

## HOUSE OF REPRESENTATIVES STAFF FINAL BILL ANALYSIS

**BILL #:** CS/HB 1179 Nondiscrimination in Organ Transplants  
**SPONSOR(S):** Health Market Reform Subcommittee, Fischer and others  
**TIED BILLS:** **IDEN./SIM. BILLS:** CS/CS/SB 1556

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**FINAL HOUSE FLOOR ACTION:** 111 Y's 0 N's **GOVERNOR'S ACTION:** Approved

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### SUMMARY ANALYSIS

CS/HB 1179 passed the House on February 26, 2020, and subsequently passed the Senate on March 11, 2020.

Organ and tissue donation is the process of surgically removing an organ or tissue from one person (the donor) and transplanting it into another person (the recipient). Transplantation in such cases is necessary because the recipient's organ has failed or has been damaged by disease or injury.

The Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act of 1973 prohibit discrimination on the basis of disability. HB 1179 prohibits discrimination in access to anatomical gifts and organ transplants for individuals with disabilities. Health insurance policies and health maintenance organization contracts would also be prohibited from denying coverage for an organ transplant solely on the basis of an insured's or subscriber's disability.

The bill prohibits covered entities from taking specific actions against an individual with a developmental or intellectual disability who is eligible to receive an anatomical gift (human body parts donated after death for use in transplants, therapy, research, or education) based solely on the fact that they have a disability. Covered entities include health care practitioners, health care facilities, and any other entity responsible for potential recipients of anatomical gifts.

The bill requires covered entities to make reasonable accommodations in their policies, practices, or procedures, when necessary, to allow a patient with a disability access to services unless it is demonstrated that making the modification would fundamentally alter the nature of the services.

The bill provides injunctive relief for a qualified individual who is affected by violations of these provisions committed by a covered entity.

The bill has an indeterminate, insignificant, negative fiscal impact on the Agency for Health Care Administration and the Department of Health.

The bill was approved by the Governor on June 29, 2020, ch. 2020-139, L.O.F., the effective date is July 1, 2020.

# I. SUBSTANTIVE INFORMATION

## A. EFFECT OF CHANGES:

### Present Situation

#### Organ Donation

Organ and tissue donation is the process of surgically removing an organ or tissue from one person (the donor) and transplanting it into another person (the recipient). Transplantation in such cases is necessary because the recipient's organ has failed or has been damaged by disease or injury. Transplantable organs include the kidneys, liver, heart, lungs, pancreas and intestine.<sup>1</sup> Transplantable tissues include skin used as a temporary dressing for burns, serious abrasions and other exposed areas; heart valves used to replace defective valves; tendons used to repair torn ligaments on knees or other joints; veins used in cardiac by-pass surgery; corneas used to restore sight; and bone used in orthopedic surgery to facilitate healing of fractures or prevent amputation.<sup>2</sup>

A single person can save up to eight lives through organ donation, and dozens more lives may be improved through tissue donation.<sup>3</sup> While most organ and tissue donations occur after the donor has died, some organs, including a kidney or part of a liver or lung, and tissues can be donated while the donor is alive.<sup>4</sup> There are about as many living donors every year as there are deceased donors.<sup>5</sup>

Despite advances in medicine and technology, and increased awareness of organ donation and transplantation, more donors are needed to meet the demand for transplants.<sup>6</sup> As of January 2020, there are more than 112,000 children and adults<sup>7</sup>, including over 5,000 Floridians.<sup>8</sup> Over 39,000 organ transplants were performed in 2019 with organs from more than 19,000 donors.<sup>9</sup>

Organ donation is not defined in Florida Statutes. Instead, statutes refer to anatomical gifts, which are human body parts donated after death for use in transplants, therapy, research, or education.<sup>10</sup>

#### *Organ Donation and Transplant Process*

Established by the National Organ Transplant Act of 1984, the Organ Procurement and Transplantation Network (OPTN) is a public-private partnership that links all professionals involved in the nation's donation and transplant system.<sup>11</sup> The United Network for Organ Sharing (UNOS), a private, non-profit organization based in Richmond, Virginia, serves as the OPTN under contract with the U.S. Department of Health and Human Resources.<sup>12</sup> UNOS coordinates how donor organs are matched and allocated to patients on the waiting list.<sup>13</sup> Non-profit, federally designated organ procurement organizations (OPOs) work closely with UNOS, hospitals, and transplant centers to facilitate the organ

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<sup>1</sup> Donate Life Florida, *Frequently Asked Questions*, <https://www.donatelifeflorida.org/categories/donation/> (last visited Jan. 24, 2020).

