(abi)
community

NWDSA
northwest down syndrome association

House Interim Committee on Health Care
Oregon State Capital
980 Court Street, Room 453
Salem, Oregon 97301

May 20 ,2020

Dear Committee:

Thank you for your work and the hearing to better understand the needs of vulnerable populations related to Covid-19. This is a vital discussion.

We are a grass roots organization that works with over 4,000 local families. Our staff are parents of children with disabilities or people with disabilities. Most of our families have children with significant disabilities who are at great risk from the virus and its potential impact
They are also families who are shouldering the care of their loved ones without the supports of specialists in schools and many without the support of the personal support workers that were a part of the family's network. As the risks from infection are much higher many families are trying to isolate as much as possible. Others are essential workers and carry stress about the risk their work brings to the family. This is an intersectional issue for families of color and those with disabilities. Disability is more prevalent in families of color and there are more of those families in higher risk jobs.

We work with the Latinx community through our federal Child and Parent Resource Center breaking barriers grant. We are very concerned about the higher incidence of infection in these families and the extra challenges for our undocumented families. There are other issues that become vital to our families such as the ability to access equitable health care and telehealth. This requires language access and cognitive access through use of visuals and supports. We also have worked hard to push for a care giver or parent to be with someone who has significant needs and may rely on a trusted person to help them communicate their needs and be safe in the hospital.

So far, the best we have been able to achieve is OHA guidance that not all hospitals are heeding and many parents and people with disabilities are unaware of this guidance. If English is not your first language this issue is compounded. We would like to reach and support more of our families with pre-planning as well as see this guidance become clear policy. We have no direct link to the decision-making groups that have been formed to work on these issues and that lack of voice is showing.

We have also been involved in advocacy with the DD coalition, Disability Rights Oregon and others around our needs and the Medicaid K plan and supports for adults with disabilities. As you listen to advocacy for vulnerable groups we want you to consider that there is no one at the table from the parents or organizations that serve those living this experience who are under great pressure and include all races and incomes.

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Our key worker with the Latinx community has three children one who has Down Syndrome and uses a communication device. We must navigate many systems and polices are quickly changing often without referencing our lived experiences. We have seen this in conversations about rationing care or seeking do not resuscitate orders because people have disabilities. We do not expect the deep understanding we hold of these issues and suggest that you might have a more robust and informed discussion if you were to include disability and family perspective

We are very glad that you have a group presenting that serve the Latinx community so well and understand many needs and would seek to add to that voice and deepen the reach and understanding of the vulnerable and underserved.

Respectfully

Angela Jarvis-Holland

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