives with proposed changes to 14(c).[i] And really looking at the whole idea of how to enhance integrated, competitive employment. This was very intentionally worded in the initiative. So really looking at that transformation, as you said in the beginning of our meeting, and how does the system behave today that actually limits integrated, competitive employment? And how do we look at what are the barriers to that? And how do you advance talent? So this is a continuous evolution.

Because of the governor's efforts, I was invited, while I was still serving [as Secretary], to Maryland, where they have effectively, as a state, transitioned from sheltered workshops into integrated, competitive employment. And they were utilizing the better bottom line work in that process. So it was about taking that mindset, which is sometimes the easiest part, and then figuring out how to translate that into practice, and advance that transformation into integrated, competitive employment.

And that's just one state right, but that was through the governor's work. The blueprint helped them to see the issue differently, and they were like, well, now we've got to think about this; and then the workforce investment opportunity helped to highlight the same issues. They said, how do we build that? What does that look like? Who do we talk to? The way the governor had set it up with the listening campaigns and the convening and hearing all sides - other states were doing that in their own states.

What role can employment services play in the future of support services for individuals with disabilities?

JM: Let me just say that I don't think we have any choice but for employment to play an important role in the future of support services, because if people are working, it tends to solve virtually every other problem that we have.

[i] *Section 14(c) of the Fair Labor Standards Act of 1938, which allows for employees with disabilities to be paid below the minimum wage.*

Public Health
Communications
COLLABORATIVE

Making the Decision to Get a COVID-19 Vaccine

WHY SHOULD I GET A COVID-19 VACCINE?

We are all eager to see loved ones, travel, and reopen schools and businesses. Getting vaccinated and adhering to the 3Ws—wearing a mask, washing your hands, and watching your distance—will put us closer to achieving these goals. All available COVID-19 vaccines effectively prevent moderate cases of the infection and are extremely effective at preventing the severe disease that can lead to hospitalization and death.

IS THERE A RISK OF GETTING COVID-19 FROM THE VACCINES?

No. None of the FDA-approved vaccines contain any live COVID-19 virus. Any temporary symptoms after being vaccinated are indications that the body is building immunity. The COVID-19 vaccines were developed through unprecedented government financial support and cooperation between medical experts and the public and private sectors. Every phase of every trial was carefully reviewed and approved by a safety board and the FDA.

I'VE HEARD THE COVID-19 VACCINE HAS SIDE EFFECTS. WHAT SHOULD I EXPECT?

Serious side effects are very rare. Mild side effects, like soreness, headache, or fever, are signs that your body is building up protection against the virus and typically go away in one to two days. Even if you don't experience any side effects, your immune system is still building your protection against the virus. Vaccines don't generally have long-term side effects and there is no reason to believe the COVID-19 vaccine will.

WILL THE VACCINE PROTECT ME AGAINST VARIANTS OF THE VIRUS?

All of the available COVID-19 vaccines provide some protection against known emerging variants. America's leading medical experts will continue to monitor variants and vaccine efficacy. The best way to protect yourself against the virus and variants is to get a vaccine when it's available to you.

For the latest information on the COVID-19 vaccine, visit **CDC.gov/coronavirus**
For more COVID-19 communications resources, visit **publichealthcollaborative.org**

Public Health
Communications
COLLABORATIVE

I got a COVID-19 vaccine. Now what?

HOW LONG DOES THE VACCINE TAKE TO WORK?

PFIZER-BIONTECH	MODERNA	JOHNSON & JOHNSON
7 days after the **second dose**	14 days after the **second dose**	28 days after the **single dose**

WHY DO I NEED TO COME BACK FOR A SECOND DOSE?

The FDA-authorized Pfizer-BioNTech and Moderna vaccines require a two-dose series to achieve the highest levels of immunity.

2X

WILL I GET PROOF OF VACCINATION?

Yes. After each of your shots, you'll be given a vaccination card or printout that tells you exactly which COVID-19 vaccine you received and the date and location where you were vaccinated.

DO I HAVE TO CONTINUE WITH PRECAUTIONS AFTER I'VE BEEN VACCINATED?

While vaccines must be highly effective to be approved for use, no vaccine provides 100% immunity. Public health officials estimate that 70-85% of the population needs to be vaccinated to stop the spread of the virus. In the meantime, it's important to continue to take public health precautions like wearing a mask, social distancing, and frequently washing your hands. This is especially important to protect your family and friends as they wait to get their vaccine.

HOW LONG DOES THE VACCINE LAST?

America's leading medical experts are in the process of determining how long immunity from COVID-19 vaccines last and if people will need additional booster shots to extend immunity.

For the latest information on the COVID-19 vaccine, visit **CDC.gov/coronavirus**
For more COVID-19 communications resources, visit **publichealthcollaborative.org**

Inestimable Harms: COVID-19 Vulnerability Among Delawareans with Disabilities

Elizabeth Ashford
Widener University Delaware Law School; Research Assistant, HELP-MLP
Daniel G. Atkins, J.D.
Executive Director, Community Legal Aid Society, Inc.
Michael Atkins
Brandeis University; Research Fellow, Lurie Institute for Disability Policy
David P. Donohue, M.D., F.A.C.P.
Chief Medical Officer, Progressive Health of Delaware
Caleb W. Hayman
Franklin & Marshall College; Undergraduate Intern, Delaware Psychiatric Center
Shannon Mace, J.D., M.P.H.
Director of Operations, HELP-MLP
Maija Woodruff
Franklin & Marshall College; Research Assistant, HELP-MLP

INTRODUCTION

On April 6, 2020, the Delaware Psychiatric Center confirmed its first case of COVID-19. From the beginning of the COVID-19 pandemic, the hospital had been taking every precaution to try to protect clients and staff. Leadership made surgical and other masks available to staff and clients, and encouraged their use. Hand-washing was encouraged. Traffic in and out of the hospital was curtailed. But a client in the geriatric psychiatry unit experienced a high fever and had quickly become short of breath, and on that day, it became clear that the dreaded pandemic had penetrated the hospital. As was playing out throughout the world, COVID-19 would spread–quickly, thoroughly, and relentlessly.

The infection at the Center eventually would be contained, but as the pandemic progressed, as infections and deaths escalated in Delaware's long-term care facilities, as the mortality rate climbed among the residents of the State's group homes for people with intellectual and developmental disabilities (IDD), it became fair to ask whether Delaware's disabled citizens were bearing the brunt of the pandemic. Were Delawareans with disabilities suffering disproportionately – were their rates of infection, of morbidity, of mortality, especially high?

A fair answer to those questions, it evolves, must contain two truths. First, we don't know for certain: the data is too limited, in Delaware and elsewhere. Second, what we do know very strongly suggests that the pandemic has indeed had an especially lethal impact on people with disabilities, including disabled Delawareans.

Following is a brief summary of the available data on COVID events among people with disabilities, and an attempt to gauge vulnerability based on the prevalence of known risk factors among Delawareans with disabilities.

COVID EVENTS AMONG DELAWAREANS WITH DISABILITIES

Data Generally

Data on COVID-19 event incidence (infection, hospitalization, mortality) for people with disabilities is sparse. While Congress has required that the federal government include race and ethnicity among the demographic data in its COVID analyses, the Act containing that mandate (April's "Paycheck Protection Program and Health Care Enhancement Act") did not include an explicit requirement for disability. A subsequent request to specify "disability" as among the "other relevant data" required by the Act, tendered by letter from a congressional group to the Secretary of the United States Department of Health and Human Services (HHS), was to no avail. The Centers for Disease Control and Prevention (CDC) did amend its case reporting form (the "Human Infection with 2019 Novel Coronavirus Person Under Investigation and Case Report Form") to add "Disability" to its list of "underlying medical conditions," but neither the CDC nor any other federal agency has reported disability data.[1,2]

Nonetheless, the limited direct impact evidence that is available strongly suggests that the pandemic is having an especially lethal impact on people with disabilities. A comprehensive study of death records in the United Kingdom released in June 2020, for example, determined that fully one-third of all COVID-related mortalities were people with disabilities.[3] Subsequent updates in September and in February 2021 confirmed the disparities: according to the last release, "in England, the risk of death involving the coronavirus (COVID-19) was 3.1 times greater for more-disabled men and 1.9 times greater for less-disabled men, compared with non-disabled men" and "the risk of death was 3.5 times greater for more-disabled women and 2.0 times greater for less-disabled women, compared with non-disabled women."[4]

In the United States, meanwhile, limited data started to emerge in late spring. In June, National Public Radio (NPR) released the results of a study on COVID mortality rates among recipients of IDD services:

> *In Pennsylvania, numbers obtained by NPR show that people with intellectual disabilities and autism who test positive for COVID-19 die at a rate about twice as high as other Pennsylvania residents who contract the illness. In New York, the state with the most deaths from COVID-19, people with developmental disabilities die at a rate 2.5 times the rate of others who contract the virus.*[5]

A subsequent study of New York group homes seems to confirm this understanding. The study found that case rates for people with IDD in group homes were roughly four times the overall state rate, and the case-fatality percentage roughly doubled (and overall mortality rate, as a result, is almost eight times the overall state rate).[6] A follow-up report released in September utilizing data from the New York Disabilities Advocates (NYDA) COVID-19 Survey of Providers noted that the case rates disparity disappeared in early summer, while case-fatality rates remained around two times higher for people with IDD living in group homes.[7]

doi: 10.32481/djph.2021.03.009

Finally, a study of IDD service recipients in California published in December concluded as follows:

> *Compared to Californians not receiving IDD services, in general, those receiving IDD services had a 60 percent lower case rate, but 2.8 times higher case-fatality rate. COVID-19 outcomes varied significantly among Californians receiving IDD services by type of residence and skilled nursing care needs: higher rates of diagnosis in settings with larger number of residents, higher case-fatality and mortality rates in settings that provided 24-h skilled nursing care.*[8]

California compiles and publicly reports COVID-related data for IDD service recipients; the data is updated twice weekly.[9]

Delaware data

Disability data for Delaware comes from two sources: the record of the outbreak at the Delaware Psychiatric Center, and data maintained by the Delaware Division of Developmental Disabilities Services (DDDS) for recipients of Residential Habilitation Services, euphemistically residents of group homes for people with intellectual and developmental disabilities.

THE DELAWARE PSYCHIATRIC CENTER

The Delaware Psychiatric Center is a 120-bed state run mental health inpatient facility, consisting of four civil units and two correctional units. The COVID outbreak at the facility began on April 6 on the geriatric psychiatric unit: the infected client and his roommate were both transferred to the hospital's newly purposed COVID unit. Over the next two weeks, every resident of the geriatric unit was diagnosed with COVID-19 and transferred to the COVID unit.

Of the 22 clients on the geriatric psychiatry unit, ten required hospitalization at nearby Christiana Hospital for declining respiratory function. Four required intubation and mechanical ventilation. In total, three clients died from COVID-19 during their hospitalization.

In the initial weeks, the hospital was challenged by the same shortage of personal protective equipment (PPE) that affected health care workers nationwide, forcing hospital staff to reuse masks and gowns for an extended period. Among hospital staff, the nursing staff bore the brunt of the outbreak, with additional responsibilities and pressure to keep clients safe, and with rising COVID infection rates themselves. Due to the dwindling number of available nursing staff, the Delaware National Guard was called in. Guard members arrived on April 17, 2020. Through the infection control efforts of dedicated hospital staff and the National Guard, the outbreak was contained.

After the April outbreak in the geriatric unit, the hospital experienced only occasional infections: from June through November, just 12 additional clients contracted COVID-19. None of the 12 experienced significant symptoms or required hospitalization.

Despite the challenges that a deadly pandemic has placed on long-term care facilities throughout the world, the inpatients at DPC have fared well. The psychiatry faculty report no significant challenge to their ability to achieve a satisfactory mental health outcome.

DIVISION OF DEVELOPMENTAL DISABILITIES SERVICES

The Community Services unit of the DDDS oversees the provision of, among other things, Residential Habilitation services to eligible Delawareans with IDD. Throughout the pandemic, the unit has collected data on COVID events among its service population, and has reported data to service providers, and to service recipients and their families.

At any given time during the period, roughly 1270 individuals were receiving residential habilitation services, typically in residences with a maximum of three or four service recipients. Through the end of October, the COVID positivity rate among service recipients was seven percent, compared to an overall State rate of four percent; the mortality rate, however, was 13 percent (11 total deaths), compared to an overall State rate of two percent (777 deaths). The ratios shifted dramatically with the fall surge. Between October 31 and January 31, the cumulative positivity rate for the State doubled, from four percent to eight percent, while for service recipients it tripled, from seven percent to 21 percent. Fortunately, the mortality rate saw a very different change: while the State rate held steady at two percent, the mortality rate among service recipients was more than halved, dropping from 13 percent to six percent (17 total deaths, *see Table 1*).

The one constant in the DDDS data throughout the pandemic has been the fact of disparity: as in every other state with reported data, residents with IDD are getting infected, and are dying, at significantly higher rates than the general population.

One final note on Delaware data: the mortality rate in Delaware's long term care facilities stands at 29 percent, nearly fifteen times the overall State rate, and deaths among facility residents account for over half the State's total. These numbers are also consistent with the trends in other states. As residents of the facilities are likely to have disabilities – age-related and otherwise – they are also a part of the story, though the lack of disability-specific data makes it impossible to determine to precisely what extent.

Table1. COVID Event Rates, DDDS Residential Habilitation Service Recipients

	Percent Positive	# Deaths	Percent Mortality
RHS Recipients	21	17	6
Total State	8	1195	2
Long Term Care Facilities	n/a	627	29
RHS Recipients (through 10/31)	7	11	13
Total State (through 10/31)	4	777	2

Data Courtesy of Delaware Division of Developmental Disabilities Services, and through January 31, 2021 unless otherwise specified.

COVID VULNERABILITIES AMONG DELAWAREANS WITH DISABILITIES

By itself, this data might not support generalizations about COVID event rates among Delawareans with disabilities. But they are consonant with the hypothesis that Delawareans with disabilities experience higher rates of COVID cases and higher COVID mortality rates, and that these reflect disparities in vulnerability. This is so, because Delawareans with disabilities are at greater risk of exposure and infection, and are more likely to be disadvantaged by the comorbidities and other risk factors that portend poor outcomes in COVID cases.

Infection Risk

Although fomite and other mediated modes of transmission for the novel coronavirus remain theoretically possible, the dominant (and perhaps exclusive) modes of transmission now appear to be through person-person contact or aerosolized spread. Absent immunity to infection, the persons most at risk of infection are those most likely to be exposed to other people, and as such, the risk would be impacted by a number of factors highly relevant to people with disabilities: shared or congregate living arrangements; contacts with caregivers, aides, and support networks; and the lack of suitable personal protective equipment for people with disabilities and their caregivers.[10]

These factors alone make mitigation difficult. And for a limited number of people with disabilities, masks present a special problem. Cory Ellen Nourie, MSS, MLSP, Director of Community Services for the Delaware DDDS, notes that "a lot of our service recipients cannot wear a face mask, and that's either because of an underlying health condition, or because from a behavioral standpoint, they would not be able to maintain wearing it."

> *"That's one of the reasons," she explains, "that we advocated so strongly to make sure that our service recipients have access to the vaccine, because otherwise the mitigation strategies that you think of being that three legged stool – mask wearing, maintaining social distance and extreme hand hygiene, some of those three legs they don't have access to in their daily life."*

Morbidity and Mortality Risks

Some biological risk factors for COVID morbidity and mortality are now fairly well-established, including a variety of comorbidities. Among the risk factors currently listed by the CDC, diabetes, kidney disease, hypertension, cardiovascular disease, obesity, and pulmonary disease, seem most prevalent in the literature on comorbidities.[11–15] Most of these unequally burden people with disabilities.

Some of these comorbidities are not merely correlated with disability, rather the relationship is definitional: if the condition is severe enough, it is itself disabling. Federal regulations, for example, recognize as "disabilities" for the purpose of Social Security Disability benefits: diabetes (regulations do not distinguish among the types), kidney disease, pulmonary diseases (including COPD), and a variety of cardiovascular diseases.[16] In these cases, people with disabilities are at risk solely by virtue of their disability.

Moreover, whether or not they are disabling, the COVID comorbidities are more prevalent among people with disabilities.

According to the 2019 Behavioral Risk Factor Survey, 12.8 percent of Delaware adults have been diagnosed with diabetes, but that percentage is nearly doubled – to 23.2 percent – for adults with disabilities. Nearly half – 46.4 percent – of Delawareans with diabetes report having a disability.[17]

A logistic regression analysis of data by the Delaware Division of Public Health determined that disability status was "consistently associated with coronary heart disease and angina in Delaware during all years from 2011 to 2015"; disability was also correlated with heart attack and stroke.[18]

Data from the 2017 Behavioral Risk Factor Surveillance System (BRFSS) reveal high blood pressure among 26.8 percent of U.S. adults without disabilities, and 42.9 percent among adults *with* disabilities; in Delaware, high blood pressure was reported by 29.2 percent of adults without disabilities, and 45.1 percent of adults with disabilities.

The same survey data yields similar results for obesity: obesity was found among 25.3 percent of U.S. adults without disabilities, and among 39.6 percent of adults with disabilities; in Delaware, obesity was reported by 26.3 percent of adults without disabilities, and 41.4 percent of adults with disabilities.

The CDC has also identified among its risk factors a behavioral determinant: smoking. According to the 2017 BRFSS, 14.6 percent of US adults without disabilities smoke, a proportion more than doubled – to 30.6 percent – for adults with disabilities. In Delaware, 17.6 percent of adults without disabilities smoke, compared to 33.3 percent of adults with disabilities.[19]

Immunities

The immune system is the body's natural defense against all pathogens, including viruses, such as COVID-19. With the immune system functioning normally, pathogens are typically dispatched without the individual noticing; illness occurs when the immune system is not properly equipped to handle an infection. There is thus at least a theoretical basis for the need for a strong immune system in the prevention and treatment of COVID-19.[20,21]

There is evidence to suggest that immunity can be enhanced by specific behaviors: that exercise is positively correlated with immune function, and can reduce the incidence of respiratory illnesses[22]; that adequate nutrition is critically important to proper immune functioning[23]; and that the human immune system and sleep are associated and mutually influenced.[24]

But exercise, nutrition, and sleep all can be problematic for people with disabilities. Exercise opportunities are subject to both physical and environmental limitations, thus data from the BRFS indicates that 24.3 percent of U.S. adults without disabilities are "inactive" (and 25.2 percent in Delaware), while the percentage of adults with disabilities who are "inactive" is nearly doubled, at 43.0 percent (and 42.6 percent in Delaware). Nutrition may be compromised by food insecurity: a 2013 study by the United States Department of Agriculture found "a strong association between disability and food insecurity," as one-third of U.S. households with a working-age adult unable to work due to disability were food insecure, and one-quarter of households with other disabled working-age adults were food insecure, compared to 12 percent of households with no disabled working age adults.[25] And sleep problems are disproportionately common among people with disabilities, both with physical disabilities[26] and intellectual disabilities.[27]

COVID Testing, Treatment, and Prevention.

Testing, treatment, and prevention measures–including vaccines–need to be both available and accessible. Too often they are neither. The Federal Emergency Management Agency notes that "People with disabilities may not be able to access COVID-19 testing sites which include, but are not limited to, community-based drive-through testing sites." "Drive-through testing," FEMA observed, "is especially inaccessible in urban areas, where fewer people have access to cars."[28]

Access to testing, treatment, and vaccines can be especially problematic for homebound or institutionalized persons. Transportation and other accessibility issues help explain why people with disabilities are more likely to report delayed or unmet medical care needs.[29]

In the case of vaccines, availability is a particular concern: in spite of the overwhelming evidence that they are at risk, people with disabilities have struggled to get vaccination priority.[30] Marissa Band, Managing Attorney for the Disabilities Law Program (DLP) of Community Legal Aid Society, Inc. (CLASI), says that "demand is really exceeding supply, and people with disabilities are not as far up the list as we'd like them to be." The Division of Public Health, she notes, did move people with serious mental illness and with intellectual and developmental disabilities, as well as those living in group and congregate care, higher up on the list than they were previously. "Those are steps in the right direction," she concludes, "but it's still not yet the ideal."

Treatment may also be limited by another critical factor: discrimination, including through medical care rationing and Crisis Standards of Care. The SARS-CoV-2 pandemic has resulted in record levels of hospitalizations, creating scarce resources in hospitals across the country, and prompting state agencies and hospitals to implement crisis standards of care policies.[31] According to disability and aging advocates, many of these policies include official guidance which would result in the rationing of medical treatment "based on discriminatory assumptions about the life worth of people with disabilities."[32] In some cases, policies overtly discriminate based on disability[33,34]; other policies rely on "neutral" criteria like the patient's Sequential Organ Failure Assessment (SOFA) score, which may disproportionately harm people with disabilities "due solely to their underlying condition and not their actual prognosis."[35] Many of these polices were modified after disability rights organizations filed complaints in court, with state agencies, or with the federal Health and Human Services Office of Civil Rights.[36]

Well-conceived policies, however, and well-crafted guidelines, are essential tools in preventing discriminatory treatment based on deeply rooted biases and assumptions about disabled lives. Without guidelines and accountability, individual discretion drives treatment decisions, a hazardous route when 82.4 percent of US physicians report that "people with significant disability have worse quality of life than nondisabled people," and only 40.7 percent feel "very confident about their ability to provide the same quality of care to patients with disability."[37] Care decisions made behind closed doors may well be disproportionately adverse to people with disabilities (and to older and heavier adults, and people of color),[38] and people with disabilities "have expressed concern that crisis triage protocols have not adequately prioritized their lives when determining how to allocate access to life-saving health care resources."[39] It is of significant concern, then, that twenty-two states have no crisis standards of care publicly available, or simply no plan in existence at all.[40]

At the start of the SARS-CoV-2 pandemic, Delaware was relying on a pandemic flu plan originally created in 2008 to guide medical crisis standards of care. The original plan made no mention of specific practices to prevent the discrimination of people with disabilities. While the 2008 plan did not use discriminatory SOFA score criteria, it also did not include any specific criteria for ways to prevent discrimination when rationing lifesaving care in emergency situations.

In April 2020, CLASI's DLP sent a letter to Governor John Carney and state officials, calling on the state to take "specific steps to ensure that life-saving care is not illegally withheld from Delawareans with disabilities ... due to discriminatory resource allocations or altered standards of care." Shortly after, the Delaware Health and Social Services Division of Public Health released the Crisis Standards of Care Concept of Operations. The updated guidelines adopted a number of anti-discrimination policies, including orders to maintain the anonymity of triaged patients "to ensure no biases are introduced into the process;" that medical care rationing should "prioritize the number of patients who will recover over the number of life-years saved;" an insistence that "intermediate or long-term prognosis or survival may not be factors in determining priority for emergency lifesaving treatment;" and that vulnerable populations receive the same "resource allocation strategies as all other populations without differentiation as a result of disabilities or vulnerabilities."

CONCLUSION

The available data on COVID events all indicates that people with disabilities are getting infected more often than people without disabilities, and are dying at much higher rates. This is true in Delaware as it is elsewhere. And that limited data is consistent with everything we know about the situation of people with disabilities, and the determinants of COVID risk: people with disabilities are necessarily exposed to greater interpersonal contact and thus to COVID infection; people with disabilities have higher prevalence rates for the comorbidities that predict poorer outcomes in COVID cases; people with disabilities may be less able to bolster their immune systems in ways that might protect against COVID; and people with disabilities confront distinctive barriers to COVID testing, treatment, and prevention. In short, the evidence is overwhelming that people with disabilities are distinctively vulnerable to the ravages of the COVID-19 virus.

The precise nature and extent of their vulnerability is made difficult to gauge by the relative paucity of data; that in turn makes it difficult to formulate and implement preventive, mitigating, and remedial measures. "It's problematic," observes Marissa Band, of CLASI's DLP, "that we really don't know the prevalence in the state, and where it's hitting the hardest, to really help us make decisions." And, she notes, "it's the people with disabilities living in the broader community that are likely to be missed when they're not collecting that data." "That data," she concludes, "would be very useful."

