

Healthcare Discrimination and Inequities Facing People with Disabilities

A Gap Analysis | 10.14.2020



The Center for Dignity in Healthcare for People with Disabilities (the Center) aims to improve access to anti-discrimination medical protocols for people with intellectual and developmental disabilities. To identify and address healthcare inequities, the Center conducted a gap analysis relying on a review of literature in these focus areas:

- Aging and end of life care
- Lifesaving treatment (organ transplant)
- Mental health and suicide prevention for people with developmental disabilities
- Prenatal genetic testing
- COVID- 19
- Legal aspects of all focus areas
- Other

We used a multi-step gap analysis process for five of the seven focus areas. Analysis of the 219 unique entries in the Center database was used to identify gap categories in the focus areas. Last, we found themes related to potential solutions to address the gaps.

Aging-End of Life

Gaps highlighted by the Center partners in the aging end of life focus area fell into five broad groups:

1. diagnosis and treatment
2. healthcare systems/services
3. healthcare professional related
4. patient related
5. information and research

Potential solutions to address the gaps include:

1. healthcare professional training,
2. including people with developmental disabilities in decisions,
3. developing models of care, and
4. having more information and research.

Plans to close the gaps in this focus area included:

- implementing a framework for transplant centers that ensures transparency
- addressing biases and assumptions
- utilizing collaborative medical decision-making models

Lifesaving Treatment

Like the aging and end of life care focus area, gaps highlighted in the Center partners in the lifesaving treatment (organ transplant) focus area fell into gaps of five groups:

1. policy and legislation
2. healthcare system and services
3. healthcare professional
4. patient
5. ableism

Potential solutions to address the gaps include:

- integrated solutions
- increased transparency
- better policies
- more data

Plans to close the gaps include:

- creating universal practice guidelines
- collecting more research in the field
- ensuring training and educational materials include a person-centered approach.

Mental Health and Suicide Prevention

Gaps highlighted by the Center partners in the mental health and suicide prevention focus area fell into five groups:

1. diagnosis and treatment
2. healthcare systems and services
3. healthcare professionals
4. patients
5. information and research

Recommendations to address the gaps include:

1. healthcare professional training
2. increase public health awareness
3. improved healthcare system
4. better diagnosis and treatment
5. more research and policy changes

Plans to close the gaps in this focus area include:

- a required for course on disability for all medical and psychiatric training programs
- checking the effectiveness of the Columbia -Suicide Severity Rating Scale (C-SSRS) suicide screening tool
- setting a benchmark for training and effective performance

Prenatal Genetic Testing

The prenatal genetic testing focus area document review data highlights the gaps in six focus areas:

1. policy and legislation
2. research and data
3. healthcare professional
4. patient
5. ableism
6. funding

Potential solutions to address the gaps fell into four categories:

1. healthcare professional training and accountability,
2. better patient experiences,
3. policy and guidelines
4. robust data collection and related research.

Plans to close the gaps in the prenatal genetic testing focus area include:

- a research study to investigate the impact medical outreach on healthcare providers
- evaluate the quantity and quality of information patients receive

Additionally, this focus area intends to use the results of the gap analysis to inform the development of future protocols.

COVID-19

We added the COVID-19 focus area halfway through the project because the impact of the pandemic on people with disabilities began to amplify existing gaps in healthcare for people with disabilities. The Center partners note discussions on the effect of scarcity of resources exclude people with disabilities. They also mention a persons' disability status can be a reason to deny care. It is unknown how the scarcity of resources impact care. Potential solutions to address the gaps include:

- taking steps to show the impact of COVID-19 on people with disabilities
- helping people understand how to adapt to unfamiliar health situations
- include people with disabilities in the discussions of crisis standards of care

In response to the urgency to close the gap, the Centers partners' created fact sheets to inform patients of their rights and to inform healthcare providers of how to safeguard against discrimination.

Legal Aspects for All Focus Areas

The Center partners conducted a 50-state survey to determine which states and territories have enacted the Down Syndrome Information Act. Organ transplant protection and wrongful life/wrongful death laws were also surveyed. Twenty states have enacted Down Syndrome Information Acts and three additional states have attempted to pass a Down Syndrome Information Act. Sixteen states and territories have enacted some legislation providing organ transplant protection for people with disabilities. Whereas only 12 states have enacted legislation related to wrongful life and wrongful birth; three states allow claims and nine prohibit claims.

Other

The 'other' focus area includes related concerns to inequity and discrimination in people with disabilities healthcare, and that are not addressed in the existing focus areas. The 'other' focus area included several documents which tied directly into four of the existing focus areas. Most of the documents reviewed emphasized new topics such as intersectionality, topics specific to Autism Spectrum Disorder or Cerebral Palsy, health insurance related issues, and healthcare professional training.

