

Reference Committee on Amendments to Constitution and Bylaws

BOT Report(s)

14 Protection of Physician Freedom of Speech

CEJA Report(s)

01* Competence, Self-Assessment and Self-Awareness

02* Study Aid-in-Dying as End-of-Life Option / The Need to Distinguish "Physician-Assisted Suicide" and "Aid-in-Dying"

03* Amendment to E-2.2.1, "Pediatric Decision Making"

04* CEJA Role in Implementing H-140.837, "Anti-Harassment Policy"

05* Physicians' Freedom of Speech

Resolution(s)

001 Support of a National Registry for Advance Directives

002* Protecting the Integrity of Public Health Data Collection

003* Mental Health Issues and Use of Psychotropic Drugs for Undocumented Immigrant Children

REPORT OF THE BOARD OF TRUSTEES

B of T Report 14-I-18

Subject: Protection of Physician Freedom of Speech
(Resolution 5-I-17)

Presented by: Jack Resneck, Jr. MD, Chair

Referred to: Reference Committee on Amendments to Constitution and Bylaws
(Todd M. Hertzberg, MD, Chair)

1 INTRODUCTION

2
3 Resolution 5-I-17, introduced by the American Academy of Pain Medicine (AAPM), consisted of
4 the following proposals:

5
6 RESOLVED, That our American Medical Association strongly oppose litigation challenging
7 the exercise of a physician's First Amendment right to express good faith opinions regarding
8 medical issues; and be it further

9
10 RESOLVED, That our AMA's House of Delegates encourage the AMA Litigation Center to
11 provide such support to a constituent or component medical society whose members have been
12 sued for expressing good faith opinions regarding medical issues as the Litigation Center
13 deems appropriate in any specific case.

14
15 The reference committee heard testimony that physicians had been sued for expressing their
16 opinions on such politically sensitive issues as the treatment of chronic pain or the potential
17 benefits of medical marijuana. Physicians testified that these lawsuits are expensive, produce
18 anxiety, and impact physicians' willingness to speak publicly on controversial public issues. While
19 testimony generally supported the resolution, concerns were raised regarding the term "good faith,"
20 which the reference committee found to be "a complex and sensitive issue." The resolution was
21 referred to the Board of Trustees in order to investigate the optimal language needed to accomplish
22 the goals of Resolution 5.

23
24 This report is submitted in response to that referral. Notably, though, the scope of the House
25 referral and thus of this report is much narrower than the heading, "Protection of Physician
26 Freedom of Speech," might suggest. Physician freedom of speech encompasses far more than the
27 subject of Resolution 5. In conformity with the Board's interpretation of the request from the
28 House, this report is focused on the specific proposals of Resolution 5 and particularly on the term
29 "good faith."

30 31 FIRST RESOLVE

32
33 The Board believes that the term "good faith" should be omitted from AMA policy based on the
34 first resolve of Resolution 5. Thus, AMA policy would appropriately read as follows:

1 RESOLVED, That our American Medical Association strongly oppose litigation challenging
2 the exercise of a physician's First Amendment right to express opinions regarding medical
3 issues.
4

5 The problem with the "good faith" limitation is that there is no simple test of whether a specific
6 opinion has been made in good faith or in bad faith. For example, suppose a physician were to
7 opine on a medical issue without disclosing that the physician's interests were financially
8 conflicted regarding that issue. As another example, suppose a physician were to advocate for a
9 specific treatment option, but the physician had previously recommended a different option and
10 failed to acknowledge this discrepancy. As a third example, suppose a lawsuit were brought against
11 a physician because of the physician's opinion on a medical issue, and the lawsuit, without setting
12 forth a further basis for the statement, alleged that the opinion had been rendered in "bad faith."
13 Each of these examples might suggest that the physician's opinion lacked good faith, but the
14 ultimate determination of that issue would require a much fuller factual development than has been
15 set forth.
16

17 AAPM introduced Resolution 5 to protect physicians' First Amendment right to express opinions.
18 A tenet of First Amendment law is that expression of opinions should be encouraged, and the bad
19 faith ones will be ultimately discredited in the "marketplace of ideas." The truth will prevail.
20 *McCullen v. Coakley*, 134 S. Ct. 2518, 2529 (2014). If the AMA is to stand behind the right of free
21 expression, it should not be undercut by a policy requiring that it ascertain at some point whether a
22 physician's opinion has been expressed in good faith.
23

24 If the first resolve of Resolution 5 is modified as suggested, it will be similar, but not quite
25 identical, to existing Policy H-460.895, "Free Speech Applies to Scientific Knowledge," which
26 states as follows: "Our AMA will advocate that scientific knowledge, data, and research will
27 continue to be protected and freely disseminated in accordance with the U.S. First Amendment."
28

29 SECOND RESOLVE

30

31 The Board believes that the second resolve of Resolution 5 would be undesirable. During the June
32 2017 Open Meeting of the Litigation Center, AAPM publicly discussed the abusive litigation
33 which led to Resolution 5. Thus, the Litigation Center is aware of the problem and is already
34 committed to taking whatever appropriate steps may be available to assist AAPM and its members.
35

36 Unfortunately, the problems AAPM faces are not, at least presently, readily susceptible to
37 assistance from the Litigation Center. Abusive litigation must be combatted under the procedures
38 available through the legal system. The Litigation Center has communicated closely with AAPM to
39 ascertain the point at which assistance might be helpful. The various lawsuits that have been
40 brought against AAPM and its members have simply not reached that point – if the point will ever
41 be reached.
42

43 As it happens, though, adoption of the first resolve, with the modification suggested above (*viz.*,
44 deletion of the "good faith" requirement), will increase the likelihood that the Litigation Center will
45 ultimately be able to support AAPM. In other words, the Litigation Center would find it difficult to
46 support AAPM if it had to convince itself that the physicians in question had written or spoken in
47 good faith. With the removal of the good faith impediment, the Litigation Center can premise its
48 support on the general principle of protecting free speech, without a detailed analysis of the facts
49 underlying a specific case.

1 The Board and the Litigation Center appreciate that AAPM has been respectful of the discretion
2 accorded to the Litigation Center. Nevertheless, the second resolve suggests that the Litigation
3 Center might benefit from additional encouragement from the House of Delegates. Such
4 encouragement, in this situation, would be unnecessary and might undercut the ability of the
5 Litigation Center to act according to its determination of how the interests of the AMA can be best
6 served through advocacy in the courts.

7
8 RECOMMENDATION

9
10 The Board of Trustees recommends that the following be adopted in lieu of Resolution 5-I-17 and
11 the remainder of this report be filed:

- 12
13 1. That our American Medical Association strongly oppose litigation challenging the exercise of a
14 physician's First Amendment right to express opinions regarding medical issues. (New HOD
15 Policy); and
16
17 2. That AMA Policy H-460.895, "Free Speech Applies to Scientific Knowledge," be reaffirmed
18 (Reaffirm HOD Policy).

Fiscal Note: Less than \$500

REPORT 1 OF THE COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS (1-I-18)
Competence, Self-Assessment and Self-Awareness
(Reference Committee on Amendments to Constitution and Bylaws)

EXECUTIVE SUMMARY

The expectation that physicians will provide competent care is central to medicine. It undergirds professional autonomy and the privilege of self-regulation granted to medicine by society.

The ethical responsibility of competence encompasses more than knowledge and skill. It requires physicians to understand that as a practical matter in the care of actual patients, competence is fluid and dependent on context. Importantly, the ethical responsibility of competence requires that physicians at all stages of their professional lives be able to recognize when they are and when they are not able to provide appropriate care for the patient in front of them or the patients in their practice as a whole.

Self-aware physicians discern when they are no longer comfortable handling a particular type of case and know when they need to obtain more information or need additional resources to supplement their own skills. They recognize when they should ask themselves whether they should postpone care, arrange to have a colleague provide care, or otherwise find ways to protect the patient's well-being.

To fulfill their ethical responsibility of competence, physicians at all stages in their professional lives should cultivate and exercise skills of self-awareness and active self-observation; take advantage of tools for self-assessment that are appropriate to their practice settings and patient populations; and be attentive to environmental and other factors that may compromise their ability to bring their best skills to the care of individual patients. As a profession, medicine should provide meaningful opportunity for physicians to hone their ability to be self-reflective.

REPORT OF THE COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS*

CEJA Report 1-I-18

Subject: Competence, Self-Assessment and Self-Awareness

Presented by: James E. Sabin, MD, Chair

Referred to: Reference Committee on Amendments to Constitution and Bylaws
(Todd M. Hertzberg, MD, Chair)

1 The expectation that physicians will provide competent care is central to medicine. This
2 expectation shaped the founding mission of the American Medical Association (AMA) and runs
3 throughout the AMA *Code of Medical Ethics* [1-4]. It undergirds professional autonomy and the
4 privilege of self-regulation granted to medicine by society [5]. The profession promises that
5 practitioners will have the knowledge, skills, and characteristics to practice safely and that the
6 profession as a whole and its individual members will hold themselves accountable to identify and
7 address lapses [6-9].

8
9 Yet despite the centrality of competence to professionalism, the *Code* has not hitherto examined
10 what the commitment to competence means as an ethical responsibility for individual physicians in
11 day-to-day practice. This report by the Council on Ethical and Judicial Affairs (CEJA) explores this
12 topic to develop ethics guidance for physicians.

13 14 DEFINING COMPETENCE

15
16 A caveat is in order. Various bodies in medicine undertake point-in-time, cross-sectional
17 assessments of physicians' technical knowledge and skills. However, this report is not concerned
18 with matters of technical proficiency assessed by medical schools and residency programs,
19 specialty boards (for purposes of certification), or hospital and other health care organizations (e.g.,
20 for privileging and credentialing). Such matters lie outside the Council's purview.

21
22 The ethical responsibility of competence encompasses more than knowledge and skill. It requires
23 physicians to understand that as a practical matter in the care of actual patients, competence is fluid
24 and dependent on context. Importantly, the ethical responsibility of competence requires that
25 physicians at all stages of their professional lives be able to recognize when they are and when they
26 are not able to provide appropriate care for the patient in front of them or the patients in their
27 practice as a whole. For purposes of this analysis, competence is understood as "the habitual and
28 judicious use of communication, knowledge, technical skills, clinical reasoning, emotions, values,
29 and reflection in daily practice for the benefit of the individual and the community being served"
30 and as "developmental, impermanent, and context dependent" [10].

31
32 Moreover, the Council is keenly aware that technical proficiency evolves over time—what is
33 expected of physicians just entering practice is not exactly the same as what is expected of mid-

* Reports of the Council on Ethical and Judicial Affairs are assigned to the Reference Committee on Amendments to Constitution and Bylaws. They may be adopted, not adopted, or referred. A report may not be amended, except to clarify the meaning of the report and only with the concurrence of the Council.

1 career physicians or physicians who are changing or re-entering practice or transitioning out of
 2 active practice to other roles. Each phase of a medical career, from medical school through
 3 retirement, carries its own implications for what a physician should know and be able to do to
 4 practice safely and to maintain effective relationships with patients and with colleagues.

5
 6 The concept that informs this report differs as well from the narrower definition of competence as
 7 the knowledge and skills an individual has to do a job. Rather, this report explores a broader notion
 8 of competence that encompasses deeper aspects of wisdom, judgment and practice that enable
 9 physicians to assure patients, the public, and the profession that they provide safe, high quality care
 10 moment to moment over the course of a professional lifetime.

11 FROM SELF-ASSESSMENT TO “INFORMED” SELF-ASSESSMENT

12
 13
 14 Health care institutions and the medical profession as a whole take responsibility to regulate
 15 physicians through credentialing and privileging, routinely testing knowledge (maintenance of
 16 certification, requirements for continuing education, etc.) and, when needed, taking disciplinary
 17 action against physicians who fail to meet expectations for competent, professional practice.
 18 However, the better part of the responsibility to maintain competence rests with physicians’
 19 “individual capacity, as clinicians, to self-assess [their] strengths, deficiencies, and learning needs
 20 to maintain a level of competence commensurate with [their] clinical roles” [11].

21
 22 Self-assessment has thus become “integral to many appraisal systems and has been espoused as an
 23 important aspect of personal professional behavior by several regulatory bodies and those
 24 developing learning outcomes for students” [12]. Undergraduate and graduate medical education
 25 programs regularly use self-assessment along with third-party evaluations to ensure that trainees
 26 are acquiring the knowledge and skills necessary for competent practice [5,10,13-16].

27
 28 Yet how accurately physicians assess their own performance is open to question. Research to date
 29 suggests that there is poor correlation between how physicians rate themselves and how others rate
 30 them [5,12,13]. Various studies among health professionals have concluded that clinicians and
 31 trainees tend to assess their peers’ performance more accurately than they do their own; several
 32 have found that poor performers (e.g., those in the bottom quartile) tend to over-estimate their
 33 abilities while high performers (e.g., those in the top quartile), tend to under-estimate themselves
 34 [5,12,17].

35
 36 The available findings suggest that self-assessment involves an interplay of factors that can be
 37 complicated by lack of insight or of metacognitive skill, that is, ability to be self-observant in the
 38 moment. Similarly, personal characteristics (e.g., gender, ethnicity, or cultural background) and the
 39 impact of external factors (e.g., the purpose of self-assessment or whether it is designed to assess
 40 practical skills or theoretical knowledge) can all affect self-assessment [12,18]. The published
 41 literature also indicates that interventions intended to enhance self-assessment may seek different
 42 goals—improving the accuracy of self-assessors’ perceptions of their learning needs, promoting
 43 appropriate change in learning activities, or improving clinical practice or patient outcomes [12].

44
 45 Self-assessment tools alone are not sufficient measures of physicians’ ability to provide safe, high
 46 quality care. Feedback from third parties is essential—or as one researcher has observed, “The road
 47 to self-knowledge may run through other people” [19]. However, physicians are often wary of
 48 assessment. They have indicated that while they want feedback, they are not sure how to use
 49 information that is not congruent with their self-appraisals [20]. Physicians can be hesitant to seek
 50 feedback for fear of looking incompetent or exposing possible deficiencies or out of concern that
 51 soliciting feedback could adversely affect their relationships with those whom they approach [20].

1 They may also question the accuracy and credibility of the assessment process and the data it
 2 generates [21].
 3

4 To be effective, feedback must be valued both by those being assessed and by those offering
 5 assessment [14]. When there is tension between the stated goals of assessment and the implicit
 6 culture of the health care organization or institution, assessment programs can too readily devolve
 7 into an activity undertaken primarily to satisfy administrators that rarely improves patient care [20].
 8 Feedback mechanisms should be appropriate to the skills being assessed—multi-source reviews
 9 (“360° reviews”), for example, are generally better suited to providing feedback on communication
 10 and interpersonal skills than on technical knowledge or skills—and easy for evaluators to
 11 understand and use [14]. High quality feedback will come from multiple sources; be specific and
 12 focus on key elements of the ability being assessed; address behaviors rather than personality or
 13 personal characteristics; and “provide both positive comments to reinforce good behavior and
 14 constructive comments with action items to address deficiencies” [22]. Beyond such formal
 15 mechanisms, physicians should welcome and seek out informal input from colleagues. They should
 16 be willing to offer timely comments to colleagues as well.
 17

18 One study among physicians and physicians in training found that participants used a dynamic,
 19 multidimensional process to assess their own abilities. Under this process of what researchers
 20 identified as “informed self-assessment,” participants interpreted and responded to multiple types
 21 of information, such as cognitive and affective data, from both formal and informal sources [23].
 22 Participants described “critically reflecting ‘in action,’ that is, during an activity or throughout the
 23 day:”
 24

25 I think we do a lot of it without thinking of it as reflection. We do it every day when we look at
 26 a patient’s chart. You look back and see the last visit, “What did I do, or should I have done
 27 something different?” I mean that’s reflection, but yet I wouldn’t have thought of that as self-
 28 assessment or self-reflection, but we do it dozens of times a day [23].
 29

30 EXPERTISE & EXPERT JUDGMENT

31
 32 On this broad understanding of competence, physicians’ thought processes are as important as their
 33 knowledge base or technical skills. Thus, understanding competence requires understanding
 34 something of the nature of expertise and processes of expert reasoning, themselves topics of
 35 ongoing exploration [24,25,26,27]. Prevailing theory distinguishes “fast” from “slow” thinking;
 36 that is, reflexive, intuitive processes that require minimal cognitive resources versus deliberate,
 37 analytical processes that require more conscious effort [26]. Some scholars take expertise to
 38 involve “fast” processes, and specifically decision making that involves automatic, nonanalytic
 39 resources acquired through experience [24]. Others argue that expertise consists in using “slow,”
 40 effortful, analytic processes to address problems [24]. A more integrative view argues that
 41 expertise resides in being able to transition between intuitive and analytical processes as
 42 circumstances require. On this account, experts use automatic resources to free up cognitive
 43 capacity so that they maintain awareness of the environment (“situational awareness”) and can
 44 determine when to shift to effortful processes [24].
 45

46 Expert judgment is the ability “to respond effectively in the moment to the limits of [one’s]
 47 automatic resources and to transition appropriately to a greater reliance on effortful processes when
 48 needed” [24], a practice described as “slowing down.” Knowing when to slow down and be
 49 reflective has been demonstrated to improve diagnostic accuracy and other outcomes [26]. To
 50 respond to the unexpected events that often arise in a clinical situation, the physician must
 51 “vigilantly monitor relevant environmental cues” and use these as signals to slow down, to

transition into a more effortful state [25]. This can happen, for example, when a surgeon confronts an unexpected tumor or anatomical anomaly during a procedure. “Slowing down when you should” serves as a critical marker for intraoperative surgical judgment [24].

INFLUENCES ON CLINICAL REASONING

Clinical reasoning is a complex endeavor. Physicians’ capabilities develop through education, training, and experiences that provide tools with which to shape their clinical reasoning. Every physician arrives at a diagnosis and treatment plan for an individual in ways that may align with or differ from the analytical and investigative processes of their colleagues in innumerable ways. When something goes wrong in the clinic, it can be difficult to discern why. Nonetheless, all physicians are open to certain common pitfalls in reasoning, including relying unduly on heuristics and habits of perception, and succumbing to overconfidence.

Heuristics

Physicians often use various heuristics—i.e., cognitive short cuts—to aid decision making. While heuristics can be useful tools to help physicians identify and categorize relevant information, these time-saving devices can also derail decision making. For example, a physician may mistakenly assume that “something that seems similar to other things in a certain category is itself a member of that category” (the representative heuristic) [28], and fail to diagnose a serious health problem. Imagine a case in which a patient presents with symptoms of a possible heart attack or a stroke that the physician proceeds to discount as stress or intoxication once the physician learns that the patient is going through a divorce or smells alcohol on the patient’s breath. Or a physician may miscalculate the likelihood of a disease or injury occurring by placing too much weight “on examples of things that come to mind easily, . . . because they are easily remembered or recently encountered” (the availability heuristic) [28]. For example, amidst heavy media coverage of an outbreak of highly infectious disease thousands of miles away in a remote part of the world, a physician seeing a patient with symptoms of what is actually a more commonplace illness may misdiagnose (or over diagnose) the exotic condition because that is what is top of mind.

Clinical reasoning can be derailed by other common cognitive missteps as well. These can include misperceiving a coincidental relationship as a causal relationship (illusory bias), or the tendency to remember information transferred at the beginning (or end) of an exchange but not information transferred in the middle (primary or recency bias) [28,29,30].

Habits of Perception

Like every other person, physicians can also find themselves prone to explicit (conscious) or implicit (unconscious) habits of perception or biases. Physicians may allow unquestioned assumptions based on a patient’s race or ethnicity, gender, socioeconomic status, or health behavior, among other features, to shape how they perceive the patient and how they engage with, evaluate and treat the individual. Basing one’s interactions with a patient on pre-existing expectations or stereotypes demeans the patient, undermines the patient’s relationship with the physician and the health care system, and can result in significant health disparities across entire communities [31]. This is of particular concern for patients who are members of minority and historically disadvantaged populations [31]. Physicians may fall victim to the tendency to seek out information that confirms established expectations or dismiss contradicting information that does not fit into predetermined beliefs (confirmatory bias) [28]. These often inadvertent thought processes can result in a physician pursuing an incorrect line of questioning or testing that then leads to a misdiagnosis or the wrong treatment.

No matter how well a patient may seem to fit a stereotype, it is imperative that the physician look beyond categories and assumptions to investigate openly the health issues experienced by the patient. Although all human beings exhibit both conscious and unconscious habits of perception, physicians must remain vigilant in not allowing preconceived or unexamined assumptions to influence their medical practice.

Overconfidence

Finally, another obstacle to strong clinical reasoning that physicians may encounter is overconfidence. Despite their extensive training, physicians, like all people, are poor at identifying the gaps in their knowledge [28,30]. Physicians may consider their skills to be excellent, when, in fact, their peers have identified areas for improvement [30]. Overconfidence in one's abilities can lead to suboptimal care for a patient, be it through mismanaging resources, failing to consider the advice of others, or not acknowledging one's limits [28,30].

To avoid falling into such traps, physicians must recognize that many factors can and will influence their clinical decisions [28]. They need to be aware of the information they do and do not have and they need to acknowledge that many factors can and will influence their judgment. They should keep in mind the likelihood of diseases and conditions and take the time to distinguish information that is truly essential to sound clinical judgment from the wealth of possibly relevant information available about a patient. They should consider reasons their decisions may be wrong and seek alternatives, as well as seek to disprove rather than confirm their hypotheses [28]. And they should be sensitive to the ways in which assumptions may color their reasoning and not allow expectations to govern their interactions with patients.

Shortcomings can be an opportunity for growth in medicine, as in any other field. By becoming aware of areas in which their skills are not at their strongest and seeking additional education or consulting with colleagues, physicians can enhance their practice and best serve their patients.

Physicians' ability to practice safely can be affected by their own health, of course. The *Code of Medical Ethics* addresses such situations in guidance on physicians' health and wellness ([E-9.3.1](#)) and their responsibilities to impaired colleagues ([E-9.3.2](#)).

FROM INFORMED SELF-ASSESSMENT TO SELF-AWARENESS

Recognizing that many factors affect clinical reasoning and that self-assessment as traditionally conceived has significant shortcomings, several scholars have argued that a different understanding of self-assessment is needed, along with a different conceptualization of its role in a self-regulating profession [32]. Self-assessment, it is suggested, is a mechanism for identifying both one's weaknesses and one's strengths. One should be aware of one's weaknesses in order to self-limit practice in areas in which one has limited competence, to help set appropriate learning goals, and to identify areas that "should be accepted as forever outside one's scope of competent practice" [32]. Knowing one's strengths, meanwhile, allows a physician both to "act with appropriate confidence" and to "set appropriately challenging learning goals" that push the boundaries of the physician's knowledge [32].

If self-assessment is to fulfill these functions, physicians need to reflect on past performance to evaluate not only their general abilities but also specific completed performances. At the same time, they must use self-assessment predictively to assess how likely they are to be able to manage new challenges and new situations. More important, physicians should understand self-assessment as an ongoing process of monitoring tasks during performance [3]. The ability to monitor oneself in

the moment is critical to physicians' ethical responsibility to practice safely, at the top of their expertise but not beyond it.

Expert practitioners rely on pattern recognition and other automatic resources to be able to think and act intuitively. As noted above, an important component of expert judgment is transitioning effectively from automatic modes of thinking to more effortful modes as the situation requires. Self-awareness, in the form of attentive self-observation (metacognitive monitoring), alerts physicians when they need to direct additional cognitive resources to the immediate task. For example, among surgeons, knowing when to "slow down" during a procedure is critical to competent professional performance, whether that means actually stopping the procedure, withdrawing attention from the surrounding environment to focus more intently on the task at hand, or removing distractions from the operating environment [25].

Physicians should also be sensitive to the ways that interruptions and distractions, which are common in health care settings, can affect competence in the moment [34,35], by disrupting memory processes, particularly the "prospective memory"—i.e., "a memory performance in which a person must recall an intention or plan in the future without an agent telling them to do so"—important for resuming interrupted tasks [35,36]. Systems-level interventions have been shown to help reduce the number or type of interruptions and distractions and mitigate their impact on medical errors [37].

A key aspect of competence is demonstrating situation-specific awareness in the moment of being at the boundaries of one's knowledge and responding accordingly [33]. Slowing down, looking things up, consulting a colleague, or deferring from taking on a case can all be appropriate responses when physicians' self-awareness tells them they are at the limits of their abilities. The capacity for ongoing, attentive self-observation, for "mindful" practice, is an essential marker of competence broadly understood:

Safe practice in a health professional's day-to-day performance requires an awareness of when one lacks the specific knowledge or skill to make a good decision regarding a particular patient This decision making in context is importantly different from being able to accurately rate one's own strengths and weaknesses in an acontextual manner. . . . Safe practice requires that self-assessment be conceptualized as repeatedly enacted, situationally relevant assessments of self-efficacy and ongoing 'reflection-in-practice,' addressing emergent problems and continuously monitoring one's ability to effectively solve the current problem [32].

Self-aware physicians discern when they are no longer comfortable handling a particular type of case and know when they need to obtain more information or need additional resources to supplement their own skills [32]. Self-aware physicians are also alert to how external stressors—the death of a loved one or other family crisis, or the reorganization of their practice, for example—may be affecting their ability to provide care appropriately at a given time. They recognize when they should ask themselves whether they should postpone care, arrange to have a colleague provide care, or otherwise find ways to protect the patient's well-being.

MAINTAINING COMPETENCE ACROSS A PRACTICE LIFETIME

For physicians, the ideal is not simply to be "good" practitioners, but to excel throughout their professional careers. This ideal holds not just over the course of a sustained clinical practice, but equally when physicians re-enter practice after a hiatus, transition from active patient care to roles as educators or administrators, or take on other functions in health care. Self-assessment and self-awareness are central to achieving that goal.

1 A variety of strategies are available to physicians to support effective self-assessment and help
2 physicians cultivate the kind of self-awareness that enables them to “know when to slow down” in
3 day-to-day practice. One such strategy might be to create a portfolio of materials for reflection in
4 the form of written descriptions, audio or video recording, or photos of encounters with patients
5 that can provide evidence of learning, achievement and accomplishment [16] or of opportunities to
6 improve practice. A strength of portfolios as a tool for assessing one’s practice is that, unlike
7 standardized examinations, they are drawn from one’s actual work and require self-reflection [15].
8

9 As noted above, to be effective, self-assessment must be joined with input from others. Well-
10 designed multi-source feedback can be useful in this regard, particularly for providing information
11 about interpersonal behaviors [14]. Research has shown that a four-domain tool with a simple
12 response that elicits feedback about how well one maintains trust and professional relationships
13 with patients, one’s communication and teamwork skills, and accessibility offers a valid, reliable
14 tool that can have practical value in helping to correct poor behavior and, just as important,
15 consolidate good behavior [14]. Informal arrangements among colleagues to provide thoughtful
16 feedback will not have the rigor of a validated tool but can accomplish similar ends.
17

18 Reflective practice, that is, the habit of using critical reflection to learn from experience, is
19 essential to developing and maintaining competence across a physician’s practice lifetime [38]. It
20 enables physicians to “integrate personal beliefs, attitudes, and values in the context of professional
21 culture,” and to bridge new and existing knowledge. Studies suggest that reflective thinking can be
22 assessed, and that it can be developed, but also that the habit can be lost over time with increasing
23 years in practice [38].
24

25 “Mindful practice,” that is, being fully present in everyday experience and aware of one’s own
26 mental processes (including those that cloud decision making) [39], sustains the attitudes and skills
27 that are central to self-awareness. Medical training, with its fatigue, dogmatism, and emphasis on
28 behavior over consciousness, erects barriers to mindful practice, while an individual’s unexamined
29 negative emotions, failure of imagination, and literal-mindedness can do likewise. Mindfulness can
30 be self-taught, but for most it is most effectively learned in relationship with a mentor or guide.
31 Nonetheless, despite challenges, there are myriad ways physicians can cultivate mindfulness.
32 Meditation, which may come first to mind, is one, but so is keeping a journal, reviewing videos of
33 encounters with patients, or seeking insight from critical incident reports [39].
34

35 “Exemplary physicians,” one scholar notes, “seem to have a capacity for self-critical reflection that
36 pervades all aspects of practice, including being present with the patient, solving problems,
37 eliciting and transmitting information, making evidence-based decisions, performing technical
38 skills, and defining their own values” [39].
39

40 RECOMMENDATION

41

42 The Council on Ethical and Judicial Affairs recommends that the following be adopted and the
43 remainder of this report be filed:
44

45 The expectation that physicians will provide competent care is central to medicine. It
46 undergirds professional autonomy and the privilege of self-regulation granted by society. To
47 this end, medical schools, residency and fellowship programs, specialty boards, and other
48 health care organizations regularly assess physicians’ technical knowledge and skills.
49

50 However, as an ethical responsibility competence encompasses more than medical knowledge
51 and skill. It requires physicians to understand that as a practical matter in the care of actual

1 patients, competence is fluid and dependent on context. Each phase of a medical career, from
2 medical school through retirement, carries its own implications for what a physician should
3 know and be able to do to practice safely and to maintain effective relationships with patients
4 and with colleagues. Physicians at all stages of their professional lives need to be able to
5 recognize when they are and when they are not able to provide appropriate care for the patient
6 in front of them or the patients in their practice as a whole.

7
8 To fulfill the ethical responsibility of competence, individual physicians and physicians in
9 training should strive to:

- 10
11 (a) Cultivate continuous self-awareness and self-observation.
12
13 (b) Recognize that different points of transition in professional life can make different
14 demands on competence.
15
16 (c) Take advantage of well-designed tools for self-assessment appropriate to their practice
17 settings and patient populations.
18
19 (d) Seek feedback from peers and others.
20
21 (e) Be attentive to environmental and other factors that may compromise their ability to
22 bring appropriate skills to the care of individual patients and act in the patient's best
23 interest.
24
25 (f) Intervene in a timely and appropriate manner when a colleague's ability to practice
26 safely is compromised by impairment, in keeping with ethics guidance.

27
28 Medicine as a profession should continue to refine mechanisms for assessing knowledge and
29 skill and should develop meaningful opportunities for physicians and physicians in training to
30 hone their ability to be self-reflective and attentive in the moment.

(New HOD/CEJA Policy)

Fiscal Note: Less than \$500.

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REPORT OF THE COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS*

CEJA Report 2-I-18

Subject: Study Aid-in-Dying as End-of-Life Option
(Resolution 15-A-16)
The Need to Distinguish “Physician-Assisted Suicide” and “Aid in Dying”
(Resolution 14-A-17)

Presented by: James E. Sabin, MD, Chair

Referred to: Reference Committee on Amendments to Constitution and Bylaws
(Todd M. Hertzberg, MD, Chair)

At the 2016 Annual Meeting, the House of Delegates referred Resolution 15-A-16, “Study Aid-in-Dying as End-of-Life Option,” presented by the Oregon Delegation, which asked:

That our American Medical Association (AMA) and its Council on Judicial and Ethical Affairs (CEJA), study the issue of medical aid-in-dying with consideration of (1) data collected from the states that currently authorize aid-in-dying, and (2) input from some of the physicians who have provided medical aid-in-dying to qualified patients, and report back to the HOD at the 2017 Annual Meeting with recommendation regarding the AMA taking a neutral stance on physician “aid-in-dying.”

At the following Annual Meeting in June 2017, the House of Delegates similarly referred Resolution 14-A-17, “The Need to Distinguish between ‘Physician-Assisted Suicide’ and ‘Aid in Dying’” (presented by M. Zuhdi Jasser, MD), which asked that our AMA:

(1) as a matter of organizational policy, when referring to what it currently defines as ‘*Physician Assisted Suicide*’ avoid any replacement with the phrase ‘*Aid in Dying*’ when describing what has long been understood by the AMA to specifically be ‘*Physician Assisted Suicide*’; (2) develop definitions and a clear distinction between what is meant when the AMA uses the phrase ‘*Physician Assisted Suicide*’ and the phrase ‘*Aid in Dying*’; and (3) fully utilize these definitions and distinctions in organizational policy, discussions, and position statements regarding both ‘*Physician Assisted Suicide*’ and ‘*Aid in Dying*.’

This report by the Council on Ethical and Judicial Affairs addresses the concerns expressed in Resolutions 15-A-16 and 14-A-17. In carrying out its review of issues in this area, CEJA reviewed the philosophical and empirical literature, sought input from the House of Delegates through an I-16 educational program on physician-assisted suicide, an informal “open house” at A-17, and its I-17 Open Forum. The council wishes to express its sincere appreciation for participants’ contributions during these sessions and for additional written communications received from multiple stakeholders, which have enhanced its deliberations.

* Reports of the Council on Ethical and Judicial Affairs are assigned to the Reference Committee on Amendments to Constitution and Bylaws. They may be adopted, not adopted, or referred. A report may not be amended, except to clarify the meaning of the report and only with the concurrence of the Council.

The council observes that the ethical arguments advanced today supporting and opposing “physician-assisted suicide” or “aid in dying” are fundamentally unchanged from those examined in CEJA’s 1991 report on this topic [1]. The present report does not rehearse these arguments again as such. Rather, it considers the implications of the legalization of assisted suicide in the United States since the adoption of Opinion E-5.7, “Physician-Assisted Suicide,” in 1994.

“ASSISTED SUICIDE,” “AID IN DYING,” OR “DEATH WITH DIGNITY”?

Not surprisingly, the terms stakeholders use to refer the practice of physicians prescribing lethal medication to be self-administered by patients in many ways reflect the different ethical perspectives that inform ongoing societal debate. Proponents of physician participation often use language that casts the practice in a positive light. “Death with dignity” foregrounds patients’ values and goals, while “aid in dying” invokes physicians’ commitment to succor and support. Such connotations are visible in the titles of relevant legislation in states that have legalized the practice: “Death with Dignity” (Oregon, Washington, District of Columbia), “Patient Choice and Control at the End of Life” (Vermont), “End of Life Options” (California, Colorado), “Our Care Our Choice Act” (Hawaii), and in Canada’s “Medical Aid in Dying.”

Correspondingly, those who oppose physician provision of lethal medications refer to the practice as “physician-assisted suicide,” with its negative connotations regarding patients’ psychological state and its suggestion that physicians are complicit in something that, in other contexts, they would seek to prevent. The language of dignity and aid, critics contend, are euphemisms [2]; their use obscures or sanitizes the activity. In their view such language characterizes physicians’ role in a way that risks construing an act that is ethically unacceptable as good medical practice [3]. Still others, meanwhile, argue that the choice by terminally ill patients to take action to end their own lives with the assistance of their physician is distinct from what is traditionally understood as “suicide” [4].

The council recognizes that choosing one term of art over others can carry multiple, and not always intended messages. However, in the absence of a perfect option, CEJA believes ethical deliberation and debate is best served by using plainly descriptive language. In the council’s view, despite its negative connotations [5], the term “physician assisted suicide” describes the practice with the greatest precision. Most importantly, it clearly distinguishes the practice from euthanasia [1]. The terms “aid in dying” or “death with dignity” could be used to describe either euthanasia or palliative/hospice care at the end of life and this degree of ambiguity is unacceptable for providing ethical guidance.

COMMON GROUND

Beneath the seemingly incommensurate perspectives that feature prominently in public and professional debate about writing a prescription to provide patients with the means to end life if they so choose, CEJA perceives a deeply and broadly shared vision of what matters at the end of life. A vision that is characterized by hope for a death that preserves dignity, a sense of the sacredness of ministering to a patient at the end of life, recognition of the relief of suffering as the deepest aim of medicine, and fully voluntary participation on the part of both patient and physician in decisions about how to approach the end of life.

Differences lie in the forms these deep commitments take in concrete decisions and actions. CEJA believes that thoughtful, morally admirable individuals hold diverging, yet equally deeply held, and well-considered perspectives about physician-assisted suicide that govern how these shared commitments are ultimately expressed. For one patient, dying “with dignity” may mean accepting

the end of life however it comes as gracefully as one can; for another, it may mean being able to exercise some measure of control over the circumstances in which death occurs. For some physicians, the sacredness of ministering to a terminally ill or dying patient and the duty not to abandon the patient preclude the possibility of supporting patients in hastening their death. For others, not to provide a prescription for lethal medication in response to a patient's sincere request violates that same commitment and duty. Both groups of physicians base their view of ethical practice on the guidance of [Principle I](#) of the AMA *Principles of Medical Ethics*: "A physician shall be dedicated to providing competent medical care, with compassion and respect for human dignity and rights."

So too, how physicians understand and act on the goals of relieving suffering, respecting autonomy, and maintaining dignity at the end of life is directed by identity-conferring beliefs and values that may not be commensurate. Where one physician understands providing the means to hasten death to be an abrogation of the physician's fundamental role as healer that forecloses any possibility of offering care that respects dignity, another in equally good faith understands supporting a patient's request for aid in hastening a foreseen death to be an expression of care and compassion.

IRREDUCIBLE DIFFERENCES IN MORAL PERSPECTIVES ON PHYSICIAN-ASSISTED SUICIDE

How to respond when coherent, consistent, and deeply held beliefs yield irreducibly different judgments about what is an ethically permissible course of action is profoundly challenging. With respect to physician-assisted suicide, some professional organizations—for example, the American Academy of Hospice and Palliative Medicine [6]—have adopted a position of "studied neutrality." Positions of studied neutrality neither endorse nor oppose the contested practice, but instead are intended to respect that there are irreducible differences among the deeply held beliefs and values that inform public and professional perspectives [6,7], and to leave space open for ongoing discussion. Nonetheless, as a policy position, studied neutrality has been criticized as neither neutral or appropriate for organized medicine [8], and as being open to unintended consequences, including stifling the very debate it purports to encourage or being read as little more than acquiescence with the contested practice [9].

CEJA approaches the condition of irreducible difference from a different direction. In its 2014 report on exercise of conscience, the Council noted that "health care professionals may hold very different core beliefs and thus reach very different decisions based on those core beliefs, yet equally act according to the dictates of conscience. For example, a physician who chooses to provide abortions on the basis of a deeply held belief in protecting women's autonomy makes the same kind of moral claim to conscience as does a physician who refuses to provide abortion on the basis of respect for the sanctity of life of the fetus" [10].

Importantly, decisions taken in conscience are not simply idiosyncratic; they do not rest on intuition or emotion. Rather, such decisions are based on "substantive, coherent, and reasonably stable" values and principles [10]. Physicians must be able to articulate how those values and principles justify the action in question.

The ethical arguments offered for more than two decades by those who support and those who oppose physician participation in assisted suicide reflect the diverging "substantive, coherent, and reasonably stable" values and principles within the profession and the wider moral community. While supporters and opponents of physician-assisted suicide share a common commitment to "compassion and respect for human dignity and rights" (AMA [Principles of Medical Ethics](#), I),

they draw different moral conclusions from the underlying principle they share. As psychiatrist Harvey Chochinov observed with respect to the stakeholders interviewed by Canadian Supreme Court’s advisory panel on physician-assisted death, “neither those who are strongly supportive nor those who are opposed hold a monopoly on integrity and a genuine concern for the well-being of people contemplating end of life. Equally true: neither side is immune from impulses shaped more by ideology than a deep and nuanced understanding of how to best honor and address the needs of people who are suffering” [11].

THE RISK OF UNINTENDED CONSEQUENCES

From the earliest days of the debate, a prominent argument raised against permitting physician-assisted suicide has been that doing so will have adverse consequences for individual patients, the medical profession, and society at large. Scholars have cited the prospect that boundaries will be eroded and practice will be extended beyond competent, terminally ill adult patients; to patients with psychiatric disorders, children; or that criteria will be broadened beyond physical suffering to encompass existential suffering; or that stigmatized or socioeconomically disadvantaged patients will be coerced or encouraged to end their lives. Concerns have also been expressed that permitting the practice will compromise the integrity of the profession, undermine trust, and harm the physicians and other health care professionals who participate; and that forces outside medicine will unduly influence decisions.

The question whether safeguards—which in the U.S. jurisdictions that permit assisted suicide, restrict the practice to terminally ill adult patients who have decision-making capacity and who voluntarily request assisted suicide, along with procedural and reporting requirements—can actually protect patients and sustain the integrity of medicine remains deeply contested. Some studies have “found no evidence to justify the grave and important concern often expressed about the potential for abuse—namely, the fear that legalized physician-assisted dying will target the vulnerable or pose the greatest risk to people in vulnerable groups” [12], others question whether the available data can in fact support any such conclusions, finding the evidence cited variously flawed [13], inadequate [14], or distorted [15].

Although cross-cultural comparisons are problematic [16], current evidence from Europe does tell a cautionary tale. Recent findings from studies in Belgium and the Netherlands, both countries that permit euthanasia as well as physician-assisted suicide, mitigate some fears but underscore others [17]. For example, research in the Netherlands has found that “requests characterized by psychological as opposed to physical suffering were more likely to be rejected, as were requests by individuals who lived alone,” mitigating fears that “solitary, depressed individuals with potentially reversible conditions might successfully end their lives.” At the same time, however, among patients who obtained euthanasia or assisted suicide, nearly 4 percent “reported only psychological suffering.” At the level of anecdote, a description of a case of euthanasia in Belgium elicited widespread concern about the emergence of a “slippery slope” [18].

Studies have also raised questions about how effective retrospective review of decisions to provide euthanasia/assisted suicide is in policing practice [19,20]. A qualitative analysis of cases that Dutch regional euthanasia committees determined had not met legal “due care criteria” found that such reviews focus on procedural considerations and do not “directly assess the actual eligibility” of the patients who obtained euthanasia [19]. A separate study of cases in which psychiatric patients obtained euthanasia found that physicians’ reports “stated that psychosis or depression did or did not affect capacity but provided little explanation regarding their judgments” and that review committees “generally accepted the judgment of the physician performing EAS [euthanasia or physician-assisted suicide]” [20]. It remains an open question whether reviews that are not able to

1 assess physicians' reasoning truly offer the protection they are intended to provide. To the extent
 2 that reporting and data collection in states that permit physician-assisted suicide have similar
 3 limitations, oversight of practice may not be adequate.

4
 5 Medicine must learn from this experience. Where physician-assisted suicide is legalized,
 6 safeguards can and should be improved—e.g., “[t]o increase safeguards, states could consider
 7 introducing multidisciplinary panels to support patients through the entire process, including
 8 verifying consent and capacity, ensuring appropriate psychosocial counseling, and discussing all
 9 palliative and end-of-life options” [21]. Both the state and the medical profession have a
 10 responsibility to monitor ongoing practice in a meaningful way and to address promptly
 11 compromises in safeguards should any be discovered. It is equally important that strong practices
 12 be identified and encouraged across all jurisdictions that permit physicians to assist suicide. Health
 13 care organizations in California and Canada, for example, have shared richly descriptive reports of
 14 practices adopted in response to the recent legalization of “aid in dying” in those jurisdictions that
 15 seek to address concerns about quality of practice and data collection [22,23].

16
 17 Medicine must also acknowledge, however, that evidence (no matter how robust) that there have
 18 not yet been adverse consequences cannot guarantee that such consequences would not occur in the
 19 future. As a recent commentary noted, “[p]art of the problem with the slippery slope is you never
 20 know when you are on it” [17].

21 22 SAFEGUARDING DECISIONS AT THE END OF LIFE

23
 24 CEJA has found that just as there are shared commitments behind deep differences regarding
 25 physician-assisted suicide, there are also shared concerns about how to understand the available
 26 evidence. For example, in the council's recent Open Forum, both proponents and opponents of
 27 physician-assisted suicide observed that in the U.S., debate occurs against the backdrop of a health
 28 care system in which patients have uneven access to care, including access to high quality end-of-
 29 life care. They also noted that patients and physicians too often still do not have the conversations
 30 they should about death and dying, and that too few patients are aware of the range of options for
 31 end-of-life care, raising concern that many patients may be led to request assisted suicide because
 32 they don't understand the degree of relief of suffering state-of-the-art palliative care can offer.
 33 Participants who in other respects held very different views concurred as well that patients may be
 34 vulnerable to coercion, particularly patients who are in other ways disadvantaged; and expressed
 35 concern in common that forces external to medicine could adversely influence practice.

36
 37 These are much the same concerns the Institute of Medicine identified in its 2015 report, *Dying in*
 38 *America* [24]. They are concerns echoed in a February 2018 workshop on physician-assisted death
 39 convened by the National Academies of Science, Engineering and Medicine [25]. They underscore
 40 how important it is to understand *why* a patient requests assisted suicide as a starting point for care
 41 [26].

42
 43 Patient requests for assisted suicide invite physicians to have the kind of difficult conversations that
 44 are too often avoided. They open opportunities to explore the patient's goals and concerns, to learn
 45 what about the situation the individual finds intolerable and to respond creatively to the patient's
 46 needs other than providing the means to end life—by such means as better managing symptoms,
 47 arranging for psychosocial or spiritual support, treating depression, and helping the patient to
 48 understand more clearly how the future is likely to unfold [5,27]. Medicine as a profession must
 49 ensure that physicians are skillful in engaging in these difficult conversations and knowledgeable
 50 about the options available to terminally ill patients [28]. The profession also has a responsibility to
 51 advocate for adequate resources for end-of-life care [16,28], particularly for patients from

disadvantaged groups. The availability of assisted suicide where it is legal must not be allowed to interfere with excellent care at the end of life.

CONCLUSION

At the core of public and professional debate, the council believes, is the aspiration that every patient come to the end of life as free as possible from suffering that does not serve the patient's deepest self-defining beliefs and in the presence of trusted companions, including where feasible and when the patient desires, the presence of a trusted physician. As Timothy Quill noted more than 20 years ago, "dying patients do not have the luxury of choosing not to undertake the journey, or of separating their person from their disease" [27]. Decisions about how to approach the end of life are among the most intimate that patients, families, and their physicians make. Respecting the intimacy and the authenticity of those relationships is essential if our common ideal is to be achieved.

While supporters and opponents of physician-assisted suicide share a common commitment to "compassion and respect for human dignity and rights" ([AMA Principles of Medical Ethics](#), I), they draw different moral conclusions from the underlying principle they share. Where one physician understands providing the means to hasten death to be an abrogation of the physician's fundamental role as healer that forecloses any possibility of offering care that respects dignity, another in equally good faith understands supporting a patient's request for aid in hastening a foreseen death to be an expression of care and compassion.

RECOMMENDATION

The Council on Ethical and Judicial Affairs has reviewed the literature and received thoughtful input from numerous individuals and organizations to inform its deliberations, and is deeply grateful to all who shared their insights. CEJA engaged in extensive, often passionate discussion about how to interpret the *Code of Medical Ethics* in light of ongoing debate and the irreducible differences in moral perspectives identified above. The council recognized that supporters and opponents share a fundamental commitment to values of care, compassion, respect, and dignity, but diverge in drawing different moral conclusions from those underlying values in equally good faith. The council further recognized that medicine must learn from experience of physician-assisted suicide, and must ensure that, where the practice is legal, safeguards are improved.

