



February 15, 2017

TO: Senator Mitch Greenlick, Chair
House Committee on Health Care
FR: Bob Joondeph, Executive Director
RE: HB 2839

Disability Rights Oregon periodically receives calls from family members and case workers on behalf of individuals with disabilities who need organ transplants but have either been denied access or are experiencing delays or other difficulties in obtaining the needed organ.

In many of those cases, the concerned caller believes that the denial or difficulty is based solely on the potential recipient's autism, down syndrome, mental illness or addiction history. When disability discrimination is alleged, DRO will investigate the circumstances and attempt to resolve the matter, if possible.

The first challenge for us is to determine who acts as the gatekeeper for access to the needed organ. Once that is determined, DRO requests records and gathers other information about the decision.

In most cases, the deciding party will deny discriminating on the basis of disability. The decision, we are told, is based upon their assessment of the individual's ability to self-care following the transplant or, in the case of liver transplants for individuals with a history of addiction (not present use), a concern that the individual will return to past behaviors and defeat the efficacy of the transplant.

In some cases, the concerns about future behavior that is secondary to the disability are well-founded. However, we have found a number of cases in which false assumptions and stereotypes have come into play. For example, an individual who lives in a residential care environment and receives ongoing assistance with taking medication and other health care needs has been deemed unable to follow through with medical self-care following a transplant. Similarly, individuals with long histories of recovery from addiction have been considered unsuitable for a liver transplant due to their status of being in recovery.

From our experience, professionals who work in the organ transplant field strongly believe in the national and local standards that have been developed for making the very difficult decisions about who may be a recipient. All claim not to discriminate. However, our experience has also convinced us that ingrained attitudes persist about the quality and nature of the lives of individuals with disabilities and these may result in denials that are actually based upon the individual's disability status.

For these reasons, DRO supports HB 2839.