A New Routine: Assisting Patients in Responding to Prenatal Diagnosis

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ASSISTING PATIENTS IN RESPONDING TO 
PRENATAL DIAGNOSIS

I. INTRODUCTION

For many women and couples, learning of a pregnancy brings great joy and excitement for the future. However, with increased frequency, this joy is soon crowded by fear, grief, difficult decisions, and the internal and external conflict arising from abnormal prenatal test results. As technology has advanced in recent years, prenatal testing has moved from the offices of genetic counselors to those of obstetricians and "entered the domain of routine prenatal care." The medical community’s embrace of this technology is at least partially rooted in legal necessity, as providers acknowledge the modern legal climate: one in which failure to offer testing and failure to detect fetal abnormalities may result in malpractice or wrongful birth lawsuits.

Pregnant women and their partners face troubling test results with considerable frequency. Approximately 65% of pregnant women seeking prenatal care received Maternal Serum Alpha-Fetoprotein (MSAFP) screening by the early 1990s; however, the screen has high false positive rates and the "vast majority" of women who receive abnormal results carry fetuses without abnormality. According to the American Pregnancy Association, as many as one in twenty women tested will receive abnormal MSAFP results, while only three out of every one hundred women receiving these abnormal results actually carry a fetus with a birth defect. Therefore, 97% of the women who are told something may be wrong based on MSAFP results are carrying a fetus that does not have any of the defects that MSAFP screens.

2. Id. at 250–51.
3. Id. at 252–53, 263. MSAFP screens for neural tube defects. Id. at 251. By definition, screening tests are not precise enough to be considered diagnostic alone. Id. at 263–64. Even more accurate diagnostic tests such as amniocentesis “are not infallible.” Id. at 264.
5. Id.
In some states, offering such screening to patients is now mandated by statute or case law. Whether a patient's choice to undergo screening or testing arises out of true, informed consent presents a crucial question in itself. The extent and quality of the information provided to patients both before testing and upon delivery of the test results is a matter of critical importance because these results demand decisions concerning whether to abort, proceed with further tests, plan for adoption, or make special birth arrangements.

In the face of these decisions, many patients experience confusion due to a lack of information about their options or a lack of means by which to deal with conflict that arises during the decision-making process. Conflict and confusion may arise regarding proper parenting roles, the morality of selective abortion and other ethical dilemmas, financial, practical, and emotional considerations, and many other issues. Conflict may surface within the patient internally, between the patient and the other parent or partner, among extended family members, or among medical personnel. This Comment examines why current methods and systems offered to patients struggling with such conflict and need for information are often inadequate.

Concern about the inadequacy of the information provided to patients and the subsequent decision-making process is further heightened by drastic results: currently about 80% of fetuses diagnosed

6. See, e.g., CAL. CODE REGS. tit. 17, § 6527(a) (2002); cf. Dumer v. St. Michael's Hosp., 233 N.W.2d 372, 377 (Wis. 1975) (holding that in a case where the doctor failed to diagnose the mother with rubella, the doctor had a duty to inquire whether the mother was pregnant and if so, "to inform her of the probable effects of rubella upon the fetus, including its irreversible nature," but the doctor did not have a duty to inform the mother of the availability of an abortion).

7. For a brief description of the doctrine of informed consent, its origins, and its legal elements, see FURROW ET AL., HEALTH LAW 356 (5th ed. 2004).

8. See Lori B. Andrews, Prenatal Screening and the Culture of Motherhood, 47 HASTINGS L.J. 967, 974–75 (1996); Suter, supra note 1, at 256.

9. Although legal conflicts may arise in this setting, the conflict this Comment focuses on is that which is personal, emotional, ethical, or relational in nature and does not have its root in legal proceedings. In most pregnancies, there is no debate surrounding the legal right of a patient to make decisions concerning her pregnancy. However, in making these decisions, a woman is likely to encounter other, non-legal conflict.

