

Health Committee JOINT FAVORABLE REPORT

Bill No.: SB-388

Title: AN ACT CONCERNING INTERSEX PERSONS.

Vote Date: 4/1/2019

Vote Action: Joint Favorable Substitute

PH Date: 2/25/2019

File No.:

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SPONSORS OF BILL:

The Public Health Committee

REASONS FOR BILL:

To provide the intersex community relief from potential discrimination in areas such as housing, employment and public accommodations, as well as providing a third option for gender designation on state documentation to more accurately reflect their sex.

RESPONSE FROM ADMINISTRATION/AGENCY:

Raul Pino, MD, MPH, Commissioner of the Department of Public Health (DPH): This proposed legislation would prohibit discrimination against individuals with intersex characteristics; prohibit medically unnecessary surgeries without the consent of the individual; and provide for a third option for gender designation on state documents. The testimony from the Department addresses this third point. A third gender designation is currently offered on birth certificates as an 'X' to indicate a non-binary gender status. However, the process to record 'sex' on a birth certificate differs from the one used to record gender identity. The term "gender designation" as used in this bill conflates the two. The Department points out that statutory language will be necessary to ensure that the provisions of this bill are clearly delineated from the requirements as outlined in Sec. 19a-42(i) of the Connecticut General Statutes (CGS) which set forth the process by which a birth certificate may be changed to indicate gender identity. The Department is available to the Committee to assist in drafting language.

Judeen Wrinn, Acting Commissioner of the Department of Motor Vehicles (DMV):

In her testimony, Acting Commissioner Wrinn addresses the provision in the bill which would provide a third option for gender designation. She points out issues of concern to the DMV. In the performance of its responsibilities, the DMV must interact with multiple systems, both in and out of state. Adding a new gender identity will require coordination and adjustments to these systems. A few examples of state organizations whose systems would require adjustments include town tax assessors, the state police, the National Law Enforcement System (NCIC), and other state agencies, such as , The Department of Public Health (DPH) that handle death notices to cancel handicap placards. These changes would also impact federal agencies such as the Department of Homeland Security (DHS), the Commercial Driver License Information System (CDLIS), Problem Driver Pointer Systems (PDPS) and Social Security Online Verification (SSOLV). In addition to the numerous changes required for all IT systems involved with interfacing license-related systems, additional training for employees would be required, as well as outreach to all stakeholders (banks, insurance companies etc.) to inform them of the new gender identification. Lastly, replacement of agency forms would need to be printed. The Department anticipates the costs to update all systems, the associated forms, and the time necessary to complete this extensive undertaking will require additional funding.

NATURE AND SOURCES OF SUPPORT:

David McGuire, Executive Director of the American Civil Liberties Union of CT. (ACLU-CT):

Mr. McGuire is in support of this bill which would protect intersex individuals from discrimination faced throughout all areas of their lives. These individuals are blocked from single-gender space, such as bathrooms, and face discrimination in sports due to hormone levels. Intersex individuals are frequently subjected to medically unnecessary and irreversible surgeries in an effort to make their bodies “normal” because they do not conform to traditional expectations. This bill would prohibit licensed health care providers from providing surgeries without the consent of intersex individuals. Finally, providing a third gender option on state and personal identification documents would not force individuals with intersex traits to choose between genders with which they do not identify.

Gretchen Raffa, Director of Public Policy, Planned Parenthood (PP):

Planned Parenthood is a trusted medical provider that believes every person deserves the right to live free from stigma and bias and to make their own fully informed choices when it comes to their healthcare. Planned Parenthood joins with other organizations worldwide, such as The World Health Organization, Physicians for Human Rights, Amnesty International, UN experts, Lambda, and the ACLU, as well as support groups for intersex people and their families, in condemning the practice of non-consensual surgery and they advocate for the right and freedom of intersex people to live their lives free of discrimination and harm. People achieve reproductive freedom when they have full autonomy over their own bodies and lives. We also support the part of this bill which would provide a third option for gender designation on state documentation and personal identification records so that intersex people are not forced to choose a gender category with which they do not identify. Planned Parenthood urges the Committee to provide these freedoms to the intersex community and urges passage of the bill.

Georgiann Davis, PhD, Board President of interact: Advocated for Intersex Youth: Ms. Davis is a medical sociologist and an intersex person. She is in strong support of this legislation. Through her research and personal experience she can confidently assure the Committee that medically unnecessary surgeries designed to erase a person's intersex trait are psychologically and physically harmful when performed without the patient's consent. There are no health risks associated with waiting to perform any irreversible and medically unnecessary surgeries until the patient is mature enough to express their wishes to such cosmetic interventions. No one is against medical interventions; rather the root issue in SB 388 is the protection of intersex person's right to control what happens to their body.