<sup>2</sup> Id.

<sup>3</sup> Id.

<sup>4</sup> Health Resources and Services Administration, *How Organ Donation Works*, <https://organdonor.gov/about/process.html> (last visited Jan. 24, 2020).

<sup>5</sup> Id.

<sup>6</sup> Organ Procurement and Transplantation Network, U.S. Department of Health & Human Services, <https://optn.transplant.hrsa.gov/> (last visited Jan. 24, 2020).

<sup>7</sup> Id.

<sup>8</sup> Supra, note 1.

<sup>9</sup> Id.

<sup>10</sup> S. 765.511(2), F.S.

<sup>11</sup> U.S. Department of Health and Human Services, *Organ Procurement and Transplantation Network – About the OPTN*, <https://optn.transplant.hrsa.gov/governance/about-the-optn/> (last visited Jan. 24, 2020).

<sup>12</sup> Id.

<sup>13</sup> U.S. Government Information on Organ Donation and Transplantation, U.S. Department of Health & Human Services, *The Organ Transplant Process*, <https://organdonor.gov/about/process/transplant-process.html> (last visited Jan. 24, 2020).

donation and transplantation process,<sup>14</sup> including conducting a thorough medical and social history of the potential donor to help determine the suitability of his or her organs for transplantation.<sup>15</sup>

The donation process begins when a person decides to become an organ donor. A deceased person's family may also decide to donate the organs of the decedant, if the decedant was not already registered as a donor before brain death. After brain death is declared, the donor's body is kept functioning by artificial means, such as a ventilator support.<sup>16</sup> Specially-trained medical practitioners from the OPO evaluate the patient to determine if they are medically suitable to donate their organs.<sup>17</sup> The deceased donor's blood type, height, weight, the hospital zip code, and other data are entered into UNOS' national computer system to begin the organ allocation process.<sup>18</sup> If the patient is suitable, their organs are surgically removed and sent to the transplant hospitals where transplant candidates are waiting.<sup>19</sup>

Transplant candidates are patients on the transplant waiting list. A patient is usually referred to a transplant center by their physician for placement on the waiting list.<sup>20</sup> The transplant center's transplant teams, composed of transplant physicians, surgeons and other practitioners, perform a medical evaluation of the patient.<sup>21</sup> Each transplant center sets its own criteria to help determine if a patient is a good or bad candidate.<sup>22</sup> Typical criteria includes weight, age, and health history. If the patient is a bad candidate, the patient is not placed on the waiting list, but can try to get placed on the waiting list at another transplant center or be reconsidered by the same transplant center if their condition improves (for example, losing weight as directed).<sup>23</sup> If a patient is determined to be a good candidate for an organ transplant, they are placed on the waiting list by the transplant center and wait for an organ to become available. Candidates are able to be placed on the waiting list at more than one transplant center.<sup>24</sup>

When an organ becomes available, the OPO will query the OPTN database for a match based on a variety of factors, including relative location of the recipient to the organ, blood type, weight, and age.<sup>25</sup> If a match is found, the transplant surgeon will evaluate the potential recipient of the organ transplant and make a determination on whether the potential recipient is medically suitable.<sup>26</sup> The transplant team only has one hour to make this determination.<sup>27</sup> If suitable, the organ is transported to the transplant center where the recipient is waiting and the transplant surgery is performed; otherwise, the potential recipient remains on the waiting list.

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<sup>14</sup> Donate Life Florida, *Organ Procurement Organizations and Transplant Centers*, <https://www.donateliflorida.org/local-resources/transplant-centers/> (last visited Jan. 24, 2020).

<sup>15</sup> Organ Procurement and Transplantation Network, U.S. Department of Health & Human Services, *The Basic Path of Donation*, <https://optn.transplant.hrsa.gov/learn/about-donation/the-basic-path-of-donation/> (last visited Jan. 24, 2020).