10. These are merely a few examples of relationships in which conflict may arise. As recently noted by Nancy N. Dubler, "The last decade has been one of exponentially increasing conflict in medicine. . . . The doctor-patient relationship has become rather crowded . . . . There are simply more parties to any decision and thus greater potential for misunderstanding, misinformation, disagreement, and dispute." Nancy N. Dubler, Conflict and Consensus at the End of Life, 35 HASTINGS CENT. REP. S19, S22 (November 1, 2005).
with Down Syndrome through prenatal tests are aborted. Some have questioned the effect this has on social attitudes toward the disabled, and even some in favor of the right to legal abortion have questioned the moral implications of such selective termination. In recent years, the number of cases of Down Syndrome and other birth defects recorded among our nation's population has decreased significantly, a fact hardly surprising considering the high abortion rates for fetuses diagnosed with the condition. This reduction may appear to be a success, as statistics now show a decrease in babies born with birth defects. However, these statistics, because they include only births without reference to the number of pregnancies and prenatal diagnoses, present the public with misleading information concerning the prevalence of birth defects and their prevention or treatment.

In response to such concerns, Senators Brownback of Kansas and Kennedy of Massachusetts have introduced a bill titled The Prenatally Diagnosed Condition Awareness Act ("the Act"). The introduction to the Act describes its purpose to "amend the Public Health Service Act to increase the provision of scientifically sound information and support services to patients receiving a positive test diagnosis for Down syndrome or other prenatally diagnosed conditions." The Act would mandate a more standardized provision of information to patients. It would further fund and facilitate supportive services for patients such as adoption registries, peer-support programs, and an informational

14. Id.
15. Id. See also Prenatally Diagnosed Condition Awareness Act, S. 609, 109th Cong. § 2 (2005).
16. Republican Senator Sam Brownback has represented Kansas in the U. S. Senate since 1996. Democratic Senator Edward Kennedy of Massachusetts is currently the second most senior member of the U.S. Senate. While the author does not wish to comment here on the debate surrounding the constitutionality of abortion, as it well exceeds the scope of this piece, it is interesting to note that support for this legislation concerning prenatal care has been sponsored by senators espousing opposite positions in the abortion debate. Compare Senator Brownback's website, http://brownback.senate.gov/LILife.cfm (last visited Oct. 18, 2006) (including a page entitled "culture of life"), with NARAL Pro-Choice America website, http://www.naral.org/choice-action-center/in-congress/congressional-record-on-choice/state.html?state=MA (last visited Oct. 18, 2006) (giving Senator Kennedy a "Pro-Choice Score" of 100%).
17. S. 609.
18. Id.
hotline. Congressman Sensenbrenner of Wisconsin has introduced the companion version of the bill in the House of Representatives. The proposed legislation is currently on referral before congressional subcommittees.

The resources and supportive services offered by the Act have not yet been developed in greater detail; however, this Comment proposes that the Act incorporate a model of mediation as one such service. Mediation, as a facilitated discussion between interested persons, could assist patients and others in gathering and re-examining information, as well as addressing conflict.

Part II of this Comment examines in more detail the situation the bill seeks to address: the prevalence of prenatal screening, testing, and diagnosis, with respect to the modern medical, social, and legal climates. Part III discusses current assistance offered to patients upon prenatal diagnosis and the proposed Prenatally Diagnosed Condition Awareness Act aimed at improving that assistance. Part IV presents mediation services as a forum for information gathering and conflict resolution, suggesting that the Act should include mediation as a supportive resource to be provided for patients facing prenatal diagnosis in the future. Part V summarizes this Comment.

II. THE ROUTINIZATION OF PRENATAL TESTING

A. The Modern Medical and Social Climate

Prenatal screening and testing procedures have indeed become a routine part of prenatal care. Testing may be done for medical or non-medical reasons—to detect diseases such as cystic fibrosis, conditions like Down Syndrome, or the gender of a fetus. Within most of the medical community and general social culture at large, genetic information about a developing fetus is now regarded as “necessary and inherently beneficial.” While this form of information-gathering once required patients to make a special visit to a genetics clinic or research laboratory, non-geneticist obstetricians now perform tests regularly. This routinization of testing has been complemented by the American

20. Suter, supra note 1, at 241.
21. See Robertson, supra note 12, at 455–62.
22. Suter, supra note 1, at 265.
23. Id. at 242.
society's general perspective that "the gathering of information [is] a sign of responsible behavior and good decision making." \(^{24}\) Popular pregnancy resource books, such as *What to Expect When You're Expecting*, refer to prenatal testing alongside recommendations such as abstaining from alcohol and smoking. \(^{25}\)

