ELSI Friday Forum Transcript July 9, 2021

**Current Legal Challenges to Abortion: Implications for Prenatal Genetics**

>> Sandra Lee: Hello. I'm Sandra Lee from the Division of Ethics at Columbia University. I'm delighted to welcome you to our final Friday ELSI Friday Forum of the academic year, Current Legal Challenges to Abortion: Implications for Prenatal Genetics.

For those of you who are joining us for the very first time, ELSI Friday Forum is hosted by the Center for ELSI Resources and Analysis, or CERA for short. ELSI Friday Forum is held the second Friday of every month for one hour starting at 12:00 noon Eastern and 9:00 a.m. Pacific.

Following today's session, we invite you to a separate Zoom room for a half hour of continued discussion. The link will be posted in the chat box at the end of this session.

The CERA is a multidisciplinary, multiinstitutional center that aims to foster a community for scientists, scholars, policymakers, journalists, members of the public and others interested in research on the ethical, legal and social implications of genetics and genomics, otherwise known as ELSI. CERA is funded by the National Human Genome Research Institute at NIH and is managed by teams at Stanford and Columbia Universities in partnership with the Hastings Center and Harvard University.

CERA's online platform, ELSIHub.org, offers a number of resources including the recording and transcript of this forum and associated reference materials. It also offers the ELSI literature database, a research instrument repository, a scholar directory, news and events and much more. Please go to the website to sign up for newsletters and other events like this one at ELSIHub.org. You can also get daily updates and news on Twitter at ELSIHub.

We are pleased to announce the publication of a new ELSIHub collection curated by our panelists, Ellen Wright Clayton and Marsha Michie. Please use the link in the chat to access this essential reading list on today's topic.

So now for just a few housekeeping tips. If you wish to use closed captioning, please turn on the CC button at the bottom of your screen. We encourage an active exchange of ideas between our panelists and all of you. The panelists' presentations will be brief so that you can use a significant portion of our time in discussion.

Please use your Q&A button which you will find at the bottom of your screen to ask the panelists questions. You can register your enthusiasm for a question and elevate it up the list by using the upvote button in the Q&A box.

We will be posting links to resources, referenced in today's discussion in the chat. The resources in the chat will also be e‑mailed to registrants after the forum. If you have any questions, please e‑mail info@ELSIHub.org at any time.

Now it is my pleasure to introduce our moderator today, Laura Hercher. Laura is the Director of Research in Human Genetics at Sarah Lawrence College. She is also the cofounder of and regular contributor to the DNA Exchange as well as the host of the podcast The Beagle Has Landed. And now I will hand off to Laura.

>> Laura Hercher: Thank you, Sandra. And I would like to thank the ELSI Friday Forum folks for deciding to dedicate some time to this incredibly important and incredibly timely topic. I don't think anyone has escaped the realization that there's been a rapid escalation in the number of restrictions on abortion, and that the rights of women throughout the United States to all have some access to abortion is itself under threat.

What we are talking about today very specifically is the focus on abortion following prenatal diagnosis. And I think this first hit my radar screen in 2012 when I heard Rick Santorum who was then running for Republican nomination for president say insurance companies should not be required to cover prenatal testing at all because prenatal like amniocentesis, this is what he said, amniocentesis led to abortion more often than not, quote/unquote. And the reaction to this focused largely on that obvious and glaring mistake. Most of the time amniocentesis does not lead to abortion. Most of the time amniocentesis leads to reassurance.

But gloating about how stupid it was that he said that ignored the major issue, and the major issue was that the antiabortion movement had prenatal testing very much in its focus. And one year later that emerged in the first of these reason bans which are laws that restrict the use of abortions specifically in circumstances where they are used because of a prenatal diagnosis. And those now exist in eleven states. In some states they are enjoined. I'm sure we will hear more about that.

But I think it's very interesting that the antiabortion movement in general has identified termination after fetal diagnosis as an area where they can make inroads against abortion not only legally but I think in terms of a battle for hearts and minds.

And these two battles overlap, but they are not the same. Abortion I think we can pretty much agree is going to get harder if not impossible across great swaths of the United States. And that's going to be a big challenge for prenatal genetics. But even beyond that, a successful campaign to stigmatize individuals who choose termination after prenatal diagnosis will make it harder on everyone, patients and practitioners and supportive services and legislators and anyone interested in protecting these rights. And as Rick Santorum himself suggested, it can take other forms. I think theoretically, they could look to make it difficult to fund prenatal testing just as we have seen threats to the funding of abortion or birth control.

So overarching, it's important and crucial in maintaining access to prenatal testing to make the case that genetic testing is routine prenatal care and has values for those who do not terminate. That's helpful. But at the same time that we try to do that, we are interested in not validating the narrative that abortion after prenatal diagnosis is shameful.