The Center partners facilitated an active discussion addressing several questions related to protocols in focus area specific breakout sessions at the American Academy of Developmental Medicine & Dentistry 2020 'One Voice for Inclusive Health' Educational Conference. The discussion highlighted key considerations in protocol development and dissemination. These considerations included:

- ideas about the platforms to use
- components to ease healthcare provider decision making
- strategies for addressing buy-in and bias
- ways to improve the quality and quantity of data

Executive Summary

The Center for Dignity in Healthcare for People with Disabilities (CDHPD) aims to improve access to anti-discrimination medical protocols for people with intellectual and developmental disabilities. To identify and address healthcare inequities, CDHPD conducted a gap analysis which relied on review of various types of literature to identify gaps in the following focus areas: aging and end of life care, lifesaving treatment (organ transplant), mental health and suicide prevention for people with ID/DD, prenatal genetic testing, COVID- 19, legal aspects of all focus areas, and other. A multi-step gap analysis process was applied to five of the seven focus areas. Analysis of the 219 unique entries in the CDHPD Database revealed gap categories in the focus areas. Themes related to potential solutions to address the gaps were also identified.

Gaps highlighted by CDHPD Partners in the aging end of life focus area fell into five broad categories-- issues related to diagnosis and treatment, gaps in healthcare systems and services, healthcare professional related, patient related, and lack of information and research. Potential solutions to address the gaps were grouped in four categories: healthcare professional training, including people with ID/DD in decisions, developing models of care, and having more information and research. Plans to close the gaps in this focus area included implementing a framework for transplant centers that ensures transparency, addressing biases and assumptions, and utilizing collaborative medical decision-making models.

Similar to the aging and end of life care focus area, the lifesaving treatment (organ transplant) focus revealed gaps in five focus areas: policy and legislation, healthcare system and services, healthcare professional, patient, and ableism. Potential solutions to address the gaps were clustered in four categories: integrated solutions, increased transparency, better policies, and more data. Plans to close the gaps included creating universal practice guidelines, collecting more research in the field, and ensuring that training and educational materials includes a person-centered approach.

Analysis of the mental health and suicide prevention focus area data revealed gaps in the following five categories: issues related to diagnosis and treatment, gaps in healthcare

systems and services, healthcare professionals related, patient related, and lack of information and research. The potential solutions to address the gaps were grouped into five categories: healthcare professional training, increased public health awareness, improved healthcare system, better diagnosis and treatment, and more research and policy changes. Plans to close the gaps in this focus area included a requirement for disability training components in all medical and psychiatric training programs, checking the effectiveness of the Columbia -Suicide Severity Rating Scale (C-SSRS) suicide screening tool, and setting a benchmark for training and effective performance.

The prenatal genetic testing focus area document review data highlighted gaps in six focus areas: policy and legislation, research and data, healthcare professional, patient, ableism, and funding. Potential solutions to address the afore mentioned gaps fell into five categories: healthcare professional training and accountability, better patient experiences, policy and guidelines, and robust data collection and related research. Plans to close the gaps in the prenatal genetic testing focus area included a research study to investigate the impact medical outreach on healthcare providers and to evaluate the quantity and quality of information received by patients. Additionally, this focus area intends to use the results of the gap analysis to inform the development of future protocols.

The COVID- 19 focus area was added halfway through the project as the impact of the pandemic on people with disabilities began to amplify existing gaps in healthcare for people with disabilities. CDHPD partners noted that people with disabilities were not broadly represented in discussions about the effect of scarcity of resources on people with disabilities. They also mentioned people with disabilities were being denied care based on their disability status and that the impact of COVID -19 is unknown in terms of the way the situations of resource scarcity will be handled. Potential solutions to address the gaps included taking steps to identify the impact of COVID-19 on people with disabilities, getting people to imagine that they can adapt to unfamiliar health situations, and include people with disabilities in crisis standards of care discussions. In response to the urgency to close the gap, CDHPD Partners

created fact sheets to inform patients of their rights and to inform healthcare providers of how to safeguard against discrimination.

CDHPD Partners conducted a 50-state survey to determine which U.S. states and territories have enacted the Down Syndrome Information Act (DSIA), laws that provide organ transplant protection for people with disabilities, and wrongful life/ wrongful death legislation. The DSIA is enacted in more states than any of the other types of laws examined the legal aspects for all focus area. Thirty six percent of state have enacted DSIA and three additional states have tried to introduce but failed to pass such legislation. Twenty-nine percent of U.S states have enacted some form of legislation that provides organ transplant protection for people with disabilities. Whereas only twenty-two percent of U.S. States have enacted legislation related to wrongful life and wrongful birth; three states allow claims and nine prohibit claims.

The 'other' focus area was included to address concerns that some issues related to inequity and discrimination in the healthcare of people with disabilities might not be addressed in the existing focus areas. The 'other' focus area included several documents which tied directly into four of the existing focus areas. The majority of the documents reviewed emphasized new topics such as intersectionality, topics specific to Autism Spectrum Disorder or Cerebral Palsy, health insurance related issues, and healthcare professional training.

CDHDP Partners presented at the American Academy of Developmental Medicine & Dentistry (AADMD) 2020 One Voice for Inclusive Health Virtual Conference. They hosted a facilitated discussion addressing several questions related to protocols in focus area specific breakout sessions. The results of discussions were compiled to highlight key considerations in protocol development and dissemination. These considerations included ideas about the platforms that should be used, components that would facilitate good healthcare provider decision making, strategies for addressing buy-in and bias, and ways to improve the quality and quantity of data.