This shift toward testing as a routine part of normal prenatal care has had an impact on the manner of obtaining consent for the tests, the delivery of test results, and the decision-making process that follows. For example, obstetricians often lack the training in non-directiveness given to genetic counselors and may unabashedly recommend or encourage testing. \(^{26}\) Alternatively, obstetricians may fail to provide patients with a clear understanding of the purpose or limitations of screening tests, such as when an obstetrician incorporates screening tests as standard care, which may leave patients surprised and confused upon later news of abnormal results. \(^{27}\) Physicians have routinely described MSAFP screening, for example, as "a simple blood test [to see] how [the] baby is developing." \(^{28}\) A woman is likely to "consent" to such a test without understanding its implications, knowing whether she wants the information the test provides, or being aware of the test's accuracy limitations. This same directiveness and lack of information may permeate the entire decision-making process as patients determine whether to test further and whether to continue pregnancy. \(^{29}\)

The modern medical and social climate supports the widespread provision of prenatal tests and diagnosis but does little to support and inform patients when they fulfill these expectations.

### B. The Modern Legal Climate

These social and medical climates are joined and often fueled by a modern legal climate equally as influential in the routinization of prenatal testing. Most jurisdictions currently recognize wrongful-birth

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24. *Id.* at 246.
25. *Id.* at 247 (citing *ARLENE EISENBERG ET AL., WHAT TO EXPECT WHEN YOU'RE EXPECTING* 50 (2d ed. 1996)).
26. J.G. GRUDZINSKAS ET AL., SCREENING FOR DOWN'S SYNDROME 278 (1994) (explaining that obstetricians are more likely to counsel directly, especially with regard to advising termination of a pregnancy, than genetic counselors); see also Suter, *supra* note 1, at 242, 245.
28. *Id.* (internal quotations omitted).
29. Some studies suggest that physicians pressure women to abort upon diagnosis of fetal defects. Suter, *supra* note 1, at 248.
actions, by which a patient may sue a physician for failure to offer prenatal tests or for failure to detect abnormalities when a child is subsequently born with defects that could have been detected in time to terminate the pregnancy.\textsuperscript{30} Such legal liability was anticipated among legal and medical professionals. For example, in the 1970s, the legal department of the American College of Obstetricians and Gynecologists, following the release of Alpha-Fetoprotein screening kits, began advising that obstetricians offer the procedure to patients in order to provide a defense to later legal actions against them if a baby was born with a defect.\textsuperscript{31} Screening procedures in particular, with their high rate of false-positives, offer healthcare providers the greatest likelihood of being able to tell a patient, “There may be something wrong,” therefore guarding against their own liability.\textsuperscript{32} Thus, testing as a standard of care has been largely rooted in legal rather than medical necessity.\textsuperscript{33}

In addition to professional guidelines and case law suggesting that physicians should provide access to prenatal testing, some legislatures have issued mandates to that effect. For example, California mandates that physicians offer screening, like MSAFP, to all pregnant women.\textsuperscript{34} With the pressure of legal liability and even legislative mandates to offer testing, physicians have become very aware that the “clearest evidence of compliance is to have a patient take the test . . . prompt[ing] many healthcare professionals, at a minimum, to encourage . . . screening.”\textsuperscript{35}

One problem with such medical, social, and legal pressures to test, combined with the widespread belief that testing is “routine,” is the potential lack of full informed consent that ought to precede testing.


A wrongful birth claim differs from the usual medical malpractice claim because the child's deformities are genetic and therefore not caused by any act or omission of the physician. The physician is not accused of causing the child's deformities, but is rather accused of causing its birth, by failing to detect the defects and therefore denying the parents the opportunity to abort.


\textsuperscript{31} Kristol, \textit{supra} note 13, at 19.

\textsuperscript{32} An example, as mentioned in the Introduction of this Comment, is the ability of health care providers to tell one in twenty patients something may be wrong with a fetus based on MSAFP screening results. See American Pregnancy Association, \textit{supra} note 4.

\textsuperscript{33} Suter, \textit{supra} note 1, at 252–53.

\textsuperscript{34} See \textit{Cal. Code Regs.} tit. 17, § 6527(a) (2002).

\textsuperscript{35} Suter, \textit{supra} note 1, at 253.
That issue exceeds the scope of this Comment, but deserves some mention. Nonetheless, the reality of most modern pregnancies now includes prenatal screening and testing procedures.