And speaking on behalf of genetic counselors to do that will remain good and thoughtful allies to individuals with conditions like Down syndrome and their families. So trying to balance all of those is a difficult task in case you thought being a prenatal genetic counselor was an easy job.

So one of the things that's interesting to me about this battle for hearts and minds business is that all of this change has happened absent any shift in public opinion. Really, in fact, consistently you look at any set of numbers. The public opinion is at least 50 percent supportive of the right to abortion and more supportive of the right to abortion when there's a medical issue.

I just grabbed the recent Gallup poll numbers about abortion in the third trimester. But these are typical in this case, these are recent, if a woman doesn't want a child for any reason, 20 percent of people said they supported abortion nonetheless. They asked what if there was a life‑threatening illness in the fetus. And they said that went up to 48 percent.

And they asked specifically what if there's Down syndrome? And that went down to 29 percent. And I just want to point out that that difference is really I think the driving difference why the first ban in North Dakota said that abortion should not be legal after a diagnosis of any genetic anomaly, and the next law in Ohio specifically prohibited abortion if the unborn child has Down syndrome. And it went from being a misdemeanor to being a felony and so on.

So these laws have gotten increasingly draconian. The most recent one passed in Arizona not only includes a felony conviction and potential loss of license for a physician who does an abortion following prenatal diagnosis but includes also a $15,000 fine for any medical practitioner who knows that this abortion is going on and doesn't turn them in, turning people like genetic counselors into theoretical, you know, people who are monitoring their patients and what they do.

So it's a terrible position that we are now in. Of course, none of these bans are actually going to end abortion or abortion after prenatal diagnosis because borders between states are highly porous. And restrictions won't stop someone from getting an abortion if they have access to money, the internet, an airplane, child care, social supports, so on, which is to say the effect of all these changing laws will fall most heavily on those who already are the most burdened. In a sense, this is of course an ethical issue of self‑determination but also a social justice issue with profound societal ramifications.

So background and framing, I say why I'm extremely excited to listen to these two distinguished women whose work I have followed for years talk about this subject. Ellen Wright Clayton is Professor of Pediatrics and Health Policy in the Center for Biomedical Ethics and Society in Vanderbilt University Medical Center and a Professor of Law in Vanderbilt's Law School. The primary focus of her scholarship has been the ethical, legal, and social implications of genetics research and its translations in clinical care in the larger society. Recently she has served as co‑PI of the Get Precise and Law Seek projects and has been involved in E‑Merge since its inception. A passionate advocate of women's rights, she has also been actively engaged in leadership in the National Academy of Medicine.

Marsha Michie is an anthropologist and an empirical bioethicist who researches ethical and social issues related to genetics and genomics, biomedical research and reproductive ethics. She's assistant professor in the Department Bioethics at Case Western Reserve University School of Medicine. She currently leads the PREPARE Study on the ways families prepare for a child with a genetic condition and she co‑leads a new study creating an ethical framework for research on genomic interventions in pregnancy. Without further ado I turn the presentation over to Ellen.

>> ELLEN WRIGHT CLAYTON: Well, thank you for the opportunity to be with you all today. So first of all I have no pertinent financial disclosures to make. I have been thinking about these issues for a while. This was my very first publication which occurred in 1978 which is my note about prenatal diagnosis.

And I have been thinking about it for a good bit of time before then. The messages I want to give today are these. First of all, that the dramatic expansion of prenatal diagnosis has enabled women to choose whether to continue their pregnancies. I also want to talk about the impact of choice on people with disabilities because the narrative that is out there is incomplete and in many ways misleading and also to follow up on the point that women's choices are already being severely limited in some states.

>> Marsha Michie: Hi Ellen. I don't think your slides are showing up. So maybe you can share them again.

>> ELLEN WRIGHT CLAYTON: Okay. There you go. Okay.

>> Marsha Michie: Great.

>> ELLEN WRIGHT CLAYTON: Thank you. So I would say that the availability of abortion has played an important role in the expansion of prenatal diagnosis. In the late '60s and early '70s, it became impossible to learn something about the health of the fetus. Before that, the uterus was a black box. We knew the fetus was in there, but we knew very little about it.

But what we were able to know at that period of time was actually quite limited. This is a picture of an ultrasound that was available during that period. That really doesn't show very much that real people can interpret and that there was amniocentesis that was done in the second trimester which could diagnose Down syndrome and other trisomies by about week 16 or 17 when women were very clearly already pregnant.

There was very little to be done during pregnancy if problems were detected that would affect or improve fetal outcome. Therefore, the only choice that women had during this period was whether or not to continue the pregnancy. And these were and are agonizing decisions. There was important literature at that time, Barbara Rothman (authors), many others talking about the fact that women deciding to terminate pregnancies at this point were really quite complicated.