<sup>16</sup> Donate Life Florida, *Frequently Asked Questions - Donation*, <https://www.donateliflorida.org/categories/donation/> (last visited Jan. 24, 2020).

<sup>17</sup> UNOS, *Deceased Donation*, <https://unos.org/transplant/deceased-donation/> (last visited Jan. 24, 2020).

<sup>18</sup> Id.

<sup>19</sup> Id.

<sup>20</sup> Health Resources & Services Administration, *The Organ Transplant Process*, <https://www.organdonor.gov/about/process/transplant-process.html#list> (last visited Jan. 24, 2020).

<sup>21</sup> U.S. Department of Health and Human Services, *The Transplant Team*, <https://optn.transplant.hrsa.gov/learn/about-transplantation/the-transplant-team/> (last visited Jan. 24, 2020).

<sup>22</sup> UNOS, *Frequently Asked Questions – What do I need to do to be considered for a transplant?*, <https://unos.org/transplant/frequently-asked-questions/> (last visited Jan. 24, 2020).

<sup>23</sup> UNOS Transplant Living, *Frequently Asked Questions – Are there age limits or medical conditions that rule out organ transplantation?*, <https://transplantliving.org/before-the-transplant/frequently-asked-questions/> (last visited Jan. 24, 2020).

<sup>24</sup> UNOS, *What Every Patient Needs to Know* (2019), <https://unos.org/wp-content/uploads/unos/WEPNTK.pdf> (last visited Jan. 24, 2020).

<sup>25</sup> Health Resources & Services Administration, *Matching Donors and Recipients*, <https://www.organdonor.gov/about/process/matching.html#criteria> (last visited Jan. 24, 2020). See also Health Resources & Services Administration, *Find Your Local Organ Procurement Organization*, <https://www.organdonor.gov/awareness/organizations/local-opo.html> (last visited Jan. 24, 2020).

<sup>26</sup> UNOS Transplant Living, *Frequently Asked Questions – How does the matching process work?* <https://transplantliving.org/before-the-transplant/frequently-asked-questions/> (last visited Jan. 24, 2020).

<sup>27</sup> Id.

Medical urgency, blood type, size of the organ, whether the recipient is an adult or a child, relative distance between the donors and recipients, and the degree of immune-system match between the donor and the recipient can impact who is prioritized for an organ for transplant.<sup>28</sup> Transplant centers may also include other factors in prioritization, such as the ability to take care of oneself after surgery, attend post operation doctor appointments, and stay current with medications.<sup>29</sup>

## Disability

The term “disability” as enacted in the federal Americans with Disabilities Act (ADA)<sup>30</sup> means a physical or mental impairment that substantially limits one or more major life activities such as caring for oneself, performing manual tasks, seeing, walking, hearing, standing, learning, thinking, and communicating. Individuals with a previous record of such an impairment and, under certain circumstances, who are generally regarded as having such an impairment are also considered to have a disability. Types of disabilities include ambulatory, hearing, cognitive, vision, independent living, and self-care.<sup>31</sup> Disabilities can be related to conditions present at birth, associated with developmental conditions, related to an injury, or associated with a longstanding condition.<sup>32</sup> Individuals with disabilities are a diverse group of people with a wide range of needs.<sup>33</sup>

In addition to physical impairments, mental impairments can significantly interfere with the everyday activities of life. Anxiety disorders, mood disorders, and schizophrenia disorders are all types of mental impairments. Mental disorders are among the most common causes of disability.<sup>34</sup> Additionally, individuals with intellectual disabilities, characterized by significant limitations in both intellectual functioning and adaptive behavior, suffer disproportionately from substance use problems.<sup>35</sup>

Approximately 12.7% of the U.S. population (over 40 million people) has a disability.<sup>36</sup> Florida’s disability population is estimated at 13.6% (over 2.8 million people).