III. ASSISTING PATIENTS WHO RECEIVE ABNORMAL TEST RESULTS

A. Current Methods of Providing Information and Support

Imagine the devastation and concern of parents upon the news that a baby they have been eagerly awaiting may have a serious birth defect, such as Down Syndrome. As described in Part II, this situation is not uncommon. How do health care providers deliver such news? What support and information is given to a patient in such a setting? The answers to these essential questions vary in different health care facilities and among different individual health care providers.

Patients in this situation experience a multitude of emotions and may be particularly vulnerable. Information provided during this time should facilitate informed decision-making and demonstrate respect for a patient's autonomy. Health care providers must use care that materials provided do not discourage a patient from careful consideration or asserting her wishes. For example, a March of Dimes publication provided to patients describes the decision to continue pregnancy after diagnosis of a defect as "nonroutine." Yale University Medical School's prenatal testing unit provides patients who have received an unfavorable diagnosis with literature discussing the inevitable grief experienced upon abortion, as though that decision was assumed.

Under the appropriate model of informed consent, it would be naïve to assume that the patient herself has made any decisions. In fact, the news is likely to spark conflict for the woman both internally and externally, as she discusses options with other parties, perhaps including her partner, extended family, religious or cultural authorities, friends,

36. The principle of autonomy is central in modern bioethical analysis; for a prominent explanation, see TOM L. BEAUCHAMP & JAMES F. CHILDRESS, PRINCIPLES OF BIOMEDICAL ETHICS 120–81 (4th ed. 1994).
37. Kristol, supra note 13, at 22.
38. Id.
39. Robert Gatter, Unnecessary Adversaries at the End of Life: Mediating End-of-Life Treatment Disputes to Prevent Erosion of Physician-Patient Relationships, 79 B.U. L. REV. 1091, 1101 (1999). "To fulfill [the] obligations [of informed consent], the physician must ... allow the patient to decide which, if any, of the proposed treatments to undergo." Id.
and medical providers. What systems are in place to handle such conflict?

Currently, there are few official methods commonly used in such settings. One is ethics consultation by an individual, small team, or committee.40 There are multiple models of ethics consultation, and within these models, methods range from a heavily “authoritarian approach” to a “pure facilitation approach.”41 The “authoritarian approach” emphasizes a decision-making role for the consultant(s), while the “pure facilitation approach” promotes consensus between interested persons without the consultant engaging in any evaluation of the decision-making.42 Either model has the potential to become problematic. The authoritarian approach, at its worst, can override proper decision-making authority, substituting a consultant’s values for those of the parties.43 However, a purely facilitative approach may lead to consensus for its own sake, “without independent justification.”44 Ideally, consultants under any model aim for a balance between these extremes, an ideal the American Society for Bioethics and Humanities has termed “ethics facilitation.”45

Depending on the institution in which it occurs, a health care provider or a patient may call a consultant; although traditionally, initiation by a patient has been rare or even forbidden.46 Once commenced, many bioethics consultants follow a “medical model,” reviewing a patient’s chart and talking to those involved, such as the medical team, patient, and family members, then “appl[y]ing his or her specific skill [ethics] to the medical facts of the case[,]” and delivering his or her opinion to the attending physician—just as a medical specialist

40. For a more complete description of the individual, team, and committee models, and their respective benefits and challenges, see generally Cynda Rushton et al., Models for Ethics Consultation: Individual, Team, or Committee?, in ETHICS CONSULTATION: FROM THEORY TO PRACTICE 88 (Mark P. Aulisio et al. eds., 2003).

41. For further explanation of these terms, see AMERICAN SOCIETY FOR BIOETHICS AND HUMANITIES, CORE COMPETENCIES FOR HEALTH CARE ETHICS CONSULTATION 5-6 (1998).

42. Id.

43. Mark P. Aulisio, Meeting the Need: Ethics Consultation in Health Care Today, in ETHICS CONSULTATION: FROM THEORY TO PRACTICE 3, 10–12 (Mark P. Aulisio et al. eds., 2003).