The states even then had a vexed response to how we thought about prenatal diagnosis from the beginning. Some states provided access to comprehensive genetic services. California in fact mandated offering MSAFP screening for neural tube defects and chromosome anomalies, raising some very interesting issues.

Some states, however, forbade funding of abortion after prenatal testing. Of course the federal government very shortly after Roe v. Wade was handed down forbade use of any federal funds all together. Some states for testing might lead women to choose abortion.

This is true in Tennessee where you couldn't do any sort of prenatal diagnosis for women whose pregnancies were covered on Medicaid because it might lead them to choose pregnancy. And a few tried to ban abortion following prenatal diagnosis even early on.

But nonetheless, the availability of abortion played a major role in part due to the potential liability on behalf of physicians who refused to offer it. Before abortion was available, women had no legal claim if physicians refused to advise or perform prenatal diagnosis because there was nothing they legally could do.

Following the decision in Roe v. Wade, many states recognized causes of action for wrongful birth by parents who were denied the opportunity to choose to terminate their pregnancy. The courts were less favorable to claims on behalf of the child.

At the same time, several courts and several legislatures refused to recognize any legal claims particularly if the woman alleged that she was denied opportunity to have an abortion. And the citation which is here and which is also available which is available on the list recites some of that early history which is otherwise hard to come by.

So let's fast‑forward approximately fifty years to where we are today. The American College of Obstetrics and Gynecology and the Society of Maternal‑Fetal Medicine have for years recommended that all women be offered prenatal screening and diagnosis.

And the face of this technology has changed dramatically. In addition to amniocentesis and MSAFP, it's now possible early on to do sex determination. The development of so‑called noninvasive prenatal diagnosis was driven by the fact that women wanted to know whether this is a choice that they wanted to make early, you know, from eight weeks, ten weeks, before, you know, before they were visibly showing and so this was an opportunity that they had. Many other methodologies, I'm pointing out the arrows here because they will be salient later. Six weeks, eight weeks, and 15 weeks. I want to say a little bit more about noninvasive testing. This has been a real game‑changer. Advertised in women's magazines, it is actually really quite accurate or quite sensitive in detecting having an extra chromosome, particularly for Down syndrome.

And I would also note at the bottom there are huge global market projections for these tests. Companies want to sell these tests and the value of it primarily from their perspective is to enable women to be able to make choices.

So what are the options following prenatal diagnosis in 2021? It's important to note that it's still very unlikely to be able to intervene during pregnancy to improve fetal outcome. You can do it in some cases in spina bifida. There are a few others. But the fact of the matter is there is nothing that can be done during pregnancy most of the time to improve fetal outcome.

That may change, but that is still the case. More frequently, prospective parents can use the information to make chases about whether to deliver and other plans, and Marsha is going to give the latest data about this really important. But it's very clear that in many cases having a child who you know is going to have a serious problem is better to deliver in a high‑risk nursery.

And it is, in fact, the case that some women choose to terminate pregnancies following prenatal diagnosis, but the estimates are this accounts for less than five percent and usually much less than five percent of all abortions. So the question that I want to ask, and it's one that has been highlighted in the media recently is, are people with Down syndrome going to disappear in the U.S.?

And the answer to that is no. It's not true. And so it's really hard to get evidence about why women choose to terminate pregnancies. But this is the best that we have. And it is true that some women as designated here in green do choose to terminate pregnancies with Down syndrome. But the majority of children with Down syndrome go onto term.

So that's what the data actually show. And what's more is that the narrative around Down syndrome has changed dramatically in the last fifty years. In the early days of prenatal diagnosis that it was common practice to institutionalize children with Down syndrome. It was often the case that these children were not offered curative therapy for surgical issues that they had.

Their life expectancy was really fairly limited. And then you look at today. First of all, medical care is routine. It would be unthinkable not to do some of the surgeries that were foregone fifty years ago. Educational opportunities are better. At Vanderbilt we have a parallel program that parallels college for children with Down syndrome.

But the other thing I want you to look at is this graph which is life expectancy in the 1950s was really quite low and there were very many people with Down syndrome. And look at where we are today. The life expectancy is a lot better. The quality of life is better. And the acceptance is much more expansive.

So this idea that the availability of choice is going to lead to worsen discrimination against people with disabilities is simply not true. Yeah, as Laura has already alluded to, a number of states have issued reason bans based on characteristics. The most common one is sex selection. There are some based on race and increasingly there are some based on the context of genetic anomaly, sometimes specifically Down syndrome, but sometimes not.

So what does the future hold for reason bans? And here I think we really have to think about this very clearly. Justice Thomas concurrent in Box versus Planned Parenthood a case decided in 2019, he analogized choice to terminate pregnant of fetuses with Down syndrome with state‑mandated eugenics. Now, I can go off on why that is completed fallacious reasoning.