Table of Contents

Introduction	11
Gap Analysis Process	12
Methodology	14
Analytical Considerations	17
Aging and End of Life Care	18
Current State	18
Ideal Future State	18
Gaps Identified	18
Potential Solutions to Address the Gaps	22
Plan to Close the Gaps	23
Life-Saving Treatment (Organ Transplant)	24
Current State	24
Ideal Future State	24
Gaps Identified	24
Potential Solutions to Address the Gaps	27
Plan to Close the Gaps	29
Mental Health and Suicide Prevention	30
Current State	30
Ideal Future State	30
Gaps Identified	30
Potential Solutions to Address the Gaps	33
Plan to Close the Gaps	35
Prenatal Genetic Testing	36
Current State	36
Ideal Future State	36
Gaps Identified	39
Potential Solutions to Address the Gaps	44
Plan to Close the Gaps	51
COVID- 19	52
Current State	52
Ideal Future State	52
Gaps Identified	52
Potential Solutions to Address the Gaps	54
Plan to Close the Gaps	54

Legal Aspects for All Focus Areas	55
50 State Surveys	55
Other	60
Recategorization	60
Considerations for Development and Dissemination of Protocols	63
Protocol Platforms, Utility, and Other Considerations	63
Protocol Components to Facilitate Good Healthcare Provider Decision Making	65
Strategies for Addressing Implicit Bias, Diagnostic Overshadowing, and Policy Violations	67
Strategies for Gaining Healthcare Provider Buy-in for Supported Medical Decision Making..	68
Ways to Improve the Quantity and Quality of Medical Data	69
Appendix A: Gaps Highlighted Comment Tables	70
Table 1: Aging and End of Life Document Review – Gaps Highlighted Comments	70
Table 2: Life-Saving Treatment (Organ Transplant Document Review – Gaps Highlighted Comments	73
Table 3: Mental Health and Suicide Prevention Document Review – Gaps Highlighted Comments	76
Table 4: Prenatal Genetic Testing Document Review – Gaps Highlighted Comments	78
Table 5: COVID-19 Document Review – CDHPD Partner Comments	79
Table 6: Other Document Review – Focus Area Recategorization	101
Appendix B: 50 State Legislative Surveys	107
Prenatal Care – Down Syndrome Information Acts - States and Territories	107
Organ Transplant Protections for People with Disabilities – States and Territories.....	114
Wrongful Birth and Wrongful Life – States and Territories	119
Appendix C: CDHPD Database	145
CDHPD Database Data Entry Screen Example	145
Appendix D: Gap Analysis - Document Review Bibliography	148
Center for Dignity in Healthcare for People with Disabilities - Gap Analysis Document Review Bibliography	148
Appendix E: CDHPD COVID- 19 Tools	156
Do you Know Your Rights with COVID-19? - Fact Sheet	156
Safeguard Against Disability Discrimination During COVID-19 - Fact Sheet	157
Appendix F: AADMD Conference Notes	158
The American Academy of Developmental Medicine & Dentistry (AADMD) Dignity in Healthcare Conference - Panel Breakout Discussion Session Results Notes.....	158