44. Id. at 12–13.

45. Id. at 13.

consulted for expertise.\textsuperscript{47} When consultants make such “recommendations,” these are usually officially deemed “advisory” but may become the final say in the matter.\textsuperscript{48} This authority and finality may result from a number of factors, including: “the psychological impact on the disputants,” the weight of the advice as to institutional policy, “limitations on . . . resources” to pursue judicial review or other dispute resolution methods, and perhaps the effect on future litigation, as some courts now accept consultants’ recommendations as evidence or even accord these recommendations some judicial deference.\textsuperscript{49}

In the case of prenatal diagnosis, ethics consultation may be requested with the belief that a patient or health care provider may benefit from the perspectives offered by an ethicist when addressing issues such as deciding whether to continue pregnancy, planning a course of action for the remainder of the pregnancy, or planning for a baby’s birth.

As another form of support, many facilities provide patients with access to some form of pastoral care, as well as more formal personal counseling. These services vary widely between institutions, and certainly, they play an important role. But are these options enough? Do they provide adequate opportunity to gather information and clear up misunderstanding? Are they efficient? Do they effectively preserve patient autonomy while addressing the many forms of conflict that arise?

Counseling, for example, may prove an excellent way to address some of the emotional needs of the patient. But what opportunity exists behind the closed door of a private counseling session for a patient to conduct further information gathering as to the opinions, feelings, and knowledge of other “parties”?\textsuperscript{50} Similarly, little help is given to the patient in sharing her opinions with others.

Consider alternatively the model of an ethics consultation. Here, one would expect more emphasis on information gathering. But who is learning the whole of the information? The third-party consultant, rather than the patient, conducts the investigative process. Although

\begin{itemize}
\item \textsuperscript{47} NANCY N. DUBLER \& CAROL B. LIEBMAN, BIOETHICS MEDIATION: A GUIDE TO SHAPING SHARED SOLUTIONS 7 (2004).
\item \textsuperscript{48} See Wolf, supra note 46, at 810.
\item \textsuperscript{49} Id. at 809–11; see also Randall B. Bateman, Attorneys on Bioethics Committees: Unwelcome Menace or Valuable Asset?, 9 J.L. \& HEALTH 247, 268 (1994–1995).
\item \textsuperscript{50} Here, the term “parties” is used to refer to other persons who have some interest in the result of the decision-making process, including, but not limited to: partners, parents, family and friends, medical professionals, ethicists, and religious and legal authorities.
\end{itemize}
the patient’s perspectives are hopefully included, interested parties sometimes hear other perspectives only through the final recommendation of the consultant or committee, if ever. There may be little opportunity for direct discussion between all those involved that would result in greater information sharing and potentially lead to greater understanding. Such opportunity may be missed in both a consultation and in private counseling sessions.

Consider how these available models address conflict. Although personal, private counseling sessions may offer a much-needed chance to address the internal conflict a patient may experience concerning her options in response to a prenatal diagnosis, they may not facilitate any resolution of the conflict that may arise between this woman and her doctor, partner, family, friends, etcetera. Ethics consultations often serve an adjudicatory role in addressing such conflict. Certainly there are times when agreements cannot be reached or ethical issues are not fully understood, and the expertise of a bioethicist is essential in such a setting. But is the consultancy model always appropriate, or may parties feel they have lost control of the situation yet further, by placing decision-making authority in the hands of a third-party ethicist or committee? Certainly patients and medical professionals already experience a feeling of loss of control when facing situations such as the diagnosis of an incurable defect. Immediate intervention through ethics consultation may be inappropriate. In other cases, a consultation may be necessary and appropriate for its intended purpose of analyzing the ethical issues but may be limited in its ability to address other emotional, relational, and informational interests and conflicts.

Although the current practices of ethics consultation, personal counseling, and pastoral care are often helpful services for patients who have received abnormal prenatal test results, alone these approaches may not be enough to meet patients’ needs for information and methods of conflict resolution.

B. The Prenatally Diagnosed Condition Awareness Act

To address the problem of inconsistent and inadequate provision of information and resources upon prenatal diagnosis, Senator Brownback, Senator Kennedy, and Congressman Sensenbrenner have sponsored the “Prenatally Diagnosed Condition Awareness Act.”51 The Act would amend the existing Public Health Service Act by adding a section

entitled, "Support for Patients Receiving a Positive Test Diagnosis of Down Syndrome or Other Prenatally Diagnosed Conditions." The bill contains multiple propositions, including authority to award grants to "collect, synthesize, and disseminate current scientific information" and to enter into cooperative agreements with existing support service organizations to coordinate an information clearinghouse, peer-support programs, registries of those willing to adopt children with special needs, and an informational hotline and website. Under the proposed legislation, a health care provider reporting to a patient "a positive test diagnosis for Down syndrome or other prenatally diagnosed conditions" would have to provide written information about the diagnosis and prognosis as well as referral information to supportive services like those mentioned above.