## Organ Transplant Discrimination

Taking care of oneself post-transplant involves quite a bit of effort. Transplant recipients usually need to take an array of medications or prevent the body from rejecting the transplanted organ sometimes for life. Some medications may need to be taken several times a day and others only on certain days.<sup>37</sup> Dosages may be adjusted weekly or every few days in order to find the best combination for maximum benefits and minimum side effects. Managing medications can become complex and confusing.<sup>38</sup> Doctors monitor transplant patients for years after transplant surgery and laboratory tests become routine.<sup>39</sup> Living a healthy lifestyle that includes eating a balanced diet and exercise plays a key role in maintaining health after a transplant.<sup>40</sup>

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<sup>28</sup> UNOS, *How We Match Organs*, <https://unos.org/transplant/how-we-match-organs/> (last visited Jan. 24, 2020).

<sup>29</sup> *Supra*, note 24.

<sup>30</sup> 42 U.S.C. 12102.

<sup>31</sup> United States Census Bureau, *Types of Disabilities*, <https://www.census.gov/library/visualizations/2019/comm/types-of-disabilities.html> (last visited Jan. 24, 2020).

<sup>32</sup> Centers for Disease Control and Prevention, *Disability Health Overview*, <https://www.cdc.gov/ncbddd/disabilityandhealth/disability.html> (last visited Jan. 24, 2020).

<sup>33</sup> *Id.*

<sup>34</sup> Office of Disease Prevention and Health Promotion, *Mental Health and Mental Disorders*, <https://www.healthypeople.gov/2020/topics-objectives/topic/mental-health-and-mental-disorders> (last visited Jan. 24, 2020).

<sup>35</sup> Shawna L. Carroll Chapman and Li-Tzy Wu, *Substance Abuse among Individuals with Intellectual Disabilities*, (July 2012) <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3328139/> (last visited Jan. 24, 2020).

<sup>36</sup> United States Census Bureau 2018 American Community Survey, *Disability Characteristics*, <https://data.census.gov/> (last visited Jan. 24, 2020).

<sup>37</sup> Health Resources & Services Administration, *The Organ Transplant Process – After Your Transplant*, <https://www.organdonor.gov/about/process/transplant-process.html#list> (last visited Jan. 24, 2020).

<sup>38</sup> *Id.*

<sup>39</sup> *Id.*

<sup>40</sup> *Id.*

Overall, long-term survival rates after transplants have increased since 1970.<sup>41</sup> In order for continued improvement in survival rates, long-term management and approaches post operation must continue to improve.<sup>42</sup>

The National Council on Disability (NCD) produced a report relating to discrimination against individuals with disabilities in the organ transplant process.<sup>43</sup> The NCD found many organ transplant centers<sup>44</sup> have policies that bar or caution against placing people with HIV, psychiatric disabilities, or intellectual and developmental disabilities on the waiting list to receive an organ transplant because of concern the patient may not be able to take care of themselves after transplant surgery. Some transplant centers had or currently have policies that treat HIV or AIDS, psychiatric disabilities, or intellectual and developmental disabilities as relative or absolute contraindications for transplant, meaning that a transplant should not be performed on people with such conditions because it could be harmful. The NCD found that some personal and transplant center physicians sometimes refuse to recommend that a person with a disability receive an organ transplant by telling the patient outright that they will not be placed on the transplant waiting list. Transplant centers may also refuse to evaluate a disabled person as a candidate for a transplant or place a disabled person on the transplant waiting list.

Additionally, the NCD reviewed clinical studies on the impact of intellectual and developmental disability, psychiatric disability, and HIV on the success of an organ transplant and found that such studies consistently determined that transplant outcomes for people with disabilities are no worse than outcomes for people without disabilities.<sup>45</sup>

The NCD also examined applicable federal and state laws, the disability-related policies of various transplant centers, and policies of the OPTN. The ADA and Section 504 of the federal Rehabilitation Act of 1973 prohibit discrimination on the basis of disability. Similarly, nine states<sup>46</sup> have enacted laws expressly prohibiting such discrimination. However, in the NCD found that discrimination continues to occur in those states.<sup>47</sup>

### Patient Protection and Affordable Care Act

The Patient Protection and Affordable Care Act (PPACA)<sup>48</sup> imposed extensive requirements on health insurers and health insurance policies relating to required benefits, rating and underwriting standards, review of rate increases, and other requirements.<sup>49</sup> Among its sweeping changes to the U.S. health care system are requirements for health insurers to make coverage available to all individuals and employers, without exclusions for preexisting conditions and without basing premiums on any health-related factors.<sup>50</sup>

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<sup>41</sup> Abbas Rana, MD and Elizabeth Louise Godfrey, BSBE, *Outcomes in Solid-Organ Transplantation: Success and Stagnation*, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6379008/> (last visited Jan. 24, 2020).