Introduction

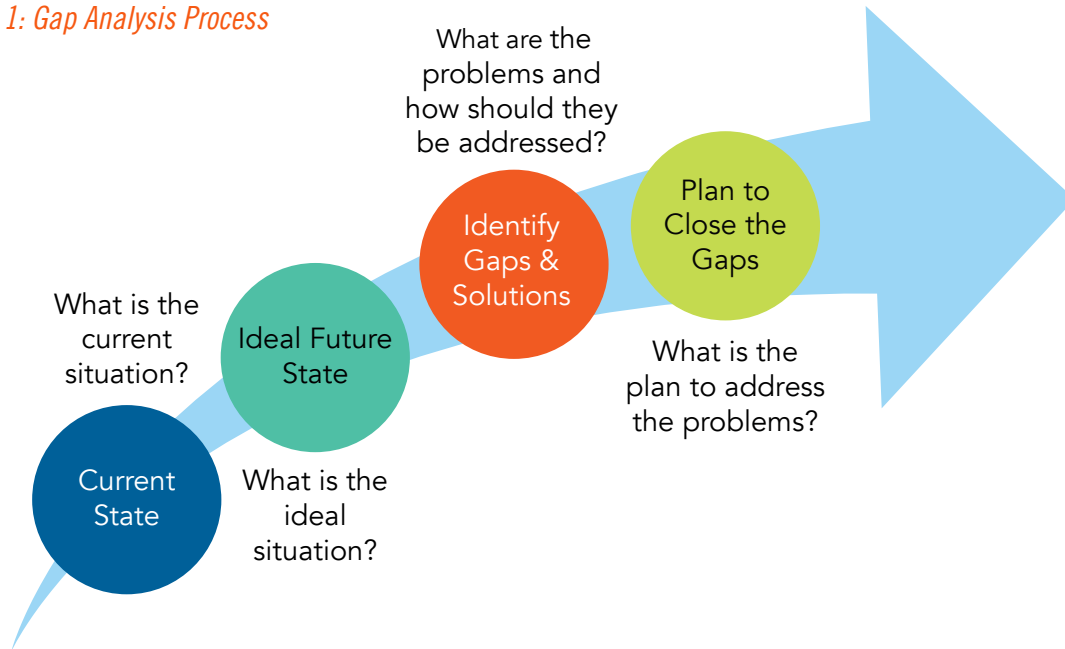
In September 2020, the Administration on Community Living awarded a 3-year grant to the University of Cincinnati and its partners to form the Center for Dignity in Healthcare for People with Disabilities (CDHPD). The CDHPD Partners include the: University of Cincinnati Center for Excellence in Developmental Disabilities, University of Kentucky - Human Development Institute, American Academy of Developmental Medicine and Dentistry, Maryland Center for Developmental Disabilities at Kennedy Krieger Institute, Vanderbilt Kennedy Center for Research on Human Development, Family Voices, Autistic Self-Advocacy Network, and Boggs Center on Developmental Disabilities. The CDHPD aims to “identify and reduce life-limiting healthcare inequities for people with intellectual and developmental disabilities (ID/DD) by improving access to anti-discrimination medical protocols.” To identify and address healthcare inequities for people with intellectual and developmental disabilities, CDHPD conducted a gap analysis focused on discrimination and disparities in healthcare. In particular the gap analysis concentrates on the following focus areas: aging and end of life care, lifesaving treatment (organ transplant), mental health and suicide prevention for people with ID/DD, prenatal genetic testing, COVID- 19, legal aspects of all focus areas, and other.

This report details the findings of the gap analysis. This report is divided into nine sections including the seven focus area sections and the considerations for protocols. The first five focus areas are organized in the same manner. Each one contains subsections that correspond to the four steps in the gap analysis process as outlined in the gap analysis process section. The last two focus area sections are organized differently. The legal aspects for all focus area includes an overview and maps detailing the states that have legislation relating to organ transplant protections for people with disabilities, the Down Syndrome Information Act, and wrongful birth/ wrongful life laws. The seventh focus area section is the ‘other’ focus area which simply explores the types of documents that were categorized as other in the CDHPD database and discusses the characteristics on those documents.

Gap Analysis Process

A gap analysis is typically a multi-step process used to analyze the current state, identify the ideal future state, find the gaps and evaluate solutions, then create and implement a plan to close the gaps. Figure 1 displays the four key steps employed in the gap analysis process.¹

Figure 1: Gap Analysis Process



A series of documents such as organizational statements, policy guidance documents, media coverage, governmental reports, existing curricula and research literature were reviewed by CDHPD Partners to identify gaps and investigate the impact of discrimination and disparities in the healthcare of people with ID/DD. This process concentrated on documents that discussed “social justice issues where direct discrimination was involved.” Each document was categorized into one of seven focus areas (aging and end of life care, lifesaving treatment (organ transplant), mental health and suicide prevention for people with ID/DD, prenatal genetic testing, COVID- 19, legal aspects of all focus areas, or other). It should be noted that the COVID-19 focus area was added halfway through the Gap analysis process in response to the COVID-19 pandemic. It should also be noted that each focus area had a subcommittee.

¹ The Center for Dignity in Healthcare for People with Disabilities. Narrative, Grant Proposal to the Human Dignity and Civil Rights for People with Disabilities, Department of Health and Human Services Administration for Community Living. 2019. PDF Narrative.

Each document was scored using the following scale:

Not evident (1)	No evidence of disparities or discrimination faced by people with disabilities. No evidence related to pathways that ensures equal access to medical care and intervention for people with disabilities and their families
Somewhat evident (2)	There is some evidence of disparities or discrimination faced by people with disabilities. There is some evidence related to pathways that ensures equal access to medical care and intervention for people with disabilities and their families
Clearly evident (3)	There is clear evidence of disparities or discrimination faced by people with disabilities. There is clear evidence related to pathways that ensures equal access to medical care and intervention for people with disabilities and their families

Documents were also scored for their utility in the development of protocols using the following scale:

Not useful (1)	The document will not inform the protocol development
Somewhat useful (2)	One or two parts of the document can be used to inform protocol development
Very useful (3)	Several parts or the whole document can be used as template or inform protocol development

A CDHPD Database was designed using a web-based platform, to collect and manage information amassed during the document review process. Partners were able to enter information directly into the online database. Additional information collected included the lead partner, focus area, team member, role, document title, document source, brief document description, document type, evidence score, utility score, notes, gaps highlighted in the document, gaps missing in the document, APA citation, and document link. An example of the data entry screen can be viewed in Appendix C. A bibliography of the documents reviewed can be found in Appendix D. All information in the bibliography was exported from CDHPD Database.