In the interim, we are left to record the suffering:

> *"Right after the Thanksgiving surge," recalls Cory Nourie, of Delaware's DDDS: "I was on my provider phone call on Thursday morning, and we had gone, I think, eight hours without anyone sending me an email with a new positive case. And I was getting ready to celebrate that it had been eight whole hours. And then the emails started coming through, and on that call. Now the providers send me emails and a lot of them preface it with, "I'm so sorry to have to tell you this." And I'm like, "no, please. I don't mean for you to take on my sadness here," but the fatigue is real, it's real. And every time a new positive comes in, my heart just sinks a little lower because it's real. And I think about all of the staff who are trying so hard and their leadership of the provider organizations, and it's just really, really difficult."*

REFERENCES

1. Centers for Disease Control and Prevention (CDC). (2020). Human infection with 2019 novel coronavirus person under investigation (PUI) and case report form. Retrieved from: https://epi.dph.ncdhhs.gov/cd/coronavirus/Interim%20Person%20Under%20Investigation%20Form.pdf?ver=1.1
2. CDC. (2021, Feb 3). Reporting COVID-19 cases to CDC. Retrieved from: https://www.cdc.gov/coronavirus/2019-ncov/php/reporting-pui.html
3. Office for National Statistics. (2020, Jun 19). Coronavirus (COVID-19) related deaths by disability status, England and Wales: 2 March to 15 May. Retrieved from: www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/coronaviruscovid19relateddeathsbydisabilitystatusenglandandwales/2marchto15may2020
4. Office for National Statistics. (2021, Feb 11). Updated estimates of coronavirus (COVID-19) related deaths by disability status, England: 24 January to 20 November 2020. Retrieved from: https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/coronaviruscovid19relateddeathsbydisabilitystatusenglandandwales/24januaryto20november2020
5. Shapiro, J. (2020, Jun 9). COVID-19 infections and deaths are higher among those with intellectual disabilities. NPR. Retrieved from: https://www.npr.org/2020/06/09/872401607/covid-19-infections-and-deaths-are-higher-among-those-with-intellectual-disabili
6. Landes, S. D., Turk, M. A., Formica, M. K., McDonald, K. E., & Stevens, J. D. (2020, October). COVID-19 outcomes among people with intellectual and developmental disability living in residential group homes in New York State. Disability and Health Journal, 13(4), 100969. https://doi.org/10.1016/j.dhjo.2020.100969
7. Landes, S. D., Turk, M. A., Formica, M. K., & McDonald, K. E. (2020, Sep 16). COVID-19 trends among adults with intellectual and developmental disabilities (IDD) living in residential group homes in New York State through July 10, 2020. Lerner Center for Public Health Promotion: Public Health Research Brief Series, 13. https://surface.syr.edu/lerner/13
8. Landes, S. D., Turk, M. A., & Wong, A. (2020). COVID-19 outcomes among people with intellectual and developmental disability in California: The importance of type of residence and skilled nursing care needs. Disability and Health Journal, 101051. Advance online publication.
9. California Department of Developmental Services. (2021). Reported positive COVID-19 tests and deaths of regional center consumers. Retrieved from: https://www.dds.ca.gov/corona-virus-information-and-resources/data/
10. World Health Organization. (2020, Mar 26). Disability considerations during the COVID-19 outbreak. Retrieved from: https://www.who.int/publications/i/item/WHO-2019-nCoV-Disability-2020-1
11. Richardson, S., Hirsch, J. S., Narasimhan, M., Crawford, J. M., McGinn, T., Davidson, K. W., . . . Zanos, T. P., & the the Northwell COVID-19 Research Consortium. (2020, May 26). Presenting characteristics, comorbidities, and outcomes among 5700 patients hospitalized with COVID-19 in the New York City Area. JAMA, 323(20), 2052–2059. https://doi.org/10.1001/jama.2020.6775
12. Harrison, S. L., Fazio-Eynullayeva, E., Lane, D. A., Underhill, P., & Lip, G. Y. H. (2020, September 10). Comorbidities associated with mortality in 31,461 adults with COVID-19 in the United States: A federated electronic medical record analysis. PLoS Medicine, 17(9), e1003321. https://doi.org/10.1371/journal.pmed.1003321
13. Ssentongo, P., Ssentongo, A. E., Heilbrunn, E. S., Ba, D. M., & Chinchilli, V. M. (2020, August 26). Association of cardiovascular disease and 10 other pre-existing comorbidities with COVID-19 mortality: A systematic review and meta-analysis. PLoS One, 15(8), e0238215. https://doi.org/10.1371/journal.pone.0238215
14. Gold, M. S., Sehayek, D., Gabrielli, S., Zhang, X., McCusker, C., & Ben-Shoshan, M. (2020, November). COVID-19 and comorbidities: A systematic review and meta-analysis. Postgraduate Medicine, 132(8), 749–755. https://doi.org/10.1080/00325481.2020.1786964
15. Guzik, T. J., Mohiddin, S. A., Dimarco, A., Patel, V., Savvatis, K., Marelli-Berg, F. M., . . . McInnes, I. B. (2020, August 1). COVID-19 and the cardiovascular system: Implications for risk assessment, diagnosis, and treatment options. Cardiovascular Research, 116(10), 1666–1687. https://doi.org/10.1093/cvr/cvaa106
16. Social Security Administration. (n.d.). Listing of impairments. 20 CFR 404, subpart P, appendix 1. Retrieved from: https://www.ssa.gov/OP_Home/cfr20/404/404-app-p01.htm
17. Delaware Health and Social Services (DHSS). (n.d.). More than 1 in 10 Delaware adults report having diabetes in 2019. Retrieved from: https://www.dhss.delaware.gov/dhss/dph/dpc/diabetes02.html
18. DHSS. (2018, Nov). The burden of cardiovascular diseases and transient ischemic attack in Delaware, 2011-2015. Retrieved from: https://dhss.delaware.gov/dhss/dph/dpc/files/cvd_final.pdf
19. CDC. (2020, Sep 16). Disability & health U.S. state profile data: Delaware. Disability & Health Data System. Retrieved from: https://www.cdc.gov/ncbddd/disabilityandhealth/impacts/delaware.html

20. Chowdhury, M. A., Hossain, N., Kashem, M. A., Shahid, M. A., & Alam, A. (2020, November). Immune response in COVID-19: A review. Journal of Infection and Public Health, 13(11), 1619–1629. https://doi.org/10.1016/j.jiph.2020.07.001
21. Tufan, A., Avanoğlu Güler, A., & Matucci-Cerinic, M. (2020, April 21). COVID-19, immune system response, hyperinflammation and repurposing antirheumatic drugs. Turkish Journal of Medical Sciences, 50(SI-1), 620–632. https://doi.org/10.3906/sag-2004-168
22. Lange, K. W., & Nakamura, Y. (2020, December 16). Movement and nutrition in COVID-19. Movement and Nutrition in Health and Disease, 4, 89-94.
23. Marcos, A., Nova, E., & Montero, A. (2003, September). Changes in the immune system are conditioned by nutrition. European Journal of Clinical Nutrition, 57(Suppl 1), S66–S69. https://doi.org/10.1038/sj.ejcn.1601819
24. Asif, N., Iqbal, R., & Nazir, C. F. (2017, December 20). Human immune system during sleep. American Journal of Clinical and Experimental Immunology, 6(6), 92–96.
25. Coleman-Jensen, A., & Nord, M. (2013, May 6). Disability is an important risk factor for food insecurity. U.S. Department of Agriculture, Economic Research Service. Retrieved from: https://www.ers.usda.gov/amber-waves/2013/may/disability-is-an-important-risk-factor-for-food-insecurity
26. Vega, R., Miró, J., Esteve, R., Ramírez-Maestre, C., López-Martínez, A. E., & Jensen, M. P. (2019, October). Sleep disturbance in individuals with physical disabilities and chronic pain: The role of physical, emotional and cognitive factors. Disability and Health Journal, 12(4), 588–593. https://doi.org/10.1016/j.dhjo.2019.04.001
27. Surtees, A. D. R., Oliver, C., Jones, C. A., Evans, D. L., & Richards, C. (2018, August). Sleep duration and sleep quality in people with and without intellectual disability: A meta-analysis. Sleep Medicine Reviews, 40, 135–150. https://doi.org/10.1016/j.smrv.2017.11.003
28. Federal Emergency Management Agency. (2020, Jul 17). COVID-19 testing considerations for people with disabilities. Retrieved from: https://www.fema.gov/case-study/covid-19-testing-considerations-people-disabilities
29. Henning-Smith, C., McAlpine, D., Shippee, T., & Priebe, M. (2013, November). Delayed and unmet need for medical care among publicly insured adults with disabilities. Medical Care, 51(11), 1015–1019. https://doi.org/10.1097/MLR.0b013e3182a95d65
30. Contrera, J. (2021, Jan 13). People with disabilities desperately need the vaccine. But states disagree on when they'll get it. Washington Post. Retrieved from: https://www.washingtonpost.com/dc-md-va/2021/01/13/disabled-coronavirus-vaccine-states/
31. Lund, E. M., & Ayers, K. B. (2020, August). Raising awareness of disabled lives and health care rationing during the COVID-19 pandemic. Psychol Trauma, 12(S1), S210–S211. https://doi.org/10.1037/tra0000673
32. Disability Rights Education & Defense Fund. (2020). State medical rationing policies and guidance project. Retrieved from: https://dredf.org/state-medical-rationing-policies-and-guidance-project/
33. Center for Public Representation. (2021, Feb 12). COVID-19 medical rationing & facility visitation policies. Retrieved from: https://www.centerforpublicrep.org/covid-19-medical-rationing/
34. Essley Whyte, L. (2020, Apr 8). State policies may send people with disabilities to the back of the line for ventilators. Center for Public Integrity. Retrieved from: https://publicintegrity.org/health/coronavirus-and-inequality/state-policies-may-send-people-with-disabilities-to-the-back-of-the-line-for-ventilators/
35. Justice in Aging. (2020, September). Combatting discriminatory crisis standards of care. Retrieved from: https://justiceinaging.org/wp-content/uploads/2020/09/Combatting-Discriminatory-Crisis-Standards-of-Care.pdf
36. Center for Public Representation. (2021, February 12). COVID-19 medical rationing & facility visitation policies. Retrieved from: https://www.centerforpublicrep.org/covid-19-medical-rationing/
37. Iezzoni, L. I., Rao, S. R., Ressalam, J., Bolcic-Jankovic, D., Agaronnik, N. D., Donelan, K., . . . Campbell, E. G. (2021, February). Physicians' perceptions of people with disability and their health care. Health Affairs (Project Hope), 40(2), 297–306. https://doi.org/10.1377/hlthaff.2020.01452
38. Disability Rights Education & Defense Fund. (2020, Mar 25). Preventing discrimination in the treatment of COVID-19 patients: The illegality of medical rationing on the basis of disability. Retrieved from: https://dredf.org/the-illegality-of-medical-rationing-on-the-basis-of-disability/
39. Chen, K. L., Brozen, M., Rollman, J. E., Ward, T., Norris, K., Gregory, K. D., & Zimmerman, F. J. (2020). Transportation access to health care during the COVID-19 pandemic: Trends and implications for significant patient populations and health care needs. UCLA: Institute of Transportation Studies. Retrieved from: https://escholarship.org/uc/item/22b3b1rc
40. Cleveland Manchanda, E. C., Sanky, C., & Apel, J. M. (2020). Crisis standards of care in the USA: A systematic review and implications for equity amidst COVID-19. Journal of Racial and Ethnic Health Disparities,1-3. Advance online publication.

www.fic.nih.gov

GLOBAL HEALTH MATTERS

JAN/FEB 2021

Inside this issue

Fogarty Fellow studies the impact of stress in South Africa . . . p. 37

FOGARTY INTERNATIONAL CENTER • NATIONAL INSTITUTES OF HEALTH • DEPARTMENT OF HEALTH AND HUMAN SERVICES

Biden team elevates science, global engagement

In his first weeks in office, U.S. President Joe Biden has taken steps to elevate the role of science in government, re-engage with the global community to combat the COVID-19 pandemic and advance global health, and renew the U.S. commitment to the WHO.

The White House has released a 200-page strategy for COVID-19 response and pandemic preparedness, which includes plans to restore U.S. leadership in strengthening global capacity to combat future disease threats. "The United States will promote sustainable global health and global health security, rebuild health security alliances, elevate U.S. efforts to support the Global Health Security Agenda, and revitalize U.S. leadership," the document states.

On his second day in office, the President signed measures to allow the U.S. to rejoin the WHO and invited the NIH's Dr. Anthony Fauci to represent the U.S. at the WHO's virtual board meeting. Fauci told the gathering the U.S. will honor its financial commitments and rebuild U.S. engagement with the organization. "The United States stands ready to work in partnership and solidarity to support the international COVID-19 response, mitigate its impact on the world, strengthen our institutions, advance epidemic preparedness for the future, and improve the health and wellbeing of all people throughout the world," said Fauci.

U.S. President Joe Biden visited NIH recently, where he was greeted by Dr. Anthony Fauci (center) and Dr. Francis Collins (right). Biden has appointed Fauci his chief medical adviser on COVID-19 and asked Collins to remain as NIH director.

Photo courtesy of the White House

WHO Director-General Dr. Tedros Adhanom Ghebreyesus welcomed the pledge. "WHO is a family of nations," he said. "And we are all glad that the United States is staying in the family."

Fauci also reported the U.S. will stop its draw down of staff seconded to the WHO and will resume engagement both directly and through its WHO Collaborating Centers. "The United States sees technical collaboration at all levels as a

. . . continued on next page

NIH, Fogarty see budget increases for Fiscal Year 2021

U.S. appropriations passed and signed into law in late December provide budget increases for both NIH and Fogarty. NIH received $42.9 billion, nearly a $1.5 billion hike from Fiscal Year 2020. Fogarty was allocated a little over $84 million, about a 4% rise.

The measure also included $1.25 billion for NIH to support COVID-19 research and clinical trials related to the long-term effects of the virus. Another $12.5 million was earmarked for NIH studies on firearm violence prevention. Finally, about $3.1 billion will support Alzheimer's disease and related dementias research.

Fiscal Year 2021 began on Oct. 1, 2020.

FOCUS

Scientists discuss importance of research in humanitarian crises

- Case studies describe unique challenges, lessons learned
- Flexibility, communication and strong partnerships are essential
- Outcomes can help guide policy, improve response efforts

Read More on pages 39-42

Biden team elevates science, global engagement

. . . continued from previous page

fundamental part of our relationship with WHO, one that we value deeply and will look to strengthen going forward," he said.

The U.S. also has announced it will join the ongoing international efforts to develop, produce and equitably distribute COVID-19 vaccines, therapeutics and diagnostics—the COVID-19 Vaccines Global Access Facility, known as COVAX, and the Access to COVID-19 Tools (ACT) Accelerator.

In a show of support for Africa, Biden addressed the virtual African Union Summit in February to express a willingness to help defeat COVID-19, advance health security and combat climate change. "The United States stands ready now to be your partner in solidarity, support and mutual respect," he said. "We believe in the nations of Africa and in the continent-wide spirit of entrepreneurship and innovation."

The White House also issued an executive order to rescind the so-called Mexico City policy, which withheld U.S. funding from international organizations that provide—or offer information about—abortions.

In personnel matters, the Administration announced that NIH Director Dr. Francis S. Collins—who has served since 2009—has been asked to remain in his position. NIH's other political appointee, Dr. Ned Sharpless, was also invited to stay on as head of the National Cancer Institute. In addition to continuing in his role leading the National Institute of Allergy and Infectious Diseases, Fauci was named the President's chief medical adviser on COVID-19.

Biden also re-established the Directorate on Global Health Security and Biodefense at the U.S. National Security Council. In addition, he announced he is resurrecting the President's Council on Science and Technology and elevating the White House Office of Science and Technology Policy Director to a cabinet-level position.

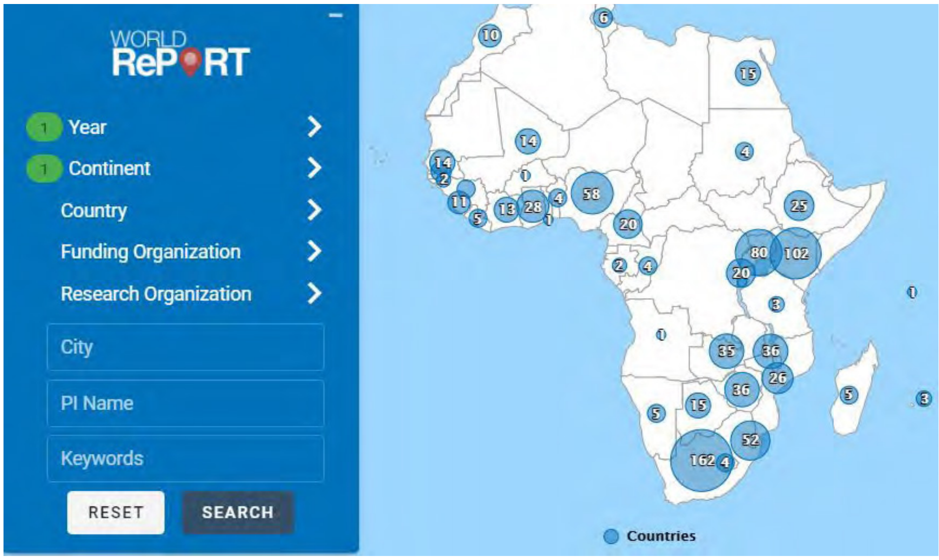
Finally, Biden issued a plan to review existing government scientific integrity policies to determine if they adequately prevent "improper political interference" in the conduct of research and data collection, and stop suppression or distortion of findings. The President stated his Administration will make evidence-based decisions guided by the best available science and data. "Scientific findings should never be distorted or influenced by political considerations."

New funding data available in World Report mapping tool

2019 research funding information from a number of international organizations is now available online in World Report, an open-access, interactive mapping database.

The database now includes over 500,000 records that depict funding data from 2012 through 2019. Users can search projects by using keywords and filter them by location, funding organization, research body, principal investigator or any combination. Data, now including abstracts and visualizations, can also be exported.

World Report provides a public means to track international research activities and partnered investments, increase awareness of funding opportunities, and share results with the broader research and funding community. Its goal is to improve understanding of the research landscape, identify gaps in funding and areas where there might be a duplication of effort, and enable funders to more effectively synergize investments.



World Report is hosted by the NIH and managed by a steering committee of 13 participant organizations.

RESOURCES

https://worldreport.nih.gov

Pandemic prevention more effective than response

By Susan Scutti

Unless urgent action is taken to change the global approach to infectious diseases, pandemics will emerge more often, spread more rapidly, do more damage to the economy and kill more people than COVID-19, according to a recent report issued by a group of the world's leading experts on biodiversity and pandemics. The cost of COVID-19 in the U.S. alone may reach as high as $16 trillion by the end of 2021, the study estimated. By comparison the price tag for reducing risks to prevent pandemics would be about 100 times less.

The report is the result of a workshop chaired by longtime Fogarty grantee Dr. Peter Daszak that was convened by the Intergovernmental Science-Policy Platform on Biodiversity and Ecosystem Services. The independent body was established by a U.N. resolution in 2012 and is comprised of 130 member countries. In addition, Daszak was a member of the WHO delegation that investigated the coronavirus outbreak in Wuhan, China.

Photo courtesy of the EcoHealth Alliance

NIH grantee Dr. Peter Daszak advocates for a One Health approach to prevent rather than respond to pandemics.

There are as many as 1.7 million undiscovered viruses lurking in animals with up to 827,000 of them estimated to be infectious in humans, the report stated. Human activities that disrupt nature—increasing contact among wildlife, farm animals, pathogens and people—can lead to the moment when an infectious germ jumps from animal to human. Such "spillover" events, made more likely by deforestation, mining activities, land use change and wildlife trade, increase the risk of pandemics.

"We did an analysis of emerging diseases that showed the events that lead to pandemics are increasing in frequency," said Daszak, who is also president of the nonprofit EcoHealth Alliance. "When is it going to stop? We can't sustain this level of pandemic impact. If this happened every 10 years, it would be disastrous."

The report highlights the relationship between financial systems and pandemic risk. "Rapid economic development in low- and middle-income countries often has pretty devastating impacts on the environment and that often leads to health issues, whether that's pollution, mercury leakage into the rivers or infectious diseases," said Daszak. "The drivers of that rapid economic growth are customers in richer countries, so it is our globalized consumption patterns that drive economic growth and also drive the risk of pandemics."

Daszak has led studies of zoonotic diseases with NIH funding for several decades. He received his first-ever federal grant from Fogarty's Ecology and Evolution of Infectious Diseases (EEID) program, which supports studies of emerging global threats. With it, he explored the origins of Nipah and Hendra viruses in Malaysia and Australia. Though some thought Nipah emerged due to climate change or maybe deforestation, "the real reason turned out to be the dynamics of pig farm production," explained Daszak. Farms had grown large so farmers segmented pig production, which allowed the virus to continually cycle through the swine population and this caused an outbreak. Daszak says the EEID initiative, which is also supported by the National Science Foundation, is "visionary, ground-breaking and high-reward."

His Fogarty grants have given him access to places where there is high risk of disease outbreaks, he said. "It's a win-win. You're not just doing science but also advancing international relations. It's helping people in developing countries by building their scientific capacity and teaching them new techniques but it's also protecting our own health by stopping the spread of disease."

Today, with support from the NIH's National Institute of Allergy and Infectious Diseases, Daszak is launching a research hub to connect U.S. emerging disease researchers with peers in Thailand, Singapore and Malaysia. These three "economic powerhouses" have an "incredible diversity of wildlife," said Daszak. "With every species of wildlife there's a group of pathogens not yet discovered—we can discover them by getting infected or we can go out and try to find them."

Daszak believes scientists and policymakers need to stop expecting "to design our way out of every threat we detect" and begin to prevent problems through better public health measures and by taking a multidisciplinary One Health approach. "We need to better understand why diseases trickle over from animals to humans and cause outbreaks, and what behaviors need to change so we can reduce the need to scramble to produce new vaccines every 10 years."

RESOURCES

http://bit.ly/PandemicPrevention

Fogarty Fellow studies the impact of stress in South Africa

By Susan Scutti

Andrew Kim, Ph.D.

Fogarty Fellow:	2019-2020
US Institution:	Northwestern University (HBNU consortium)
Foreign Institution:	University of the Witwatersrand
Research area:	Apartheid-based prenatal stress

During the first six weeks of South Africa's pandemic lockdown, Fogarty Fellow Dr. Andrew Kim and his research team surveyed 220 Soweto adults about the mental health impacts of COVID-19. Respondents who perceived themselves at high risk of contracting the new coronavirus experienced more severe symptoms of depression, while one in four reported increased anxiety, fear of infection or "thinking too much," the researchers found.

The biological anthropologist had never conceived of such a study back in August 2019 when he moved to Johannesburg and began the groundwork for his core Fogarty project, an examination of intergenerational effects of apartheid-based prenatal stress on birth outcomes, neuroendocrine function, and mental illness risk across subsequent generations. His research is based on a 30-year longitudinal birth cohort study conducted in 1990 in Soweto at the time of the dissolution of the apartheid regime, explained Kim. The original researchers examined the effects of apartheid on 3,000 pregnant women with funding from the South African Medical Research Council. The mothers and their children now span three generations. "I am doing a follow-up on 250 mother-child pairs of the second and third generations," said Kim.

Until mid-March 2020, his follow-up study was "running strong" but then the pandemic forced a stop to the work. Disappointment soon gave way to inspiration. "I realized this is an important opportunity to assess how people are affected by something as drastic as a lockdown and global pandemic," said Kim. He hypothesized that the adversity of a pandemic would compound ongoing histories of HIV, unemployment, poverty and racism. "Growing research suggests that past experiences of stress and trauma—especially during early periods of development—predispose you to worse reactions to stress in the future as well as greater risk for mental and physical illnesses," he said. "I wrote a quick ethics revision and shifted my Fogarty project to a telephone interview basis, where we called people asking their experiences in the lockdown."

Kim's desire to continue working in South Africa despite the pandemic was also fueled by an "ethical obligation" to support his research assistants, whom he'd already trained in survey data collection, interview technique, biomarker sample collection, and project administration. During lockdown, he provided psychoeducation for his team to help them cope.

While gearing up the COVID-19 project, Kim was able to analyze existing data to see how prenatal stress from apartheid affected health outcomes intergenerationally. He discovered younger women who experienced greater levels of stress and trauma during apartheid while pregnant had children with greater levels of psychiatric morbidity at 17 years old, said Kim. "Younger maternal age and greater levels of social adversity were perpetuating a stronger association between prenatal stress and late adolescent or earlier adulthood psychiatric risk."

His Fogarty fellowship gave him new insights and helped him grow scientifically. "Doing long-term immersive research is very important when you don't know the context in which you're working and is very much a part of anthropology," said Kim. He believes his connection with other Fogarty fellows has also helped him advance scientifically through special monthly development webinars and other sessions on relevant research topics. His gratitude to Fogarty includes providing him with a greater sense of confidence and the ability to visualize a long-term career that includes global health research.

His advice for others is uncomplicated. "If you really are interested in doing this capacity building work, you have to be both patient and tenacious and know your place. You need to realize the best ways for you to assist in a context where you are a guest."

RESOURCES

http://bit.ly/andrew-kim

Q&A

ADOLFO RUBINSTEIN, MD, PHD

Dr. Adolfo Rubinstein served as Argentina's Minister of Health for two years ending in 2019 and subsequently was the founding director of his country's Center for Implementation and Innovation in Health Policies. Rubinstein is also a professor of public health and family medicine at the University of Buenos Aires and a visiting professor at Harvard. A recipient of numerous Fogarty and NIH grants, Rubinstein has published more than120 papers. His research focuses on the epidemiology and implementation of preventive interventions to control noncommunicable diseases (NCDs) and the evaluation of health programs and policies.

Please tell us about your varied career.

My journey through medicine has been a long one! I was trained as a general internist first and then moved to primary care and retrained to be a family doctor. I created a very large academic division of family medicine at one of the largest teaching hospitals in Argentina and was the chairman there for 20 years. Along with teaching, I was like the "founding father" of the Institute for Clinical Effectiveness and Health Policy, which is devoted to research and capacity building mainly in the areas of NCD research and epidemiology.

During my term as health minister, we developed programs focused on chronic diseases—not only research and training, but also implementation. For instance, we devoted a lot of our research budget to chronic disease implementation research projects. We also supported the Global Alliance for Chronic Diseases and, under this umbrella, we conducted research while forging programs at a national level to counter hypertension, diabetes and cardiovascular disease.

What was the goal of your Fogarty NCD grant?

