January 11, 2021

Dear Members of the California COVID-19 Vaccine Drafting Guidelines Workgroup,

We write as members of California’s Community Advisory Vaccine Committee who collectively represent people with a wide range of disabilities and chronic health conditions across the age spectrum. After consulting with one another on the proposed 1b vaccine prioritizations proposed by the Drafting Guidelines Workgroup last week, we ask the Workgroup to include two changes to the proposed priority tiers under phase 1b:

- Include people with disabilities of any age who receive long-term services and supports (LTSS) through Medi-Cal waiver services and programs, the In-Home Supportive Services (IHSS) program, the Program for All-Inclusive Care for the Elderly (PACE), and through Regional Centers.

- Provide a “safety valve” for people with disabilities and chronic health conditions of any age who can demonstrate with medical evidence that they are at great risk of severe health consequences including death if they acquire COVID-19.

We appreciate the Workgroup’s inclusion of people with comorbid conditions ages 64-75 years in category 1b. However, we also recognize that age, in itself, is a highly inexact proxy for the disability communities, particularly lower-income people with disabilities of color, who remain at high risk for COVID infection and/or severe illness. An individual with developmental disabilities in their 50s who lives in a small group home is, in fact, at significantly higher risk of acquiring COVID-19 than someone in their 60s who can safely shelter in place without visitors because of daily exposures to direct support workers in the small group home. Moreover, the CDC’s list of recognized comorbid conditions, does not include either real-time research into how people with different disabilities experience the virus (e.g., Landes, SD, Turk, MA, & Wong, AWWA (in press), “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), nor the impact of medical rationing and implicit bias on people with significant disabilities. For example, a high-weight individual with multiple healthcare conditions may be unable to access regular therapy for severe lymphedema without risking COVID-19 infection and, if they end up with COVID-19 during a surge resulting in health care rationing, they also are at risk of being denied care because of the application of crisis standard of care guidelines.

There is also the equitable consideration that many people with disabilities receiving home and community-based long-term services and supports require nursing home levels of care but fought to stay out of institutions or return to the community, potentially living with family in multi-generational homes. These individuals have not been subject to the tragic rates of infection in nursing homes, where they would ironically be receiving the vaccination now, but their risks of infection and severe illness
during a time of rising community infection rates should accord them a place in category 1b, regardless of their age. Studies are beginning to bear out the disproportionate impact COVID is having on people with specific disabilities, including developmental disabilities, who are 3 times more likely to die, and people with Down Syndrome, who are 10 times more likely to die. ([https://tinyurl.com/y2a5f9ql](https://tinyurl.com/y2a5f9ql); [https://www.acpjournals.org/doi/10.7326/M20-4986](https://www.acpjournals.org/doi/10.7326/M20-4986)), but people with less frequently occurring disabilities could also bear disproportionate impacts that have not yet been the subject of study.

We support the prioritized inclusion of personal care assistants who are coming into the homes of disabled people as front-line healthcare workers in category 1a, but since we don’t know the infectious capacity of those who have been vaccinated, those who receive personal assistance services must be separately evaluated for vaccination.

In order to provide some sense of the number of individuals that are being raised here we have some approximate figures below. Please bear in mind that there is considerable overlap both among the groups listed below as well as with other groups that are already proposed for inclusion in 1b (e.g., persons over 75 and persons between 64 and 75 with comorbid conditions).

CA Assisted Living Waiver: 5,000, with 4,500 on the waitlist

CA Community Based Adult Services Program: 40,000

CA HCBS Waiver for Californians w/DD: 95,000

CA HIV/AIDS Waiver: 1,500

CA Home and Community Based Alternatives Waiver: 5,500, with 600 on the waiting list

CA Multipurpose Senior Services Program: up to 12,000

CA Self-Determination Program for Individuals with Developmental Disabilities: 350

Community First Option: 250,000 (most overlapping with other categories in this list)

IHSS: 600,500

Regional Center Service recipients: 350,000

PACE participant: 10,000
Our recommendation would include an approximate 1.1 million Californians who would very likely have fallen within 1a if they were not being cared for in the community.

Finally, we encourage the Workgroup to recommend sub priorities within 1b based on who has been most impacted by the pandemic. For example, all older adults 75+ have not been similarly situated, with death and infection rates disproportionately impacting older adults of color. Further sub prioritization based on considerations like race and community would be consistent with sub prioritization guidance for phase 1a and is critical in ensuring a vaccine allocation grounded in equity.

Thank you for the opportunity to provide our input to the Drafting Guidelines Workgroup.