Methodology

The current state for each focus area in this report was derived from the CDHPD grant proposal narrative submitted to the U.S. Department of Health and Human Services as part of the grant proposal to establish the Center for Dignity in Healthcare for People with Disabilities. The current state relies entirely on the CDHPD Partners' expertise and literature review.

To identify the future ideal state, a multi-step process was employed. At the start of the gap analysis, an overall ideal state applicable to all focus areas was developed. The overall ideal state conceptualized at the start of the project was as follows-- CDHPD Partners envisioned a future in which equitable healthcare is easily accessible to individuals with disabilities in a manner that is free from bias and discrimination. As the partners began to identify the gaps in each focus area, the overall ideal state was revisited by each focus area subcommittee. The Prenatal Genetic Testing CDHPD Partners drafted and administered a survey to their subcommittee members to conceptualize the ideal future state in that focus area. The textual data provided by the open ended survey responses were analyzed using thematic analysis and themes were reported. A facilitated discussion during the focus area specific subcommittee/ workgroup meetings was used to generate the ideal future state in the remaining focus areas. Through an open-ended discussion about the ideal future state, three subcommittees decided to change the overall ideal future state statement to better align with the vision they have for their focus area.

Data collected during the CDHPD document review process was used in the gaps identified and potential solutions to address the gaps sections of this report. The information generated by the CDHPD Partners' document review produced a mixture of qualitative and quantitative data. Appendix C includes a screenshot of the CDHPD data entry screen. The CDHPD Database was closed on July 10, 2020 for all the focus areas except prenatal genetic testing and legal aspects for all, as those focus areas required an additional time to complete data entry. For the purpose of this analysis, instances in which two or more entries for the same article were entered by different reviewers, the entries were counted as separate records

because each review provided different comments on the article. A total of 219 unduplicated document reviews were entered into the CDHPD Database. Entries were considered duplicates if the same reviewer entered data in more than one record for the same document. Only two duplicate entries were identified; both were deleted. If a CDHPD Partner selected a secondary focus area for a document, the document was analyzed in both the first and second focus areas. This occurred with 19 documents.

The data was divided by focus area, exported from the CDHPD Database, and uploaded into Dedoose Version 8.3.17², a web-based platform developed by social science researchers intended for qualitative and mixed method data analysis. Documents categorized in more than one focus area were analyzed in each focus area. All quantitative data fields were labeled as descriptors in Dedoose. Four descriptions were analyzed for this report (lead partner, document type, evidence score, and utility score). Ratings from the evidence and utility scores were treated as Likert scales. As such, frequencies were calculated to get a broad snapshot of the documents under each focus area.

The open-ended responses provided by CDHPD Partners in the Gaps Highlighted field produced textual data which was explored using thematic analysis. Dedoose allows textual data to be excerpted and coded using a code tree similar to a family tree in that super-ordinate codes are called parent codes and subordinate codes are called child codes. All responses were analyzed using a three-step coding process. The first round of coding the textual data produced two parent codes used to categorize responses as either gaps or potential solutions to address the gaps. The second round of coding explored the topics discussed in each response and attached descriptive child codes to text excerpts. The third round of coding refined the child codes by searching for themes among the child codes, grouped related descriptive child codes into themed categories, and created a second set of parent codes which represented the theme categories.

² Dedoose Version 8.3.17, web application for managing, analyzing, and presenting qualitative and mixed method research data (2018). Los Angeles, CA: SocioCultural Research Consultants, LLC www.dedoose.com

The three-step coding process produced two main parent codes, Gaps Highlighted and Potential Solutions each with their own secondary themed parent codes and those themed parent codes were further defined by subject specific child codes. In this report, the Gaps Highlighted category was divided into themed subsections, responses categorized under each theme were analyzed, and explored. The Potential Solutions category was also divided into theme related subsections and potential solutions mentioned by CDHPD Partners were excerpted and listed under the corresponding themed subsections.

Because of the level of analysis, a date to discontinue data entry was established to allow evaluators time to analyze the data. As a result, the data included in this report is reflective of information entered into the database on or before July 10, 2020 for all focus areas except prenatal genetic testing and legal aspects for all. The prenatal genetic testing focus area completed data collection on July 17, 2020. This focus area reviewed 76 documents. Because of the large volume of data supplied for this focus area, the prenatal genetic testing data was analyzed in two phases, data entered on or before June 3, 2020 was analyzed first and data between June 3, 2020 and July 17, 2020 was analyzed separately and combined with the results from the first round of analysis in that focus area. The legal aspects for all focus area completed data entry on August 7, 2020.

While the documents reviewed through CDHPD database was the main source of data analysis, information from other sources were also included where appropriate e.g. The American Academy of Developmental Medicine & Dentistry (AADMD) Conference - Dignity in Healthcare Panel Breakout Discussion Sessions and subcommittee/workgroup meeting notes.

