January 18, 2021

Ms. Ann Lewandowski and Dr. Jonathan Temte
SDMAC- Vaccine Subcommittee
Department of Health Services
1 West Wilson Street
Madison, WI 53703

Dear Co-Chairs:

We are writing as organizations who support and advocate for the more than 75,000 people with disabilities and older adults who are eligible for the Medicaid long-term waiver under home and community-based services (HCBS) through Family Care, Family Care Partnership, PACE, and IRIS programs. The undersigned organizations deeply appreciate and strongly support the subcommittee's inclusion of Family Care and IRIS recipients as a separate priority group in the phase 1b vaccine group and urge the Department of Health Services to designate **all Family Care and IRIS members as a 1b priority group.**

A proportion of the people with disabilities served within these programs would have already been eligible for vaccine under group 1a due to their residential environment; however, a significant yet critical group has been left out: those participants who live in smaller congregate living settings and those who live in their own homes or supported apartments. This population includes people with a range of disabilities and chronic health conditions who are eligible based on their need for a nursing home level of care, much as frail elders in the program are eligible.

In Wisconsin, the death rate for people with disabilities accessing Wisconsin's long-term care system is higher than the general population of Wisconsin. As of 1/5/2021, the Department of Health Services reported 10.7 % death rate of members in long-term care contracting the virus compared to a 1% death rate for all people contracting the virus in Wisconsin. [1]

Recent data indicates that people with intellectual and developmental disabilities (IDD) are at higher risk for acquiring the coronavirus and early data also suggests a higher risk of death and increased disability due to the virus. A recent FAIR Health white paper which analyzed a massive number of insurance claims documented that across all age groups, people with intellectual disabilities have the third highest risk of COVID-19 death. [2] The data also demonstrated that people with IDD have a greater mortality risk than people with heart failure and chronic lung disease. The paper highlights the death rate among all patients with COVID-19 was 0.6%. But, for people with developmental disorders it was 1.22% and 3.37% of those with intellectual disabilities.

In addition to these statistics, there are multiple risk factors for people with disabilities in the long-term care system that should be considered in your decision-making process.

1. People in long-term care disproportionately live at congregate settings. Congregate settings include licensed and unlicensed homes in Wisconsin. This would include assisted living, 1-2/bed or 3-4 bed adult family homes, and community based residential facilities (CBRF). People in these setting are often

[1] Medicaid Adult Home and Community-Based Services: COVID-19 Data | Wisconsin Department of Health Services

[2] FAIR Health White Paper. Risk Factors for COVID-19 Mortality among Privately Insured Patients: A Claims Data Analysis. November 11, 2020.

unable to make decisions regarding who and how many outside people provide supports and services, often in intimate proximity that does not allow for physical distancing, putting them at higher risk of exposure. Individuals who live in group homes or other congregate residential settings should be considered at equivalent risk to older adults who live in congregate settings. Many settings that are not formally licensed through the state Division of Quality Assurance, but which are still congregate in nature have not been notified they are eligible for vaccination schedule and many verified 1a congregate settings have yet to be vaccinated. This comment also supports the subcommittee's recommendation that residents of smaller licensed or certified congregate settings be prioritized in phase 1b regardless of their participation in either Family Care or IRIS.

2. People in long-term care disproportionately attend daily services in congregate settings, including adult day care, day service centers, and sheltered workshops. They also use congregate transportation, such as buses, to get to those settings. These settings bring together people with disabilities and care providers from many different households, increasing the risk of contracting the virus. While many have policies in place to mitigate risk, it is often impossible to eliminate all risk.
3. People in long-term care who live in their own homes or supported apartments are still at great risk of contracting COVID-19. The nature of their support needs is such that most of these people have multiple caregivers providing hands on care to them. Although technically covered under phase 1a, most of these workers are not connected to any health care system and do not have ready access to the vaccine. Thus, even though nearly 30% of health care workers have been vaccinated, almost none of those are in the care force that supports the IRIS and Family Care population living in non-congregate settings. Vaccination under phase 1a that was supposed to protect this vulnerable population (by protecting its care force), has not been implemented at this time leaving both the caregiver and the person they serve vulnerable.
4. People in long-term care receive personal and supportive care services from paid and unpaid caregivers that put them at higher risk due to close contact during these supports. Paid caregivers may also be working with multiple individuals at multiple locations, increasing the risk of spreading the virus between individuals.
5. People in long-term care are often supported at home by elderly parent caregivers who are also at high risk of contracting the virus. Elderly caregivers may be at higher risk of contracting the virus and death resulting in the person with the disability at risk of being placed in a nursing care facility due to lack of support.
6. Some people in long-term care often have limited ability to follow the recommendations of the CDC to reduce the potential for contracting and spreading the virus, including mask wearing, adequate handwashing, and physical distancing. Sensory issues, receptive and expressive language disorders, inability to assess safety risks are all typical symptoms of intellectual disabilities that make it far more likely that this population will be unable to comply with basic preventative protocols. The largest national survey of Direct Support Professionals (completed by the University of MN and the National Alliance for Direct Support Professionals - 9,000 DSP's) indicates that approximately 40% of the people supported by DSPs have either only fair or poor social distancing practices. [3]
7. People in long-term care are experiencing extreme social isolation. Many people with disabilities living in congregate settings or sheltering at home have not been allowed to leave their homes, visit with family and friends, or continue their employment. Many do not have access to phones or other technology to remain virtually connected to family and friends. For many people, this has led to increased mental health concerns, escalated behavioral challenges and the need for additional supports and services in their residential settings. For people in this group this is more than just the typical lack of

[3] https://publications.ici.umn.edu/community-living/covid19-survey/results-dsp-covid-19-experiences

social contact a person without intellectual disability is experiencing during this ordeal. Social and community integration experiences are typically written into IRIS and Family Care care plans. For this group, being able to experience the larger world is treatment-not recreation or entertainment.