Sincerely,
Aaron Carruthers, California State Council on Developmental Disabilities
Andy Imparato, Disability Rights California
Christina Mills, California Foundation for Independent Living Centers
Denny Chan, Justice in Aging
Silvia Yee, Disability Rights Education and Defense Fund

And the following 272 organizations:

24 Hour Home Care
A Better Life Together, Inc
A Home for Chris
AbilityPath
Adaptive Learning Center
Advocate for Down Syndrome
Ala Costa Centers
Alegria Community Living
Alliance for Leadership & Education
Amato Home
American Academy of Developmental Medicine and Dentistry
American Conservatory Theater
Anthesis
Aphasia Recovery Connection
Arcadia Home Care
Aspire to Greatness Silicon Valley
Autism, Advocacy and Intervention
Autism Society of America
Autism Society of Los Angeles
Autism Society of San Diego
Autism Society of San Francisco
Autism Speaks
Avenues Supported Living Services
Bakersfield A.R.C.
Becky Coffey, ILS
Behavior Analysis Technologies Residential Services
BHH Services
Blossoms
Board of Registered Nursing
Building Bridges for Special Needs-Coachella Valley
Bungalow Support Services
Cal-TASH
California Association of Public Authorities for IHSS
California Community Living Network
California Council of the Blind
California Disability Services Association
California Disaster Coalition
California Down Syndrome Advocacy Coalition
California IHSS Consumer Alliance
California School Employees Association
California School Nurses Organization (CSNO)
California State Teachers’ Retirement System
California’s State Independent Living Council
Camp Krem
Care Parent Network
Careco Inc.
Casa Pacifica ADHC Center
Center for Independence of Individuals with Disabilities
Center on Deafness Inland Empire (CODIE)
Central Coast Center for Independent Living
Centro de Ninos y Padres
Channel Islands Social Services
CHOICESS
Christina’s House Inc.
Climb, Inc
Climb Transition Services
Club 21 Learning and Resource Center
Chime Institute Early Education Programs
Coastal Heaven Families
Coastal Kids Home Care
COLLABORATIVE DESIGN AND PLANN
Community Access Services
Community Catalysts of California
Community & Employment Links
Community Integrated Support Services, Inc
Community Interface Services
Community Living Options
Community Resources for Independent Living
Compass LLC
Comprehensive Continuum of Services Inc.
Conexiones Educativas
Connections for Life
Creative Support Alternatives
Creativity Explored
DCBA of Danville, CA
Deaf and Hard of Hearing Service Center
Deaf Plus Adult Community
Designing Accessible Communities
Developmental Services Network
Devereux CA
Diocese of San Diego Mental Health Ministry
Disability Community Resource Center, Inc.
Disability Rights California and the Association of California State Employees with Disabilities
Disability Rights Education and Defense Fund
Disability Voices United
Down Syndrome Association of Central California
Down Syndrome Association of Los Angeles
Down Syndrome Connection of Bay Area
Down Syndrome Connection of the Bay Area
Downs Town
Downsyndromeconnections.com
Dysautonomia International California Support Group
Early Learning Institute
East Bay Autism Parents
East Bay Innovations
Elective Support Services
Elk Grove Adult Community Training
Enjoy Life More, Inc.
Exceptional Children’s Foundation
Exceptional Family Center
Express Air Testing Inc.
Family Focus Resource Center
Family Resource Navigators
Family Voices of California
Far Northern Regional Center
Fenix Home
Filipino Cursillo
Fran Gelb and Company, Inc.
FREED Center for Independent Living
Friends of Children with Special Needs
Functional Determination
Full Circle of Choices, Inc
Futures Explored/Vte
Gaining Groun
Golden Gate Regional Center
Gratia Home
Greater Los Angeles Agency on Deafness
Hand in Hand: The Domestic Employers Network
Heather’s House
Helping Hands East Bay
Hodges Care Home
Home care nurse
Home Community Based Alternatives
Home of Guiding Hands
Hope Services
Housing Consortium of the East Bay
Inclusions Services LLC
Ideal Care, LLC.
Illumination Institute
Independent Living Resource Center San Francisco
Institute for Applied Behavior Analysis
Institute for Holistic Health Studies
Integrated Resources Institute
International Association of Black Actuaries
Janet Pomeroy Recreation and Rehabilitation Center
Janis Escamilla Supported Living Services, LLC
Jaqui’ Foundation, Inc.
Jay Nolan Community Services
John P Kelly & Associates
Journey of Choice, Inc.
Kaiser Oakland Medical Center
KB Way Supported Living Services, LLC