The chronic disease burden—cardiovascular disease, cancer, diabetes, pulmonary disease and mental health problems—is trending up in Argentina as it is in the rest of the world, with NCDs accounting for more than 70% of the total disease burden. Yet we lack the professional capabilities, mainly in terms of research, to deal with this. The priority of my project was to train new researchers and young investigators and get them involved in NCD research, particularly cardiovascular problems. The most significant results are the continuing careers of the young investigators we trained—three PhDs and six master's degree students. At the same time, hundreds of people received short-term education through the faculty development program. These trainees did not come solely from Argentina, but also Uruguay, Brazil, Peru, Chile, Paraguay, Bolivia and other countries in the region. Overall, the experience was marvelous. We learned not only a lot of *things* but also a lot of *perspectives* on how to address noncommunicable disease research and teaching.

Fogarty plays such an important role for developing countries. My institution has also sponsored a lot of U.S. Fogarty fellows who came to receive training and experience in a developing country. In turn, they elevated our research standards and helped us to advance.

What research are you doing now?

Currently, I focus more on delivery science as I'm trying to bridge the gap between implementation *research* and implementation in the *real world*. I examine the streams of policy changes and the politics behind them. The center that I created in 2000 is mainly devoted to translating science into practice, which, of course, must be founded on evidence-based research. Essentially, what I'm trying to do is to interact with different stakeholders and to understand how politicians, particularly, think and how I might influence them to advance evidence-based policies. How do we inspire them to prioritize policies that reduce the NCD burden? For example, I believe front-of-package labeling for processed foods would have a direct impact on individual and population health. While minister, I worked on adopting this policy and I continue to work on this.

What should the Fogarty community consider?

I often find investigators are very far from policy. If you want your research to have impact, you have to think how policymakers think, you have to learn why they do what they do. By listening more, we will begin to have more innovative, out-of-the-box thinking in global health. One of the most important things is to bridge the worlds of research and policymaking. We have to try to bring both worlds closer together. Young investigators in global health need to understand both arenas. If you want your research to result in changes, you have to think how policymakers think.

RESOURCES

http://bit.ly/adolfo-rubinstein

Scientists describe challenges and lessons learned when conducting research in humanitarian crises

Hundreds of millions of people around the world are affected by humanitarian crises such as armed conflict, forced displacement, natural disasters and major disease outbreaks. Globally, one in six children lives in or near a conflict zone and nearly 80 million people have been forcibly displaced from their homes, according to the U.N. The frequency, intensity and complexity of these crises has steadily increased over the past several decades. Just in the past few years—as parts of the world faced hurricanes, wildfires and floods—armed conflicts continued unabated and millions of refugees remain unable to return home. On top of all of this, the world is now dealing with the deadly COVID-19 pandemic.

These crises take a staggering toll on human health, directly and indirectly, and especially in low-resource settings. Yet there is a dearth of high-quality, reliable evidence to inform the governments, non-governmental organizations (NGOs) and humanitarian groups responding to them. To bring together the diverse actors in this field, Fogarty launched an effort in 2018 called Advancing Health Research in Humanitarian Crises, managed by its Center for Global Health Studies. A meeting was convened and a steering committee was formed, representing academic institutions, humanitarian NGOs and several other NIH institutes. The overarching goals are to catalyze timely, high-quality, ethical and actionable research in humanitarian crises; and encourage uptake of evidence into the policy and practice of organizations that respond to these crises.

Fogarty and its partners are working to catalyze timely, high-quality health research in humanitarian crises and encourage evidence-based decision making in response efforts.


UN Photo/Tobin Jones

The partners agreed there are examples of high-quality, ethical and actionable studies and there is much that can be learned from this small but growing body of humanitarian health research. A call for proposals describing such examples was issued and a number were selected to be developed into case studies, which are being published as an open-access collection by the journals *Conflict and Health* and *BMC Public Health*. The projects cover several different types of humanitarian crises across diverse geographic locations, populations, diseases and health risk factors, including maternal and child health, nutrition, mental health, infectious diseases and gender-based violence.

Unlike traditional research papers, the case analyses in the collection go beyond *what* research was conducted and explain *why* the research was important and *how* it was conducted in these extremely challenging settings, the authors noted. The papers emphasize the importance of health research in the humanitarian context, provide critical analyses of the unique challenges for scientific work in these settings and share the strategies used to address them. The authors also identify scientific areas of high public health significance that can best be addressed through research in humanitarian settings.

Each case analysis follows a standardized format enabling both researchers and humanitarian actors to review lessons learned from research conducted in the field. Ultimately, the collection makes the case for why humanitarian research is integral to progress in global health and deserves greater attention from the global health research community.

The studies summarized here took place prior to the COVID-19 pandemic. Nevertheless, the experiences described are relevant as the humanitarian crises currently facing the world become more common, complex and interrelated. Additional case studies are being reviewed and a complete collection is expected to be published in spring 2021.

Resources: http://bit.ly/research-humanitarian-crises

Conducting research in a war zone

In South Sudan, the 2016 civil war led to mass displacement that severely limited access to health care, with pregnant women and newborns among the most vulnerable. Translation of newborn guidelines into public health practice, particularly during periods of ongoing violence, are not well studied during humanitarian emergencies. A research team assessed the delivery of newborn interventions in displaced person camps to understand implementation outcomes. Attacks against humanitarian aid workers required research partners to modify study plans on an ongoing basis to ensure staff and patient safety. South Sudan faced devastating cholera and measles outbreaks that shifted programmatic priorities. Costs associated with personnel travel and equipment transport kept rising due to hyperinflation. A number of strategies used to address these challenges are applicable to other humanitarian settings. These include: collaborating with non-research partners to identify operational solutions; maintaining a locally-based study team; being flexible with budgets and timelines; using mobile data collection to conduct timely data entry and remote quality checks; and deploying a cascade approach for training field staff. Engagement of national and local stakeholders can ensure health services and data collection continue and findings translate to public health action, even in contexts facing severe and unpredictable insecurity, the researchers suggested.

Providing palliative care to refugees

Another research team studied how ethically and contextually appropriate palliative care might be provided during humanitarian crises by examining refugee settings in Jordan and Rwanda. An unintended outcome of the research was lessons learned about the ethical dimensions of transnational research partnerships. Common experiences across study settings revealed the importance of building relations that are sensitive to multiple vulnerabilities and unequal power among both research partners and research participants. Also imperative is the need to create spaces that facilitate sharing of knowledge and experiences. The authors said their analysis sheds light on the importance of understanding cultural norms in all research roles, building relationships with decision makers, and developing teams that include investigators from within humanitarian crisis settings to ensure that mutually beneficial study outcomes are ethical, as well as culturally and contextually relevant.

This collection of case studies illustrates the unique challenges involved in conducting research in humanitarian crises and strategies used to address them.

UN Photo/JC McIlwaine

Studying sexual and reproductive health

Since 2017, Rohingya people have been sheltering in the refugee camps of Cox's Bazar, Bangladesh due to armed conflict in the Rakhine state of Myanmar. With half the population made up of adolescent girls and women, sexual and reproductive health (SRH) services are vital. A research team examined the population's SRH needs and barriers to care by conducting a cross-sectional survey, in-depth interviews and group discussions. They also assessed health facility readiness and supply-side difficulties. The investigators encountered three key challenges including sensitivity regarding the study topic, identification of appropriate sampling strategies and community trust issues. To overcome them, researchers actively engaged community members and gatekeepers to access respondents, identified sensitive issues through the survey and interviews, and contextually modified the sampling strategy. Another key insight reported was that including researchers from the host country may create distrust among refugee populations, which could make them reluctant to cooperate with the research team.

Natural disasters exacerbate challenges

There are a number of lessons learned from obstacles faced while undertaking field studies after natural disasters such as earthquakes and tsunamis, one research team reported. Particular issues of post-disaster settings include challenges with uncharted ethical and cultural considerations; and non-standardized methods of record keeping, data sharing and dissemination. Relying on local partners and making quick decisions to tackle issues is imperative for navigating both foreseen and unforeseen complications, they said. While pre-emptive action to address these concerns is the most efficient means to expedite research protocols, adaptability and contingency planning are key components of practical research implementation in dynamic situations. Research is not always a priority in humanitarian settings, so innovative methods are necessary to conduct meaningful and situationally appropriate research in these venues. The team suggested that hurdles to conducting research can be overcome by understanding available resources, local culture, and political considerations; and working efficiently and decisively.

Examining the lived experience of hurricanes

Two devastating hurricanes in 2017 destroyed much of Puerto Rico's residential and environmental infrastructure, displacing thousands of people and resulting in an unprecedented migration to the mainland U.S. Researchers studied the impact on survivors, both in Puerto Rico and in central Florida, a major resettlement hub. The scientists faced challenges such as the emotional distress of participants and team members, difficulty accessing affected populations and precarious environmental factors. One tool used was the Critical Medical Ecological model, which considers how a number of sociocultural, biologic, health care and natural factors impact communities, households and individuals. The researchers also collected cathartic narrative accounts of the lived experience of hurricane survivors. All participants received a pamphlet that included the contact information for mental health services. The researchers said the project demonstrates the value of pre-existing partnerships, critical consciousness in the field team and medical ecological modeling as an organizing tool to help understand the community and individual impact of environmental disasters.

Studying mental health in tsunami aftermath

The Indian Ocean tsunami in 2004 caused a major loss of life and subsequent emotional trauma for survivors. Psychosocial needs in the aftermath of this disaster were extensive, yet the cohesion and effectiveness of the response were limited due to lack of preparedness and relevant policies. One organization that responded to the crisis saw the need to study the difficulties, successes and limitations of psychosocial interventions. Since temples, mosques and churches were places that people accessed to find healing and peace, the team reported that adding mental health resources in those settings reduced stigma surrounding care and increased available services. Capacity was also bolstered by training community level workers on psychosocial intervention methods, which also provides long-term resources. Care offered to survivors included one-on-one interactions, medications from nearby hospitals and group activities. These sessions ranged from dance and music programs to role-plays, which worked well with children in particular. Video consultations with psychiatrists were also offered. Research results have informed state and national disaster response plans.

Conducting research amid armed conflict

The provision of health and nutrition interventions for women and children in conflict zones was the topic of study for research teams in Afghanistan, Mali, Pakistan and Somalia. Security was a fundamental obstacle in all study contexts, with restricted geographical access and concerns for personal safety affecting sampling and data collection plans, and requiring reliance on digital communications, remote study management and off-site team meetings wherever possible. The researchers drew several conclusions from their work. Strong local partners are essential to the success of any project, contributing not only technical and methodological capacity but also the insight needed to truly understand and interpret local dynamics. Maintaining realistic expectations of data that are typically available in conflict settings is also essential, while pushing for more resources and further methodological innovation to improve data collection. Finally, successful health research in the complex, dynamic and unpredictable contexts of conflict settings requires flexibility and adaptability of researchers, as well as sponsors and donors.

Building trust in times of unrest

Ethiopia has high numbers of people displaced by conflict, which makes both routine and humanitarian research very difficult. A team studying childhood nutrition discovered communities were suspicious of outsiders. Some reactions were so hostile that researchers were fearful about returning to some households. As a result, the team designed strategies to respond, including establishing community advisory boards using village elders and local youth. Data collection team members received training in principles of ethics, consent and crisis management, and were provided on-going support. As the researchers built trust with the community, they were regularly asked to provide relief and aid, which resulted in ethical dilemmas. Sometimes severely malnourished children were identified during data collection. The research team decided to provide medical assistance where appropriate, and transportation to and from nearby health facilities where necessary. While this can provide misconceptions if the communities believe they must participate in order to receive the other benefits, researchers decided that the children's health outweighed these concerns. Lessons learned from these studies are already being used to inform other research projects.

Conducting research in conflict zones poses unique challenges.

UN Photo/Luke Powell

Conducting research in unstable settings is challenging but vital to ensure refugee health interventions are evidence-based.

UN Photo/Tim McKulka

Studying the health of Ebola survivors

In late 2015, the Sierra Leone government established a program to improve the well-being of the country's 3,466 registered Ebola virus disease survivors. A mixed-methods study sought to determine survivors' access to health services offered, their health and disability status, and psychosocial and mental health issues faced. Qualitative data from survivors and stakeholders at multiple levels complemented and contextualized the survey results to shed light on the unique health and associated socioeconomic complexities that survivors face, which could be applied to other crisis settings. The study faced several challenges, including working in a low-resource setting marked by constantly changing priorities and activities of donors and implementers. The research aimed to measure sensitive topics, such as mental health and disability, with standardized tools that required careful contextualization for accurate reporting of findings. Flexibility is paramount when conducting high-quality research for representative and useful results, the authors noted. Timely research and ongoing sharing of the findings with stakeholders is critical to ensure that they benefit study subjects.

Determining the long-term impact of war

Globally, one in four children lives in a country affected by armed conflict or disaster, often accompanied by exposure to a range of adversities including violent trauma and loss. A study in Sierra Leone is examining the long-term effects of children's experiences in the country's eleven-year (1991–2002) civil war on their adult mental health and functioning, in addition to exploring the potential mechanisms by which intergenerational transmission of emotional and behavioral disruptions due to war trauma may operate. The research project utilizes mixed methodologies that incorporate qualitative and quantitative data to unpack risk and protective factors involved in social reintegration, psychosocial adjustment, parenting and interpersonal relationships. There are unique ethical issues posed by this type of research, the authors acknowledge, making it important to recognize the power differential that exists between scientists and vulnerable populations. Also, there is the potential for risk of suicide, physical or sexual abuse, or other harm. Researchers should anticipate and plan how to respond to these risks before their studies begin, the authors suggested. Flexibility, strong communications channels and robust partnerships are also vital to the process.

Lessons learned from research in South Sudan

Scientists evaluating health interventions among South Sudanese refugees sheltering in Ethiopia confronted a number of barriers. They faced ongoing local political and tribal conflicts, extreme weather conditions, difficulty implementing a new digital data monitoring system, the need for staff capacity building and low-literacy research subjects. Investigators noted the need for flexibility to ensure staff and participant safety, and outreach activities to find subjects who may have relocated due to safety concerns. To overcome the lack of data expertise and slow internet, data uploads were conducted at night or at partner organizations with stronger internet connections. Remote training sessions were conducted and weekly calls held to monitor progress and troubleshoot any issues. Local staff provided input to help ensure study measures and interview questions were understandable among participants, with pictorial representations developed for low-literacy respondents.

Measuring profound stress among youth

One research team measured the effectiveness of a structured psychosocial intervention designed to alleviate stress and build resilience among Syrian refugees and Jordanian host-community youth. The scientists overcame significant obstacles to implement the study. It was difficult to establish a fair and transparent randomization process for research subjects and challenging to collect biological samples and test cognitive skills in difficult field conditions. Also, the team had to reconcile different demands and timeframes for dissemination of results in peer-reviewed academic journals vs. influential policy reports. They discovered it was important to develop a strong sense of local ownership through engagement with communities, and to rely on local partners to recruit and track participants. Researchers discovered young people were keen to participate in the study, viewing it as cutting-edge science and a means to tell their stories. They also appreciated toiletries offered as compensation for their time, in addition to professional hair styling as part of the sample collection to measure stress by testing cortisol levels.

By Dr. Roger I. Glass, Director, Fogarty International Center

Hoping for a healthier and more equitable future

As I take stock at the beginning of a new year and a new U.S. administration, I am hopeful that we are on our way toward reducing COVID-19's terrible toll and entering a period of healing and reconciliation.

We have all been touched by the pandemic and grieve for those we have lost, and those who continue to suffer. But I believe we are resilient and that there is some cause for optimism. In record time, we have seen the development of vaccines, diagnostics and treatments that are much needed if we are to bring this awful pandemic under control. It is difficult to comprehend the horrendous death toll—well over 2 million lives lost and rising. But the investments made to develop vaccines and affordable, speedy diagnostics are beginning to pay off, thanks to the hard work and dedication of NIH and extramural scientists.

In early January, it was shocking to watch the violent attack on our nation's Capitol, the heart of our democracy. But I was heartened to witness the peaceful transfer of power two weeks later and the return to what I hope will be a government where science is valued and supported, and data and evidence play a role in decision making. It is also encouraging to see the U.S. is reclaiming its role in the global community, rejoining the Paris climate accord, honoring commitments and working in partnership with the WHO, and expressing renewed interest in collaborating with African nations to advance discoveries and improve health for all. I was delighted that the contributions of NIH are valued by the new Administration and that Dr. Francis S. Collins will remain NIH director and Dr. Tony Fauci has been invited to advise on COVID-19. I'm grateful for their continued strong leadership and deep support for global health research and training.

The coronavirus pandemic has laid bare the inequities in our health systems—both at home and abroad. There is much hard work ahead for all of us. It is imperative that we dig deeper into the fundamental causes of disparities to understand contributing factors and identify possible effective interventions. At Fogarty, we are examining how we can improve diversity among our staff and in the global health research workforce.

The vaccines against COVID-19 provide hope the pandemic can be tamed.

We continue to consider how we can support efforts to decolonize and democratize global health research and have begun informal consultations with members of our community to determine what Fogarty can do to be part of the solution. It is a complex problem but I am encouraged by the enthusiastic response from our constituents and the creative ideas that have been suggested already. I welcome your thoughts and will depend on your support as we move forward with this endeavor.

I'm also excited that the NIH Common Fund initiative to build data science in Africa has received such a robust response and look forward to awards being issued later this year. There is tremendous potential for this program that was developed to meet the need for data analysis expertise in Africa, which was requested by African scientists and will be African-led.

I remain inspired by the Fogarty staff and my NIH colleagues as we continue to navigate this largely virtual world. I look forward to the day we can again travel the globe, strengthening our existing connections and forming new partnerships. In the meantime, NIH offers us all a beacon of hope.

RESOURCES

http://bit.ly/roger-glass-health-equity

PEOPLE

Zimbabwean scientist Hakim has died

University of Zimbabwe professor and Fogarty grantee Dr. James Hakim has died from COVID-19. Hakim was principal investigator of his country's Medical Education Partnership Initiative (MEPI) award and chaired the MEPI PI Council for several years. He was also a member of the UNAIDS expert committee on HIV/AIDS.

Fogarty grantee Katzenstein is lost to COVID

Stanford University professor emeritus Dr. David Katzenstein died after contracting COVID-19 while on a visit to Zimbabwe. His long connection with the country began in 1986, when he was a lecturer at the University of Zimbabwe. He was PI on numerous NIH grants for HIV/AIDS research and training, including several from Fogarty.

Walensky appointed to lead US CDC

President Joe Biden has named Dr. Rochelle Walensky to direct the U.S. CDC. Walensky was previously chief of infectious diseases at Massachusetts General Hospital and a professor at Harvard Medical School. She received her M.D. from Johns Hopkins University and her MPH from Harvard. The appointment does not require Senate confirmation.

Cameron will direct global health at NSC

Dr. Elizabeth Cameron is returning to the U.S. National Security Council as senior director for global health security and biodefense, the Biden Administration has announced. She held the same position in the Obama Administration and helped launch its Global Health Security Agenda. Cameron holds a Ph.D. in biology from Johns Hopkins University.

Karim, Fauci receive honors for defending science

Drs. Salim S. Abdool Karim and Anthony Fauci have been awarded the 2020 John Maddox Prize for standing up for science during the coronavirus pandemic. Abdool Karim, a longtime Fogarty grantee, is an infectious diseases epidemiologist in South Africa. The prize is presented by the charity Sense about Science and the journal *Nature*.

Fauci, director of NIH's National Institute of Allergy and Infectious Diseases, serves on the U.S. coronavirus task force and was appointed President Biden's chief medical adviser on COVID-19. He has also won the $1 million Dan David Prize for defending science, advocating for coronavirus vaccines and for his leadership of HIV/AIDS research.

Global HEALTH Briefs

WHO issues genomic sequencing guide

The growing global investment in applying genomic sequencing to rapidly diagnose, monitor and track the evolution of SARS-CoV-2 has spurred the WHO to release guidance on how to maximize these efforts. The publication includes practical considerations for implementing genomic sequencing programs and an overview of public health objectives.
Website: http://bit.ly/WHOgenomic

Refugees' survey shows COVID impact

The COVID-19 pandemic has had a highly negative impact on the living and working conditions of refugees and migrants, according to a WHO study. Of the more than 30,000 refugees and migrants around the world who were surveyed, more than half reported greater levels of depression, fear, anxiety and loneliness.
Full report: http://bit.ly/WHOrefugees

Measles cases, deaths continue global rise

In 2019, global measles cases increased to over 860,000 and deaths rose to more than 207,000, according to a report jointly issued by the U.S. CDC and the WHO. Measles deaths have steadily increased by 50% since achieving a record low in 2016. Insufficient vaccination of the world's children is to blame, the study said.
Full report: http://bit.ly/GlobalMeasles2019

Toolkit launched to combat TB

WHO and TDR have developed an interactive web-based toolkit that supports national tuberculosis programs and other partners to conduct implementation research designed to evaluate digital technologies for TB care. The resource guides users through the steps to conceptualize, budget and prepare for an IR study.
Website: http://bit.ly/WHO_TBtoolkit

WHO reveals leading causes of death

Noncommunicable diseases now make up seven of the world's top 10 causes of death, according to the WHO's Global Health Estimates report, which provides data from 2000 to 2019. Heart disease remains the number one killer, while diabetes and dementia have now entered the top 10.
Full report: http://bit.ly/WHOdeaths

Funding Opportunity Announcement	Deadline	Details
International Research Scientist Development Award K01 Independent Clinical Trial Required K01 Independent Clinical Trial Not Allowed	Mar 9, 2021	http://bit.ly/IRSDAK01
Japan Society for the Promotion of Science (JSPS) Fellowships for U.S. Postdoctoral Scientists in Japan	Mar 31, 2021	http://bit.ly/JSPSforUS
International Bioethics Training R25 Clinical Trial Not Allowed D43 Clinical Trial Optional	Jun 4, 2021	http://bit.ly/BioethicsTraining
Global Infectious Disease (GID) Research Training Program D43 Clinical Trials Optional	Aug 3, 2021	http://bit.ly/IDtraining
Fogarty HIV Research Training for LMIC Institutions D43 Clinical Trial Optional D71 Clinical Trial Not Allowed G11 Clinical Trial Not Allowed	Aug 20, 2021	http://bit.ly/NIHGlobalHIV

For more information, visit **www.fic.nih.gov/funding**

Global Health Matters

January / February 2021
Volume 20, No. 1 ISSN: 1938-5935

Fogarty International Center
National Institutes of Health
Department of Health and Human Services

Managing editor: Ann Puderbaugh
Ann.Puderbaugh@nih.gov

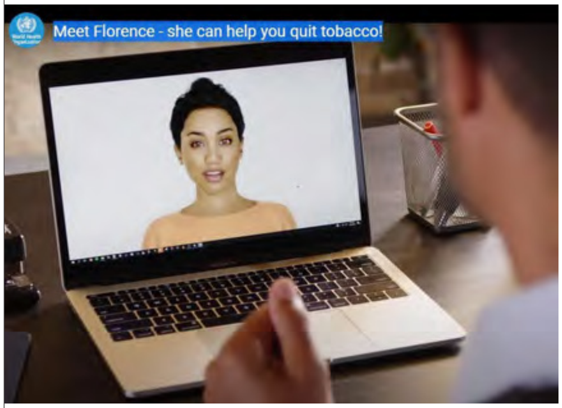
Web manager: Anna Pruett Ellis
Anna.Ellis@nih.gov

Writer/editor: Susan Scutti
Susan.Scutti@nih.gov

Designer: Carla Conway

SUBSCRIBE:
www.fic.nih.gov/subscribe

WHO offers tobacco users 100 reasons to quit



WHO's tobacco cessation campaign includes Florence, a digital health worker, who is available 24/7 to answer questions and direct users to resources.

Image courtesy of the WHO

The WHO has launched a year-long "Commit to Quit" campaign to encourage the 780 million people worldwide who say they would like to stop using tobacco. The effort is intended to help create healthier environments that are conducive to quitting tobacco by advocating for strong tobacco cessation policies, increasing access to cessation services, raising awareness of tobacco industry tactics and empowering tobacco users to make successful quit attempts through "quit & win" initiatives.

Quitting tobacco is challenging, especially with the added social and economic stresses that have come as a result of the pandemic, the WHO noted. "Smoking kills 8 million people a year, but if users need more motivation to kick the habit, the pandemic provides the right incentive," said WHO Director-General, Dr. Tedros Adhanom Ghebreyesus.

WHO released a scientific brief recently showing that smokers are at higher risk of developing severe disease and death from COVID-19. Tobacco is also a major risk factor for noncommunicable diseases like cardiovascular disease, cancer, respiratory disease and diabetes.

RESOURCE

More information: http://bit.ly/WHOquit

Delaware Foundation Reaching Citizens

Anthony Glenn, Ed. D
Executive Director, Delaware Foundation Reaching Citizens

DFRC, the Delaware Foundation Reaching Citizens with intellectual disABILITIES, was born in 1956 when two Delaware sports enthusiasts, Jim Williams and Bob Carpenter, Jr., decided that an all-star football game would be a popular opportunity for high school students to compete and, at the same time, raise funds for services to support people with intellectual disABILITIES. There were nationwide fundraising drives for other causes, but not much was being done for people who were intellectually challenged. From that simple beginning, Mr. Williams and Mr. Carpenter could not have dreamed this cause would expand and develop into all it is today, altering the thoughts and attitudes of people throughout Delaware. The DFRC family is dedicated to our mission to enrich the lives of Delawareans with intellectual disABILITIES. We are dedicated to raising funds and consciousness through quality events to support enrichment programs so that all Delawareans with intellectual disABILITIES can maximize their potential, independence, and enjoyment of life.