<sup>42</sup> *Id.*

<sup>43</sup> National Council on Disability, *Organ Transplant Discrimination Against People with Disabilities*, (Sept. 25, 2019) [https://ncd.gov/sites/default/files/NCD\\_Organ\\_Transplant\\_508.pdf](https://ncd.gov/sites/default/files/NCD_Organ_Transplant_508.pdf) (last visited Jan. 24, 2020).

<sup>44</sup> *Supra*, note 43, at 55. Includes the University of Florida Health transplant center and Tampa General Hospital.

<sup>45</sup> *Supra*, note 43, at 38.

<sup>46</sup> California, Delaware, Kansas, Maryland, Massachusetts, New Jersey, Ohio, Oregon, and Pennsylvania.

<sup>47</sup> *Supra*, note 43.

<sup>48</sup> Patient Protection and Affordable Care Act (PPACA), Pub. L. No. 111-148.

<sup>49</sup> Most of the insurance regulatory provisions in PPACA amend Title XXVII of the Public Health Service Act (PHSA), 42 U.S.C. 300gg et seq.

<sup>50</sup> Under PPACA, the prohibition on preexisting condition exclusion refers to the fact that health insurance companies cannot refuse coverage or charge higher premiums to those who have a "pre-existing condition" — that is, a health problem that existed before the date that health coverage starts. Prior to passage of the PPACA, employers and insurers could exclude coverage for pre-existing conditions for a period of time if an individual had not maintained continuous insurance coverage, unless prohibited by state law.

Many of the changes in the PPACA apply to individual and small group markets, except those plans that have grandfathered status under the law.<sup>51</sup> For example, the PPACA requires coverage offered in the individual and small group markets to provide the certain categories of services, called essential health benefits.<sup>52</sup>

Also, the PPACA requires that premiums for individual and small group policies may vary only by:<sup>53</sup>

- Age, up to a maximum ratio of 3 to 1. This means that the rates for older adults cannot be more than three times greater than the rates for younger adults.
- Tobacco, up to a maximum ratio of 1.5 to 1.
- Geographic rating area.
- Whether coverage is for an individual or a family.

The PPACA prohibits an insurer from establishing rules for eligibility based on any of the following health status-related factors: health status, medical condition, claims experience, receipt of health care, medical history, genetic information, disability, evidence of insurability (including conditions arising out of domestic violence), or any other health-status related factor deemed appropriate by the U.S. Department of Health and Human Services.<sup>54</sup>

### State Regulation of Health Insurance

The regulatory oversight of health insurance is generally reserved to the states, except when explicitly preempted by federal law. In Florida, the Office of Insurance Regulation (OIR) is responsible for all activities concerning insurers and other risk bearing entities, including licensing, rates, policy forms, market conduct, claims, issuance of certificates of authority, solvency, viatical settlements, premium financing, and administrative supervision, as provided under ch. 627, F.S., the Florida Insurance Code.<sup>55</sup> The OIR and the Agency for Health Care Administration (AHCA) jointly regulate health maintenance organizations (HMOs) under ch.641, F.S.

Current law prohibits a health insurer from refusing to provide coverage or charging higher rates to a person solely based on a mental or physical disability.<sup>56</sup> It also prohibits insurers and HMOs which offer group plans from denying enrollment of a person or dependent based on a disability.<sup>57</sup> Thus, current law addresses the ability of a disabled person to obtain a health insurance policy or health plan coverage, but does not specifically address insurance coverage of organ donation procedures for disabled people.

### Effect of the Bill

HB 1179 prohibits discrimination in access to anatomical gifts and organ transplants for individuals with disabilities. It prohibits health insurance policies, health maintenance organizations, and group health policies from denying coverage for a transplant based on a disability.