8. People in the long-term care system are eligible for a nursing home level of care but have been able to live in the community with supports and services. To quality for Wisconsin's long-term care waiver services, an individual must be found eligible to need a nursing home level of care. This group of Wisconsinites would have fallen into 1a if they were not being cared for in the community under the home and community-based waivers.

In addition to the risk factors listed above, people in long-term care are easily identified for vaccine delivery. The Department of Health Services already has access to their location, health conditions, and the service systems that deliver their care. These members and participants have monthly contact with a care manager or IRIS consultant who can help them gain information on how to receive a vaccination, where to receive the vaccine, and facilitate reminders when the second dose needs to be administered.

We would respectfully ask that you include the entire population in the Medicaid long-term waiver under home and community-based services (HCBS) through Family Care, Family Care Partnership, PACE, and IRIS in the 1b priority group.

Sincerely,

Beth Swedeen, Executive Director
Wisconsin Board for People with Developmental Disabilities

Lisa Pugh, Executive Director
The Arc Wisconsin

Survival Coalition, Co-Chairs
Kit Kerschensteiner, Lisa Pugh, and Beth Swedeen

Leann Smith DaWalt, PhD, Director
University Center for Excellence in Developmental Disabilities (UCEDD), Waisman Center

Qiang Chang, PhD, Director
Waisman Center, and Waisman Center Intellectual and Developmental Disabilities Research Center (IDDRC)

Lea Kitz, Executive Director
Disability Rights Wisconsin

Joel Kleefisch, Government Affairs Manager
A-Team Grassroots

Kirsten Cooper, Executive Director
Autism Society of Greater Wisconsin

Kirsten Engel, Executive Director
Autism Society of South Central

Emily Levine, Executive Director
Autism Society of Southeastern Wisconsin

Todd Costello, Executive Director
Community Living Alliance

Lisa M. Davidson, CEO
Disability Service Provider Network (DSPN)

Wes Martin, Board Chair
Greater Wisconsin Agency on Aging Resources, Inc. (GWAAR)

Trista Brandt, Board Chair
InControl Wisconsin

Cindy Bentley, Executive Director
People First Wisconsin

Lisa Schneider, Executive Director
Respite Care Association of Wisconsin

Marion Holmberg, Leadership Team
SAVE IRIS, Wisconsin's Self Direction Advocates

Marit C. Waack, Executive Director
The Arc Eau Claire, Inc.

Liz Morrell, Executive Director
The Arc Fond Du Lac

Julie Briggs, Executive Director
The Arc Greater Columbia County, Inc.

Anna Stevens, Executive Director
The Arc-Dane County

Serryn Erickson, Executive Director
The Arc-Dunn County

Robert Kellerman, Chair
Wisconsin Aging Advocacy Network (WANN)

Jennifer Felty, Co-Chair
Wisconsin APSE(Association of People Supporting Employment First)

Jessica Smith, CSW
Wisconsin Association of Benefit Specialists

Maureen Ryan, Executive Director
Wisconsin Coalition of Independent Living Centers, Inc.

Barbara Katz, Co-Director
Family Voices of Wisconsin

Sarah Bass, Board Chair
Wisconsin Long-Term Care Workforce Alliance

Todd Costello, Board Chair
Wisconsin Personal Services Association

Kenneth Munson, CEO
Community Care, Inc.

Mark K. Hilliker, CEO
Inclusa, Inc.

Thomas H. Lutzow, CEO
Independent Care Health Plan (iCare)

Jennifer Harrison, COO
Lakeland Care, Inc.

Joe Arzbecker, CEO
Lutheran Social Services of Wisconsin and Upper Michigan, Inc.

Maria Ledger, CEO
My Choice Wisconsin

Shanna Jensen, President
TMG

Mary Kessens, President and CEO
APTIV

Cynthia Brown, President and CEO
C Renee Consulting and Management Group

Dawn Nuoffer, Executive Director
Down Syndrome Association of Wisconsin

Tracy Nelson, CEO
East Shore Industries, Inc.

Jennifer Felty, Director
Headwaters, Inc.

Julie Strenn, CEO and President
Opportunity Development Center Inc.

Sara Satterfield, Program Director
Oppportunity, Inc.

Erin Schultz, Executive Director
SOAR Fox Cities, Inc.

Derek Kruempel, Executive Director
Southwest Opportunity Center

Pete Condon, President
The Arc Green County