But nonetheless, this has been an incredibly important decision. And the court in Box did not address statutes banning such abortions simply because at that time there were no Circuits flipped. The 7th Circuit where Indiana is had enjoyed the ban saying it violated Roe. Now there's this flip. So this is going to be on the table.

In the 6th Circuit where I live both Ohio and Tennessee passed laws making it a felony to do an abortion if the woman is terminating the pregnancy because the fetus has Down syndrome. In both cases, the court en banc, all the judges together refused to enjoin these provisions relying heavily on Justice Thomas's analysis.

This is a big deal. It's setting the table. But the other thing that I want to talk about is the critical importance of what we are seeing in the Mississippi case that the Supreme Court has already accepted session. And I want to point out that 14 states have already passed laws that would ban abortion prior to eight weeks.

43 weeks have passed limits overall, but before viability, but 14 have already said eight weeks. So why does this matter? It matters because, go back to this case. The bar in blue is at six weeks. There is no way that a woman can know that the fetus has a problem before six weeks. She can barely know this before eight weeks.

If those law also upheld, 15 weeks which is Mississippi, it is possible to know and be able to make a decision before 15 weeks. But I see no reason or no way that the Supreme Court can uphold a 15‑week limit and not immediately lose any ground to go to prevent earlier bans. So I think that what we are going to see is in addition to reason bans, the bans that potentially are based on the timing of pregnancy are going to make prenatal diagnosis for purposes of allowing a woman to make a choice whether to continue her pregnancy or not are going to be banned or made impossible in many, many parts of the country.

So I think the questions before us are these. And then I will turn this over to Marsha. If women lose the right to choose, what role will there be for prenatal diagnosis? Is it enough that the overwhelming majority of women will receive reassurance? I have to tell that you health insurers don't pay for reassurance. They pay for action.

And so is this going to get rid of their ability to pay for this? And if they do continue to make this available, at what cost will it be to women who do not get reassuring news and who find something out catastrophic out about the fetus? I think these are tremendous questions before us. And now I am going to turn this over to Marsha so she can share some of her work in this domain. I look forward to our conversations.

>> Marsha Michie: I just realized I was muted. Thanks so much, everybody. I just want to add a few things to the excellent points that Ellen and Laura have already made. I will start by reiterating the important linkages historically between prenatal testing and termination in this landmark paper where they discuss the disabilities rights critique of prenatal genetic testing.

They talk about, as Ellen did, the rarity of interventions that can take place during pregnancy, and also the rarity of people who really are using this information just to prepare for the birth of a child with a disability. Meaning that most of the time, positive prenatal test results are useful primarily as a basis of a decision whether or not to terminate a pregnancy.

This was 1999 and I think that things have changed a bit along the preparation front. But I will get to that in just a moment. But you can see historically, and this is a slightly different perspective from what Ellen shared, that once we were able to do any kind of prenatal diagnosis, fetal sex in 1955, it didn't take long to move to terminations for hemophilia.

Once we could do karyotypes to diagnose Down syndrome, we very quickly moved to abortions for Down syndrome. And once amniocentesis was determined to be safe, it didn't take long before these wrongful birth suits began for providers that did not have ‑‑ had not offered these tests to their patients.

But a lot has changed since then. As Ellen hinted at we have certainly have seen a lot of more mainstreaming and acceptance of people with disabilities, different language to talk about people with disabilities, lots more support groups including adoption networks for people who don't feel like they themselves can raise a child with a disabling condition but do not want to terminate.

And certainly a lot more really great information that's collaboratively produced by medical organizations and support organizations so that they can support both families and frontline prenatal providers who are informing them about these conditions and about the tests that look for them. So that's a huge thing.

And it means that preparing is more feasible now, but we still don't really fully know what this means for different families, families that are demographically quite diverse or how it differs by diagnosis. We are not just talking about Down syndrome. We are talking about a huge range of genetic conditions with very different prognoses conditions.

What does that mean for the families? What is most important to them? This kind of clinical preparations like surveillance or possibly interventions, delivery‑day preparation, social preparation like connecting support groups psychologically just preparing for a different future than even anticipated.

And that's what our study is working on. This is an NHGRI‑funded study. And I don't have a lot of data to present to you today. We will be presenting more in the fall at ASBH on this.

But I will note that we also really cannot alleviate the inherent uncertainty that goes along with prenatal testing. We cannot always give people a hundred percent definitive diagnosis, and even when we can, for Down syndrome which is one of the best understood conditions that we diagnose during pregnancy, we still cannot tell you everything about what your child is going to experience during their life if you go on to have your baby.