Today, 66 years strong, we have learned a great deal, most significantly recognizing that we are people first, and our ABILITIES and disABILITIES are merely a part of who we are. We are all *differently-abled* and each life that comes into the world has great meaning and purpose. Over time, the objective of the DFRC Blue-Gold Football Program has evolved to include, not only raising funds, but also focusing on awareness about ABILITIES. We all want to be recognized for whatever our ABILITIES allow us to accomplish. We all want to have friends and be involved, included, and respected. DFRC strives to provide opportunities to learn from each other and translate those lessons into ways that create a meaningful impact in the world.

In the DFRC Blue-Gold Football Game Program, each high school in Delaware is asked to select exceptional individuals in their school community who are upstanding citizens with integrity and good character to represent their school. These participant football players, ambassadors, cheerleaders and band members are offered the opportunity to be paired with a child or young adult who has an intellectual disABILITY, their buddy. This matching, the DFRC Blue-Gold Hand-in-Hand Program, was added to the DFRC Blue-Gold All-Star Football Program in 1974, and it is truly the heart of everything we do. The Hand-in-Hand Program helps raise awareness about ABILITIES and also enriches the DFRC Blue-Gold experience for participants, buddies, and their families by providing them an opportunity to nurture relationships. We've learned that while seeking to provide for people with intellectual disABILITIES, our buddies shine through and teach us all valuable life-lessons of love and dignity for everyone. The DFRC Blue-Gold All-Star Football Program involves more than 150 volunteers, 250 participants, and 125 buddies and their families who come together from across the entire state to celebrate one of Delaware's finest traditions.

In addition to funds raised by DFRC's Blue-Gold Football Game, DFRC sponsors six other awareness and fundraising events: the Blue-Gold Northern Golf Classic, Blue-Gold Southern Golf Classic,
Blue-Gold Sussex Auction, Blue-Gold 5K Run/Walk, Blue-Gold Bash, and the Blue-Gold Online Auction. In our 66-year history, DFRC has distributed $6.3 million to support programs and services throughout Delaware involving advocacy, research, education and training for people who are intellectually challenged. DFRC receives grant requests annually, which the Beneficiaries Committee reviews and makes funding recommendations. The Board of Trustees considers those recommendations and determines final grant funding awards. The DFRC family is very proud of the work being accomplished throughout the state of Delaware by our efforts and those of our beneficiaries.

The endeavors of DFRC are led by our Executive Director and supported by the DFRC Trustees, office staff and dedicated volunteers who embody a profound sense of family.

doi: 10.32481/djph.2021.03.010

CORONAVIRUS
(COVID-19)

PLAY SAFELY

- Wash your hands or use hand sanitizer.
- Wear a mask.
- Stay home if you're sick.
- Physically distance when possible.

de.gov/coronavirus

CORONAVIRUS
(COVID-19)

PICKING UP KIDS FROM CHILD CARE?

WEAR A MASK

PROTECT YOUR NEIGHBORS

#MaskUpDE

de.gov/coronavirus

Created 6/24/2020

Let's Talk About Sex: Sex and Relationship Education for People with Intellectual Disabilities

Isabella Weber, M.P.H. & Izzy Kaufman, M.Ed.
Planned Parenthood of Delaware

THE CRITICAL IMPORTANCE OF SEX EDUCATION FOR ALL

Sex education empowers people to make informed and healthy choices about their bodies and their relationships, but it is often not available or accessible for people with intellectual disabilities. All people, including people with intellectual disabilities, deserve full access to medically accurate and shame-free information about sex and relationships. All people deserve to have their questions about sexuality answered without judgment. All people deserve the opportunity to develop the skills they need to protect their health. Comprehensive sex education helps people avoid negative health outcomes; communicate better with parents, partners, and medical providers on sexuality topics; understand healthy and unhealthy relationships; have autonomy over their bodies; respect others' bodily autonomy; and show respect for people regardless of sexual orientation or gender identity.[1] Despite the evidence of the positive effects of sex education, only 30 states and the District of Columbia require sex education to be taught in schools, only 21 of those require information about contraception to be included, and only 10 require education on sexual consent.[2]

MYTHS SURROUNDING SEXUALITY AND DISABILITY

The barriers to comprehensive sex education for people with intellectual disabilities are significant, and contribute to the lack of sex education for this population. They are sometimes denied access, have limited access, or receive inadequate sex education in school. Misperceptions held by caregivers, professionals, and our society perpetuate negativity around disability and sexuality and result in limited access to sex education. Reviews of the literature by Sinclair et al. and Campbell indicate that many parents and caregivers believe that people with intellectual disabilities are asexual, which feeds the myth that this population has no need for sex education.[3,4] However, people with intellectual disabilities report dissatisfaction with their single relationship status and actively desire relationships.[5] The myth of asexuality does not align with how people with intellectual disabilities see themselves. Another common myth is that people with intellectual disabilities are hypersexual or overtly sexual in public, when in fact, they often have not received any education on the difference between public and private behaviors.

Due to societal myths, teachers, parents, and/or caregivers often believe that sex education is inappropriate for people with intellectual disabilities, that they will not understand the content, or that they are not sexual and therefore have no need for the information. Whittle and Butler found that people with intellectual disabilities want to discuss sexuality with care staff, but care staff are unequipped or unwilling to discuss the topic.[5] This leaves people with intellectual disabilities with few opportunities to discuss sexuality with those closest to them. In schools, health educators may lack the training needed to teach to students with intellectual disabilities, while special education instructors may lack the training needed to teach sex education.[6] This limited access to sex education infringes on the right of people with intellectual disabilities to access sexual health information and denies them the tools and skills they need to independently care for their sexual health. This creates barriers to developing positive and pleasurable sexual and/or romantic relationships. Comprehensive sex education empowers people to make informed and healthy choices about their bodies and their relationships.

SEX (POSITIVE) EDUCATION AND SEXUAL SELF-ADVOCACY

Many sex education programs and curricula for people with intellectual disabilities focus heavily on the prevention of sexually transmitted infections, pregnancy, and sexual assault,[7] or focus solely on sexual assault prevention.[8] While information about prevention and safety is important, comprehensive sex education includes much more. Comprehensive sex education covers the full range of human experience related to our sexual self and sexual relationships with others. It includes care for our bodies, accessing accurate sexuality information, decision-making about our bodies, and how we feel inside our own skin. Comprehensive sex education includes to whom we are attracted and with whom we want to experience intimacy. It includes talking about sexual feelings and how people respond to sexual feelings. It also includes understanding sexual violence and how past experiences of violence affect us.

People with intellectual disabilities experience sexual assault at rates seven times that of people without intellectual disabilities.[9] They are victimized at higher rates in part because they are more likely to have others help them with day-to-day necessities such as bathing and dressing. This provides perpetrators of abuse and assault with the opportunity to groom for abuse and to be in a private space with the person while their body is exposed.[9] Comprehensive sex education addresses these topics by discussing appropriate touch; private vs. public spaces and touches; information about sexual abuse and assault; and what to do if someone makes you uncomfortable or violates

doi: 10.32481/djph.2021.03.011

your boundaries. Research suggests that comprehensive sex education, which includes skill building around refusal of unwanted sex, may be an effective strategy for preventing sexual assault[10] and increasing the likelihood of reporting any potential violation.

Sex education provides people with the skills to refuse unwanted touch, and more importantly, teaches people how to respect others' boundaries and practice affirmative consent. People must be taught to ask for consent to touch, to listen to the answer, and to respect the answer. People need to learn that if they do not have enthusiastic, freely given, informed and specific consent for each touch, they must not engage in that touch. All people need the information and skills to understand and practice consent, to recognize red flags in a relationship, and to advocate for their body and their rights. While sexual violence prevention is an important component of sex education, ultimately, comprehensive sex education must be sex positive. This means that the overarching goal of education is to learn how to have pleasurable, healthy, mutually supportive, consensual, and responsible sexual relationships with oneself and others. For many people with intellectual disabilities, their understanding of sex and sexuality is through a lens of sexual violence or past trauma. Sex positive education teaches that people can and do heal from past trauma and that sexuality can be pleasurable, safe, healthy, and consensual.

Individuals with intellectual disabilities in the U.S. are still living in a society that does not fully accept their rights, desires, and needs. The self-advocacy movement in the disability community redirects the focus to empowering the individual to reach their goals in a way that is accessible to them. Self-advocates speak for themselves and make their own decisions. Sexual self-advocacy enables people with intellectual disabilities to make informed decisions about sexuality and relationships in their own lives. Everyone has sexual rights and responsibilities both individually and when interacting with others. These rights include the right to privacy; the right to be curious about sexuality; to ask questions and have them answered; and to make their own decisions about whether, when, and with whom they want to pursue a romantic relationship.[11] Sexual self-advocacy should be included in comprehensive sexuality education programs for people with intellectual disabilities.

SEX EDUCATION FOR PEOPLE WITH INTELLECTUAL DISABILITIES IN DELAWARE

For over 10 years, Planned Parenthood of Delaware (PPDE) has been providing a variety of sex education and professional training for people with intellectual disabilities, their parents and caregivers, and the professionals who support them. We do this with support from the Delaware Division of Developmental Disabilities Services, the Delaware Developmental Disabilities Council, and the Planned Parenthood Federation of America. We provide tailored sex education lessons for individuals and groups, and workshops to build confidence and skills for parents and caregivers to have open discussions about sexuality with their loved ones. We also have a support group for LGBTQ+ adults with intellectual disabilities to learn sexual health information, advocacy skills, and build their social networks. In addition, we provide training for disability-serving professionals to build their understanding and confidence in supporting people with intellectual disabilities in their sexuality and relationship goals.

In 2019, we developed a sex education curriculum for people with intellectual disabilities entitled "You're in Charge: A Customizable Sex and Relationship Education Program for Self-Advocates with Intellectual and Developmental Disabilities."[12] The curriculum is divided into two parts: Unit 1, Your Sexuality, contains basic sex education on anatomy and reproduction, sexual health, puberty changes, public vs. private, sexual identity, sexual feelings, masturbation, and sexuality explicit media. Unit 2, Sexuality with a Partner, includes lessons that address healthy relationships, dating (including online dating), consent, safer sex practices, and sexual self-advocacy. The curriculum is designed to be taught by one educator to one student so that the learning experience is entirely customizable. The curriculum features positive and diverse representations of people with disabilities including illustrations of people with mobility devices and physical disabilities.

The curriculum uses multiple pedagogical methods to meet the diverse learning needs of people with intellectual disabilities. Plain language is used throughout the curriculum, handouts, and activities, so that the information is accessible. Mixed teaching methods are used to meet the diverse needs of learners. For example, the section on lesbian, gay, bisexual, transgender, and queer (LGBTQ+) inclusivity features illustrated handouts with definitions; opportunities for brainstorm; a video from Rooted in Rights (a disability justice organization based in Washington State); online resources; and a role-play to practice the experience of coming out. These mixed method lessons keep the learner engaged by ensuring the content is accessible, personal, and applicable to real life.

The goal of our programs and curriculum are to empower people with intellectual disabilities to advocate for their sexual lives, to pursue romantic relationships if they choose, and to learn the information needed to make the choices that are best for them. When people with intellectual disabilities are fully included in the sex education classroom and have access to sex-positive, comprehensive sex education, they can acquire the information and skills needed to be sexually healthy self-advocates.

ADDITIONAL RESOURCES

Elevatus Training curriculum and professional development: https://www.elevatustraining.com/

National Council on Independent Living sex education videos for and by people with IDD: https://ncil.org/sex-ed-for-individuals-with-i-dd/

REFERENCES

1. Bridges, E., & Hauser, D. (2014). Sexuality Education: Building an evidence- and rights-based approach to healthy decision making. Advocates for Youth. Retrieved from: https://www.advocatesforyouth.org/resources/fact-sheets/sexuality-education-2/
2. Guttmacher Institute. (2021). Sex and HIV Education. Retrieved from: https://www.guttmacher.org/state-policy/explore/sex-and-hiv-education
3. Sinclair, J., Unruh, D., Lindstrom, L., & Scanlon, D. (2015). Barriers to sexuality for individuals with intellectual and developmental disabilities: A literature review. *Education and Training in Autism and Developmental Disabilities*, *50*(1), 3–16.
4. Campbell, M. (2017). Disabilities and sexual expression: A review of the literature. *Sociology Compass*. https://doi.org/10.1111/soc4.12508
5. Whittle, C., & Butler, C. (2018, April). Sexuality in the lives of people with intellectual disabilities: A meta-ethnographic synthesis of qualitative studies. *Research in Developmental Disabilities*, *75*, 68–81. https://doi.org/10.1016/j.ridd.2018.02.008
6. Shearer, N. (2019). Sexual health education for individuals with disabilities: A call to action. Nevada Today. Retrieved from: https://www.unr.edu/nevada-today/news/2019/sexual-health-for-individuals-with-disabilities
7. Plunkett, S., & Laganà, L. (2012). The controversies surrounding the sexuality education of people living with developmental disabilities. in Handbook on Sexuality: Perspectives, Issues and Role in Society. Edited by N. Peterson and W. Campbell. Nova Science Publishers
8. Wacker, J., Macy, R., Barger, E., & Parish, S. (2009, August). Sexual assault prevention for women with intellectual disabilities: A critical review of the evidence. *Intellectual and Developmental Disabilities*, *47*(4), 249–262. https://doi.org/10.1352/1934-9556-47.4.249
9. Shapiro, J. (2018). The Sexual Assault Epidemic No One Talks About. Retrieved from: https://www.npr.org/2018/01/08/570224090/the-sexual-assault-epidemic-no-one-talks-about
10. Santelli, J. S., Grilo, S. A., Choo, T. H., Diaz, G., Walsh, K., Wall, M., . . . Mellins, C. A. (2018, November 14). Does sex education before college protect students from sexual assault in college? *PLoS One*, *13*(11), e0205951. https://doi.org/10.1371/journal.pone.0205951
11. Sandman, L., Arnold, K., Bolyanatz, L., Friedman, C., Saunders, C., & Wickey, T. (2014). In My Voice: Sexual Self-Advocacy. Sexuality and Disability Consortium, University of Illinois at Chicago Department of Disability and Human Development. Retrieved from: https://www.elevatustraining.com/wp-content/uploads/2017/04/SexualSelf-Advocacybook.pdf
12. Planned Parenthood of Delaware. (2019). You're in charge. Retrieved from: https://www.plannedparenthood.org/planned-parenthood-delaware/local-training-education/purchase-sex-education-program

ChristianaCare's Center for Special Health Care Needs

ChristianaCare's Center for Special Health Care Needs is a medical home for many patients and families with intellectual/developmental disability. Early in the pandemic, when day programs closed like schools, many were home without a routine. Many suffered the acute loss of essential therapies and skills. Many were isolated, alone, and in crisis. Social workers Laurie McNamara and Kim Prinski started a weekly support group early in the pandemic as a direct result of listening to caregivers and realizing that peer support and innovation was just as important as professional. This session met by zoom weekly, living by the mantra "If you are brave enough to share, we are brave enough to listen". The caregivers wanted to share how the support group has evolved to be one part advocacy, one part group think tank, and equal parts love.

https://christianacare.org/services/primarycare/center-special-health-care-needs-primary-care/

ChrsitianaCare has been running community vaccination events since February 2021. As Delaware moved to stage 1c for COVID-19 vaccination including both adults age 16-64 with a chronic medical condition, and the unpaid caregiver, Christiana was ready to expand their community events to include these important groups. Planning a mass vaccination event for patients and families from the Center for Special Health Care Needs took a bit of extra thought to ensure comfort and success. The Caregiver support group noted above and volunteer services collaborated with the Center to plan such an event Friday March 19. Volunteers were told that many of the patients would not speak for themselves, but that they had many ways of telling the volunteer how they felt. Addressing the patient directly was paramount. So too was preparing for all sorts of noises as patients celebrated being out of the house. Vaccinator's were told to be swift and confident and to use a variety of tools for needle anxiety and distraction, from Buzzy to sensory tiles, to bubble wrap. Patients were told to stomp the sensory tile while getting their shots and a quiet room was available for those who needed it. Pacing and jumping the line were all facilitated for those who needed to move. Stations were prepared to have wheelchairs and other equipment table side, and a drive through option was utilized when needed. Many patients and families celebrated their joy and relief! One family mentioned that the event was a reset to thinking the hospital was a safe place once again.

ChristianaCare™

Special Olympics is a Viable Well-Being Choice for Healthcare Providers' Patients with Intellectual Disability

Jon Buzby
Director, Unified Champion Schools, Special Olympics Delaware

The mission of Special Olympics Delaware is to provide sports training and athletic competition in 19 sports for more than 4,200 children and adults with intellectual disabilities. The program is provided at no cost to the athletes.

Yet, the positive impact on the athletes' lives is far greater than just the thrill of victory. The number of physical, emotional and social benefits the athletes gain during their participation in the program expands far beyond any number of medals won.

It all starts with a focus on being a healthy person off the field in order to maximize potential on it.

The Centers for Disease Control and Prevention (CDC) states that people with intellectual disabilities (ID) – difficulty with thinking, learning, remembering, and reasoning – experience poorer access to quality health care and have poorer health outcomes than people without ID.[1] For instance, people with ID are more likely to have difficulty receiving quality healthcare services, often receiving fewer preventive checkups such as cancer screenings.[2,3]

The passive healthcare that people with ID frequently receive is often a result of there being a minimum amount of formal training in medical schools for how to care for patients with ID, along with communication gaps that can occur between patient and provider.

Special Olympics, in collaboration with the CDC, has created a worldwide all-inclusive health movement through its Healthy Communities and Healthy Athletes programs.[4,5] The Healthy Athletes program provides athletes with needed screenings – vision, hearing, dental and podiatry (*figures 1-3*) in Delaware – and also gives medical professionals hands-on experience screening people of all ages with ID (*see figure 4*). Imagine the difference for a runner if now they can compete pain-free or a softball player who, for the first time, can see the ball as soon as it leaves the pitcher's hands. Soccer teammates can hear each other better while communicating on the field, and that painful tooth is no longer a distraction to the athlete on the bocce court.

The result of the findings from these screenings further encouraged the organization to create additional programs focused on fitness, nutrition and other components that contribute to one's healthy lifestyle.

This is just the first step in creating a holistic, healthy Special Olympics athlete, so that each can then reap the same benefits as those who participate in sports who do not have disabilities.

- *Physical benefits:* Weekly sports-specific practices combined with additional fitness opportunities and offseason training enable athletes to improve their cardiovascular endurance.
- *Emotional benefits:* Research has shown that when people are successful, they feel emotionally better about themselves. Success on the fields and in the gyms gives the athletes confidence, which then contributes to their performance in school or work.
- *Social benefits:* For many of our athletes, the highlight of their week is gathering for practice. It's there that they socialize with their friends, without any inhibition.
- Despite all the plusses to belonging to the organization, there are thousands of people with intellectual disabilities who are still "on the sideline;" not engaged, and not reaping the healthy lifestyle benefits the organization provides.

> *"Inclusion in sports with its tenants of team and physical fitness readily makes its way into the healthcare arena. An empowered Special Olympics athlete who enters my office is a healthier patient. I continue to encourage all of my patients to increase physical activity. Special Olympics just makes that a safe, fun, effective and easy option for me to recommend in my busy office for athletes, Unified partners and volunteers."- Jennifer LeComte, DO, FACP, FAAP; Director, Rowan Integrated Special Needs (RISN) Center; Division Chief of General Internal Medicine, RowanSOM/ Department of Medicine*

For some it's by choice. But for the majority, it is because they and their caregivers are not aware of the program, or at least do not realize that the person in their care is eligible, because the stereotype still exists that Special Olympics is for children with Down Syndrome who run on a track.

Special Olympics offers sports programs for people of every athletic ability, and therefore is a very viable choice for any person whose physician or healthcare worker recommends that they "get more exercise" or become "more active" for their physical, social and emotional well-being.

REFERENCES

1. Centers for Disease Control and Prevention. (2020, Sep 16). CDC and special Olympics: inclusive health. Retrieved from: https://www.cdc.gov/ncbddd/disabilityandhealth/features/special-olympics-heroes.html
2. Krahn, G. L., Hammond, L., & Turner, A. (2006). A cascade of disparities: Health and health care access for people with intellectual disabilities. Mental Retardation and Developmental Disabilities Research Reviews, 12(1), 70–82. https://doi.org/10.1002/mrdd.20098
3. Krahn, G. L., Walker, D. K., & Correa-De-Araujo, R. (2015, April). Persons with disabilities as an unrecognized health disparity population. American Journal of Public Health, 105(Suppl 2), S198–S206. https://doi.org/10.2105/AJPH.2014.302182
4. Special Olympics. (2021). Inclusive health. Retrieved from: https://www.specialolympics.org/our-work/inclusive-health
5. Special Olympics. (2021). Healthy athletes. Retrieved from: https://www.specialolympics.org/our-work/inclusive-health/healthy-athletes

doi: 10.32481/djph.2021.03.012

Figure 1. Dental Screening

Figure 2. Vision Screening

Figure 3. Podiatric Screening

Figure 4. General Medical Screening

Health Checks for Care

Margot West
Student Intern, Delaware Academy of Medicine/Delaware Public Health Association

INTRODUCTION

I have volunteered for Meals on Wheels in its Newark Delaware location for over four years. What started as a way to gather community service hours before medical school quickly became one of my favorite volunteer experiences. The entire workplace has a great outlook on their non-profit program. From the numerous volunteers, to the cooks, and the administrative staff, everyone involved was so welcoming and had the same objective: to serve and help seniors unable to care for themselves. After being assigned a regular weekly route and getting to know each of my 10-14 clients, I noticed some common themes. Often, clients would voice certain issues regarding their health, talking about the medications they were on, worsening health issues, and concerns about the in-home care that they were receiving. Homebound, most clients have little social interaction throughout the day, with their daily meal deliveries being (at times) the first chance they get to talk to another person. As I was just a volunteer, I realized I could only listen to their concerns and advise them to go to someone else for help. As many clients are unwell and possess worsening health issues, a good number of the clients on my original route four years ago are no longer with us. After seeing several clients that I came to see as friends pass away, I began to wonder if there was a possible way to use this scheduled meal delivery time to further help the clients. What if there was a way to track the changing health of clients and catch the warning signs of major health issues like strokes or heart attacks? Could checking in on clients to make sure they were getting the best care for their specific situations help them to live longer and happier lives? During my internship at the Delaware Academy of Medicine/Delaware Public Health Association, I decided to study this further. I developed the plan *Health Checks For Care* during my internship to help answer these questions and provide help to the aging population of Newark.

LITERATURE REVIEW

Introduction

Meals on Wheels is a community-based service that delivers fresh meals directly to the homes of seniors and individuals with disabilities who are unable to purchase or prepare their own meals. Since its inception as a demonstration project in 1968 and its establishment by Congress in 1972, Meals on Wheels America supports more than 5,000 community-based senior nutrition organizations across the country. This network serves virtually every community in America and, along with more than two million staff and volunteers, enables America's seniors to live their lives with independence and dignity.[1]

Approximately 90 percent of older people want to stay in their communities, rather than move to institutionalized care. "The fear of having to enter a nursing home, with its associated loss of independence and threat of impoverishment, weighs heavily on the minds of many older persons and their caregivers," former American Association of Retired Persons (AARP) Senior Vice President Joyce A. Rogers stated in a letter to lawmakers.[2] Food programs like Meals on Wheels help save money on medical costs and strengthen independence for seniors. "The changing demographics of our country are such that we have to devote more resources, become more innovative and pay more attention to issues that affect older Americans" Senator Susan Collins, chairwoman of the Senate Special Committee on Aging, purposed when reflecting on the need for increased funding to senior citizen wellbeing.[2] With screening for malnutrition and the strengthening of programs for meals brought to homes, meal delivery can greatly combat isolation and help seniors in achieving better health outcomes.

The Newark Delaware Meals on Wheels location serves around 140 seniors each day out of the Newark Senior Center. Meals On Wheels Delaware (MOWD) provides financial resources to this program, and supports another four meal-delivery locations statewide. The average Delaware resident receiving meals is in their late 70s, and often lives alone. The MOWD webpage details that, "Many are struggling to balance their needs on a fixed income, and are unable to shop or prepare a hot meal for themselves. Most meals are a long-term lifeline."[3] In 2018, more than a thousand individuals volunteered their time to deliver meals for this organization in Delaware, while another 150 individuals volunteered to fundraise for these programs. In 2018, close to 700,000 meals were delivered statewide to over 4,600 seniors. The MOWD organization itself is greatly involved within the community, sponsoring various initiatives around Delaware by hosting auctions, health walks, game nights and other events all around the state to benefit Delaware residents in need.