Among the listed purposes of the legislation include a desire to increase patient referrals to support services, create a patient and provider outreach program, incorporate prenatal testing results into government birth defect surveillance programs, and provide patients access to more current information about the accuracy rates of tests. Congressional findings listed include an assertion that women who choose prenatal testing should have nondirective counseling about the process and qualified interpretation of the results; additionally, all testing should be the product of informed consent.

The Act's mandates would be implemented by the Secretary of Health and Human Services, through the Director of the National Institutes of Health, the Director of the Centers for Disease Control and Prevention, or the Administrator of the Health Resources and Services Administration, in cooperation with state and local health departments.

The Act's breadth presents both great possibility and great challenge. At this early stage, specific plans for its inception have not been revealed. The precise nature of the resources and content of the required written information have not yet been developed. Ensuring that these comport with legal and bioethical standards will be a

52. Id. § 3.
53. Id. § 3(b)(1).
54. Id. § 3(b)(2)(A)–(E).
56. Id. § 2(b).
57. Id. § 2(a)(1).
58. Id. § 3(b).
challenge in itself. However, having examined the modern climate of prenatal testing and diagnosis, and the potential inadequacies of common models to address the conflict, emotion, and need for information sharing that arises in this climate, this Comment proposes that mediation services, as a complimentary option, become a portion of the resources made available under the Act.

IV. MEDIATION AS ANOTHER OPTION

Mediation is a discussion between disputing parties facilitated by a trained, neutral third-party who has no power to impose any outcome. Mediation may prove a particularly helpful process for handling conflict, information gathering, and decision-making upon news of a prenatal diagnosis by assisting parties in defining and expressing their personal interests and motivations. By focusing on meeting each person's interests rather than each person's position in a given matter, mediation allows parties to examine possible solutions. In mediation, although the patient retains the right to autonomous decision-making, she may discuss the perspectives of other interested parties and gain further information in the process. Similarly, mediation facilitates a safe forum for the patient to share her concerns, wishes, and emotions.

Professor Eva Soeka, Director of the Marquette University Center for Dispute Resolution Education, has suggested that three factors be considered to determine the general appropriateness of the mediation model in a given situation: (1) the "relationship between the parties"; (2) the potential "need for privacy"; and (3) the potential need for "creative and flexible resolutions." Mediation may be particularly appropriate in the setting of prenatal diagnosis under the first standard: relationship of the parties.

60. This model of mediation is commonly known as "interest-based bargaining." For an explanation of this approach to mediation, see ROGER FISHER & WILLIAM URY, GETTING TO YES (2d ed. 1991).
61. Professor Eva Soeka received her law degree from Marquette University, where she serves as Associate Professor of Law, in addition to serving as the Director of the Center for Dispute Resolution Education. Professor Soeka served two terms as the Chair of the Wisconsin Judicial Council and also served as Chair of the Judicial Council's Alternative Dispute Resolution committee. Marquette University Center for Dispute Resolution: Eva Soeka, http://www.marquette.edu/disputeres/faculty/soeka.shtml (last visited Oct. 18, 2006). In 1994, the Wisconsin Supreme Court appointed her as the only non-judge member of its Committee on Mediator Qualifications and Standards. Id.
Relationships often implicated in such decision-making and the conflicts that may surround it include: patient-doctor, husband-wife (or other partnerships), parent-child, and other friendships and familial relationships. These are relationships that are likely to continue after the conflict. Situations involving such ongoing relationships are “often the most suitable for mediation.”

Similarly, the situation is generally appropriate with consideration for the need for privacy in such cases. As patients struggle to determine the appropriate course of action, they address very personal moral beliefs and private medical information.

Finally, mediation is appropriate under the third category: the need for flexible, creative solutions. Because every prenatal diagnosis may have differing consequences and will arise within a very unique setting dependent upon the personal needs and situations of those involved, especially the pregnant patient, flexibility and creativity are essential to coping with the conflict that may arise. For example, planning for the duration of a high-risk pregnancy and the birth of a baby with special medical needs is in some ways similar to cases in which decisions and plans must be made as to the appropriate provision of special education for children with mental or physical disabilities, cases where mediation has often proven effective.