And so when people are faced with uncertain information, oftentimes they immediately go to the worst‑case future scenario when they are making those decisions about whether to continue. This is a quote from David Wasserman in that well‑read Down syndrome article where he says there is profound risk aversion at work here. And why not? Having a baby is quite scary, so it's understandable that people feel that way.

But I want to point out that even preparation for many families really depends on an awareness of the availability of termination as this information about the pregnancy evolves during the pregnancy. So you may have a soft marker early in pregnancy and go on to have much more definitive information later, and maybe much more serious information about a life‑limiting condition that could cause suffering.

And furthermore, it's really important for preparation to be able to have open and honest communication with your healthcare providers about what options you are willing to consider. So if parents can't discuss their options with their doctor because he or she could be prosecuted, then who is the knowledgeable person who is going to help them work through these possible futures?

It's not just diagnosis we are talking about either. As Ellen mentioned we have increasingly accurate but not diagnostic prenatal genetic screening techniques. And their positive predictive value varies wildly depending on the condition, the a priori risk. And who is going to explain that to the parents?

We know for a fact there have been plenty of parents who terminated pregnancy based on NIPT results. We also know now that Ohio laws have been passed, our local freestanding abortion provider who was the organization that brought the court case, they now have a large‑print notice on their website that says we are not going to ask you about why you are terminating your pregnancy because we are no longer legally allowed to.

So parents who have results that they don't fully understand are not going to have people to work through that with them. And it's abundantly clear these laws are just the first step. Nobody seriously thinks that it's going to stop here, that women are never going to be prosecuted for terminations or even miscarriages because we know that it has already happened and it will continue to happen. And nobody really seriously thinks that there won't be more limits to access. This is just one more step in a journey to prevent access to termination all together.

Another thing that's really changed, Ellen pointed to the Baby Doe cases. The 1980s when we were still fairly routinely denying interventions to already birthed babies who had Down syndrome and other conditions on the basis of an assumption that they would have a quite low quality of life even if the intervention succeeded.

That's changed, of course, radically since then. We now have tremendously sophisticated surgical techniques for spina bifida and other conditions during pregnancy. We are seeing great successes with stem cell treatments, lots of interventions using possibility CRISPR maybe in research trials soon. And those interventions are developing rapidly.

But laws that criminalize physicians who end a pregnancy could make doctors and researchers subject to prosecution if those interventions are unsuccessful or if they have to be terminated for any reason, safety or another reason. And I should also note if these are under our research protocol this could affect IRB approval of research

In institutional risk management officials think that this is too risky and exposes the institution to liability, then this research could be forestalled. And research that we have seen really life‑saving, amazing results from might never happen in the future if these laws scare people away from doing the research and institutions away from sponsoring it.

So with that, I just want to thank the organizers and of course Laura and Ellen for all their great thoughts and the funding from NHGRI for my two studies, the PREPARE study how people get ready for a child with a disabling condition and the FAIRER study, brand‑new study on genomic interventions during pregnancy. All the collaborators and participants in those studies and CERA and ELSIHub and of course you for listening. Thanks so much.

>> ELLEN WRIGHT CLAYTON: Laura, I think you're muted.

>> Laura Hercher: I just got a note saying the host would like you to unmute which seems really reasonable. So, thank you Marsha and Ellen for those two great talks. And I want to leap right into questions because I have questions and the audience had questions. And we have some time, but here we go. So quickly, Ellen, one person asked if you could explain more about what it means to have a Circuit split.

>> ELLEN WRIGHT CLAYTON: Oh, sure. Quickly, the Supreme Court often when it's deciding a case wants first of all to make sure that the lower courts have had a chance to look at the issue closely so they have a background to work on. And if the Circuits are going in different directions, some of them are saying that something is a problem, others of them are saying that it's not, then the Supreme Court will step in and say, you know, we need to come in and fix this.

If all the lower courts agree about the way forward, you know, the Supreme Court may still step in. But in general they are much more likely to step in when there is a clearer conflict between appellate courts in different parts of the country.

>> Laura Hercher: So to stay with a question that relates to how the courts will react to this with our court‑related question, one of the audience mentions quite correctly that NIPT has been a big game‑changer. It was first introduced in 2011. It has grown incredibly fast. And the audience member points out this sort of indicates the parents have a preference for this information.

Maybe Marsha would like to argue with that a little bit what that indicates. But in general, I think that's not wrong, right? It indicates that there's interest in this information. And she asks will the courts take that into account? To what extent will these revealed preferences be considered in Supreme Court and other policy decisions? And let me let Ellen say that first and then I will go to Marsha who might have more to add.

>> ELLEN WRIGHT CLAYTON: I don't think they care.

>> Laura Hercher: Yeah, that's what I think, too.

