## Dear Legislator,

## Today, we are writing this letter in Support of SB 1606 Access to Care for Oregonians with Disabilities.

Home Life is an agency in Corvallis, Oregon who assists adults with Intellectual and Developmental Disabilities (I/DD) to enjoy active, productive, and empowered lives. Throughout the state of Oregon there still are injustices for individuals who need staff support in a medical facility.

On Weds, June 17<sup>th</sup>, after the individual we support was transported to the Emergency Room by ambulance, our Direct Support Professional was denied entry into Corvallis Good Samaritan Hospital to provide support for the individual that we work with. She was able to gain some limited entry for support and visitation after explaining she was a support staff. However, we want to advocate that in these situations, the medical field is aware of the rights of adults with Intellectual and Developmental Disabilities to have their trusted staff join them in the hospital.

Prior to the COVID-19 Pandemic, our Direct Support Professionals were always invited to be a part of the conversation with medical personnel because they provide so much valuable input and knowledge for ensuring that our clients are receiving the best possible care. Corvallis hospital has not historically been a barrier for us to assist while in their care, but many hospitals across the state have not been so understanding. This is a system and civil rights issue which has sometimes affected people in dire ways who are not supported while in a hospital setting.

In many cases, people with disabilities receive support from agencies because they may not be able to answer questions about their complex medical situation or history without a staff person. Individuals may receive support because they need help explaining something, re-phrasing the questions or even having a staff be the voice for someone who may not be able to speak themselves.

Someone who has an Intellectual a developmental disability may require different language around medical terms to ensure that they are receiving the best treatment with informed consent. At times staff are able to ease anxiety, support person with positive behavior support techniques and make the individuals' experience in the care of the hospital a comfortable one. If there is no staff support when making a medical decision which literally could be life or death, the individual may not be able to make the right choice or have their desires honored.

Home Life is in full support of the points made in the "solution" section of LC 52, requested by Senator Gelser, which includes the following:

"Mandate hospitals to allow support people to patients as required by the ADA, consistent with the order recently released by US Health and Human Services and current OHA guidelines. Although OHA has issued guidelines on this matter, the agency does not have the resources to enforce. Hospitals continue to deny access to support even when presented with the OHA document, arguing they are simply guidelines.

Clarify that Crisis Care Guidance in Oregon may not include provisions that consider the presence of a disability as a determinant factor in the decision of who gets care and who does not clarify that DNR/POLST/DNI orders are not a requirement for admission to a hospital or provision of care for a person with a disability, elderly person or resident of a longer term care or congregate care facility.

Specify that coercion of an individual or their representative to sign orders to waive care are not permitted during a public health emergency, require hospitals to contact Disability Rights Oregon prior to withholding or withdrawing lifesaving treatment or making a hospice election for individuals with disabilities who are in the care of the state when that decision is directed by a hospital or health care provider or the instrument allowing the decision was signed at admission to the hospital, after admission to the hospital or within the 14 days prior to hospital admission."

In close, Home Life is asking you to add SB 1606 to your bills in consideration for the June 24th Special Session. Lives are at risk due to this discrimination every day, and even more so, during this crisis. Oregonians with IDD cannot afford for this inequity to continue. Their very lives are at stake.

We thank you for your consideration, and are happy to help support this effort in any way we can.

Respectfully,

Home Life Administrative team

Dave Zaback, Executive Director Emily Albers, Program Director Ashley Marcus, Program Director Jennifer Cossell, HR Director Casey Cox, Finance Director

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