Roger Misbach, Vice Chair of the Libertarian Party of Connecticut, (LP-CT): Mr. Misbach supports this legislation which recognizes a person's right to control their own bodies and to prohibit discrimination against persons with intersex characteristics as it relates to gender identification on government documents. For medically unnecessary surgeries, the current practice is to leave this decision solely to parents and doctors. This is appalling. SB 388 would correct this process by requiring consent from the patient. Regarding the matter of government documentation, this bill does not go far enough. The government has no right to define a person's biological sex using only two binary choices. If Libertarians and small government advocates were given the chance, both sex and gender identification would be removed from all government records.

Arlene Baratz, MD: Dr. Baratz is a physician and the mother of two intersex women. For nearly 20 years, Dr. Baratz has worked with the largest support group for intersex children and their families, the Androgen Insensitivity Syndrome-Differences of Sex Development (AIS_DSD). She is in favor of this legislation because she believes unnecessary surgeries are based in fear of difference, homophobia and transphobia and are a form of conversion therapy that have deeply harmful outcomes. This bill does not seek to limit necessary medical procedures related to a person's health, but rather sends a message that it is time to put policies in place that focus on the rights of the individual to control their own destiny. We must ensure that intersex children are not denied the right to make irreversible decisions about their own bodies.

Nicole Lotko: Ms. Lotko has non-binary friends whose rights she respects and writes in support of this legislation. Scientific knowledge makes clear that there are more chromosomal differences beyond XX and YY, such as XXX, XXY, XYX and XXYY. This indicates there are more than two sexes. Based on this fact, Connecticut should join with 14 other states that provide a third option on government identification. She is also opposed to unnecessary medical surgeries.

Testimonies in support SB 388 and expressing similar views were submitted by 19 other individuals.

NATURE AND SOURCES OF OPPOSITION:

DR. Joseph Wagner, MD, President, Connecticut Urology Society (CUS), etal: Dr. Wagner submitted testimony on behalf of preeminent organizations representing urologists in the US including CUS, Societies for Pediatric Urology (SPU), The American Association of Clinical Urologists (AACU), and the American Urological Association. Collectively, these organizations represent more than 150 urologists in Connecticut and 18,000 nationally who care for patients with conditions affecting the urinary tract system and reproductive organs. These specialists study seven to eight years after medical school to acquire the expert training needed to manage the health of children and adolescents. As part of a multidisciplinary team, they oppose any form of discrimination toward gender and sexual minorities and recognize the value of the intersex community in Connecticut. However, this proposed legislation arises from arguments that include many inaccuracies, references to outdated medical procedures and asks the state to promote policies that are potentially harmful to vulnerable children. Dr. Wagner referenced two other states that were considering a similar proposal. After hours of testimony from experts, as well as compelling stories from children and families who were overwhelmingly satisfied with the outcomes of their surgeries, their legislatures concluded that “unnecessary surgery” could not be defined and prohibition of early surgical procedures should not become law.

Recently a deep review of this subject was conducted by a group of medical experts from the American Medical Association, including those calling for a moratorium on surgery. This group developed a policy of informed consent that maintained parental rights and did not call for a moratorium on surgery. *See testimony for specifics of this policy.*

In summary and speaking on behalf of the diverse membership of the above groups, Dr. Wagner is opposed to any legislation that would prevent the option of surgery in these children. Also, proponents of this legislation are referring to practices and procedures that were replaced more than 20 years ago. If this legislation moves forward, it would fail to acknowledge overwhelming patient satisfaction with early surgical intervention. These organizations respect a parent’s right to be involved in their child’s growth, development and medical care. Limiting the role of parents sets a dangerous precedent.

The following doctors are all from the Connecticut Children’s Medical Center:

Dr. Priya Phulwani, Co-Director, Clinic for Variations of Sexual Development, Medical Director, Gender Program Clinic,

Dr. Rebecca Riba-Wolman, Clinical Director of Pediatric Endocrinology & Diabetes;

Dr. Emily Germain-Lee, Professor, Department of Pediatrics, UCONN School of MedicineChief Division of Pediatric Endocrinology & Diabetes;

Their joint testimony addressed the second part of the proposed legislation which concerns “unnecessary surgery”. The decisions concerning surgical interventions in children should not be regulated by legislation but supported by individualized care to best serve the interests of the child. No one wants medically unnecessary surgeries performed on any child without consent, and when possible, the assent of the child. However, regulation of medical practice in this very individualized situation may cause more harm than good. A multidisciplinary team comprised of clinicians from urology, endocrinology and mental health is required to provide the

compassionate and comprehensive care, planning and implementation needed in each individual situation.