>> ELLEN WRIGHT CLAYTON: That's just an off‑the‑cuff answer. Clearly, if you look at Justice Thomas's argument, I mean, he really thinks that this is an anti‑disability rights, that women's choices are anti‑disability right government choices. And so, and you have to know that Justice Comey was a dissenter in the 7th Circuit case which decided to actually say that the ban ought to be allowed to be held.

So I think we have to be worried that Justice Comey would side with Justice Thomas. I think that this is really, I mean, the tension between the ability of pregnant women and their partners to decide, you know, whether to continue a pregnancy or not is directly under assault.

You know, and depending on this, you know, the view of the fetus. I tried to testify in front of the Tennessee Supreme Court a few years ago. I wasn't allowed to testify. But the legislator who was coming up with the heartbeat bill, the only thing he said is I'm saving babies. That's what this is about.

>> Laura Hercher: I think also what I was trying to say in the beginning was is this is not leading from public opinion. This movement to restrict abortion is not a rising ‑‑ it doesn't reflect public opinion. It is an attempt to lead public opinion, in fact, against these. I want to give Marsha the chance to talk about this issue of what NIPT use reflects. Do you want to add anything to that?

>> Marsha Michie: Well, I actually agree that people really value this information. It reflects a lot of things. It reflects extremely heavy marketing on the part of these commercial companies, sometimes deceptive marketing. And it also reflects I think a whole new market for prenatal testing which is people who have zero intention of terminating a pregnancy.

We know that this test is very popular among people who just want information. They want to know if they are going to have a boy or a girl. They want to know how to get ready in some sort of vague way even though we don't always have good supports for them. But people who are very, very averse to terminating pregnancy are generally going to say no to amniocentesis or to anything that poses any kind of risk, however minuscule, to the pregnancy. Ellen, you wanted to make a point?

>> ELLEN WRIGHT CLAYTON: I was going to make a point it's just a blood test. If you have an amniocentesis where they put a needle in the uterus, you know it if you have a CVS which I have had, and they put a needle in your vagina, you know it. But, you know, but like all adults, every time I go to the doctor, they withdraw my entire blood volume.

So, you know, there is a real thing about this isn't putting the baby at risk because there's no needle going near it. And it's not as big a deal. I mean, just a blood test.

>> Laura Hercher: In terms of the timing that you mentioned before, I mean, we know from experience and from statistics and from observation that if people rely on NIPT results, then there's going to be mistakes made and there are going to be times when those results are wrong. So we always advocate for people to double‑check those results with invasive procedures like CVS or amnio if there's no time to do that.

The time slide, if they do that, there's no time to double‑check. One of the sad ironies is you are going to have people terminating what will turn out to be healthy fetuses because they didn't have time to check on those results. That's true and rare for Down syndrome, but it will be true and less rare because for other conditions you can find with NIPT because as Marsha pointed out, the positive predictive values are really, really different.

In fact, there was a question. I think an interesting area to get into this question of how Down syndrome is sort of synonymous with prenatal testing in ways that I think are unfortunate, really, because prenatal testing is expanding very fast. It's one of the many trends we are tracking here is prenatal testing what we can test for is expanding very fast.

So the audience member said what extent do you feel the example of Down syndrome is or is not analogous to rare genetic diseases which are collectively much more common though currently not as easy to detect on prenatal screening? And how does the potential for moving forward towards genome sequencing as a prenatal screening option change or expand the ethical challenges in this area? Marsha, do you want to start with that?

>> Marsha Michie: I will say you make a very good point that Down syndrome is synonymous with prenatal testing not just for providers but for patients, too. It may be the only genetic condition people have heard of. And we know from the previous research on prenatal testing and what people do with results is people don't always make a meaningful distinction between Down syndrome and other results that are quite different like trisomy 13 or trisomy 18 or much, much milder conditions.

So it's a challenging thing to understand that Down syndrome isn't the genetic condition. And I think that people don't always fully really distinguish between with a particular phenotype of Down syndrome and the many, many other kinds of conditions that you might find out about, some of which you might never find out about if you didn't have genetic testing, others which are very, very likely to result in the fetus itself spontaneously terminating.

>> Laura Hercher: Ellen, do you want to add anything to that?

>> ELLEN WRIGHT CLAYTON: I think that we don't know how to use this in terms of taking care of people who are already born. I mean, we are in the process of learning when and how and how to interpret genome sequencing on a broad scale. I mean, huge research about it. And I think if we don't know how to do that with regard to people who are already among us to think this should then be implemented in prenatal testing is just, well, I mean, it will happen because of the market. But it will ‑‑ but I think that it raises a whole host of questions about whether people can even make meaningful results on the basis of that.

>> Laura Hercher: So sort of continuing in this question from Leila Jamal, it sounds like you are arguing the tension between disability rights and reproductive choice is less fixed than many people. The data you cite suggests that at any rate whether or not that's true, it seems like debunking that tension is essential to mounting a counterargument to Clarence Thomas.