Additionally, conflict concerning the proper course of action upon prenatal diagnosis can be highly emotional. As mediators Nancy Rogers and Richard Salem have explained, “inability to reach a [decision] may be due as much to the emotions of the case as to facts.” In mediation, “parties are provided a forum where they can vent their feelings while telling their ‘stories’ so that they feel heard and understood.”

By providing a forum in which parties can share their interests and opinions with the aid of a neutral third-party, mediation offers an opportunity to address these conflicts in a manner inclusive of all parties, without interfering in the patient’s right to make such decisions. Mediation allows for creative option-generation by the parties themselves, who play active roles in exposing the issues that gave rise to the conflict. This role stands in contrast to some ethics consultations, where patients and other parties may feel removed from the process.

63. Id.
64. Id.
66. Id.
and the third-party ethicist generates a solution none of the parties may feel any ownership over, fulfilling an adjudicatory role. Mediation also exceeds the limits of personal counseling, which, although it may well serve the needs of a patient dealing with internal conflict, provides little opportunity for sharing between all parties.

One bioethicist has explained, "conflicts [are] often fueled by different perceptions of the medical facts, different understandings of the prognosis . . . and different personal value hierarchies." Other bioethics consultants have noted, "most often the conflict rather than the bioethical issue becomes the key to the case." Mediation allows parties to come together to gather the appropriate information with the aid and to the benefit of all those involved and to directly address the interests behind the conflict. Just as bioethicists, counselors, and medical professionals provide their respective skills to a case, a mediator brings a unique expertise to the situation and can provide parties with new tools to address conflict.

Because mediation is so well suited to the nature of bioethical disputes, the term and practice of "bioethics mediation" has emerged and, as one example, has been utilized in varying types of cases by Monefiore Medical Center in New York since 1994. Bioethics mediator Nancy Dubler has clarified that mediation need not be solely an alternative to ethics consultation or counseling but may serve a complementary role.

Mediation has also been used successfully in neonatology units in New York and Colorado. Writing about the promise of mediation in neonatology decision-making, Kimberlee Kovach notes that in at least one case, "mediation concerning potential treatment and care took place prior to the birth of the infant, as the parties were aware of the potential problems." She notes the potential benefit of mediation.

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68. Dubler & Liebman, supra note 47, at xvi.


70. Dubler & Liebman, supra note 47, at 14. "Bioethics mediation and bioethics consultation may both be employed in a particular case at different points in the process. . . . Either or both may be required in any complex case, even within a single meeting." Id.


72. Id. at 289.
before birth, commenting on the urgency of critical care decisions after
the birth of an infant in need of specialized medical treatment. The
developed bioethics mediation and neonatology mediation models may
serve as ideal guides for implementing mediation in the prenatal
diagnosis setting.

Certainly, in any of these medical settings, mediators must exercise
cautions to address concerns such as power imbalance, the ethical and
legal scope of agreements, protection of patient rights, and avoidance of
“moral iatrogenesis.” Some reservation about the appropriateness
of mediation in medical settings centers on the concern that the “model
strips away due process protection . . . especially [because medical
professionals] could try to intimidate patients and their families by use
of jargon.” However, power imbalances and patient rights are in some
cases better addressed by mediation than by more adjudicatory
methods. For example, some consultations involve a format like “non-
binding arbitration,” where “patients and physicians vie for committees’
or consultants’ recommendations.”

Frequently[] . . . the patient’s voice is muted, if not lost, and the patient’s
ability to vindicate his or her interests is overpowered. The power
imbalance in a hospital setting comes from many sources: the difference in
level of knowledge and expertise . . . the highly technical and unfamiliar
physical setting, and the imperfectly aligned interests of the patient and
the treatment team members.