Programming

Despite the mounting evidence that the trusted Meals on Wheels model is associated with improvement in overall health and well-being among older adults, funding for these vital programs has not kept pace with growing demand. This has resulted in millions of fewer meals provided, thousands of seniors going unserved, and the growth of waiting lists for services. Meals on Wheels America has set out to validate that Meals on Wheels delivers so much more than just a meal.[4] A newly published study confirms another benefit of visitors knocking on the doors of seniors in need: a significant reduction in their feelings of loneliness. Kali Thomas, an assistant professor at Brown University School of Public Health, analyzed data from a randomized, controlled trial in which more than 600 study participants in eight cities who were on Meals on Wheels waiting lists were either given access to daily fresh meal delivery, weekly frozen meal delivery, or simply remained on the waiting list as a control group.[5] The study staff interviewed seniors in all three groups at the beginning of the 15-week study and again at the end so they could measure how the seniors' responses changed. At the beginning of the study there were no statistically significant differences among the three study groups in their relative degree of loneliness. More than half lived alone, 14 percent reported having no one to call on for help, and 20 percent had contact with friends and family less than once or twice a month. Both groups receiving meal deliveries showed a reduction in self-reported feelings of loneliness to a statistically

doi: 10.32481/djph.2021.03.013

significant degree, compared to not receiving delivery. Daily recipients were three times more likely than weekly recipients to indicate that home-delivered meal service helped them feel less lonely. The study is one of the first randomized, controlled trials to assess the effect of meal delivery on loneliness, which has been linked by many studies to an increased risk of functional decline and death,[6] emergency department visits,[7] and nursing home placement.[8] This research has also shown that daily meal deliveries help seniors' mental health and ease their fears of being institutionalized. Thomas also estimated that if all states increased the number of older people receiving these meals by one percent, they would save more than $100 million.[5]

Previously Launched Programs

In 2019, The Gary and Mary West Health Institute, Meals on Wheels America, and a research group in the Brown University Center for Gerontology and Healthcare Research collaborated on a two-year research program called *More Than a Meal Phase 3*. This program investigates opportunities to improve the well-being of homebound seniors by integrating health and safety screenings into daily meal delivery services. It was conducted within select major cities, with the main objective being of standardizing reporting mechanisms and improving communication with healthcare providers to prevent an adverse health event. The assessment helps to identify a participant's health, safety and social needs such as loneliness, depression or fall risk. By providing volunteers with simple screening tools and user-friendly technology to perform check-ins on participants, the study was designed to improve care coordination across the medical and home community, informing providers and caregivers of changing conditions before health events occur.[9] This program has its limitations. With close partnership to a major health institute and funding provided by Brown University, only a small portion of struggling senior citizens could benefit from this unique program. Standardizing these reporting mechanisms and making the program as cost-effective as possible is essential to expand this program to a nation-wide level.

This program is similar to what Meals on Wheels America has done in partnership with Johns Hopkins Bayview Medical Center and Meals on Wheels of Central Maryland in 2019. Formally called *Together in Care,* the program aimed to keep seniors at home and reduce their need for costly health services specifically after hospitalization. Trained volunteers reported red flags and ensured that patients were following physician's health advice (for example, that patients with congestive heart failure are weighing themselves regularly and eating properly). Specifically, program participants received daily delivery of meals, an in-home safety assessment, help with removing any hazards or completing minor repairs or modifications, and a monthly visit from a care manager and phone calls between visits. Dan Hale, who lead this project from the Johns Hopkins Bayview Medical Center, explained that the meal delivery volunteers can help track patients' health even months after discharge and keep them from returning to the hospital: "It ultimately makes sense financially."[10] This program has some limitations, as it was sponsored and funded on a limited basis, and thus free meals and health visits were only provided for three months for participants.

These two highlighted programs are not uncommon. Meals on Wheels America and several other local programs around the country have launched partnerships with insurers, hospitals and health systems. By reporting to providers any physical or mental changes they observe, volunteers can help improve seniors' health and reduce unnecessary emergency room visits and nursing home placements. "It is a small investment for a big payoff," said Ellie Hollander, CEO of Meals on Wheels America.[11] Visitors from Meals on Wheels can be the only people some seniors see all day. The volunteers get to know them and can quickly recognize problems. "You notice if they are losing weight, if their house is a mess, if they are talking awkwardly," said Chris Baca, executive director of Meals on Wheels West in Santa Monica. "Our wellness check is critical. We know we are keeping people out of the hospital, seven dollars a day is cheaper than $1,300 a day."[12] After reviewing the information, research, and prospected programs regarding Meals on Wheels and their unique relationship with seniors in need, it is proposed that a similar program to *More than A Meal: Phase 3* and *Together in Care*, called *Health Checks For Care*, be conducted in the Newark Delaware location.

THE THEORY OF PLANNED BEHAVIOR

To implement this program, volunteers must be willing to participate, and attention to the theory of planned behavior will be needed. Originally coined as the theory of reasoned action in 1980, the Theory of Planned Behavior is used to predict an individual's intention to engage in a behavior at a specific time and place. The theory is intended to explain all behaviors over which people have the ability to exert their own control. The key component to the planned behavior theory is behavioral intent, or the likelihood that a person will engage in a certain behavior. Behavioral intentions are influenced by the attitude about the likelihood that the behavior will have the expected outcome, and the subjective evaluation of the risks and benefits in participating in that behavior.[13] Since *Health Checks For Care* targets the behaviors of the volunteers specifically, a change in attitudes and a knowledge of expected outcomes by the volunteers is required for success.

To implement *Health Checks For Care*, cooperation between the staff, volunteers, and participants is imperative. Volunteers must complete the required coursework to successfully conduct wellness checks and change their usual routine to include these checks. They must also report back any and all findings to the facilities staff members after their deliveries. The theory of planned behavior can be referenced when viewing this change in the regular dynamic between volunteer delivery driver and client. Volunteers will have to shift their behaviors and attitudes towards their clients. Volunteers in Newark are accustomed to their regular routine and have certain attitudes towards the clients with whom they have developed relationships. Often, volunteers have been delivering meals to the same clients for years, developing a rigid behavioral pattern over time. They expect certain behaviors to generate certain outcomes, and, because of the theory of planned behavior, may not want to partake in the suggested program that requires them to change these behaviors.

Changing the routine of volunteers already donating their time to volunteer work is essential for conducting wellness checks, but will be difficult to change. Volunteers may feel uncomfortable with reporting what they see as they deliver to clients, as this could feel like a breach of privacy. They may also be less inclined to guide clients towards healthy living habits because this goes beyond their original training and the comfortable routine they have grown accustomed to. Taking time from their day to learn more about how to spot red flags in clients' homes and how to operate the given screening tools may also feel like too much work, since volunteers deliver with no cost incentive. Often, volunteers themselves are retired from work and spend their mornings delivering as a leisurely way to give back to the community. The wellness checks and health screenings need to be easy for volunteers to conduct without them feeling like they are going the extra mile for no reason.

To combat the challenges presented, *Health Checks for Care* will be geared towards appropriately educating volunteers and reminding them of how valuable their roles are for the success of this program. The training required will be on the volunteer's own time, and presented in a way that is convenient and easy to learn, creating a seamless transition into their delivery drives. There will be no "time limits" on the completion of training, and volunteers will be informed about the main purpose of the program before starting training. This will likely cause more volunteers to participate, as the program will be flexible to the schedules of volunteers. Volunteers can opt out of participating, and will only be instructed to give paper surveys to participants who have already agreed to being in the program, in an effort to make survey delivery as seamless as possible. With this, they won't feel forced into a new, unforeseen behavior, and more volunteers will be willing to participate. The volunteers will be informed of easy ways to incorporate wellness checks into even a thirty second interaction with clients, and may learn how their own role is vital in preventing adverse health events with the clients with whom they have developed lasting relations.

HEALTH CHECKS FOR CARE

Logistics

The *Health Checks for Care* plan will conduct wellness checks on existing MOW clients being served from the Newark Senior Center location. Similar plans have been launched by the West Health Institute (*More than a Meal*) and the Johns Hopkins Bayview Medical Center (*Together in Care*). Both projects aim to keep seniors at home and reduce their need for costly health services after hospitalization. The plan proposed for the Newark Delaware location focuses on using elements from these two projects to uniquely target Delaware residents. Trained volunteers will use their interactions with often isolated senior citizens to report red flags and conduct a monthly wellness check as they deliver meals. *Health Checks for Care* will become the "eyes and ears" of health providers, specifically benefitting clients who suffer from chronic illnesses or do not have family nearby. The Newark location can standardize reporting mechanisms and improve communication with primary healthcare providers to prevent adverse health events in seniors already benefiting from daily meals.

In this program, basic health information recorded via paper survey will be sent to primary health physicians for interpretation through the Delaware Health Information Network (DHIN). This program does not rest specifically on monitoring participant health after major surgery (like *Together in Care*), but rather targets warning signs of major health changes, in an effort to "catch" health problems before they arise (similar to *More Than A Meal: Phase 3*). To appropriately conduct this program, certain aspects of the two highlighted programs will be incorporated. First, it should be recognized that both programs had affiliations with hospitals (John Hopkins Bayview Medical Center and The Gary and Mary West Health Institute). This affiliation is vital, as standardizing how various primary care physicians view and interpret the given healthcare surveys is vital for program success. As a public health initiative, this operation will operate on a tier system, where medical surveys will be completed by participants, returned by Meals on Wheels volunteers, assorted by the Meals on Wheels office staff, and sent electronically to the participant's primary health physician for interpretation. To create a secure and easily accessible outlet for survey results, the DHIN could be utilized, as participant surveys can be retrieved on a patient portal by Delaware physicians. An association with a large healthcare institution like ChristianaCare will be imperative for the program's success. Arranging a partnership with an institution will ensure that participants with primary care physicians affiliated with the hospital will receive adequate care based on their survey outcomes. Once affiliated with an institution, physicians with patients within the program will be instructed to take survey questions into consideration, and, if the information is deemed alarming, will request that a participant come in for a visit. This system will help to ensure that ominous "warning signs" of potential health risks will not go unnoticed, as improved communication with healthcare providers can prevent an adverse health event

Methods

The Institutional Review Board (IRB) is an administrative body established to protect the rights and welfare of human research subjects. As *Health Checks for Care* uses participant's health survey answers, IRB approval will be needed. The University of Delaware has IRB protocol review and approval procedures geared towards their institution.[14] If this program is lead under the University of Delaware, research will be registered on IRBNet and must be sponsored by a faculty advisor before IRB approval. As training in the protection of human subjects in research is required, volunteers for this project will complete the Collaborative Institutional Training Initiative (CITI) Program, and training completion certificates will be linked in IRBNet for IRB review submission. Informed consent from research participants will be obtained and properly documented by the use of written consent forms before a survey is administered.

For this program to be successful, the consideration and execution of HIPAA (Health Insurance Portability and Accountability Act) guidelines, as well as proper medical research methodology, must be properly followed. Volunteers will undergo training on human research etiquette (PHRP or CITI training) before becoming a part of this program. Survey responses can be considered as a participant's own personal medical information, therefore volunteers within the program must be instructed on HIPAA guidelines and regulations. Each participant will be randomly assigned a number upon program agreement and this number will be listed on their survey as the only identifier. A survey will be given to patients once a month with this identifier, and the patient will seal the survey in an envelope without the help of the volunteer. From there, other volunteers trained in human research etiquette within the MOW office will input the information into the DHIN using the patient's identifier and using a secure password. Participants will be made aware of this entire process by signing a consent form detailing this procedure in order to enter the program. Volunteer drivers will not be allowed to view the participants' answers, and will be instructed to help participants only if clarification is needed, but under no circumstance will they aid in helping them answer any questions. Once these surveys have been uploaded, written responses will be immediately shredded.

Survey Instrument

As the program's main initiative is to watch for warning signs and symptoms of potential health risks in senior citizens, questions will be centered around evaluating overall changes in health. This survey (*see Tables 1-5*) will address common issues that could be aided by the assistance of a primary healthcare provider (e.g. need for a nursing aide, blood testing, psychiatric consult, or even additional medical equipment). The American Family Physicians Journal recommends the geriatric assessment to assess the health of patients 65 years and older. This validated survey is a multidimensional, multidisciplinary assessment designed to evaluate an older person's functional ability, physical health, cognition and mental health, as well as socio-environmental circumstances. Specific elements of physical health that are evaluated include nutrition, vision, hearing, fecal and urinary continence, and balance. This questionnaire is unique in that it includes nonmedical domains by emphasizing functional capacity and quality of life. Determining the most suitable living arrangements for older patients is an important function of the geriatric assessment. This assessment usually yields a more complete and relevant list of medical problems, functional problems, and psychosocial issues.[15] Validated previously within a more general aging population, the geriatric assessment will be monitored and could potentially be found to be a valid assessment of the health of the Meals on Wheels population. This questionnaire will be given to participants monthly, and changes to question responses will be tracked by physicians to "catch" potential health problems before an incident occurs. The Geriatric Assessment has some functional limitations. The full breadth of this assessment includes some medical instruction, a physical screening, and a lab test. As volunteers are administering this assessment in the homes of participants, the Geriatric Assessment will be limited to its survey outcomes. Based on the outcomes of the surveys, physicians may suggest further testing for their individual clients.

The Geriatric Assessment targets activities of daily living, cognitive capacity, hearing, independence, and nutritional health. These questions are taken from the Mini Cognitive Assessment, Activities of Daily Living, Hearing Handicap Inventory, and Nutritional Health Checklist parts of the Geriatric Assessment.[15] These survey components were acquired by utilizing all of the questionnaires from the original assessment that is specifically targeted towards an aging population. The Nutritional Health Checklist and The Activities of Daily Living surveys have been adapted to prevent participant self-scoring. Each portion will be divided into separate sheets of paper, with the Mini-Cognitive Assessment Instrument being the only survey conducted with the volunteer's involvement (as they must say words for the participant to repeat). This process will be HIPAA approved, as volunteers conducting the Mini-Cognitive Assessment will write down the three words used and their repeated results on the survey's envelope. The clock drawn for this assessment will also be illustrated on the envelope by the participant, and this will be the final step in the Mini-Cognitive Assessment. As all results will be written on the envelope, volunteers will not have access to survey outcomes themselves.

DISCUSSION

Health Checks for Care can be implemented well within the confines of the Meals on Wheels food delivery system. Volunteers within this program already have closely developed relationships to their clients; utilizing their scheduled visits to document their client's well-being is both time-effective and free. By implementing an already researched Geriatric Health Assessment, costs for the program will be restricted to the costs of volunteer research training and a purposed partnership with a healthcare institution like ChristianaCare. However, a program like *Health Checks for Care* has the potential to substantially lower healthcare costs around Newark and the State of Delaware, by keeping seniors out of the hospital and reducing their need for costly health services. If care is taken in creating and implementing this program, and these highlighted key elements are considered, the clients of Meals on Wheels in Newark, Delaware can benefit greatly from these public health services.

Limitations

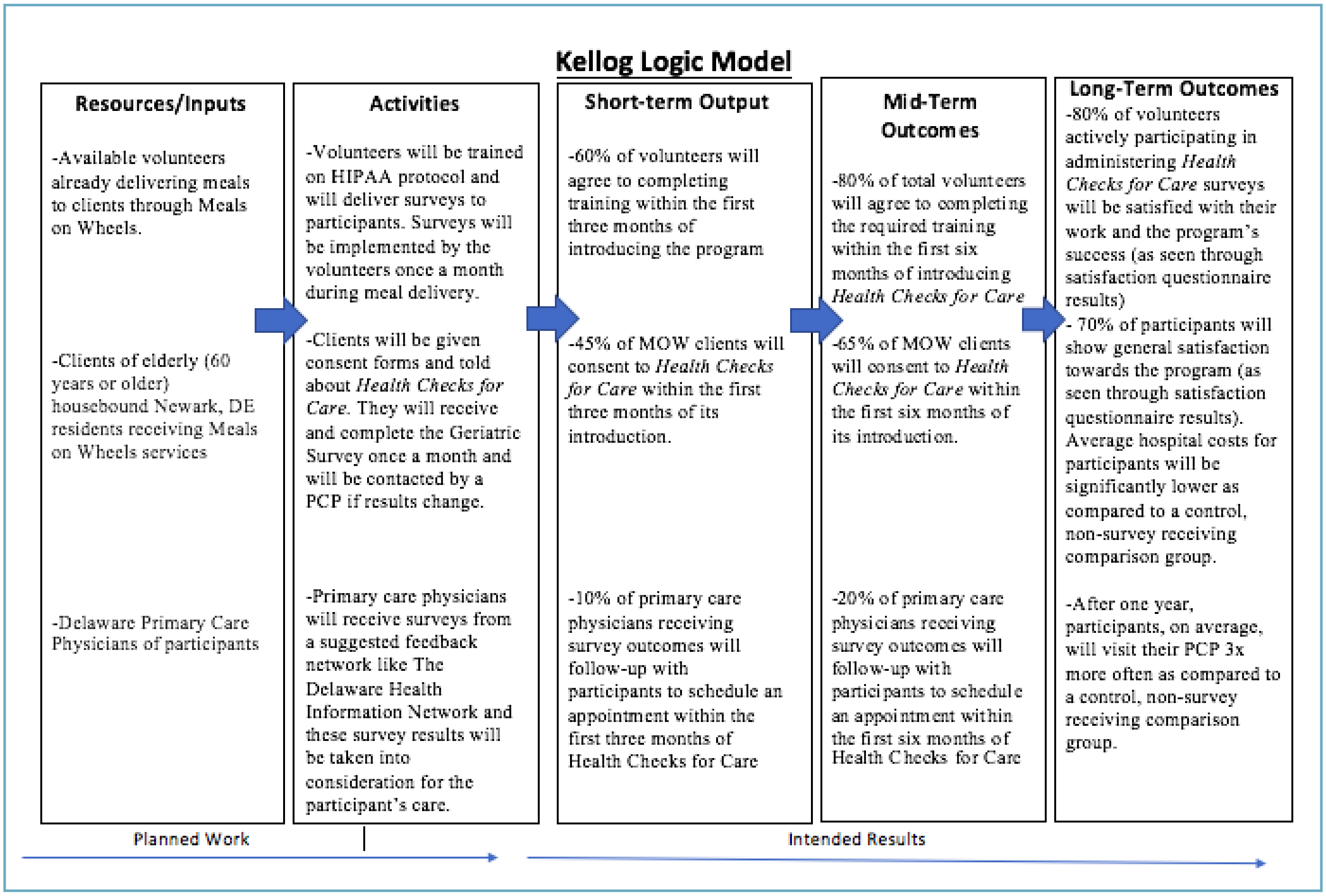
Possible limitations to *Health Checks for Care* include attaining the support and agreement of primary care physicians, volunteers, and participants, as all respective groups will need to be in agreement with program expectations for its success. Health checks will be conducted using only paper surveys, so limitations could also arise due to a lack of response or even biases in participant responses. As the Geriatric Assessment formally utilizes a physical exam to determine geriatric health, relying on its survey response components could limit the breadth of the assessment's effectiveness. Another limitation could be the survey's length and how long it will take for participants to complete. For the first six months of *Health Checks for Care*, volunteers will deliver the full survey and expect it to be completed fully. If survey responses aren't completed to the fullest, or if participants refuse to comply in completing the surveys length, surveys can be sent out by volunteers and then subsequently picked up later in that week.

Further Research

To combat these limitations, further research could focus on recruiting medical personnel to volunteer in conducting these wellness checks. With this, survey responses would not be a participant's only form of health check-in, and participants can stay in their homes to receive medical advice. Another area of further research could rely on crafting a health assessment that targets MOW participants specifically. This area of research could focus on targeting the common health issues of the typical MOW participant, and create an assessment that "catches" all health concerns tailored specifically to this population.

LOGIC MODEL

Health Checks For Care uses the Kellogg Logic Model for program evaluation. The Kellogg Logic Model (*see Figure 1*) initiates and completes outcome-oriented evaluation, providing practical assistance to a presented program. On a broader scale, a logic model is also a graphic depiction or a road map for a given project, presenting shared relationships among resources, activities, outputs, outcomes, and impacts. This road map simplifies results, and depicts a relationship between a program's description and its intended effects.



Kellog Logic Model

Resources/Inputs	Activities	Short-term Output	Mid-Term Outcomes	Long-Term Outcomes
-Available volunteers already delivering meals to clients through Meals on Wheels.	-Volunteers will be trained on HIPAA protocol and will deliver surveys to participants. Surveys will be implemented by the volunteers once a month during meal delivery.	-60% of volunteers will agree to completing training within the first three months of introducing the program	-80% of total volunteers will agree to completing the required training within the first six months of introducing *Health Checks for Care*	-80% of volunteers actively participating in administering *Health Checks for Care* surveys will be satisfied with their work and the program's success (as seen through satisfaction questionnaire results)
-Clients of elderly (60 years or older) housebound Newark, DE residents receiving Meals on Wheels services	-Clients will be given consent forms and told about *Health Checks for Care*. They will receive and complete the Geriatric Survey once a month and will be contacted by a PCP if results change.	-45% of MOW clients will consent to *Health Checks for Care* within the first three months of its introduction.	-65% of MOW clients will consent to *Health Checks for Care* within the first six months of its introduction.	- 70% of participants will show general satisfaction towards the program (as seen through satisfaction questionnaire results). Average hospital costs for participants will be significantly lower as compared to a control, non-survey receiving comparison group.
-Delaware Primary Care Physicians of participants	-Primary care physicians will receive surveys from a suggested feedback network like The Delaware Health Information Network and these survey results will be taken into consideration for the participant's care.	-10% of primary care physicians receiving survey outcomes will follow-up with participants to schedule an appointment within the first three months of Health Checks for Care	-20% of primary care physicians receiving survey outcomes will follow-up with participants to schedule an appointment within the first six months of Health Checks for Care	-After one year, participants, on average, will visit their PCP 3x more often as compared to a control, non-survey receiving comparison group.

Figure 1. Health Checks for Care Logic Model

In *Health Checks for Care,* the resources needed are already plentiful and cost little to acquire. Volunteers perform as drivers and deliver meals to participants through the organization. They have a set driving route and have previously developed relationships with their elderly clientele. *Health Checks for Care* seeks to use this already established system as a resource, with other desk and office volunteers to input these wellness checks and upload them to a patient's electronic medical record at no cost to the program. The Meals on Wheels clientele are often homebound, have little to no social contact throughout the day, and are not generally able to cook meals for themselves. Meals on Wheels participants are ideal candidates to receive wellness checks, as participants may not have anyone to advise them on healthcare, drive them to doctors' appointments, or properly monitor their changing health issues. Primary care physicians will receive these patient surveys and take the results into consideration for the participant's care.

Another key part of the *Health Checks for Care* Logic Model is the intended results section of proposed research, which includes the identification of outputs, outcomes, and impacts. The outputs of this partnership with Meals on Wheels can be financially computed with estimations, as the program's key goal is to keep seniors out of the hospital or from having an adverse health event. A control matched population of clients not receiving wellness checks could be monitored for costly health events or hospital stays and labeled as a comparison group. This comparison group could be tracked for a year's time to compare the average healthcare costs of Meals on Wheels clients with and without *Health Checks for Care,* as well as their average amount of visits to a primary care physician each year. Another key output is participant satisfaction. Interviewing the participants about the effectiveness of these wellness checks would be an important output of this plan. The outcomes, or participant benefits of this proposal can potentially be substantial, as catching health warning signs and keeping participants out of the hospital would likely reduce their insurance costs, keep them living independently, and even save their lives if warning signs of major health concerns are caught and monitored. The greater impacts of this proposal, if all intended results are met, could be widespread, as Meals on Wheels is a nationwide organization. If other cities with a large network of primary care physicians and a hub of available volunteers were to get on board with this proposal, communities across the U.S could see great financial and health benefits from conducting these wellness checks.

DISCUSSION OF INTERNSHIP

During my experience interning with the Delaware Academy of Medicine, I became aware of the vast complexities of writing a formal research proposal. One of my most challenging experiences was simply choosing a topic to pursue, as I found that narrowing down options was much harder than I originally thought. After thinking about my time volunteering, it became clear that I wanted to utilize my experience to seek out possible ways to improve the Meals on Wheels non-profit program. With help and guidance, I realized quickly that looking into the logistics of other programs and seeing how they implemented improvements to MOW branches was a great way to get started. Something I was fascinated to learn is how different a research proposal is from the standard college paper. Taught previously by some professors to use ostentatious wording in an effort to sound "smart," I was surprised to find that research proposals did not operate in the same way. I believe that drafting this proposal has taught me to be more succinct in the wording of sentences, yet broad in the coverage of material. I will definitely be using the tools I've learned grammatically to better my writing in the future.

This experience has also taught me a lot about my own interest in public health. I've become much more aware of how the public health system operates, and all the hard work that goes into making programs, like my own, come to life. As I am in the process of applying to medical schools, conducting research on the overall complexities of the aging population's health has also proved enlightening. After my research, it became clear how a person's health is not merely physical, but covers a broad spectrum of areas that I hope to one day take into consideration as a physician. I am excited to utilize all the new skills and information I have learned to benefit after my internship.

