

September 8, 2023

The Honorable Xavier Becerra  
Secretary of Health and Human Services  
U.S. Department of Health and Human Services  
200 Independence Avenue SW  
Washington, DC 20201

Dear Secretary Becerra:

We were recently made aware that the National Institute of Minority Health and Health Disparities (NIMHD) Advisory Committee recommended against designating people with disabilities as a health disparity population. As you may know, the NIH Advisory Committee to the Director (ACD) Working Group on Diversity convened a Subgroup on Individuals with Disabilities which specifically called on NIMHD to include disability as a health disparity population. To summarize, it states, “This Subgroup report will highlight the need to designate people with disabilities as a health disparity population, engage various disability communities in health disparities research, and increase disability representation in the biomedical and behavioral research workforce more broadly.”<sup>1</sup>

Because the ACD Subgroup on Individuals with Disabilities report’s conclusion that people with disabilities should be a health disparity population was **rejected** by the NIMHD Advisory Committee, people with disabilities will continue to be excluded from NIH funding and programs focused on addressing health disparities, also adversely impacting efforts to increase the representation of researchers with disabilities and improve inclusion of people with disabilities in research studies. We share concerns that this is inconsistent with the administration’s commitment to people with disabilities; disrupts current NIH Diversity, Equity, Inclusion, and Accessibility (DEIA) efforts; fails to consider current models and theories of disability; and does not reflect the perspectives of people with disabilities.

We have reviewed and share the concerns in the attached letter from the disability research community to NIMHD, which asserts that:

- All required criteria have already been met for the director of the NIMHD to designate people with disabilities as a health disparity population.
- The NIMHD Advisory Committee’s recommendation undermines current NIH DEIA initiatives and contradicts the Biden administration’s equity efforts.
- The NIMHD Advisory Committee’s stated reasons for not designating people with disabilities as health disparity population are based on ableist assumptions and a biased view of disability.

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<sup>1</sup> See [https://www.acd.od.nih.gov/documents/presentations/12092022\\_WGD\\_Disabilities\\_Subgroup\\_Report.pdf](https://www.acd.od.nih.gov/documents/presentations/12092022_WGD_Disabilities_Subgroup_Report.pdf) (page 13)

- The NIMHD Advisory committee did not include anyone with a disability, which is deeply problematic.

Their policy analysis provides a detailed accounting of how this decision was made and provides strong supporting evidence for its inconsistency with the administration's goals to advance policies supporting and including people with disabilities. While we are very disappointed in the decision made by the NIMHD Advisory Committee, we also recognize that the recommendation **not** to include people with disabilities as a health disparity population is just that – a recommendation. We know from prior experience that you have worked diligently to advance issues important to the disability community. Therefore, we also urge you to advance a swift course correction on this issue and move to designate people with disabilities as a health disparity population.

Please feel free to reach out to Tony Coelho ([hontonycoelho@gmail.com](mailto:hontonycoelho@gmail.com)) with any questions or for additional information.

Sincerely,

- Tony Coelho
- SCIBoston
- Access Care Anywhere
- Alliance for Aging Research
- Allies for Independence
- ALS Association
- American Association of Kidney Patients
- American Association of People with Disabilities
- American Association on Health and Disability
- American Foundation for the Blind
- Aphasia Nation, Inc.
- Autism Society of America
- Autism Speaks
- Autistic Self Advocacy Network
- Baylor University and Go Baby Go
- Bazelon Center for Mental Health Law
- CancerCare
- Caring Ambassadors Program
- Celiac Disease Foundation
- Center for Independent Living of Northwest Florida
- Center for Public Representation
- Center on Disability Studies University of Hawai'i at Mānoa
- Colorado Cross-Disability Coalition
- CommunicationFIRST
- cutaneous lymphoma foundation

- Diabetes Leadership Council
- Diabetes Patient Advocacy Coalition
- DiabetesSisters
- Disability Network Southwest Michigan
- Disability Rights Education and Defense Fund (DREDF)
- Epilepsy Foundation
- EvalCentric, LLC
- Flagler Health+
- Global Liver Institute
- Health Hats
- HealthHIV
- Hearing Loss Association of America
- Helen Keller Services
- ICAN, International Cancer Advocacy Network
- Lakeshore Foundation
- Living with Hearing Loss
- Lupus and Allied Diseases Association, Inc.
- M-CM Network
- Mass General Brigham
- Massachusetts Coalition for Health Equity
- Mental Health & Inclusion Ministries
- Michigan Developmental Disabilities Council
- Michigan Elder Justice Initiative
- Mind, Body & Play Therapies
- MLD Foundation
- Multiple Sclerosis Foundation
- National Disability Rights Network (NDRN)
- National Down Syndrome Society
- National Federation of the Blind of Maryland
- National Organization of Nurses with Disabilities (NOND)
- NBIA Disorders Association
- Not Dead Yet
- Parent Project Muscular Dystrophy
- Partnership for Inclusive Disaster Strategies
- Partnership to Improve Patient Care
- Patients' Rights Action Fund
- Perspectum
- Second Thoughts MA: Disability Rights Advocates against Assisted Suicide
- SYNGAP1 Foundation
- The Arc Detroit
- The Arc Michigan
- The Arc of Aurora