The following physicians submitted similar testimony in opposition to the Section of the bill related to surgery:

Dr. Courtney Rowe, Pediatric Urologist Connecticut Children's Medical Center
Dr. Angela Arlen, Assistant Professor of Pediatric Urology, Yale School of Medicine
Dr. Konrad Szymanski, Division of Pediatric Urology, Riley Hospital for Children, Indianapolis, IN
Dr. Sarah Lambert, Assistant Professor of Urology, Yale University
Dr. Douglas Camming Professor of Urology, Chief of Urology, Children's Hospital of Philadelphia
Dr. Christina Kim, health care provider and parent.

Connecticut Hospital Association (CHA): CHA has concerns that the bill, as written, will create unintended consequences that could reduce access to care and services to intersex people. This concern includes children mature enough to provide consent. The bill prevents "medically unnecessary" procedures, but does not explain what is considered unnecessary or how that conclusion is determined. The lack of clarity in the language severely impedes a provider's ability to perform necessary procedures leading to lack of access. Also, the bill is unclear as to when a child would be old enough to provide consent. A situation could occur when an individual is able to understand and consent to recommended surgery, but has not reached the age of 18. This reduces the personal control of intersex individuals.

The following testimonies were submitted by parents of children born with various conditions that could be considered "intersex". Most either provided only first names or were sent anonymously to protect their children.

Anonymous, Mother of a child born with hypospadias: In her testimony, this mother shared that at the time her son was born; she had been working in a field involving clinical research. She sought any information available to decide how to proceed with her son's situation. She and her husband worked with a urologist and other expert clinicians in this field and, as a team, realized that there were only two options available, perform surgery or wait. Based on the information gained through the consultations, they chose to do the surgery which resulted in no complications and a short healing period. The surgery was performed when her son was 2 months old. If this bill were to have passed, her son would have had to wait until he was 18 as his surgery would have been considered "unnecessary". At that age, the surgery would have been much more involved, painful, require an extended healing time and greatly increase the risk of complications. She also noted the psychological issues that her son would have faced during his teenage years had the surgery not been performed when he was a child. She understands the motivation behind this bill but strongly believes it would cause more harm than good and set a very dangerous precedent. She urges rejection of this bill.

Jackie W. a concerned parent: In her testimony, she expressed great concern regarding the limitation of parental rights. She loves her children more than anything else and would never make careless decisions based upon her own needs or desires.

Christopher and Marybeth: These individuals are the parents of a daughter born with Congenital Adrenal Hyperplasia (CAD). This is an inherited disorder of the adrenal glands and can manifest a masculinization of the genitalia that requires surgical intervention to correct structural defects in external and internal parts of the genital-urinary tract. The need for surgical intervention on or before a child's first birthday, from their perspective and experience, was critical to addressing the serious medical, developmental and psychological issues that could have occurred. If this bill had been passed they would not have had the opportunity to provide their daughter with the happy life she now enjoys.

Anonymous: This woman gave birth to a child who was born with Congenital Adrenal Hyperplasia (CAH). However, her daughter was genetically a female based on the complete pair of XX chromosomes. This parent weighed her options and, in consultation with a multidisciplinary team, the decision was made to have the surgery. The surgery went extremely well and her daughter's recovery was remarkable. Because she was an infant, the potential extended healing time, as well as psychological and emotional stress, was eliminated.

Michelle from Stratford: This mother testified on behalf of parental rights. Her daughter was born with CAD and was given the surgery. She is now a normal, healthy teenager. If this mother had not been allowed the option to choose surgery for her daughter, her daughter's life would have been very different. She would have had many complications as she reached puberty and potentially be subjected to abuse and bullying, especially in high school. This mother shared a story of changing her 4 month old child in a mall bathroom and had multiple people stare and ask what was wrong. Parents of children with CAD have to make serious choices to improve the health and wellbeing of their children to live normal, happy, and active lives. Taking this right away from parents is clearly wrong.

Testimonies in opposition to SB 388 and expressing similar views were submitted by 15 other parents.

Reported by: Kathleen Panazza

Date: April 12, 2019