What evidence that people with disabilities agree their views may land on either side of this argument and will probably be very influential in the public discussion?

>> ELLEN WRIGHT CLAYTON: You know, I think it's a contentious area among people with disability rights. But I think that, but I think that at least some of them would say that, at least some of them would say that denying women choices and basically is also a problem in and of itself.

I actually think that the most, the most powerful antidiscrimination movement in this country over the last fifty years has been in terms of success, has been individuals ‑‑ has been increasing the opportunities and the healthcare and the support of individuals with disabilities.

I mean, and I mean, when I think about the way things were when I was growing up versus the way they are now, I'm a general pediatrician by training, I just think that it is an amazing transformation. Is there more work to do? Absolutely. Is there more work to do on race and gender discrimination? Yes.

But I think that, but I think that they are all ‑‑ but I think that this, there is tension, I guess, across this. But I really strongly believe that the disability critique or the disability critique as implemented in the legislatures and by Justice Thomas has been really an antiwomen critique primarily.

>> Laura Hercher: Well, yeah. Marsha, do you want to add to that talking about the tension between disability rights and reproductive rights?

>> Marsha Michie: I think that it's really risky and a bit incorrect to lump everyone speaking for disability together. So if you are talking about a condition like trisomy 18 where parents sometimes seek a termination and don't even think of it as a termination, they think of it as just losing a pregnancy and patient support groups are supporting them through that grief experience that they have for a child that they just don't feel can survive, that's a very, very different perspective than an organization or a group of people that maybe supports or self‑advocates for people who have other kinds of diagnoses that could result in a very long life without a lot of intervention.

And so I think one of the things that we really have to do as ELSI scholars is not think about the disability perspective but think about the range of perspectives that people may have based on their own life experience but also the particular diagnosis that's at stake.

>> Laura Hercher: There's just nothing simple about these issues. I just recently did a series of interviews with parents with young children with Down syndrome. And asked them, and almost entirely in 35 interviews, the parents we were talking to supported access to prenatal testing for a variety of reasons as Marsha has pointed out, whether it was for preparedness or because they felt like they couldn't handle a second child with special needs, and at the same time expressed fear of how people exercising that choice would impact their children down the road.

But without generalizing to say this is everybody or whatever, what many people who are Down syndrome activists have focused on is less restricting access to the information than making sure that the information people get prenatally on Down syndrome is good and balanced information. And I feel like that's been the greater focus from within that activist community.

>> Marsha Michie: Absolutely. I agree. Information is sort of the rallying cry for that.

>> Laura Hercher: Yeah. And fair enough. And yeah, I think this is like I said, it's one of those balls in the air that we have here around this issue. But I would just like to point out that I was looking at Ellen's numbers on that chart. The chart ended in 2013 which is just about the time that NIPS comes into play.

So it is just about the time that suddenly prenatal testing for Down syndrome goes from being something that is for a high‑risk population to everybody, expanding at that point in time. And the question there wasn't how many people who were given the diagnosis when on to continue, but simply how many pregnancies with Down syndrome went on to continue.

So it's an open and really important question of, you know, what percentage of people will go on to ‑‑ what decisions people will make. But for today, you are talking about giving that option to some people and taking it away from other people, right.

So if it's unequal, the access, I think it's pretty safe to say that in the communities don't that don't have access, we are going to see a lot more families with genetic diseases and people with Down syndrome, and not in other families. And I think it's another disability rights issue to say how harmful could that be to those families if Down syndrome turns into something that only comes up in certain communities?

>> ELLEN WRIGHT CLAYTON: So I have a couple of thoughts here. One of the things about that study I cited is that we do not collect data reasons why pregnancies are chosen ‑‑ I mean, why abortions are chosen. You know, and the truth is, you know, if you don't count it, it doesn't count. So you don't actually know.

And we are going to make sure that we don't know because at least in many states, a physician or anyone else who is involved with a termination for a child with a fetal anomaly is going to go to prison. I mean, we are not talking just fines. We are talking prison time. I mean, that's huge.

And so I think that as we, you know, as we move forward here, and of course who gets access to NIPT? I suspect that it is more available to people who have commercial insurance or are insured through their employers and through Medicaid at least in many states. So I think we are going to see this widening disparity.

There's been a lot of discussion about that. But the other thing is that we don't know what's going to happen because we don't collect the data. And that, and so I mean, it is a major, it's an issue in this country. And women are not going to want to talk. Well, actually, they do talk about this. But it is not something that, you know, that people do lightly.

So I mean, there are many things to say there. But you're right about the 2013, no question about that. But the other thing is that we just don't know.

