FAMILY ISSUES FACT SHEET

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Organ Transplant Discrimination Prevention in Arizona

HB 2659 Organ Transplants; Disabilities; Discrimination; Prohibition

EXECUTIVE SUMMARY

HB 2659 prohibits covered entities from determining that an individual is ineligible to receive a transplant, deny an organ transplant or related service, refuse to refer the individual to an organ transplant center, refuse to place an individual on a waiting list, or decline insurance coverage for a transplant or related service based solely on the fact that the individual has a disability.

WHAT DOES THE BILL DO?

HB 2659 ensures that health care practitioners, facilities, and others responsible for potential recipients of anatomical gifts or organ transplants may not discriminate against people solely on the basis of disability. It is similar to laws in 22 other states.

The bill also recognizes the importance of auxiliary aids and services, the ability of an individual's support network to help with post-operative care, and the need for reasonable modifications to policies and procedures to make organ transplant systems and facilities more accessible to people with disabilities. At the same time, the bill respects the professional judgement of health care providers by clarifying how disability should properly be considered in an individualized treatment plan.

Finally, if a covered entity violates these rules, the bill empowers patients with disabilities to sue in the appropriate court to stop the violation or for money damages. This right is not only a way to hold covered entities accountable, but it also provides access to a legal mechanism for establishing the facts. During this extremely trying and confusing time for a family – and for covered entities – getting to the bottom of what did – or didn't – happen may otherwise prove very difficult.

TALKING POINTS

1. Although the Americans with Disabilities Act outlaws discrimination on the basis of disability, including discrimination by doctors, some health providers fail to recognize that this can apply to discriminatory denials of organ transplants. HB 2659 clarifies that doctors, hospitals, transplant centers, and other health care providers are prohibited from denying access to necessary organ transplants solely on the basis of a qualified individual's disability.

- 2. Many families can't effectively enforce their rights under the Americans with Disabilities Act because they must go through a long process of filing a lawsuit in federal court. This process can take years, cost thousands of dollars, and in the meantime people may die from their underlying medical conditions. SB 2040 includes a fast-track procedure for challenging discrimination to ensure that people in urgent need of an organ transplant can obtain timely resolutions to their claims.
- 3. Health care providers retain their professional judgement about how best to care for their patients with disabilities, but they are not allowed to deny transplants or related care just because of those disabilities.

CONCLUSION

Despite existing civil rights protections, individuals with Down syndrome and other disabilities continue to face both willful and unintended discrimination in organ transplantation which threatens their ability to access health care when they need it most. At the same time, health care providers need clarity and guidance about how to account for and accommodate disability in their practice. HB 2659 addresses both issues by spelling out what is and isn't allowed and providing new avenues for families to seek timely relief, a critical consideration due to the urgency of these situations.