

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://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  
CHOICCESS  
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](http://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.