Analytical Considerations

Several considerations must be noted. First, the textual data analyzed in this report was expert commentary on documents selected by CDPHD Partners relating to discrimination and inequities in the healthcare of people with intellectual or developmental disabilities. The CDHPD Partners include advocates, healthcare professionals, lawyers, academics, and other interested stakeholders in the document review process for each of the seven focus areas. The CDHPD partners are notable experts in the field. All documents were selected by CDHPD Partners and the textual data was driven by the commentary from the perspective of a select group of experts. There is possibility that selection bias could have been introduced via the documents selected or commentary on the documents, thereby limiting the generalizability of findings.

Second, this analysis is subject to the threat of history. During the data collection period of the gap analysis, a worldwide pandemic began, COVID-19, which amplified gaps in the healthcare of people with disabilities. These issues were discussed in the news and may have sharpened attention and concern about the kinds of issues this gap analysis sought to identify. As such, the impact of COVID-19 related news and stresses might have had an influence on the perspectives of the CDPHD partners and therefore on the textual data highlighted in the database.

Third, the number of documents reviewed differed in each focus area. As expected, the COVID- 19 section only included six documents whereas the prenatal genetic testing focus area includes 76 documents. The breadth of document types and number of CDHPD documents was also different in each focus area.

Aging and End of Life Care

Current State

CDHPD Partners relied on a literature review to gauge the current state of aging and end of life medical treatment and care within the population of people with intellectual and developmental disabilities (ID/DD). CDHPD Partners noted that people with ID/DD typically have a shorter life expectancy than the general public, however the life expectancy of people with ID/DD has improved overtime. While that is a good outcome, the growing aging population of individuals with ID/DD has introduced many challenging social, cultural, and nebulous aging and end of life considerations to grapple with and address.³

Ideal Future State

To conceptualize the ideal future state, CDHPD Partners envision a future in which equitable healthcare and supports are easily accessible across the lifespan for people with visible and invisible disabilities. Aging and end of life care should be provided in a manner that is person-centered and free from bias and discrimination.

Gaps Identified

There were 37 documents reviewed in this focus area. More than half of the documents reviewed in this focus area (51%) were classified as manuscripts and 19% were classified as other and policy related, respectively. Please refer to Table 1 for more details.

Table 1: Aging and End of Life- Documents Reviewed by Type

Document Type	Frequency	Percent
Manuscript	19	51%
Other	7	19%
Policy Related Document	7	19%
Curricula	2	5%
Organizational Statement	2	5%

³ The Center for Dignity in Healthcare for People with Disabilities. Narrative, Grant Proposal to the Human Dignity and Civil Rights for People with Disabilities, Department of Health and Human Services Administration for Community Living. 2019. PDF Narrative.

Five organizations reviewed documents related to this focus area. The Boggs Center on Developmental Disabilities reviewed nearly half (46%) of the documents. Table 2 displays the percentage of documents reviewed by each CDHPD Partner.

Table 2: Number of Documents Reviewed by CDHPD Partners

CDHPD Partners	Frequency	Percent
The Boggs Center on Developmental Disabilities	17	46%
University of Cincinnati Center for Excellence in Developmental Disabilities	12	32%
Maryland Center for Developmental Disabilities at Kennedy Krieger Institute	3	8%
Vanderbilt Kennedy Center for Research on Human Development	3	8%
American Academy of Developmental Medicine and Dentistry	2	5%

Of the 37 documents reviewed in this focus area, 24 clearly identified evidence of disparity or discrimination and eleven somewhat presented evidence. Table 3 displays the number of documents by each evidence category.

Table 3: Evidence Scores – Aging and End of Life

	Clearly Evident	Somewhat Evident	Not Evident	Total
Aging and End of Life	24	11	2	37

Twenty-one of the documents in this focus area were considered useful in the development of protocols and 16 were somewhat useful. Table 4 displays the number of documents by each utility category.

Table 4: Utility Scores – Aging and End of Life

	Clearly Useful	Somewhat Useful	Not Useful	Total
Aging and End of Life	21	16	0	37

The document review processes highlighted gaps clustered in five categories: diagnosis and treatment, healthcare system and services, healthcare professional, patient, and research. The most frequently mentioned gaps were patient related and largely focused on the uncertainty in many aspects of aging and end of life matters. Of the 37 documents reviewed, 14 did not have any information recorded in the Gaps Highlighted field and two discussed

aspects of the document but did not list any gaps. Figure 2 highlights the categories of gaps identified in this focus area as well as the specific types of gaps classified under each category. The open ended CDHPD Partner responses provided in the Gaps Highlighted field for this focus area can be found in Appendix A.

Figure 2: Aging and End of Life - Identified Gaps

Diagnosis & Treatment	Healthcare System/ Services	Healthcare Professional	Patient	Research
<ul style="list-style-type: none"> • Underdiagnosis • Diagnosis overshadowing • Lack of prompt treatment 	<ul style="list-style-type: none"> • Inadequate care • Lack of access • Lack of accessible medical equipment • Variation in hospice policy and documentation 	<ul style="list-style-type: none"> • Inadequate training • Partnership issues • Lack of role clarity 	<ul style="list-style-type: none"> • Consent issues • Honoring of end of life wishes • Voices not heard 	<ul style="list-style-type: none"> • Lack of research • Unclear aging trajectory • Unclear self-determination

Diagnosis & Treatment

CDHPD Partners mentioned gaps related to diagnosis and treatment that ranged from misdiagnosis to underdiagnosis. Diagnostic overshadowing was discussed as a gap that can impact the quality of healthcare an individual receives. Another issue noted was the decreased “chance of receiving prompt treatment” faced by individuals with disabilities.