- The Arc of Northwest Wayne County
- The Headache and Migraine Policy Forum
- The National Center for Disability, Equity, and Intersectionality
- The Ohio State University & Brown University
- United Cerebral Palsy
- United Spinal Association
- University of California, San Francisco
- Victoria Gregorio, Children's Specialized Hospital
- Warriors on Wheels of Metropolitan Detroit
- World Institute on Disability
- Adrienne Robertiello, Children's Specialized Hospital
- Ann Chakwin, PhD
- Anna Malia Beckwith, Children's Specialized Hospital
- Ashley Albright
- Barbara Niederhoff
- Benjamin Wallen
- Blake Perkins, PT, DPT, ATP
- Bryan Farley
- Carolyn Foster, MD, MS
- Carolyn Grawi, MSW, LCSW, LMSW, ACSW, ADAC
- Cecile Poretz, Assistant Director, Disability Access and Inclusion, University of California, San Francisco (UCSF)
- Cheri Blauwet, Chief Medical Officer, Spaulding Rehabilitation Network
- Christina Rose Bauder, PhD, MPH, LPCC
- Christopher Raffi Najarian, M.D., M.P.H.
- Cindy Stevens
- Claire Marchetta, Children's Specialized Hospital
- Colin O'Reilly, Children's Specialized Hospital
- Constance Wold
- Dana Lorenz
- Danielle Delise, MAS, MEd
- David Estrada, Co-Chair, Council on Disability Awareness
- Dawn Howard
- Dawn Welshman
- Cheryl Hanley-Maxwell, Dean, College of Applied Health Sciences, University of Illinois - Urbana
- Denise Braun
- Diane Coleman
- Diane L Smith
- Diane Ngo, University of California San Francisco
- Donna Sablan
- Douglas Frey

- Dr. Laura J. Mattie
- E. VanderYacht
- Elayne R. Otstot
- Elise Armstrong, PT, DPT, University of California San Francisco
- Elizabeth T. Hsiao-Wecksler
- Ellen Leigh
- Emily C Marcinowski, PhD, Assistant Professor of Kinesiology, Louisiana State University
- Eric Welsby, Advocacy Director, Detroit Disability Power
- Erin Costanzo
- Erin Hickey, MD
- Evan Stevens
- Finn Gardiner, Director of Policy & Advocacy, Autistic People of Color Fund
- Former State Senator Richard T. Moore
- Georgine Booms
- Gustaf Van Acker
- Isabel Munoz Orozco
- James Sulzer, PhD, MetroHealth Medical Center
- Jamie Ballard, Cleveland State University
- Jean L. Minkel, PT, ATP
- Jessica Lizardi
- Jessica Solomon Sanders, MD
- Jill Harris, Children's Specialized Hospital
- Jo Booms
- Jonathan Prugh
- Josh Leonardis
- JoyAnn Ruscha
- Julie Reiskin, Co-Executive Director Colorado Cross-Disability Coalition
- Kara Ayers, PhD
- Karen A. Turner, Patient Navigator for Autism and Developmental Disabilities, Massachusetts General Hospital
- Kathryn Mosher, MD
- Kelly Keefe Marcoux, Children's Specialized Hospital
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- Madeleine Jacobs MD
- Maria Brucato
- Mark Simon
- Mark Stimson
- Marlene Murillo

- Martha Mason
- Mary Milidonis
- Maryann Ford
- Max Hornick
- Megan Braun
- Megan Morris, PhD, Director and Founder of the Disability Equity Collaborative
- Megan Rogers, Independence Care System
- Meighen Lovelace
- Michael Dribbon, Children's Specialized Hospital
- Michael S Shen, MD
- Mohammed Malek Aljamal
- Mona Vyas, Special Project Manager, CCDC
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- Patricia F. Anderson
- Pamela Herd, Georgetown University
- Rachael Stacom
- Robert Stevens
- Robin Cunconan-Lahr
- Rodney J Vergotine
- Sarah J Hein
- Shannon Swiger
- Skye Carlson
- Susan Aguinaga
- Ted A. Barrios, PhD
- Teri Langley, Executive Director, Disability Network/Michigan
- Toni Iacolucci, HLAA Communication Access in Health Care Program
- Yue Liu
- Yuliana Soto
- Zary Amirhosseini

CC:

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