After careful consideration, CEJA concludes that in existing opinions on physician-assisted suicide and the exercise of conscience, the *Code* offers guidance to support physicians and the patients they serve in making well-considered, mutually respectful decisions about legally available options for care at the end of life in the intimacy of a patient-physician relationship.

The Council on Ethical and Judicial Affairs therefore recommends that the *Code of Medical Ethics* not be amended, that Resolutions 15-A-16 and 14-A-17 not be adopted and that the remainder of the report be filed.

Fiscal Note: None.

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REPORT OF THE COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS*

CEJA Report 3-I-18

Subject: Amendment to E-2.2.1, “Pediatric Decision Making”
(Resolution 3-A-16, “Supporting Autonomy for Patients with Differences of Sex Development [DSD]”)
(Resolution 13-A-18, “Opposing Surgical Sex Assignment of Infants with Differences of Sex Development”)

Presented by: James E. Sabin, MD, Chair

Referred to: Reference Committee on Amendments to Constitution and Bylaws
(Todd M. Hertzberg, MD, Chair)

At the 2016 Interim Meeting, the American Medical Association (AMA) House of Delegates referred Board of Trustees Report 7-I-16, “Supporting Autonomy for Patients with Differences of Sex Development (DSD),” responding to Resolution 3-A-16 of the same title introduced by the Medical Student Section, which asked:

That our AMA affirm that medically unnecessary surgeries in individuals born with differences of sex development are unethical and should be avoided until the patient can actively participate in decision-making.

Testimony regarding BOT 7-I-16 expressed concern about lack of expert insight into the medical complexities in treating differences of sex development in pediatric patients in its analysis and possible unintended consequences of its recommendations.

Resolution 13-A-18, “Opposing Surgical Sex Assignment of Infants with Differences of Sex Development,” brought by the Michigan Delegation, asked

That our American Medical Association oppose the assignment of gender binary sex to infants with differences in sex development through surgical intervention outside of the necessity of physical functioning for an infant and believes children should have meaningful input into any gender assignment surgery.

Noting that the issue was under study by the Council on Ethical and Judicial Affairs (CEJA), the House of Delegates referred this resolution so that the council could address it during its ongoing deliberations in this area.

This CEJA report provides ethics guidance for physicians in relation to the concerns expressed in Resolutions 3-A-16 and 13-A-18. The council is grateful for participants’ contributions during reference committee hearings and for additional written communications received from multiple stakeholders, which have greatly enhanced its deliberations.

* Reports of the Council on Ethical and Judicial Affairs are assigned to the Reference Committee on Amendments to Constitution and Bylaws. They may be adopted, not adopted, or referred. A report may not be amended, except to clarify the meaning of the report and only with the concurrence of the Council.

1 CLARIFYING THE QUESTION

2
3 Resolutions 3-A-16 and 13-A-18 speak to clinical decisions that have enormous significance for
4 individual patients and families, decisions that also implicate socially and culturally sensitive issues
5 of embodiment, gender, and sexuality. Each asks AMA to endorse specific broadly framed
6 statements intentionally limiting the range of decisions physicians, patients, and families should
7 reach. Yet as multiple stakeholders have pointed out, the label “differences [or disorders] of sex
8 development” is problematic in that it encompasses a very broad range of conditions that carry
9 quite variable implications for patients’ immediate and longer-term health, making for an
10 extremely complex clinical picture overall [e.g., 1,2,3].

11
12 It is, moreover, a clinical picture in which the body of evidence available to inform decisions
13 remains both limited and contested in important ways. In part, this reflects the difficulty in
14 collecting data, given the relative rarity of these conditions and the sheer range of conditions
15 currently labeled “differences of sex development” [e.g., 4]. Importantly, it reflects divergence
16 among understandings of children’s physical and psychosocial development on which
17 stakeholders’ perspectives rest [e.g., 4,5,6,7,8,9].

18
19 Literature reviews that stakeholders have provided to help inform CEJA’s deliberations indicate
20 ongoing, significant differences in how the published evidence is interpreted [e.g., 1,10]. Concerns
21 have been expressed about not just the quantity, but also the quality of the data available to inform
22 clinical decisions, with questions raised about whether studies have asked the “right” question and
23 about how well the framing of key research questions and the methodology, sample size, and data
24 analysis support the conclusions drawn in a given study [e.g., 11]. Stakeholders concur on the need
25 for systematic, well-designed research to provide robust evidence on the long-term outcomes that
26 are meaningful to patients of different clinical approaches.

27
28 CEJA appreciates the challenge this state of affairs poses for families and physicians who strive to
29 make clinically well-informed decisions for individual children. Thoughtful stakeholders differ in
30 good faith, at times profoundly, about whether and at what developmental stage in the child’s life
31 intervention should be considered medically essential, preferred, or acceptable for children born
32 with differences of sex development. Despite these differences, stakeholders clearly share a deep
33 professional commitment to serving the best interest of pediatric patients.

34
35 However, to the extent that Resolutions 3-A-16 and 13-A-18 call on the council to address the lack
36 of clinical consensus, they seek guidance that is not within CEJA’s purview to offer. It is not the
37 council’s role to adjudicate clinical disagreement or to prescribe what manner of decision is
38 “correct” or “best,” but rather to clarify the values at issue and identify what factors must be
39 considered to arrive at an *ethically sound* decision in any given patient’s unique situation.

40 MAKING DECISIONS FOR PEDIATRIC PATIENTS

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42
43 Health care decisions for pediatric patients necessarily have a different character than decisions for
44 adult patients. Decisions for children are made in the context of a three-way relationship among
45 patient, parents (or guardians), and physician rather than the patient-physician dyad typical of
46 decision making for most adult patients. Further, except for emancipated minors, who are
47 authorized to make their own health care decisions, or certain decisions that other minor patients
48 are permitted to make independently (e.g., [E-2.3.3](#), Confidential Care for Minors), decisions for
49 pediatric patients are made, not by the patient, but by parents/guardians acting on the patient’s
50 behalf. Finally, the substituted judgment standard for surrogate decision making on behalf of adult
51 patients is for the most part unavailable to those who make decisions for minors, insofar as

children, especially very young children, are unlikely to have formed settled views and preferences upon which substituted judgment could be based.

The Patient's "Best Interests"

Ethically, and legally, then, parents are expected to make health care decisions in their children's best interests. As the persons best positioned to understand their child's unique needs and interests, parents/guardians are asked to fulfill the dual responsibility of both protecting their children and, at the same time, empowering them and promoting development of the child's capacity to become an independent decision maker. Parents/guardians are expected to safeguard their children's physical health and well-being *and* to nurture their children's developing personhood and autonomy.

Best interests, and thus goals for care, then, should be understood broadly, as encompassing more than simply medical considerations. Parents/guardians are indeed expected to weigh the clinical benefits and risks of treatment alternatives, including the option of no treatment or the timing of interventions, but to do so against the broader background of likely impact on the child's psychosocial well-being, relationships within the family, and family resources and values. As CEJA noted in its original report on decisions for pediatric patients (2007), because families provide a child's usual, often only, source of support and care, the family's needs and interests can also be relevant to treatment decisions. The council further observed that, "If none of the reasonable alternatives the health care team recommends can be reconciled with the family's circumstances, deciding on the best course of treatment may be 'an exercise in psychosocial, as well as technical medical, expertise'" [12].

The Committee on Bioethics of the American Academy of Pediatrics similarly holds that best interest should be understood broadly, to encompass more than purely clinical considerations. The committee urges decision makers to "acknowledge the pediatric patient's emotional, social, and medical concerns along with the interests of the child's family in the process of medical decision making" [13]. However, the committee argues, the concept of "harm" may be a "more realistic standard" for decisions on behalf of pediatric patients, noting that,

The intent of the harm principle is not to identify a single course of action that is in the minor's interest or is the physician's preferred approach, but to identify a harm threshold below which parental decisions will not be tolerated ... [13].

Using the harm principle to inform choices for individual patients, including pediatric patients, requires that decision makers take into account the kind, degree and duration of foreseeable harms, as well as the likelihood of their occurrence.

Engaging Children in Care Decisions

Absent reason to believe otherwise, parents/guardians are understood to be best able to take a child's long-term interests to heart in reaching a decision about care and in general their decisions should be respected. But that does not mean children should have no role in the decision-making process. In its original report CEJA noted that "the ethical principle of respect for persons also applies to children" and urged physicians to seek pediatric patients' assent to decisions made on their behalf [12,13]. Assent, the council observed, "weighs a child's ability to understand options and potential outcomes and to communicate preferences" [12].

CEJA recognized that "the notion of assent can be applied most readily to adolescent patients," but instructed physicians to evaluate younger patients' "cognitive capacities and judgment to determine

if they can understand the risks and benefits of treatment” and to engage them accordingly in the decision-making process. Not all information is cognitively and emotionally appropriate for every pediatric patient, nor is it necessary to communicate all information about a diagnosis and proposed care all at once. As for any patient, physicians should assess the amount of information the individual is capable of receiving at a given time and tailor disclosure to meet patients’ needs, preferences, and ability to understand ([E-2.1.3](#), Withholding Information from Patients).

Respecting children as (developing) persons also entails seeking to understand their reasons for disagreeing with treatment decisions. When an intervention is not immediately necessary to safeguard the child’s welfare, CEJA has argued, physicians (and parents/guardians) should respect a child’s refusal to assent to proposed treatment. Even when immediate treatment is essential to preserve well-being, physicians should explore the child’s reason for dissent, when circumstances permit. The more mature a minor patient is, the better able to understand what a decision will mean, and the more clearly the child can communicate preferences, the stronger the ethical obligation to engage young patients in decisions about their own care. As CEJA noted in refining its guidance on decisions for pediatric patients in 2010, communicating even sensitive and potentially frightening information—about HIV status or a terminal diagnosis, for example—can improve a child’s well-being [14].

Preserving Future Choices

In fulfilling their responsibility to nurture their children’s developing capacity to make autonomous decisions, parents/guardians are expected to make health care decisions that will least impinge on children’s opportunity to make important life choices themselves in the future. In general, decisions taken now on a child’s behalf should be made with an eye not to foreclose decisions the child can reasonably be expected, in time, to want and be able to make independently, realizing that choosing *not* to have a treatment or procedure performed also forecloses a future choice. This “right to an open future” is not absolute, of course. Parents/guardians must balance their responsibility to preserve the child’s opportunity for future exercise of self-determination with the need to protect the child’s immediate well-being. Physicians should be prepared to support them in that process, providing the best available data to inform their decision and directing them to appropriate psychosocial and other resources.

Finally, the opportunity to meet with and learn from others who have faced similar decisions can provide valuable firsthand insight and support that clinicians themselves may not be able to offer. Physicians should familiarize themselves with local peer support groups as resources to help inform decision making by parents and their minor children.

A CONTINUUM OF DECISIONS

The degree of difficulty faced by parents/guardians in making well-considered, ethically justifiable decisions for young patients who are not able to make their own health care choices varies across a continuum. At one end of that continuum are decisions that involve interventions about which there is consensus in the professional community, whose benefits are significant, supported by robust evidence, and significantly outweigh the risks they pose (the likelihood and magnitude of which are themselves well understood). In those situations, physicians have a responsibility to persuade reluctant parents/guardians to accept the intervention on their child’s behalf. Where the intervention would preserve life or avert serious harm and disagreement persists despite efforts to resolve the tension, physicians have legal and ethical obligations to seek court interventions against parental refusal of treatment.

At the other end are decisions that involve interventions that carry significant risk of harm or that currently available evidence would suggest offer little prospect of clinical benefit or cannot reasonably be expected to achieve the intended goal. In these cases, physicians have a responsibility to dissuade parents/guardians from pursuing the intervention, especially when it is irreversible, and should decline to provide the requested care when a patient's parents/guardian persist, in keeping with ethics guidance (e.g., [E-5.5](#), Medically Ineffective Interventions).

Between are decisions that involve interventions about which physicians may in good faith reach diverging professional judgments, and for which evidence as to short- and long-term benefit and risk is limited, equivocal, or contested. In such situations, how physicians interpret available evidence and its implications for an individual patient is shaped in significant part by their understanding of how to balance the competing values of beneficence and respect in upholding medicine's foundational commitment to serve the patient's (best) interests. In this "grey zone" physicians are challenged to negotiate with decision makers a shared agreement about how to understand this patient's medical and psychosocial interests and what plan of care will best serve those interests in the individual's unique circumstances and in most cases should give great deference to parental preferences.

SHOULD DECISIONS ABOUT DSD BE DIFFERENT FROM OTHER DECISIONS?

Helping parents/guardians make decisions for young patients with differences of sex development is inescapably challenging given the range of conditions at issue and the physiological/clinical complexity of many of those conditions. The fact that DSDs are entangled with socially and culturally sensitive issues of bodies, genders, and sex compounds that challenge—the more so in an environment in which a binary understanding of sex and gender is increasingly contested.

Yet whether these decisions are more challenging than decisions for pediatric patients with other diagnoses—say, decisions about cochlear implants for congenitally deaf newborns—is far from clear. The specific interventions about which decisions must be made and the timing of those decisions will be sensitive to the child's clinical situation, of course, but the fundamental task facing parents/guardians and physicians will still be to agree on a path forward that balances safeguarding the child's well-being, short and longer term, and nurturing the child's development as an individual with capacity to make decisions autonomously.

Regardless of the specific decision at issue, it is important that parents/guardians and physicians appreciate the fact that a pediatric patient will of necessity live out the consequences of a choice made by others—one with which the individual may ultimately come to disagree. Moreover, when decisions implicate issues that are socially and culturally divisive, such as sex assignment and "normalizing" surgery for DSD patients, patients and their families can be thrust into the role of agent of social change or preserver of the status quo, knowingly, willingly, or otherwise [4]. Ensuring that parents/guardians have the information and—absent immediate, life-threatening emergency—the time to make well-considered decisions is essential.

For physicians, supporting thoughtful, ethically sound decision making for all pediatric patients, especially very young patients, requires that they consider several fundamental questions and tailor recommendations to the individual's specific circumstances:

- What is this child's likely developmental course without (immediate) intervention? How strong is the evidence to support this prognosis?
- What are these parents/guardians' (and this patient's) overall goals for care?

- To what extent is the clinical anomaly a significant threat to health, immediately and in the long term?
- Is providing the proposed intervention at this stage in the child’s development supported by clear, high quality evidence?
- Could other interventions reasonably be staged developmentally to allow the patient and family time to gain experience living with the condition and to reflect on and perhaps adjust goals for care?
- To what extent would the proposed intervention (or lack of intervention) foreclose important life choices for the adolescent and adult the child will become? Are there reasonable alternatives that would address immediate clinical needs while preserving opportunity to make important future choices?
- What resources will the child and family need to support the child’s healthy physical and psychosocial development? How can the physician assist in making those resources available to the patient and family?

COMING TO COMMON GROUND

Parents/guardians are expected to make health care decisions in children’s “best interest.” In doing so, they are expected both to protect children and, at the same time, to empower children and promote children’s developing capacity to become independent decision makers. To nurture this developing capacity, health care decisions are preferable that will least impinge on children’s opportunity to make important life choices themselves in the future.

Making decisions for children that involve socially or culturally sensitive issues—for example, whether or how to discuss a terminal diagnosis with a child, or whether, when, or how to intervene medically for conditions that involve differences of sex development—is always challenging. The greater the uncertainty or lack of robust evidence supporting alternative courses of action, the more difficult the task becomes.

In such circumstances, despite a common commitment to serving the best interest of pediatric patients, thoughtful stakeholders may, in good faith, differ about whether a particular intervention, at a particular time is medically essential, preferred, or acceptable. When no single approach can be said a priori to be “best.” Ethically sound practice requires that decisions be carefully tailored for each patient in a process of shared decision making among parents/guardians, physician and the patient (in keeping with the child’s capacity to participate). Decision makers should seek a shared understanding of goals for care in creating a treatment plan that respects the unique needs, values, and preferences of the individual patient and family.

RECOMMENDATION

In light of the foregoing analysis, the Council on Ethical and Judicial Affairs recommends that Opinion E-2.2.1, “Pediatric Decision Making,” be amended by substitution as follows in lieu of Resolutions 3-A-16, “Supporting Autonomy for Patients with Differences of Sex Development (DSD),” and 13-A-18, “Opposing Surgical Sex Assignment of Infants with Differences of Sex Development,” and the remainder of this report be filed:

As the persons best positioned to understand their child’s unique needs and interests, parents (or guardians) are asked to fill the dual responsibility of protecting their children and, at the same time, empowering them and promoting development of children’s capacity to become independent decision makers. In giving or withholding permission for medical treatment for

1 their children, parents/guardians are expected to safeguard their children's physical health and
 2 well-being and to nurture their children's developing personhood and autonomy.

3
 4 But parents' authority as decision makers does not mean children should have no role in the
 5 decision-making process. Respect and shared decision making remain important in the context
 6 of decisions for minors. Thus, physicians should evaluate minor patients to determine if they
 7 can understand the risks and benefits of proposed treatment and tailor disclosure accordingly.
 8 The more mature a minor patient is, the better able to understand what a decision will mean,
 9 and the more clearly the child can communicate preferences, the stronger the ethical obligation
 10 to seek minor patients' assent to treatment. Except when immediate intervention is essential to
 11 preserve life or avert serious, irreversible harm, physicians and parents/guardians should
 12 respect a child's refusal to assent, and when circumstances permit should explore the child's
 13 reason for dissent.

14
 15 For health care decisions involving minor patients, physicians should:

- 16
 17 (a) Provide compassionate, humane care to all pediatric patients.
- 18
 19 (b) Negotiate with parents/guardians a shared understanding of the patient's medical and
 20 psychosocial needs and interests in the context of family relationships and resources.
- 21
 22 (c) Develop an individualized plan of care that will best serve the patient, basing treatment
 23 recommendations on the best available evidence and in general preferring alternatives that
 24 will not foreclose important future choices by the adolescent and adult the patient will
 25 become. Where there are questions about the efficacy or long-term impact of treatment
 26 alternatives, physicians should encourage ongoing collection of data to help clarify value to
 27 patients of different approaches to care.
- 28
 29 (d) Work with parents/guardians to simplify complex treatment regimens whenever possible
 30 and educate parents/guardians in ways to avoid behaviors that will put the child or others at
 31 risk.
- 32
 33 (e) Provide a supportive environment and encourage parents/guardians to discuss the child's
 34 health status with the patient, offering to facilitate the parent-child conversation for
 35 reluctant parents. Physicians should offer education and support to minimize the
 36 psychosocial impact of socially or culturally sensitive care, including putting the patient
 37 and parents/guardians in contact with others who have dealt with similar decisions and
 38 have volunteered their support as peers.
- 39
 40 (f) When decisions involve life-sustaining treatment for a terminally ill child, ensure that
 41 patients have an opportunity to be involved in decision making in keeping with their ability
 42 to understand decisions and their desire to participate. Physicians should ensure that the
 43 patient and parents/guardians understand the prognosis (with and without treatment). They
 44 should discuss the option of initiating therapy with the intention of evaluating its clinical
 45 effectiveness for the patient after a specified time to determine whether it has led to
 46 improvement and confirm that if the intervention has not achieved agreed-on goals it may
 47 be discontinued.
- 48
 49 (g) When it is not clear whether a specific intervention promotes the patient's interests, respect
 50 the decision of the patient (if the patient has capacity and is able to express a preference)
 51 and parents/guardians.

- 1 (h) When there is ongoing disagreement about patient's best interest or treatment
- 2 recommendations, seek consultation with an ethics committee or other institutional
- 3 resource.

(Modify Current HOD/CEJA Policy)

Fiscal Note: Less than \$500

REFERENCES

1. Joint communication from the American Urological Association, Societies for Pediatric Urology, American Association for Clinical Urologists, American Congress of Obstetricians and Gynecologists, Pediatric Endocrine Society, and North American Society for Pediatric and Adolescent Gynecology. March 7, 2018. See Appendix A.
2. Communication from Arlene B. Baratz, MD, on behalf of Androgen Insensitivity Syndrome—Differences of Sex Development (AIS-DSD) Support Group. September 14, 2018. See Appendix B.
3. Communication from Dina M. Matos, Executive Director, and Karen Lin Su, MD, Medical Director, CARESFoundation. September 4, 2018. See Appendix C.
4. Constitutional Court of Colombia. Sentencia SU-337/99, Parts I–III (in Spanish). Available at <http://www.isna.org/node/516>. Accessed August 28, 2018.
5. Communication from Kyle Knight, Researcher, Human Rights Watch. February 2, 2018. See Appendix D.
6. Communication from Homer Venters, MD, MS, Director of Programs, Physicians for Human Rights. February 1, 2018. See Appendix E.
7. Communication from Tara Demant, Director, Gender, Sexuality, and Identity Program, Amnesty International USA. February 21, 2018. See Appendix F.
8. Communication from Eliza Byard, PhD, Executive Director, GLSEN. January 31, 2018. See Appendix G.
9. American College of Pediatricians. *Gender Ideology Harms Children*, September 2017. Available at <https://www.acpeds.org/the-college-speaks/position-statements/gender-ideology-harms-children?highlight=gender%20ideology>. Accessed October 5, 2018.
10. Communication from Jerome Jeevaraj and Kieran McAvoy, Delegates, on behalf of the American Medical Association Medical Student Section. February 15, 2018. See Appendix H.
11. Baratz AB, Feder EK. Misrepresentation of evidence favoring early normalizing surgery for atypical sex anatomies [letter]. *Arch Sex Behav*. 2015; March 26. DOI 10.1007/s10508-015-0529-x.
12. American Medical Association. *Proceedings of the AMA House of Delegates*, Council on Ethical and Judicial Affairs Report 8-I-07, Pediatric Decision Making, November 2007. Available at http://ama.nmtvault.com/jsp/viewer.jsp?doc_id=ama_arch%252FHOD00005%252F00000005&view_width=640.0&rotation=0&queryl=&collection_filter=All&collection_name=Iee24daa-2768-4bff-b792-e4859988fe94&zoom_factor=current&search_doc=Pediatric%2520Decision%2520Making&sort_col=publication+date&highlightColor=yellow&color=&CurSearchNum=-1&search_docl=Pediatric+Decision+Making&page_name=&page_name=&submit.x=0&submit.y=0, pp. 120–125. Accessed October 5, 2018.
13. American Academy of Pediatrics, Committee on Bioethics. Informed consent in decision-making in pediatric practice. *Pediatrics* 2016;138(2):1–7. Available at <http://pediatrics.aappublications.org/content/early/2016/07/21/peds.2016-1484>. Accessed October 5, 2018.
14. American Medical Association. *Proceedings of the AMA House of Delegates*, Council on Ethical and Judicial Affairs Report 1-I-10, Pediatric Decision Making, November 2010. Available at http://ama.nmtvault.com/jsp/viewer.jsp?doc_id=ama_arch%252FHOD00006%252F00000003&view_width=640.0&rotation=0&queryl=&collection_filter=All&collection_name=Iee24daa-2768-4bff-b792-e4859988fe94&zoom_factor=current&search_doc=Pediatric%2520Decision%2520Making&sort_col=publication+date&highlightColor=yellow&color=&CurSearchNum=-1&search_docl=Pediatric+Decision+Making&page_name=&page_name=&submit.x=0&submit.y=0, pp. 65–69. Accessed October 5, 2018.

From: [Zwarick, Kathleen](#)
To: [Elliott Crigger](#)
Cc: ["Lucia DiVenere"](#); ["Lorraine O'Grady"](#); [Ally Lopshire](#); ["Lee, Peter"](#); [Stine, Bradley](#); [Kristan, Johnathon](#); ["Anne-Marie Amies"](#); [Sheppard, Mike](#)
Subject: CEJA DSD Report - Overview of Comments
Date: Wednesday, March 07, 2018 4:46:12 PM
Attachments: [CEJA Comments - DSD Report with Appendix -March 2018.docx](#)

Dear Elliott,

As you know, the urological societies convened with other medical societies with expertise in the area to discuss the AMA Council on Ethical and Judicial Affairs (CEJA) Report 3-I-17, "Supporting Autonomy for Patients with Differences of Sex Development (DSD)". The attached is a high-level overview that incorporates the redlined edits we shared with you throughout our conversations. These comments reflect the comprehensive communications between the American Urological Association, Societies for Pediatric Urology, American Association for Clinical Urologists (AACU), American Congress of Obstetricians and Gynecologists, American Academy of Child & Adolescent Psychiatry, North American Society for Pediatric and Adolescent Gynecology, The Endocrine Society, Pediatric Endocrine Society, GLMA: Health Professionals Advancing LGBT Equality, and Medical Students Section discussed. The Medical Students Section indicated that they will submitting a separate analysis of the literature you previously were handed before our February 28th call.

Prior to submitting this to you, the urological delegation circulated the document to the groups who provided redlined edits. The following groups reviewed the attachment and noted that it fairly reflected the discussions:

American Urological Association
Societies for Pediatric Urology
American Association for Clinical Urologists
American Congress of Obstetricians and Gynecologists
Pediatric Endocrine Society

The North American Society for Pediatric and Adolescent Gynecology (NASPAG) is reviewing the document.

We hope you find this useful for the discussions this week,
Kathy

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March 7, 2018

The Council on Ethical and Judicial Affairs
Attn: Elliott J. Crigger, CEJA Secretary
American Medical Association
330 N. Wabash Ave., Suite 39300
Chicago, IL 60611

Re: CEJA Report 3-I-17, Supporting Autonomy for Patients with Differences of Sex Development

The following represents a high-level overview of the AMA Council on Ethical and Judicial Affairs (CEJA) Report 3-I-17, “Supporting Autonomy for Patients with Differences of Sex Development (DSD). The overview is a result of communications between the American Urological Association, Societies for Pediatric Urology, American Association for Clinical Urologists, American Congress of Obstetricians and Gynecologists, American Academy of Child & Adolescent Psychiatry, North American Society for Pediatric and Adolescent Gynecology, The Endocrine Society, Pediatric Endocrine Society, GLMA: Health Professionals Advancing LGBT Equality, and Medical Students Section discussed. It is our understanding that the Medical Students Section will be submitting a separate analysis of the literature.

I. A Note on Terminology: “DSD” versus “Intersex”

To use “DSD” (serving as an abbreviation for differences of sex development) in the Report could have overly broad implications for conditions that are not intended to be at issue for its purposes. DSD is highly heterogeneous, with each condition exhibiting its own spectrum of severity, and depending on the stakeholder, may include or exclude various conditions, ambiguous or not, affecting the genitalia. For example, DSD includes syndromes such as Turner’s and Klinefelter’s that usually do not include genital ambiguity and are more prevalent than syndromes involving genital ambiguity.

We believe that the AMA opinions issued in its Code of Medical Ethics should continue to meet the standard of broad application, and avoid providing specific clinical recommendations for DSD per se. As such, we believe that the term “DSD” as used in the Report ought to be replaced by a term that specifically denotes patients with intersexuality. That being said, however, for the purposes of simplicity and clarity, we will mimic the terminology used in the Report and continue to refer to these patients as patients with DSD in the following comments.

II. Gaps in the Report’s Literature Review

A. There are a number of additional references that are relevant to the Report that are not considered in the literature review or included in the bibliography.

As is evident in the additional references cited in the redlined report containing edits from various organizations, we believe that there are a number of additional references that are not included in the Report’s bibliography that are relevant to the analysis and would allow for a more complete literature review.¹ To name a few, it does not contain the latest references that address the considerable evidence for risk of social stigma associated with genital ambiguity or that survey the parents of affected patients,

¹ For a complete list of additional references, see *infra* Appendix A.

nor does it include the available articles related to all the surveys of samples of DSD patients showing the majority of adult patients queried favor surgery before the age of consent.

For example, after detailing the findings from a 2006 National Institute of Diabetes and Digestive and Kidney Diseases article on the lack of outcomes data regarding DSD patients, the Report goes on to note that “[a] decade later, outcomes data remain limited” (AMA Council on Ethical and Judicial Affairs, Report 3-I-17, 2017, p. 2 [hereinafter *CEJA Report*]). The Report’s reference to a “small study carried out in 2011–2012 among medical students in Zurich” that examined the impact of how physicians discussed treatment for a child with DSD on the choice for or against surgery is interesting, but it does not, however, address our increasing knowledge of outcomes, based on the current literature (*CEJA Report*, p. 2).

The available data, as noted in more detail in the Appendix, suggest that satisfactory outcomes occur, even in patients who underwent procedures prior to important refinements that have occurred in the past fifteen to twenty years. Results vary with diagnosis, genetic variant, and may be independent of surgery, in that those who do not have surgery may have unsatisfactory outcomes.² We propose that when revising the Report, the Council should consider including a brief review of the literature from the past decade regarding the available outcomes data.³

Similarly, the Report could also consider two opinions issued by the Constitutional Court of Colombia, which capture the complexities particularly with respect to social norms and ethical considerations when treating patients born with DSD/intersex. Importantly, the court rejected a “no surgery” moratorium by stating that it would force social experimentation by forcing children to be raised with genital ambiguity or genitalia contrary to their gender of rearing. In detailing the precedent set in the earlier case opinion on the same legal question in a similar case involving intersex surgery in infants, the Court noted:

This Court then assessed whether, due to the characteristics of the surgeries and hormonal interventions designed to reshape the genitals, these therapies should be postponed until the person can authorize them. The ruling concluded that the adoption of that extreme measure by a constitutional court was problematic, since there is also no evidence that these therapies in infants are in all cases harmful and unnecessary. On the contrary, there is evidence that these medical interventions have had positive effects in certain events... Therefore, the mandatory postponement of these surgeries until the person could consent could put these children and their parents in a difficult situation, because they should lead difficult social transformations to ensure spaces of tolerance for their unusual anatomy. *The prohibition of risky medical treatment without the consent of the person itself then translated into the implementation of an equally risky social experimentation, whose consequences for minors, that is the essential interest that this Court must protect, are unpredictable* (internal citations omitted; emphasis added).

² For an example of a more thorough review of outcomes data to include in the revised report, see *infra*, Appendix B.

³ Some of the outcomes data omitted include: Binet A, et al. Should we question early feminizing genitoplasty for patients with congenital adrenal hyperplasia and XX karyotype? *J Pediatr Surg.* 2016;51(3):465-468; Fagerholm R, et al. Sexual function and attitudes toward surgery after feminizing genitoplasty. *J Urol.* 2011;185(5):1900-1904; Nordenskjöld A, et al. Type of mutation and surgical procedure affect long-term quality of life for women with congenital adrenal hyperplasia. *J Clin Endocrinol Metab.* 2007;93(2):380-386. For a complete list of omitted references, see *infra*, Appendix A.

Sources like those highlighted above are critical to not only providing a complete review of the literature, but also to understanding the complexities and nuances involved in treating these patients.

B. Other conclusions could be drawn for certain literature referenced in the Report.

In addition to omitting some references, we believe that other conclusions or key points could be drawn from some of the literature the Report does include in its review. For example, the Report references a recent interviews conducted by Human Rights Watch, noting that the interviews “examine patient experience and underscore the value of organizing dedicated multidisciplinary care teams” (*CEJA Report*, p. 3). However, it should be recognized that these interviews are not scientifically representative of the full population of patients treated, and although anecdotes are powerful, scientific conclusions must be based on broad and systematic population studies.

Additionally, the Report notes that “DSD communities and a growing number of health care professionals have condemned such genital ‘normalizing,’ arguing that except in the rare cases in which DSD presents as life-threatening anomalies, genital modification should be postponed until the patient can meaningfully participate in decision making [5,8,9,10]” (*CEJA Report*, p. 3). However, the statements cited here, specifically Wiesemann (5) and Gillam (9), are not consistent with the sentence to which they refer. It would be much more accurate to instead state that health care professionals and ethicists recognize that medical decision-making in DSD/intersex should be individualized, taking into account multiple factors, including the child’s perspective, parental choice and the parent-child relationship, and psychosocial as well as physical risks to the child which may or may not be life-threatening or impact future fertility [5, 9]. The risk exists that “Postponing this decision [medical or surgical intervention] to the age of consent, however, means closing an important window of opportunity for the child. The future adult’s consent, thus, will be meaningless, because no decision will undo the consequences of a waiver of treatment in the past” [5]. Efforts to preserve the “child’s right to an open future” by postponing “genital modification” when the situation is not life-threatening, may instead adversely affect psychological, psychosocial or developmental health.

In all, given the gaps in the references considered in the Report as noted above, we urge the Council to undertake a more thorough review of the literature during the revision process.

III. **The Role of Medical Necessity and Informed Consent in Early Treatment Decisions**

Recently, there has been concern among certain groups that early surgical intervention is not always medically necessary—i.e. in cases of cosmetic surgeries, or in what is referred to as “gender normalizing” surgeries—and therefore it should be cautioned against as an option at least until the patient can give informed consent. However, given the complexity and highly individualized nature of this condition and that there is no general consensus on how to define medical necessity in this context, **we are strongly against a moratorium on early surgical intervention in infants as an umbrella policy, even if such a policy were restricted to cases of medical unnecessary.** In our opinion, there is simply no scientific evidence to support such a position, and it ultimately would hinder our ability to provide the highest quality of care to our patients.

A. The term “medically necessary” has been used in too narrow a context for children with DSD and is an insufficient standard at the present time.

We agree that it is important to “respect the decisions of the patient and parents/guardian when it is not clear whether a specific intervention promotes the patient’s best interest” (*CEJA Report*, p. 6). Assuredly, long-term, prospective randomized studies are lacking in this field, in large part due to the nature and marked heterogeneity of the conditions included under the DSD umbrella, the complexity of these conditions, and the logistical problems inherent in randomization and long-term follow-up. Although some adults have experienced unsatisfactory outcomes after surgery in childhood for DSD, others have outcomes that are equivalent to the general population, and the majority of adults queried in multiple studies express agreement with the option for early surgery. Limited data suggest that affected individuals can do “well” with psychosocial support, but other data suggest that affected individuals for whom surgery is postponed are subject to psychosocial harm. We believe that the term “medically necessary” has been used in too narrow a context for children with DSD. Based on the WHO definition of health, surgical treatment may be medically necessary to optimize not only physical but also psychological, psychosocial, and/or developmental health.

We also agree that with respect to DSD, “decisions about a child’s best interests and appropriate interventions involve sensitive issues of sex, gender, and sexuality, and interventions that may be irreversible” (*CEJA Report*, p. 4). However, we feel that any recommendations that specifically focus on these issues have the potential to generate unintended consequences that run the risk of being more generally harmful. This is particularly true in view of some efforts to consolidate many, unrelated conditions under a signal diagnosis, namely DSD. The heterogeneity of developmental conditions affecting the genitalia warrants adherence to an existing standard of individualized care.

For example, DSD presentations may range from a female with CAH who may be born with ovaries and a uterus but completely male external genitalia; ovotesticular DSD in which both gonads may be functional during early infancy, impacting gender development, genital development and potential fertility; and other diagnoses such as partial androgen insensitivity syndrome which involves the spectrum of essentially none to considerable androgen responsiveness within the central nervous system or reproductive organs, among others. Obstructive anomalies may not only impact fertility, but may result in urinary leakage due to urinary hydrocolpos, pain, and infection; early surgery may be alleviate these symptoms. Indeed, in recent years, advances in the field have helped to clarify which individuals are likely to benefit from early surgery, and those for whom such surgery is best delayed, although further outcome studies are needed.

In all, we believe that the scientific literature is clear that early surgery is potentially beneficial for a certain subset of patients. Unfortunately, there is no way to determine with any degree of certainty what that subset explicitly entails, and thus it is virtually impossible to come to a general consensus on how to concretely define medical necessity in the context of patients with DSD. As a result, until such a time that we are able to do so, we must continue not to take a “one size fits all” approach and instead treat each patient based on the patient’s individual needs.

B. Postponing surgery until the age of assent or consent poses additional concerns to adequate treatment and may negatively affect a patient’s future.

Ethicists in the field note that universal postponement of surgery to the age of consent—typically, but not necessarily, at age 18—may close a window of opportunity for the child that can negatively affect

that child's future. And while some may suggest that postponing surgery to the age of assent—which occurs at some arbitrary time during adolescent before the age of consent—is preferable, such a postponement is still problematic on its own. In the first place, determining the age of assent is highly difficult and varies across fields, treatment type, and even states. But even if there was a way to garner a consensus on the age of assent among the medical community for treatment of patients with DSD, this approach may still put patients who could best be served by intervention prior to the age of assent at a potentially significant disadvantage and facilitate psychosocial harm that, in some cases, will not be adequately addressed by psychosocial interventions. For example, fertility may be negatively impacted without surgical intervention for some conditions and therefore to delay surgery until the age of assent or consent may close a window of opportunity to optimize fertility for some patients.

In sum, an approach that requires patient assent or consent for surgical intervention, or any medical intervention for that matter, impinges upon the rights of patients who would otherwise benefit from care, and from the rights of their parents to make well-informed decisions for their children.

IV. Parental Rights and Informed Consent

We endorse the importance of parents in medical decision-making for their children that protects all rights, based on all available options; allows for individualized care; and protects physicians, surgeons and families who must struggle with these complex issues and decisions. The current treatment approach among the medical community seeks to respect both parental authority as well as the rights of the child and offer medical, non-surgical, and surgical options, when appropriate, for management in conjunction with multidisciplinary review of each individual case based on treatment standards.

A. The role of parents in the decision-making process is paramount to informed consent and an individualized treatment approach.

As is recognized in existing AMA policy, “decisions for pediatric patients usually involve a three-way relationship among the minor patient, the patient’s parents (or guardian), and the physician... parents or guardians are expected, and authorized, to provide or decline permission for treatment for minor patients” (*CEJA Report*, p. 5). However, as the Report correctly notes, we understand that treatment decisions and appropriate interventions for children with DSD involve complex issues of sex, gender, and sexuality, and there is a need to recognize the rights of the individual involved as best as possible.

As physicians who treat patients with DSD, we know that medical care requires respect for the individual, their parents, and their culture, and we are committed to the current as well as the future health and well-being of all children entrusted to our care. We also know that parents generally act in the best interest of their children and should be respected as their representatives, and should be allowed to make a well-informed, shared decision after extensively and repeatedly discussing all treatment options, including the risks and benefits of each choice, with the multidisciplinary team of physicians.

We respect both parental authority as well as the rights of the child and offer medical, non-surgical, and surgical options, when appropriate, for management in conjunction with multidisciplinary review of each individual case based on treatment standards. If surgery is considered, complete informed consent with counseling and support should be provided prior to proceeding with any surgical intervention. Each child's diagnosis and treatment options are presented to parents based on best available science.

True informed consent should include discussion of immediate risks and benefits, including those associated with early and late surgical intervention, as well as known and unknown long-term outcomes.

- B. The rapid evolution in the treatment approach underscores the need for a multidisciplinary approach that is transparent and includes open discussion of options with parents to determine the best course of action for the patient.

Evolving surgical approaches since 1999 that reflect advances in knowledge of genital anatomy and innervation may limit negative outcomes that are currently reported by some adults. Over the past two to three decades, there have been major shifts towards syndrome-specific and syndrome-severity-specific recommendations, both in policies of gender assignment (to reduce the risk of later gender dysphoria) and in techniques used in genital surgery to reduce adverse side effects (i.e., replacement of clitorrectomy by clitoral reduction surgery). In addition, there has been a clear trend towards caution with respect to genital surgery for psychosocial indications, with various guidelines recommending against such surgery in mild cases of genital atypicality and the performance of surgeries exclusively at centers of excellence with relatively high rates of such surgeries.

Multidisciplinary teams are now convened to treat a patient born with DSD and generally include experts in the areas of pediatric and reproductive endocrinology, genetics, urology, gynecology, psychiatry and cytogenetics with close involvement of family members. As a result of specialized training, surgery is performed in rare situations and after comprehensive evaluation and consideration of all the available evidence for the patient's best health and interests.

V. Conclusion

As highlighted above, there is simply no discernable set of circumstances under which early surgical intervention is never (or always, for that matter) appropriate. Based on the available data, neither total postponement of surgery to the age of consent nor performing surgery early is free of risk, and methods of risk quantification at this stage are too imperfect to allow a clear decision between the options. Under these circumstances, it is clear that joint decision-making on genital surgery and its timing between parents and physicians, after detailed thorough information has been provided to the parents about the likely effects and risks, is most appropriate. In all, we strongly believe that the need for a multidisciplinary approach that is transparent and includes open discussion of all options, including surgical as well as nonsurgical ones, with open disclosure about the potential complications is paramount to providing each patient with the highest quality care.

We appreciate the opportunity to provide comments on this important Report, and look forward to working with the Council throughout the revision process.

Encl: Appendix

APPENDIX A

Additional References: Supplemental Annotated Bibliography

Baskin LS., Erol A, Li YW, Liu WH, Kurzrock E, Cunha GR. Anatomical studies of the human clitoris. J Urol. 1999;162:1015-1020.

Binet A, Lardy H, Geslin D, Francois-Fiquet C, Poli-Merol ML. Should we question early feminizing genitoplasty for patients with congenital adrenal hyperplasia and XX karyotype? J Pediatr Surg. 2016;51(3):465-468. doi: 10.1016/j.jpedsurg.2015.10.004.

- Retrospective case study over 40 yrs.
 - 21 patients from 3 French Centers.
 - 3 parent-child controls for each patient.
 - Sex assigned at birth concordant with gender identity in 85.7%.
- None of the CAH patients identified themselves as male. No difference in sexual satisfaction between early and late surgical groups. Sexual satisfaction was higher than control groups (p<0.05).
- Significant difference in self-assessed gender morphotype between CAH patients and controls.
- Overall 90% of CAH patients (100% of early surgical group) and only 52% of controls believed that genitoplasty should be performed during first year of life.
- 50% of CAH parents brought up difficulty discussing genital surgery with their adolescent child.
- Relationship between child and parents was statistically different 50% in the late surgery group vs the control 71% and early surgical group 78%.
- Social integration during childhood between all groups was not statistically different.
- 90% of parents and 95% of CAH children reported a positive vision of their relationship with the medical world.
- 89.7% of patients and 100% of parents thought genitoplasty should be performed in first year of life.
 - Controls thought surgery should be later.
- Conclusions:
 - “Resolving early on the adequacy of genital anatomy with the sex assigned is promoted by patients as well as parents.”
 - “The results of this study promote, in our opinion, the early surgical management of DSD in CAH-DSD genotypic females.”

Bradley SJ, Oliver GD, Chernick AB, Zucker KJ. Experiment of nurture: ablatio penis at 2 months, sex reassignment at 7 months, and a psychosexual follow-up in young adulthood. Pediatrics 1998;102(1): e9.

Cassia Amaral R., Inacio M, Brito VN, et al. Quality of life in a large cohort of adult Brazilian patients with 46,XX and 46,XY disorders of sex development from a single tertiary centre. Clin Endocrinol (Oxf). 2015;82(2):274-279. doi: 10.1111/cen.12572.

Dangle PP, Lee A, Chaudhry R, Schneck FX. Surgical Complications Following Early Genitourinary Reconstructive Surgery for Congenital Adrenal Hyperplasia-Interim Analysis at 6 Years. Urology 2017;101:111-115. doi: 10.1016/j.urology.2016.11.027.

- Retrospective review identifying 26 patients from April 2003 to April 2015 with CAH who underwent genitourinary reconstructive surgeries.
- The average age at the time primary surgery was 17 ± 20 (5-87) months and the average length of follow-up was 72.56 ± 36.95 (4.5-142) months.
- The average length of the common urogenital sinus was 4.5 ± 1.9 (2.5-6.4) cm, and 15 out of 22 (68%) patients had high confluence.

- A total of 7 complications were observed in 7 (27%) patients, 2 required revision surgery.
- Authors note that, “there have been very limited reports of long-term outcomes of genitourinary reconstructive surgery with contemporary surgical approach. One important observational study in 2001 showed poor clinical outcomes of a cohort of adolescent girls who had undergone feminizing surgery in early childhood...authors acknowledge that these surgeries were performed prior to the era of new surgical approach, and since then there have been major changes in surgical techniques, sutures, and antibiotics.”
- This contemporary series suggests that genitourinary reconstructive surgery for CAH patients is technically feasible and safe at a young age, with a low complication rate.

Dayner JE, Lee PA, Houk CP. Medical treatment of intersex: parental perspectives. J Urol. 2004;172(4 Pt 2):1762-1765; discussion 1765.

- Questionnaire: 21 parents of 17 CAH patients at a single center to assess parental perception of education and initial medical management, extent of treatment of options, the role parents were allowed to participate in decision and feelings about disclosure of diagnosis to child.
- Children were 8mos-13yrs.
- Most parents were “completely or partially satisfied” with information provided to them in neonatal period concerning education of condition and treatment options.
- Uniformly all parents felt that the condition should be discussed with their children.
- “All parents disagreed with postponing genital surgery until children were old enough to consent.”
- All parents felt they were involved in the treatment decisions.
- Parents saw genital surgery as an integral part of their child’s care, they were not impacted by arguments made by some to defer or delay surgery and felt satisfied with their decision to undergo early genital surgery.

Dessens AB, Slijper FM, Drop SL Gender dysphoria and gender change in chromosomal females with congenital adrenal hyperplasia. Arch Sex Behav. 2005;34(4):389-397.

Fagerholm R, Santtila P, Miettinen PJ, Mattila A, Rintala R, Taskinen S. Sexual function and attitudes toward surgery after feminizing genitoplasty. J Urol. 2011;185(5):1900-1904. doi: 10.1016/j.juro.2010.12.099.

- Questionnaire of adult women who had undergone genital surgery in Finland to assess whether early surgical intervention for ambiguous genitalia impairs sexual function in adult woman.
- 45 pts. >15yo sent questionnaires: 24(53%) participated.
- 16 had prenatal androgen exposure (CAH; age 15.5yo – 36.7yo (median 25yo) and 8 had androgen sensitivity.
- 19 had undergone clitoral reduction (mean age of 3.8 years) and 21 had vaginal reconstruction mean age 4.5yrs (0.4-19.2).
- Most important:
 - Only two patients regretted the operation, one of which had a procedure that is no longer performed (clitoral resection without nerve preservation.) The other patient had creation of a sigmoid vaginoplasty and had distressful hospital experience.
 - None thought surgery was performed too early, while 17 thought it was done at the proper age.
 - 3 pts thought it was too late (age at surgery 9yrs, 14yrs, 17yrs).
 - In terms of sexual experience/function in comparison to adult control females, the index group started activity at a later age (19.2 vs 17.1)p=0.002. and engaged less frequently in sexual activity. Most importantly, sexual function was similar to that of controls.
 - “Early surgery is preferred by the patients.”