The bill prohibits covered entities from taking specific actions against an individual with a developmental or intellectual disability who is eligible to receive an anatomical gift based solely on the fact that they have a disability. The bill prohibits certain actions by licensed health care practitioners, health care facilities, and any other entity responsible for potential recipients of anatomical gifts; such

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<sup>51</sup> For an insured plan, grandfathered health plan coverage is group or individual coverage in which an individual was enrolled on March 23, 2010, subject to conditions for maintaining grandfathered status as specified by law and rule. See PPACA s. 1251; 42 U.S.C. s. 18011.

<sup>52</sup> PPACA s. 1302; 42 U.S.C. 300gg-6.

<sup>53</sup> PPACA s. 1201; 42 U.S.C. 300gg.

<sup>54</sup> PPACA s. 1201; 42 U.S.C. s. 300gg-4.

<sup>55</sup> S. 20.121(3)(a)1., F.S. The OIR's commissioner is the agency head for purposes of final agency action, and its rulemaking body is the Financial Services Commission (the Governor and the Cabinet).

<sup>56</sup> S. 627.644, F.S.

<sup>57</sup> Ss. 641.31073 and 641.65625, F.S.

entities may not consider a qualified individual ineligible to receive an anatomical gift or organ transplant, deny medical or other services related to an organ transplant, refuse to refer the individual to an OPO or a specialist for a transplant evaluation, refuse to place the individual on the waiting list, or give the individual a lower priority position on the waiting list.

The bill authorizes a covered entity, when making treatment or coverage recommendations for a patient, to take a disability into account if, after an evaluation, a physician finds the disability to be medically significant to the receipt of an anatomical gift. Additionally, a covered entity may not consider the patient's inability to comply with post-transplant medical requirements as medically significant if they have a support system to assist with such compliance.

The bill requires covered entities to make reasonable accommodations in their policies, practices, or procedures, when necessary, to allow a patient with a disability access to services unless it is demonstrated that making the modification would fundamentally alter the nature of the services. The accommodations include communicating with the people responsible for supporting the patient with their post-transplant care and the consideration of support networks available to the patient.

Under the bill, a covered entity must take the necessary steps to ensure that a person with a disability is not denied services due to the absence of auxiliary aids and services, including interpreters for those with hearing impairments, effective methods of delivering information to people with visual impairments, and supported decision making services. Such services may include the use of a support person to help make medical decisions and communicate information, disclosing health information to a person designated by the patient, using a court appointed guardian or other legal representative who is authorized to make health care decisions on behalf of the patient, and any other aid or service that can be used to understandably convey information to the patient.

The bill provides injunctive or other equitable relief for a qualified individual who is affected by a violation of such provisions committed by a covered entity.

The bill expressly states that it may not be interpreted as requiring a covered entity to make a referral or recommendation for, or to perform, a medically inappropriate transplant.

The bill prohibits discrimination by insurers against individuals who are recipients of organ transplants. This prohibition includes issuers of fully-insured individual and group health plans, as well as HMOs. The bill does not require coverage of organ transplant services, but prohibits plans that do cover organ transplants from denying coverage for an organ transplant solely on the basis of a covered individual having a disability.

The bill provides an effective date of July 1, 2020.

## **II. FISCAL ANALYSIS & ECONOMIC IMPACT STATEMENT**

### **A. FISCAL IMPACT ON STATE GOVERNMENT:**

#### **1. Revenues:**

None.

#### **2. Expenditures:**

The bill has an indeterminate, insignificant, negative fiscal impact on the Agency for Health Care Administration Division of Health Quality Assurance and the Department of Health Division of Medical Quality Assurance due to the investigation of complaints and enforcement relating to violations of any act proposed under this bill committed by a health care facility or a licensed health care practitioner, respectively. The impact can be absorbed within current resources.

The bill has an indeterminate, insignificant, negative fiscal impact on the Office of Insurance Regulation and the Agency for Health Care Administration due to the investigation of complaints and enforcement relating to violations of any act proposed under this bill committed by insurance companies and HMOs. The impact can be absorbed within current resources.

**B. FISCAL IMPACT ON LOCAL GOVERNMENTS:**

1. Revenues:

None.

2. Expenditures:

None.

**C. DIRECT ECONOMIC IMPACT ON PRIVATE SECTOR:**

None.

**D. FISCAL COMMENTS:**

None.