REFERENCES

1. Meals on Wheels National Office. (2019). Learn more. Retrieved from: https://www.mealsonwheelsamerica.org/learn-more/national
2. Lytle, T. (2019, April 05). Funding is set to expire for the Older Americans Act. Retrieved from: https://www.aarp.org/politics-society/advocacy/info-2019/older-americans-act-funding.html
3. Meals on Wheels Delaware. (2020). About us. Retrieved from: https://mealsonwheelsde.org/about-us/
4. Medicare Claims Analyses. (2017). Retrieved from: https://www.mealsonwheelsamerica.org/learn-more/research/more-than-a-meal/medicare-claims-analyses
5. Thomas, K. S., Akobundu, U., & Dosa, D. (2015). More than a meal? A randomized control trial comparing the effects of home-delivered meals programs on participants' feelings of loneliness. The Journals of Gerontology Series B: Psychological Sciences
6. Shankar, A., Mcmunn, A., Banks, J., & Steptoe, A. (2011). How do loneliness and social isolation impact behavioral and biological health in older adults? PsycEXTRA Dataset. https://www.doi.org/10.1037/e513892012-009
7. Molloy, G. J., McGee, H. M., O'Neill, D., & Conroy, R. M. (2010, August). Loneliness and emergency and planned hospitalizations in a community sample of older adults. *Journal of the American Geriatrics Society*, *58*(8), 1538–1541. https://doi.org/10.1111/j.1532-5415.2010.02960.x
8. Russell, D. W., Cutrona, C. E., de la Mora, A., & Wallace, R. B. (1997, December). Loneliness and nursing home admission among rural older adults. *Psychology and Aging*, *12*(4), 574–589. https://doi.org/10.1037/0882-7974.12.4.574
9. Climax, M. (2019, May 02). West Health Institute launches exciting research study with Meals. Retrieved from: https://www.westhealth.org/press-release/west-health-institute-launches-exciting-research-study-meals-wheels-brown-university/
10. McQuay, J. (2019, June 27). Community Partnerships. Retrieved from: https://www.hopkinsmedicine.org/johns_hopkins_bayview/community_services/service_called_to_care/community_partnerships.html
11. O'Dowd, P., & Paris, F. (2019, December 20). Senior nutrition programs get $30M more in funding next year. Meals on Wheels America CEO says that's still not enough. Retrieved from: https://www.wbur.org/hereandnow/2019/12/20/meals-on-wheels-food-insecurity-funding-seniors
12. Gorman, A. (2017, January 10). Meals On Wheels wants to be the 'eyes and ears' for hospitals, doctors. Retrieved from: https://khn.org/news/meals-on-wheels-wants-to-be-the-eyes-and-ears-for-hospitals-doctors/
13. LaMorte, W. (2009, September 9). Behavioral change models. Retrieved from: http://sphweb.bumc.bu.edu/otlt/MPH-Modules/SB/BehavioralChangeTheories/BehavioralChangeTheories3.html
14. University of Delaware. (2015). Human subjects in research. Retrieved from: http://www1.udel.edu/research/preparing/irbnet-ataglance.html#tab-2
15. Elsawy, B., & Higgins, K. E. (2011, January 1). The geriatric assessment. American Family Physician, 83(1), 48–56. https://pubmed.ncbi.nlm.nih.gov/21888128/

SURVEY INSTRUMENT TABLES

Table 1.
The Lawton IADL Scale
For each question, circle the points for the answer that best applies to your situation.

1. Can you use the telephone?	
Without help	3
With some help	2
Completely unable to use the telephone	1
2. Can you get to places that are out of walking distance?	
Without help	3
With some help	2
Completely unable to travel unless special arrangements are made	1
3. Can you go shopping for groceries?	
Without help	3
With some help	2
Completely unable to do any shopping	1
4. Can you prepare your own meals?	
Without help	3
With some help	2
Completely unable to prepare any meals	1
5. Can you do your own housework?	
Without help	3
With some help	2
Completely unable to do any housework	1
6. Can you do your own handyman work?	
Without help	3
With some help	2
Completely unable to do any handyman work	1
7. Can you do your own laundry?	
Without help	3
With some help	2
Completely unable to do any laundry	1
8a. Do you use any medications?	
Yes (If "yes," answer question 8b)	1
No (If "no," answer question 8c)	2
8b. Do you take your own medication?	
Without help (in the right doses at the right time)	3
With some help (take medication if someone prepares it for you or reminds you to take it)	2
Completely unable to take own medication	1
8c. If you had to take medication, could you do it?	
Without help (in the right doses at the right time)	3
With some help (take medication if someone prepares it for you or reminds you to take it)	2
Completely unable to take own medication	1
9. Can you manage your own money?	
Without help	3
With some help	2
Completely unable to handle money	1

Note: Scores have meaning only for a particular patient (e.g., declining scores over time reveal deterioration). Some questions may be sex-specific and can be modified if needed.

Table 2.
Katz Index of Independence in Activities of Daily Living

Independence YES=INDEPENDENT NO=DEPENDENT	YES	NO
Bathing	Bathes self completely or needs help in bathing only a single part of the body, such as the back, genital area, or disabled extremity	Needs help with bathing more than one part of the body, getting in or out of the bathtub or shower; requires total bathing
Dressing	Gets clothes from closets and drawers, and puts on clothes and outer garments complete with fasteners; may need help tying shoes	Needs help with dressing self or needs to be completely dressed
Toileting	Goes to toilet, gets on and off, arranges clothes, cleans genital area without help	Needs help transferring to the toilet and cleaning self, or uses bedpan or commode
Transferring	Moves in and out of bed or chair unassisted; mechanical transfer aids are acceptable	Needs help in moving from bed to chair or requires a complete transfer
Fecal and urinary continence		Is partially or totally incontinent of bowel or bladder
Feeding	Gets food from plate into mouth without help; preparation of food may be done by another person	Needs partial or total help with feeding or requires parenteral feeding

Table 3.
Nutritional Health Checklist

STATEMENT	YES	NO
I have an illness or condition that made me change the kind or amount of food I eat.		
I eat fewer than two meals per day.		
I eat few fruits, vegetables, or milk products.		
I have three or more drinks of beer, liquor, or wine almost every day.		
I have tooth or mouth problems that make it hard for me to eat.		
I don’t always have enough money to buy the food I need.		
I eat alone most of the time.		
I take three or more different prescription or over-the-counter drugs per day.		
Without wanting to, I have lost or gained 10 lb in the past six months.		
I am not always physically able to shop, cook, or feed myself.		

Note: The Nutritional Health Checklist was developed for the Nutrition Screening Initiative. Read the statements above, and circle the “yes” or “No” column for each statement that applies to you.

0 to 2 = You have good nutrition. Recheck your nutritional score in six months.

3 to 5 = You are at moderate nutritional risk, and you should see what you can do to improve your eating habits and lifestyle. Recheck your nutritional score in three months.

6 or more = You are at high nutritional risk, and you should bring this checklist with you the next time you see your physician, dietitian, or other qualified health care professional. Talk with any of these professionals about the problems you may have. Ask for help to improve your nutritional status.

Table 4.
Screening Version of the Hearing Handicap Inventory for the Elderly

QUESTION	YES	SOMETIMES	NO
Does a hearing problem cause you to feel embarrassed when you meet new people?	_____	_____	______
Does a hearing problem cause you to feel frustrated when talking to members of your family?	______	______	______
Do you have difficulty hearing when someone speaks in a whisper?	______	______	______
Do you feel impaired by a hearing problem?	______	______	______
Does a hearing problem cause you difficulty when visiting friends, relatives, or neighbors?	______	______	______
Does a hearing problem cause you to attend religious services less often than you would like?	______	______	______
Does a hearing problem cause you to have arguments with family members?	______	______	______
Does a hearing problem cause you difficulty when listening to the television or radio?	______	______	______
Do you feel that any difficulty with your hearing limits or hampers your personal or social life?	______	______	______
Does a hearing problem cause you difficulty when in a restaurant with relatives or friends?	______	______	______
Raw score (sum of the points assigned to each of the items)			

Table 5. Mini-Cognitive Assessment Instrument

Step 1. Ask the patient to repeat three unrelated words, such as "ball," "dog," and "window."

Step 2. Ask the patient to draw a simple clock set to 10 minutes after eleven o'clock (11:10). A correct response is drawing of a circle with the numbers placed in approximately the correct positions, with the hands pointing to the 11 and 2.

Step 3. Ask the patient to recall the three words from Step 1.

One point is given for each item that is recalled correctly. Scoring will be done by Meals on Wheels office volunteer.

Interpretation:

NUMBER OF ITEMS CORRECTLY RECALLED	CLOCK DRAWING TEST RESULT	INTERPRETATION OF SCREEN FOR DEMENTIA
0	Normal	Positive
0	Abnormal	Positive
1	Normal	Negative
1	Abnormal	Positive
2	Normal	Negative
2	Abnormal	Positive
3	Normal	Negative
3	Abnormal	Negative

Protect Against COVID-19.

I GOT MY
COVID-19
VACCINE!

A safe and effective vaccine to protect against COVID-19 is now available.

Learn how you can get a COVID-19 vaccine.
cdc.gov/coronavirus/vaccines

What 2020 Taught Us about the Politics and Teaching of Public Health

Erin Knight, Ph.D., M.P.H. and Corinne Bogan
University of Delaware

ABSTRACT

The COVID-19 pandemic has illuminated the critical need to make greater investments in public health and build the capacity of the public health workforce. Among the professional competencies needed to address the ongoing morbidity and mortality associated with COVID-19, as well as other current and future public health challenges, is the ability to effectively engage in the political process. While we acknowledge that public health institutions and workers are under-resourced and are grateful for their tireless efforts to control the pandemic, we argue that their efforts have been severely hampered by a notable absence from politics. We argue that our ability to protect and promote public health has been further challenged by divisive political rhetoric from the former presidential administration, which has amplified a culture of self-interest and individualism. Such values are counter to public health and threaten our ability to address the disproportionate impacts of COVID-19 on low-income communities and communities of color, along with the myriad of health inequities experienced by marginalized communities in the US. We assert that public health professionals must be better equipped and supported in their efforts to challenge powerful majorities that have generated such unhealthy and unequal social and environmental conditions. Policy change related to social determinants of health should be an integral component of our intervention strategies and political advocacy should be considered a core competency for training future public health professionals. The field needs professionals comfortable and adept at working within the political sphere; students are eager for skills that allow them to translate their passion for social justice in health; and the persistent and pervasive health inequities experienced by marginalized communities demand such action.

INTRODUCTION

Most of us can agree that 2020 was a year unlike any in our recent memory, characterized by a range of domestic and global challenges affecting our health, economy, environment and even our democracy. Among 2020's litany of challenges, the COVID-19 pandemic obviously stands out has having particular relevance for public health. We argue that the global pandemic provides important, if not new, lessons for health professionals. While much has already been written about this, including for example, the need to invest in public health infrastructure[1] and the need for better coordination across jurisdictions,[2] we present lessons related to the politics of COVID-19.We argue that staying within the confines of the science of public health without paying appropriate attention to both politics and policy is not sufficient; further, it will stunt our ability to promote health equity. We believe that many of the lessons to be learned from the past year related to the interplay of politics, social justice and science are not new[3–5]; but rather, that the events of 2020 and the magnitude of health inequities and their structural precursors that have been exposed by the pandemic,[6,7] call for increased urgency to apply those lessons. While we recognize that health has always been political,[5] the devastation associated with COVID-19, especially in communities of color, coupled with the Trump administration's influential disregard for science[8] and ethnonationalist rhetoric,[9] have created a particularly polarized environment for addressing health inequities[7,8] which requires an enhanced set of competencies for public health professionals. Specifically, public health professionals of the future must be equipped to engage more fully with the political process in order to reduce ongoing morbidity and mortality associated with COVID-19, and to address other current and future public health challenges. This commentary evolved from a graduate Master of Public Health (MPH) class assignment and represents the combined perspective of a first-year MPH student and her instructor.

DISPROPORTIONATE IMPACTS OF COVID-19

As many have argued, COVID-19 has exposed persistent inequities that have systematically undermined the physical, social, economic, and emotional health of minority populations within the US. The disproportionate burden of COVID-19 on vulnerable communities, especially Black, Indigenous and people of color (BIPOC),[10] should be of no surprise to public health professionals; the economic and health insecurities magnified by COVID-19 have existed for decades and a concerted effort to address them is long overdue. With this in mind, we believe public health professionals must do more to protect at-risk communities from COVID-19. In the short-term, this includes securing protective equipment for essential workers and BIPOC who are less likely to have the privilege of working from home[11]; expanding testing, contact tracing, and healthcare services (including vaccination) in low-income neighborhoods with overcrowded apartments and high rates of homelessness; and extending the national moratorium on evictions. Public health professionals must also advocate on behalf of the incarcerated population, approximately 40% of which is Black, despite the fact that African Americans make up just 13% of the overall population.[12] Personal protective equipment should be secured for correctional facilities and inmates as social distancing is not possible. Additionally, states should consider policies to release nonviolent inmates, particularly those that are medically compromised, to mitigate inevitable and uncontrollable outbreaks.

INDIVIDUALISM, NATIONALISM AND HEALTH INEQUITIES

While important, the aforementioned strategies are merely Band-Aids, and do not address the years of lacking upstream investment in the country's social and economic system.[13] More important is the need for the public health sector to lead targeted efforts to address

doi: 10.32481/djph.2021.03.014

the structural racism that underlies the pervasive and persistent health inequities experienced by BIPOC in the US. Documenting inequities, describing social determinants of health, and developing upstream interventions is necessary but insufficient. As the Black Lives Matter protests of 2020 (and the events that precipitated them) remind us, good intentions are not enough, and we must do more to actively dismantle racist policies, institutions and structures.[14]

Despite clear evidence that death and disability are collective problems,[15] progress in responding to COVID-19 through a comprehensive public health approach has been stunted by the debilitating first language of individualism in American culture, described by Wallack and Lawrence.[16] This language and preoccupation with individual freedoms, personal responsibility, and limited government have been amplified by the former administration's nationalist and populist rhetoric,[8] and has contributed to a fragmented Federal pandemic response, individual non-compliance with COVID-19 safety mandates, and the lack of a coordinated national strategy for disaster relief and vaccine distribution. Stone argues that "presidents lead as much with their rhetoric as with their policy goals" and goes so far as to assert that former President Trump's rhetoric is "destroying the 'culture of community' necessary for progress on health equity".[17] Encouraging individuals, especially those who have been vaccinated, to behave in ways that prioritize collective well-being over individual freedom may prove to be even more difficult as the pandemic wears on and as vaccines offer a false sense of absolute protection. Individualism is not a sufficient public health strategy16; nor is an ideology of ethnonationalism, which prioritizes those with a narrowly defined American identity (i.e. native-born, English-speaking whites with a European and/or, Christian background).[9]

Within the US, efforts to mitigate the disproportionate impact of COVID-19 call for prioritizing high-risk communities in vaccine distribution and for targeted strategies to ensure equitable access among BIPOC even within other high-risk categories, such as essential workers and those with underlying health conditions.[18] However, people of color are less likely to be vaccinated compared to their white counterparts for a number of reasons, including distrust of the healthcare system grounded in historical abuses and ongoing racism.[18] We worry that barriers to vaccination among communities of color have been exacerbated by racist rhetoric,[19] which has been demonstrated to have a ripple effect causing others to express racists views.[20]

While contemporary American politics may prioritize individualism and limited regulation, the nature of disease (including, but not limited, to COVID-19) starkly reminds us that human life is interconnected. Globally, the need for equity in the allocation and distribution of vaccines across wealthy, middle-income and low-income countries is both a matter of social justice as well as one of national self-interest. Achieving herd immunity through vaccination rests on our ability to reach all parts of the globe. Yet, as of mid-January, more than half of the seven billion vaccine doses that have been purchased globally have gone to high-income countries, despite the fact that these countries are home to just 16% of the world's population.[21] Further, "vaccine nationalism"[22] has economic implications for the global economy. Just as our health is dependent on the health of our neighbors, we must recognize the interconnection of our economic wellbeing. According to a recent study, "the global economy stands to lose as much as $9.2 trillion if governments fail to ensure developing economy access to COVID-19 vaccines, as much as half of which would fall on advanced economies" such as the US.[23]

MARKET JUSTICE VS. SOCIAL JUSTICE

Clearly, the COVID-19 pandemic has raised important considerations regarding the appropriate balance between health and economic well-being, and it behooves us to remember that economic conditions are critical determinants of health. However, the central issue remains the injustice of a dominant market ethic described by Beauchamp in Public Health as Social Justice.[24] In this landmark 1976 paper, Beauchamp describes how the market model encourages victim blaming and attention to individual behavior rather than the social preconditions of such behavior.[24] In doing so, the market model unfairly protects majorities and powerful interests from their fair share of the burdens of prevention, while spreading the costs of public problems among the general public.[24] The free-market ethic is alive and well today, for during the worse economic downturn since the great depression,[25] Jeff Bezos added $74 billion to his networth.[26] Meanwhile, 10.7 million people in the US were unemployed as of December 2020,[27] and social services are unable to keep up with increasing demand. If public health professionals want to sustainably and meaningfully address the health inequities that have been magnified by COVID-19, we must prioritize addressing poverty and economic inequality—the strongest determinants of health—while developing America's second language of community.[16] Further, we must do better at "finding ways to align with constituencies, lend our science and our knowledge, and create a base of power for progressive social change."[28]

While the field of public health has already expressed support for reducing income inequality to advance health,[29] the current and incoming generation of professionals should push to reclaim public health's power as a leader of progressive social change on a larger scale. Of equal importance is the need to shift cultural understanding of social welfare and the interdependence of human beings—a shift that has started taking place in the context of environmentalism and ecosystems. Now is the opportunity to initiate a change in conversation and in mindset at the national and global level and push for community values to be reflected in public policy.

HEALTH AND POLITICS

Admittedly, making decisions about mask mandates, restrictions on businesses and vaccine distribution—not to mention things like poverty reduction or income redistribution—is complex, and policymaking invariably results in "winners" and "losers." Even before COVID-19, health has always been profoundly political.[5] According to Bambra and colleagues, health is political because 1) it is unequally distributed; 2) social determinants are amenable to political interventions and dependent on political action; and 3) the right to health is, or should be, an aspect of citizenship and a human right.[5] However, politics is not inherently bad—at its best, it is an essential component of a democracy. It is the process of making decisions, and while those decisions should be grounded in the best possible evidence, science alone does not tell us how to act. Rather, policy decisions are also grounded in values and power. While a full discussion of power in politics is beyond the scope of this paper, we know that those with more power have greater influence in the political process when they wield their influence. Understanding the interplay of science or evidence, values, and power in political decision-making sheds light on why the former administrations' disregard for science,[8] their racist and xenophobic rhetoric,[7,9,17,19] and their powerful influence were such a dangerous combination for efforts to control COVID-19. From a public health perspective, policy decisions about how to protect and promote health must be grounded in accurate information and evidence, as well as the field's underlying value of social justice,[24] and the interests of communities most affected or most at risk (rather than those with the most power).

PUBLIC HEALTH'S ROLE IN THE POLITICAL PROCESS

While public health institutions have been stretched thin and workers deserve our gratitude for their exhausting and important efforts to test, trace, treat and vaccinate against COVID-19 since early 2020, we argue that public health professionals have shied away from political engagement, focusing primarily on epidemiology and the promotion of individual behavior change, at the expense of our collective wellbeing. Active and consistent involvement in the political process is necessary for public health professionals to address this pandemic, and other public health challenges. Fairchild and colleagues describe the shifting mission of the public health profession over time, describing the tension between our science-based identity and one that is more closely tied with social reform, and call for a "Back to the Future" realignment of public health that reclaims its place as part of an emerging reform movement.[28] They remind us, for instance, the progress of sanitarians who led reform efforts in the 19th and early 20th centuries.[28] Requiring housing to have indoor plumbing, improving tenement laws, and imposing housing density regulations had positive effects on rates of tuberculosis and other diseases.[30] We agree with Fairchild and colleagues that in recent decades "the field of public health has been constrained by self-imposed limitations and, all too often, has avoided engagement with those who challenge complacency and existing power relationships"[28] and we argue that being science - or evidence-based is not incongruent with advocating for social change.

Reclaiming our place as part of social reform means advocating for universal policies that protect and promote the health of all, such as paid sick leave policies and stronger social security and income protection programs; as well as targeted strategies to address health inequities. This includes, most notably, advocating for policy and practice changes in housing, healthcare and criminal justice to address residential segregation, implicit bias in the healthcare system, and mass incarceration.[31] As referenced earlier, the disproportionate burden of COVID-19 on BIPOC is just one of many examples throughout our history where marginalized communities experience health inequities. Improvement in this area thus depends on significant political engagement from public health professionals, challenging the powerful special interests that have generated such unhealthy and unequal social and environmental conditions, and amplifying the voices of communities.

LESSONS FOR TRAINING FUTURE PUBLIC HEALTH LEADERS

Ultimately, the events of 2020 and their impact on health inequities speak to the need for public health professionals to participate more fully in the political process, and this means training public heath students on how politics works and how to work within politics.[5] We are a field grounded in evidence-based decision making, but we must do a better job advocating for the use of our evidence, and do so in ways that align with the field's underlying values of social justice and community. This means building skills related to advocacy, communication and community engagement. It also means understanding the ways in which values underlie policymaking and building the capacity of public health workers to confidently engage in political debates from a strong position of scientific authority, as well as moral leadership. Similarly, we need to train future public health leaders to understand their role in building and maintaining trust and collaboration between and among the health system, government entities, and communities. This includes the ability to be empathetic, learning from and respecting diverse perspectives, and holding ourselves and each other to the highest ethical standards. Finally, we need future public health professionals to be better equipped to work within the complexity that is health and politics. This includes communicating in a way that is accessible but not overly simplistic, and building bridges across disciplines, sectors, communities, political parties, and foreign nations.

The Council on Education for Public Health (CEPH), which is an independent accrediting body for programs and schools of public health, has identified a list of 22 competencies meant to be incorporated in training for students preparing for careers in public health.[32] While several of the competencies for MPH schools and programs are consistent with our recommendations, we encourage CEPH to consider more explicit language that ensures we are universally training students to be effective in the political sphere, and to address the structural and political determinants of health inequities, as they revise their accreditation criteria this year.[33] As CEPH continues to promote flexibility in the way in which instructors and programs meet the various competencies, we encourage greater attention to public health pedagogy among instructors, such that innovations in how these critical skills may be developed are shared and replicated. In our experience, students are passionate about social justice in health, and are eager for training that allows them to apply this passion in ways to advance public health and health equity. Similarly, training students to be competent in areas related to politics and advocacy is challenging and often outside of our more "scientific" comfort zones. We look forward to learning from and working with others to help our students meet the public health challenges of 2021 and beyond.