Gillam LH, Hewitt JK, Warne GL. Ethical principles for the management of infants with disorders of sex development. *Horm Res Paediatr.* 2010;74(6):412-418. doi: 10.1159/000316940.

Gonzalez R, Ludwikowski BM. Should CAH in Females Be Classified as DSD? *Front Pediatr.* 2016;4: 48. doi: 10.3389/fped.2016.00048.

Johannsen TH, Ripa CPL, Carlsen E, et al. Long-Term Gynecological Outcomes in Women with Congenital Adrenal Hyperplasia due to 21-Hydroxylase Deficiency. *Int J Pediatr Endocrinol.* 2010;2010:784297. doi:10.1155/2010/784297.

- Prospective study 33 CAH patients, 33 age matched controls.
- Looked at reproductive outcomes, genital appearance, function and sexuality, and were correlated to genotype and surgery.
- As expected, satisfaction with genital appearance was lower with more significant virilization.
- Three important points:
 - “A tendency for higher satisfaction with clitoral function was observed the younger the age at clitoral surgery.”
 - Type of surgery and timing of surgery is important for development of body image.
 - Significantly lower rating of clitoral appearance and function versus controls whether or not they had surgery.

Johnson EK, Rosoklija I, Finlayson C, et al. Attitudes towards "disorders of sex development" nomenclature among affected individuals. *J Pediatr Urol.* 2017;13(6):608 e601-608 e608. doi: 10.1016/j.jpuro.2017.03.035.

Kolesinska Z, Ahmed SF, Niedziela M, et al. Changes Over Time in Sex Assignment for Disorders of Sex Development. *Pediatrics.* 2014;134:e710–e715. doi: 10.1542/peds.2014-1088.

- Cases of disorders of sex development reported as partial androgen insensitivity syndrome (PAIS; n = 118), disorder of gonadal development (DGD; n = 232), and disorder of androgen synthesis (DAS; n = 104) were divided into those who were born before 1990, 1990–1999, and after 1999.
- Of the 118 cases in the pre-1990 cohort, 41 (35%) were raised as boys; of the 148 cases in the 1990–1999 cohort, 60 (41%) were raised as boys; and of the 188 cases in the post-1999 cohort, 128 (68%) were raised as boys.
- There are clear temporal trends in this practice pointing toward an increased likelihood of affected infants being raised as boys.

Lean WL, Deshpande A, Hutson J, Grover SR. Anatomical and Cosmetic Outcomes of Feminizing Genital Surgery for Intersex Disorders. *J. Pediatr Surg.* 2005;40(12):1856-1860.

- Retrospective cross-sectional study.
- Really is a review of John Hutson's patients.
- 30 pts treated at Royal Children's Hospital, Melbourne. 20 operated at RCH, 47% CAH
- Conclusions:
 - Planned one stage repair better cosmetic and overall outcomes than staged procedures.
 - Patients with initial surgery < 2 yo same outcomes as those operated after 2yo.
 - “Results do not support abandonment of childhood genital reconstruction.”

Lee PA., Nordenstrom A, Houk CP, et al. Global Disorders of Sex Development Update since 2006: Perceptions, Approach and Care. *Horm Res Paediatr.* 2016;85(3):158-180. doi: 10.1159/000442975.

Lin-Su K, Lekarev O, Poppas DP, Vogiatzi MG. Congenital adrenal hyperplasia patient perception of 'disorders of sex development' nomenclature. Int J Pediatr Endocrinol. 2015;2015(1):9. doi: 10.1186/s13633-015-0004-4.

Marei MM, Fares AE, Musa N, et al. Timing and Outcome Concerns regarding Feminizing Genitoplasty from the Perspective of Egyptian Families of Girls with Virilized External Genitalia. Horm Res Paediatr 2016;85:49-57. doi: 10.1159/000442200.

- Prospective analysis of parental attitudes regarding feminizing genitoplasty in 30 Egyptian girls who underwent surgery at a mean age of 22 months with a follow-up period ranging from 9-54 months.
- All of the parents stated that they believe that their girls would have had a significant psychological disturbance without surgery. Over half (70%) felt the surgery was performed at a suitable time and the rest (30%) felt it should have been performed earlier.
- The majority (93%) of families reported that the communications they received regarding their child's care were satisfactory.
- Egyptian parents wish the surgery to be performed at the earliest possible age due to a combination of intrafamilial pressures and beliefs, and to avoid stigmatization of their girls within their schools and society.

Meyer-Bahlburg HF. Intersex Care Development: Current Priorities. LGBT Health. 2017;4(2):77-80. doi: 10.1089/lgbt.2017.0021.

Meyer-Bahlburg HF. Introduction to the Special Section on Culture and Variants of Sex/Gender: Bias and Stigma. Arch Sex Behav. 2017;46:337–339. doi: 10.1007/s10508-016-0871-7.

- Historically, societies adhered to a binary gender system in alignment with the reproductive need for binary gender. As a result, those deviating from the binary construct in body, behavior, and/or identity have been accorded a special status, usually of inferior rank and associated with varying degrees of social stigma. The adherence to the binary system of gender are codified in the traditional religious systems and their rules of conduct.
- In the current world, the waning reliance on muscle power and importance of reproduction for survival has pared the traditional division of labor between the genders and, therewith, the traditional arguments for a binary gender system. Consequently, full human rights are increasingly demanded by, and gradually accorded to, both genders and, more slowly, to those not fitting the traditional gender categories.
- Variations in the rigidity/flexibility of the binary sex system and in gender bias between countries and subculture, including parental response to newborn genital ambiguity, are associated with major differences in gender socialization in childhood.
- Professionals conducting research or providing medical, mental-health, and social services to those with somatic intersexuality and to their parents and families, must gain familiarity with the diverse cultural and subcultural contexts affecting gender development and gender-related decision-making.
- Clinicians and researchers should be aware of religious diversity and avoid drawing stereotypic conclusions about a given religious gender ideology. Respectful inquiry of the role of religion in a given family is necessary, and the results taken into careful consideration for gender-related joint decision-making.
- Clinicians need to take into account the widespread potential of gender-related stigma in developing comprehensive, culturally competent clinical management policies.

Meyer-Bahlburg HF, Migeon CJ, Berkovitz GD, Gearhart JP, Dolezal C, Wisniewski AB. Attitudes of adult 46, XY intersex persons to clinical management policies. J Urol. 2004;171(4):1615-1619; discussion 1619.

- 72 English speaking patients with 46,XY, including 32 men and 40 women 18 to 60 years old,

completed the questionnaire.

- “The majority of respondents stated that they were mainly satisfied with being the assigned gender, did not have a time in life when they felt unsure about gender, did not agree to a third gender policy, did not think that the genitals looked unusual (although the majority of men rated their penis as too small), were somewhat or mainly satisfied with sexual functioning, did not agree that corrective genital surgery should be postponed to adulthood and stated that their genital surgeries should have been performed before adulthood, although there were some significant and important differences among subgroups.”

Meyer-Bahlburg HF, Reyes-Portillo JA, Khuri J, Ehrhardt AA, New MI. Syndrome-Related Stigma in the General Social Environment as Reported by Women with Classical Congenital Adrenal Hyperplasia. Arch Sex Behav. 2017;46(2):341-351. doi: 10.1007/s10508-016-0862-8.

- To assess the presence of stigma associated with women with somatic intersexuality, a report was generated based on in depth retrospective interviews with 124 adults with Congenital Adrenal Hyperplasia. The purpose of the report was (1) to document the existence of intersex-related stigma (Goffman’s “undesired differentness”) and to highlight its emotional impact, (2) to identify plausibly contributing factors, and (3) to make examples of stigma experiences readily available for use in the training of professional staff who care for such patients.
- Close to 2/3rd of women reported stigma.
 - Stigma conveyed by parents.
 - Occurred when bathing with other girls as a child.
 - Parental reaction conferred this was a condition that is not to be openly discussed.
 - Stigma conveyed by peers.
- Concerns about taking medicine.
 - Concerns about aberrant hair growth and teasing.
 - Stigma enacted by others at adulthood.
- Atypical bodies features (deep voice, hair distribution).
 - Being mistaken as a man.
 - Undue stress created by Media was a major issue for some women. They never thought themselves as neither man nor woman but the media portrayed it this way.
 - Stigma was often anticipated to be felt by girls with CAH from others that knew they were different. It impacted their ability to form close friendships.
 - Anticipated stigma coping as Adults.
 - Would engage in techniques or avoid activities to avoid situations that created stress with breast development or hair distribution.
 - Stigma internalization as adults was not uncommon.
 - The appearance of masculine features was particularly disturbing or need to address (such as shaving back hair).
 - In summary, anticipating, experiencing and internalizing stigma associated with CAH was quite common.

Meyer-Bahlburg HFL, Khuri J, Reyes-Portillo J, Ehrhardt AA, New MI. Stigma Associated with Classical Congenital Adrenal Hyperplasia in Women's Sexual Lives. Arch Sex Behav. 2017. doi: 10.1007/s10508-017-1003.

Meyer-Bahlburg HFL, Khuri J, Reyes-Portillo J, New MI. Stigma in Medical Settings As Reported Retrospectively by Women With Congenital Adrenal Hyperplasia (CAH) for Their Childhood and Adolescence. J Pediatr Psychol. 2017;42(5):496-503. doi: 10.1093/jpepsy/jsw034.

- The natural history of having atypical genitalia in intersex individuals that is not surgically corrected is not well described although preliminary evidence would suggest that there are

significant psychosocial consequences in such individuals.

- In females with CAH, the most common form of intersex, there is significant stigma related to their medical condition. Most individuals describe experiencing, anticipating, and/or internalizing stigma related to their medical condition. The emotional impact can be intense, and the psychosocial implications pervasive.
- There is a high incidence of internalization of this stigma within the context of their romantic / sexual lives. The presence of stigma is especially true in cases where there are internal and/or features that are not completely consistent with a female phenotype. This conclusion may also apply to other syndromes of intersexuality as well.

Mouriquand PD, Gorduza DB, Gay CL, et al. Surgery in disorders of sex development (DSD) with a gender issue: If (why), when, and how? J Pediatr Urol. 2016;12(3):139-149. doi: 10.1016/j.jpuro.2016.04.001.

- Late surgery can have a better accompanying process, allowing the individual to participate in the decision process. It may also reduce the risk of a second procedure to enlarge the vaginal introitus as the patient complies with post-operative vaginal dilatations if necessary.
- Pubertal or post-pubertal surgery has a much greater risk of morbidity compared with surgery earlier in childhood. Blood loss and infection are more common in adult genital surgery. Very few surgeons have experience with late feminization.
- Several cohorts of adult patients who underwent a feminization procedure at various ages have recently been interviewed in different French hospitals and all claimed that early surgery is highly preferable to late surgery [Binet et al, Carval et al (in French)].
- When asked retrospectively when feminizing surgery should occur, more women with CAH responded that surgery should occur early compared with later in development [Wisniewski et al, Fagerholm et al].
- Women with DSD because of CAH who received genitoplasty reported higher satisfaction with their care than those who did not receive early genital surgery [Thyen et al].
- Girls who received early genital surgery have a good or satisfactory cosmetic outcome, as assessed by healthcare providers, good quality of life, and a low incidence of gender dysphoria as reported by their parents [Crawford et al, Cassia Amaral et al].

Nordenskjold AG, Holmdahl G, Frisen L, et al. Type of mutation and surgical procedure affect long-term quality of life for women with congenital adrenal hyperplasia. J Clin Endocrinol Metab. 2007;93(2):380-386. doi: 0.1210/jc.2007-0556.

- In a case-control follow up study in Sweden, 62 women aged 18-63 and 62 age-matched controls were recruited for review of prior medical records, examination and completion of a questionnaire regarding social life, fertility, sexuality, function of the clitoris and vagina, satisfaction with results and experience of health care as children.
- Clitoroplasty and/or vaginoplasty were performed in 49 girls and of these 16 had only one procedure, 10 of these at puberty. The majority had surgery between age 6 months and 9 years and 20% reported that they were not satisfied with the surgery. Some of the procedures performed (clitoral amputation and burying) are not routinely performed currently.
- Clitoral sensitivity and orgasm capability may be decreased by clitoral amputation or recession but the results are variable but is intact in the majority of operated patients.
- A total of 37.5% of patients need reoperative vaginal surgery and 60% considered the size of their clitoris to be normal.
- The outcome is dependent upon the severity of the initial condition.
- Many aspects of quality of life are affected by CAH, such as sexual debut, fertility, partnership, and sexual relationships. It should be taken into account, when providing psychosocial support for

patients, that the incidence of homosexuality and bisexuality is significantly higher than in controls.

- The experience of medical checkups was regarded as “mostly positive” and most CAH women who responded preferred early surgery (70%).
- The authors argue that the medical, surgical, and psychological treatment of CAH patient should be centralized to specialized teams.

Sudai M. Changing ethical and legal norms in the management of differences of sex development. *Lancet Diabetes Endocrinol.* 2017;5(10):764-766. doi: 10.1016/S2213-8587(17)30043-8.

Szymanski KM, Whittam B, Kaefer M, et al. Parental decisional regret and views about optimal timing of female genital restoration surgery in congenital adrenal hyperplasia. *J Pediatr Urol.* 2017. doi: 10.1016/j.jpuro.2017.11.012.

- Cross-sectional online study.
- 39 parents questioned median 4.4 years after Child had Feminizing Genital Restoration Surgery.
- Decisional Regret scores 0 to 100 (higher means more regret).
- Median DR score after FGRS was 0, mean was 5.
- Most parents reported no regret after surgery and when they did it was generally mild.
 - No one reported strong or very strong regret.
- In total 20.5 % had some mild or moderate decisional regret after surgery but if you look at other reported scores, FGRS DR scores were much less:
 - Adenotonsillectomy: DR in 41-45%
 - Hypospadias: DR in 50-92%
 - Ped. Cancer treatment: DR in 61-72%
- Daughters of parents who wanted earlier surgery had FGRS at median 24 mos, those who wanted it at the same time had surgery at median 8mos.
- No parent preferred delaying surgery even in those with some decisional regret.
- 18% preferred earlier surgery.

Thyen U, Lux A, Jürgensen M, Hiort O, Köhler B. Utilization of Health Care Services and Satisfaction with Care in Adults Affected by Disorders of Sex Development (DSD). *J Gen Intern Med.* 2014;29(Suppl 3):752-759. doi:10.1007/s11606-014-2917-7.

Wang LC, Poppas DP. Surgical outcomes and complications of reconstructive surgery in the female congenital adrenal hyperplasia patient: What every endocrinologist should know. *J Steroid Biochem Mol Biol.* 2017;165(Pt A):137-144. doi: 10.1016/j.jsbmb.2016.03.021.

- Surgical techniques for genital feminization in female CAH patients have evolved significantly over time as more has been learned about clitoral neurovascular anatomy, vaginoplasty outcomes, improved surgical techniques and patient satisfaction with functional and cosmetic outcomes.
- After Baskin et al. reported on the detailed neurovascular anatomy of the clitoris in 1999, previous clitoroplasty techniques which resulted in the complete or partial loss of the nerves associated with the clitoris, were abandoned.
- Today, reduction clitoroplasty, where a portion of the erectile bodies is excised, with complete or partial glans sparing, is predominantly utilized for optimal cosmetic effect with minimal consequences to clitoral function.
 - Dessens et al. found that the large majority (94.8%) of CAH 46, XX patients assigned female gender identified as female. However, of the 5.2% of CAH patients who experienced gender dysphoria, 30% wanted to change gender, which exceeds the rate in the general population of chromosomal females.
 - Twenty-six (87%) of the 30 CAH women reported having genital surgery and 65.4% were very satisfied with surgical treatment, 60.0% were very satisfied with genital

appearance, and 60.9% were very satisfied with genital function (Zucker et al 2004).
Women with simple virilizing CAH and those assigned female at birth were more likely (p=0.10) than patients with salt-wasting CAH and those with delayed assignment or male assignment to report higher levels of sexual arousability.

Wisniewski AB, Migeon CJ, Malouf MA, Gearhart JP. Psychosexual outcome in women affected by congenital adrenal hyperplasia due to 21-hydroxylase deficiency. J Urol. 2004;171 (6 Pt 1):2497-2501.

- Confidential Questionnaire Study.
- 134 women with CAH seen, 73 not eligible for study.
 - 61 questionnaires sent, 41 women with CAH studied.
 - Had 30 controls.
- Adult women with salt-losing CAH are more likely to question their female gender, report sexual concerns and worse genital function and are less likely to have sexual relations with a partner than those with simple virilizing CAH.
- Overall, women with CAH were moderately satisfied with the cosmetic appearance of the genitalia. Women with the salt-losing form were judged to have a worse cosmetic outcome of genital reconstruction than women with simple virilizing form.
- The most common response concerning the optimal timing for genital reconstruction was during infancy and early childhood and only 5% advocated for surgery in adulthood.
- “Women in both salt wasting and simple virilizing most frequently reported that infancy and early childhood were the best time for genital reconstructive surgery.”
 - (31% of SW and 18% of SV did not answer the question about timing.)

Yankovic F, Cherian A, Steven L, Mathur A, Cuckow P. Current practice in feminizing surgery for congenital adrenal hyperplasia; a specialist survey. J Pediatr Urol. 2013;9(6 Pt B):1103–1107. doi: 10.1016/j.jpuro.2013.03.013.

- Specialists surveyed at IVth World Congress of the International Society of Hypospadias and DSD.
- 161 delegates and 61 responded to survey (30 % Ped. Surgeons, 30% Ped. Urologists).
- Delegates were from around the world.
- Early surgery before age 2 years preferred by 78%.
- Most recommended doing clitoroplasty, labioplasty and vaginoplasty in single stage.

Zhang H, Pan J, Ji H, et al. Long-Term Evaluation of Patients Undergoing Genitoplasty due to Disorders of Sex Development: Results from a 14-Year Follow-Up. Scientific World J. 2013; 2013: 298015. doi: 10.1155/2013/298015262.

- 262 patients (96 children, 133 adolescents, and 33 adults) with mixed diagnoses cohorted into 6 groups based on karyotype (XY, XX), androgen effects (partial, none), gender assignment (male, female).
- Older cohort (mean age at diagnosis 14.3 ± 2.8 yrs (2–38 yrs)) followed every 6 mos.
- Sex assignment according to patients’ considerations, psychological gender, dominant gonad, and external genitalia development. The urological surgeon, endocrinologist, and pediatric psychiatrist provided important advice for sex assignment. However, the final decision should be made by the DSD patients and/or their relatives.
- Majority of women (93%) and men (62%) were satisfied with the outcome.
- Majority of women (83%) and men (54%) had favorable psychosocial adjustment.
- Female sex assignment less likely to have secondary surgery (3% vs 21%).

APPENDIX B

Example Paragraphs: More Thorough Review of Outcomes Data

Note: the following section is a revision of the Report, page 2, starting at line 35.

Since 2006, a number of published studies have helped to clarify attitudes and outcomes in the DSD/intersex population, although limitations include the rarity of DSD/intersex, the heterogeneity of the associated conditions and their treatment, and the difficulties inherent in long-term follow-up. For example, in a systematic review of follow-up of psychological outcomes of intervention for patients with DSD published in 2015, Brazilian researchers found a lack of prospective long-term evaluations of psychological outcomes of sex assignment surgery [13]. They noted concerns about the quality of published studies, citing variable sample size, inconsistent methodologies, and poorly defined outcome measures. However, most modern data demonstrate successful though variable, but often acceptable post-surgical outcomes in DSD/intersex patients. Satisfactory initial results and low complication rates were reported (Dangle et al. 2017, Wang and Poppas 2017) using surgical techniques that evolved with new (Baskin et al. 1999), detailed knowledge of clitoral neurovascular anatomy. In one of the largest long-term studies of CAH, clitoral sensitivity was most commonly impaired in women who underwent older types of surgeries that are currently considered suboptimal. Even so, there were no significant differences in orgasmic function among controls, operated, and unoperated patients (Nordenskjold et al. 2008). The severity of disease has been associated with worse outcomes (Wisniewski et al. 2004, Nordenskjold et al. 2008, Johannsen et al. 2010, Wang and Poppas 2017) and suboptimal sexual function occurs with equal frequency in operated and non-operated cases (Nordenskjold et al. 2008). A trend towards higher satisfaction with clitoral function in individuals undergoing surgery at a younger age has been reported (Johannsen et al. 2010). In mixed DSD/intersex series, quality of life scores were inversely correlated with age at surgery (Cassia Amaral et al. 2015), and 83% of 94 adults reported a “good” or “average” level of satisfaction with regard to sexual function (Thyen et al. 2014). Reporting multiple measures of sexual function, many studies suggest that outcomes for individuals who underwent genital surgery in childhood are similar to controls (Meyer-Bahlburg et al. 2004, Fagerholm et al. 2011, Binet et al. 2016).

Current studies of psychological well-being point to satisfaction with early repair. Particularly in CAH, the most common form of intersex, the majority of affected individuals remained satisfied with female gender, comprising 98.4% of a large series of 250 affected individuals (Dessens et al. 2005). Finally, a majority (69-100%) of adult DSD/intersex individuals and their families reported that early surgery is desirable, and some individuals in these series noted that surgery was performed too late (Dayner et al. 2004, Meyer-Bahlburg et al. 2004, Wisniewski et al. 2004, Nordenskjold et al. 2008, Fagerholm et al. 2011, Binet et al. 2016, Marei, Fares et al. 2016, Szymanski et al. 2017). Moreover, in extensive studies of individuals with CAH, Meyer-Bahlburg and colleagues reported that stigma, defined as “undesired differentness”, is common among adult women with CAH and remains a potential risk associated with delayed intervention (Meyer-Bahlburg et al. 2017).

Prospective studies are ideal but not yet available, and controversies remain. However, increasing evidence suggests that genital surgery in childhood typically provides good outcomes. There is limited data regarding delaying surgery until later in life, but evidence exists that early surgery may be preferred and psychosocial distress may be a significant risk for individuals in whom surgery is delayed.

**Testimony for the Council on Ethical and Judicial Affairs
of the American Medical Association**

Ethical and scientific issues in early childhood genital surgery for intersex/differences of sex development (DSD): the case of feminizing genitoplasty in 46, XX congenital adrenal hyperplasia

Arlene B. Baratz MD

Coordinator of Medical and Research Affairs: Androgen Insensitivity Syndrome-Differences of Sex Development (AIS-DSD) Support Group

Chair of Medical and Research Policy Committee: interACT Advocates for Intersex Youth

Introduction

As Coordinator of Medical and Research Affairs for the Androgen Insensitivity Syndrome-Differences of Sex Development Support Group (AIS-DSD SG) and Chair of Medical and Research Policy Committee for interACT Advocates for Intersex Youth, I submit this written testimony in support of Michigan resolution 013, “Opposing Surgical Sex Assignment of Infants with Differences of Sex Development,” introduced to the Reference Committee on Amendments to Constitution and Bylaws.

I am a physician member of AMA and the mother of 2 intersex women with the DSD complete androgen insensitivity syndrome (CAIS). My older daughter, Katharine Dalke MD, is a psychiatrist, AMA member, and fellow intersex advocate. My clinical practice since 1990 is in diagnostic radiology as a breast imaging radiologist. For the last 18 years, I have worked extensively in support and advocacy for families and individuals affected by intersex/DSD. My service to the intersex/DSD community includes participation on the boards of the Intersex Society of North America (ISNA), the AIS-DSD SG, Accord Alliance, and interACT Advocates for Intersex Youth (abbreviated as interACT from here on); I am a founding member of the latter 2 groups. My educational efforts include coordinating the AIS-DSD SG continuing medical education program since 2011, as well as co-authorship of book chapters and peer-reviewed articles, including the 2016 Global Disorders of Sex Development Update since 2006: Perceptions, Approach and Care. In addition to presenting at meetings of the International DSD Symposium (I-DSD); Societies for Pediatric Urology (SPU); World Professional Association for Transgender Health (WPATH); GLMA Health Professionals Advancing LGBT Equity; North American Society for Pediatric and Adolescent Gynecology (NASPAG); and Philadelphia Trans Wellness Conference, I’ve been a consultant/advisor on 2 NIH-funded research projects: Short Term Outcomes of Interventions for Reproductive Dysfunction (1R01HD074579-01A1) and Disorders of Sex Development: Platform for Basic and Translational Research (1R01HD068138-01A1). My CV is appended to this testimony as Appendix A.

Why is the practice of early genital surgery a matter for the Council for Ethical and Judicial Review?

Differences or disorders of sex development (DSD), also known as intersex conditions (these terms will be used interchangeably), are unexpected patterns of sex traits, including chromosomes, gonads, or genitalia, that may challenge traditional binary concepts of sex and gender. Some conditions are associated with significant gender uncertainty. Unless associated with urinary obstruction or abdominal wall defect, these traits pose no intrinsic threat to physical health. This testimony is specifically focused on elective cosmetic surgery and does not call for what proponents in the Societies for Pediatric Urology (SPU) characterize as “a moratorium on all surgery...[and] extending the moratorium to other genital surgery not even related to this area.” [1] While sex and gender fluidity are well-accepted by many clinicians, medicalized portrayals of the

variation of sex traits occurring in DSD/intersex as inherently “disordered” and stigmatizing perpetuate a long-standing paradigm focused on treatments aimed at eradicating physical differences, including normalizing surgery to create dimorphic-looking genitals. Such surgery is performed on children with healthy genitals to avert future psychosocial issues presumed to arise from intact genital difference, even though a causal relationship has never been proved. When genital surgery is performed on children who are too young to express their gender, sexuality, or what they want their bodies to look like, it is a form of conversion therapy- an unconsented, irreversible medical intervention to “treat” hypothetical adult psychopathology. When surgery aligns genital appearance with a gender that is discordant with a child’s future gender identity, it is also a form of involuntary sex reassignment. Our AMA has strongly repudiated conversion or reparative therapy for LGBT people (policy H-160.991), and my testimony is intended to demonstrate why the Committee for Ethical and Judicial Affairs (CEJA) should endorse this resolution recommending that the analogous practice of early surgery on intersex children be deferred until children can participate meaningfully in decision-making.

Feminizing genitoplasty: who, what, why, when, and how much does it cost?

In current debates in our AMA and in the California legislature (regarding the recently-approved CA SCR-110) about deferring genital surgery until children can consent for themselves, surgery proponents focus on early feminizing genitoplasty (FG) in 46,XX classical congenital adrenal hyperplasia (CAH), the most common operation for “correcting” genital difference. To address their contentions, and because the majority of studies on genital surgery address feminizing genitoplasty (FG) in 46,XX classical congenital adrenal hyperplasia (CAH), I will also focus on it in this testimony. In CAH, reductions in fetal 21-hydroxylase enzyme activity cause diversion of cortisol +/- aldosterone steroid precursors into pathways that produce of unusually large quantities of androgens, resulting in varying degrees of genital difference. In salt-wasting (SW) CAH, genetic alteration of 21-hydroxylase enzyme causes life-threatening decreases in both cortisol and aldosterone that require medical management; in a milder form of CAH, “simple virilizing” (SV), only cortisol is diminished. Genital difference ranges from a clitoris that is slightly larger than usual to development of a penis, scrotum, and urogenital sinus with a single external opening from the vagina and bladder. The continuum of genital atypia is described by the Prader scale of 1-5, with higher numbers indicating less female-typical genitals. This interactive video demonstrates the spectrum of genital differences: (<https://pie.med.utoronto.ca/htbw/module.html?module=sex-development>) The usual situation in which FG would be considered is moderate-to-severe genital atypia, as defined by a Prader 3-5. [2]

FG consists of procedures to change the appearance of the external genitals to look more female, including clitoroplasty and perineal procedures, as well as separation of the urethra and vagina (vaginoplasty). Ideally, these procedures would “spare” neurovascular structures. Justifications for FG in CAH, usually performed between the 2nd and 6th month, include creation of “normal” looking feminine external genitalia; allowing “normal” penetrative sexual intercourse (as a female); and facilitating future reproduction (as a female). [3] Purported psychosocial benefits include promotion of parental bonding and prevention of assumed future psychosocial issues, which have never been proved. [4, 5]

The birth of a child with CAH can be overwhelming for parents. The presence of genital difference in a child with a life-threatening medical illness understandably creates an atmosphere of distress. Clinicians as well as parents are vulnerable to an urgent desire to “fix” something as soon as possible. Families rely on physicians to provide them with evidence-based care, but authoritative guidelines from organizations such as our AMA are lacking. With CAH being both rare and having implications for gender and sexuality, there are fundamental disagreements among stakeholders over research methods, relevant outcomes, and what should even be considered “evidence.” Conflicting values and beliefs are manifest in ethical controversies including who has the right to choose when children’s fundamental human rights to bodily autonomy are at stake, and what constitutes informed consent when parents are distraught and vulnerable. Unfortunately, high-visibility clashes over early surgery obscure the overarching goal of advocates for children with DSD/intersex traits, which is to implement effective psychosocial interventions as primary treatment for families experiencing psychosocial issues such as distress at the birth of a child with atypical sex traits. [6]

Ongoing disputes over surgery divert attention and resources from development of and reimbursement for such interventions, perpetuating lack of access to appropriate providers for many families. [6]

There is no study of genital surgery showing its noninferiority to psychosocial intervention. Nonetheless, as standard practice in many clinics, FG is usually performed by age 2, before children can assent or consent. [7] Providing a view of the current state and cost of surgical care in the US, recent review of a national billing database from 2004-2014 shows that 544 (12%) of 4617 children assigned female with 46 XX, CAH at 43 hospitals underwent initial genital surgery at median age 10 months (all under 19 months). [8] Three high volume centers (> 30 procedures over 10 years) accounted for 30% of the surgery. Of the 1229 FG procedures performed, 92% of children underwent a vaginal procedure, 48% had a clitoral procedure, and 85% had a non-clitoral perineal procedure (involving the perineal musculature and soft tissues in conditions with atypical perineal anatomy). Between 2004 and 2014, the rate of clitoral surgery increased from about 50% to about 70%. During the initial stay, 4% of children suffered perioperative surgical complications, and 2% required reoperation. Postoperatively, 14% were readmitted within 30 days, with the most common diagnoses being CAH (21.3%), surgical complication or hemorrhage (16.0%), infectious enteritis or gastroenteritis (10.7%), and urinary tract infection (5.3%). The mean cost of care for initial surgery was \$12,258, with \$20,000 in operating room expenses; readmission costs were not specified.

The surgical paradigm has its roots in the 1950's "optimal gender" theory of psychologist John Money: in cases where genitals do not clearly indicate natal sex, proper nurture and surgical creation of binary-appearing genitals capable of heteronormative penetrative intercourse can trump biological uncertainty to prevent future psychological problems.[9] With the right socialization, a child's gender would reflect the appearance of his or her genitals. Given the role of surgery in cosmetic alteration, technological considerations also influenced gender assignment. For example, despite the presence of normal testes, a child with a small phallus considered "inadequate" for vaginal penetration was castrated and assigned female, because, as some quipped, "it's easier to dig a hole than build a pole."

Although the optimal gender theory was later discredited, surgery retains a prominent role in intersex treatment. The purpose of normalizing genital surgery is to avert projected consequences of uncorrected genital difference: to "restore functional genital anatomy to allow future penetrative intercourse (as a male or a female); facilitate future reproduction (as a male or a female) when possible; ... foster development of 'individual' and 'social identities;' avoid stigmatization related to atypical anatomy; [and] respond to the parents' desire to bring up a child in the best possible conditions." [3] Conflict is inevitable because these goals, which strongly prioritize binary gender and heteronormative sexuality, are not shared by all stakeholders.

Known risks of FG

Early FG for medically-vulnerable children with CCAH exposes them to many risks, including perioperative adrenal crisis, for which preventive steroid "stress dosing" is given to supplement chronic steroid replacement. The 14% 30-day readmission rate discussed may reflect significant stress related to surgery, given that in general about a third of patients with SWCAH are hospitalized during childhood, mostly for infectious conditions during the first 2 years of life. [8, 10] Because steroid excess in CCAH may impair wound healing, a 4-week period of postoperative immobilization is recommended, with placement of a restrictive dressing preventing children from opening their legs. [7] Risks and complications of FG include the harms of anesthesia, postoperative pain, vascular injury, bleeding, hemorrhage, hematoma, wound infection, glans necrosis, flap necrosis and dehiscence, nerve damage, femoral nerve neuropathy, permanent reinforcement of misassigned gender, necessity of multiple procedures, clitoral re-enlargement, vaginal stenosis, hair growth in the vagina, dysuria, UTI, urinary retention, urinary incontinence, sexual dysfunction and loss of sexual sensation [7, 11-14]. Vaginal stenosis requiring revision surgery is a common complication of vaginoplasty. In a review of procedures performed after 1985, the rate of vaginal stenosis was 6–57% and the rate of revision vaginoplasty was 3–36%. [7] Although nerve-sparing clitoroplasty may leave some with normal sensation and orgasmic potential, in long-term follow up, only one out of every

three women who have had such procedures demonstrate sensitivity to temperature and vibration that is similar to unaffected women. [15]

The risk of exposing medically-fragile children to anesthesia for elective procedures deserves special ethical consideration. In 2017, the US Food and Drug Administration (FDA) announced that pediatric anesthesia may negatively affect brain development, and issued its strongest possible warning. [16] The potential consequences of avoidable anesthetic risk for children with SWCAH may be inferred from a large 2018 population-based study of anesthesia risks with results that are generalizable because of the number of children studied. Schneuer et al, in *The Impact of General Anesthesia on Child Development and School Performance: a Population-based Study*, correlate school data with anesthetic exposure in children from Australia's state of New South Wales (NSW). [17] For children exposed to general anesthesia (excluding those with major congenital and neurocognitive conditions), internationally-validated developmental assessment measures for 82,156 children were available, and nationally-validated school test results for reading and numeracy (ability to work with numbers) for 153,025 children. 16% of all children were exposed to anesthesia. To assess development at school entry, children in NSW are given the AvEDI, a developmental test that assesses social competence as well as 5 domains: physical health and well-being, emotional maturity, communication skills and general knowledge, language, and cognitive skills (numeracy and literacy). Scores in the lowest 10% in 2 or more domains indicate high developmental risk. Children undergo reading and numeracy testing in Grade 3. [17] Schneuer et al found that a single hospitalization with anesthesia exposure is associated with poorer numeracy. Children with more than one general anesthetic exposure are at risk of poor developmental outcomes before starting school, and with substandard reading and numeracy scores on school testing. [17]

In children with CCAH, for whom repeat surgery in early childhood is not uncommon, these findings may have particular relevance. A prospective US study of elective early FG performed by expert surgeons in multidisciplinary care settings found that in the first year alone, 7% of children under expert care underwent repeat surgery, placing them at risk of poor developmental outcomes and low school performance. [18] This risk adds to the known cognitive disadvantage conferred by CCAH treated with current glucocorticoid regimens, confirmed by brain imaging and cognitive assessment in adults showing widespread reductions in white matter structural integrity, and decreased working memory, processing speed, and digit span and matrix reasoning scores relative to controls of similar education and intelligence.[19] Parents interviewed for a recent report by Human Rights Watch (HRW) and interACT Advocates for Intersex Youth (interACT) were not informed of potential neurotoxic effects of anesthesia.[20] Disclosure of anesthetic risk for procedures that are completely elective and unlikely to affect short-term health, such as early FG, deserve serious discussion and consideration of deferring those procedures, especially in the setting of pre-existing cognitive risk. [21] A consent procedure for pediatric anesthesia developed by Texas Children's Hospital, which includes reviewing "the possibility that the procedure could be delayed until after 3 years of age," might be adapted for this use. [22]

Limitations of current research in intersex/DSD

Most evidence that is claimed to support the standard of early surgery comes from research that focuses primarily on techniques, cosmetic outcomes, and patient "satisfaction," with methods devised only by clinicians, some of whom have circumvented advocates' efforts to engage in community-based participatory research (see Appendix B). [23] NIH classifies DSD/intersex as a sex and gender minority, a health disparity population deserving special attention, but its status as a rare condition is often neglected in research design. [24] The extant literature mostly fails to address patient-centered outcome measures (PCOM) of importance to families and patients, such as developing viable and effective psychosocial and educational alternatives. [5, 25] A recent position paper by the International Rare Diseases Research Consortium (IRDiRC) provides a road map for collaborative development of PCOM on the premise that patients are the experts on the outcomes that resonate with their daily experience of a condition, across a continuum of manifestations, and their preferences, expectations and values.[26] For example, for many years, studies on Duchenne muscular dystrophy (DMD) have focused on ability to walk. However, when boys and young men with DMD were interviewed, their narratives revealed that what mattered to them was retention of upper body function: to

be able to use a computer keyboard, brush their teeth, and pour a drink. PCOMs should be developed in collaboration with patient groups but too often foundational patient qualitative works are ignored in intersex/DSD research. A traditional psychometric data-driven approach to PCOM is inherently inappropriate in rare conditions because, of limited available data to drive the decisions, a common complaint about intersex/DSD research. Because there is no inherent constraint on the intelligence we could use in this research, IRDiRDC describes the use of mixed methods psychometric research as the best fit for rare conditions, citing its ability to synthesize qualitative and quantitative research methods to most efficiently use data from small samples [27], and to determine content validity by optimizing clinical relevance, improving understanding of study constructs, and avoiding potential early measurement issues. Processes that implement such PCOM research for intersex/DSD is rare.

Supporters of early FG agree with advocates of deferral that there are currently insufficient data to support assertions that adult women are satisfied with the results of early surgery.[28] Since there is no research directly comparing outcomes of early and late FG, we cannot know which is better, although some gynecologists who perform both primary FG and surgery to treat subsequent complications in older patients advocate for deferral. [2] [29] Unsupported assertions of superiority of early FG distract from the uncomfortable truth that pediatric specialists themselves prefer it because they are not trained to perform surgery in older, consenting individuals. Six-year follow up of successful single-stage adult genitoplasty with preservation of orgasm was reported by Tjalma in 2016; the operation preserving the erectile tissue of the corpora cavernosa in a previously-orgasmic woman with CCAH also eliminated the need for revision vaginoplasty because the woman was already sexually active.[30]

Prospective study of outcomes of modern neurovascular-sparing surgery in the “ideal” setting of multidisciplinary centers does not show the hoped-for reduction in complications: after just one year, 10% of FG procedures had serious complications. The short-term complication rate for proximal hypospadias surgery was 40%, consistent with statistics for complications of these procedures performed in other settings.[31, 32]

Although some centers provide anecdotal evidence of adult CCAH patients requesting primary or revision surgery, there are corresponding anecdotes of unoperated intersex adults who are grateful to have been spared infant surgery, such as 60-year-old Jim Costich, who posted on Facebook: “I did not have any genital surgery to make me look any different and... my love life, my social life, my gym life, even my life as a nudist has not been adversely affected!”

Human rights focus in advocacy for children with intersex/DSD

Follow up studies of FG that have mostly focused on surgical results, sexual function and psychosexual outcome show unsatisfactory long-term consequences in many cases, corroborating the complaints of adults subjected to surgery. [2, 15, 33] The paradigm of early genital surgery has been publically challenged by intersex adults and community advocates since formation of the Intersex Society of North America (ISNA) in 1993. [9] Over the years, vocal advocacy efforts have culminated in increasing calls from governmental and human rights organizations to recognize intersex patients’ autonomy and end nonconsensual childhood genital surgery. [34] In 2015, the World Health Organization (WHO) published a report specifically examining childhood intersex genital surgery titled [Sexual Health, Human Rights and the Law](#), which calls for deferring surgery and allowing children to make their own decisions, and the United Nations condemned the practice of medically-unnecessary normalization of intersex children’s genitals, finding it a violation of their rights to physical integrity and to be free from torture. [35, 36] The same year, the European Union Agency for Fundamental Rights advised member states to avoid surgery, and Malta instituted a national moratorium. [37] In 2017, a US State Department press release declared, “At a young age, intersex persons routinely face forced medical surgeries without free or informed consent. These interventions jeopardize their physical integrity and ability to live freely,” and ACLU posted that “[i]t is plainly unethical, cruel, and unnecessary to perform surgeries on the genitals of children and infants because we are afraid that their bodies do not seem normal and out of an impulse to ‘assign’ a binary sex to a child before that child can articulate their gender.” [38, 39]

Physician leaders and organizations have expressed similar ideas. In 2016, our AMA Board of Trustees issued a report recognizing that “DSD communities and a growing number of health-care professionals have condemned. . . genital ‘normalizing,’ arguing that except in the rare cases in which DSD presents as life-threatening anomalies, genital modification should be postponed until the patient can meaningfully participate in decision making,” and recommending that our AMA support care that “(1) seeks to foster the well-being of the child and the adult he or she will become; (2) respects the rights of the patient to participate in decisions and, except when life-threatening circumstances require emergency intervention, defers medical or surgical intervention until the child is able to participate in decision making; and provides psychosocial support to promote patient and family well-being.”[40] In 2016, GLMA: Health Professionals Advancing LGBT Equality became the first medical association to officially recommend “delay of any surgical interventions and gender-related medical interventions for DSD that are not deemed medically necessary until the patient can provide informed consent/assent to these interventions.”[41] In 2017, three former U.S. Surgeons General wrote that “[c]osmetic genitoplasty should be deferred until children are old enough to voice their own view about whether to undergo the surgery. Those whose oath or conscience says ‘do no harm’ should heed the simple fact that, to date, research does not support the practice of cosmetic infant genitoplasty.”[42] The same year, Physicians for Human Rights advocated for “an end to all medically unnecessary surgical procedures on intersex children before they are able to give meaningful consent to such surgeries,” and the American Medical Student Association endorsed “the deferment of elective surgical interventions to standardize genitals as strictly male or female on intersex children until they reach a level of maturity at which they can participate in this life-altering decision and provide (or withhold) informed consent to such treatment,” adding, “[a]s future medical professionals, we chose this path in order to help others, not to do harm. If current practices are harmful, we should not perpetuate them through inertia. We can—and must—change medical education and practice to safeguard vulnerable patients.” [43] [44] In 2018 the American Academy of Family Physicians stated, “many intersex children are subjected to genitalia-altering surgeries in infancy and early childhood without their consent or assent. The surgery can lead to decreased sexual function and increased substance use disorders and suicide. Scientific evidence does not support the notion that variant genitalia confer a greater risk of psychosocial problems.”[45] Also in 2018, the Michigan Medical Society proposed a resolution recommending “[t]hat our American Medical Association oppose the assignment of gender binary sex to infants with differences in sex development through surgical intervention outside of the necessity of physical functioning for an infant and believes children should have meaningful input into any gender assignment surgery.” [46]

The issue of non-consensual early intersex surgery was raised in US consciousness in July 2017 when Human Rights Watch (HRW) and interACT released a highly-publicized landmark report, *“I Want to be Like Nature Made Me: Medically Unnecessary Surgeries on Intersex Children in the US,”* a high-profile investigation of current medical care and its scientific basis. [20] Unlike most research in this area, methods were developed in collaboration with the intersex community; the research design was reviewed by HRW’s children’s rights division, health and human rights program, LGBT rights program, women’s rights division, disability rights division, and legal department. Participants were recruited from support group networks and online networking groups for intersex people. Parents and adults expressing concern were also interviewed. In total, 32 adults, 23 parents, and 2 teens were interviewed. 218 formal outreach letters soliciting a wide range of views were sent to clinicians; although follow up letters were sent, 195 never responded. 21 clinicians were interviewed. The HRW/interACT report found that current surgical practices for intersex/DSD with “procedures that could be delayed until intersex children are old enough to decide whether they want them” lack evidence-based scientific justification, fail to provide adequate education to families considering surgery, and violate children’s rights to self-determination and bodily autonomy. [20]

On 02/27/18, in the wake of the HRW/interACT report, California Senator Scott Wiener, interACT, and Equality California introduced [California Resolution SCR-110](#) . Passed on 8/28/2018, it affirms that the legislature “considers intersex children a part of the fabric of our state’s diversity to be celebrated rather than an aberration to be corrected; ...[t]hat the [l]egislature recognizes that intersex children should be free to choose whether to undergo life-altering surgeries that irreversibly—and sometimes irreparably—cause harm; and ... [t]hat the [l]egislature calls upon stakeholders in the health professions to foster the well-being of children born with variations of sex characteristics, and the adults they will become, through the enactment of policies and procedures that ensure individualized, multidisciplinary care that respects the

rights of the patient to participate in decisions, defers medical or surgical intervention, as warranted, until the child is able to participate in decisionmaking, and provides support to promote patient and family well-being.” [47]

In July 2018, Lambda Legal published a policy guide for hospitals providing care to intersex people, [*Providing Ethical and Compassionate Health Care to Intersex Patients*](#). *Intersex-Affirming Hospital Policies*. [37] Model policies that hospitals can adapt for their own use are offered on topics including sex characteristics and intersex status nondiscrimination policy; patients’ bill of rights; medical treatment of intersex youth; and protocols for interaction with intersex patients and their families.

Ethical issues and consent

Who has the right to choose?

The ethics of FG are subject to fierce ongoing debate, and leading experts in the field condemn early FG. [9, 48, 49] NIH founded an Office of Sex and Gender Minority Research in 2015 and convened a workshop on DSD research. The ethicist NIH included in that workshop concluded that “[b]ecause children born with DSD have a right to an open future, and because the openness of their future is clearly enhanced by delaying cosmetic genitoplasty until they themselves can participate meaningfully in decision-making, early genitoplasty is ethically supportable only when medically indicated (e. g., when the child is unable to urinate without surgical intervention).” [49] [24] Proponents of early FG cite 2010 articles by Wiesemann et al [50] and Gillam et al [51] as supportive of the practice. Advocates of deferring surgery agree on basic ethical principles of treatment described by Wiesemann et al: fostering the wellbeing of the child and future adult; upholding the rights of children and adolescents to self-determination; and respecting family relationships.[50] Difficulties in actual management arise because these principles often conflict, particularly with respect to the value assigned to parental authority vs. children’s rights to autonomy. Wiesemann et al articulate this conflict in recommendations that absent “a compelling medical indication... interventions that might have irreversible consequences for the person’s sex or negative consequences on their sexuality or reproductive capability... should be left up to the affected persons themselves,” while at the same time “the family environment, the cultural context, and the preferred value system of the affected family must be given due consideration.” [50] Without exploring their own assumptions and beliefs, parents may not consider that their values conflict with their child’s best interests and right to autonomy. [52] The prioritizing of parental authority over child autonomy is implicit in current practices that allow parents to make irreversible decisions about the shape of their pre-verbal children’s genitalia.