Healthcare System and Services

Gaps pertaining to the healthcare system and services were largely related to barriers to access. CDHPD Partners noted that people with disabilities face inequity in access to hospice and other palliative care. Additionally, it was mentioned that policies related to hospice care are not uniformly interpreted. Also discussed was the lack of accessible medical equipment.

Healthcare Professional

The driving themes for gaps related to healthcare professionals were inadequate education and training, the lack of collaborative approach to end of life care, and uncertainty. The document review process revealed a “lack of experience and low levels of confidence among

ID staff and palliative care staff in caring for individuals with ID during end-of-life and in providing adequate care.” CDHPD Partners discussed a need for cross – training of healthcare professionals involved in each aspect of end of life care. It was also noted that healthcare professionals and guardians face challenges in planning for and communicating end of life care with individuals with ID/DD. Furthermore, it was mentioned that provider attitudes and bias contribute to gaps in access to healthcare and services. Another gap discussed was uncertainty surrounding the “role of guardian vs. doctor vs. person with IDD [sic].” Lack of cooperation in a partnership approach to palliative care was highlighted as a gap and it was suggested that differing professional interests cause those partnerships to fail.

Patient Voice

CDHPD Partners found that the voices of people with ID/DD are sometimes not included in their own end of life decisions. It was noted that some adults with disabilities face communication challenges that preclude them from expressing their end of life wishes to caregivers or guardians and guardianship laws often do not clarify or provide guidance as where authority lies for end of life decisions. Additionally, CDHPD Partners mentioned that issues of death and dying are “taboo in our society” and rely heavily cultural norms, as such conversations, about these issues are sometimes avoided. Other gaps highlighted included the difficult matters of “eliciting information about a person’s own end of life care wishes, determining capacity, and resolving disagreements around end of life decisions-supporting someone through end of life particularly to age in place.”

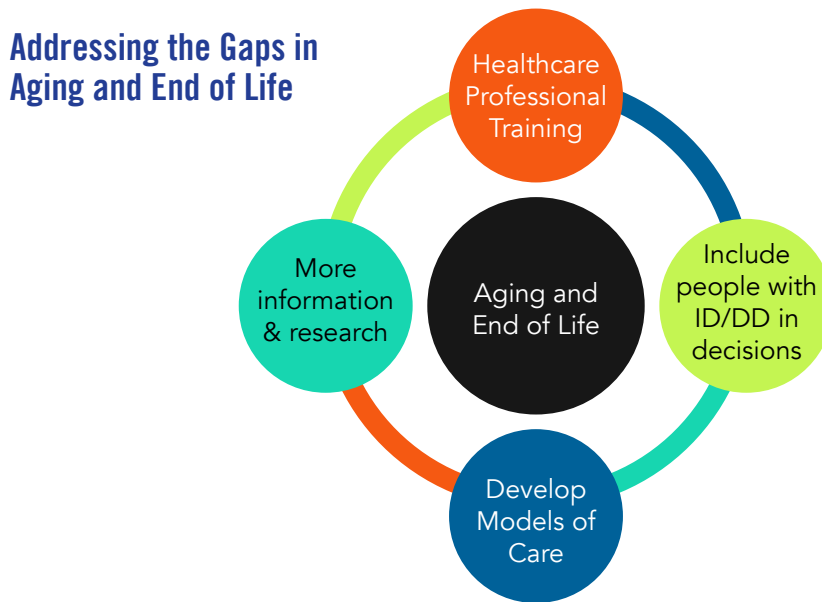
Research

The document review process revealed a great deal of uncertainty surrounding the way aging impacts individuals with disabilities. CDHPD Partners mentioned that some research investigating the impact of aging on people with Autism Spectrum Disorder does exist. However, the research and information on people with Autism Spectrum Disorder as well as the entire population of people with disabilities is lacking and so much remains unknown. Additionally, it was noted that “the extent to which they perceive and have self-determination in their own lives at their end of life is not well understood.”

Potential Solutions to Address the Gaps

CDHPD Partners provided suggestions for addressing the gaps in the Aging and End of Life focus area. This information was recorded in the Gaps Highlighted and Notes fields in the CDHPD Database. Potential solutions presented in this section represent a mixture of the CDHPD Partners’ original ideas and ideas discussed in the documents they reviewed. This process led to the creation of four unique potential solution categories. Figure 3 displays the four categories aimed at addressing the gaps in the Aging and End of Life focus area.

Figure 3: Aging and End of Life– Potential Solutions for Addressing the Gaps



Below are the potential solutions that were provided:

Calls for models of care including variables related to translation, sustainability, accessibility (e.g., affordability, availability), acceptability (e.g., culturally relevant, satisfaction), and equity to be developed.