73. Id.
74. DUBLER & LIEBMAN, supra note 47, at 25 (“In bioethics mediation there are almost
always two predictable sources of power imbalance: disparity in knowledge and information
and disparity in emotional status.”).
75. See id. at 11. Dubler and Liebman mention that other considerations for
institutional policy, ethical/social acceptance, and the law must accompany and may limit an
agreement between the parties. See id. at 13–14. They refer to an agreement that
appropriately includes such factors as a “principled resolution.” Id. at 11.
76. See Cohen, supra note 67 at 309.
77. Jacquelyn Slomka, Clinical Ethics and the Culture of Conflict, 35 HASTINGS CENT.
REP. 45, 46 (2005) (reviewing DUBLER & LIEBMAN, supra note 47). The term “moral
iatrogenesis” has been used to articulate the concern that “[w]hen conflict is framed in ethics
discourse, and when [involved parties] are able to call upon the mediator to sort out their
ethical and clinical conundrums, they may lose confidence in their ability to do so
themselves.” Id.
78. Cohen, supra note 67, at 309.
79. Gatter, supra note 39, at 1095.
patients without any facilitative process likewise creates a disadvantage for patients who might not have access to all the information and experience concerning their situation that doctors and other professionals may. Therefore, power imbalance is not a concern unique to mediation. However, the dynamic of a neutral third-party facilitating communication may guard against power disparity. Indeed, mediation has been seen as an effective tool for “leveling the playing field.”

Patient rights are likewise a concern in any approach to resolving conflict that arises in the health care setting. Again, mediation offers the benefit of high levels of patient involvement, and the voluntary nature of mediation would allow patients to withdraw and seek a different approach at any time. Similarly, the danger that patients and professionals will begin deferring ethical decisions to others rather than claiming personal responsibility (moral iatrogenesis) seems more likely in adjudicatory models than mediation. A mediator, unlike an arbitrator, judge, or even an ethics consultant, does not construct a solution to the problem, but rather facilitates the process as the parties arrive at their own solution. The mediation process “may also have a modeling function,” teaching disputants effective communication and dispute resolution processes that can allow them to avoid “resorting to adjudication.”

The concern that mediation can lead to unethical, unlawful agreements because they are the product of the parties can also be alleviated by an understanding that mediation is not simple negotiation; the mediator may guide the process such that any resolution will fall within acceptable boundaries. Bioethics mediation is likely to focus on personal, relational conflict that does not involve the negotiation of any legal rights, but assists parties in making plans that meet the non-legal interests of those involved. For this reason, agreements are not likely to run afoul of legal or ethical standards. Still, mediators in many contexts, including bioethics mediation, must assure that parties reach an agreement that is lawful and comports with applicable policy and ethical standards. The concern, however legitimate, is hardly unique to the

80. DUBLER & LIEBMAN, supra note 47, at 11.
82. See DUBLER & LIEBMAN, supra note 47, at 11 (discussing principled resolution). This challenge also presents itself in ethics consultations. For more on consultants guiding discussion among morally acceptable options, see AMERICAN SOCIETY FOR BIOETHICS AND HUMANITIES, supra note 41, at 7.
health care or prenatal settings, and a trained mediator will capably address this issue.

The mediation model would provide another option to meet patients' needs for information gathering and conflict resolution that existing models may inadequately address. Therefore, this Comment proposes that mediation programs should be included among the resources provided under the proposed Prenatally Diagnosed Condition Awareness Act.

IV. CONCLUSION

Today pregnant women are faced with choices and conflicts never presented to their mothers and grandmothers, as prenatal testing and diagnosis have become routine occurrences. These technologies have moved, for better or worse, into the normal experience of patients and their loved ones, with motivation and reinforcement from medical, social, and legal climates. As the reality of the experience of pregnancy changes, so ought the processes offered to patients struggling to traverse this new terrain.

Of particular concern is the adequacy of the information given to patients about the procedures themselves, the diagnosis of their fetuses, the prognosis for individuals with those conditions, and the options available. The Prenatally Diagnosed Conditions Awareness Act proposed by Senators Brownback and Kennedy would address this issue in part by mandating that health care providers convey such information in writing to patients at the time of diagnosis, as well as referral information to supportive services also to be developed and incorporated into the Act.\textsuperscript{83}

This Comment recommends that mediation should be offered to patients as one such supportive service, given its propensity to aid participants in open communication that would both assist with information gathering and address conflict that may arise. In this way, patients confronting the new modern reality of prenatal testing and diagnosis will also have the benefit of new approaches to handling the results.

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\textsuperscript{83} See Prenatally Diagnosed Condition Awareness Act, S. 609, 109th Cong. § 3(d) (2005).