Normalizing genital surgery is analogous to reparative or conversion therapy for LGBTQ people, which our AMA opposes (policy H-160.991), since it assumes *a priori* that genital difference is a pathologic state causing mental disorders. It is clear that the assumed risks of genital difference are psychosocial rather than physical. For example, in their ethics paper, Gillam et al describe the possibility of a “child... not [being] accepted by parents in the chosen sex of rearing, leading to impaired bonding; ... of social or cultural disadvantage to child, for example, reduced opportunities for marriage or intimate relationships or reduced opportunity for meaningful employment and capacity to earn an income; [and] of social isolation, restrictions or difficulties, for example caused by embarrassment or social stigma associated with having genitalia which do not match the gender in which the person lives.”[51] International experts even express pessimism regarding the widespread impact intact genitalia could have, not only on parents and children, but on “society.”[3, 34]

Lack of psychosocial support for families

The SPU states, “if surgery is considered, complete informed consent with counseling and support should be provided prior to proceeding with any surgical intervention” in a 2017 online post responding to the HRW/interACT report.[1] The reality of the current paradigm, which often presents new parents with options of doing surgery or doing “nothing,” is that it neglects the psychosocial component of health for distressed families who desperately want to help their children. [25] The lack of effective psychosocial

support means families often consent to early surgery in a state of emotional distress that impairs cognitive processing of information, and without a full understanding of the scientific, ethical, and human rights controversies surrounding these procedures. [53] Absence of a feasible psychoeducational care pathway leaves families “between a rock and a hard place,” with no meaningful alternative to surgery.[25] As one parent of a child with CCAH said, “It’s close to no choice... we figured that it had to be done.”[54]

Arguments over surgery as the primary measure to alleviate future psychosocial distress eclipse advocates’ primary mission: the development and implementation of effective psychosocial interventions, including routine inclusion of peer support, prior to irreversible decisions when the contemplated procedures violate human rights standards. [6] The need to address families’ emotional health was detailed in the original 2006 International Consensus Statement on Management of Intersex Conditions, which stressed psychosocial support. [55] While surgery may be helpful in some specific situations, criteria to define those who will benefit have not been defined. In the era of precision medicine, application of targeted measures used elsewhere in medicine such as behavioral phenotyping could improve the success of various psychosocial interventions. [56]

The availability of support is of international concern. A German survey of parents found that although 40% of parents of children with DSD expressed a subjective need for psychological support, only about half of those parents received it adequately or partly, and half needed it but received no support. [57] In the US, where in a recent practice survey of multidisciplinary teams by the NIH-funded Translational Research Network (TRN) reported that psychologists or psychiatrists are always available or available by consult, 1/3 of families still lack routine access to psychological services. [58] Among barriers requiring urgent attention are the limited number of behavioral health providers with specialized training and experience, lack of reimbursement, and few centers providing services promoting acceptance of differences. [6] A needs analysis of international counselors involved in intersex care revealed significant unmet needs. [52] Most were counseling parents rather than children or adults, and felt that current systems do not adequately address concerns with gender dissatisfaction, confusion, reassignment and cross-gender behavior, which are much stronger than results of parent and patient satisfaction surveys indicate. They endorsed expertise in sexual issues and collaboration with sex therapists, with an emphasis on acceptance of genital difference, to reinforce coping and resilience. [52] Replacing irreversible surgery with a dynamic approach prioritizing psychosocial interventions could address potential consequences of genital difference that are expected to vary with life stages. Dealing with issues raised by families, children, adolescents and adults will require clinicians to confront unconscious assumptions and overcome systemic barriers to prioritizing psychosocial care within teams. [59]

Allowing children to grow up with intact genitalia that may not match their gender identity is not a form of “social experimentation.” Parent acceptance of deferred surgery is confirmed by early encouraging results from a study of parents favoring initial endocrine treatment, indicating that “so far girls and their parents have not experienced significant concerns regarding genital ambiguity.”[60] In non-intersex children, increased rates of suicide and self-harm are observed in adolescents with gender dysphoria, who by definition have genitalia discordant with their gender identity, but well-known research demonstrates that support for identity and social transitioning are primary factors promoting self-esteem and mental health. [61] [62] Living with discordant genitalia is not the primary challenge to their mental health.

Psychosocial consequences of genital difference

Stigma in adults with CCAH, which surgery is meant to prevent, has recently received attention. [3] Several recent studies documented that stigma was experienced by adult women with CCAH in a variety of settings, even though most of the women had previous surgery. [28,29,30] Stigma experienced by nearly 2/3 of adults in the general social environment was related to obvious physical differences, such as hirsutism or a deep voice, rather than genital difference.[63] 25% of the same women reported that doctors’ actions caused stigma, mostly via frequent genital exams in teaching settings. [64] This is a significant finding because despite years of patient complaints about traumatizing genital exams, the practice continues in contemporary multidisciplinary clinics, of which the TRN found that 30% still perform genital exams for teaching. [58] Sexual stigma was experienced by 40% of the women studied, whether they had surgery (the

majority) or not, but nearly all women described maladaptive coping in interviews, including secrecy, hiding genitalia, sex avoidance or abstinence, and substance abuse. [28] Rather than being a consequence of genital difference, shame can result from the mere fact of having genitals that “required surgery,” suggesting significant iatrogenic moderators of the relationship between genital difference and sexual stigma. [28]

Studies of adults with CCAH show that surgery does not avert psychiatric issues, which are increased relative to the general population. One study found significantly increased rates of counseling for severe symptoms, and a multicenter European study found 8.8% had longstanding psychological problems. [65, 66]. The types of problems observed in adults include depressive mood disorders and anxiety [67, 68], suicidality,[66, 69] and paranoid ideation.[70]

Reports of psychometric test results, stigma, and psychiatric diagnoses do not capture the full spectrum of challenges to wellbeing in adults, including barriers to intimacy, evolving identities, and poor education about their medical and surgical histories. [59] In a qualitative study, many adults felt that CCAH had a strong negative impact on their lives, with over half saying their sexual lives were severely affected. [71] Narrative analysis of patient accounts reveals that many who endure serious ongoing trauma are in fact thriving, which should prompt us to regard them as “survivors.” [72] The single biggest factor in thriving was finding peer support. [72] Collaborative research with those who are doing well could investigate factors known to promote thriving in survivors of other types of trauma such as childhood cancer and abuse.[72]

FG proponents acknowledge the need for some form of intersex-related psychosocial intervention in some women, but demur on actual recommendations such evidence since there is little evidence for effectiveness of specific interventions in CCAH. Social and professional psychological support have been found to positively impact adult well-being. [73] A needs assessment study of a group of men with the DSD congenital hypogonadotropic hypogonadism, or Kallmann syndrome, found that patients are receptive to online interventions aimed at addressing their unmet needs, including peer support to enhance coping and promote health.[74]

Informed consent

The way in which intersex is presented influences parent attitudes. Streuli et al conducted a study of the effects of contrasting professional counselling behaviors on decision-making; 2 groups of 3rd-year medical students functioning as proxies for parents were assigned randomly to watch one of 2 videos, the first a medicalizing presentation discussing “disorders,” “congenital malformation,” and “surgical options,” and the second emphasizing less pathologizing, more supportive information. When asked to decide for or against early surgery, 2/3 of those who watched the medicalizing video and 1/4 of those who watched the demedicalizing video chose surgery. [75] Significantly, neither group felt the presentation influenced their decision.

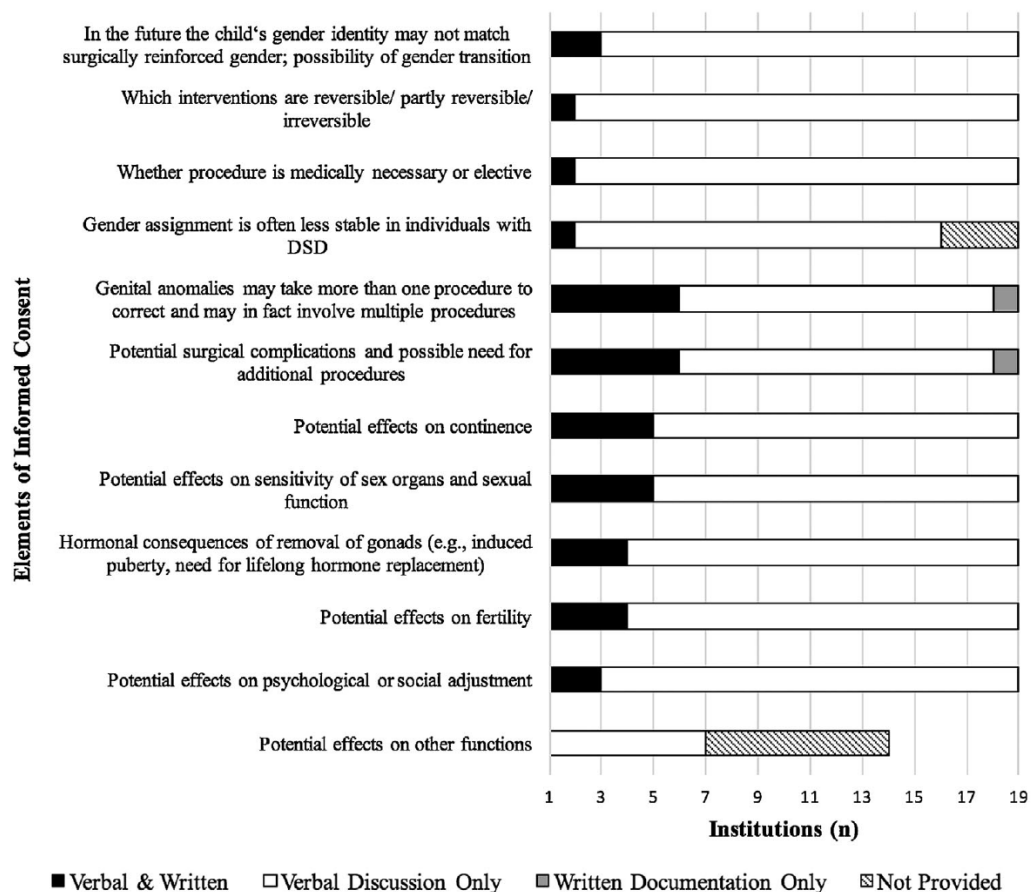
The SPU affirms that “societal norms do not dictate whether a child may be a candidate for surgery,” but doctors themselves are an important repository of the beliefs and values that reflect societal norms. [1] Female genital mutilation and FG are sometimes compared because, although they are performed for very different reasons, either can result in anger and resentment over their imposition at a time when children are too young to understand, and subsequent powerful negative emotions can impair sexuality beyond the purely physical sequelae of either intervention. [76] While noninvasive “pricking” of the clitoris of Muslim girls is prohibited in the US because it is culturally motivated, surgeons admit that they sometimes perform FG because of “cultural concerns.” This suggests that some physicians have a troubling double standard of “acceptable” and “unacceptable” cultural motivations based on race, ethnicity or immigration status. [76]

Overwhelmed families who may not have previously considered their feelings about genital difference are distressed, anxious, and protective toward their children [54, 77-79]. In a vacuum of previous experience with genital difference, they may unknowingly be influenced by implicit clinician attitudes. There has been no systematic investigation of the foundation of physician attitudes, but in *Fixing Sex*, Karkazis found that some physicians expressed disgust toward “ambiguous” genitalia. [9] In a qualitative study of clinicians

designed to build on the research of Streuli et al, Roen and Hegarty interviewed 32 clinicians involved in the care of children with genital difference. They found that institutional practices such as automatic referral to surgeons leave parents terrified that something is wrong with their child, and that clinicians themselves did not realize the impact of their personal beliefs (that parents want surgery) and parents' expectations (surgery can fix anything) on their discussions with families. [80] The presentation of "doing nothing" as the alternative to surgery can seem unacceptable to families in the face of strong norms in favor of surgery, especially when the choice is repeatedly presented. They concluded that clinicians underestimate the effect of framing in influencing parental decisions. Noting that some psychological specialists are actively framing genital difference in ways that support parents' abilities to raise happy, flourishing children with unconditional love, and focusing on cultivating psychological health, well-being, and self-esteem, they suggested that a psychosocial approach to genital difference would frame genital difference in non-medicalizing ways in discussions with parents.

In addition to questions of framing, current informed consent practices may exclude information that intersex people themselves believe parents should know. For an NIH-funded Translational Research Network (TRN) study of clinical practice, intersex advocates created a list of key points of information to be discussed with families considering genital or gonadal surgery for their children which was used to survey centers on informed consent practices. While centers believed they had discussed most of these points, this chart summarizes how few actually documented what they told parents, especially regarding medical necessity, irreversibility, and gender uncertainty. [58] (see Figure 1.)

Figure 1. How specific elements of informed consent are documented by multidisciplinary teams.
(Reproduced with permission from Aimee Rolston)



In retrospective surveys like this, the content of discussions is subject to recall by families and clinicians. Without a formal education process, guidelines, documentation, or assessment of parent knowledge, there is a strong possibility that many parents may not have received or understood important information. Even if they did, only half the centers imposed a thinking period before surgery to allow families to assimilate complex information.[58] Looking at physician influence and consent from another perspective, in a prospective study of postoperative cosmesis that did not specify elements of informed consent, 30% of mothers and 50% of fathers who were invited to participate were satisfied with the preoperative appearance of their children's genitals, while 100% of surgeons were dissatisfied/very dissatisfied. [31] Despite the rate of parental satisfaction, 96% of families agreed to surgery. [31] Rates of consent that parallel surgeons' rather than parents' dissatisfaction with appearance may reflect surgeons' attitudes toward necessity, raising questions of how genital difference is framed and of how "informed" consent actually is in the face of surgeons' preference for early surgery.

Analysis of specific arguments for early surgery

Evidence underlying several assertions that arise repeatedly in support of early FG deserves additional exploration.

Gender dysphoria is unusual in CCAH

Regarding the background prevalence of GD in the general population, CDC's Behavioral Risk Factor Surveillance System recent data analysis estimates that 0.7% of youth in the general population identify as trans. [81]

Publications favoring early FG in CCAH contain statements such as, "female assignment is suggested for those with 46,XX and CAH, since 95% develop female gender identity," or "there is usually no gender issue in this group," but the literature in this area is seriously flawed. [3, 34] In children with CCAH, as in all children, gender identity is a result of "complex, multiple and interactive developmental processes." [82] It is not fixed at birth, nor is it confirmed by "fixing" genitals with surgery aimed at creating dimorphism.

FG proponents minimize the significance of surgical reinforcement of gender misassignment with claims that multiple studies show a low rate of GD in CCAH. A 2015 literature review by Pasterski found the results of older studies often cited as supporting early surgical reinforcement of female gender assignment are unreliable because they used flawed methodologies including inconsistent, insufficient, or unvalidated measurements; even those using measurements based on DSM-IV or self-report questionnaires/ interviews confounded gender identity with gender role behaviors. [83] Among those discredited studies is one that is frequently cited by surgery proponents for its numerical significance, a 2005 literature analysis by Dessens et al that reports on 250 people. [84] Similarly, in a 2018 study, "Gender Dysphoria and Gender Change in Disorders of Sex Development/Intersex Conditions: Results from the dsd-LIFE Study," which is the largest investigating gender outcomes in intersex/DSD, the data collected ostensibly show a 0.4% rate of GD in CAH, but the authors themselves caution that multiple methodologic issues challenge the study's validity. [85] Although it was a mixed methods study, quantitative questionnaires were not developed on the basis of clinical interviews. Of 221 female-assigned participants with CAH, 174 had confirmed CCAH, but 47 were not specified. "Because their gender did not correspond with the usual gender for their diagnosis," those living as male were excluded. Finally, 36% of scores on questions meant to assess GD were missing; only questions on recent sexual activity had a similar rate of missing responses.

In order to avoid methodologic limitations, Pasterski et al performed their own study *prospectively* assessing gender identity of 81 female-assigned 4- to 11-year old children using mixed qualitative and quantitative methods, including the existing gold standard, DSM 4 criteria for gender dysphoria (GD). [83] They found that cross-gender identification was significantly increased in these children relative to both XY siblings with CAH and unaffected siblings. The results in 12% of female-assigned children met all 5 DSM criteria for GD, qualifying them for referral to a GD clinic. 12% is not rare; it equates to 1 out of 8 patients, the same as the

proportion of women who will develop breast cancer in their lifetimes, which is not considered unusual. It is also nearly 20 times higher than the rate of GD in non-intersex children.

Among all studies of adult gender identity outcomes, there is one that stands out for utilizing the type of mixed methods- interviews plus quantitative scales developed from those interviews- recommended by the IRDiRC for research on rare conditions. [26] Schweizer et al studied 69 people with diverse intersex/DSD, including 17 patients with CCAH. [86] Although the sample size is small, the investigation yielded details unmatched in richness, providing complex and nuanced insights not found in other studies. Among those 17 patients, with one non-responder, 11/16 (69%) identified as women, 4/16 (25%) reported a 'mixed' two-gender identity and 1/16 (6%) a male gender identity. 10 of 12 of those originally assigned female (2 born with female genitalia and 8 with ambiguity), were fairly to highly satisfied with assignment (83%). Among the satisfied 10, however, 1 had mixed identity. Of the 2 (17%) not satisfied with female birth assignment, both had genital ambiguity; 1 was reassigned male at age 7 based on medical recommendations following signs of male development, and continued living as male but had a mixed 2 gender identity. The other person not satisfied with female assignment had mixed identity and lived in a 3rd gender in adulthood. 5 people were assigned male before age 1, 4 having male genitalia; 1 (20%) was ultimately satisfied and lived in a male role. Two who were reassigned female before age 2 (1 with ambiguous and 1 with male genitalia at birth) later identified and lived as female. One person with male genitalia at birth and assigned male, who was reassigned female before age 1 and self-reassigned male at 35, had mixed gender identity and lived in a 3rd gender; they stated, "The definition as female and the iatrogenic trauma connected with it destroys identity." [86] The 5th person assigned male, who had male genitalia at birth and underwent many medical male-sex-assigning interventions, later identified as female and was considering a male to female gender transition.

The results show that gender assignment based on genital appearance alone is not predictive of adult gender identity. There is significant dissatisfaction with gender assignment, both male and female, even in the absence of gender transition. Among the study's surprising findings was that 7/16 (41%) people, including some who were satisfied with gender assignment, had markedly low scores on the certainty of belonging to one specific gender (CG) scale. Schweizer et al concluded that their findings indicate

"... the inadequacy of the dichotomous, one-dimensional male/ female 12categorization for the purpose of allowing an authentic sense of gender identity in individuals with DSD. Our research further suggests that treatment goals should be re-directed from 'successful' gender outcome in binary terms to psychological well-being regardless of feeling male, female, both or neither.

Though the [2006] consensus statement [55] offers useful suggestions for clinical management, a fundamental weakness lies in its perpetuation of 'optimal gender' thinking (e.g. 'successful gender assignment is dependent on this procedure [phalloplasty]'. [55] Whilst prediction of adult gender identity remains illusive, social allocation of a gender to facilitate gender identity development should continue. However, non-emergency sex-assigning interventions should be the subject of much tighter scrutiny." [86]

The finding that 25% of people with CAH have identities not encompassed in current terminology makes it clear that more expansive understandings of gender as dynamic and non-binary are needed. [86] With errors in early childhood gender assignment a significant possibility, deferring surgery in children preserves options for later transition. Social assignment is easily changed, but irreversible surgery compounds the magnitude of harm from misassignment to catastrophic proportions, as in the removal of a healthy penis from a child subsequently identifying as male.

Surgery that spares neurovascular structures will preserve sensation and function

Over-optimism regarding surgical outcomes is pervasive. In a typical argument for continuing to offer early surgery to families, while "each child's diagnosis and treatment options are presented to parents based on best available science," evidence regarding the most up-to-date procedures is lacking because patients

presented in recent reports “were treated decades before physicians began to specialize in pediatric urology, and many of the related procedures are no longer being performed.” [87] Since today’s surgery is technically more advanced, “current study results do not support abandonment of childhood genital reconstruction.” [88] In other words, since functional outcomes of today’s procedures will not be known for 15-20 years, data invalidating the prediction of superior outcomes will be irrelevant, because there will be even more sophisticated techniques by that time, permitting endlessly unproven speculation to fuel the continued practice of early FG. In the face of data on poor outcomes, because we will not know the outcomes of today’s surgery for many years, the supposed benefits of early surgery justify its continued execution. Advocates of delaying surgery point out that postponement respects children autonomy and allows future access to expanded knowledge and improved procedures.

One particular unsupported contention is the belief that preservation of neurovascular structures assures better outcomes. The anatomic knowledge underpinning modern “neurovascular-sparing” surgery, according to proponents, is derived from 2 papers elucidating clitoral anatomy published by Baskin et al in 1999. [7, 89, 90] The original papers describe typical human fetal genital anatomy; but a hypothesis that atypical “masculinized” female anatomy should parallel typical human male anatomy replaces an actual demonstration of atypical anatomy in CCAH. [89, 90] Since actual specimens of “masculinized” human fetuses with CCAH were unavailable to confirm this idea, Baskin’s group sought an animal model. They chose the female spotted hyena, which has unusually high androgen levels, and has a long phallus-like clitoris through which it urinates, copulates and delivers young. Proof of concept was reported when fetal female hyena anatomy was correlated with predictions of how “masculinization” would affect the developing human clitoris. [91] However, the spotted hyena urogenital sinus (UGS) is intrinsically very different from the UGS in CCAH. The relevance of hyena neurovascular anatomy to FG in CCAH is questionable because hyena clitoris does not provide sexual pleasure, which is the sole purpose of the human clitoris. While the hyena UGS extends the entire length of the clitoris, the human UGS opens on the perineum in CCAH. Unlike androgen-mediated clitoral development in fetuses with CCAH, development of the “masculinized” female hyena clitoris is androgen-independent: female offspring of pregnant hyenas given androgen-blockers have clitorises that are not significantly different from untreated offspring. [92] . The cephalad orientation of the hyena UGS opening limits sexual access of potential mates; limited clitoral distensibility requires significant tearing to accommodate delivery and causes frequent entrapment of hyena pups in the UGS during birth, with a 60% rate of stillbirth in first-time deliveries. [92] Despite these fundamental functional and developmental differences, FG techniques are still based on the correlation of hyena and human anatomy.

Beliefs that that procedures preserving the predicted locations of neurovascular structures will protect sexual sensation and function persist despite histologic demonstration of branches of the dorsal nerve in 23 of 27 clitoral tissue specimens removed during nerve-sparing clitoroplasty by Poppas’s group; they described those nerves as insignificant. [93] Their subsequent study of functional outcomes prompted outrage when Poppas et al published a report in which young children’s postoperative sensitivity was assessed using a cotton tip applicator and a vibratory device to test genital sensation at various points of the inner thigh and genitalia- labia majora, labia minora, vaginal introitus and clitoris. [94] As a leading psychologist commented at the time, “Applying a vibrator to a six-year-old girl’s surgically feminized clitoris is developmentally inappropriate.” [95] A complaint was filed with the Office for Human Research Protections (OHRP) in 2010 by Alice Dreger, Advocates for Informed Choice and others, asserting that the research was unethical, not IRB-approved, and could psychologically harm children with no direct benefit to them. [95] [96] Although Poppas wrote in response to a 2017 inquiry by Human Rights Watch (HRW) that he discontinued clitoral sensitivity testing in 2006, he was observed discussing it with parents as part of surgical follow up in 2015. [20, 97, 98] The complaint was eventually dismissed by OHRP on the grounds that the research was not federally funded. [99] Today, claims of intact postoperative clitoral sensation with current early FG techniques remain unconfirmed because of varying surgical procedures and assessment techniques. [100, 101]

Early surgery is better

Supporters of early FG agree with advocates of deferral that there are currently insufficient data to support assertions that adult women are satisfied with the results of early surgery.[28] Since there is no research

directly comparing outcomes of early and late FG, we cannot know which is better, although some gynecologists who perform both primary FG and surgery to treat subsequent complications in older patients advocate for deferral. [2] [29] Unsupported assertions of superiority of early FG distract from the uncomfortable truth that pediatric specialists themselves prefer it because they are not trained to perform surgery in older, consenting individuals. [1] Six-year follow up of successful single-stage adult genitoplasty with preservation of orgasm was reported by Tjalma in 2016; the operation preserving the erectile tissue of the corpora cavernosa in a previously-orgasmic woman with CCAH also eliminated the need for revision vaginoplasty because the woman was already sexually active.[30]

Although many retrospective studies of FG opine that outcomes should be improved when surgery is performed by expert surgeons in the ideal setting of multidisciplinary care, a recent prospective study of outcomes of modern neurovascular-sparing surgery in that setting does not show the hoped-for reduction in complications: after just one year, 10% of FG procedures had serious complications. [18] The short-term complication rate for proximal hypospadias surgery, also a controversial procedure, was 40%, consistent with statistics for these procedures performed in other settings.[18, 32]

While some centers support early surgery with anecdotal evidence of adult CCAH patients requesting primary or revision surgery, there are corresponding anecdotes of unoperated intersex adults who are grateful to have been spared infant surgery, such as 60-year-old Jim Costich, who posted on Facebook: “I did not have any genital surgery to make me look any different and... my love life, my social life, my gym life, even my life as a nudist has not been adversely affected!”

Surgery on older children and adolescents must still be approached carefully. The lessons of adolescent labiaplasty remind us that there is a strong developmental urge to erase variation and conform to unrealistic cosmetic standards promoted by social media. As the American College of Obstetrics and Gynecology states, psychosocial services and counseling are essential: “Although reconstructive procedures aimed at correction of abnormalities (caused by congenital defects, trauma, infection, or disease) or cosmetic procedures performed to reshape normal structures may improve function, appearance, and self-esteem, not all adolescents are suited for surgical intervention. Appropriate counseling and guidance of adolescents with these concerns require a comprehensive and thoughtful approach, special knowledge of normal physical and psychosocial growth and development, and assessment of the physical maturity and emotional readiness of the patient.” [102]

FG is reversible

This claim is based on a technique described by Pippi Salle et al in 2007. Noting that patients undergoing FG for CAH may have gender dysphoria later in life and wish that they could reverse decisions made by parents and caregivers earlier in their lives, Pippi Salle et al introduced corporeal sparing dismembered clitoroplasty as a conservative technique intended to preserve all clitoral structures, providing potential for surgical transition back to an intact phallus. [103] Although a PubMed search shows that the technique is referenced in 6 papers, none is an outcomes study. Nonetheless, 2 prominent proponents of FG present it in a 2017 review among cutting-edge techniques. [11]

Adult women and parents prefer early surgery

The oft-repeated contention that women “clearly” prefer early surgery relies on uncritical acceptance of the conclusions of very few studies, and is contradicted by closer scrutiny of the actual study methods and data. [104, 105] One of these studies included the following question: “Some people argue that children born with unfinished sex organs (ambiguous genitalia) should not be surgically corrected before they are adult and can fully understand and consent to the procedures. Do you agree?” [106] Framing genital difference inaccurately as “unfinished sex organs” could promote a bias in responses. Also, those who “preferred” early surgery were not informed of the alternative of not having surgery at all; that delaying surgery could have reduced the rate of reoperation for vaginal stenosis; or that there had been significant technical modernizations predicted to improve outcomes since their early childhood surgery. [104] As for parents, families who chose early FG because it was presented as helpful and necessary would be expected to wish it

had been done even earlier. [100, 107]

Surgery prevents UTIs

It was commonly believed in the past that early FG prevents UTIs, as in 2002 Pediatric Endocrine Society guidelines. [108] Today we know that girls with CAH who have a common urogenital sinus are not predisposed to UTI prior to surgery, and an intact urogenital sinus does not predispose to UTI later. [108, 109] In spite of these facts, many families continue to testify anecdotally that they have been told FG will prevent UTI. Surgery also does not prevent significant non-infectious urinary issues. In long-term follow up of adults, whether they had surgery or not, adults with CCAH were more likely to have urinary symptoms, particularly incontinence, than age-matched controls, and those with urinary symptoms were 9 times as likely as symptomatic controls to report an adverse effect on their lives. [14]

Conclusion

Children have borne the risk of “disappointing” surgical results of FG for decades. The current costly paradigm, in which many children with certain anatomic features undergo surgery to prevent presumed psychosocial issues, even though we know that some of them will experience a lifetime of serious harm, is neither ethical nor practical and violates children’s human rights. Families remain bewildered and underinformed in the current situation. As a doctor who has been a patient, I come to our AMA because the bedrock of the doctor-patient relationship is truthfulness. Families who choose early FG in CCAH don’t understand what a 1 in 8 chance of involuntary sex reassignment means, nor are they thoroughly educated about the other long-term risks and complications that intersex people themselves think they should know.

The debate over the current resolution highlights that although all stakeholders in the care of children with genital variation want what is best, polarized viewpoints on treatment reflect the values, priorities, and experience they bring to the situation. The medicalized perspective relies on studies with serious limitations, including nonadherence to principles of research for rare conditions and lack of community participation in study design. Absence of long-term follow up of patients, many of whom may be alienated by stigmatizing medical experiences, is reflected in both research outcomes and in many doctors’ personal experience. The validity of existing studies is also restricted by low participation rates and unsuitable methodologies. Consequently, there are no data showing that deferring surgery and implementing psychosocial interventions is noninferior to early FG. Continuing the status quo until more and “better” research is done, and suggesting that changing current practice to defer surgery requires proof that *not* performing early FG is not harmful, does not constitute evidence-based medicine.

Our AMA already opposes conversion therapy based upon the assumption that homosexuality is a mental disorder. Early FG to avert mental health problems assumed to be intrinsic to genital difference deserves the same consideration. I ask our AMA to support this resolution that promotes patient-centered medical care by giving children an open future with time to learn who they are before they undergo any irreversible surgery, providing parents a meaningful psychoeducational alternative, and encouraging doctors to develop effective psychosocial interventions that support children’s right to autonomy and self-determination.

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Appendix A

Arlene B. Baratz MD

Curriculum Vitae

Personal

Home: 1355 Oak Ledge Ct Pittsburgh PS 15241

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Work: Dept. of Radiology Allegheny General Hospital 312 E. North Ave Pittsburgh PA 15212

Work phone: 412 359 8106

Position/Title

Attending physician Department of Radiology, Division of Breast Imaging

Allegheny Health Network

Temple University School of Medicine

Pittsburgh PA

Coordinator of Medical and Research Affairs:

Androgen Insensitivity Syndrome- Differences of Sex Development (AIS-DSD) Support
Group (<http://aisdsd.org/>)

Chair of Medical and Research Policy Committee:

InterACT- Advocates for Intersex Youth
(<http://interactadvocates.org>)

Education/Training

Institution and Location	Degree	Year	Field of Study
Bryn Mawr College, Bryn Mawr, PA	AB	1976-80	Biology, History of Science
University of Pittsburgh School of Medicine Pittsburgh, PA	MD	1980-84	Medicine
University of Pittsburgh Medical Center Magee- Womens Hospital	Internship	1984-85	Obstetrics/gynecology

University of Pittsburgh Medical Center	Residency	1985-86	Anatomic pathology
University of Pittsburgh Medical Center	Residency	1986-90	Diagnostic radiology

Employment

Attending physician. Women's imaging radiologist. Fogel and Weinstein Imaging. Pittsburgh, PA. 1990-1991.

Attending physician. Associate professor. University of Pittsburgh Department of Radiology. Breast Imaging Division. 1991-97.

Attending physician. Shadyside Hospital. Pittsburgh PA. Department of Radiology. Breast Imaging Division. 1997-2001.

Attending physician. Allegheny Health Network. Pittsburgh PA. Department of Radiology. Breast Imaging Division. 2001-present.

Other Experience and Professional Membership

Global DSD Update Group. Co-chair: Peer Support Committee. Supported by Pediatric Endocrine Society. Organizers: Lee PA, Nordenström, A, Houk, C. 2014-2016.

Androgen Insensitivity Syndrome-Differences of Sex Development (AIS-DSD) Support Group

Coordinator of Medical and Research Affairs 2015-present.

Board of directors 2008-2015.

Medical adviser 2001-present.

InterACT Advocates for Intersex Youth

Chair of Medical and Research Policy Committee 2015-present.

Medical adviser 2007-present.

Board of directors 2007- present.

Founding member 2007.

American Urological Association (AUA) member. 2016.

AIS-DSD Parents Group. Moderator: 2002-2015.

Adviser. Short-term outcomes of interventions for reproductive dysfunction. NIH 1R01HD074579-01A1. Principal investigators: Wisniewski, AB and Mullins, LL. 2013- 2016.

Advocacy Advisory Network. Disorders of Sex Development: Platform for Basic and Translational Research. NIH 5R01HD068138-05. Principal investigators: Vilain EJ and Sandberg DE. 2011-2015.

Pittsburgh Youth and Young Adult Gender and Sexual Development Network. 2012-present.

dsdFamilies.org. An information and support resource for families with children, teens and young adults who have a DSD. Contributor and adviser since 2011.

Advocacy/ Education committee chair. Guidelines for the Development of Comprehensive Care Centers for Congenital Adrenal Hyperplasia: Guidance from the CARES Foundation Initiative. Organizers: Auchus, R, Witchel, S, and Congenital Adrenal Hyperplasia Education, Support, and Research (CARES) Foundation. 2010-2011.

North American Society for Pediatric and Adolescent Gynecology (NASPAG) member 2010-present

Children's Hospital of Pittsburgh DSD committee 2008-present

Accord Alliance Founding member 2007

Society of Breast Imaging 1991-present

Honors

2016. AIS-DSD Support Group Honorary Life Member Award: to honor a member who has made a significant impact on another individuals or group of individuals specifically in the AIS-DSD Support Group.

2016. Arlene Baratz Scholarship Fund established in my honor by AIS-DSD Support Group.

1989-1990. University of Pittsburgh Medical Center chief resident in diagnostic radiology.

Publications (for the last 7 years)

Disorders of Sex Development/Intersex: Gaps in Psychosocial Care for Children.

Ernst MM, Liao LM, Baratz AB, Sandberg DE. Pediatrics. 2018 Aug;142(2). pii: e20174045. doi: 10.1542/peds.2017-4045. No abstract available. PMID:30045929

Identifying and Counting Individuals with Differences of Sex Development Conditions in Population Health Research. Tamar-Mattis S, Gamarel KE, Kantor A, **Baratz A**, Tamar-Mattis A, Operario D. LGBT Health. 2018 Jul;5(5):320-324. doi: 10.1089/lgbt.2017.0180. PMID:29979641

The Ethics of Fertility Preservation for Pediatric Patients with Differences (Disorders) of Sex Development.

Campo-Engelstein L, Chen D, Baratz AB, Johnson EK, Finlayson C. J Endocr Soc. 2017 Jun 1;1(6):638-645. doi: 10.1210/js.2017-00110. PMID: 28944319

Interdisciplinary care in disorders/differences of sex development (DSD): The psychosocial component of the DSD-Translational research network. Sandberg DE¹, Gardner M¹, Callens N^{1,2}, Mazur T³; DSD-TRN

Psychosocial Workgroup, the DSD-TRN Advocacy Advisory Network, and Accord Alliance. Am J Med Genet C Semin Med Genet. 2017 Jun;175(2):279-292. doi: 10.1002/ajmg.c.31561. Epub 2017 Jun 2. PMID: 28574671

Disorders of sex development (DSD): Clinical service delivery in the United States. Rolston AM, Gardner M, van Leeuwen K, Mohnach L, Keegan C, Délot E, Vilain E, Sandberg DE; members of the DSD-TRN Advocacy Advisory Network; Accord Alliance. Am J Med Genet C Semin Med Genet. 2017 Jun;175(2):268-278. doi: 10.1002/ajmg.c.31558. Epub 2017 May 30. PMID: 28557237

Ethical Controversy About Hysterectomy for a Minor. Burgart AM, Strickland J, Davis D, Baratz AB, Karkazis K, Lantos JD. Pediatrics. 2017 Jun;139(6). pii: e20163992. doi: 10.1542/peds.2016-3992. Epub 2017 May 12. PMID: 28562274

Response to 'Re. Attitudes towards disorders of sex development nomenclature among affected individuals'. Johnson EK, Rosoklija I, Finlayson C, Chen D, Yerkes EB, Madonna MB, Holl JL, Baratz AB, Davis G, Cheng EY. J Pediatr Urol. 2017 Dec;13(6):610-611. doi: 10.1016/j.jpuro.2017.04.007. Epub 2017 May 6. No abstract available. PMID: 28552319

Attitudes towards "disorders of sex development" nomenclature among affected individuals. Johnson EK, Rosoklija I, Finlayson C, Chen D, Yerkes EB, Madonna MB, Holl JL, Baratz AB, Davis G, Cheng EY. J Pediatr Urol. 2017 Dec;13(6):608.e1-608.e8. doi: 10.1016/j.jpuro.2017.03.035. Epub 2017 May 8. PMID: 28545802

Re: "Surgery in disorders of sex development (DSD) with a gender issue: If (why), when, and how?" Baratz AB. J Pediatr Urol. 2016 Dec;12(6):442-443. doi: 10.1016/j.jpuro.2016.07.013. Epub 2016 Sep 14. No abstract available. PMID: 27697469

Global Disorders of Sex Development Update since 2006: Perceptions, Approach and Care. Lee PA, Nordenström A, Houk CP, Ahmed SF, Auchus R, **Baratz A**, Baratz Dalke K, Liao LM, Lin-Su K, Looijenga LH 3rd, Mazur T, Meyer-Bahlburg HF, Mouriquand P, Quigley CA, Sandberg DE, Vilain E, Witchel S; Global DSD Update Consortium. Horm Res Paediatr. 2016;85(3):158-80. doi: 10.1159/000442975. Epub 2016 Jan 28. Review. Erratum in: Horm Res Paediatr. 2016;85(3):180. Koopman, Peter [added]. PMID: 26820577

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Misrepresentation of evidence favoring early normalizing surgery for atypical sex anatomies. Baratz AB, Feder EK. Arch Sex Behav. 2015 Oct;44(7):1761-3. doi: 10.1007/s10508-015-0529-x. No abstract available. PMID: 25808721

Disorders of sex development peer support. Baratz AB, Sharp MK, Sandberg DE. Endocr Dev. 2014;27:99-112. doi: 10.1159/000363634. Epub 2014 Sep 9. Review. PMID: 25247648

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July 2018. Caring for Adults with DSD/Intersex Traits. Baratz A, Baratz Dalke K. Baratz A. AIS-DSD Support Group and Lurie Children's Hospital CME program. Chicago IL.

November 2017. Evolving Role of Patient Advocacy in Intersex Care. Baratz A, Wong L, Baratz Dalke K. Gay Lesbian Medical Association meeting. Philadelphia PA.

April 2017. Nothing About Us Without Us. North American Society for Pediatric and Adolescent Gynecology Annual Clinical and Research meeting. Baratz A. Chicago IL.

July 2016. The Long and Winding Road- Past, Present and Future of Intersex Care. Baratz A. AIS-DSD Support Group and Colorado Children's Hospital CME program. Aurora CO.

May 2016. Community and Clinicians Creating Change Together. Baratz A. Society of Pediatric Urology meeting. San Diego CA.

April 2016. Managing Genital Difference in Children with Anesthesia Risks: An Alternative Approach. Baratz A. North American Society for Pediatric and Adolescent Gynecology Annual Clinical and Research Meeting. Toronto, Canada.

June 2015. Helping the "I" in LGBTQI: Resources for People Living with Intersex and Diverse Reproductive Development. Philadelphia Trans Health Conference. Malouf M and Baratz A. Philadelphia PA.

June 2015. Managing Genital Difference in Children with Anesthesia Risks: An Alternative Approach. Baratz A. 5th International DSD (I-DSD) symposium. Ghent, Belgium

June 2015. Decision-Making Checklist: Complete Androgen Insensitivity Syndrome. 5th International Disorders of Sex Development (I-DSD) symposium. Graziano K, Hernandez SJ, Baratz A, Muscarella M. Ghent, Belgium.

September 2014. Adding the "I" to LGBTI: Research Priorities for the NIH LGBTI Initiative. Arlene Baratz and Katharine Baratz Dalke. Gay Lesbian Medical Association meeting. Baltimore MD.

July 2014. Where Have We Been and Where Are We Going? Baratz A. University of California San Francisco Medical Center and AIS-DSD Support Group CME program. San Francisco CA.

June 2014. Gender and differences of sex development (DSD) *what we wish clinicians knew. Baratz A, Malouf M. Philadelphia Trans Health Meeting. Philadelphia PA.

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Appendix B

Letter of resignation of AAN from TRN

November 24, 2015

To: NIH Translational Research Network and NIH Research Coordinating Committee for Sexual and Gender Minorities
From: AAN Members
Re: Statement of resignation of some AAN Members from TRN

The original invitation to join the Advocacy Advisory Network (AAN) of the NIH Translational Research Network (TRN) evoked an idealistic vision of patients and clinicians setting aside differences and working together to make life happier and healthier for people living with reproductive difference. Rejoicing at the opportunity to have a voice in major decisions about research and care that affect our community in powerful ways, representatives of multiple peer support and advocacy groups eagerly joined. AAN members include advocates with diverse lived experience, who are affected adults, parents, and children, who are affected by a variety of differences, and who range in life stage from youth to maturity. We bring skills from careers in business, academia, law, social work, conflict resolution, project management, counseling, psychology, genetics, non-profit executive directorship, and medicine. We have decades of combined experience in peer support and leadership. Additionally, for the upcoming Global DSD Update sponsored by Pediatric Endocrine Society, Arlene Baratz is co-chair of the committee on patient perspectives and peer support. Despite our representation of our community and many valuable contributions of expertise and experience since we joined AAN four years ago, we are extremely disappointed that TRN has not lived up to its initial promise.

[Alice Dreger](#) and [Tiger Devore](#) recently announced their resignations from AAN on Alice's blog. We agree with some of their ideas, and would like to clarify our own perspective. AIS-DSD Support Group, Advocates for Informed Choice, and our allies listed below are also withdrawing from AAN because of ongoing miscommunication and lack of meaningful inclusion. At this point, having our names associated with TRN is doing more harm than good because chronic issues with TRN prevent meaningful advocacy input. From its inception, despite our requests, TRN failed to include advocates in the design and goals of the project. Having been denied a presence at the initial meeting of investigators, we hoped that subsequent close involvement in projects could influence the direction of research, but most were already IRB-approved by the time we saw them. Instead of an opportunity to contribute, we have experienced a pattern of misrepresentation in which our involvement and concurrence have been falsely implied. Missed deadlines and absence of key project deliverables also frustrate us.

Let us be clear that our resignation has nothing to do with the TRN clinicians and researchers who devote their lives to caring for and about us. We deeply appreciate your presence at our support group meetings, your availability to our members, and your ability to listen and change. Outside TRN, we are delighted to be involved in ongoing projects whose design and goals reflect successful cooperative relationships. We have found we can be extremely effective in supporting the development of research that meets the needs of our communities when we are involved from the beginning in the design of research goals, when we are able to give input into sensitive language, and when we are engaged to ensure that the specific concerns of this community regarding human research ethics and informed choice are addressed. Examples of successful research we have engaged in include projects on parent experiences with making decisions about genital difference;

how young women living with DSD share health information with peers; and parent experiences with genetic testing. Currently, we are working with TRN clinicians on outside projects investigating language, how medical care is experienced, ways to deliver psychosocial care, and evidence-based best practices in CAIS. We look forward to future opportunities to work with anyone from within or outside TRN who is interested in designing research that is inclusive of community concerns.

Although clinicians may have interacted with Accord Alliance as the designated community representative, we found that indirect transmission was effectively censoring our written and verbal communications. This is disturbing because Accord Alliance was founded in 2006 by Bo Laurent (Cheryl Chase), Katrina Karkazis, Arlene Baratz, and David Sandberg to improve medical care by replacing ISNA's confrontational tactics with a fresh, collaborative approach involving multiple stakeholders. At its closure, ISNA's funds and assets were transferred to Accord Alliance, including the *Handbook for Parents* and *Guidelines for Clinicians*. Accord Alliance hosted a research and quality improvement symposium in 2009, but hasn't sponsored any non-medical events since then, according to its blog. Laurent, Karkazis, and Baratz are no longer involved. Supported in its early days by community donations, Accord Alliance's current major source of funding is the TRN grant, which in turn designates the function of DSD community representative to Accord Alliance. This suggests a major conflict of interest. Reinforcing this impression is TRN's repeated failure to share AAN opinions and concerns about various projects with TRN clinicians for example, serious and widespread AAN concerns that a proposed photography project posed potential harm to pediatric research subjects were not conveyed accurately to clinicians. When the time came to submit that proposal, clinicians were surprised to learn our opinion. Having further misled clinicians to believe that only a minority of AAN members requested further input on the proposal, TRN circumvented its requirement for AAN support with a letter from Accord Alliance implying our approval. It was an embarrassment to all of us that the proposal was withdrawn after AAN protested the deceptive letter.

Similarly, AAN members were extensively involved for four years in writing and editing numerous drafts of educational material for a TRN family decision support tool. However, ever since we insisted recently that families be made aware of major international human rights policies involving DSD treatment, our contributions are mysteriously absent. Despite our repeated requests, a version of the decision support tool omitting human rights education is already being piloted with families. Ethics and common decency suggest that shared decision-making should include informing families that many international human rights organizations have new statements strongly affirming the right of children with diverse sex characteristics to make their own choices about irreversible interventions. The [UN High Commissioner for Human Rights](#) and the [UN Special Rapporteur on Health](#), working closely with Advocates for Informed Choice (AIC), have both endorsed these as basic human rights. DSD/intersex is increasingly prominent on an international landscape in the midst of tectonic shifts. AIC will continue to advocate for an informed consent process requiring family counseling to include discussion of both social and medical controversies. Otherwise, how will children feel later when they discover that their parents made important decisions about irreversible interventions using decision support tools that consciously excluded vital information on children's human rights? Parents have a right to know just how controversial these procedures are before they make irreversible decisions.

Finally, the original TRN grant proposal included individual letters of support from AAN member organizations. In May, we were asked to draft a new letter jointly supporting a proposal to fund

TRN for the next funding cycle. After requesting changes in the grant to provide AAN more direct involvement as a condition of support, we never saw such a letter. The grant was later submitted, leaving us to wonder if the controversy was resolved by submitting a letter from Accord Alliance without our knowledge. If so, another five years of advocate dissatisfaction and AAN misrepresentation of our constituents' concerns are practically guaranteed.

AIS-DSD Support Group's mission is to foster successful stakeholder collaborations that promote community through peer support, informed decision-making, and advances in evidence-based care. You see our passionate commitment in the vibrant community of affected people, clinicians, and allies that we nurture. You see it at meeting we sponsor in partnership with DSD teams around the country. You see when you attend our support group meetings, hear how people experience treatment, and learn about research that matters to patients. Likewise, AIC's mission is to advocate for the legal and human rights of children born with intersex traits. Neither organization, can effectively support or advocate for our constituents through the AAN, and so our consciences dictate that our members must resign.

All of us see how hard you work and how much you care. We know you want to see intersex people thrive as much as we do. The world is already changing because of our mutual dedication. Together, we have the power to transform it and we look forward to further collaborations outside the TRN.