REFERENCES

1. Sheehan, M. C., & Fox, M. A. (2020, July). Early warnings: The lessons of COVID-19 for public health climate preparedness. *Int J Health Serv*, *50*(3), 264–270. https://doi.org/10.1177/0020731420928971
2. Ruebush, E., Fraser, M. R., Poulin, A., Allen, M., Lane, J. T., & Blumenstock, J. S. (2021, January/February). COVID-19 case investigation and contact tracing: Early lessons learned and future opportunities. *J Public Health Manag Pract*, *27*(Suppl 1, COVID-19 and Public Health: Looking Back, Moving Forward), S87–S97. https://doi.org/10.1097/PHH.0000000000001290
3. Levy, B. (2019). Social injustice and public health (3rd edition). Oxford University Press. https://doi.org/10.1093/med/9780199939220.001.0001
4. Khan, O. A., Liu, K., Lichtveld, M., & Bancroft, E. A. (2012, March). Synergism of science and social justice. *American Journal of Public Health*, *102*(3), 388–389. https://doi.org/10.2105/AJPH.2011.300533
5. Bambra, C., Fox, D., & Scott-Samuel, A. (2005, June). Towards a politics of health. *Health Promotion International*, *20*(2), 187–193. https://doi.org/10.1093/heapro/dah608

6. Berkowitz, S., Cené, C.W. & Chatterjee, A. (2020). COVID-19 and health equity—Time to think big. New England Journal of Medicine, 383(12), e76(1)-e76(3).
7. Bailey, Z. D., & Moon, J. R. (2020, December 1). Racism and the political economy of COVID-19: Will we continue to resurrect the past? *Journal of Health Politics, Policy and Law*, *45*(6), 937–950. https://doi.org/10.1215/03616878-8641481
8. Gollust, S. E., Nagler, R. H., & Fowler, E. F. (2020, December 1). The emergence of COVID-19 in the US: A public health and political communication crisis. *Journal of Health Politics, Policy and Law*, *45*(6), 967–981. https://doi.org/10.1215/03616878-8641506
9. Bonikowski, B. (2019). Trump's populism: The mobilization of nationalist cleavages and the future of U.S. democracy. In K. Weyland & R. Madrid (Eds.) When Democracy Trumps Populism: Lessons from Europe & Latin America (110-131). Cambridge University Press.
10. Centers for Disease Control and Prevention. (2021). Health Equity Considerations and Racial and Ethnic Minority Groups. https://www.cdc.gov/coronavirus/2019-ncov/community/health-equity/race-ethnicity.html
11. U.S. Bureau of Labor Statistics. Job flexibilities and work schedules – 2017-2018. Data from the American Time Use Survey. https://www.bls.gov/news.release/pdf/flex2.pdf
12. Federal Bureau of Prisons. (2020). Inmate Statistics. https://www.bop.gov/about/statistics/statistics_inmate_race.jsp
13. Galea, S., Ettman, C. K., & Abdalla, S. M. (2020, December). Learning from the US COVID-19 response toward creating a healthier country. *American Journal of Public Health*, *110*(12), 1794–1796. https://doi.org/10.2105/AJPH.2020.305921
14. Leitch, S., Corbin, J. H., Boston-Fisher, N., Ayele, C., Delobelle, P., Gwanzura Ottemöller, F., Wicker, J. (2020, December 10). Black Lives Matter in health promotion: Moving from unspoken to outspoken. *Health Promotion International*, 1–10. https://doi.org/10.1093/heapro/daaa121
15. Powers, M., & Faden, R. R. (2006). Social justice: the moral foundations of public health and health policy (Ser. Issues in biomedical ethics). Oxford University Press.
16. Wallack, L., & Lawrence, R. (2005, April). Talking about public health: Developing America's "second language". *American Journal of Public Health*, *95*(4), 567–570. https://doi.org/10.2105/AJPH.2004.043844
17. Stone, D. (2017, October). Health Equity in a Trump Administration. *Journal of Health Politics, Policy and Law*, *42*(5), 995–1002. https://doi.org/10.1215/03616878-3940517
18. Artiga, S., & Kates, J. (2020). Addressing racial equity in vaccine distribution. KFF Issue Brief, December 20, 2020. https://www.kff.org/racial-equity-and-health-policy/issue-brief/addressing-racial-equity-vaccine-distribution/
19. Saul, J. (2017). Racial figleaves, the shifting boundaries of the permissible, and the rise of Donald Trump. *Philosophical Topics*, *45*(2), 97–116. https://doi.org/10.5840/philtopics201745215
20. Schaffner, B. (2020). The acceptance and expression of prejudice during the Trump era. Cambridge University Press. https://doi.org/10.1017/9781108924153
21. Marcus, M. B. (2021). Ensuring everyone in the world gets a COVID vaccine. Voices of Duke Global Health Institute, January 20, 2021. https://globalhealth.duke.edu/news/ensuring-everyone-world-gets-covid-vaccine
22. Fidler, D. P. (2020, August 14). Vaccine nationalism's politics. *Science*, *369*(6505), 749. https://doi.org/10.1126/science.abe2275
23. Çakmakli, C., Demiralp, S., Kalemli-Özcan, S., Yeşiltaş, S., & Yildirim, M. (2021). The economic case for global vaccinations: An epidemiological model with international production networks. National Bureau of Economic Research Working Paper #28395. https://www.nber.org/papers/w28395
24. Beauchamp, D. E. (1976, March). Public health as social justice. *Inquiry*, *13*(1), 3–14.
25. Georgieva, K. (2020). The great lockdown: Worst economic downturn since the Great Depression – Statement by Kristalina Georgieva, Managing Director of IMF. Press release. https://www.imf.org/en/News/Articles/2020/03/23/pr2098-imf-managing-director-statement-following-a-g20-ministerial-call-on-the-coronavirus-emergency
26. Pitcher, J. (2020). Jeff Bezos Adds Record $13 Billion in a Single Day to Fortune. Bloomberg, July 20, 2020. https://www.bloomberg.com/news/articles/2020-07-20/jeff-bezos-adds-record-13-billion-in-single-day-to-his-fortune
27. Bureau of Labor Statistics. (2020). The Employment Situation-December 2020. https://www.bls.gov/news.release/pdf/empsit.pdf
28. Fairchild, A. L., Rosner, D., Colgrove, J., Bayer, R., & Fried, L. P. (2010, January). The EXODUS of public health. What history can tell us about the future. *American Journal of Public Health*, *100*(1), 54–63. https://doi.org/10.2105/AJPH.2009.163956
29. American Public Health Association. (2017). Policy statement on reducing income inequality to advance health. https://www.apha.org/policies-and-advocacy/public-health-policy-statements/policy-database/2018/01/18/reducing-income-inequality-to-advance-health
30. Blackmar, E. (1995). Accountability for Public Health: Regulating the Housing Market in Nineteenth-Century New York City. In D. Rosner (Ed.), Hives of Sickness: Public Health and Epidemics in New York City (42-64). Rutgers University Press.
31. Knight, E., McDonough, K., & Codes-Johnson, C. (2019). Health equity guide for public health practitioners and partners, 2nd Edition. Division of Public Health, Delaware Health and Social Services. https://dhss.delaware.gov/dhss/dph/mh/healthequityguide.html
32. Council on Education for Public Health. (2016). Accreditation criteria for Schools of Public Health & Public Health Programs. https://media.ceph.org/documents/2016.Criteria.pdf
33. Council on Education for Public Health. (2021). 2021 Revisions to accreditation criteria timeline and plan. https://ceph.org/about/org-info/criteria-procedures-documents/criteria-procedures/2021-revisions-criteria/

Know As You Go: Pilot Program of Point-of-Care SARS-CoV-2 Antigen Screening Testing in Delaware Schools

Richard M. Pescatore, D.O.
Dana Carr, M.P.H.
Christopher M. Gaeta
Christine Alois, Ed.D.
Susan Haberstroh, M.P.A., Ed.D.
Kendall Massett
Mitch Weiss, Ed.D.
Ann Covey, B.S.N., R.N., N.C.S.N.
Karen Kleinschmidt, M.Ed., N.C.S.N., R.N.
Rebecca D. Walker, Ph.D., J.D., M.S.N.
William Chasanov, D.O., M.B.A.
Susan Bunting, Ed.D.
Molly Magarik, M.S.
Karyl T. Rattay, M.D., M.S.
Rick Hong, M.D.

Delaware Department of Health and Social Services

INTRODUCTION

In Delaware, the first case of coronavirus disease 2019 (COVID-19) was identified on March 11, 2020 and the first death attributed to COVID-19 occurred on March 26, 2020. As of March 5, 2021, 88,891 cases were diagnosed and 1,492 Delawareans died due to complications associated with COVID-19. Since the first case was announced, Delaware moved rapidly to institute statewide mitigation and suppression strategies to limit effects on the populace and health infrastructure, including widespread access to testing and sweeping public restrictions such as school and business closings and stay-at-home orders. Public schools were closed by executive order on March 13th, 2020. On March 24, 2020, private schools closed with the State's stay-at-home order.

Since then, the Delaware Department of Education (DDOE), in close collaboration with the Division of Public Health (DPH), provided extensive guidance to help schools reopen safely and to provide in-person instruction to the greatest extent possible. The guidance was crafted to prioritize the health and safety of students and staff while maintaining the goal of providing a high-quality, equitable education for all Delaware learners. Data continue to demonstrate that while the risk remains low for sustained, person-to-person transmission in schools when mitigation strategies are implemented consistently; emerging data suggest that students face significant risks resulting from the disruption caused by school closures, including but not limited to learning loss, increases in adverse mental health outcomes for youth, dropout risk, lack of access to nutritious meals, and potential safety concerns such as abuse or neglect.[1–6]

With this in mind, DDOE's *Returning to School Guidance*[7] was designed to:

- Be a general framework for districts and charters, allowing flexibility for each district and charter to meet its community's unique needs;
- Help districts/charters, families/caregivers, and staff understand and articulate risks and benefits, which are inherent and inevitable when reopening schools during a pandemic;
- Reflect the best available evidence, science, and best practices in both education and public health, with required flexibility as new evidence and best practices have shifted recommendations and guidance; and
- Leverage the cooperation and coordination of students, staff, families/caregivers, and the community with the goal of creating and maintaining safe, healthy, and supportive learning environments.

The guidance outlines specific mitigation strategies for districts, school buildings, and classrooms that, in combination, are designed to reduce the risk of transmission of COVID-19. These strategies include ensuring physical distancing, required use of face coverings for all who are able to wear them, cleaning and disinfection practices, access to handwashing facilities and supplies or sanitizer, proper ventilation, and cohorting of students as possible. These strategies were codified in Governor John Carney's Twenty-Seventh Modification to the Emergency Order and guidance from the Delaware Division of Public Health, which required that all schools, public and private, comply with these practices. The guidance emphasizes that these mitigation strategies are intended to be layered to work optimally; no one strategy is sufficient alone.

To complement these strategies in schools, Delaware offered accessible community polymerase chain reaction (PCR) testing statewide for symptomatic and asymptomatic individuals. From the beginning of the school year, all teachers and school staff in the state have had access to routine PCR at-home testing, as well as community testing sites as needed. This broad use of community testing has allowed DPH to identify and isolate positive cases, as well as conduct contact tracing and quarantine close contacts. In schools, DPH collaborated with school nurses, present in every public school (14 Del.C., Ch.13, §1310) and many private, parochial, and independent schools, to identify and isolate positive cases that were potentially contagious in the school environment, as well as to conduct contact tracing of school exposures of close contacts. DPH and DDOE also worked closely with dedicated "COVID coordinators" – personnel appointed within schools and districts as subject matter experts and points of communication regarding COVID recommendations and mitigation measures. Despite such interventions, testing results often took several days to be returned, with positive individuals in the school environment in the interim.

Building on this critical linkage between DPH, school nurses, and DDOE, schools in Delaware scaled up the use of SARS-CoV-2 antigen tests, which are relatively inexpensive and can be used at the point-of-care in schools. In addition to the

doi: 10.32481/djph.2021.03.015

benefit of rapid response in the general school environment, antigen testing offered an added level of protection in classroom environments where students were not able to consistently employ mitigation strategies, such as young children or students with special needs unable to wear face coverings and who require close contact with staff. Currently authorized devices can return results in approximately 15 minutes, providing schools another critical mitigation strategy to more quickly respond and limit potential transmission.

ANTIGEN TESTING BACKGROUND

Antigen tests for SARS-CoV-2 are generally less sensitive than nucleic acid viral tests that use PCR for detection. Proper interpretation of antigen test results is important for accurate clinical management of patients with suspected COVID-19, or for identification of potentially infected persons when used for screening.

The sensitivity of rapid antigen tests is generally lower than PCR. The first two antigen tests that have received Food and Drug Administration (FDA) Emergency Use Authorizations (EUAs) demonstrate sensitivity of 84% and 97% compared to PCR. Studies have shown that antigen levels in some patients who have been symptomatic for more than five days may drop below the limit of detection of the test. Scant data are available regarding performance in asymptomatic individuals.

The specificity of rapid antigen tests is generally as high as PCR – the first two antigen tests that received FDA EUAs reported specificity of 100%– which means that false positive results are unlikely. While all published datasets reflect specificities of 100%, cases of false positives have been reported—it is unclear at this time whether these incidents represent actual false positives, contamination, or test performance failure (false positives are a known phenomenon when certain transport media [e.g. Remel M4 or or M4RT] are used). Positive and negative predictive values of all in-vitro diagnostic tests vary depending upon the pretest probability of the patient being tested. Pretest probability is impacted by the prevalence of the target infection in the community, as well as the clinical context of the recipient of the test.

Definition of Screening Testing

Screening testing for SARS-CoV-2 is intended to help identify infected persons who are asymptomatic (asymptomatic carriers) and without known or suspected exposure to SARS-CoV-2. Screening testing is performed to identify persons who may be contagious so that measures can be taken to prevent further transmission. Examples of screening include testing in congregate settings, such as a long-term care facility or a correctional facility, a workplace testing its employees, or a school testing its students, faculty, and staff.

Use of Antigen Tests for Screening Testing

Modeling studies have convincingly demonstrated that point-of-care or self-administered surveillance tests with fast turnaround time or frequent testing have high epidemiological value, and can attenuate surges of infection in highly congregate settings, such as military bases and centers of education.[8] Universal high-frequency testing holds significant promise in stopping the spread of disease.[9] In testing of asymptomatic individuals, however, community prevalence significantly influences test utility.

IMPLEMENTATION

DPH, in partnership with DDOE, schools, and school districts throughout the State of Delaware, identified point-of-care lateral flow immunoassays ("rapid antigen tests") as useful diagnostic tools for COVID-19, and subsequently developed guidance for use and implementation of such tests within the school setting. DPH and DDOE implemented a process to readily identify asymptomatic students in the school setting to keep the community safe and healthy, as well as to better understand the prevalence of asymptomatic children and adolescents in the community.

Beginning in December of 2020, schools throughout the state were given access to rapid antigen testing platforms that had been purchased by DPH (BD Veritor) or provided by the federal government (Abbott BinaxNOW). A physician's standing order for testing was provided by DPH, and a multidisciplinary workgroup comprised of representatives from DPH, DDOE, and the education community collaborated to develop guidance for school rapid antigen testing implementation, including a test interpretation algorithm (*see Figure 1*), information regarding certifications and licensure, permission forms for testing, and web-based training.[10]

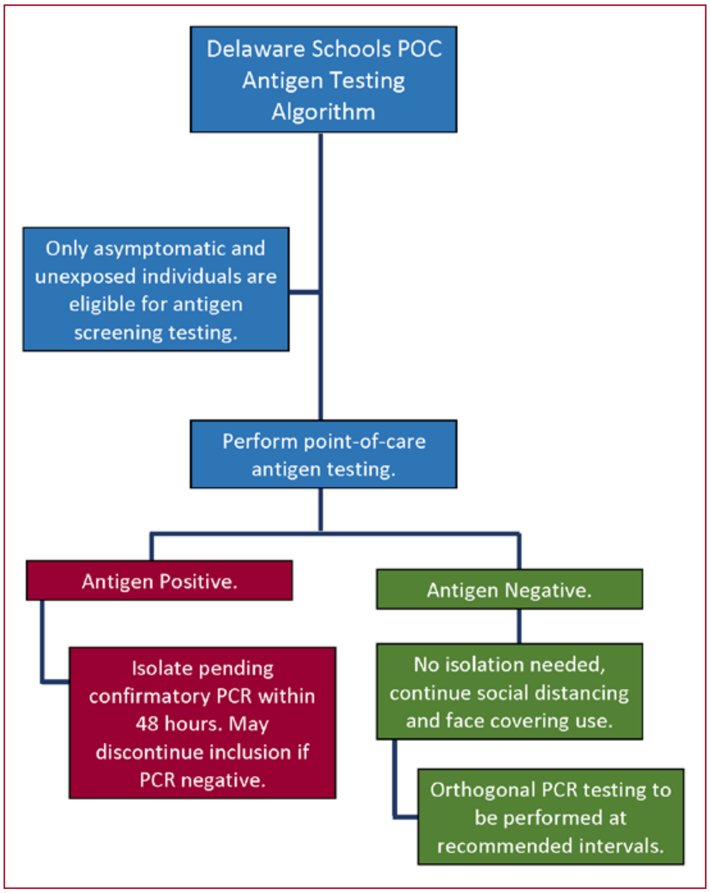


Figure 1. Delaware schools antigen testing algorithm

Uptake and implementation across schools and school districts was brisk, with more than two dozen educational settings beginning antigen testing as of February 1, 2021, with heterogeneous implementation across locations reflective of the unique landscape and needs of each educational setting. Many schools opted to introduce students and families to the process through initial drive-through testing events, where parents could assist students with self-swabbing techniques and witness test performance to gain confidence and insight into the testing process. Sites developed testing processes that best suited their students and facilities. For example, many schools had students perform and process tests shortly after school arrival and prior to entrance into the educational environment. Other districts opted for a "classroom service" model, placing testing equipment on a mobile cart within hallways and moving between classrooms to test small groups of students at a time. Nearly all students performed self-swabbing, though assistance could be rendered by testing personnel if needed. In the first three months of testing, 13 schools and districts throughout Delaware performed 3,739 tests, of which 16 (0.43%) were positive. All positive antigen tests were subsequently confirmed positive by PCR.

CHALLENGES AND LESSONS LEARNED

Implementation of the *Know As You Go* antigen screening program faced a number of challenges and lessons learned during development and operationalization. Early on, clear guidance regarding obtaining parental consent for and addressing legal requirements surrounding testing became paramount, and DDOE collaborated closely with legal counsel from the Delaware Department of Justice (DOJ) to ensure compliance. Additionally, continuous feedback from all stakeholders allowed for program improvement and sustainability, and involvement of school nurses as on-site technical experts was quickly identified to play a critical role in enhancing communication and engaging all participants in testing.

Staffing showed itself to be the greatest challenge throughout program implementation. Staff are needed for testing supervision and performance, as well as documentation and state-mandated results reporting. Automated reporting processes were identified as a critical area for staffing improvement.

CONCLUSION

Studies have convincingly demonstrated that high-frequency point-of-care antigen testing has high epidemiological value, and can attenuate surges of infection in highly congregate settings such as schools. Delaware's schools have demonstrated how an antigen testing program can be easily and successfully integrated into school operations to help protect against COVID-19 infection within educational settings.

REFERENCES

1. Dorn, E., Hancock, B., Sarakatsannis, J., & Viruleg, E. (2020, Dec 8). COVID-19 and learning loss—disparities grow and students need help. McKinsey Group: Washington, DC. Retrieved from: https://www.mckinsey.com/industries/public-and-social-sector/our-insights/covid-19-and-learning-loss-disparities-grow-and-students-need-help#
2. Feeding America. (2021, March) The impact of coronavirus on food insecurity in 2020 & 2021. Retrieved from: https://www.feedingamerica.org/sites/default/files/2021-03/National%20Projections%20Brief_3.9.2021_0.pdf
3. Leeb, R. T., Bitsko, R. H., Radhakrishnan, L., Martinez, P., Njai, R., & Holland, K. M. (2020, November 13). Mental health–related emergency department visits among children aged <18 years during the COVID-19 pandemic— United States, January 1–October 17, 2020. *MMWR. Morbidity and Mortality Weekly Report*, *69*(45), 1675–1680. https://doi.org/10.15585/mmwr.mm6945a3
4. Singh, S., Roy, D., Sinha, K., Parveen, S., Sharma, G., & Joshi, G. (2020, November). Impact of COVID-19 and lockdown on mental health of children and adolescents: A narrative review with recommendations. *Psychiatry Research*, *293*, 113429. https://doi.org/10.1016/j.psychres.2020.113429
5. Baron, E. J., Goldstein, E. G., & Wallace, C. T. (2020, October). Suffering in silence: How COVID-19 school closures inhibit the reporting of child maltreatment. *Journal of Public Economics*, *190*, 104258. https://doi.org/10.1016/j.jpubeco.2020.104258
6. Kovler, M. L., Ziegfeld, S., Ryan, L. M., Goldstein, M. A., Gardner, R., Garcia, A. V., & Nasr, I. W. (2020, September 25). Increased proportion of physical child abuse injuries at a level I pediatric trauma center during the Covid-19 pandemic. *Child Abuse & Neglect*, 104756. https://doi.org/10.1016/j.chiabu.2020.104756
7. Delaware Department of Education. (2021, Jan). Returning to school: Planning a safe, efficient, and equitable return to school for students and staff. Retrieved from: https://www.doe.k12.de.us/cms/lib/DE01922744/Centricity/Domain/600/ddoe_returningtoschools_guidance2.pdf
8. Larremore, D. B., Wilder, B., Lester, E., Shehata, S., Burke, J. M., Hay, J. A., . . . Parker, R. (2020). Test sensitivity is secondary to frequency and turnaround time for COVID-19 surveillance. MedRxiv, 3. Retrieved from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7325181/ https://doi.org/10.1101/2020.06.22.20136309
9. Peto, J., Alwan, N. A., Godfrey, K. M., Burgess, R. A., Hunter, D. J., Riboli, E., & Romer, P., & the 27 signatories. (2020, May 2). Universal weekly testing as the UK COVID-19 lockdown exit strategy. *Lancet*, *395*(10234), 1420–1421. https://doi.org/10.1016/S0140-6736(20)30936-3
10. Delaware Department of Education. (2020). COVID-19 school health forms & resources. Retrieved from: https://www.doe.k12.de.us/Page/4243

CORONAVIRUS
(COVID-19)

DELAWARE HEALTH
AND SOCIAL SERVICES
Division of Public Health

PREVENT THE SPREAD

STAY HOME IF YOU'RE SICK

WASH OR SANITIZE HANDS OFTEN.

WEAR A FACE COVERING OR MASK

! *Required for those Kindergarten age and up.*

STAY AT LEAST 6 FT APART

PROTECT YOURSELF AND OTHERS.

Thank you.

For more information please visit:

de.gov/coronavirus

Updated 9/3/2020

From the history and archives collection

One for All and All in One?

Sharon Folkenroth-Hess, M.A.
Collections Manager, Delaware Academy of Medicine / Delaware Public Health Association

Just inside the entrance of the Delaware Academy of Medicine sits one of the largest objects in our collection. Unlike many of the items on display, visitors can immediately identify its purpose (*see figure 1*). The wheelchair is synonymous with disability. This association is in part due to the success of the International Symbol of Access (ISA) or 'Handicap Sign' as it is colloquially known (*see figure 2*).

Since its creation in 1968, the blue square overlaid with a white line image of a person in a wheelchair has been used to mark areas of accessibility for wheelchair use. Over time the ISA has been used "shorthand" to mark available access resources, including those that have nothing to do with mobility. This symbol now represents the over twelve percent of Americans living with disabilities, even if they do not use a mobility aid.[1] After fifty-three years, designers and advocates are pushing for a new symbol. For some, the original is too passive. Others believe it does not accurately represent most people with disabilities.

Those in the first camp are led by the Accessible Icon Project in the US and the Forward Movement in Canada. To them, the current sign is about the chair and not the person in it. If the circular "head" in the image is removed, all that remains is a wheelchair. Both groups revamped the original symbol to make the "person" the focal point and suggest movement. Over the last ten years, stores, hospitals, and other public entities around the world have adopted the new sign. However the new symbol is not without controversy. Showing movement implies a level of independence and ability that is not obtainable by some wheelchair users. For them the new design is not as representative as the original.[2]

Representation and inclusion play a major role in other projects seeking to redesign the ISA. In 2018, McCann London, a European marketing firm, developed the Visablity93 campaign to create an open source suite of invisible disability signs.[3] The name behind the project alludes to the "93%" of people with disabilities that do not use a wheelchair.

Figure 1. Folding Invalid Carrying Travel Chair, c. 1890s

doi: 10.32481/djph.2021.03.016

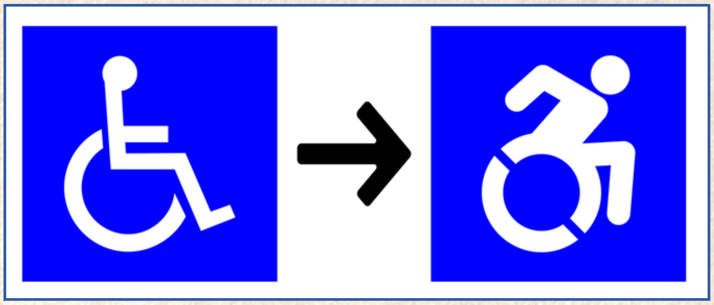


Figure 2. International Symbol of Access and the Dynamic Symbol of Access created by the Forward Movement.

The firm's twenty-seven icons depicted 'invisible' disabilities like epilepsy and diabetes with a promise to unveil a new IOS icon to replace to ISA by the end of 2019 (*see Figure 3*).[4] While the Visability93 campaign has ended, "invisible disability" advocates continue to fight against the stereotypical image of a person with a disability looks like. Often able-bodied people see the ISA as a guide for who it is intended to benefit. Advocates argue a new, more inclusive access symbol would represent all people with disability and therefore reduce misunderstandings over who is allowed to use these resources.

From 1595, when the first wheeled chair was designed, to the mid-twentieth century, mobility devices were limited to a privileged few. The luxury of mobility that our chair once provided its owner is now recognized as a basic human right by the World Health Organization. Even if the original ISA is changed to become more inclusive, the wheelchair will remain a powerful symbol in the history of disability and accessibility.

REFERENCES

1. Erickson, W., Lee, C., & von Schrader, S. (2021). Disability statistics from the 2018 American Community Survey (ACS). Ithaca, NY: Cornell University Yang-Tan Institute (YTI). Retrieved from Cornell University Disability Statistics website: www.disabilitystatistics.org
2. Frost, N. (2018). The controversial process of redesigning the wheelchair symbol. Atlas Obscura. Retrieved from https://www.atlasobscura.com/articles/wheelchair-symbol-redesign
3. Invisible Disability Project. (2021). Mission statement. Retrieved from: https://www.invisibledisabilityproject.org/our-mission/
4. Dawood, S. (2018). Why the wheelchair symbol should be rethought to include 'invisible disabilities'. Design Week. Retrieved from: https://www.designweek.co.uk/issues/30-july-5-august-2018/why-the-wheelchair-symbol-should-be-rethought-to-include-invisible-disabilities/

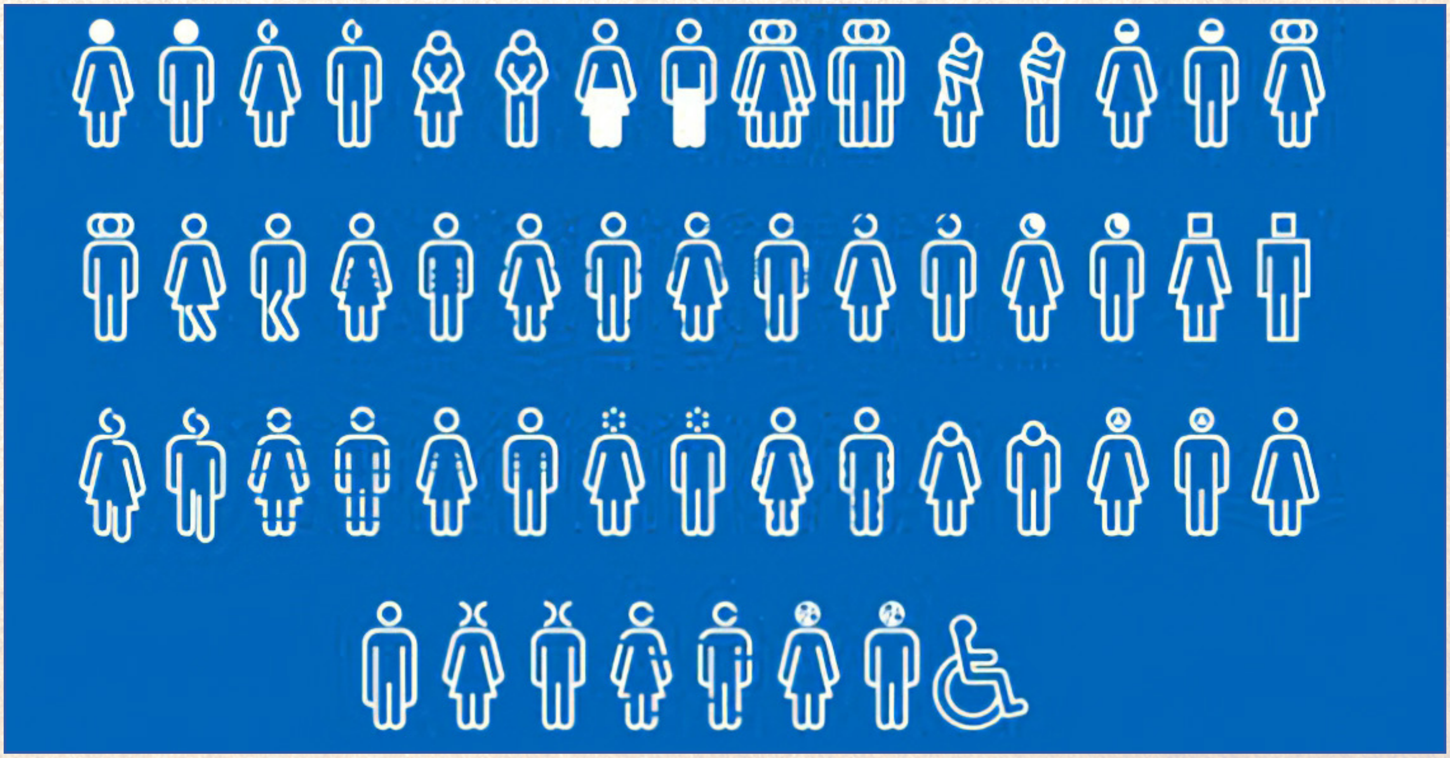


Figure 3. Visibility93 suite of icons.