Kern Down Syndrome Network
Law Offices of Mark B. Freschi
Liahona Community Care
Libertana
Liberty Support Services, Inc.
Life Works
Lighthouse living services red bluff
Living Inside the Puzzle
Major Impact Theater
Marin Center for Independent Living (Marin CIL)
Marin Ventures
Mark’s Way
Marysville People First
Maxim Health Care; RN
McGarvey Home
Media Mahima/Radio Dehotties
Men of Color Connected for Higher Achievement
Monarch Independent Living Services, Inc.
Mother Lode Rehabilitation Enterprises Inc.
Mt. Diablo Adult Education
National Alliance on Mental Illness
National Association for the Advancement of Colored People
National Disability Mentoring Coalition
National Task Group on Intellectual Disabilities and Dementia Practices (NTG)
Naval Facilities Engineering Command Southwest
NCI Affiliates
Networx SLS
New Horizons
Ninos Del Cielo, Inc
Noah Homes
NorCal Services for Deaf and HH
North Coast Supportability, LLC
Northern California ADAPT
NorthStar Services
Nurturing Independence through Artistic Development
Oceanside Supported Living Services
One Step Beyond, Inc.
Opportunity for Independence
Options for All
Orange County Deaf Equal Access Foundation
Palm Tree Residential Care Home #2
PANAN USA
Pangea Legal Services
Parent Infant Program
Parents Advocating Together
Parents Helping Parents, Inc.
Parkside Villa SLS
Partnerships With Industry
PathPoint
Pathway to Choices, Inc
PCDH19 Alliance
Peco Care Home
People Creating Success, Inc.
Person Centered Services of Stockton, CA
Personal Assistance Resource
Pihl & Associates
Placer Independent Resource Services
Pomeroy Recreation and Rehabilitation Center, Inc.
PRAGNYA
Progressions: Developmental-Behavioral Pediatrics
Progressive Employment Concepts
Quality Connections Living Services Inc.
Quality Respite and Home Care Inc
RC Elite Services
REACH Services
Redwood Coast Regional Center
Regional Center of The East Bay
Remi Vista Supported Living
Rest & Relax Respite Agency
Rolling Start, Inc.
Roslil Inc.
S&P Corporation/Bordon Homes
San Andreas Regional Center
San Diego Regional Center
Santa Cruz Supported Living
SEIU 2015
Self-Determination Local Advisory Committee
Senior and Disability Action
Sentry Living Solutions
Serafin Care Home
Service Center for Independent Life
Shared Adventures
Silicon Valley Down Syndrome Network
Silicon Valley Independent Living Center
Sister and support to brother with Down Syndrome
Social Vocational Services
Sonic Forest Productions
Southside Unlimited
Special Care Services
Special Care Supported Living Services
Special Educator, Down Syndrome Society
Speech Language and Learning Services of Northern California
Spread Your Wings
St. John Boys Home, Inc.
St. John Corinthian Care, LLC.
St. Madeleine Sophie's Center
Stanford Autism Center, Parent Advisory Board
STEP Inc.
Steppin' Out Dance Studio
Student Recruitment and Retention Center
Sunny Days of California
Summer House Inc.
Support for Families of Children with Disabilities
Tailored Living Choices Supported Living Services LLC
The Adult Skills Center (TASC)
The Arc of Amador and Calaveras
The Arc of Butte County
The Arc of California
The Arc of the East Bay
The Arc Fresno/Madera Counties
The Arc of Imperial Valley
The Arc of Placer County
The Arc of San Diego
The Arc of San Francisco
The Arc of Solano
The Arc of Ventura
The Aurelia Foundation
The Autism Community in Action
The Awareness Show
The California Sibling Leadership Network
The Cronin Law Group
The Dayle McIntosh Center
The Emily Johnson Trust
Thrive Support Services, Inc
Tierra del Sol Foundation
Tollner Law Offices
Tri-County GLAD
Trilogy adult services
UC San Diego Health
UCP WORK Inc.
Ukiah Valley Association for Habilitation
United Administrators of San Francisco
United Automobile, Aerospace and Agricultural Implement Workers of America
United Cerebral Palsy Central California
United Cerebral Palsy of the Inland Empire
United Cerebral Palsy of the North Bay
United Cerebral Palsy of Orange County
United Cerebral Palsy of San Joaquin
United Cerebral Palsy of Stanislaus County
United Educators of San Francisco
UVAH
Valley Mountain Regional Center
Visbal Strategic Consulting
Vista Center for the Blind & Visually Impaired
Vista Hill Foundation
Walsh McKean Furcolo LLP
WarmLine Family Resource Center
Whistlestop Wheels at Vivalon

While the letter is focused on organizational signatures from state, regional and local organizations, an additional 550 individuals who have disabilities, are family members or service providers also submitted sign-ons.