Sincerely,

Arlene B. Baratz, MD
Coordinator of Clinical and Research Affairs AIS-DSD SG
Moderator, AIS-DSD Parents Group
AIC Board of Directors and Medical Adviser

Tiger Devore, PhD
Founding member, past president and vice president, Hypospadias Epistasis Association

Amber Jones
Operations Coordinator, AIS-DSD Support Group Moderator,
AIS-DSD Parents Group
Past member, AIS-DSD SG Board of Directors

Jim Lake
Executive Director, Hypospadias Epispadias Association Lissa

Lissa Moran, MPH

Meg Robertson
AIS-DSD SG Board of Directors
Moderator, AIS-DSD Parents Group

Karen Walsh
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Kimberly Zieselman, JD
Executive Director, Advocates for Informed Choice AIS-
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Dina M. Matos

September 4, 2018

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Kelly and Adam Leight

The Council on Ethical and Judicial Affairs
Attn: Elliott J. Crigger, CEJA Secretary
American Medical Association
330 N. Wabash Ave., Suite 39300
Chicago, IL 60611

Dear Dr. Crigger:

Thank you for the opportunity to comment on the AMA Students proposed guidelines banning surgical procedures on girls with congenital adrenal hyperplasia (CAH). A widespread moratorium on all early surgical intervention for girls with CAH, without consideration for patients' individual needs, is a dangerous proposition for children with a life-threatening medical condition and has the potential to cause permanent undue harm, both physically and psychologically.

CAH is a life-threatening endocrine disorder affecting approximately 1 in 15,000 live births and affects boys and girls in equal numbers. Surgical intervention for female CAH patients born with atypical genitalia is not a decision that is taken lightly by the parents who make it on behalf of their children nor by the expert urologists who perform them. CARES Foundation takes great pride in educating parents and adult patients on making such informed decisions by providing them with the pros and cons of the procedure(s), referring patients to expert surgeons, and connecting families to parents and patients who can offer advice and support. We strongly recommend that these decisions be made in consultation with a multidisciplinary team of experts at CAH centers of excellence.

Surgical intervention is never automatically recommended, nor is it ever imposed upon parents as the anti-surgery activists assert. When parents or patients consult with expert urologists or seek CARES' guidance, they have often already done their independent research and decided to move forward with surgery. On occasions when parents decide to delay surgery, our expert surgeons support that decision, as does CARES Foundation.

Over the last two decades, a standard of care has emerged among a select group of pediatric urologists who are highly-specialized in surgical interventions for CAH patients. Infants born with clear chromosomal and gonadal sex and a discordant anatomy **are not re-assigned** to the opposite gender for ease of reconstruction. Rather, the procedures restore function to the existing anatomy. The reconstruction allows for appropriate voiding and normal reproductive function.

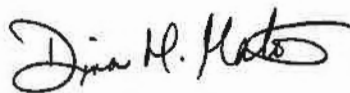
Without surgery, many CAH patients may face incontinence, vaginal reflux and increased risk of infections, which can lead to hospitalizations, life-threatening emergencies, and permanent damage. The vast majority of girls born with CAH identify as female. Forcing them to grow up with a physical appearance that does not match their identity, as proposed by activists, has the potential to cause a lifetime of psychological distress and body dysphoria.

The misguided intent to help these girls with a widespread ban has the potential to be extremely harmful, such as the young child who did not have surgery as an infant and nearly died as a result of an adrenal crisis because she had an internal infection; or the 19 year old who is sitting in a hospital after having surgery (because she didn't have it as an infant) as she is supposed to be starting her sophomore year in college and enjoying life like her friends - something she has not been able to do because of her condition. Parents have stated that the option of early surgery "was necessary for our daughter to have normal urinary function as a child and normal menstrual function as a young woman." An adult patient writes that "surgery has allowed me to have a normal sex life with my husband and I have two beautiful children." Patients' lives and psychologically well-being should not be put at risk to benefit political agendas.

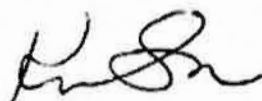
Another important and dangerous consequence of removing the option for surgical intervention and taking away the role of parents in the decision-making process is the detrimental effect it will have on the rights of parents to make medical decisions for their children. Limiting the rights of parents to make medical decisions for their children will negatively impact all pediatric medical care.

We urge you to listen to the voices of patients, families, and medical experts in the field and not be swayed by harmful rhetoric being put forth by those with a political agenda. On behalf of patients and the families of those who live with this condition, we urge you to carefully and critically scrutinize the current proposed moratorium and consider all of its potential negative ramifications.

Sincerely,



Dina M. Matos
Executive Director



Karen Lin Su, MD
Medical Director

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February 2, 2018

Dennis Agliano, MD,
Chair, Council on Ethical and Judicial Affairs
American Medical Association

Dear Dr. Agliano:

It was an honor to address the Reference Committee at the AMA House of Delegates interim meeting in Honolulu last year regarding CEJA report 3, on supporting autonomy for patients with Differences of Sex Development (DSD). As I mentioned during my testimony in the RefCom, Human Rights Watch thanks CEJA for its careful consideration of the ethical elements of care for children with DSD, and we were glad to see our July 2017 report “*I Want To Be Like Nature Made Me*” cited in your report on the matter.

As you may know, we published a second report on intersex/DSD issues in October 2017. This report highlights the voices of providers who care for children with DSD and advise their families. I have attached a copy to this letter for your reference [Appendix 1].

As lead researcher on the project, I interviewed nearly two dozen providers—urologists, psychologists and psychiatrists, gynecologists, endocrinologists, and geneticists—who provide expert care to children and families affected by DSD. In our report, we contextualize the information gathered from the doctors in information we gathered from individuals with DSD and parents of children with DSD, as well as a thorough literature review.

As a public policy analyst, and as someone who is not a doctor, not a parent, and not a person with a DSD, gathering honest, anonymized data and testimony from providers on the front lines of caring for children with

DSD and their families was crucial to developing a nuanced and fact-based perspective on the needed policy changes to protect children, families, and doctors. My co-investigator, Dr. Suegee Tamar-Mattis, brought decades of experience to the matter: she is a practicing physician, a parent, and an intersex person. Human Rights Watch's extensive vetting process, through experts in children's rights, health and human rights, disability, women's rights, law and policy, and outside pediatrician reviewers ensured that our data and recommendations were processed under exacting scrutiny and are of the highest standard.

During the AMA House of Delegates meeting in Hawaii, I met dozens of doctors who were interested in issues surrounding DSD care—from veteran pediatricians to medical students aiming to be OBGYN surgeons. All of these physicians were eager to see the AMA develop coherent policy and standards of care for this vulnerable population.

My time at the HoD reminded me of when Human Rights Watch started our own engagement on intersex/DSD issues. We combed the available medical literature, examined the ethnographic and historical volumes on the topic, and consulted ethicists and healthcare providers with decades of experience. But our most important consideration was that of the community we were engaging with: intersex adults, and parents of children with DSD/intersex traits. It was their experiences we were setting out to document in our report, and it was their experiences we needed to first reflect in our research design.

As I traveled the United States over the course of eight months with Dr. Tamar-Mattis, meeting adults, parents, and providers whose lives had been deeply impacted by DSD, the stories I heard from affected individuals were sometimes overwhelming. The accounts from parents about their feelings of confusion and even coercion to select an irreversible high-risk surgery on their child were striking; the discomfort I heard from doctors involved in the cases—that there were no central guidelines despite decades of data and debates—was bewildering. My own sleepless nights led me to realize that what was lacking in this situation was leadership. There were concerned, compassionate physicians too afraid to speak out about how early unnecessary surgeries were still being conducted in their hospitals; there were intersex adults who spent decades avoiding healthcare, even

in emergencies, because they feared medical professionals; and there were parents who sought nothing other than facts – unadulterated by the gender stereotypes, hubris, or aesthetic preferences of the surgeon they happened to encounter – so they could make the best decisions for their young children.

As CEJA deliberates the ethical issues surrounding care for young patients with DSD, I urge you to consider the following:

Physicians and Parents Alike Need Guidance: As I traveled the country in 2016 and 2017 conducting interviews with parents and physicians, I heard two main themes emerge in their experiences. First, both parents and doctors want to do the best thing possible for their children—both in the immediate sense and for the future; Second, no parent wants to make decisions on hypotheticals or fear, but on facts, and no physician wants to guide parents with anything but the best science. It is in clinical situations such as these where guidance from the AMA is crucial—to protect physicians and parents from making decisions based on fears and not facts, and to protect children from harm and to preserve their open future.

The Parallels with So-Called Gay Conversion Therapy: It was the medical community’s shift in thinking about sexual orientation—that it was a natural variation of human experience and not something in need of treatment—that set the groundwork for important progress on non-discrimination and equal access to quality care in healthcare and society. In the 1990s, medical bodies, including the AMA recognized that there was no evidence that “conversion therapy” delivered on its promise (it did not turn people heterosexual), and ample evidence that it caused harm in the process (it traumatized individuals and furthered anti-LGBT stigma in society). As analyzed by Human Rights Watch, Physicians for Human Rights, dozens of United Nations entities, the World Health Organization, and surgeons-general Dr. Satcher, Dr. Carmona, and Dr. Elders [Appendix 2], medically unnecessary surgeries on children with DSD occupy a similar space at this point in history: There is no evidence that they deliver on their promise of a “normal” life, and there is ample evidence that they carry high risk of negative outcomes. It is time to excise this practice from modern medicine.

The Advances in Medical Support for Transgender Youth: Recent decades have seen medical professionals take significant strides in producing data and

providing affirmative, evidence-based care for transgender and gender non-conforming youth. The AMA's policies in this matter have served as essential guidance for practitioners and policymakers, and supported the health and development of countless young people who need the affirmation of their healthcare providers to survive the violence and discrimination many continue to face in daily life. Modern medicine, including the AMA, has established that trans and gender non-conforming youth need psycho-social support and reversible interventions such as hormone therapies until they are old enough to consent to irreversible surgeries themselves—a paradigm that is supported by transgender advocacy groups, pediatrics bodies, and parent groups alike. A similar approach to youth affected by DSD is supported by medical evidence, medical ethics, current legal frameworks, and intersex community groups. Currently, absent guidance, surgeons around the country who would not countenance genital surgeries on 8-year-old children are conducting similar procedures on 8-month-old children—too young to walk or speak, let alone consent to a sex-assignment operation.

Please do not hesitate to contact me with any questions.

Kind regards,

A handwritten signature in black ink, appearing to read 'Kyle Knight', with a stylized, cursive script.

Kyle Knight
Researcher
Human Rights Watch

CC:

Elliott Crigger, CEJA director, AMA

Craig Johnson, Minority Affairs Section director, AMA



A CHANGING PARADIGM

US Medical Provider Discomfort with Intersex Care Practices

HUMAN
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A Changing Paradigm

US Medical Provider Discomfort with Intersex Care Practices

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A Changing Paradigm

US Medical Provider Discomfort with Intersex Care Practices

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Summary

Historically, when children with atypical sex characteristics were born in the United States, the people around them—parents and doctors—made their best guess and assigned the child a sex. Parents then reared them per social gender norms. Sometimes these people—intersex people—experienced harassment and discrimination as a result of their atypical traits. But many lived well-adjusted lives as adults. During the 1960s, however, based largely on the unproven recommendations of a single prominent psychologist, medical norms in the US changed dramatically. Doctors began recommending surgical solutions to the supposed “problem” of intersex traits—internal sex organs, genitalia, or gonads that do not match typical definitions of male and female. This medical paradigm remains the status quo nearly everywhere in the world today.

Defaulting to surgery resulted in stigmatization, confusion, and fear. In some cases, doctors advised parents to conceal the diagnosis and treatment from the child, instilling feelings of shame in parents and children both. And as a result, many in an entire generation of intersex people did not learn about their conditions until they saw their medical files as adults—sometimes as late as in their 50s.

Over time and with support and pressure from advocates, some medical norms have evolved. Today, intersex children and their families often consult a team of specialists, and not just a surgeon. The medical community has changed its approach to intersex cases—which doctors often categorize as “Differences of Sex Development” or “DSD”—by establishing “DSD teams.” These teams convene multiple healthcare specialists, including mental health providers, to advise on and treat intersex patients. Disclosure of a child’s intersex traits to the child is widely recommended. During this evolution in care, cosmetic surgeries on intersex children’s genitals have become highly controversial within the medical community. However, while the establishment of “DSD teams” has been perhaps the most significant evolution in care and has changed practices considerably, it has not addressed the fundamental human rights issues at stake.

Most medical practitioners now acknowledge that in some cases parents may prefer to leave their child’s body intact as a way of preserving the person’s health, sexual function, fertility options, autonomy, and dignity. Consensus among specialists in intersex health has evolved

to acknowledge data gaps and controversies—namely that there has never been sufficient research to show either that these surgeries benefit patients or that there is any harm from growing up with atypical genitals. A growing number of doctors are opposed to doing unnecessary early surgery under such conditions. Practitioners also increasingly recognize the suffering of intersex patients who underwent the operations without their consent.

However, despite these promising developments in care for intersex people, the field remains fraught with uneven, inadequate, and piecemeal standards of care—and with broad disagreements among practitioners that implicate the human rights of their intersex patients. While there are certain surgical interventions on intersex children that are undisputedly medically necessary, such as the creation of a urinary opening where one does not exist, some surgeons in the US continue to perform medically unnecessary “normalizing” surgeries on children, often before they are one year of age. These operations include clitoral reduction surgeries—procedures that reduce the size of the clitoris for cosmetic reasons. Such surgery carries the risk of chronic pain, nerve damage, and scarring. Other operations include gonadectomies, or the removal of gonads, which result in the child being sterile and forced onto lifelong hormone replacement therapy.

Healthcare providers are an important source of information and comfort amidst confusion. “Clinicians and parents alike refer to the period after the birth of an infant for whom gender assignment is unclear as a ‘nightmare,’” wrote Katrina Karkazis, a medical ethicist at Stanford University. “Not only does a child with ‘no sex’ occupy a legal and social limbo, but surprise, fear, and confusion often rupture the parents’ anticipated joy at the birth of their child.”

An endocrinologist told Human Rights Watch: “I understand the impulse for a parent to create something that looks normal—or at least normal according to a surgeon—at birth before the kid knows anything about it. I follow the logic pattern, but you have to run it against risks.” He said: “It’s important to be clear that a certain percentage of the time, something does go wrong and you have to do a re-op, and there’s a loss of sensitivity. So then the do-no-harm becomes: don’t do anything. What problem were you solving with surgery anyway?”

In July 2017, three former US surgeons-general, including one who was a pediatric endocrinologist, wrote that they believed “there is insufficient evidence that growing up with

atypical genitalia leads to psychosocial distress,” and “while there is little evidence that cosmetic infant genitoplasty is necessary to reduce psychological damage, evidence does show that the surgery itself can cause severe and irreversible physical harm and emotional distress.” They said: “These surgeries violate an individual’s right to personal autonomy over their own future.” The three doctors concluded:

[B]abies are being born who rely on adults to make decisions in their best interest, and this should mean one thing: When an individual is born with atypical genitalia that pose no physical risk, treatment should focus not on surgical intervention but on psychosocial and educational support for the family and child.

For more than 50 years, the medical community in the United States has often defaulted to treating intersex children by conducting irreversible and unnecessary surgeries. Even after two decades of controversy and debate, there remains no research showing that early, medically unnecessary surgery is helpful to the intersex child. Nonetheless, to date, none of the clinics we surveyed have firmly instituted a moratorium on such operations. The evidence is overwhelming that these procedures carry risk of catastrophic harm. And while increasing numbers of doctors believe it is wrong to conduct these procedures, recent data demonstrate that many clinics continue to do so. Alice Dreger, a bioethicist who has written two books on intersex issues and served on a National Institutes of Health multi-site research project before resigning in protest in 2015, wrote of her two decades of engagement on the intersex surgery controversy: “While many clinicians have privately shared my outrage about these activities, in public, the great majority have remained essentially silent.”

International human rights bodies have recognized the practice as implicating and potentially violating a range of fundamental rights, including the rights to health, autonomy, integrity, and freedom from torture. At present, many of the doctors who advise or conduct surgeries on intersex infants and young children cite a lack of data on the outcomes for children who do not undergo surgery. “We just don’t know the consequences of not doing it,” a gynecologist told Human Rights Watch regarding medically unnecessary surgery. Others continue to call for data collection regarding the impact of the intact intersex body on families and society—as if intersex people are a threat to the social order.

For example, a 2015 article co-authored by 30 DSD healthcare providers reflecting on genital surgeries published in the *Journal of Pediatric Urology* stated:

There is general acknowledgement among experts that timing, the choice of the individual and irreversibility of surgical procedures are sources of concerns. There is, however, little evidence provided regarding the impact of non-treated DSD during childhood for the individual development, the parents, society....

Human Rights Watch and interACT believe this approach has it exactly backwards: the experience of those who have undergone the surgery and principles of medical ethics suggest that unless and until there is outcome data establishing that the medical benefits of specific surgical procedures on infants and young children outweigh the potential harms, they should not be used.

Doctors have said they are seeking guidance on the issue so that they can avoid repeating the mistakes of the past. For example, in 2017, Dr. Ilene Wong, a urologist in Pennsylvania, acknowledged the harm in which she took part when she conducted surgery on an intersex child without her consent. She wrote: “Eight years ago, I did irrevocable damage to the first intersex person I ever met.” She said:

While some would argue that surgical practice has improved in the past decades, the fact remains that few attempts have been made to assess the long-term outcomes of these interventions. The psychological damage caused by intervention is just as staggering, as evidenced by generations of intersex adults dealing with post-traumatic stress disorder, problems with intimacy and severe depression. Some were even surgically assigned a gender at birth, only to grow up identifying with the opposite gender.

Others have offered similar testimony. Dr. Deanna Adkins, the Director of the Duke University Center for Child and Adolescent Gender Care, made an expert declaration to oppose North Carolina’s HB2, a sweeping statewide law repealing non-discrimination ordinances protecting lesbian, gay, bisexual, and transgender (LGBT) people and barring transgender people from shared facilities. In her statement, referring to intersex children, Dr. Adkins argued:

It is harmful to make sex assignments based on characteristics other than gender identity. For example, in cases where surgery was done prior to the ability of the child to understand and express their gender identity, there has been significant distress in these individuals who then have to endure further surgeries to reverse the earlier treatments. It has become standard practice to wait until the gender identity is clear to make permanent surgical changes in these patients unless the changes are required to maintain the life or health of the child.

An endocrinologist on a DSD team told Human Rights Watch: “That’s an adage in medicine—above all do no harm.” He added: “I don’t think you’re going to find anybody that runs a DSD clinic that would argue with the fact that outcomes are better when you delay intervention in general.” A DSD specialist Human Rights Watch interviewed argued that “there’s probably rare if any situations where surgery is absolutely necessary.” She said doctors needed “clear guidelines, clear practice standards”—what she called “general principles of care and make it very clear that the emerging data is in favor of not intervening.”

Such guidelines have begun to emerge. In 2016, the American Medical Association Board of Trustees issued a report recognizing that “DSD communities and a growing number of health care professionals have condemned...genital ‘normalizing,’ arguing that except in the rare cases in which DSD presents as life-threatening anomalies, genital modification should be postponed until the patient can meaningfully participate in decision making.” The board recommended adoption of a resolution that, “except when life-threatening circumstances require emergency intervention, [doctors should] defer medical or surgical intervention until the child is able to participate in decision making.”

Accordingly, Human Rights Watch and interACT are urging the AMA, the American Academy of Pediatrics, and other medical bodies, in line with the oath to “Do No Harm,” to support a moratorium on all surgical procedures that seek to alter the gonads, genitals, or internal sex organs of children with atypical sex characteristics too young to participate in the decision, when those procedures both carry a meaningful risk of harm and can be safely deferred.

Methodology

A Note on Terminology

In an effort to be inclusive, accurate, and efficient, this report uses “intersex” to describe people with anatomies that are considered “atypical” for either male or female bodies.

Human Rights Watch and interACT recognize and respect that some people may feel alienated by this definition, some people may disagree with the definition, or some people may object to the use of labels to describe their identities, conditions, or experiences. During each interview, researchers asked interviewees to explain which terms they preferred and identified with. In cases where Human Rights Watch interviewed individuals who specifically rejected the label of “intersex” either for themselves or for their children, we have referred to them using their preferred terminology in this report.

Throughout this report, we reference “medically unnecessary intersex surgeries.” By this we mean: All surgical procedures that seek to alter the gonads, genitals, or internal sex organs of children with atypical sex characteristics too young to participate in the decision, when those procedures both carry a meaningful risk of harm and can be safely deferred.

This report draws heavily on and includes excerpts from the July 25, 2017 report by interACT and Human Rights Watch titled *“I Want to Be Like Nature Made Me”: Medically Unnecessary Surgeries on Intersex Children in the US*. Whereas that previous report examined the experiences of intersex adults, parents of children with intersex traits, and medical practitioners who work on intersex cases, this report focuses largely on the role of medical practitioners and changing medical views of intersex issues. In preparing the current report, we interviewed additional medical practitioners and consulted additional secondary sources, such as recently-published peer-reviewed medical journal articles, relevant to the medical paradigms under consideration.

A Human Rights Watch researcher and a research consultant who is a practicing physician in California conducted the interviews cited in this report. In all, we conducted in-depth interviews with 30 intersex adults, 2 intersex children, 17 parents of intersex children, 21

and healthcare practitioners, including gynecologists, endocrinologists, urologists, psychologists, and other mental health providers who work with intersex people.

In the course of this research, Human Rights Watch wrote letters requesting interviews to 218 relevant health practitioners—either because they were publicly affiliated with a DSD team (a team of specialist healthcare providers who treat patients with intersex traits, or as they are sometimes called in medicine, differences of sex development—“DSD”), or because their name appeared on a published article about intersex medical care. Letters were sent by mail, and followed up by email (see Appendices I and II). In some cases, Human Rights Watch called specific practitioners’ offices to follow up. We interviewed all practitioners who responded to our request; in addition, we interviewed some practitioners who came recommended by other practitioners we had interviewed. Two months after sending the initial letter, Human Rights Watch sent a follow-up letter by mail and email to all practitioners who had not responded to our original request for an interview. We received several written responses declining to be interviewed. All references to practitioners or researchers relevant to intersex medical care that are cited by name are derived from published articles and statements.

In both the initial letter and the follow-up letter to healthcare practitioners, Human Rights Watch explained that we sought a wide range of views. Understanding that providers would not be able to share patient contact information with us, we requested that providers invite their patients and networks to participate in our research. We specifically mentioned that we were eager to interview people who had undergone early surgical interventions and were pleased with the outcomes. Approximately half of the providers we interviewed said they would invite their patients to participate. We received one response based on this request.

All interviews contained a discussion and agreement on informed consent, and interviewees were informed of how the information they shared would be used in Human Rights Watch publications and advocacy. All interviewees are represented only by pseudonyms; in the cases of healthcare providers, they are represented only by their specialty. Neither the names of doctors nor their institutions are mentioned anywhere in the report.

Background

Today, intersex children and their families often consult a team of specialists, and not just a surgeon. The medical community has evolved in its approach to intersex cases—which doctors often categorize as “Differences of Sex Development” or “DSD”—by establishing “DSD teams.” These teams convene multiple healthcare specialists, including mental health providers, to advise on and treat intersex patients. Disclosure of a child’s intersex traits to the child is widely recommended and commonly undertaken. During this evolution in care, cosmetic surgeries on intersex children’s genitals have become highly controversial within the medical community.

Most medical practitioners now acknowledge that in some cases parents may prefer to leave their child’s body intact as a way of preserving the person’s health, sexual function, fertility options, autonomy, and dignity. Consensus among specialists in intersex health has evolved to acknowledge data gaps and controversies—namely that there has never been sufficient research to show either that these surgeries benefit patients or that there is any harm from growing up with atypical genitals. A growing number of doctors are opposed to doing unnecessary early surgery under such conditions. Practitioners also increasingly recognize the suffering of intersex patients who underwent the operations without their consent.

However, despite these promising developments in care for intersex people, the field remains fraught with uneven, inadequate, and piecemeal standards of care—and broad disagreements among practitioners that implicate the human rights of their intersex patients. While there are certain surgical interventions on intersex children that are undisputedly medically necessary, such as operations to repair bladder exstrophy, some surgeons in the US continue to perform medically unnecessary, cosmetic surgeries on children, often before they are one year of age.

A practitioner told Human Rights Watch: “We’re listening to the adult patients who are telling us that they feel they were mistreated and mutilated and that’s a very powerful thing.” She said, “When somebody tells you what they went through at the hands of well-intentioned physicians and they feel like their rights were not respected, you can’t just

blow that off.”¹ Another practitioner said: “And a lot of advocacy work from patients to speak with the physicians at medical conferences and talk about their experience just made a huge difference—I think that's certainly a big part of where I learned about it and got a better understanding of what the outcomes are really like and what the repercussions are for the patients as adults. You know, because as a pediatrician, it's hard to know what happened to them 25 years down the road.”²

The impact has been tangible for some practitioners. An endocrinologist explained: “Many years ago, we thought we were doing the best thing for these patients. And then we started listening to the patients themselves.” Now, he said, “We've evolved our approach. We used to think that we had to make a decision immediately. We know that that's not the case and there's time for families to sort this out.”³

Doctors and researchers in recent years have increasingly spoken out against medically unnecessary non-consensual surgeries on intersex children. For example, in a 2017 article published in the *Journal of Pediatric and Adolescent Gynecology*, Wiebren Tjalma, a surgeon in Belgium, documented a case of genital surgery on an adult woman with Congenital Adrenal Hyperplasia (CAH). Dr. Tjalma argued that “Genital correction surgery for CAH at an older age was easier, could be done in 1 step, and enabled the preservation of orgasm.”⁴ Her results were challenged by two other doctors in a letter to the editor, in which they asserted that the surgeries should be conducted much earlier in an effort to prevent discomfort.⁵ In a response letter, Tjalma explains: “Current practice is like a ritual and not on the basis of any evidence. Dare to change your thoughts about the preservation of erectile bodies. Women should not have mutilating surgery if there is no evidence. The quality of our sex life is important.”⁶

¹ Human Rights Watch interview with a gynecologist, March 7, 2017.

² Human Rights Watch interview with an endocrinologist, February 27, 2017.

³ Human Rights Watch interview with an endocrinologist, February 1, 2017.

⁴ Wiebren A.A. Tjalma, “Assembling a Functional Clitoris and Vulva from a Pseudo-Penis: A Surgical Technique for an Adult Woman with Congenital Adrenal Hyperplasia.” *Journal of Pediatric and Adolescent Gynecology*. Vol. 30(3) (2017), pp. 425–428.

⁵ Hisham A and Mat Zain MA, “Letter to the Editor Regarding Article, ‘Assembling a Functional Clitoris and Vulva from a Pseudo-Penis: A Surgical Technique for an Adult Woman with Congenital Adrenal Hyperplasia’,” *Journal of Pediatric and Adolescent Gynecology* 30(4) (2017):513, doi: 10.1016/j.jpag.2017.02.008.

⁶ Wiebren Tjalma, “The Blessings of Erectile Bodies.” *Journal of Pediatric and Adolescent Gynecology* 30(4) (2017):514-515, [http://www.jpagonline.org/article/S1083-3188\(17\)30262-0/abstract](http://www.jpagonline.org/article/S1083-3188(17)30262-0/abstract).

Going further back, in 2004, a group of researchers and physicians convened by the Hastings Center in New York released an article in which they said “none of the appearance-altering surgeries need to be performed quickly.”⁷ In 2006, a consortium of patient advocates, parents, and medical providers published a set of clinical guidelines that urged “delay [of] elective surgical and hormonal treatments until the patient can actively participate in decision-making about how his or her own body will look, feel, and function,” promoted psychosocial support for families, and offered tools for professionals to support parents without unnecessary surgery.⁸

In 2015, bioethicists and patient advocates affiliated with the Differences of Sex Development-Translational Research Network (DSD-TRN)—a multi-site NIH-funded university research initiative—resigned, citing frustration with the ongoing use of medically unnecessary surgeries on intersex children, use of genital photography of children in research, and, as one medical ethicist put it in her resignation: “Being asked to be a sort of absolving priest of the medical establishment in intersex care.”⁹

The ethicist who wrote that, Alice Dreger, has highlighted that throughout her decades of work and two academic books¹⁰ on intersex issues, “While many clinicians have privately shared my outrage about these activities, in public, the great majority have remained essentially silent.”¹¹

This report attempts to shed light on the private analysis doctors undertake by drawing on anonymized Human Rights Watch interviews with 21 practitioners in 2016 and 2017. Many described increasing discomfort among healthcare providers with the current haphazard and insufficient standards of care for intersex youth, and a desire for clear, centralized guidelines. As demonstrated in the timeline below, medical associations have been gradually adjusting their understanding of the controversy around medically unnecessary

⁷ Joel Frader et. al., “Health Care Professionals and Intersex Conditions,” The Hastings Institute, <http://www.isna.org/pdf/Frader2004.pdf>

⁸ The Consortium on Disorders of Sex Development, “Clinical Guidelines for the Management of Disorders of Sex Development in Childhood and Handbook for Parents,” 2006. www.dsdguidelines.org

⁹ Alice Dreger, “Rejecting the Tranquilizing Drug of Gradualism in Intersex Care.” [Alicedreger.com](http://alicedreger.com/DSD_human_rights), November 21, 2015, http://alicedreger.com/DSD_human_rights.

¹⁰ Alice Domurat Dreger. *Hermaphrodites and the Medical Invention of Sex*. (United States of America: Harvard University Press, 1998); Alice Domurat Dreger. *Intersex in the Age of Ethics*. (Frederick Maryland: University Publishing Group, 1999).

¹¹ Ibid.

surgeries to reflect how their members see it—a set of issues that, while contentious is in clear need of centralized guidance to protect patients from harm.

As Dr. Katie Dalke, a psychiatrist who is also an intersex woman, wrote in a 2017 op-ed:

More than to do no harm, we want to do something *good*. We dedicate ourselves to helping our patients confront and conquer the unthinkable: sickness, pain, and death.

But as an intersex person, I know that “correcting” and concealing intersex bodies causes harm. If our community, including our caregivers and medical-care providers, are to develop standards of care that do good, they must respect bodily diversity. Doctors need to stop trying to avoid harm by trying to fix or hide our bodies and pain.

I know it’s existentially jarring to accept that physicians can be a cause of suffering. Like my peers, when I am on the receiving end of a patient’s anger, I turn to colleagues for support and scour databases to learn what I can do differently. Like my peers, knowing that a patient felt I didn’t do what was best for them lingers in my mind every time I see someone who reminds me of where I went wrong. And like my peers, my helplessness and guilt can make me want to blame or avoid my patient.

And yet, progress cannot occur without validating the anger that patients feel as a direct consequence of their treatment. Some physicians struggle to understand this, insisting that they did what they were taught was right, dismissing intersex people’s pain as non-representative, and telling us we need to not be “angry activists.”

Dr. Dalke urged her fellow healthcare providers to engage with the intersex community, not dismiss their anger:

By listening to and legitimizing the anger and hurt of intersex people, physicians can help us heal. This is absolutely critical to create affirming,

supportive, and transparent treatment models. Ending medically unnecessary non-consensual surgeries is the first step—a necessary change to build trust. Then we can all begin to build a model of care focused on healing.¹²

The Evolution of Medical Understandings and Protocol

1996: The American Academy of Pediatrics (AAP) publishes a statement saying: “The Academy is deeply concerned about the emotional, cognitive, and body image development of intersexuals, and believes that successful early genital surgery minimizes these issues.”¹³

1997: Milton Diamond and Keith Sigmundson publish a paper denouncing early genital surgery on intersex children, based on David Reimer’s outcomes. They write: “We suggest referring the parents and child to appropriate and periodic long-term counseling rather than to immediate surgery and sex reassignment, which seems a simple and immediate solution to a complicated problem.”¹⁴ David Reimer, who was surgically assigned female after a circumcision accident by Dr. John Money at Johns Hopkins, and whose case bolstered the rationale for early genital surgery, publicly renounces Dr. Money’s experiment.¹⁵

1998: The Gay and Lesbian Medical Association (now GLMA: Health Professionals Advancing LGBT Equality) passes a policy resolution calling for research on outcomes of genital-normalizing surgery, and full disclosure of risks and alternatives by physicians to parents of intersex children considering surgery.¹⁶

2000: The AAP issues a statement referring to the birth of an intersex child as “a social emergency” and urging early surgery, while recognizing that “few studies have been done

¹² Katie B. Dalke, “Why Intersex Patients Need the Truth and Doctors Need to Listen,” *The Nation*, September 12, 2017, <https://www.thenation.com/article/why-intersex-patients-need-the-truth-and-doctors-need-to-listen/>

¹³ “American Academy of Pediatrics Position on Intersexuality,” *Intersex Day*, October 15, 2010, <http://intersexday.org/en/aap-position-1996/>

¹⁴ Diamond and Sigmundson, “Sex Reassignment at Birth: Long-term Review and Clinical Implications,” *Archives of Pediatric and Adolescent Medicine*, pp. 298-304.

¹⁵ John Colapinto. “The True Story of John/Joan”. *Rolling Stone*. pp. 54–97.

¹⁶ “GLMA Passes Resolution on Intersex Surgery,” *International Foundation for Gender Education*, March 7, 1998. <http://www.ifge.org/news/1998/march/nws3218b.htm>

that address the social, psychological, and sexual outcomes...”¹⁷

2004: The National Institute of Diabetes & Digestive & Kidney Diseases states: “[t]here is currently a crisis in clinical management of children with disorders of sexual differentiation, and it has received considerable public attention. It stems from two issues. First, for some of these disorders, there are insufficient data to guide the clinician and family in sex assignment. Second, the optimal application of surgery and its timing remain unclear.”¹⁸

2006: The Consensus Statement on the Management of Intersex Disorders acknowledges the lack of meaningful research and calls for further studies, while still allowing for genitoplasty, including clitoral reduction. This statement is adopted as a position statement of the AAP.¹⁹

2010: Thirty-two academicians write to the Office of Human Research Protections (OHRP) and the US Food and Drug Administration (FDA) calling for an investigation into alleged human research violations involving intersex fetuses and children.²⁰

2010: The AAP publishes a position statement opposing all forms of female genital cutting, with no explicit exception for girls with intersex traits.²¹

2011: The National Institutes of Health gives a founding grant to form the DSD Translational Research Network (DSD-TRN) to: “Assess and respond to the specific needs of DSD patients by: developing psychosocial assessment tools specific to the needs of DSD families; developing tools to minimize the need for genital photography; assessing efficacy of and compliance to standards-of-care; discovering new genes causing DSDs.”²²

¹⁷ The American Academy of Pediatrics, “Evaluation of the Newborn with Developmental Anomalies of the External Genitalia,” *Pediatrics* 106(1) (2000), <http://pediatrics.aappublications.org/content/106/1/138>.

¹⁸ The National Institutes of Health, the National Institute of Diabetes & Digestive & Kidney Diseases, *Research Progress Report and Strategic Plan for Pediatric Urology* (2006).

¹⁹ Peter Lee, et. al., “Consensus Statement on Management of Intersex Disorders,” *Pediatrics* 118 (2) (2006): p. 554-563, <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2082839/>

²⁰ Alice Dreger et al., “Prenatal Dexamethasone for Congenital Adrenal Hyperplasia: An Ethics Canary in the Modern Medical Mine,” *Journal of Bioethical Inquiry* 9(3) (2012): p.277-294, <https://link.springer.com/article/10.1007%2Fs11673-012-9384-9>

²¹ “Policy Statement—Ritual Genital Cutting of Female Minors,” *American Academy of Pediatrics* 126(1) (2010), <http://pediatrics.aappublications.org/content/pediatrics/126/1/191.full.pdf>.

²² About the Disorders of Sex Development Translational Research Network, <https://dsdtrn.genetics.ucla.edu/aboutdsdtrn>

2011: The World Professional Association for Transgender Health (WPATH) releases revised Standards of Care that include a section calling for careful staging of medical interventions for transgender children and youth, and the delay of irreversible procedures. However, the policy allows for early surgical interventions on intersex children.²³

2012: A paper in the *Journal of Pediatric Urology* concerning the “[t]iming and nature of reconstructive surgery for disorders of sex development” explains “The ideal timing and nature of surgical reconstruction in individuals with...DSD is highly controversial... evidence-based recommendations still cannot be made,” and recognizes that “clitoroplasty is essentially a cosmetic procedure...surgery carries the risk of disruption of the nerve supply of the clitoris.”²⁴

2013: The AAP advocates psychological care prior to any desired gender-affirming surgical intervention in the case of transgender youth, but does not address similar procedures on intersex children too young to express an opinion.²⁵

2013: The World Health Organization publicly opposes early genital or sterilizing surgeries on intersex youth in its report, “Eliminating forced, coercive and otherwise involuntary sterilization.”²⁶

2014: The provisional section on Lesbian, Gay, Bisexual, and Transgender Health and Wellness of the AAP publishes “Explaining Disorders of Sex Development & Intersexuality,” which states: “If it is not medically necessary, any irreversible procedure can be postponed until the child is old enough to agree to the procedure (e.g. genital surgery).”²⁷

2015: Patient advocates and bioethicists publicly resign from the DSD-TRN, citing

²³ The World Professional Association for Transgender Health (WPATH), “Standards of Care for the Health of Transsexual, Transgender, and Gender Nonconforming People Version 7,” http://www.wpath.org/site_page.cfm?pk_association_webpage_menu=1351&pk_association_webpage=3926

²⁴ Sarah Creighton, et. al., “Timing and nature of reconstructive surgery for disorders of sex development,” *Journal of Pediatric Urology*, 8(6) (2012): 602-610, <http://www.ncbi.nlm.nih.gov/pubmed/23146296>

²⁵ David Levine, et al., “Office-Based Care for Lesbian, Gay, Bisexual, Transgender, and Questioning Youth,” *Pediatrics* 132(1) (2013), <http://pediatrics.aappublications.org/content/132/1/e297>

²⁶ United Nations World Health Organization, et. al., “Eliminating Forced, Coercive and Otherwise Involuntary Sterilization—An Interagency Statement,” *World Health Organization*, May 2014.

²⁷ “Explaining Disorders of Sex Development & Intersexuality,” Lesbian, Gay, Bisexual, and Transgender Health and Wellness of the American Academy of Pediatrics, <https://www.healthychildren.org/English/health-issues/conditions/genitourinary-tract/Pages/Explaining-Disorders-of-Sex-Development-Intersexuality.aspx>

frustration with the ongoing use of medically unnecessary surgeries on intersex children, use of genital photography of children in research, and, as one member put it in her resignation: “Being asked to be a sort of absolving priest of the medical establishment in intersex care.”²⁸

2016: The American College of Obstetricians and Gynecologists issues a committee opinion cautioning that genital surgery may not be appropriate for every adolescent with “abnormalities” and that counseling is recommended prior to surgery.²⁹

2016: Physicians publish “Global Disorders of Sex Development Update since 2006,” stating: “[t]here is no evidence regarding the impact of surgically treated or non-treated DSDs during childhood for the individual, the parents, society or the risk of stigmatization...[t]here is still no consensual attitude regarding indications, timing, procedure and evaluation of outcome of DSD surgery.”³⁰

2016: The Gay and Lesbian Medical Association takes an official position recommending delay of all medically unnecessary surgery on intersex children until the child can participate in decisions regarding their body.³¹

2016: The American Medical Association Board of Trustees issues a report recognizing that “DSD communities and a growing number of health care professionals have condemned ... genital ‘normalizing,’ arguing that except in the rare cases in which DSD presents as life-threatening anomalies, genital modification should be postponed until the patient can meaningfully participate in decision making,” and recommending adoption of a resolution supporting treatment that, “except when life-threatening circumstances require emergency

²⁸ See Appendix III for the joint resignation letter. Alice Dreger, “Rejecting the Tranquilizing Drug of Gradualism in Intersex Care.” *Alicedreger.com*, November 21, 2015, http://alicedreger.com/DSD_human_rights.

²⁹ The American College of Obstetricians and Gynecologists, Committee on Adolescent Health Care, “Committee Opinion, Number 686,” January 2017, <https://www.acog.org/Resources-And-Publications/Committee-Opinions/Committee-on-Adolescent-Health-Care/Breast-and-Labial-Surgery-in-Adolescents>.

³⁰ ³⁰ Peter A. Lee et al., “Global Disorders of Sex Development Update Since 2006: Perceptions, Approach and Care,” *Hormone Research in Pediatrics* 85(3) (2016):158-180, <https://www.ncbi.nlm.nih.gov/pubmed/26820577>

³¹ GLMA, “Medical and Surgical Intervention of Patients with Differences in Sex Development,” October 3, 2016, <http://glma.org/index.cfm?fuseaction=document.viewdocument&ID=CEB9FEE4B8DD8B7F4F7575376BD476C3A433379DD853BEA17913AFCCB8270299C0731320B03D2F5E1022F1C15602FBEA>

intervention, defers medical or surgical intervention until the child is able to participate in decision making.”³²

2016: In its final rule issued for the Affordable Care Act, the Office for Civil Rights (OCR) of the Department of Health and Human Services states that “the prohibition on sex discrimination extends to discrimination on the basis of intersex traits or atypical sex characteristics. OCR intends to apply its definition of ‘on the basis of sex’ to discrimination on these cases.”³³

2017: Three former US surgeons-general issue a statement calling for a moratorium on medically unnecessary surgeries on intersex children too young to participate in the decision, noting that “Those whose oath or conscience says ‘do no harm’ should heed the simple fact that, to date, research does not support the practice of cosmetic infant genitoplasty.”³⁴

³² American Medical Association, “American Medical Association House of Delegates (I-16), Report of Reference Committee on Amendments to Constitution and Bylaws,” 2016, <https://assets.ama-assn.org/sub/meeting/documents/i16-ref-comm-conby.pdf>

³³ Department of Health and Human Services, “Nondiscrimination in Health Programs and Activities; Final Rule. 45 CFR Part 92,” *Final Register* 81(96), May 18, 2016, <https://www.gpo.gov/fdsys/pkg/FR-2016-05-18/pdf/2016-11458.pdf>.

³⁴ Palm Center, “Re-Thinking Genital Surgeries on Intersex Infants,” June 2017, <http://www.palmcenter.org/wp-content/uploads/2017/06/Re-Thinking-Genital-Surgeries-1.pdf>

Anxieties About Social Outcomes Drive Surgery

Nationwide data on how prevalent surgeries are on intersex children do not exist. However, available data sources show that doctors continue to perform medically unnecessary cosmetic surgical procedures on children with atypical sex characteristics in the United States—often before they are one year of age. US government data compiled from several voluntary-reporting databases, for example, show that in 2014—the most recent year for which data are available—clitoral surgery was reported 70 times. Many hospitals do not participate in these databases.³⁵

Other recent medical literature demonstrates that doctors are continuing to conduct medically unnecessary surgeries on intersex children. A 2016 paper in the *Journal of Steroid Biochemistry and Molecular Biology* conducted a literature review of genital surgeries performed on intersex children between 2005 and 2012; the average age was 11.2 months.³⁶ In a 2016 paper published in the *Journal of Pediatric Urology*, doctors examined a cohort of 37 pediatric patients with atypical genitalia from children's hospitals across the country. Of the 37 cases, 35 opted for cosmetic surgery on their children and two did not.³⁷ A 2017 paper in *The Journal of Urology* documented that 25 of 26 intersex babies, whose parents were recruited for the study from 10 DSD centers of excellence across the country, were subjected to genital surgeries.³⁸

While published data show that medically unnecessary surgeries are being conducted on intersex children, practitioners interviewed for this report often reported that they observed

³⁵ This data is compiled from the HCUP National (Nationwide) Inpatient Sample (NIS), the HCUP Kids' Inpatient Database (KID), or the HCUP State Inpatient Databases (SID). United States Department of Health and Human Services, Agency for Healthcare Research and Quality Healthcare Cost and Utilization Project, HCUP-net database, <https://hcupnet-archive.ahrq.gov/> (accessed July 4, 2017).

³⁶ Lily C. Wang and Dix P. Poppas, "Surgical Outcomes and Complications of Reconstructive Surgery in the Female Congenital Adrenal Hyperplasia Patient: What Every Endocrinologist Should Know," *Journal of Steroid Biochemistry and Molecular Biology* 165(Pt A) (2016):137-144, <https://www.ncbi.nlm.nih.gov/pubmed/26995108>. Recently, doctors at a major conference presented information from one registry (which is currently inaccessible to patient groups) confirming the frequency of certain surgeries performed on infants. Regarding initial surgical intervention for children with CAH, they noted: "544 patients underwent feminizing genitoplasty between 2004-2014, median age at initial surgery: 9.9 months."

³⁷ Natalie Nokoff et al., "Prospective Assessment of Cosmesis Before and After Genital Surgery," *Journal of Pediatric Urology* 13(1) (2017): 28.e1 - 28.e6, [http://www.jpurology.com/article/S1477-5131\(16\)30279-0/abstract](http://www.jpurology.com/article/S1477-5131(16)30279-0/abstract).

³⁸ Rebecca Ellens et al., "Psychological Adjustment in Parents of Children Born with Atypical Genitalia One Year After Their Child Undergoes Genitoplasty," *The Journal of Urology*, May 11, 2017, 10.1016/j.juro.2017.05.035.

general trends toward doing fewer surgeries (though they did not always specify which procedures). While some said they insisted on multiple counseling sessions with parents who were considering medically unnecessary surgeries, none of the healthcare providers Human Rights Watch interviewed said their clinic had instituted a moratorium on all medically unnecessary procedures.

Many providers interviewed for this report described the information they shared with parents as based on hypotheticals about what it would be like to raise an intact child, and “clinical expertise,” not data on medical outcomes. This pattern is also reflected in a 2016 update to the 2006 “DSD Consensus Statement,” which includes a survey of 32 experts—mostly surgeons—on guidelines for surgeries. The document notes: “There is still no consensual attitude regarding indications, timing, procedure and evaluation of outcome of DSD surgery. The levels of evidence of responses given by the experts are low, while most are supported by team expertise.”³⁹

Medically unnecessary surgeries persist. For example, in our July 2017 report, we documented a case in which parents were urged to elect surgery on their 11-month-old child in 2010 before they had even received the child’s DSD diagnosis. We also interviewed families who faced intense pressure from doctors to elect medically unnecessary surgeries at major DSD “centers of excellence” in the past three years.

Even after two decades of controversy and debate, there remains no research showing that early, medically unnecessary genital surgery is helpful to the intersex child. Nor is there data to predict gender identity outcomes with confidence in many intersex conditions—meaning that doctors are sometimes conducting sex assignment surgeries that the children will later reject.⁴⁰ As documented in our July 2017 report, this can mean doctors give parents information about gender identity, surgical risks, and the reversibility of certain procedures that have no basis in medical literature.