>> Laura Hercher: So I want to, Marsha had mentioned in her talk and I think there are so many prenatal genetic counselors and perhaps some of them out there listening, there's a great agitation since that Ohio decision that you mentioned, Ellen, came down. And it's a really existential anxiety for genetic counselors, particularly those who work in prenatal setting and work in states that are one of these states with these reason bans, and including this issue, Marsha that you said that it sort of says just against every understanding of good medical ethics, don't tell, don't ask, don't know what your patient wants. To shut down communication between a patient and their medical provider is so many dangerous implications.

So, and they are looking at a situation of diagnosing patients and having nothing to offer them and being in this difficult situation. So there's a lot of fear and anxiety in that community out there. And I would like to end this because we are getting to the end of time here.

But asking you both what can people do? So if you feel that you are a provider with these patients and those people are going to be harmed by these laws, what can you do? The hardest question.

>> ELLEN WRIGHT CLAYTON: Well, I think, I mean, I think it's hard because I worry that the Supreme Court is going to limit abortion dramatically and it's going to leave it to the states. And I think for some of us who live in some of those states, it is going to be really hard for women.

And I think it's going to be, you know, and there are ‑‑ and I think some of the workarounds are going to have to be that if a diagnosis is made, that there needs to be another mechanism where women can go to a state that is not as limiting to, you know, to get the abortion that she wants.

And I think you are going to wonder if prosecutors are going to want to say even if you refer to Planned Parenthood who can then take, you know, arranged transport out of state if that constitutes a violation of the statute. You know, the Supreme Court has been unsympathetic to First Amendment claims by clinicians in this domain. I think it's going to be, you're right, it's an existential issue. And so Marsha, I am going to give you the last word.

>> Marsha Michie: I was hoping you weren't going to say that, Ellen. I completely agree with you. I don't know that there's a lot of substantive action we can take now in the situation of uncertainty before we really see what the ruling is going to be.

I would encourage ELSI scholars in particular to, you know, write op‑eds to really make sure that this issue doesn't get unchallenged in the media as we are supporting people with disabilities, because I don't think that's what it's about. Many of the disability rights activists that I work with don't think that's what it's about. They are very aware that they are being used as a prop for this.

And I think it's really important to think about the nuances of these issues and talk about the nuances of these issues in the ways that we have been doing today rather than simplifying it to either it's about children with disabilities or it's about women's rights, because those two don't have to be misaligned. They can be together.

>> Laura Hercher: Great, Marsha. Thank you. I totally, totally agree with that. We have two more minutes. I'm not sure how to handle the last two minutes if we have a question. But let me try.

>> Marsha Michie: Laura, I was wondering if you might want to address the question about what this means for new genetic counselors and aspirant prenatal genetic counselors.

>> Laura Hercher: Well, I mean, there's a lot of frustration because, you know, you spent time training and working to do your job the right way. And basically these are obstacles that say either you can't, you can't serve your patients in the way that you have been taught is the correct, give them good care, or you can and you're putting yourself in some danger.

And I think what they feel is that there's also that institutional problem that you referred to, Marsha. Sort of, like, in these states, I think there is going to be a lot of institutions that say, yeah, these are hard to prosecute. How do you actually figure out what motivation is, so on and so forth. What does it mean?

But I think that a lot of institutions are going to just say why would I even want to touch this? We want to have nothing to do with it. It's just easier not to sort of figure out how to tiptoe around these laws and just, you know, a lot of individual practitioners go out of practice. So it's disturbing. And I actually think it is important to separate from the also very important abortion issue in general this issue about are these issues, are these particular abortions particularly somehow to be disparaged? Because if you make that case, you start getting into, well, why should we pay for prenatal testing and so on?

I think this has places to expand. I think it can actually get worse than what we are describing even beyond this idea that the court is going to take away the right to abortion. So I see that Sandra is here on the screen which I think means she wants to wrap up.

>> Sandra Lee: That was an amazing session. I would like to thank Ellen, Marsha and Laura for this amazing ELSI Friday Forum of this academic year. We will be back in September with the launch of our second year of ELSI Friday Forum for a session entitled Remembering 9/11: The Ethical, Legal, and Social Issues with Using DNA for Disaster Victim Identification. This event will take place at our usual time on the second Friday of the month, September 10th at 12:00 noon Eastern and 9:00 a.m. Pacific.

I would like to thank all of you for making the ELSI Friday Forum series a success. I would also like to thank our planning committee. These individuals have worked tirelessly to plan and support these opportunities to engage ELSI research each month. And we are grateful for their dedication, creativity and teamwork. For those of you who can, please join us in the post‑forum discussion meeting using the link posted in the chat box below. Otherwise, we look forward to seeing you again in September. And please do fill out the survey. We really welcome your ideas for topics for the coming year. Take good care.