Delaware Journal of Public Health

Submission Guidelines

updated April, 2020

About the Journal

Established in 2015, **The Delaware Journal of Public Health** is a bi-monthly, peer-reviewed electronic publication, created by the Delaware Academy of Medicine/Delaware Public Health Association. The publication acts as a repository of news for the medical, dental, and public health communities, and is comprised of upcoming event announcements, past conference synopses, local resources, peer-reviewed content ranging from manuscripts and research papers to opinion editorials and personal interest pieces, relating to the public health sector. Each issue is largely devoted to an overarching theme or current issue in public health.

The content in the Journal is informed by the interest of our readers and contributors. If you have an event coming up, would like to contribute an Op-Ed, would like to share a job posting, or have a topic in public health you would like to see covered in an upcoming issue, please let us know.

If you are interested in submitting an article to the Delaware Journal of Public Health, or have any additional inquiries regarding the publication, please contact *DJPH* Deputy Editor Elizabeth Healy at ehealy@delamed.org, or the Executive Director of **The Delaware Academy of Medicine and Delaware Public Health Association**, Timothy Gibbs, at tgibbs@delamed.org

---

Information for Authors

Submission Requirements

The DJPH accepts a wide variety of submission formats including brief essays, opinion editorials pieces, research articles and findings, analytic essays, news pieces, historical pieces, images, advertisements pertaining to relevant, upcoming public health events, and presentation reviews. If there is an additional type of submission not previously mentioned that you would like to submit, please contact a staff member.

The initial submission should be clean and complete, without edits or markups, and contain both the title and author(s) fulls name(s). Submissions should be 1.5 or double spaced with a font size of 12. Initial submissions must also contain a cover letter with concise text (maximum 150 words). Once completed, articles should be submitted via email to Elizabeth Healy at ehealy@delamed.org as an attachment. Graphics, images, info-graphics, tables, and charts, are welcome and encouraged to be included in articles. Please ensure that all pieces are in their final format, and all edits and track changes have been implemented prior to submission.

Cover Letters must address the following four article requirements:

1. A description of what the paper adds to current knowledge, in particular with respect to material previously published in DJPH, and if systematic reviews exist on the topic.
2. The public health importance of the paper.
3. One sentence summarizing the main message(s) of the paper, which may be used to disseminate the paper on social media.
4. For individual or group randomized trials, provide the date of trial registration and the NCT number from www.Clinicaltrials.gov or other approved registry. In the cover letter only, not in the paper. Do NOT include the trial registration or NCT number in the abstract or the body of the manuscript during the initial submission.

All manuscripts must be submitted via email to Elizabeth Healy at ehealy@delamed.org.

To view additional information for online submission requirements, please refer to the website for the Delaware Journal of Public Health: https://djph.org/sample-page/submit-an-article/.

Submission Length

While there is no prescribed word length, full articles will generally be in the 2500-4000-word range, and editorials or brief reports will be in the 1500-2500-word range. If you have any questions regarding the length of a submission, or APA guidelines, please contact a staff member.

Copyright

Opinions expressed by contributors and authors do not necessarily reflect the opinions of the DJPH or affiliated institutions of authors. Copying for uses other than personal reference or interest without the consent of the DJPH is prohibited. All material submitted alongside written work, including graphics, charts, tables, diagrams, etc., must be referenced properly in accordance with APA formatting.

Conflicts of Interest

Any conflicts of interest, including political, financial, personal, or academic conflicts, must be declared prior to the submission of the article, or in conjunction with a submission. Conflicts of interest are any competing interests that may leave readers feeling misled or deceived, and/or alter their perception of subject matter. Declared conflicts of interest may be published alongside articles in the final electronic publication.

Nondiscriminatory Language

Use of nondiscriminatory language is required in all DJPH submissions. The DJPH reserves the right to reject any submission found to be using sexist, racist, or heterosexist language, as well as unethical or defamatory statements.

Additional Documents and Information for Authors

Please Note: All authors and contributors are asked to submit a brief personal biography (***3 sentences maximum***) and a headshot along submissions. These will be published alongside final submissions in the final electronic publication. For pieces with multiple authors, these additional documents are requested for all contributors.

Abstracts

Authors must submit a structured or unstructured abstract along with their article.

The word limit is ***200 words***, including headings. A title page should be submitted with this abstract as well.

Structured abstracts should employ 4-5 headings:

Objectives (begins with "To…")

Methods

Results

Conclusions

A fifth heading, Policy Implications, may be used if relevant to the article.

Trial Registration information is required for clinical trials and must be included in the final version abstract

All abstracts should provide the dates(s) and location(s) of the study is applicable.

Note: There is no Background heading.

IDD – LEXICON

Bili

Bilirubin, a reddish yellow pigment made during the normal breakdown of red blood cells. Normal levels vary slightly from lab to lab; they range from about 0.2 – 1.2 mg/dL.

Bronchomalacia

A term for weak cartilage in the walls of the bronchial tubes

Bronchoscopy

A procedure in which a thin tube is passed down the nose or mouth and into the throat and lungs to examine the lungs and air passages.

Case Fatality Percentage

The percent of people who die from a specified disease among all individuals diagnosed with the disease over a certain period of time.

Chromosome

A threadlike structure of nucleic acids and protein found in the nucleus of most living cells, carrying genetic information in the form of genes.

Congenital

Present from birth.

Copy Number Variants

The different number of copies of a particular gene from one individual to the next.

Diaphragmatic Hernia

A birth defect where there is a hole in the diaphragm (the large muscle that separates the chest from the abdomen). Organs in the abdomen (such as intestines, stomach, and liver) can move through the hole in the diaphragm and upwards into a baby's chest.

Dysphagia

Difficulty swallowing.

ECHO

Echocardiogram, a machine that uses electrodes to check the heart rhythm and ultrasound technology to determine blood flow through the heart.

Esophagogastroduodenoscopy (EGD)

A procedure in which a flexible tube with a light and camera is inserted into the mouth, down the esophagus, into the stomach and the first part of the small intestine (duodenum) to examine the lining.

GERD

Gastroesophageal Reflux Disease; stomach acid frequently flows back into the esophagus (acid reflux), which can irritate the esophagus.

Heterogeneity/Heterogeneous

Diversity in content.

Hydrocephalus

The buildup of fluid in the cavities (ventricles) deep within the brain; this increases pressure on the brain and can lead to disabilities.

Karyotype

The number and visual appearance of the chromosomes in the cell nuclei of an organism.

Microcephaly

A condition in which a baby's head is much smaller than expected.

Mortality Rate

The number of deaths in a given area or period, or from a particular issue.

Negative Predictive Value

The probability that the subjects with a negative test truly do not have the disease.

Nucleotides

The basic building blocks of nucleic acids, made of a sugar molecule attached to a phosphate group and a nitrogen containing base. In humans, these are adenine (A), thymine (T), guanine (G), cytosine (C), and uracil (U).

Positive Predictive Value

The probability that subjects with a positive test truly have the disease.

Press Ganey Scores

Press Ganey is a global organization dedicated to improving patient experiences in healthcare facilities across the world. Their scoring system determines how hospitals are dedicated to enhancing a patient's experience from the moment they enter a healthcare facility until long after they leave.

Pretest Probability

The probability of the presence of a condition before the diagnostic test.

Prevalence

The proportion of the population who has a given condition within a given time period.

Schizencephaly

An extremely rare developmental birth defect characterized by abnormal slits, or clefts, in the cerebral hemispheres of the brain.

Sensitivity

The ability of a screening test to identify true positive results.

Specificity

The ability of a screening test to identify true negative results.

Tracheomalacia

The collapse of the airway when breathing.

Trisomy

A chromosomal condition characterized by an additional chromosome (e.g. an individual with Down Syndrome has an extra copy of chromosome 21).

Delaware Ages 21 and Older Checklist- Intellectual or Developmental Disability

This checklist was compiled after several Delaware- based nonprofit organizational leaders saw individuals with intellectual and developmental disabilities (IDD) and their families struggling to navigate services and community resources, especially at ages 21 and older. The main goal of this checklist is to provide a condensed informational resource for various aspects of the individual's life so applicable elements can be explored further.

Please note this is not all encompassing but serves to provide self-advocates, parents and guardians a starting point.

This list would be helpful to you if:

- Your family moved or is moving to Delaware and has a family member with IDD who is or will be soon be age 21
- You are the caregiver or sibling of an individual with IDD who is or will soon be age 21
- You are the parent or caregiver of an individual with IDD who is or will soon be age 21
- You are an individual with IDD

Partners in Checklist Development:

Lauren Camp Gates, Executive Director, **Down Syndrome Association of Delaware**
Ed Gootzait, Board Member, **Down Syndrome Association of Delaware**
Verna Hensley, Vice President of Public Affairs, **Easterseals**
Nancy Ranalli, Director of Community Outreach & Assistive Technology, **Easterseals**
Maria Pippidis, County Director and Extension Educator, Family and Consumer Sciences, **UD Cooperative Extension**
Jennifer Tozer, Manager of Family Engagement, Delaware Department of Healthy & Social Services **(DHSS)**
Susannah Eaton-Ryan, Director of Employment and Outreach, **The Arc of Delaware**
Annalisa Ekbladh, Director, Policy & Family Services, **Autism Delaware**

Delaware Ages 21 and Older Checklist- Intellectual or Developmental Disability

Priorities (Do these things first):

1. Apply to Division of Developmental Disabilities Services (DDDS) – If you have a child aged 3 through 12 that you believe has an intellectual or developmental disability and you plan on applying to DDDS for services in the future, you can submit a request to the Division to review your child's information to possibly determine Presumptive Eligibility for Respite Services. Presumptive Eligibility ends at age 13 and individuals must complete a DDDS to access Respite services and other services (employment services, behavioral, benefits counseling, etc.). Because the application process can be lengthy and individuals are eligible at 13, it is advisable to explore eligibility at that time.
    a. A Community Navigator is provided to you, through The Columbus Organization, once you are approved and they connect you to community resources. The Division of Developmental Disabilities Services has contracted with The Columbus Organization to provide Targeted Case Management with the goal of supporting individuals in the context of their families. A Community Navigator supports by working with the family in developing a Person-Centered Plans (PCP) that captures the needs and goals of the individual and family unit; helping to identify community resources for unmet needs; assisting families to learn about eligibility-based services. The Community Navigator is the individual's key contact with the Division of Developmental Disabilities.
2. Obtain an DMV Identification Card
3. Learn more about Medicaid – consider if it is right for you or the individual, Medicaid provides access to Home & Community based services such as a day program or employment supports, this is also a low-income medical insurance for families that meet that criteria

Health and Medical Care and State Services

1. Consider Center for Special Health Care Needs at Christiana is the only center in the greater Delaware area dedicated to providing primary care for adults ages 18 and older with complex medical and social conditions that originated in childhood.
2. Consider Practice without Pressure specialized healthcare for people with disabilities (focuses on fears)
3. Understand how your Medicare benefits would affect and support the individual with the disability
4. Understand difference between the Division of Medicaid and Medicare Long Term Care Support and Services Waiver (LTSS) Vs. the DDDS Lifespan Waiver
5. Understand resources for mental Health- such as The Division of Substance Abuse and Mental Health
6. Explore the Division of Services for Aging of Adults with Disabilities
7. Issues understanding insurance options? Visit HealthInsurance4U offered by the University of Delaware Cooperative Extension

Considerations: Are your physicians covered under the insurances you are using?

Assistive Technology

1. Explore UD Assistive Technology find and try tools that support learning, communication, personal care, employment and leisure pursuits (known as DATI)
2. Easterseals Resource and Technology Demonstration Center

Considerations: If you are exploring post-secondary education, remember that by the American with Disabilities Act there will be student services available for supports

Delaware Ages 21 and Older Checklist- Intellectual or Developmental Disability

Employment

1. Division of Vocational Rehabilitation (DVR) this is a branch of the Department of Labor and is federally funded. It helps individuals with disabilities secure employment.
2. Division of Visually Impaired (DVI) has a Vocation Rehab department
3. Learn more about the Workforce Innovation and Opportunity Act (WIOA)
4. DDDS/DVI/DSAAPD manages Pathways to Employment (eligible with Medicaid, 14-25 years old) – provides Employment Navigator, internship opportunities, workplace support, other employment supports as well

Considerations: remember that your plan and goals drive the services you utilize.

Housing

1. Apply to DDDS (see above) – funds residential services through their Home and Community based waiver, the Lifespan Waiver, you have to meet the level of care to receive any of the services through the waiver
2. Housing and Urban Development
3. Section 8 – Kent and Sussex counites, reduced rent properties
4. Delaware State Housing Authority (several housing authorities- local such as Wilmington, Newark, Dover) – information on low income housing, first-time homebuyer's assistance
5. United Cerebral Palsy of Delaware- has accessible housing options available
6. Freedom Center for Independent Living – housing option and resource network in Middletown DES
7. Independent Resources Inc. – nonresidential organization but works to provide resources and make connections so individuals can live their best life
8. National Alliance on Mental Illness housing

Social and Relationships

1. Planned Parenthood – offers disability programs and workshops for caregivers and self-advocates.
2. Special Olympics – provides sports programs at no cost to individuals ages 2 and older (no upper age limit) all throughout the state
3. Best Buddies – friendship program for those with intellectual and developmental disabilities
4. Expanding Options: www.expandingoptions.org Is a parent led non-profit organization that was founded to help create social opportunities for their adult children on the Autism Spectrum. The Organization recognizes themselves as two groups, Caregivers and Adult Members, and try to coordinate meaningful content and speakers for each group at routine monthly meetings. The group welcomes anyone, 18 or older, to participate in monthly meetings and routine social outings. It is important to know that parent involvement may be necessary as they do not provide supervision/paid staff.
5. Federal Park Pass is a free, lifetime pass available to United States citizens or permanent residents, regardless of age, that have a permanent disability that can be used at over 2,000 Federal recreation sites across the nation, including National Parks, National Wildlife Refuges, and many National Forest lands.
6. Totally Awesome Players – theater group
7. Night to Shine – fun prom-like night out yearly, locations throughout the state
8. Asperger's Alliance- support groups, programming and more
9. Mary Campbell Center- adult programming, events, etc.

Delaware Ages 21 and Older Checklist- Intellectual or Developmental Disability

Financial and Legal Planning

1. Apply for Social Security Benefits (18 years and older- the sooner the better) to be eligible for Social Security Income, if you applied the first time but were denied, re-apply within 60 days- apply again and again (moves up chain of command, and can be paid retroactively.)
2. Explore SSDI
3. Explore SSI
4. ABLE Accounts – low cost savings plan that allows individuals with disabilities and their families to save for a broad range of expenses on a tax-advantaged basis without jeopardizing their benefits from supplemental security income (SSI), Medicaid and other federal programs
5. Special Needs Trusts - are designed to provide funds for someone with a disability, while preserving the person's eligibility for important government benefits
6. Miller Trust- allow individuals to receive Medicaid benefits for long term care services, like nursing home care, if their incomes are above the Medicaid eligibility limit
7. Community Legal Aid Society- provides free legal services to people with disabilities throughout the state
8. Guardianship and Alternatives – understanding all options and making the best decision for your situation in particular
    a. Supported Decision Making
9. Help through Delaware CARE Plan – in developing a personalized care plan and establishing a special needs trust - without making him or her ineligible for crucial government benefits, like Medicaid and Supplemental Security Income

Transportation

1. Para Transit: application and an interview through DELDOT – provides transportation for individuals who qualify to work and activities
2. DART
3. Uber/Lyft – riding sharing services that use applications on smartphones to schedule rides

Caregivers

1. Respite through DHSS- a service designed to give caregivers a break from the stress of taking care of an individual with special needs
2. Easterseals Respite Services, Camp Fairlee and Caregiver Support available
3. Delaware Family Voices- Medicaid questions hotline, other resources for caregivers
4. DSAAPD's Caregiver Resource Centers List
5. Brain Injury Association of Delaware

Advocacy

1. Action Alerts The ARC – you can sign up for action alerts
2. Partners in Policymaking and Junior Partners in Policymaking (Ages 15-22) - provides up-to-date information, education and skill building activities about the legislative process and local, state and national issues that affect individuals with disabilities
3. The A-Team – bi-partisan policy group centered in Delaware that works advocate with and for individuals with disabilities
4. State Council for Persons with Disabilities – mission is to ensure that individuals with disabilities are empowered to become fully integrated within the community

Delaware Ages 21 and Older Checklist- Intellectual or Developmental Disability

5. Have you register to vote? Resource guide
    a. Voting Guide
6. Do you know who your state legislator is? Have you met with them before? Find out who they are.
7. Developmental Disability Council - Working to ensure that people with developmental disabilities enjoy the same quality of life as the rest of society

Postsecondary Education

- Postsecondary Education – inclusive college options across the nation
    - UD CLSC Program
    - Spectrum Scholars UD

Other Resources

- PACER Center Workshops – webinars on housing, independence and more
- Healthy Transitions App- This interactive smartphone application uses videos produced by CDS and Healthy Transitions New York to teach young adults the skills they need to become more independent in matters of healthcare, insurance, healthy lifestyles and relationships.
- DisabilityHUB- database of resources
- Independent Resources, Inc. -provides quality services to people with disabilities, assisting them to achieve and to maintain an independent lifestyle
- $tand by Me Delaware- online resource for money management.
- The Money School – provides tools to improve financial health.
- Charting the Life Course- online toolkit to organize vision, goals, etc.

Organizations that offer programming, resources, and more:

- Down Syndrome Association of Delaware- cooking classes, boxing and fitness programs (for individuals not just with Down syndrome), dances and more for anyone with a disability
- Easterseals- adult day services, supported employment, caregiver supports, respite and more
- Autism Delaware- family support, events, employment service and training
- The ARC of Delaware- various events such as dances, informational sessions, support and more
- Hearing Loss Association of Delaware
- Fitness Fridays in Hockessin
- St. Mark's Friendship Club: open to individuals with IDD to be paired with a student, contact: psoares@stmarkshs.net, 302.757.8745
- Delaware Foundation Reaching Citizens (DFRC)- Blue Gold program, activities and events
- University of Delaware Cooperative Extension – Nutrition, Health and Financial management educational programs are provided within the community. Go to www.extension.udel.edu for a calendar of events or to contact someone for program opportunities.
- Brian Injury Association of Delaware
- New Castle County Community Services- contact Heather at Heather.Mergenthaler@newcastlede.gov, therapeutic riding, art programs, exercise programs like Zumba

Delaware Ages 21 and Older Checklist- Intellectual or Developmental Disability

Day Habilitation Services – accessed through the Home & Community Based Waiver "What am I going to do during the day?"

- Employment
- Community Participation
- Day Habilitation (through DDDS)
- Pre-Vocational

Acronym Guide

DDDS	Division of Developmental Disabilities Services
LTSS	Long Term Services & Supports
DVR	Division of Vocation Rehabilitation
WIOA	Workforce Innovation and Opportunity Act
DVI	Division for the Visually Impaired
DSAAPD	Division of Services for Aging and Adults with Physical Disabilities
SSDI	Social Security Disability Insurance
SSI	Social Security Insurance
NAMI	National Alliance on Mental Illness
ABLE	Achieving a Better Life Experience Act
DMV	Delaware Division of Motor Vehicles
DART	Delaware Area Regional Transit
DHSS	Delaware Health and Social Services

Helpful Phone Numbers

Division of Developmental Disabilities Services (DDDS)	302-836-2100
Center for Special Health Care Needs	302-320-6300
Easterseals Delaware & Maryland's Eastern Shore	302-324-4444
Down Syndrome Association of Delaware	302-995-1004
Autism Delaware	302-224-6020
UD Cooperative Extension	302-831-1239
The Arc of Delaware	302-996-9400
Special Olympics	302-831-4653
ABLE Accounts- State Treasurer's Office	302-672-6700

To request paper copies of information please email executivedirector@dsadelaware.org or call 302-994-1004 and we can provide you with a packet of brochures from many of the organizations listed. This can be mailed or picked up from an office in Middletown.

If you feel your organization may have been omitted, please email Lauren Camp Gates at executivedirector@dsadelaware.org

Last Updated: July 14, 2020

DDI – RESOURCES

All the Difference

www.allthedifference.org

All The Difference provides Delaware and surrounding areas with a way to work with children and adults with developmental and learning differences. Offering an outpatient clinic that takes an integrated approach to occupational therapy, floor time/play therapy, parent support and parent training for additional home-based work.

Community Legal Aid Society

www.declasi.org

Protects the rights of people with physical and mental disabilities. Provides counsel and advice, negotiation, representation, in administrative and court proceedings, individual and systems advocacy.

Developmental Disabilities Council

www.ddc.delaware.gov

The mission of the Delaware DDC is to ensure that people with developmental disabilities can enjoy the same quality of life as the rest of society. The council will advocate for change and will educate communities to be responsive and sensitive to the needs, preferences, and choices of all people with developmental disabilities and their families, which will ensure and enhance their participation in life and society.

Easter Seals – Delaware

https://www.easterseals.com/de/

Easterseals provides exceptional services, education, outreach, and advocacy so that people living with autism and other disabilities can live, learn, work and play in our communities.

Freedom Center for Independent Living

http://www.fcilde.org

Empower persons with disabilities to enable them to gain effective control and direction over their own lives, so that they can achieve and maintain an independent lifestyle within the community with dignity.

Practice Without Pressure

http://pwpde.org

Provides practice to prepare fearful patients for treatment as well as exams and routine care Center in Newark, DE. Together with practice specialists, PWP has dental and medical teams that provide needed services. PWP services range from dental exams, cleanings, fillings, injections, root canals, extractions and dentures to blood draws, women's health exams, pre-surgery support, nail and hair care.

Project SEARCH

https://www.projectsearch.us/

Since its inception, Project SEARCH has grown from a single program site at Cincinnati Children's to a large and continuously expanding international network of sites. Project SEARCH's primary objective is to secure competitive employment for people with disabilities.

State Council for Persons with Disabilities

www.scpd.delaware.gov

The mission of the State Council for Persons with Disabilities is to unite, in one council, disability advocates and State agency policy makers to ensure that individuals with disabilities are empowered to become fully integrated within the community. Promotes coordination among state programs, reviews state laws, regulations, policies and programs for persons with disabilities, reports to the Governor and the Legislature, and advocates for the rights of people with disabilities in the State of Delaware.

Index of Advertisers

Notes:

Notes:

DELAWARE ACADEMY of MEDICINE

DPHA
DELAWARE PUBLIC HEALTH ASSOCIATION

Delaware Academy of Medicine / DPHA

4765 Ogletown-Stanton Road
Suite L10
Newark, DE 19713

www.delamed.org | www.delawarepha.org

Follow Us:

The Delaware Academy of Medicine is a private, nonprofit organization founded in 1930. Our mission is to enhance the well being of our community through medical education and the promotion ofpublic health. Our educational initiatives span the spectrum from consumer health education tocontinuing medical education conferences and symposia.

The Delaware Public Health Association was officially reborn at the 141st Annual Meeting of the American Public Health Association (AHPA) held in Boston, MA in November, 2013. At this meeting, affiliation of the DPHA was transferred to the Delaware Academy of Medicine officially on November 5, 2013 by action of the APHA Governing Council. The Delaware Academy of Medicine, who's mission statement is "to promote the well-being of our community through education and the promotion of public health," is honored to take on this responsibility in the First State.

ISSN 2639-6378