³⁹ Lee et al., “Global Disorders of Sex Development Update Since 2006: Perceptions, Approach and Care.”

⁴⁰ Peter Lee, et al., “Review of Recent Outcome Data of Disorders of Sex Development (DSD): Emphasis on Surgical and Sexual Outcomes,” *Journal of Pediatric Urology* 8(6) (2012): 611-615 <http://dx.doi.org/10.1016/j.jpuro.2012.10.017>; L-M Liao et al., “Determinant Factors of Gender Identity: A Commentary,” *Journal of Pediatric Urology* 8(6) (2012): 597-601, <http://dx.doi.org/10.1016/j.jpuro.2012.09.009>.

Practitioners Human Rights Watch interviewed recounted the deep concerns parents of intersex children express upon discovery of intersex traits at birth, or referral to their clinic. Some practitioners cited broad parental concerns about how the child would grow up—ranging from gender identity outcomes to fears of homosexuality. For example, a gynecologist explained: “We have families who are very concerned that their child is gender non-conforming or has homosexual attraction— because it’s not OK in their community.”⁴¹ But, she said, the majority of parental concerns are more immediate and practical: “We have families who are terrified of having their daughter’s diaper changed at church or by a babysitter.”⁴²

A urologist who works with a DSD team told Human Rights Watch that parents’ fears about their children’s genitalia often drive the decision to select surgery. “The phrase ‘middle school locker room’ gets tossed around quite a bit,” he said.⁴³ As we found previously some parents who found their way to peer support groups found their fears greatly relieved when they talked to more experienced parents, and learned useful strategies for dealing with the situations they dreaded.⁴⁴

An endocrinologist on a DSD team said the most common fears she hears from parents with children who have atypical external genitalia relate to diaper changes, bathing suits, and, for boys, being able to stand to pee. “A lot of people just will not let anybody else change their child's diaper or put their child in daycare or preschool until they've had surgery,” she said.⁴⁵ This endocrinologist said such families tend to focus on the intersex traits thinking “this is a medical problem, we just need to fix a medical problem,” an observation we heard from other practitioners as well. She explained: “I think that they're very reluctant to acknowledge things beyond the medical side of it. As endocrinologists and psychologists—we’re not reluctant to bring those [non-medical] things up with families. However, I really do think most parents of infants still see surgery as a quick fix option no matter what we say.”

⁴¹ Human Rights Watch interview with a gynecologist, March 7, 2017.

⁴² Human Rights Watch interview with a gynecologist, March 7, 2017.

⁴³ Human Rights Watch interview with a urologist, February 23, 2017.

⁴⁴ Human Rights Watch, *“I Want to Be Like Nature Made Me”: Medically Unnecessary Surgeries on Intersex Children in the US*, July 25, 2017, <https://www.hrw.org/report/2017/07/25/i-want-be-nature-made-me/medically-unnecessary-surgeries-intersex-children-us>

⁴⁵ Human Rights Watch interview with an endocrinologist, February 23, 2017.

A urologist Human Rights Watch interviewed explained that societal expectations were driving the perceived need for clitoral reduction surgeries:

The girl with the big clitoris—do we make it look good before puberty or do we wait? In a perfect world, no of course we'd wait. But it's not a perfect world and parents know that—parents say: look I'd love to live in a place with that kind of body and not get any grief...⁴⁶

Another doctor on a DSD team said: “One of the surgeries that I think makes people very angry is the clitoroplasty, because it’s just an enlarged clitoris and there’s no function that you’re serving by making it smaller—you’re just treating the eye of the beholder.”⁴⁷ Another doctor explained that she understood the persistence of medically unnecessary surgeries in the field as one of inertia and resistance to change: “If this is your career as this is part of your professional identity, if this is a specialty you've become known for, it is very hard to back away from it,” she said. “I think that there are going to be a few doctors...who really built a career on providing normalizing surgeries. It's going to be very hard to back away and say, ‘yeah there's maybe another way maybe a better way to care and support these families.’”⁴⁸

A dearth of data on outcomes for intact children does not support defaulting to conducting irreversible and medically unnecessary surgeries that carry the potential for harm. Indeed, the available medical evidence points overwhelmingly in the opposite direction: that the well-documented harms of these operations should be a primary factor in doctors’ recommendation to defer them until the patient can understand and consent to (or refuse) the procedure. Or, as the former US surgeons-general argued in their 2017 article, “our review of the available evidence has persuaded us that cosmetic infant genitoplasty is not justified absent a need to ensure physical function,” explaining that the belief that surgery can lead to better psycho-social outcomes is based on “untested assumptions rather than medical research.”⁴⁹

⁴⁶ Human Rights Watch interview with a urologist, February 15, 2017.

⁴⁷ Human Rights Watch interview with a gynecologist, February 3, 2017.

⁴⁸ Human Rights Watch interview with a pediatric surgeon, April 28, 2017.

⁴⁹ Palm Center, “Re-Thinking Genital Surgeries on Intersex Infants.”

Doctors, in their clinical conversations with parents, are in a good position to correct these assumptions and put social hypotheticals into better perspective. “The pediatricians are in a position of power. And if it’s an issue of parents being scared, that is the problem that has to get solved. It’s not really a matter of if you do surgery—that doesn’t make any sense, that’s not solving anything,” an endocrinologist told Human Rights Watch. “There are no data that it’s solving anything, and there’s ample evidence that people who underwent the surgery overwhelmingly think that it shouldn’t be done.”⁵⁰ He explained:

The solution to [intersex children] fitting in or not fitting in is not solved by compelling them to do something that is the scientifically wrong thing. An example would be the approach to left-handedness. There was an era not very long ago, similar timeframe, frankly, 50 years ago, where being left-handed was considered not fitting in, whether it be for penmanship or for use of various devices or for athletics and therefore, in order to have your child fit in, your child needed to be right-handed. We went to some great lengths to make that happen. If you ask now, go back to the medical establishment, the medical establishment's role there would be to say, ‘No. Being left-handed is a biological phenomenon. You can't change that. You're going to do more harm forcing people to change. Rather, on the fitting in question, society has to change so that left-handed people are also accepted.’

According to this doctor, “It’s the role of the medical establishment to talk about the science and how we understand the biology actually to be.” He said:

When we're talking about intersex individuals, if we're going to be scientists, it does not make sense for us to suggest that there ought to be procedures in order to fix children to make them fit in, surgical procedures that are going to have negative consequences downstream.⁵¹

⁵⁰ Human Rights Watch interview with an endocrinologist, June 1, 2017.

⁵¹ Human Rights Watch interview with an endocrinologist, June 1, 2017.

Providers Increasingly Hesitant to Recommend Surgery

Some doctors have come out publicly to discuss their involvement in and discomfort with the default-to-surgery paradigm.

For example, Dr. Ilene Wong, a urologist in Pennsylvania, wrote in a 2017 op-ed:

Eight years ago, I did irrevocable damage to the first intersex person I ever met, taking out the gonads of a 17-year-old girl who found out after she never got her period that she had XY chromosomes, with internal testicles instead of ovaries and a uterus.... While some would argue that surgical practice has improved in the past decades, the fact remains that few attempts have been made to assess the long-term outcomes of these interventions. The psychological damage caused by intervention is just as staggering, as evidenced by generations of intersex adults dealing with post-traumatic stress disorder, problems with intimacy and severe depression. Some were even surgically assigned a gender at birth, only to grow up identifying with the opposite gender. The notion of performing an irreversible procedure on a child—one that will likely render her incapable of achieving sexual pleasure in the future—is utterly abhorrent to me, as an insult on the body autonomy of a minor who is, by definition, incapable of giving informed consent.⁵²

Like Dr. Wong, many providers who care for intersex children have become increasingly uncomfortable with the current paradigm. Despite the lack of clear, centralized standards of care for intersex patients, many providers express an increased sense of caution when it comes to recommending medically unnecessary surgeries for children. However, that hesitation has not resulted in comprehensive practice reform. Some doctors continue to recommend and conduct surgeries that are medically unnecessary, high-risk, and without proven benefits.

⁵² I.W. Gregorio, “Should Surgeons Perform Irreversible Genital Surgery on Children?” *Newsweek*, April 26, 2017, <http://www.newsweek.com/should-surgeons-perform-irreversible-genital-surgery-children-589353>.

Doctors Human Rights Watch interviewed at two DSD clinics said that part of their informed consent process with parents of intersex infants who were considering medically unnecessary surgeries was to tell them that United Nations experts and other human rights bodies consider the operations a form of torture. However, doctors at both clinics confirmed that that information did not prevent all parents from opting into the procedures.

Individual providers also explained the increased caution with which they and their colleagues approach medically unnecessary surgeries. For example, a urologist told Human Rights Watch, “I think we're being very cautious about anything that removes tissue.” She said her clinic sets a strict six-month minimum age for medically unnecessary surgeries, which they communicate to parents immediately. “We just explain that we really don't do any elective surgery for babies for six months, period. We reassure them that there is not going to be anything bad that happens to the child waiting for six months.”⁵³ However, this urologist clarified that this has not resulted in a complete end to cosmetic operations on children over six months old: “We're doing very, very few feminizing surgeries in general.... Since I've been here we've only done a few and I've been here three years.”⁵⁴

An endocrinologist on a DSD team said he observes “a general trend of ‘if in doubt don't do anything.’” He said: “We try to emphasize that while we're sorting things out it's best to leave things alone. If there's no urgency from a medical standpoint it's best to leave things as they are and what we have we're finding as time goes on that many of the patients are very comfortable with that.” He linked that to medical ethics: “That's an adage in medicine—above all do no harm.” He added: “I don't think you're going to find anybody that runs a DSD clinic that would argue with the fact that outcomes are better when you delay intervention in general.”⁵⁵

A urologist Human Rights Watch interviewed explained that he sees the emerging skepticism regarding early medically unnecessary surgeries on intersex children as a result of the risks involved. Calling genital surgery “an emotionally charged issue,” he said:

⁵³ Human Rights Watch interview with a urologist, February 6, 2017.

⁵⁴ Human Rights Watch interview with a urologist, February 6, 2017.

⁵⁵ Human Rights Watch interview with an endocrinologist, February 1, 2017.

If I tell you I'm going to operate on you, but if we don't there's a 50 percent chance you'll never need the operation.... If you just give that much information to a surgeon they're going to say, "why the hell would I do it?" And most patients would also say the same thing. And so in the cases of CAIS [Complete Androgen Insensitivity Syndrome], I advocate that surgery—vaginoplasty in particular since it is often required for these women who want to have an active sexual life—should be done when this person can say they want to use their vagina for sex.⁵⁶

However, an endocrinologist on a DSD team at a regional referral hospital said that, while she observed many of her peers in DSD care speaking publicly about a decrease in medically unnecessary surgeries on intersex children, "Most patients at our center have cosmetic surgery to their external genitalia." She said: "The main two groups that don't are the kids who are being raised female who have very mild virilization, and then the more developmentally delayed kids."⁵⁷

A psychologist on a DSD team told Human Rights Watch his advice to parents is: "Probably less is more.... If you don't absolutely need to do surgery, don't do it." He said: "My voice is always in that direction and I would say the rest of my team is moving in that direction." However, he said: "There are surgeries being done all around the country."⁵⁸

A mental health provider on another DSD team said she observes similar patterns—and surgeries continue. The problem, she explained to Human Rights Watch, is that some providers believe they are providing sufficient—and sufficiently clear—information, while parents fail to comprehend what is happening. She said:

I've seen surgeons present to families in a way they couldn't possibly understand, and then not present doing nothing as a viable option...and then think that they went through a full informed consent process. And clearly, they had not. They presented it basically as: 'You can medically neglect your child, or you can do surgery...' and used words that I didn't

⁵⁶ Human Rights Watch interview with a urologist, February 15, 2017.

⁵⁷ Human Rights Watch interview with an endocrinologist, February 23, 2017.

⁵⁸ Human Rights Watch interview with a psychologist, January 30, 2017.

even understand, then gave them a form to sign and they want to do it because he has a white coat on and they're scared.⁵⁹

Other practitioners spoke of cases when they felt they needed to reject parents' demands for surgery. One endocrinologist explained that while such instances were rare, "Sometimes we have to say: 'I'm sorry. We're not going to do that here. You can go to another surgeon if you would like to do that but we don't think that it's the right thing for your child at this time.'"⁶⁰ A urologist Human Rights Watch interviewed offered an example of a case in which he convinced parents to decline genital surgery. The patient was an 8-year-old with CAH whose genitals were, the doctor said, "amazingly virilized." According to the doctor, "in talking with this kid, they very clearly did not fall into one gender role or another.... So my very strong recommendation to them actually was 'we should really think about putting in a hormone blocker in her and just [give] her some time.'" The doctor explained to Human Rights Watch:

From my perspective, [a hormone blocker] is never a wrong answer because you buy time. If you look at the transgender kids—because there really isn't any data on this in DSDs—just putting on a hormone blocker actually drops her suicidality by about 80, 90 percent. So to me this is a no brainer. You know moving ahead with a massive clitoral reduction on this kid ... who may or may not want to be a boy or may or may not want to be a girl—that's an irreversible step. And to me that is a horrible disservice to this kid.⁶¹

Some providers Human Rights Watch interviewed explained how they invested time in debunking myths that parents believed. For example, a mental health practitioner on a DSD team cited the "middle school locker room" fear as an example, saying he asks parents whether they actually showered naked in front of their peers or know that it is mandatory in their local schools. "There was a time [when that was common] perhaps but it is much less so now. And certainly children can avoid having to do that for so many

⁵⁹ Human Rights Watch interview with mental health social worker, December 4, 2016.

⁶⁰ Human Rights Watch interview with an endocrinologist, February 27, 2017.

⁶¹ Human Rights Watch interview with a urologist, February 23, 2017.

reasons that do not draw attention to themselves,” he said.⁶² Indeed this is a commonly cited fear⁶³—though not necessarily one based in reality.⁶⁴

A urologist on a DSD team said they try to steer the parents’ narrative away from “Hey, can you fix this?” She said: “I don't think that for anything elective it makes any sense to make an immediate decision. We try to explain that there is no urgency.... So the first step is just letting that sink in with the family because I don't think it occurs to most of them that not having surgery is even an option.” Her clinic presents surgery as an option by giving examples: “We say: ‘Here are some of the reasons people choose surgery. Here are some of the reasons people choose not to.’” However, she observes: “I don't think there's any way that we can be totally non-biased because we're medical people and we talk in a certain way.”⁶⁵ Another urologist echoed this sentiment, saying: “There's no such thing as a value-free consultation.”⁶⁶

Other providers expressed their conflicted feelings about the default-to-surgery paradigm by exploring hypotheticals were there to be a ban on medically unnecessary operations. For example, an endocrinologist with decades of experience treating intersex children explained:

I can't think of a case right now where [doing medically unnecessary surgery] would be applicable but I don't want to be the one that says ‘never’...I'm just never comfortable with ‘never’...I don't know. I honestly can't think of a case where I would be likely [to recommend a medically unnecessary surgery]. I mean, ‘no’ would be the right answer most of the time—probably all of the time—but I don't want to find myself in a position one day of: ‘Well this is really important to have done.’ But I can't imagine one either.⁶⁷

⁶² Human Rights Watch interview with a psychologist, January 30, 2017.

⁶³ Mireya Navarro, “When Gender Isn't a Given,” *The New York Times*, September 19, 2004, <http://www.nytimes.com/2004/09/19/fashion/when-gender-isnt-a-given.html>

⁶⁴ Anne Tamar-Mattis, “What About The Locker Room?,” *Healio Endocrine Today*, March 2009, <http://www.healio.com/endocrinology/reproduction-androgen-disorders/news/print/endocrine-today/%7B1736e672-6bcc-4334-a558-055c690794b4%7D/what-about-the-locker-room>

⁶⁵ Human Rights Watch interview with a urologist, February 6, 2017.

⁶⁶ Human Rights Watch interview with a urologist, February 15, 2017.

⁶⁷ Human Rights Watch interview with an endocrinologist, February 27, 2017.

Others explored the roots of the paradigm—insofar as it relies on stereotypes about what a “typical” male or female body should look like and how it should function during heterosexual intercourse. For example, a gynecologist who treats intersex children said:

When we’re trying to force people into cultural normative, hetero-normative situations, there’s a high chance that we’re going to make some major mistakes and harm people irreparably.⁶⁸

⁶⁸ Human Rights Watch interview with a gynecologist, March 7, 2017.

Parents Anxious About Being Misled

I think more and more families are concerned about surgery on their kids. I think that the current FDA statement regarding prolonged anesthetic in children.... Once that gets out there more I suspect that will also influence families.

—Pediatric surgeon⁶⁹

Several of the parents Human Rights Watch interviewed—including parents who had elected medically unnecessary surgeries for their intersex children and those who had not—described the anxiety they felt when communicating with doctors about their child’s intersex condition. Some felt outright bullied, intimidated, and lied to. Others said their experience left them feeling like the providers charged with advising them on their child’s healthcare were judging them based on arbitrary values, and not medical evidence.

Thomas, the father of a two-year-old with Congenital Adrenal Hyperplasia (CAH)—one of the most common conditions that can cause intersex traits—told Human Rights Watch he and his wife met with multiple specialist teams within a year of their daughter being born in 2015, and received advice based not on data but on doctors’ personal opinions of atypical genitalia. For example, one urologist told him that leaving his daughter’s genitals intact would put her at 75 percent risk for a UTI. Thomas told Human Rights Watch: “Doctors provided us with [information] that’s not backed up in the literature. It’s stuff that has just always been done in medicine.” He continued:

The doctors essentially presented us with [a series of] arguments that went from ‘she won’t remember the surgery if you get it done now’ to ‘and then the skin is more plastic when she’s younger’ to ‘the outcome literature that is spotty in terms of success because it’s based on antiquated techniques these newer techniques are going to have even better outcomes’ to ‘she will avoid any social or uncomfortable experiences based on her anatomical difference,’ and finally to ‘the risk of UTI is high’—that was every doctor’s last resort when we asked questions, to talk about the UTI risk.

⁶⁹ Human Rights Watch interview with a pediatric surgeon, April 28, 2017.

Thomas told Human Rights Watch he and his wife, Tracey, who were open to the idea of doing surgery on their daughter, sought out a specialist physician who could explain the risks, benefits, and medical necessity of the operation, but never received information that corresponded with the medical literature they had read.

As Thomas explained, the urologist asserted there was a 75 percent risk of UTI, but could not say where that number came from:

[The doctor] said: ‘75 percent.’ So I replied: ‘OK where did you get that number from ... I have not found that in what I’ve read.’ And he said: ‘Well it’s just kind of in my experience.’ So I asked: ‘How many children have you seen who have not had the surgery and what are their rates of UTI?’ And he said: ‘Well I don’t know.’

Thomas was upset. As a clinician, he had access to medical databases, so he researched the topic. “It’s not 75 percent because if that’s out there somewhere it is well-hidden. I have scoured every database that I could find.” There is no reliable evidence that genital surgery will reduce rates of UTIs in children with intersex traits— in fact, surgery may increase UTI risk.⁷⁰

Thomas and Tracey echoed what Human Rights Watch heard from other parents—that the tone of the consultations suggested the doctors thought they, in rejecting surgery, were being bad parents. Tracey said: “The doctor said she would come to us begging for the surgery. Our five-month-old daughter—he could just tell that she would come to him for surgery.”⁷¹ Meanwhile, Thomas said: “Nobody told us about the effects, the potential effects of the anesthesia on a child under the age of two years let alone a six-month-old, or the possibility of frequent revision surgeries—which is really the professional advice we wanted to get.”

⁷⁰ Wang and Poppas, “Surgical Outcomes and Complications of Reconstructive Surgery in the Female Congenital Adrenal Hyperplasia Patient: What Every Endocrinologist Should Know,” *Journal of Steroid Biochemistry and Molecular Biology*; Zeina M. Nabhan, et al., “Urinary Tract Infections in Children with Congenital Adrenal Hyperplasia,” *Journal of Pediatric Endocrinology and Metabolism* vol. 19 (2006).

⁷¹ Human Rights Watch interview with Tracey A., location withheld, December 6, 2016.

Thomas and Tracey—like other parents of children with intersex traits—were left feeling isolated, but determined to make the best decision for their child’s health and future. Thomas said:

The world can be a hard place for people who are different and I am not naive to the fact that this could create some social difficulties for my daughter. However, I don't think the solution is to subject her to anesthesia and perform a surgery without her consent that's irreversible.⁷²

A mother of two children with intersex traits explained what she saw as the core struggle parents often face:

We aren’t inclined to think about our kids as humans who are going to be adults one day. We are consumed with protecting our child. If a doctor says your child is going to have a really hard time growing up with genitals that look different and I can do this surgery that will make everything fine and they won’t remember it, you’re going to say OK.⁷³

⁷² Human Rights Watch interview with Thomas A., location withheld, December 6, 2017.

⁷³ Human Rights Watch interview with Kate R., location withheld, December 4, 2017.

Lack of Informed Consent

Both international human rights and US medical standards uphold informed consent as a pillar of medical ethics. Providers are required to give sufficient and accurate information needed for patients to provide informed consent, especially when the consequences of surgery on a child's genitals or internal reproductive organs can include scarring, incontinence, loss of sexual sensation and function, psychological trauma, risk of anesthetic neurotoxicity, sterilization, the need for lifelong hormonal therapy, and irreversible surgical imposition of a sex assignment.

In some cases Human Rights Watch documented, the presentation of information as well as the content of information provided by doctors didn't give parents of intersex children a chance to provide informed consent in a meaningful way.

Providers Human Rights Watch interviewed maintained that they provide all options and share relevant scientific information with patients and their families. However, the parents of intersex patients Human Rights Watch interviewed had different experiences with medical practitioners, ranging from having doctors who were kind and supportive at first but turned dismissive when parents questioned their surgery recommendation, to doctors who provided them with incomplete or misleading information.

Judy and Carl, parents of a child with an intersex condition, said they experienced intense confusion when their child was born with atypical genitals in 2009, and doctors first assigned the child female—then four days later, male. They took their healthy baby home without a DSD diagnosis, and with a lot of lingering questions.

Two weeks later, Judy and Carl took their baby to a regional hospital to meet with an endocrinologist and a urologist. “They sent us for blood work, and a battery of other tests. They measured the phallus—there was no urethra in the little nub,” Carl said. A week later they went back and the endocrinologist told them there were no androgen issues, it probably wasn't AIS [Androgen Insensitivity Syndrome]. All other tests were inconclusive so the doctors recommended testosterone. “Let's fix the mechanics anyway,” the urologist told them. “Your son can have any size penis he wants!”

Judy and Carl agreed to the surgery when their child was 11 months old, in April 2010. The procedure required a follow-up surgery eleven months later that resulted in two post-operative infections. Two days after the family was released from post-operative infection

care, a letter arrived in the mail telling them their son, Jack, had tested positive for Partial Androgen Insensitivity Syndrome (PAIS). This meant that, according to medical data, his future gender identity was uncertain and his body would not respond like most boys to testosterone as he grew up. Judy told Human Rights Watch: “After we’ve now gone through two surgeries and we had no idea of what to think of for the next 20 years ... what’s damaged or what’s not ... the whole spectrum of horror.”

The experience left the parents devastated, and feeling betrayed. Their child, now 8, ultimately developed a female gender identity. She lives as a girl at home and school, and family and friends call her “Jackey.” The social transition from Jack to Jackey was smooth, but the effects of surgery will not be so easily undone.

“We are smart enough to rationalize things and think through the outcomes,” said Judy, wishing that they had had better information and support during the decision-making process. “It’s frustrating, we’re angry,” said Carl. “We beat ourselves up about this” Judy explained: “I want to give [the doctors] the benefit of the doubt. I can’t definitively say that they didn’t think the surgery was the right thing to do. But they certainly did not have the information they needed—even a diagnosis—and nobody interjected to slow everything down.” Carl said:

The doctors told us it was important to have the surgery right away because it would be traumatic for our child to grow up looking different. What’s more traumatic? This sort of operation or growing up a little different?⁷⁴

A pediatric surgeon Human Rights Watch interviewed expressed similar views about differences in children. She said she tries to explain to parents that “many children have differences,” explaining that:

We deal with kids with all kinds of vascular anomalies and port wine stains. And we encourage those children to be out there, we encourage those children to be in school—and they are and they do great. We’ve got kids

⁷⁴ Human Rights Watch interview with Carl B., location withheld, January 26, 2017.

with Ellis Von Creveld⁷⁵ and Treacher Collins⁷⁶ who are totally well integrated into the school and they have significant facial anomalies. And I think that it speaks to the strength of the family and the strength of the child and the support of the care team that you can have a difference and you can go out there and we don't need to necessarily create normalization to make you safe and well adjusted. ⁷⁷

⁷⁵ Ellis van Creveld (EvC) syndrome, also known as chondroectodermal dysplasia, is characterized by abnormalities in the skeleton. These abnormalities include short arms and legs, extra fingers and/or toes, and a narrow chest.

⁷⁶ Treacher Collins syndrome is a genetic, craniofacial condition that is characterized by a range of distinctive facial anomalies.

⁷⁷ Human Rights Watch interview with a pediatric surgeon, April 28, 2017.

Intersex Children Can Thrive Without Surgery

In July 2017, the AIS-DSD Support group—the largest intersex adult, children, and family support group in the US—joined Human Rights Watch in writing to the AMA to share our report on intersex issues. In the letter, supporting a proposed AMA resolution on optimal management of DSD through individualized, multidisciplinary care, AIS-DSD explained:

If the AMA adopts the proposed [Board of Trustees] resolution, we hope that the AIS-DSD Support Group will be able to shift the focus of our support efforts over time away from helping adults, youth and their families recover from medically-induced traumas, and toward support of the physical and psychological health of our members, from birth to old age.⁷⁸

Over time, support groups have been able to help parents resist pressures to elect high-risk and medically unnecessary irreversible procedures on their children. While much of the narrative of the intersex human rights movement has focused on the stories of intersex people who underwent non-consensual surgeries and suffered physical and psychological fall-out from the procedures, some intersex youth who did not undergo surgery have begun speaking out as well. Recent video segments produced by *Teen Vogue*⁷⁹ and *Buzzfeed*⁸⁰ showcase intersex youth who have not undergone surgeries, despite pressure from doctors to do so.

A 2017 *Harper's* investigative report from the Dominican Republic, where most intersex children are left intact, showed that social awareness, and parent and teacher response help mitigate bullying—as with any other kid.⁸¹ Intersex activist Hida Vilorio, who did not have surgery, told *Rolling Stone* in 2017 about her decades of telling her story publicly:

My goal was that a parent who might have recently had an intersex child or have one in the future would see my interview and think, ‘Oh, being

⁷⁸ See appendix IV

⁷⁹ Teen Vogue, “What Was Done to These Intersex People Was Not Okay,” June 18, 2017, <https://www.youtube.com/watch?v=mT4dDO-ZwcQ>

⁸⁰ BuzzFeed, “What It’s Like to Be Intersex,” March 28, 2015, <https://www.youtube.com/watch?v=cAUDKEI4QKI>

⁸¹ Sarah Topol, “Sons and Daughters—The village where girls turn into boys,” *Harper's*, August 2017, <https://harpers.org/archive/2017/08/sons-and-daughters/>

intersex is fine and this person has been able to grow up happy and successful and feel good about themselves. There's no reason I have to cut up my child's body in this non-consensual, irreversible way. I'll just let them grow up and decide later on if they want to change anything about their body, the way most people get to decide.’⁸²

Emerging data, while limited, support these observations. A 2017 paper published in the *Journal of Pediatric Urology* documented, in follow-up with seven girls with CAH up to age eight who did not have surgery, that “girls and their parents have not expressed significant concerns regarding genital ambiguity.” The authors conclude: “With these encouraging data at hand, we propose to formally address levels of anxiety, adaptation and quality of life during childhood, with an ultimate goal to assess long-term satisfaction and effects on sexuality through deferring genital surgery.”⁸³

⁸² *Rolling Stone*, “Intersex Activist and Writer Hida Vioria on Being 'Born Both',” March 20, 2017, <http://www.rollingstone.com/culture/intersex-activist-hida-vioria-on-being-born-both-w472894>

⁸³ Pierre Bougnères, “Deferring Surgical Treatment of Ambiguous Genitalia into Adolescence in Girls with 21-Hydroxylase Deficiency: A Feasibility Study,” *International Journal of Pediatric Endocrinology* 2017(3) (2017), DOI 10.1186/s13633-016-0040-8.

The Positive Role of Peer Support Groups

International DSD consensus statements and the World Health Organization have emphasized the positive role and importance of support groups. Many providers Human Rights Watch interviewed cited various ways they referred patients to support groups including directing them to websites of established groups such as CARES Foundation, AIS-DSD Support Group, or the Accord Alliance, or putting parents in touch with other parents within the hospital clinic's network.

However, many parents of intersex children reported a range of encounters with providers in regard to support groups. Some parents said that doctors provided information about such groups as a part of the regular care of their child, others said that doctors did not proactively offer information, and still others reported that they were told no such resources existed.

Regardless of how parents found support groups, across the board they expressed that the groups were life-affirming and helpful for the entire family. These groups not only helped intersex children and their parents feel like they were not alone, but they were a source of practical support, providing tools on how parents can best advocate for their children.

For intersex adults, too, accessing support groups was invaluable in gaining confidence, combatting shame and stigma, and accessing information.

Another study, published by doctors at Seattle Children's Hospital in 2017, showed that even in a case where parental discomfort with bodily difference was motivating them to elect a medically unnecessary gonadectomy on their child, and doctors wanted to carry out the parents' wishes, hospital and state ethics and sterilization policies required that the procedure be deemed medically necessary, or else let the child decide later. The paper explained:

While the DSD team supported the parents' decision for gonadectomy, hospital policy and interpretation of Washington state law prohibits parents from providing informed consent for any procedure that removes the reproductive organs of a minor (Disability Rights Washington, 2012; Seattle Children's Hospital Bioethics Policy, 2013). Exceptions are allowed if they pose a health risk, such as the oncogenic risk posed by dysplastic gonads and/or if infertility is considered inevitable with standard treatment (Seattle Children's Hospital Bioethics Policy, 2013). A court order

authorization must be obtained for any other exception. Given the knowledge available on 5 α -R2D and the patient at the time, the medical team felt this policy precluded them from offering gonadectomy to the patient without a court order.⁸⁴

What is more, doctors who work with intersex patients are increasingly understanding the advice they give parents in the context of physicians' role in caring for children with a range of differences. A pediatric surgeon told Human Rights Watch:

I live in a community where I know we have two Treacher Collin's kids in our high school. And they are well integrated and I see them in the school I see them out in the streets of our village with friends. And if those kids can do that with their facial anomalies and their surgeries and their reconstructions so that they can safely breathe, they can eat, they can swallow, I am sure that with the appropriate support and the appropriate attitude we can keep our DSD kids safe and well-integrated and well-adjusted in their school and their growing up environments without cosmetically oriented surgeries.⁸⁵

⁸⁴ Heather Byers, et al., "Unexpected ethical dilemmas in sex assignment in 46,XY DSD due to 5-alpha reductase type 2 deficiency," *American Journal of Medical Genetics*, June 2017, 175(2):260-267, <https://www.ncbi.nlm.nih.gov/pubmed/28544750#> (accessed July 3, 2017).

⁸⁵ Human Rights Watch interview with a pediatric surgeon, April 28, 2017.

Recommendations

In our July 25, 2017 report, Human Rights Watch and interACT made recommendations to a range of government, law enforcement, and medical bodies. The recommendations below are a selection of those specifically targeted at medical bodies:

To the American Medical Association

- As a matter of urgency, pass the proposed resolution as recommended in the AMA Board of Trustees report 7-I-16, that “optimal management of DSD through individualized, multidisciplinary care...: (1) seeks to foster the well-being of the child and the adult he or she will become; (2) respects the rights of the patient to participate in decisions and, except when life-threatening circumstances require emergency intervention, defers medical or surgical intervention until the child is able to participate in decision making; and (3) provides psychosocial support to promote patient and family well-being.”⁸⁶

To the American Psychological Association

- Issue a resolution on the treatment of intersex children recommending:
 - A moratorium on surgeries performed on children with atypical sex characteristics too young to participate in the decision, when those procedures both carry a meaningful risk of harm and can be safely deferred;
 - inclusion of psychologists/mental health care in treatment teams; and
 - discussion of risks, benefits, and alternatives to any proposed treatment with psychologists/mental health providers prior to any irreversible decisions.

To the American Academy of Pediatrics

- Retract the support of the AAP for the 2006 Consensus Statement as an official position statement of the AAP, and replace it with a statement that is consistent

⁸⁶ American Medical Association, “Report of the Board of Trustees: B of T Report 7-I-16: Supporting Autonomy for Patients with Differences of Sex Development (DSD) (Resolution 3-A-16),” <https://assets.ama-assn.org/sub/meeting/documents/i16-bot-07.pdf>.

with international human rights standards and with the AAP statements on Assent, Informed Permission and Consent, and on FGM. The new statement should also:

- advocate to end to surgical procedures on children with atypical sex characteristics too young to participate in the decision, when those procedures both carry a meaningful risk of harm and can be safely deferred;
- advise that parents be given complete information about their intersex child's condition and the risks, benefits, and alternatives of any recommended procedures;
- advise that children and youth with atypical sex characteristics be given complete information about their conditions in an age-appropriate way;
- recommend that doctors routinely give parents of children with atypical sex characteristics information about available peer support groups; and
- recommend that parents routinely have access to mental health support and information from mental health experts about their child's condition before making irreversible decisions about their child's health.⁸⁷

To the World Health Organization:

- In line with WHO's stated opposition to early genital or sterilizing surgeries on intersex youth in the 2013 report "Eliminating Forced, Coercive and Otherwise Involuntary Sterilization," issue guidance on how medical professional bodies and governments should combat such practices.

To the Society for Pediatric Urology, the Pediatric Endocrine Society, and the North American Society for Pediatric and Adolescent Gynecology:

- Issue guidance in line with the proposed AMA resolution as recommended in the AMA Board of Trustees report 7-I-16 "that medically unnecessary surgeries in individuals born with differences of sex development are unethical and should be avoided until the patient can actively participate in decision-making."

⁸⁷ Such a statement would bring AAP policy regarding children with atypical sex characteristics in line with existing AAP policy on Assent, Informed Permission and Consent, and on FGM.

To the World Professional Association for Transgender Health:

- Remove the intersex exception from WPATH's Standards of Care and assert that similar standards for the sequence of interventions be applied to intersex children facing partially reversible or irreversible procedures that are not necessary for physical health.

Acknowledgments

Kyle Knight, a Human Rights Watch researcher, wrote this report based on research he and Suegee Tamar-Mattis, an intersex person and family physician in California conducted in 2016 and 2017. MJ Movahedi, LGBT rights program associate, drafted some sections of the report.

The report was reviewed by Kimberly Zieselman, executive director of interACT, Sylvan Fraser, staff attorney at interACT, and Alesdair Ittelson, legal and policy director at interACT.

Graeme Reid, director of the lesbian, gay, bisexual, and transgender rights program at Human Rights Watch edited the report. Grace Meng, deputy US program director, Megan McLemore, senior health and human rights researcher, and Michael Garcia Bochenek, senior children's rights counsel reviewed the report. Chris Albin-Lackey, senior legal adviser, and Joseph Saunders, deputy program director reviewed the report. Production assistance was provided by MJ Movahedi, LGBT rights program associate; Madeline Cottingham, photo and publications coordinator; Fitzroy Hepkins, administrative manager; and Jose Martinez, senior coordinator.

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Appendix I

October 13, 2016

Dear Dr. XXXX:

I am a researcher at Human Rights Watch, an international non-governmental research and advocacy organization.

Human Rights Watch conducts research on a range of issues in more than 90 countries around the world, including the United States, where we are headquartered. Our research is designed to be objective, and take into account all perspectives so that we can conduct accurate legal and policy analysis.

I am currently undertaking a research project focusing on the experiences of intersex people in the United States. Specifically, we are interested in hearing from practitioners about medical care options available for intersex infants (or infants with DSD) and the advice and information provided to their parents. To better understand the experience of intersex children and their parents, we seek to interview healthcare providers such as yourself about the care and information you and your colleagues provide. We are also interested in interviewing any patients of yours, or their parents, to learn about their experiences living with intersex conditions and seeking care.

We are able to meet with you in person or on the phone at a mutually convenient time. The results of our research projects are public reports that are available in print and online. We are willing to anonymize the information you share with us and if you prefer, we can assure any information you share with Human Rights Watch is featured without any identifying characteristics, including name, location, exact date of the



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interview, and other possibly identifying aspects. We have undertaken the Ethical Review Board process operated by Physicians for Human Rights to ensure this research is carried out with the highest standards of professional care.

We recognize that this can be a polarizing and difficult topic, and our aim is to ensure that our research is objective and that it fully captures the whole range of different perspectives at play.

I am based in New York City, and available to answer any questions you might have in advance of arranging an interview. I can be reached at kyle.knight@hrw.org, or 917-794-6690.

I look forward to hearing from you regarding this meeting.

Sincerely,

A handwritten signature in black ink, appearing to read 'Kyle Knight', with a stylized, overlapping loop structure.

Kyle Knight
Researcher, Human Rights Watch

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Appendix II

January 18, 2017

Dear Dr. XXXX:

We wrote on October 13, 2016 requesting an interview regarding your clinic's practices with patients with disorders of sex development for an ongoing research project, and this letter is a follow up request to provide information in writing.

As mentioned in our previous correspondence, Human Rights Watch is attempting to gain a wide range of perspectives to incorporate into our report—a methodology we apply in all of our research. You can see examples of our research on a range of issues on our website at www.hrw.org.

Two examples of health-specific projects we have recently conducted are *"No Time to Waste" – Evidence-Based Treatment for Drug Dependence at the United States Veterans Administration Department of Veterans Affairs*,⁸⁸ and *Care When There Is No Cure – Ensuring the Right to Palliative Care in Mexico*.⁸⁹

For this project, we are attempting to gather a wide range of perspectives on the following topics, and we would appreciate your responses to the questions below by February 10, 2017:

- What is the process for communicating with parents regarding their child's intersex (DSD) diagnosis and treatment options?
- In addition to speaking with doctors and nurses, what resources exist for parents to learn about their child's condition?

⁸⁸ "No Time to Waste" can be found at <https://www.hrw.org/report/2014/06/30/no-time-waste/evidence-based-treatment-drug-dependence-united-states-veterans>

⁸⁹ Care When There Is no Cure can be found at http://features.hrw.org/features/HRW_2014_report/Mexico_Care_When_There_Is_No_Cure/index.html



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- What cases are considered to be candidates for surgery (genital or gonadal)?
- If a child is considered a candidate for surgery, how is the option of surgery presented to parents?
- If parents opt not to have surgery, what advice and resources are provided to them?
- For patients who have undergone surgeries in your clinic, what follow-up is advised and conducted?

If you would prefer to speak on the phone instead, please feel free to contact me to arrange a time.

As mentioned in our prior correspondence, Human Rights Watch is interested in interviewing people with DSDs who have undergone various treatments, in particular related surgeries. This is so that we can establish how the procedures have impacted their lives—including their ability to live openly according to their gender identity, form relationships, establish a positive self-concept, access ongoing healthcare, and engage in employment. We would be happy to have you share our contact information with any of your current and/or former patients who might be interested in speaking with us. We are particularly interested in interviewing individuals with DSDs who are pleased with the surgical interventions they received as children.

As reflected in the reports linked above, all of our interviews, with patients or providers, will be anonymized and are conducted with full informed consent regarding our objectives and methodology. We are keen for our report to contain a wide range of perspectives on these issues, and we understand the topics can be polarizing and challenging. Please consider participating so that your expertise and experience can be reflected in our research.

Sincerely,

A handwritten signature in black ink, appearing to read 'Kyle Knight', with a stylized, cursive-like script.

Kyle Knight
Researcher, Human Rights Watch

Appendix III

November 24, 2015

**To: NIH Translational Research Network and NIH Research Coordinating Committee
For Sexual and Gender Minorities**
From: AAN Members
Re: Statement of resignation of some AAN Members from TRN

The original invitation to join the Advocacy Advisory Network (AAN) of the NIH Translational Research Network (TRN) evoked an idealistic vision of patients and clinicians setting aside differences and working together to make life happier and healthier for people living with reproductive difference. Rejoicing at the opportunity to have a voice in major decisions about research and care that affect our community in powerful ways, representatives of multiple peer support and advocacy groups eagerly joined. AAN members include advocates with diverse lived experience, who are affected adults, parents, and children, who are affected by a variety of differences, and who range in life stage from youth to maturity. We bring skills from careers in business, academia, law, social work, conflict resolution, project management, counseling, psychology, genetics, non-profit executive directorship, and medicine. We have decades of combined experience in peer support and leadership. Additionally, for the upcoming Global DSD Update sponsored by Pediatric Endocrine Society, Arlene Baratz is co-chair of the committee on patient perspectives and peer support. Despite our representation of our community and many valuable contributions of expertise and experience since we joined AAN four years ago, we are extremely disappointed that TRN has not lived up to its initial promise.

Alice Dreger and Tiger Devore recently announced their resignations from AAN on Alice's blog. We agree with some of their ideas, and would like to clarify our own perspective. AIS-DSD Support Group, Advocates for Informed Choice, and our allies listed below are also withdrawing from AAN because of ongoing miscommunication and lack of meaningful inclusion. At this point, having our names associated with TRN is doing more harm than good because chronic issues with TRN prevent meaningful advocacy input. From its inception, despite our requests, TRN failed to include advocates in the design and goals of the project. Having been denied a presence at the initial meeting of investigators, we hoped that subsequent close involvement in projects could influence the direction of research, but most were already IRB-approved by the time we saw them. Instead of an opportunity to contribute, we have experienced a pattern of misrepresentation in which our involvement and concurrence have been falsely implied. Missed deadlines and absence of key project deliverables also frustrate us.

Let us be clear that our resignation has nothing to do with the TRN clinicians and researchers who devote their lives to caring for and about us. We deeply appreciate your presence at our support group meetings, your availability to our members, and your ability to listen and change. Outside TRN, we are delighted to be involved in ongoing projects whose design and goals reflect successful cooperative relationships. We have found we can be extremely effective in supporting the development of research that meets the needs of our communities when we are involved from the beginning in the design of research goals, when we are able to give input into sensitive language, and when we are engaged to ensure that the specific concerns of this community regarding human research ethics and informed choice are addressed. Examples of successful research we have engaged in include projects on parent experiences with making decisions about genital difference; how young women living with DSD share health information

11/24/15, re: AAN membership

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with peers; and parent experiences with genetic testing. Currently, we are working with TRN clinicians on outside projects investigating language, how medical care is experienced, ways to deliver psychosocial care, and evidence-based best practices in CAIS. We look forward to future opportunities to work with anyone from within or outside TRN who is interested in designing research that is inclusive of community concerns.

Although clinicians may have interacted with Accord Alliance as the designated community representative, we found that indirect transmission was effectively censoring our written and verbal communications. This is disturbing because Accord Alliance was founded in 2006 by Bo Laurent (Cheryl Chase), Katrina Karkazis, Arlene Baratz, and David Sandberg to improve medical care by replacing ISNA's confrontational tactics with a fresh, collaborative approach involving multiple stakeholders. At its closure, ISNA's funds and assets were transferred to Accord Alliance, including the *Handbook for Parents* and *Guidelines for Clinicians*. Accord Alliance hosted a research and quality improvement symposium in 2009, but hasn't sponsored any non-medical events since then, according to its blog. Laurent, Karkazis, and Baratz are no longer involved. Supported in its early days by community donations, Accord Alliance's current major source of funding is the TRN grant, which in turn designates the function of DSD community representative to Accord Alliance. This suggests a major conflict of interest. Reinforcing this impression is TRN's repeated failure to share AAN opinions and concerns about various projects with TRN clinicians. For example, serious and widespread AAN concerns that a proposed photography project posed potential harm to pediatric research subjects were not conveyed accurately to clinicians. When the time came to submit that proposal, clinicians were surprised to learn our opinion. Having further misled clinicians to believe that only a minority of AAN members requested further input on the proposal, TRN circumvented its requirement for AAN support with a letter from Accord Alliance implying our approval. It was an embarrassment to all of us that the proposal was withdrawn after AAN protested the deceptive letter.

Similarly, AAN members were extensively involved for four years in writing and editing numerous drafts of educational material for a TRN family decision support tool. However, ever since we insisted recently that families be made aware of major international human rights policies involving DSD treatment, our contributions are mysteriously absent. Despite our repeated requests, a version of the decision support tool omitting human rights education is already being piloted with families. Ethics and common decency suggest that shared decision-making should include informing families that many international human rights organizations have new statements strongly affirming the right of children with diverse sex characteristics to make their own choices about irreversible interventions. The [UN High Commissioner for Human Rights](#) and the [UN Special Rapporteur on Health](#), working closely with Advocates for Informed Choice (AIC), have both endorsed these as basic human rights. DSD/intersex is increasingly prominent on an international landscape in the midst of tectonic shifts. AIC will continue to advocate for an informed consent process requiring family counseling to include discussion of both social and medical controversies. Otherwise, how will children feel later when they discover that their parents made important decisions about irreversible interventions using decision support tools that consciously excluded vital information on children's human rights? Parents have a right to know just how controversial these procedures are before they make irreversible decisions.

Finally, the original TRN grant proposal included individual letters of support from AAN member organizations. In May, we were asked to draft a new letter jointly supporting a proposal to fund

TRN for the next funding cycle. After requesting changes in the grant to provide AAN more direct involvement as a condition of support, we never saw such a letter. The grant was later submitted, leaving us to wonder if the controversy was resolved by submitting a letter from Accord Alliance without our knowledge. If so, another five years of advocate dissatisfaction and AAN misrepresentation of our constituents concerns are practically guaranteed.

AIS-DSD Support Group's mission is to foster successful stakeholder collaborations that promote community well being through peer support, informed decision-making, and advances in evidence-based care. You see our passionate commitment in the vibrant community of affected people, clinicians, and allies that we nurture. You see it at the annual continuing education meeting we sponsor in partnership with DSD teams around the country. You see it when you attend our support group meetings, hear how people experience treatment, and learn about research that matters to patients. Likewise, AIC's mission is to advocate for the legal and human rights of children born with intersex traits. Neither organization, however, can effectively support or advocate for our constituents through the AAN, and so our consciences dictate that our members must resign.

All of us see how hard you work and how much you care. We know you want to see intersex people thrive as much as we do. The world is already changing because of our mutual dedication. Together, we have the power to transform it and we look forward to further collaborations outside the TRN.

Sincerely,

Arlene B. Baratz, MD
Coordinator of Clinical and Research Affairs AIS-DSD SG
Moderator, AIS-DSD Parents Group
AIC Board of Directors and Medical Adviser

Tiger Devore, PhD
Founding member, past president and vice president, Hypospadias Epispadias Association

Amber Jones
Operations Coordinator, AIS-DSD Support Group
Moderator, AIS-DSD Parents Group
Past member, AIS-DSD SG Board of Directors

Jim Lake
Executive Director, Hypospadias Epispadias Association

Lissa Moran, MPH

Meg Robertson
AIS-DSD SG Board of Directors
Moderator, AIS-DSD Parents Group

11/24/15, re: AAN membership

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Karen Walsh
AIC board of directors

Kimberly Zieselman, JD
Executive Director, Advocates for Informed Choice
AIS-DSD SG Board of Directors

11/24/15, re: AAN membership

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Appendix IV

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August 15, 2017

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President, Board of Trustees

Dennis S. Agliano, MD, FACS
Chair, Council on Ethical and Judicial Affairs

American Medical Association (AMA)
330 N. Wabash Ave. Suite 39300
Chicago, IL 60611-5885

Dear Dr. Barbe and Dr. Agliano:

We write to share with you the first ever in-depth report on the treatment of intersex youth in the United States. AIS-DSD Support Group wrote to you previously on May 19, 2017, and Human Rights Watch corresponded with the AMA's Physician Engagement Department on July 12, 2017.

As you may know, Human Rights Watch is an international non-governmental research and advocacy organization that works in more than 90 countries and is headquartered in the United States. AIS-DSD Support Group is the largest organization in the US exclusively dedicated to promoting support, education, and outreach to foster healthy outcomes for adults, youth, children, and families affected by intersex conditions, also known as Differences of Sex Development (DSD). AIS-DSD Support Group runs an annual conference for the intersex community and creates the curriculum for and co-conducts CME classes for the clinicians (physicians, psychosocial counselors, geneticists, and DSD program coordinators) who attend the conference. AIS-DSD Support Group helped Human Rights Watch connect with affected individuals, families, and doctors to conduct interviews that are included in the report.

This report, the result of 10 months of intensive research by Human Rights Watch, recommends that the American Medical Association, as a matter of urgency, pass the proposed resolution as recommended in the AMA Board of Trustees report 7-I-16, that,

Optimal management of DSD through individualized, multidisciplinary care...: (1) seeks to foster the well-being of the child and 20 the adult he or she will become; (2) respects the rights of the patient to participate in decisions 21 and, except when life-threatening circumstances require emergency intervention, defers 22 medical or surgical intervention until the

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child is able to participate in decision making; and 23 (3) provides psychosocial support to promote patient and family well-being.

Major health and human rights organizations, including the United Nations, the World Health Organization, and Amnesty International, have condemned medically unnecessary surgeries performed without informed consent. In July 2017, three former US Surgeons General, including one who was a pediatric urologist, wrote to oppose this practice because "there is insufficient evidence that growing up with atypical genitalia leads to psychosocial distress," and "the surgery itself can cause severe and irreversible physical harm and emotional distress." Every major intersex organization opposes unnecessary surgeries on intersex infants, as does every major LGBT legal organization in the United States. AIS-DSD Support Group endorsed the recommendations of the Human Rights Watch report on July 25, 2017, when it was launched in Chicago.

Human Rights Watch, AIS-DSD, and the AMA share the goals of protecting the human rights of and promoting healthy outcomes for intersex-affected individuals and their families. The nonconsensual medically unnecessary surgeries that are performed today jeopardize the lives, health, and happiness of the intersex community. If the AMA adopts the proposed resolution, we hope that the AIS-DSD Support Group will be able to shift the focus of our support efforts over time away from helping adults, youth and their families recover from medically-induced traumas, and toward support of the physical and psychological health of our members, from birth to old age. Our support will continue to respect individual's rights to physical autonomy, including the right of older children and adults to consent to surgeries; we will also continue to provide support for parents and others who have made decisions for surgeries in the past.

For the well-being of intersex children and their families, we strongly urge the AMA to issue clear, unambiguous guidance recommending a delay of all medically-unnecessary interventions. We would be happy to meet with you—in person or on the telephone—to discuss our recommendations further.

Thank you for your time and consideration.

Kind regards,

A handwritten signature in black ink, appearing to read "Kyle Knight".

Kyle Knight
Researcher, Human Rights Watch
kyle.knight@hrw.org
917 794 6690

A handwritten signature in black ink, appearing to read "Kimberly Saviano".

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A CHANGING PARADIGM

US Medical Provider Discomfort with Intersex Care Practices

Since the 1960s, doctors in the United States have routinely performed surgeries on intersex infants and children – or those born with chromosomes, gonads, or genitalia that do not correspond to traditional notions of “male” or “female” – to make their bodies conform to conventional gender presentation. But the surgeries are medically unnecessary, irreversible, often traumatizing, and carry a risk of lifelong harm. They can also be safely deferred until the person concerned is old enough to decide for themselves whether they want the procedures.

Despite increasing controversy within the medical community and condemnation from human rights organizations, however, some specialist doctors continue to recommend and carry out the operations on children too young to consent.

In *A Changing Paradigm*, Human Rights Watch and interACT Advocates for Intersex Youth document the increasing discomfort healthcare providers feel with the default-to-surgery paradigm, and the growing momentum to support care standards like those for all other patients and to respect rights to informed consent and bodily autonomy.



Dr. Katharine Dalke is a psychiatrist, an intersex woman, and a mother. She advocates for an end to medically unnecessary surgeries performed on intersex children too young to consent.

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Re-Thinking Genital Surgeries on Intersex Infants

M. Joycelyn Elders, M.D., M.S.
15th Surgeon General of the United States

David Satcher, M.D., Ph.D., FAAFP, FACPM, FACP
16th Surgeon General of the United States

Richard Carmona, M.D., M.P.H., FACS
17th Surgeon General of the United States

June, 2017

On October 26, 2016, the 20th anniversary of Intersex Awareness Day, the U.S. State Department issued a statement recognizing that “intersex persons routinely face forced medical surgeries that are conducted at a young age without free or informed consent. These interventions jeopardize their physical integrity and ability to live free.”¹

The U.S. government is one of many that have recently raised questions about infant genitoplasty, cosmetic genital surgery meant to make an infant’s genitals “match” the binary sex category they are assigned by adults entrusted with their care. Genitoplasty is often performed on infants with intersex traits, a condition known as DSD, or Disorders/Differences of Sex Development. Although well-intentioned—many parents and physicians believe it is more trying for individuals to live with atypical genitalia than to have it “corrected” early on—there is growing recognition that this belief is based on untested assumptions rather than medical research, and that cosmetic genital surgery performed on infants usually causes more harm than good.

Fortunately, a consensus is emerging that concludes that children born with atypical genitalia should not have genitoplasty performed on them absent a need to ensure physical functioning. Government agencies in Germany, Switzerland, Australia, Chile, Argentina, and Malta, as well as human rights groups, including the World Health Organization, have examined this issue and found that these irreversible medical procedures, which are performed before individuals can articulate whether they wish to undergo such surgery, are not necessary to ensure healthy physical functioning, and that such surgery is not justified when performed on infants. These bodies have called for a moratorium on cosmetic infant genitoplasty so as to allow individuals with a DSD to have substantive input into decisions affecting their own identity and appearance.

Performing cosmetic infant genitoplasty was not always the default practice. Before the middle of the twentieth century, most children born with genitalia that did not fit the male-female binary norm were not subjected to surgery. Beginning in the 1950s, however, an era when pressure to conform to social norms was often unyielding, the standard treatment protocol shifted. Infants born with atypical genitalia were subjected to surgical procedures such as clitoral reduction, vaginoplasty, gonadectomy, and hypospadias repair, primarily to “normalize” gendered appearance, not to improve function.

Since this period, as a 2016 consensus statement notes, good-faith disagreement has existed among physicians about whether and when cosmetic infant genitoplasty should be performed.² Some physicians recommend surgery because they believe it will decrease the likelihood that children will suffer emotional trauma from having atypical gender characteristics. While we do not doubt that doctors who support and perform these surgeries have the best interests of patients and their parents at heart, our review of the available evidence has persuaded us that cosmetic infant genitoplasty is not justified absent a need to ensure physical functioning, and we hope that professionals and parents who face this difficult decision will heed the growing consensus that the practice should stop.

Our view is based on three simple and compelling rationales. First, there is insufficient evidence that growing up with atypical genitalia leads to psychosocial distress. After reviewing several dozen studies that purported to examine the impact of having a DSD, we have concluded there is a dearth of persuasive evidence showing that children or adults are psychologically harmed from having atypical genitalia, or that they are better off if they undergo cosmetic genitoplasty as infants. For the most part, studies that did draw a connection between atypical genitalia and emotional distress simply assumed, rather than showed, a causal link between the two.³

Second, while there is little evidence that cosmetic infant genitoplasty is necessary to reduce psychological damage, evidence does show that the surgery itself can cause severe and irreversible physical harm and emotional distress. Although doctors strive to predict the likely gender identity of these infants, a significant percentage will develop a gender identity different from the one assigned at birth. Irreversible genital surgery, including removal of healthy genital tissue, can be traumatic if the gender assignment turns out to conflict with the individual's own gender identity.⁴

Even if the gender prediction is correct, a number of complications associated with these surgeries can arise, including loss of sexual sensation, pain during intercourse, incontinence, scarring, and the need for repeat surgeries. A gonadectomy can create a need for hormone replacement therapy, and may also preclude potential fertility available through developments in assisted reproductive technology.⁵ In short, surgeries whose purpose is to ensure physical and psychological health too often lead to the opposite result.

Finally, these surgeries violate an individual's right to personal autonomy over their own future. While surgeries such as the creation of an absent urethral opening can be justified because they ensure physical functioning, neither clitoral reduction surgery nor the creation of a vagina is ever necessary in infants to ensure physical functioning, and hypospadias repair is rarely necessary. Clitoral reductions and the removal of healthy gonads clearly infringe on the child's right to physical integrity, preservation of sexual and gender identity, and procreative freedom. In some cases, a gonadectomy may be appropriate to address a risk of cancer, but this surgery can generally wait until puberty, when the affected individuals can have a voice in the decision about whether to undergo such a procedure.⁶

Medical experts agree that more research is needed to determine the optimal treatment for children born with a DSD. In the meantime, babies are being born who rely on adults to make decisions in their best interest, and this should mean one thing: When an individual is born with atypical genitalia that pose no physical risk, treatment should focus not on surgical intervention but on psychosocial and educational support for the family and child. Cosmetic genitoplasty should be deferred until children are old enough to voice their own view about whether to undergo the surgery. Those whose oath or conscience says "do no harm" should heed the simple fact that, to date, research does not support the practice of cosmetic infant genitoplasty.

¹ U.S. Department of State, “In Recognition of Intersex Awareness Day” (statement by John Kirby, Assistant Secretary and Department Spokesperson, 2016).

² Lee PA, Nordenström A, Houk CP et al. Global disorders of sex development update since 2006: perceptions, approach and care (consensus statement). *Horm Res Paediatr*. 2016;85:158–180.

³ Ibid., 167, 176.

⁴ Cohen-Kettenis PT. Gender change in 46,XY persons with 5alpha-reductase-2 deficiency and 17beta-hydroxysteroid dehydrogenase-3 deficiency. *Arch Sexual Behav*. 2005;34(4):399-410.

⁵ Hughes IA, Houk C, Ahmed SF, Lee PA. Consensus statement on management of intersex disorders. *Arch Dis Child*. 2006;91:554-562.

⁶ Deans R, Creighton SM, Liao LM, Conway GS. Timing of gonadectomy in adult women with complete androgen insensitivity syndrome (CAIS): patient preferences and clinical evidence. *Clin Endocrinol (Oxf)*. 2012;76(6): 894-898.



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February 1, 2018

Dennis S. Agliano, MD, FACS
Chair, Council on Ethical and Judicial Affairs
American Medical Association
Dennis.Agliano@ama-assn.org

Dear Dr. Agliano:

I understand that the American Medical Association (AMA) Council on Ethical and Judicial Affairs (CEJA), which you chair, is currently considering a policy regarding supporting autonomy for individuals affected by differences of sex development (DSD), or intersex traits. I am aware that the AMA Board of Trustees in 2016 recommended a course of action, which prompted review by the CEJA. I write to express the support of Physicians for Human Rights for the AMA CEJA to adopt a policy that respects and upholds the human rights of intersex people by applying the central medical ethics standards of informed consent and medical necessity to their treatment.

As a physician, I understand that each clinical case is unique and nuanced, and that certain conditions cause considerable anxiety and confusion for patients, caregivers, and doctors alike. It is for this reason that it is crucial that the AMA develop clear guidelines for practitioners that medically unnecessary surgeries on intersex children such as vaginoplasties, clitoral surgeries, and gonadectomies absent malignancy not be offered as part of the standard care regimen. From a medical ethics perspective, carrying out an irreversible and medically unnecessary surgery before a child is old enough to consent violates internationally recognized informed consent requirements, and violates the obligation to do no harm. I urge the AMA to issue detailed policy to their members and constituencies on emerging best practices for the optimal management of the physical and mental health of intersex children and their families. Such guidance should include clear guidance to defer medically unnecessary surgeries until an individual can provide informed consent, and to provide psychosocial support for patients and families. Intersex-led peer support and advocacy groups have long highlighted the lack of meaningful evidence of physical or mental health benefits to intersex children deriving from early surgery, except in those limited cases where such surgeries are medically necessary. Medical experts are increasingly acknowledging this, and emerging data and standards of care favor deferring medically unnecessary surgeries.

In July 2017, three former U.S. Surgeons-General wrote that they believed “evidence [shows] that the surgery itself can cause severe and irreversible physical harm and emotional distress.”¹ Earlier in 2017, the Committee on Bioethics of the Council of Europe noted that “repeated systematic reviews of evidence have found no quality data confirming [the] safety and benefits for each affected child [of early surgical interventions]” and that, rather, there is evidence of harmful results of such interventions, including genital dysfunction, scarring, loss of sexual feeling, loss of fertility, chronic pain, and enforcing the wrong gender assignment – with irreversible excision of genital and gonadal tissues.² We also note that this position on establishing thresholds of medical necessity and informed consent for surgeries on children with intersex traits is supported by the World Health Organization,³ the UN Office of the High

¹ <http://www.palmcenter.org/publication/re-thinking-genital-surgeries-intersex-infants/>

² The Committee on Bioethics of the Council of Europe, “The Rights of Children in Biomedicine: Challenges Posed by Scientific Advances and Uncertainties,” Council of Europe, January 16, 2017, <http://www.coe.int/en/web/children/-/studyon-the-rights-of-children-in-biomedicine>.

³ http://www.who.int/reproductivehealth/publications/gender_rights/eliminating-forced-sterilization/en/



Commissioner for Human Rights,⁴ and organizations of intersex people and parents of intersex children in the US and around the world.⁵

In addition to the mounting health expert and medical ethics consensus that non-necessary surgeries should be deferred until consent can be given by the patients themselves, we support the analysis shared by the UN Special Rapporteur on the right to health; the UN Special Rapporteur on torture and other cruel, inhuman, or degrading treatment or punishment; the UN Special Rapporteur on violence against women, its causes and consequences; the UN Committee on the Rights of the Child; the Special Representative of the United Nations Secretary-General on Violence against Children; the UN Committee against Torture; the UN Committee on the Rights of Persons with Disabilities; the UN Committee on the Elimination of Discrimination against Women; the UN Subcommittee on Prevention of Torture and other Cruel, Inhuman or Degrading Treatment or Punishment; and the Inter-American Commission on Human Rights that medically unnecessary surgeries conducted on children with intersex traits before they are old enough to provide informed consent amount to a human rights violation and have no place in modern medicine.

I note that the debate over these early surgeries has been going on within medicine for quite some time. Indeed the 2006 “Consensus Statement on Management of Intersex Disorders” and its 2016 update both acknowledge the controversy and the lack of evidence supporting early surgical interventions being a treatment option. I worry that without clear guidance from medical bodies such as the AMA, we will be having similar unproductive discussions a decade from now as well.

I am encouraged that medical sub-specialty organizations on the front lines of providing care for children affected by DSD are developing policies that support the patient’s autonomy, human rights, and best outcomes. This includes the 2017 position statement by the North American Society for Pediatric and Adolescent Gynecology, which received an endorsement from the Pediatric Endocrine Society. It reads:

We believe in respecting the autonomy of the individual patient as well as providing ample support and guidance for the patient and family. All parents and affected patients should be actively encouraged to seek psychological counseling and peer support given the stress, confusion, and isolation that many experience. We believe that surgery alone does not address all the implications associated with DSD conditions. Some DSD conditions require early surgical intervention to optimize health and fertility. Ideally, if surgical interventions could be safely delayed, patients would have time to express their gender identity and to be actively involved in the decision making process. True informed consent or assent includes an accurate discussion of the options, benefits, known short and long term complications, expected pain and recovery, as well as need for reoperation. Finally, we believe that if there is a possibility for fertility, that this should be preserved and optimized.⁶

While I understand that medical protocols have evolved in recent decades, and that the use of multi-disciplinary teams, including endocrinologists, gynecologists, urologists, and psychologists to work on intersex cases is increasingly common, the field remains fraught with uneven,

⁴ United Nations High Commissioner for Human Rights report A/HRC/29/23 (2015)

⁵ <http://aisdsd.org/wp-content/uploads/2017/07/20170725-HRW-AISDSD-Press-Release.pdf>;
https://docs.google.com/document/u/1/d/16skW1o_ISP5pidq9WUVcttJNgndO88W5cMZw3YwB3qc/pub?embedded=true (Intersex Awareness Day Resolution signed by over twenty international intersex-led organizations).

⁶ http://c.ymcdn.com/sites/www.naspag.org/resource/resmgr/pdf's/NASPAG_Statement_on_DSD_PES_.pdf



inadequate, and piecemeal standards of care. This leaves children with intersex traits, their families, and their physicians vulnerable.

Accordingly, Physicians for Human Rights urges the AMA Council on Ethical and Judicial Affairs to adopt a policy to respect and uphold the fundamental human rights of intersex children and adults to health, to physical and mental integrity, to live free from violence and harmful practices and to be free from torture and ill-treatment, and to implement the urgent measures my mandate and other United Nations and regional experts have made in this regard.

Sincerely,

Homer Venters, MD, MS
Director of Programs
Physicians for Human Rights

CC:

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Dennis S. Agliano, MD, FACS
Chair, Council on Ethical and Judicial Affairs

American Medical Association
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February 21, 2018

Dear Dr. Agliano:

I am writing on behalf of Amnesty International USA, which conducts research, training, and advocacy to combat human rights abuses, including those based on sex or gender identity. As the AMA's Council on Ethical and Judicial Affairs considers policy protecting intersex children and ensuring that they are able to meaningfully participate in decisions about their own health, we urge you to support the AMA Board of Trustees Recommendation in report 7-1-16, in favor of multidisciplinary and individualized care for DSD.

Children and youth born with variations of sex characteristics, intersex traits, or differences of sex development (DSD), face challenges and abuses within healthcare systems that are just beginning to be recognized. An estimated 1.7% of children in the world are born every year with variations of sex characteristics, and many of these children as a consequence face medicalization of their identities and interventions that aim to “normalize” and “fix” them that can result in long term trauma.¹ The recommendations of the AMA Board of Trustees uphold a standard of care that should be available to all children,

Optimal management of DSD through individualized, multidisciplinary care:

- (1) seeks to foster the well-being of the child and the adult they will become;*
- (2) respects the rights of the patient to participate in decisions and, except when life-threatening circumstances require emergency intervention, defers medical or surgical intervention until the child is able to participate in decision making; and*
- (3) provides psychosocial support to promote patient and family well-being.*

These standards of care must be specifically affirmed because individuals with variations of sex characteristics have, in the United States as well as globally, been subjected to systematic abuse within medicine. In May 2017, Amnesty International published “First, Do No Harm: Ensuring

¹ Anne Fausto-Sterling, *Sexing the Body*, 2000, (hereinafter: Fausto-Sterling, 2000), p. 53



the Rights of Children with Variations of Sex Characteristics in Denmark and Germany.”² Over two years, we interviewed 16 individuals with variations of sex characteristics in Denmark and Germany, eight parents of children born with these variations, 15 intersex activists in Europe, and 31 medical and health professionals in European countries, in order to understand the effects of “normalizing” surgeries. We found that individuals experienced long-term negative physical or mental difficulties as consequences of these surgeries. Parents of children with variations of sex characteristics that Amnesty International interviewed report that they were provided with insufficient information to enable them to make an informed decision about medical interventions proposed for their children.

Our findings have been parallel to those in the Human Rights Watch report, “I Want to Be Like Nature Made Me: Medically Unnecessary Surgeries on Intersex Children in the US,” which documents medically unnecessary surgeries in the United States. While the negative impacts of medically unnecessary surgeries have been well documented, there are significant gaps in research on the wellbeing of intersex people, or the relative merits of intervention or non-intervention.³ For decades, intersex children have suffered trauma after trauma, often beginning in infancy, in medical settings where they should be safest. In clinics across the United States, intersex infants, sometimes merely months old, are subjected to medically unnecessary surgeries that aim to bring their bodies into conformity with the sex assigned by doctors – a dangerous procedure with no guarantee of affirming a child’s gender later in life. The physical risks and poor outcomes of these childhood surgeries are well documented,⁴ but we have found equally dire and long term psychological impacts of the procedures.

Gender stereotypes have historically driven the current paradigm of care for intersex children. Rationales for surgery on intersex children include the assertion having a vagina is so important that it should be constructed even before the child has the capacity to understand the various functions of that organ⁵; (without knowing whether the individual will have any interest in later using a vagina for penetrative sex, for example). Some proponents of early surgery also say that not performing surgery risks leaving the child confused about their sex or gender identity⁶; (as if

² Amnesty International, “First, Do No Harm: Ensuring the Rights of Children with Variations of Sex Characteristics in Denmark and Germany,” May 9, 2017, <https://www.amnesty.org/en/documents/eur01/6086/2017/en/>.

³ Amnesty International, “First, Do No Harm: Ensuring the Rights of Children with Variations of Sex Characteristics in Denmark and Germany,” May 9, 2017, <https://www.amnesty.org/en/documents/eur01/6086/2017/en/>.

⁴ Peter Lee et al., Review of Recent Outcome Data of Disorders of Sex Development (DSD): Emphasis on Surgical and Sexual Outcomes, *Journal of Pediatric Urology* (2012), available at <http://dx.doi.org/10.1016/j.jpuro.2012.10.017>; Sarah Creighton et al., Objective Cosmetic and Anatomical Outcomes at Adolescence of Feminising Surgery for Ambiguous Genitalia Done in Childhood, 358 *The Lancet* 124 (2001); N.S. Crouch et al., Sexual Function and Genital Sensitivity Following Feminizing Genitoplasty for Congenital Adrenal Hyperplasia, 179 *Journal of Urology* 634 (2008); C.L. Minto et al., The Effects of Clitoral Surgery on Sexual Outcome in Individuals who have Intersex Conditions with Ambiguous Genitalia: A Cross-Sectional Study, 361 *The Lancet* 1252 (2003).

⁵ Sarah Creighton et al., “Timing and nature of reconstructive surgery for disorders of sex development,” *Journal of Pediatric Urology*, 8(6): 602-10 (2012); Martin Kaefer, Richard C. Rink, “Treatment of the Enlarged Clitoris,” *Frontiers in Pediatrics*, 28 August 2017, <http://journal.frontiersin.org/article/10.3389/fped.2017.00125/full>.

⁶ P. Mouriquand et al., “The ESPU/SPU standpoint on the surgical management of disorders of sex development (DSD),” *Journal of Pediatric Urology* 10(1): 8-10 (2014).



surgery can make this possibility of gender dysphoria go away). Published articles have also asserted that girls with large clitorises will be lesbians or will fail to be feminine enough,⁷ and that boys who cannot stand to urinate are not “real boys” at all.⁸ These justifications are based on deeply ingrained gender stereotypes rather than the lived experiences of intersex individuals. The physical risks and poor outcomes of these childhood surgeries are well documented,⁹ and we have found equally dire and long term psychological impacts of the procedures.”¹⁰

While it is understandable for parents and doctors alike to want to improve the lives of the youth for which they care, these interventions are clearly misguided.

Despite claims based on “common sense” that growing up with atypical sex characteristics will adversely impact a child’s mental and emotional well-being, there is no evidence for this proposition – and in fact, intersex children, like all minority children, who receive support from their families and care providers thrive. What is demonstrated in medical evidence to cause harm is the practice of non-emergency, invasive and irreversible surgery with harmful effects, and that survivors of these surgeries experience depression, PTSD, and suicidality¹¹ comparable to survivors of childhood sexual abuse.¹² In addition, some intersex people end up not identifying with the sex assignment they are given as children¹³ – and if surgery was performed to enforce that assignment, this can be deeply distressing, especially when it limits options for other gender-affirming procedures that might be desired when they become consenting adolescents and adults.

The American Academy of Pediatrics affirmed over 20 years ago the importance of protecting

⁷ Sarah Creighton et al., “Timing and nature of reconstructive surgery for disorders of sex development,” *Journal of Pediatric Urology*, 8(6): 602-10 (2012); Martin Kaefer, Richard C. Rink, “Treatment of the Enlarged Clitoris,” *Frontiers in Pediatrics*, 28 August 2017, <http://journal.frontiersin.org/article/10.3389/fped.2017.00125/full>.

⁸ Hazel Glen Beh and Milton Diamond, “An emerging ethical and medical dilemma: should physicians perform sex assignment surgery on infants with ambiguous genitalia?” *Michigan Journal of Gender & Law*, 7(1): 1-63 (2000); Creighton et al., *supra* note 4.

⁹ Peter Lee et al., Review of Recent Outcome Data of Disorders of Sex Development (DSD): Emphasis on Surgical and Sexual Outcomes, *Journal of Pediatric Urology* (2012), available at <http://dx.doi.org/10.1016/j.jpuro.2012.10.017>; Sarah Creighton et al., Objective Cosmetic and Anatomical Outcomes at Adolescence of Feminising Surgery for Ambiguous Genitalia Done in Childhood, 358 *The Lancet* 124 (2001); N.S. Crouch et al., Sexual Function and Genital Sensitivity Following Feminizing Genitoplasty for Congenital Adrenal Hyperplasia, 179 *Journal of Urology* 634 (2008); C.L. Minto et al., The Effects of Clitoral Surgery on Sexual Outcome in Individuals who have Intersex Conditions with Ambiguous Genitalia: A Cross-Sectional Study, 361 *The Lancet* 1252 (2003).

¹⁰ Amnesty International, “First, Do No Harm: Ensuring the Rights of Children with Variations of Sex Characteristics in Denmark and Germany,” May 9, 2017, <https://www.amnesty.org/en/documents/eur01/6086/2017/en/>

¹¹ Marcus de Maria Arana, A Human Rights Investigation into the Medical “Normalization” of Intersex People: A Report of a Public Hearing by the Human Rights Commission of the City and County of San Francisco (April 28, 2005), available at http://sfhrc.org/site/uploadedfiles/sfhumanrights/Committee_Meetings/Lesbian_Gay_Bisexual_Transgender/HRC%20Intersex%20Report.pdf; Schützmann et al. (2009), Psychological distress, suicidal tendencies, and self-harming behaviour in adult persons with different forms of intersexuality, *Arch Sex Behav.* 2009 Feb;38(1):16-33.

¹² Tamara Alexander, *The Medical Management of Intersexed Children: An Analogue for Childhood Sexual Abuse* (1997), available at <http://www.isna.org/articles/analogue>.

¹³ Ieuan Hughes et al., Consensus Statement on Management of Intersex Disorders, 91 *Archives of Disease in Childhood* 554 (2006); P.S. Furtado et al., Gender Dysphoria Associated with Disorders of Sex Development, *Nat. Rev. Urol.* (9 October 2012), available at: [doi:10.1038/nrurol.2012.182](https://doi.org/10.1038/nrurol.2012.182); A. Binet et al., Should We Question Early Feminizing Genitoplasty for Patients with Congenital Adrenal Hyperplasia and XX Karyotype?, *Journal of Pediatric Surgery* 51:3: 465-468 (2016).



children's "developing autonomy."¹⁴ For intersex children, autonomy should include the right to make choices on what is done to their bodies as consenting adults. Intersex children are entitled to a model of care that prioritizes their well-being rather than discriminatory gender binaries. Almost all intersex children are born healthy and with no need for surgery on their genitals or reproductive organs, and these surgeries should be delayed except in emergency situations. Performing surgeries that are invasive, irreversible and performed not for emergency reasons but to 'normalise' a child's body – such as cutting down the size of a "large" clitoris, removing potentially fertile and hormone-producing gonads, or creating a vagina in a child who may never want or need one – is a violation of the child's rights to bodily integrity, to the highest attainable standard of health, and to be free from harmful practices based on gender stereotypes. The American Medical Association is in a position where it has the opportunity be a leader for its member physicians and for the patients that they care for.

It is the strongly held position of Amnesty International that intersex rights are human rights; and that intersex children deserve, as all children do, to meaningfully participate in choices about their body, health, and self. We urge you to act in support of intersex human rights defenders who have worked to end discrimination against intersex individuals, and in support of the highest attainable standard of health for intersex persons.

Sincerely,

Tarah Demant
Director
Gender, Sexuality, and Identity Program
Amnesty International USA
600 Pennsylvania Avenue SE, Washington, DC

CC: Elliott Crigger, PhD, CEJA Secretary, AMA
Craig Johnson, Minority Affairs Section, AMA
Scott Chalet, LGBTQ Section Chair, AMA
CEJA members

¹⁴ AAP Committee on Bioethics, "Informed Consent, Parental Permission, and Assent in Pediatric Practice," *Pediatrics* 95(2):314-17



January 31, 2018

Dennis S. Agliano, MD, FACS
Chair
American Medical Association
Council on Ethical Judicial Affairs
AMA Plaza
330 N. Wabash Avenue, Suite 39300
Chicago, IL 60611-5885

Dear Dr. Agliano:

We understand that the American Medical Association (AMA) Council on Ethical and Judicial Affairs (CEJA), which you chair, is currently considering a policy regarding intersex people/people affected by differences of sex development (DSD). I am aware that the AMA Board of Trustees in 2016 recommended a course of action, which prompted review by the CEJA.

As you may know, GLSEN is the leading national education organization working to create safe and affirming schools for all students, regardless of sexual orientation, gender identity, or gender expression. Our work includes a biennial survey of secondary schools students assessing school climate for lesbian, gay, bisexual, transgender, queer or questioning (LGBTQ) youth, programmatic support for students and educators across the country, a chapter network of volunteers in 26 states, and public policy advocacy at all levels of government. Since our founding in 1990, GLSEN has become a globally-recognized leader on school climate and culture.

We know that not all intersex young people identify as LGBTQ, but many certainly do. Decisions made by surgeons have longstanding consequences on these youth. We believe that the common rationale for performing medically-unnecessary surgery on intersex youth – particularly those who are subjected to surgery before even being able to walk or talkⁱ – is often rooted in sex stereotypes and serves no necessary purpose.^{ii,iii} We also believe that other lines of rationale, such as the notion that *not* performing surgery will leave the child confused about their gender,^{iv} is rooted in antiquated conceptions of gender identity development and limits the ability of young people to express their gender freely.

While it is understandable for parents and doctors to want to improve the lives of the young people they care for, medically-unnecessary surgery to “normalize” the bodies of intersex children is misguided. Indeed, making these decisions for young people is reminiscent of sexual orientation change efforts, often called “conversion therapy,” being applied to young LGB youth – efforts which have been shown to be deeply harmful, in addition to ineffective.

Intersex children, like LGBTQ children, can thrive without medical intervention if they receive social support from their families and care providers. There are no known negative psychological outcomes associated with simply being intersex, despite the baseless argument that growing up with atypical sex characteristics will adversely impact a child’s mental and emotional health. Harm, however, is caused by the practice of non-consensual, medically-unnecessary surgery. Studies have found that intersex people who have been subjected to these surgeries experience depression, PTSD, and suicidality^v and carry trauma comparable to survivors of childhood sexual abuse.^{vi} Additionally, research has found that many intersex people end up identifying with a gender that is different than the sex they were assigned as children.^{vii} Performing surgery that reinforces

that assignment can be deeply distressing and may hinder options available for gender transition when they become consenting adults.

By adopting a position opposing medically-unnecessary surgeries on intersex children and youth, the AMA would be acting in concert with leading international organizations. The United Nations Human Rights Council has determined that nonconsensual genital “normalizing” surgery on intersex children is a form of ill-treatment, and the World Health Organization has publicly opposed early genital or sterilizing surgeries on intersex youth.

GLSEN urges the AMA to pass and implement a policy in favor of respecting the autonomy of pediatric patients with DSD, including clear guidance that, unless medically necessary, no surgeries should be performed on the intersex child until they are old enough to give informed consent for the procedures. We thank you for your attention and consideration of this important issue. For additional information or to discuss further, please contact Nathan Smith, GLSEN's Director of Public Policy, at nathan.smith@glsen.org or by phone at (202) 621-5815.

Sincerely,



Eliza Byard, Ph.D.
Executive Director

CC David O. Barbe, MD, MHA, President, American Medical Association
Elliott Crigger, CEJA Director
Craig Johnson, Minority Affairs Section Director
Scott Chaiet, LGBTQ Advisory Board Chair

ⁱ Sarah Creighton and Lih-Meh Liao, “Changing attitudes to sex assignment in intersex,” *BJU International* 93: 659-64 (2004).

ⁱⁱ Sarah Creighton et al., “Timing and nature of reconstructive surgery for disorders of sex development,” *Journal of Pediatric Urology*, 8(6): 602-10 (2012); Martin Kaefer, Richard C. Rink, “Treatment of the Enlarged Clitoris,” *Frontiers in Pediatrics*, 28 August 2017, <http://journal.frontiersin.org/article/10.3389/fped.2017.00125/full>.

ⁱⁱⁱ Hazel Glen Beh and Milton Diamond, “An emerging ethical and medical dilemma: should physicians perform sex assignment surgery on infants with ambiguous genitalia?” *Michigan Journal of Gender & Law*, 7(1): 1-63 (2000); Creighton et al., *supra* note 4.

^{iv} P. Mouriquand et al., “The ESPU/SPU standpoint on the surgical management of disorders of sex development (DSD),” *Journal of Pediatric Urology* 10(1): 8-10 (2014).

^v Marcus de Maria Arana, *A Human Rights Investigation into the Medical “Normalization” of Intersex People: A Report of a Public Hearing by the Human Rights Commission of the City and County of San Francisco* (April 28, 2005), available at http://sfhrc.org/site/uploadedfiles/sfhumanrights/Committee_Meetings/Lesbian_Gay_Bisexual_Transgender/HRC%20Intersex%20Report.pdf; Schützmann et al. (2009), Psychological distress, suicidal tendencies, and self-harming behaviour in adult persons with different forms of intersexuality, *Arch Sex Behav*. 2009 Feb;38(1):16-33.

^{vi} Tamara Alexander, *The Medical Management of Intersexed Children: An Analogue for Childhood Sexual Abuse* (1997), available at <http://www.isna.org/articles/analogue>.

^{vii} Ieuan Hughes et al., *Consensus Statement on Management of Intersex Disorders*, 91 Archives of Disease in Childhood 554 (2006); P.S. Furtado et al., *Gender Dysphoria Associated with Disorders of Sex Development*, *Nat. Rev. Urol.* (9 October 2012), available at: doi:10.1038/nrurol.2012.182; A. Binet et al., *Should We Question Early Feminizing Genitoplasty for Patients with Congenital Adrenal Hyperplasia and XX Karyotype?*, *Journal of Pediatric Surgery* 51:3: 465-468 (2016).

February 15, 2018
Dennis S. Agliano, MD, FACS
Chair, Council on Ethical and Judicial Affairs
American Medical Association
AMA Plaza
330 N. Wabash Ave., Suite 39300
Chicago, IL 60611-5885

Dear Dr. Agliano:

At the 2016 AMA Annual Meeting of the House of Delegates, the Medical Student Section introduced a resolution entitled “Supporting Autonomy for Patients with Differences of Sex Development,” which asked that our AMA affirm that medically unnecessary surgeries in individuals born with differences of sex development are unethical and should be avoided until the patient can actively participate in decision-making. The House of Delegates referred this resolution for study, and the Board of Trustees returned a report at the Interim 2016 House of Delegates that was likewise referred for study. The issue then came before the Council on Ethical and Judicial Affairs; CEJA Report 3 at Interim 2017 was also referred. As the author of the original resolution that led to Council on Ethics and Judicial Affairs Report 3-I-17, the Medical Student Section is grateful for the opportunity to offer additional information and updated literature for the Council’s consideration.

As the Council heard at the Reference Committee hearing, the Medical Student Section was concerned that the Interim 2017 report did not directly address care for the population of patients with differences of sex development (DSD). A main goal of the original resolution was to address the issue of surgeries performed on this population in early infancy for the purpose of normalizing the cosmetic appearance of genitalia and/or to define patient gender, such as clitoroplasty, vaginoplasty, labiaplasty, and gonadectomy. Such surgeries have unique implications for issues of sex/gender identity, sexual orientation, procreative potential, and sexual function, each of which we believe intrinsically merits discussion. We were heartened that the Council recognized the integral role that physicians play in influencing parental decision-making for these patients, as illuminated by Streuli et al. Also noted by the Council was the lack of unanimous opinion or definitive evidence surrounding of the timing of genital surgeries for these patients, as discussed by Machado et al. In light of these considerations, we believe the Council should support the autonomy of patients with DSD by encouraging physicians to postpone cosmetic and genital-normalizing surgeries.

We believe physicians should offer optimized multi-disciplinary management for patients with differences of sex development that provides psychosocial support for both children and families, respects the rights of the patient to participate in decisions, and, except when medically necessary, defers surgical intervention for the purpose of genital normalizing until the child is able to participate in decision making. Multiple patient advocacy and medical groups have rejected early genital surgery, and instead promote multidisciplinary care and peer support similar to that which we see for a range of congenital conditions. In no way are we proposing a complete ban on cosmetic genital surgery, but that these surgeries are delayed until the child can be involved in decision-making.

Proponents of early surgery point to limited studies with adult patients who favor earlier surgery, and to a perceived greater psychological impact of late genital surgery. The studies often cited to support this position compare early versus late surgery, but do not examine outcomes of patients who did not receive surgery at all. In fact, there is a growing body of evidence that individuals with DSD who delay or do not

undergo surgery do not suffer additional harm as a result. Ultimately, there is a significant lack of definitive evidence to support the timing of surgery or decision to undergo surgery. Although the proposed concerns merit attention, we do not feel that they justify the practice of medically unnecessary treatment and surgery without consent in light of documented physical and psychological harm from these procedures. The potential psychological harm associated with delayed surgery can be addressed, while adverse outcomes of irreversible surgical intervention cannot be undone.

In the supporting materials attached to this letter, we have provided several additional arguments and literature in support of deferral.

Thank you for your consideration of these materials, and for taking on this important issue. We would be happy to offer any other information that may assist the Council in its deliberations.

Sincerely,

American Medical Association - Medical Student Section
Jerome Jeevarajan, Delegate
Kieran McAvoy, Alternate Delegate

CC:

Elliott Crigger, PhD, CEJA Secretary, AMA
Craig Johnson, Minority Affairs Section, AMA
Scott Chalet, MD, MBA, FACS, LGBTQ Section Chair, AMA

An outline of the argument in support of deferring early surgery, followed by an expanded version with specific literature:

1. Individuals with DSD can do well without early surgery, and early surgery is not necessary to assign gender at birth.
2. There is no medical reason for alteration of the clitoris, vagina, and labia.
3. Early sex assignment surgery performed on genitalia may irreversibly assign the individual a sex incongruent with their actual gender identity, a potentially catastrophic outcome with profound psychological consequences. Notably, some individuals may not identify within the male/female gender binary.
4. Early surgery on genitalia can lead to significant adverse surgical outcomes, including but not limited to loss of sensitivity, orgasmic function, and fertility, as well as chronic pain and dyspareunia. While some or even many individuals may be willing to choose such surgery, infants cannot participate in this decision. The argument that surgery should be done early in life to prevent the psychological impact associated with late surgery does not hold if there are multiple re-operations (as there frequently are) and assumes that all individuals would choose surgery as an inevitable outcome.
5. Between sexual function and cosmetic appearance, what is more important is a highly personal assessment. Ideally, both would be preserved, but in selecting surgery, appearance is often prioritized at the expense of function. Some studies indicate that some individuals would choose function over cosmetic appearance given the choice.
6. As children with atypical genitalia age, they may desire to have genital-normalizing surgery performed, as would be their prerogative. While some proponents argue that it may be easier to perform surgery on children than adults, there are no data from studies comparing this outcome. In addition, it could be argued that outcomes may be better in post-pubertal individuals with estrogenized tissues. Surgery can be performed successfully on adult women with preservation of orgasmic function.
7. Studies reporting that a high percentage of individuals prefer early surgery often do not offer individuals the option to answer the question “Would you have wanted surgery at all?” and do not often include controls with the condition in question that remain unoperated. It is also notable that individuals that are particularly displeased with their medical care may refuse to participate, though the converse may also be true.
8. While individuals with DSD may express distress with regards to their atypical genitalia, it is also quite common for individuals without DSD to experience concern over the appearance of their (“normal”) genitalia. Addressing such cases would begin with psychosocial support, education, attempting to address societal pressures and barriers, and potentially surgery if the individuals so desired. However, in such cases, it is unlikely that surgery would be the initial intervention.
9. A common argument for early intervention is the prevention of stigma with regard to atypical genitalia. However, this does not take into account whether the surgeries to make genitalia appear more typical may also cause stigma. There is no evidence that deferring early surgery causes psychological distress, and there is no evidence that performing early surgery prevents psychological distress. In addition, there is evidence that the medicalization of children with DSD and frequent genital exams contribute to distress and stigma. Finally, psychological distress should be most appropriately managed initially through psychosocial support.
10. Early surgery on genitalia has caused significant distress to many individuals with DSD.
11. Parental desire to avoid difficult decisions, concerns about hypothetical stigma, and concerns about normality should not be the main impetus for surgical management, but rather should be managed with psychosocial support. The following literature implies that parental distress stems

from an inadequate understanding of DSD and the perceived impact on their newborn. Offering psychosocial support that provides a de-medicalized explanation of their baby's genital diversity alleviates this distress and reduces perceived need for early cosmetic surgery. Regardless of the decision to postpone or proceed with surgery at any age, appropriate counseling and support for the individual and family is essential.

12. There are arguments in favor of early surgery to prevent development of malignancy; however, malignancy rates are not uniform across individuals with DSD and risk should be evaluated with respect to their specific condition.
13. Potential for fertility should remain a consideration in decision-making.
14. Early genital surgery for cosmetic purposes subjects children to unjustifiable risks of pediatric anesthetic neurotoxicity.

Expanded argument in support of deferring early surgery with specific literature:

1. Individuals with DSD can do well without early surgery, and early surgery is not necessary to assign gender at birth.
 - a. **Bougneres P, Bouvattier C, Cartigny M, Michala L. Deferring surgical treatment of ambiguous genitalia into adolescence in girls with 21-hydroxylase deficiency: a feasibility study. International Journal of Pediatric Endocrinology. 2017;2017(3). doi: 10.1186/s13633-016-0040-8.** This study is of a small sample size of seven girls up to age 8 with CAH with Prader III-IV stages who have remained unoperated. Results suggest that is “acceptable among patients and families to defer genital operation in [21-hydroxylase deficiency]...[G]irls and their parents have not expressed significant concerns regarding genital ambiguity.” The authors conclude: “With these encouraging data at hand, we propose to formally address levels of anxiety, adaptation and quality of life during childhood, with an ultimate goal to assess long- term satisfaction and effects on sexuality through deferring genital surgery.” This demonstrates that children, even those with 46,XX CAH, can be assigned and raised as a certain gender without surgical intervention. The child is free to develop their own gender identity, and at a later point express their desire for genital surgery if they wish.
 - b. **Callens N, van der Zwan YG, Drop SLS, et al. Do surgical interventions influence psychosexual and cosmetic outcomes in women with disorders of sex development? ISRN Endocrinology. 2012:1-8. doi: 10.5402/2012/276742.**

This is a study performed in Netherlands and Belgium, featuring 33 intersex participants who had not undergone surgeries, which found that women with complete absence of the vagina (e.g., CAIS) demonstrated no psychological or developmental problems until they reached menstruation and concluded vaginal surgery should be deferred until later in life. Construction of a vagina was not necessary for female gender assignment.
2. There is no medical reason for alteration of the clitoris, vagina, and labia.
 - a. **Kaefer M, Rink RC. Treatment of the enlarged clitoris. Frontiers in Pediatrics. 2017;5(125):1-11. doi: 10.3389/fped.2017.00125.** This is a review of current management of clitoromegaly, including discussion of perioperative counseling and the timing of clitoroplasty. With regard to indication for clitoroplasty, the authors comment: “At present, the decision to perform genital surgery in children with clitoromegaly is intensely debated. As with all reconstructive surgery for patients with Disorders of Sex Development (DSD), three specific reasons for intervening are typically considered: providing anatomy suitable for penile-vaginal intercourse, achieving a manner for urination commensurate with gender identity (i.e., sitting for females, standing for males), and providing a phenotypical appearance that resembles the assigned gender. Since the only known function of the clitoris itself is to provide sexual pleasure, the later goal is the only one that is relevant to the discussion of clitoroplasty.”
 - b. **Creighton SM, Michala L, Mushtaq I, Yaron M. Childhood surgery for ambiguous genitalia: glimpses of practice changes or more of the same? Psychology and Sexuality. 2013. doi: 10.1080/19419899.2013.831214.** While a main stated goal of clitoral reduction surgery is a “feminine” appearance, “[t]he size of the clitoris can vary significantly amongst women without a DSD and there is no defined normal range for children.” Because of this, “the [2006] consensus statement recommends no surgery for girls with minor and moderate degrees of clitoral enlargement until they can decide for themselves.” The perception of clitoral size, however, is ultimately subjective: “Some

families cope well with more severe degrees of clitoral enlargement and are keen to postpone surgery. Other families are very distressed by what would appear to clinicians as very minor degrees of clitoral enlargement.” Therefore, on the continuum of clitoral size, which individuals are and are not recommended for reduction surgery depends on the perception of individual doctors and/or caregivers, not defined medical standards.

- c. **Wolffenbittel KP, Crouch NS. Timing of feminising surgery in disorders of sex development. In: Hiort O, Ahmed SF, eds. Understanding Differences and Disorders of Sex Development (DSD). Endoc Dev. Basel, Karger; 2014;27:210-221:** “Vaginal surgery may be indicated either to allow unobstructed menstrual flow, such as for those with CAH, or to develop a vagina suitable for intercourse for those with vaginal hypoplasia. Where there is no uterus and no risk to obstructed menstrual flow, the only indication for the development of a vagina is when the girl is ready to become sexually active. A child has no need of a vagina, and the timing can appropriately be deferred until adolescence.”
3. Early sex assignment surgery performed on genitalia may irreversibly assign the individual a sex incongruent with their actual gender identity, a potentially catastrophic outcome with profound psychological consequences. Notably, some individuals may not identify within the male/female gender binary.
 - a. **Furtado PS, Moraes F, Lago R, et al. Gender dysphoria associated with disorders of sex development. Nature Reviews Urology. 2012;9:620-627. doi:10.1038/nrurol.2012.182.** Gender dysphoria is reported in approximately 5% of individuals with complete androgen insensitivity syndrome; 10% of individuals with congenital adrenal hyperplasia; 12.5% of individuals with ovotesticular DSD; 20% of individuals with partial androgen insensitivity syndrome; 29% of individuals with mixed gonadal dysgenesis; 39% of individuals with cloacal exstrophy; 57% of individuals with 17-beta-hydroxysteroid dehydrogenase deficiency; and 63% of individuals with 5-alpha-reductase deficiency.
 - b. **Lee PA, Houk CP, Ahmed SF, Hughes IA. Consensus statement on management of intersex disorders. Pediatrics. 2006;118(2):e488-e500. doi:10.1542/peds.2006-0738.** Rates of gender assignment rejection reach approximately 10% for individuals with congenital adrenal hyperplasia; 25% for individuals with partial androgen insensitivity syndrome, androgen biosynthetic defects, and incomplete gonadal dysgenesis; 35% for individuals with cloacal exstrophy; and 60% for individuals with 5-alpha-reductase deficiency.
 - c. **Schweizer K, Brunner F, Handforda C, Richter-Appelt H. Gender experience and satisfaction with gender allocation in adults with diverse intersex conditions (divergences of sex development, DSD). Psychology & Sexuality. 2013.** Of the 69 participants, 26% felt uncertain about belonging to a specific binary gender category.
 4. Early surgery on genitalia can lead to significant adverse surgical outcomes, including but not limited to loss of sensitivity, orgasmic function, and fertility, as well as chronic pain and dyspareunia. While some or even many individuals may be willing to choose such surgery, infants cannot participate in this decision. The argument that surgery should be done early in life to prevent the psychological impact associated with late surgery does not hold if there are multiple re-operations (as there frequently are) and assumes that all individuals would choose surgery as an inevitable outcome.

- a. **Lee P, Schober J, Nordenström A, et al. Review of recent outcome data of disorders of sex development (DSD): emphasis on surgical and sexual outcomes. Journal of Pediatric Urology. 2012;8(6):611–615. doi: <https://doi.org/10.1016/j.jpuro.2012.10.017>** In one study, among “57 46,XY DSD adults who had undergone genital surgery, 47.1% were dissatisfied with functional results, 47.4% with clitoral arousal and 37.5% with overall sex life; 44.2% had sexual anxieties, 70.6% had problems with desire and 56.3% reported dyspareunia.”
- b. **Minto CL, Liao LM, Woodhouse CR, et al. The effect of clitoral surgery on sexual outcome in individuals who have intersex conditions with ambiguous genitalia: a cross-sectional study. Lancet. 2003;361(9365):1252-7. doi: 10.1016/S0140-6736(03)12980-7:** Of 39 intersex adults living as female, all 28 who were sexually active had sexual difficulties. 18 who had undergone clitoral surgery had higher rates of non-sensuality (78%) and of inability to achieve orgasm (39%) than the 10 who did not (20% and 0%).
- c. **Creighton SM. Long-term outcome of feminization surgery: the London experience. BJU International. 2004;93(3):44-46:** “Any incision to the clitoral glans, corpora or hood may risk damage to the innervation. ...Those who had undergone clitoral surgery were significantly less likely to achieve orgasm than those who had not had surgery (26% anorgasmia vs 0%, respectively). . . .The study suggests that cosmetic surgery to the clitoris does not ensure improved adult sexual function and indeed might cause damage.”
- d. **Crouch NS, Minto CL, Liao LM, et al. Genital sensation after feminizing genitoplasty for congenital adrenal hyperplasia: a pilot study. BJU International. 2003;93(1):135-8. doi: 10.1111/j.1464-410X.2004.04572.x** In a sample of six women with CAH who had previously undergone surgery, all six were found to have “highly abnormal” results for sensation in the clitoris following thermal, vibratory, and light-touch sensory threshold assessment. Results for the unoperated upper vagina were within the normal range.
- e. **Nordenskjöld A, Holmdahl G, Frisen L, et al. Type of mutation and surgical procedure affect long-term quality of life for women with congenital adrenal hyperplasia. Clin Endocrinol Metab 2008;93:380–386:** There were 62 women with CAH studied. Of the 49 women with CAH who had surgery, 16 had only one procedure, and of these, 10 had the operation at puberty. 33 of the women had multiple re-operations, with 11 women having five or more surgeries. 20.4% of patients were unhappy with surgery. With regard to cosmetic appearance, “[t]he highest scores were given in the nonoperated group.” Operated women experience reduced sensitivity. Six women stated they never achieved orgasm, with five of the six having clitoral surgery.
- f. **Fagerholm R, Santtila P, Miettinen PJ, Mattila A, Rintala R, Taskinen S. Sexual function and attitudes toward surgery after feminizing genitoplasty. Journal of Urology 2011;185:1900-1904. DOI:10.1016/j.juro.2010.12.099:** 43% of patients who underwent vaginoplasty surgeries in infancy needed re-operations. 54% required vaginal dilations under general anesthesia starting at a median age of 13 years. 58% ended up needing to perform vaginal self-dilations as a result of these surgeries starting at a median age of 17 years (range 14 to 23). Of the 14 patients with vaginal self-dilations 6 (46%) experienced the dilations as distressing. Nearly 1 in 4 patients reported dissatisfaction with genital sensation -- both vaginal and clitoral. The pain index was worse in the patients (especially in the CAH group) than in the controls.

5. Between sexual function and cosmetic appearance, what is more important is a highly personal assessment. Ideally, both would be preserved, but in selecting surgery, appearance is often prioritized at the expense of function. Some studies indicate that some individuals would choose function over cosmetic appearance given the choice.
 - a. **Nordenström A et al. Sexual function and surgical outcome in women with congenital adrenal hyperplasia due to *CYP21A2* deficiency: clinical perspective and the patients' perception. *The Journal of Clinical Endocrinology & Metabolism*. 2010;95(8):3633–3640, <https://doi.org/10.1210/jc.2009-2639>:** “Our study shows that the sexual function score, but not the score for genital appearance, was higher in the patients satisfied with their sexual life and in the patients who stated that they were satisfied with the surgical result. This confirms that function should be of higher priority than genital appearance in treatment decisions.”
6. As children with atypical genitalia age, they may desire to have genital-normalizing surgery performed, as would be their prerogative. While some proponents argue that it may be easier to perform surgery on children than adults, there are no data from studies comparing this outcome. In addition, it could be argued that outcomes may be better in post-pubertal individuals with estrogenized tissues. Surgery can be performed successfully on adult women with preservation of orgasmic function.
 - a. **Tjalma WW. Assembling a functional clitoris and vulva from a pseudo-penis: a surgical technique for an adult woman with congenital adrenal hyperplasia. *Journal of Pediatric and Adolescent Gynecology*. 2017;30:425e428:** This is a case report of a woman with CAH who underwent a corpora-preserving clitoroplasty as an adult. The author states this technique is typically used in children, and there may need to be removal of the corpora cavernosa and recurrent procedures. In this case, due to the patient's age, she was able to have a single-stage procedure and preservation of the corpora cavernosa. At the patient's 6 year follow-up, she remained able to orgasm and had a good cosmetic result. While this is a solely a case report, it does demonstrate the feasibility of delaying surgery, with arguably better results in adulthood.
7. Studies reporting that a high percentage of individuals prefer early surgery often do not offer individuals the option to answer the question “Would you have wanted surgery at all?” and do not often include controls with the condition in question that remain unoperated. It is also notable that individuals that are particularly displeased with their medical care may refuse to participate, though the converse may also be true.
 - a. **Nordenskjöld et al.** 20 of the women surveyed preferred early timing of surgery, while 9 preferred surgery at puberty; however, the opinions of the remaining 33 women are not indicated. It is possible these 33 women would have preferred no surgery at all if given the option.
 - b. **Wisniewski AB, Migeon CJ, Malouf MA, Gearhart JP. Psychosexual outcome in women affected by congenital adrenal hyperplasia due to 21-hydroxylase deficiency. *Journal of Urology*. 2004;171:2497–2501:** When asked about the optimal timing for surgery, 31% of the simple virilizing (SV) group and 41% in the salt-losing group, responded “during infancy,” a minority response. However, 31% of participants in the SV group did not answer -- the same number as answered that the optimal timing was during infancy. Participants were not asked if they would rather not have had surgery at all. From this, it would be misleading to conclude that patients surveyed felt the optimal timing was during infancy.

- c. **Binet A, Harty H, Geslin D, Francois C, Poli-Merol ML. Should we question early feminizing genitoplasty for patients with congenital adrenal hyperplasia? Journal of Pediatric Surgery. 2016;51:465-468:** The sample was divided into early and late surgery groups, with age-matched controls. However, there was no control group of intersex individuals who did not have surgery. While 90% of CAH patients responded that genitoplasty should be performed during the first year of life, there was no response option for patients who would not want to have surgery at all.
 - d. **Fagerholm et al.** While the authors state 17 of 24 patients thought that genital surgery was performed at a proper age (infancy), notably the outreach for this original survey yielded a 50% response rate, meaning it is possible that only those who were happy with their surgical outcomes volunteered to participate in the research. The authors failed to take into account respondents who did not want surgery at all, with the only opportunity to indicate this being the last response option on a question about timing of surgery (“Was the genital surgery done at the proper age?”), which may lead respondents to believe genital surgery was an inevitable part of treatment. Regardless, two patients reported believing that their surgery should not have been done at all.
8. While individuals with DSD may express distress with regards to their atypical genitalia, it is also quite common for individuals without DSD to experience concern over the appearance of their (“normal”) genitalia. Addressing such cases would begin with psychosocial support, education, attempting to address societal pressures and barriers, and potentially surgery if the individuals so desired. However, in such cases, it is unlikely that surgery would be the initial intervention.
 - a. **Lloyd J, Crouch NS, Minto CL, Liao L-M, Creighton SM. Female genital appearance: ‘normality’ unfolds. BJOG: An International Journal of Obstetrics & Gynaecology. 2005;112:643–646. doi:10.1111/j.1471-0528.2004.00517.x:** This study of 50 women found wide variations in the dimensions and appearance of the external female genitalia measured, expanding the definition of “normal” female genitalia.
 - b. **Schick VR, Calabrese SK, Rima BN, Zucker AN. Genital appearance dissatisfaction: Implications for women's genital image self-consciousness, sexual esteem, sexual satisfaction, and sexual risk. Psychology of Women Quarterly. 2010;34(3):394-404.** There is significant evidence that even women with “normal” genitalia experience concern over the appearance of their genitalia due to societal pressures.
 - c. **Vaginal "rejuvenation" and cosmetic vaginal procedures. ACOG Committee Opinion No. 378. American College of Obstetricians and Gynecologists. Obstet Gynecol 2007;110:737–8. And Breast and labial surgery in adolescents. Committee Opinion No. 686. American College of Obstetricians and Gynecologists. Obstet Gynecol 2017;129:e17-9.** As ACOG has noted in its own policies, there are wide ranges of “normal” appearances for genitalia, and “surgical alteration of the labia that is not necessary to the health of the adolescent, who is younger than 18 years, is a violation of federal criminal law.”
9. A common argument for early intervention is the prevention of stigma with regard to atypical genitalia. However, this does not take into account whether the surgeries to make genitalia appear more typical may also cause stigma. There is no evidence that deferring early surgery causes

psychological distress, and there is no evidence that performing early surgery prevents psychological distress. In addition, there is evidence that the medicalization of children with DSD and frequent genital exams contribute to distress and stigma. Finally, psychological distress should be most appropriately managed initially through psychosocial support.

- a. **Meyer-Bahlburg HF, Reyes-Portillo JA, Khuri J, Ehrhardt AA, New MI. Syndrome-related stigma in the general social environment as reported by women with classical congenital adrenal hyperplasia. Archives of Sexual Behavior. 2017;46:341–351. doi: 10.1007/s10508-016-0862-8:** “Whether the discovery of having genitals different from those of other girls or women became an adverse experience appeared to depend in part on parental reactions,” suggesting that if parents were counseled appropriately, these negative experiences could be avoided. Stigma was associated with many features not related to genital appearance (such as hirsutism), and “stigma related to genital ambiguity was rarely reported for the specific social contexts [stigma by parents, media, peers] on which the present article is focused.” When stigma is experienced, it does not necessarily follow that the best solution is surgical “normalization” rather than psychosocial support. (Note that the Meyer-Bahlburg et al. articles reference the same group of women, and that their generalizability is limited due to not including a significant number of women with CAH who were unoperated.)
 - b. **Meyer-Bahlburg HF, Khuri JR, et al. Stigma associated with classical congenital adrenal hyperplasia in women’s sexual lives. Archives of Sexual Behavior. 2017.** While 40% of the 62 women reported stigma with respect to romantic/sexual partners, concerns surrounded features (such as hirsutism) that are not addressable by surgery in addition to atypical genitals. While some were happy to have genital surgery, some reports of stigma came from women who had early genital surgery with an unsatisfactory outcome, indicating that early genital surgery does not eliminate experienced stigma.
 - c. **Meyer-Bahlburg HF, Khuri JR, et al. Stigma in medical settings as reported retrospectively by women with congenital adrenal hyperplasia (CAH) for their childhood and adolescence. Journal of Pediatric Psychology. 2016. doi: 10.1093/jpepsy/jsw034:** Of the approximately two-thirds of participating women with CAH who reported stigma experiences, “[a]ccounts pertaining specifically to medical settings were provided by 17 women (27%)...About a quarter of the participating women with CAH reported experiencing the genital examinations in childhood and adolescence as adverse events that contributed to their sense of [stigma].”
 - d. **Callens et al.** Notably, a third of the 91 patients refused a gynecological exam during the study as they had undergone exams that were experienced as shameful. This also raises the question whether “the very approach that was adopted to prevent psychological maladjustment to DSD [genital surgery] is in fact the cause of the high levels of psychological and sexual distress reported.”
10. Early surgery on genitalia has caused significant distress to many individuals with DSD.
- a. **a. Schützmann K, Brinkmann L, Schacht M, Richter-Appelt H. Psychological distress, suicidal tendencies, and self-harming behaviour in adult persons with different forms of intersexuality. Archives of Sexual Behavior 2009;38(1):16-33. doi: 10.1007/s10508-007-9241-9.** In a sample of 37 intersex people (all but one of whom had previously undergone genital surgery, gonadectomy, or both): 59% met the criteria for clinical distress, with a history of gonadectomy significantly linked to increased distress; 46% reported having had suicidal thoughts, again significantly linked to previous

gonadectomy. Suicidal ideation was comparable between intersex respondents and women who had experienced physical or sexual abuse, while rates of self-harming behavior were higher than in women with a history of either kind of abuse.

- b. **The Foundation for Narrative Inquiry in Bioethics. VOICES Personal Stories from the Pages of NIB: Normalizing Intersex. John Hopkins University Press; 2016.** http://narrativebioethics.com/wp-content/uploads/2017/07/Voices_2016_INTERSEX_FINAL.pdf: Multiple personal accounts exist from individuals with DSD who experienced trauma as a result of early surgery.
 - c. **Schweizer K, Brunner F, Gedrose B et al. Coping with diverse sex development: treatment experiences and psychosocial support during childhood and adolescence and adult well-being. Journal of Pediatric Psychology. 2017;42(5):504–519.** <https://doi.org/10.1093/jpepsy/jsw058>: Of the studied 69 participants: 64% had gonadectomy, 55% had genital surgery, of which 44% had repeated surgery. 62% experienced psychological distress; the lifetime prevalence of suicidality was 45%. A history of gonadectomy was correlated with prevalence of suicidal thoughts.
11. Parental desire to avoid difficult decisions, concerns about hypothetical stigma, and concerns about normality should not be the main impetus for surgical management, but rather should be managed with psychosocial support. The following literature implies that parental distress stems from an inadequate understanding of DSD and the perceived impact on their newborn. Offering psychosocial support that provides a de-medicalized explanation of their baby's genital diversity alleviates this distress and reduces perceived need for early cosmetic surgery. Regardless of the decision to postpone or proceed with surgery at any age, appropriate counseling and support for the individual and family is essential.
- a. **Bennecke E, Werner-Rosen K, Thyen U, et al. Subjective need for psychological support (PsySupp) in parents of children and adolescents with disorders of sex development (dsd). European Journal of Pediatrics. 2015;174(10):1287-97. doi: 10.1007/s00431-015-2530-8.** "Our data show that sex assignment surgery neither reduces nor increases the need for [psychological support] in parents. **Schober argues that surgery makes parents and doctors more comfortable, but counselling makes people comfortable too, and it is not irreversible.** As surgery does not reduce the need for [psychological support] in parents, the fears and concerns of parents should not be the reasons for sex assignment surgery." Notably, 40% of parents in this study felt they needed psychological support. However, only half of these parents received any support.
 - b. **Tamar-Mattis A, Baratz A, Dalke KB, Karkazis K. Emotionally and cognitively informed consent for clinical care for differences of sex development. Psychology & Sexuality. 2014;5(1):44-55. doi: 10.1080/19419899.2013.831215.** The authors discuss the need for psychosocial support for families to help facilitate processing emotions in order to make informed decisions. They also note that quality peer support and sharing real-life perspectives is "very effective" for parents raising a child with DSD. They also note that "above all, parents must understand that there is no medical or surgical cure for the complex realities of rearing a child who has a physical difference."
 - c. **Binet et al.** The article cites the difficulty of discussing genital surgery with adolescent children as a reason to perform surgery during infancy. While the conversation may be difficult, the solution is to provide adequate counseling and therapy, not to unilaterally perform surgery simply to avoid this conversation.

- d. **Streuli JC, Vayena E, Cavicchia-Balmer Y, Huber J. Shaping parents: impact of contrasting professional counseling on parents' decision making for children with disorders of sex development. Journal of Sexual Medicine. 2013;10(8):1953-60. doi: 10.1111/jsm.12214.** This study assessed parental decision-making using third-year medical students as "parent" subjects. Found that 66% of "parents" chose genitoplasty for their hypothetical child when information was presented in a medicalized way by an endocrinologist, vs. 23% when information was presented in a de-medicalized way by a psychologist. Because the perception and assessment of their child's condition and treatment options can be heavily influenced by providers' framings, not all given parents have an inevitable preference for surgery. Management of parents' emotional and decision-making processes may pre-empt any desire for irreversible surgery on the child.
 - e. **Dayner JE, Lee PA and Houk CP. Medical treatment of intersex: Parental Perspectives. 2004;172:1762–1765. doi: 10.1097/01.ju.0000138519.12573.3a:** This study focuses on 21 parents of children with CAH and atypical genitalia, relying solely on parental perception of child genital appearance as an indicator of successful outcomes. All of the parents were advised by physicians to consent to genital surgery during their child's infancy, and 89% did consent. 95% of parents indicated that they would consent to genital surgery even if a reduction in their child's sexual sensation or responsiveness were certain, disregarding their children's potential prioritization of sensation over appearance. The study asserts that "[m]any parents related that the physical and psychological benefits of surgery in infancy permitted a more normal childhood by avoiding ostracism from others," but this claim has never been demonstrated in literature. No intersex patients were interviewed.
12. There are arguments in favor of early surgery to prevent development of malignancy; however, malignancy rates are not uniform across individuals with DSD and risk should be evaluated with respect to their specific condition.
 - a. **Spoor JA, Oosterhuis JW, Hersmus R, et al. Histological assessment of gonads in DSD: relevance for clinical management. Sex Development. 2017. doi:10.1159/000481757:** "In DSD, the malignancy risk is highly heterogeneous, but recent studies allow now to discriminate between high- and low-risk conditions."
 - b. **Lee PA, Houk CP, Ahmed SF, Hughes IA. Consensus statement on management of intersex disorders. Pediatrics. 2006;118(2), e488-e500. doi:10.1542/peds.2006-0738:** Lee et al provides further examples of the heterogeneity of patients who fall under the DSD umbrella. Patients with complete androgen insensitivity syndrome (CAIS) can defer surgery until adolescence, "recognizing that the earliest reported malignancy in CAIS is at 14 years of age." The risk of malignancy in a patient with mixed gonadal dysgenesis or streak gonads may justify earlier removal as a matter of medical necessity.
 - c. **Abacı A, Çathı G, Berberoğlu M. Gonadal malignancy risk and prophylactic gonadectomy in disorders of sexual development. 2015;28(9-10):1019-27. doi:10.1515/jpem-2014-0522:** "In the past, early gonadectomy was recommended for all cases of 46,XY DSD, however, according to current approaches, gonadal tumor risk is predicted based on the molecular diagnosis and the timing of the gonadectomy depends on the result of molecular analysis."
 - d. **Huang H, Wang C, Tian Q. Gonadal tumour risk in 292 phenotypic female patients with disorders of sex development containing Y chromosome or Y-derived sequence.**

Clinical Endocrinology Oxford. 2017;86(4):621-627. doi: 10.1111/cen.13255: The authors conclude that with monitoring and close follow-up, patients with AIS could postpone bilateral gonadectomy until or after adolescence.

13. Potential for fertility should remain a consideration in decision-making.
 - a. **Finlayson C, Fritsch MK, Johnson EK, et al. Presence of germ cells in disorders of sex development: Implications for fertility potential and preservation. The Journal of Urology. 2017;197(3):937-943.** “Germ cells were present in the majority of our cohort and the presence decreased with age. This novel, fertility driven evaluation of germ cell quantity in a variety of disorders of sex development suggests that fertility potential may be greater than previously thought.”
 - b. **Campo-Engelstein L, Chen D, Baratz AB, Johnson EK, Finlayson, C. The ethics of fertility preservation for pediatric patients with differences (disorders) of sex development. Journal of the Endocrine Society. 2017;1(6)638-645. doi: 10.1210/js.2017-00110** Future fertility potential should be considered in decision-making for individuals with DSD.
14. Early genital surgery for cosmetic purposes subjects children to unjustifiable risks of pediatric anesthetic neurotoxicity.
 - a. **Andropoulos DB, Greene MF. Anesthesia and developing brains — Implications of the FDA warning. New England Journal of Medicine. 2017;376:906-907.** In 2016, the FDA issued a warning that general anesthesia used in children less than 3 years old “may affect the development of children’s brains.” Texas Children’s Hospital limits procedures exposing young children to prolonged anesthesia to “serious or life-threatening congenital conditions for which there are no alternative treatments and for which treatment cannot be delayed.”

Multiple organizations oppose early genital surgeries/gender normalizing/assignment surgeries or support deferral until the patient can provide informed consent. These include:

World Health Organization

The United Nations Special Rapporteur on the Right to Health

The UN Secretary General's Special Representative on Violence Against Children

The UN High Commissioner for Human Rights

The United Nations Committee on the Rights of the Child

The United Nations Committee to End All Forms of Discrimination Against Women

The United Nations Committee Against Torture

The United Nations Committee on the Rights of Persons with Disabilities

United Nations agencies including UNICEF (children) and UNFPA (reproductive health)

North American Society for Pediatric and Adolescent Gynecology (NASPAG)

Pediatric Endocrine Society

Human Rights Watch

Physicians for Human Rights

The American Civil Liberties Union (ACLU)

German Ethics Council

Council of Europe Bioethics Commission

Parliamentary Assembly of the Council of Europe

DSD communities, including the AIS-DSD Support Group, and InterAct oppose early genital surgeries.

REPORT OF THE COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS*

CEJA Report 4-I-18

Subject: CEJA Role in Implementing H-140.837, “Anti-Harassment Policy”

Presented by: James E. Sabin, MD, Chair

Referred to: Reference Committee on Amendments to Constitution & Bylaws
(Todd M. Hertzberg, MD, Chair)

At the 2018 Annual Meeting the American Medical Association (AMA) House of Delegates (HOD) adopted with amendment the recommendations of Board of Trustees Report 20-A-18, “Anti-Harassment Policy.” The HOD amended the Board’s recommendations for a process to address allegations of harassment during meetings associated with the AMA to give the Council on Ethical and Judicial Affairs (CEJA) the authority and responsibility for taking disciplinary action (Policy H-140.837).

CEJA has discussed at length the recommendations of BOT Report 20-A-18 and believes that promoting safe engagement among physicians, students, staff, and other attendees during professional meetings affiliated with the AMA is an urgent organizational responsibility. However, while respecting the deliberations of the HOD, CEJA has concluded that the council is not in a position to carry out this new responsibility as defined in the recommendations as adopted.

CEJA concluded that the responsibility to adjudicate allegations of harassment is qualitatively different from its normal judicial function. In assessing individual physicians’ fitness for membership in the AMA, CEJA does not have direct, primary responsibility for taking punitive action. Rather, CEJA’s decisions rest on review of extensive case files compiled by state medical boards that have already taken disciplinary action and, with rare exceptions, an interview with the physician.

With respect to allegations of harassment, CEJA is deeply concerned that this new role will be much more analogous to that of a state medical board; it also foresees the need to engage with *both* parties before reaching a final determination. CEJA strongly believes that the task demands a different set of skills than its usual adjudications, and that therefore council members would need appropriate training (provided annually as new members join the council). CEJA is also uncertain that the range of [disciplinary options](#) available to it in its judicial function are appropriate with respect to allegations of harassment.

CEJA is further concerned that the council as a whole has neither the resources nor flexibility required to carry out this additional responsibility effectively. The council has a substantial ongoing workload in its normal judicial function, requiring at least one full day at each of its four in-person meetings every year. CEJA believes that allegations of harassment should be dealt with as close as possible to the time of the event by a body able to convene on an ad hoc basis. Moreover, the council has reason to anticipate a significant volume of cases, particularly in the current social climate.

* Reports of the Council on Ethical and Judicial Affairs are assigned to the Reference Committee on Amendments to Constitution and Bylaws. They may be adopted, not adopted, or referred. A report may not be amended, except to clarify the meaning of the report and only with the concurrence of the Council.

1 Finally, CEJA is concerned as well that in reaching decisions that parties (and their supporters) see as
2 either excessive or inadequate may undermine confidence in the council, to the detriment of both its
3 judicial and policy work.

4
5 For these reasons, CEJA respectfully requests that H-140.837(3), “Disciplinary Action,” be
6 reconsidered.

7
8 **RECOMMENDATION**

9
10 The Council on Ethical and Judicial Affairs recommends that the following be adopted and the
11 remainder of this report be filed:

- 12
13 1. That provision (3) of H-140.837, “Anti-Harassment Policy” be rescinded (Directive to Take
14 Action); and
15
16 2. That the process for implementing AMA’s anti-harassment policy be referred to the Board of
17 Trustees for further study (Directive to Take Action)

Fiscal Note: Less than \$500

REPORT OF THE COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS*

CEJA Report 5-I-18

Subject: Physicians' Freedom of Speech
(Resolution 6-I-17)

Presented by: James E. Sabin, MD, Chair

Referred to: Reference Committee on Amendments to Constitution & Bylaws
(Todd M. Hertzberg, MD, Chair)

At the 2017 Interim Meeting the American Medical Association (AMA) House of Delegates (HOD) referred Resolution 6-I-17, "Physicians' Freedom of Speech," brought forward by the Minority Affairs Section. Resolution 6-I-17 asked the AMA to "encourage the Council on Ethical and Judicial Affairs (CEJA) to amend Ethical Opinion E-1.2.10, 'Political Action by Physicians'," by addition to read as follows:

Like all Americans, physicians enjoy the right to advocate for change in law and policy, in the public arena, and within their institutions. Indeed, physicians have an ethical responsibility to seek change when they believe the requirements of law or policy are contrary to the best interests of patients and community health. However, they have a responsibility to do so in ways that are not disruptive to patient care.

Physicians who participate in advocacy activities should:

(a) Ensure that the health of patients is not jeopardized and that patient care is not compromised.

(b) Avoid using disruptive means to press for reform. Strikes and other collection actions may reduce access to care, eliminate or delay needed care, and interfere with continuity of care and should not be used as a bargaining tactic. In rare circumstances, briefly limiting personal availability may be appropriate as a means of calling attention to the need for changes in patient care. Physicians should be aware that some actions may put them or their organizations at risk of violating antitrust laws or laws pertaining to medical licensure or malpractice.

(c) Avoid forming workplace alliances, such as unions, with workers who do not share physicians' primary and overriding commitment to patients.

(d) Refrain from using undue influence or pressure colleagues to participate in advocacy activities and should not punish colleagues, overtly or covertly, for deciding not to participate.

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Furthermore, physicians:

(e) Should indicate they are expressing their personal opinions, which are guaranteed under the First Amendment of the U.S. Constitution, and should refrain from implying or stating that they are speaking on behalf of their employers;

(f) Should be allowed to express their personal opinions publicly without being subjected to disciplinary actions or termination.

Testimony supported the spirit of this resolution; however, concerns were expressed regarding the appropriate wording of the additional clauses offered by the author.

AMA ETHICS POLICY

As Opinion E-1.2.10 indicates, the AMA *Code of Medical Ethics* recognizes that physicians have a right to advocate for change in law and policy, and indeed have a responsibility to do so when existing law or policy is contrary to patients' interests, a responsibility codified in Principle III of the [AMA Principles of Medical Ethics](#), which states, "A physician shall respect the law and also recognize a responsibility to seek changes in those requirements which are contrary to the best interests of the patient."

The *Code* also recognizes that we have the right to communicate our personal political views to patients and patients' families, within the constraints set out in Opinion [E-2.3.4](#), "Political Communication."

Similarly, the *Code* recognizes our right to due process in disciplinary actions and decisions regarding credentialing and privileging in Opinions [E-9.4.1](#), "Peer Review and Due Process"; [E-9.4.3](#), "Discipline and Medicine"; and [E-9.4.4](#), "Physicians with Disruptive Behavior," all of which prohibit unwarranted or malicious action against physicians.

In Opinion [E-2.3.2](#), "Professionalism in the Use of Social Media," the *Code* recognizes that "participating in social networking and other similar opportunities can support physicians' personal expression, enable individual physicians to have a professional presence online, foster collegiality and camaraderie within the profession, provide opportunities to widely disseminate public health messages and other health communication." However, E-2.3.2 also cautions physicians to be aware that "actions online and content posted may negatively affect their reputations among patients and colleagues, may have consequences for their medical careers (particularly for physicians-in-training and medical students) and can undermine public trust in medicine."

Although the *Code* does not, and indeed cannot, dictate the terms of physician employment as such, several additional opinions do address relationships between physicians and the institutions with which they are affiliated, as employees or otherwise. Thus Opinion [E-8.7](#), "Routine, Universal Immunization of Physicians," provides that physicians who decline to be immunized must accept decisions of medical staff leadership or other authority to adjust practice activities. [E-11.2.3](#), "Contracts to Deliver Health Care Services," calls on us to carefully review the terms of contracts and "negotiate modification or removal of any terms that unduly compromise physicians' ability to uphold ethical standards," while [E-11.2.3.1](#), "Restrictive Covenants," holds that we should not enter into agreements that "unreasonably restrict" our right "to practice for a specified time or in a specific geographic area on termination of a contractual relationship."

ACTIONS AGAINST PHYSICIANS' LICENSES OR EMPLOYMENT

The Federation of State Medical Boards does not systematically track violations of online professionalism, but a 2012 survey indicated that medical and osteopathic boards have acted against physicians for violating patient privacy or professional boundaries, and other unprofessional or offensive conduct online [Greyson et al 2012]. Researchers found at the time that the total number of actions was small but observed that “this is likely to change as the use of social media continues to grow.”

Information about termination or other actions taken against physicians by their employers is limited primarily to media accounts of individual cases [Advisory Board 2011, Canosa 2016, Anderson 2018]. Publicly reported incidents involve both patient-related issues, such as violation of confidentiality, and offensive personal conduct, such as racist speech [Canosa, Anderson].

FREEDOM OF SPEECH

Although constitutional protection for “freedom of speech” is often invoked as an argument against disciplinary action by employers, it is important to note that this concept does not apply to private places of employment. The First Amendment “limits only the government’s ability to suppress speech” [Cox 2015].

Private employers generally have the power to terminate an employee because of the employee’s speech. For example, Thomas Jefferson University Hospital noted in a statement regarding the hospital’s decision to dismiss a nurse for a racially charged post,

An employee’s decision to post inflammatory comments on social media is an unfortunate choice and one that is not tolerated at Jefferson Whether we choose to acknowledge it or not, we must recognize that what we say on social media can directly affect how people perceive Jefferson — particularly when those comments put into question Jefferson’s commitment to the care of our patients, treatment of our fellow colleagues and education of our students [Craig].

Protections for an employee regarding their speech in the private workplace, are possible, but come from outside of the sphere of constitutional law. Instead such protections may be found in contract and employment law. For example, common law analysis of the standard “employment-at-will” doctrine (where an employer can terminate an employee at any time for any reason), provide for exceptions, such that employers may not “contravene public policy” or that employers must act in accordance to an “implied convent of good faith and fair dealing” [McGinley 2012]. Or an employer may simply have an employment policy or agreement that outlines acceptable speech, providing an employee with contract remedies. These possible speech protections are sourced from contract and employment law, illustrating that “freedom of speech” in the private workplace is an employment law issue, not a constitutional rights issue.

CONCLUSION

In CEJA’s view, the situation of physicians who express personal views on political and social issues online is importantly like that of physicians who participate professionally in the media. We should recognize that even when we speak personally, we are likely to be viewed by the public through the lens of our professional status and our relationships with health care institutions and should not conduct ourselves in ways that are likely to undermine trust in our profession or health care institutions. As Opinion [E-8.12](#), “Ethical Physician Conduct in the

1 Media,” observes, physicians in the public sphere “should be aware of their ethical obligations to
2 patients, the public, and the medical profession; and that their conduct can affect their medical
3 colleagues, other health care professionals, as well as institutions with which they are affiliated.”
4

5 CEJA concludes, thus, that in its present form, the *Code of Medical Ethics* provides appropriate
6 guidance with respect to physicians’ rights to express ourselves on matters of social and political
7 importance and underscores our right to due process when our conduct is subjected to disciplinary
8 review.
9

10 RECOMMENDATION

11
12 For the foregoing reasons, the Council on Ethical and Judicial Affairs recommends that
13 Resolution 6-I-17, “Physicians’ Freedom of Speech,” not be adopted and the remainder of this
14 report be filed.

Fiscal Note: Less than \$500

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AMERICAN MEDICAL ASSOCIATION HOUSE OF DELEGATES

Resolution: 001
(I-18)

Introduced by: Wisconsin

Subject: Support of a National Registry for Advance Directives

Referred to: Reference Committee on Amendments to Constitution and Bylaws
(Todd M. Hertzberg, MD, Chair)

1 Whereas, Advanced Care Planning (ACP) may include but is not limited to appointing a
2 Healthcare Power of Attorney, completing a living will, and/or completing an advance directive;¹
3 and
4

5 Whereas, ACP has the central goal of ensuring that a patient's wishes and preferences in
6 relation to his or her healthcare decisions are respected;² and
7

8 Whereas, ACP improves respecting end-of-life wishes and patient and family satisfaction while
9 reducing family member anxiety and stress;³⁻⁴ and
10

11 Whereas, Studies suggest that ACP is cost-effective in end-of-life care;⁵⁻⁶ and
12

13 Whereas, ACP documentation varies by state and region and is often difficult to locate;⁷⁻¹⁰ and
14

15 Whereas, There is no central database of ACP documentation that is confidential, secure, free
16 of charge, and readily accessible for healthcare providers; therefore be it
17

18 RESOLVED, That our American Medical Association advocate for the establishment and
19 maintenance of a national, no-charge, confidential and secure method for the storage and
20 retrieval of advance directive documents by authorized agents. (New HOD Policy)

Fiscal Note: Modest - between \$1,000 - \$5,000.

Received: 09/25/18

RELEVANT AMA POLICY

Encouraging the Use of Advance Directives and Health Care Powers of Attorney H-140.845

Our AMA will: (1) encourage health care providers to discuss with and educate young adults about the establishment of advance directives and the appointment of health care proxies; (2) encourage nursing homes to discuss with resident patients or their health care surrogates/decision maker as appropriate, a care plan including advance directives, and to have on file such care plans including advance directives; and that when a nursing home resident patient's advance directive is on file with the nursing home, that advance directive shall accompany the resident patient upon transfer to another facility; (3) encourage all physicians and their families to complete a Durable Power of Attorney for Health Care (DPAHC) and an Advance Directive (AD); (4) encourage all medical schools to educate medical students and residents about the importance of having a DPAHC/AD before becoming severely ill and encourage them to fill out their own DPAHC/AD; (5) along with other state and specialty societies, work with any state that has technical problems with their DPAHC/AD to correct those problems; (6) encourage every state medical association and their member physicians to make information about Living Wills and health care powers of attorney continuously available in patient reception areas; (7) (a) communicate with key health insurance organizations, both private and public, and their institutional members to include information regarding advance directives and related forms and (b) recommend to state Departments of Motor Vehicles the distribution of information about advance directives to individuals obtaining or renewing a driver's license; (8) work with Congress and the Department of Health and Human Services to (a) make it a national public health priority to educate the public as to the importance of having a DPAHC/AD and to encourage patients to work with their physicians to complete a DPAHC/AD and (b) to develop incentives to individuals who prepare advance directives consistent with our current AMA policies and legislative priorities on advance directives; (9) work with the Centers for Medicare and Medicaid Services to use the Medicare enrollment process as an opportunity for patients to receive information about advance health care directives; (10) continue to seek other strategies to help physicians encourage all their patients to complete their DPAHC/AD; and (11) advocate for the implementation of secure electronic advance health care directives.

Citation: CCB/CLRPD Rep. 3, A-14; Reaffirmed: BOT Rep. 9, I-15; Reaffirmed: Res. 517, A-16; Reaffirmed: BOT Rep. 05, I-16; Reaffirmed in lieu of: Res. 121, A-17

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AMERICAN MEDICAL ASSOCIATION HOUSE OF DELEGATES

Resolution: 002
(I-18)

Introduced by: GLMA: Health Professionals Advancing LGBTQ Equality

Subject: Protecting the Integrity of Public Health Data Collection

Referred to: Reference Committee on Amendments to Constitution and Bylaws
(Todd M. Hertzberg, MD, Chair)

1 Whereas, Our American Medical Association is dedicated to improving the nation's health; and

2
3 Whereas, The National Institutes of Health (NIH) has underscored the need to better
4 understand the health of sexual and gender minorities and the 2011 Institute of Medicine report
5 on the Health of Lesbian, Gay, Bisexual, and Transgender People and a follow-up report in
6 2013 both highlighted the need for inclusion of sexual and gender identity data collection in
7 federal and state surveys, surveillance systems, and health registries¹⁻²; and

8
9 Whereas, Healthy People 2020 Guidelines highlight the importance of sexual orientation and
10 gender identity data collection in national surveys³; and

11
12 Whereas, There have been several attempts to remove sexual orientation and gender identity
13 data from national surveys and surveillance systems, including but not limited to the National
14 Survey of Older American Act⁵ and National Crime Victimization Survey⁶; and

15
16 Whereas, This is part of an alarming trend within the federal government aimed at limiting
17 knowledge about sexual and gender minority (i.e. lesbian, gay, bisexual, transgender, queer)
18 people, despite the fact that these data are vital to policy making and designing evidence-based
19 interventions to improve health and well-being; and

20
21 Whereas, The collection of sexual orientation and gender identity data allows researchers,
22 clinicians, and public health professionals to address health disparities and ensure individuals
23 can lead long, healthy lives and appropriate data collection allows for the reduction in disease
24 transmission and progression, increases in mental and physical well-being, reductions in health
25 care costs, and improved quality of life; and

26
27 Whereas, To eliminate health disparities, there must be widespread collection of sexual
28 orientation and gender identity data using standard, reliable questions⁷; therefore be it

29
30 RESOLVED, That our American Medical Association advocate for the inclusion of demographic
31 data inclusive of sexual orientation and gender identity in national and state surveys,
32 surveillance systems, and health registries; including but not limited to the Current Population
33 Survey, United States Census, National Survey of Older Americans Act Participants, all-payer
34 claims databases (New HOD Policy); and be it further

35
36 RESOLVED, That our AMA advocate against the removal of demographic data inclusive of
37 sexual orientation and gender identity in national and state surveys, surveillance systems, and
38 health registries without plans for updating measures of such demographic data. (New HOD
39 Policy)

Fiscal Note: Modest - between \$1,000 - \$5,000.

Received: 10/11/18

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RELEVANT AMA POLICY

Promoting Inclusive Gender, Sex, and Sexual Orientation Options on Medical Documentation H-315.967

Our AMA: (1) supports the voluntary inclusion of a patient's biological sex, current gender identity, sexual orientation, and preferred gender pronoun(s) in medical documentation and related forms, including in electronic health records, in a culturally-sensitive and voluntary manner; and (2) will advocate for collection of patient data that is inclusive of sexual orientation/gender identity for the purposes of research into patient health.

Citation: Res. 212, I-16; Reaffirmed in lieu of: Res. 008, A-17

Health Care Needs of Lesbian, Gay, Bisexual, Transgender and Queer Populations H-160.991

1. Our AMA: (a) believes that the physician's nonjudgmental recognition of patients' sexual orientations, sexual behaviors, and gender identities enhances the ability to render optimal patient care in health as well as in illness. In the case of lesbian, gay, bisexual, transgender, queer/questioning, and other (LGBTQ) patients, this recognition is especially important to address the specific health care needs of people who are or may be LGBTQ; (b) is committed to taking a leadership role in: (i) educating physicians on the current state of research in and knowledge of LGBTQ Health and the need to elicit relevant gender and sexuality information from our patients; these efforts should start in medical school, but must also be a part of continuing medical education; (ii) educating physicians to recognize the physical and psychological needs of LGBTQ patients; (iii) encouraging the development of educational programs in LGBTQ Health; (iv) encouraging physicians to seek out local or national experts in the health care needs of LGBTQ people so that all physicians will achieve a better understanding of the medical needs of these populations; and (v) working with LGBTQ communities to offer physicians the opportunity to better understand the medical needs of LGBTQ patients; and (c) opposes, the use of "reparative" or "conversion" therapy for sexual orientation or gender identity.

2. Our AMA will collaborate with our partner organizations to educate physicians regarding: (i) the need for sexual and gender minority individuals to undergo regular cancer and sexually transmitted infection screenings based on anatomy due to their comparable or elevated risk for these conditions; and (ii) the need for comprehensive screening for sexually transmitted diseases in men who have sex with men; (iii) appropriate safe sex techniques to avoid the risk

for sexually transmitted diseases; and (iv) that individuals who identify as a sexual and/or gender minority (lesbian, gay, bisexual, transgender, queer/questioning individuals) experience intimate partner violence, and how sexual and gender minorities present with intimate partner violence differs from their cisgender, heterosexual peers and may have unique complicating factors.

3. Our AMA will continue to work alongside our partner organizations, including GLMA, to increase physician competency on LGBTQ health issues.

4. Our AMA will continue to explore opportunities to collaborate with other organizations, focusing on issues of mutual concern in order to provide the most comprehensive and up-to-date education and information to enable the provision of high quality and culturally competent care to LGBTQ people.

Citation: CSA Rep. C, I-81; Reaffirmed: CLRPD Rep. F, I-91; CSA Rep. 8 - I-94; Appended: Res. 506, A-00; Modified and Reaffirmed: Res. 501, A-07; Modified: CSAPH Rep. 9, A-08; Reaffirmation A-12; Modified: Res. 08, A-16; Modified: Res. 903, I-17; Modified: Res. 904, I-17; Res. 16, A-18

Goal of Health Care Data Collection H-406.999

The AMA (1) continues to advocate that health care data collected by government and third party payers be used for education of both consumers and providers; and (2) believes that government, third party payers and self-insured companies should make physician-specific utilization information available to medical societies.

Citation: BOT Rep. W, A-92; Reaffirmed: Res. 719, A-93; BOT Rep. Y, I-85; Reaffirmed CLRPD Rep. 2, I-95; CMS Rep. 10, A-96; Reaffirmed: CMS Rep. 8, A-06; Reaffirmed: CMS Rep. 01, A-16

AMERICAN MEDICAL ASSOCIATION HOUSE OF DELEGATES

Resolution: 003
(I-18)

Introduced by: Indiana

Subject: Mental Health Issues and Use of Psychotropic Drugs for Undocumented Immigrant Children

Referred to: Reference Committee on Amendments to Constitution and Bylaws
(Todd M. Hertzberg, MD, Chair)

Whereas, Federal government immigration officials recently elected to separate children from their parent or parents and to place these children in foster care situations or other public facilities. The children were as young as 3 years of age. In some cases, this occurred with little or no forewarning, so that the parents were not able to prepare their children for the separation. Some children became quite stressed and agitated. In some cases, the children were moved thousands of miles for the foster care. Previous administrations have had a policy allowing unaccompanied minors access to the U.S. This policy produced concerns about the possibility of entry into gangs and the risk of physical and mental trauma in the absence of a supervising adult; and

Whereas, A single major childhood emotional trauma can predispose a person to chronic psychiatric disease as an adult. Many of these border-crossing children have experienced multiple traumas already on their travels to the U.S.; and

Whereas, Some of the minor immigrant children were given psychotropic drugs without parental permission or court order. These children protested injection verbally. They were held by guards at detention centers and psychotropic drugs were given; therefore be it

RESOLVED, That our American Medical Association officially object to policies separating undocumented immigrant parents and/or guardians from children, as well as allowing unaccompanied undocumented minors access to the U.S. (New HOD Policy); and be it further

RESOLVED, That our AMA condemn the practice of administering psychotropic drugs to immigrant children without parental or guardian consent or court order except in the case of imminent danger to self or others (New HOD Policy); and be it further

RESOLVED, That our AMA support a position whereby federal immigration officials would become more aware of the emotional decompensation in this immigrant population, with the establishment of policies designed to decrease stress and emotional trauma. (New HOD Policy)

Fiscal Note: Modest - between \$1,000 - \$5,000.

Received: 10/09/18

RELEVANT AMA POLICY

<https://policysearch.ama-assn.org/policyfinder/search/undocumented%20children/relevant/1/>