More work is needed to address the gaps in knowledge about health risk and wellness factors related to adults with ID.

Urge for policy makers to recognize and improve the understanding of partnerships to effectively develop successful partnerships to alleviate gaps in health care for individuals with ID.

Guidance needed

Future studies using prospective, longitudinal methods are needed in order to identify the nature of age-related changes in behavior, cognition, and neurobiology.

People with intellectual disability should learn about dying and death just as they learn about every other aspect of life.

Highlights a need to develop training curricula that emphasizes relationship and person-centered care approaches.

Plan to Close the Gaps

CDHPD Partners met monthly in focus area specific subcommittees from May to July with the purpose of developing a plan of action to close the gaps. During their July 17, 2020 meeting, the Aging and End of Life Subcommittee members established a plan to identify and work towards three priorities. The subcommittee's priorities and action plan to close the gaps are listed below:⁴

Intellectual disability, dementia, and palliative care orgs to create universal practice guidelines on end-stage care and support.

More research needed on best practices in identifying end of life and an aging trajectory for adults with IDD.

Training curricula must address IDD and emphasize relationships and person-centered care and support approaches.

⁴ Smith, L., (personal communication, July 22, 2020) discusses the Aging and End of Life Subcommittee Priorities.

Life-Saving Treatment (Organ Transplant)

Current State

CDHPD Partners relied on a literature review to gauge the current state of life-saving treatment (organ transplant) within the population of people with intellectual and developmental disabilities (ID/DD). CDHPD Partners noted that “organ transplantation is one of many life-saving treatments that have been historically denied to individuals with ID/DD based on assumptions about the and value of their lives.”⁵

Ideal Future State

To conceptualize the ideal future state, CDHPD Partners envision a future in which equitable healthcare is easily accessible to individuals with disabilities in a manner that is free from bias and discrimination.⁶

Gaps Identified

CDHPD Partners were tasked with reviewing several types of documents to identify gaps in the life-saving treatment (organ transplant) focus area. Twenty-nine documents were reviewed in this focus area. Forty-one percent of the documents were classified as other and 17% were legal documents. Please refer to Table 5 for more details.

Table 5: Life-Saving Treatment (Organ Transplant) - Documents Reviewed by Type

Document Type	Frequency	Percent
Other	12	41%
Legal Document	5	17%
Media Report	5	17%
Policy-Related Document	4	14%
Manuscript	3	10%

Six separate groups reviewed life-saving treatment (organ transplant) related documents. Forty-eight percent of the documents were reviewed by the Autistic Self-Advocacy Network. Please refer to Table 6 to view the percentage of documents reviewed by each CDHPD Partner.

⁵ The Center for Dignity in Healthcare for People with Disabilities. Narrative, Grant Proposal to the Human Dignity and Civil Rights for People with Disabilities, Department of Health and Human Services Administration for Community Living. 2019. PDF Narrative.

⁶ Center for Dignity in Healthcare for People with Disabilities (CDHPD) - Gap Analysis Template. 2019.

Table 6: Number of Documents Reviewed by CDHPD Partners

CDHPD Partners	Frequency	Percent
Autistic Self-Advocacy Network	14	48%
Maryland Center for Developmental Disabilities at Kennedy Krieger Institute	5	17%
Family Voices	3	10%
Vanderbilt Kennedy Center for Research on Human Development	3	10%
University of Cincinnati Center for Excellence in Developmental Disabilities	2	7%
The Boggs Center on Developmental Disabilities	2	7%

Every document was assigned an evidence score. Of the 29 documents reviewed in this focus area, 24 clearly identified evidence of disparity or discrimination and three somewhat presented evidence. Table 7 displays the number of documents in each evidence category.

Table 7: Evidence Scores – Life-Saving Treatment (Organ Transplant)

	Clearly Evident	Somewhat Evident	Not Evident	Total
Life-Saving Treatment (Organ Transplant)	24	3	2	29

Each document was assigned a utility score by CDHPD. More than half of the documents in this focus area (15) were considered useful in the development of protocols and 13 were somewhat useful. Table 8 shows the number of documents in each utility category.

Table 8: Utility Scores – Life-Saving Treatment (Organ Transplant)

	Clearly Useful	Somewhat Useful	Not Useful	Total
Life-Saving Treatment (Organ Transplant)	15	13	1	29

Gaps were clustered in five areas, policy and legislation, healthcare system and services, healthcare professional related, patient related, and ableism. The most frequently mentioned gaps were patient related. Of the 29 documents reviewed, four did not have any information recorded in the Gaps Highlighted field. Figure 4 displays the categories of gaps identified in this focus area as well as the specific types of gaps classified in each category. The open-ended responses provided in this focus area can be found in the Appendix A.

Figure 4: Life-Saving Treatment (Organ Transplant) - Identified Gaps

Life-Saving Treatment (Organ Transplant) – Identified Gaps

Policy/ Legislation	Healthcare System/ Services	Healthcare Professionals	Patient	Ableism
<ul style="list-style-type: none"> • ADA ambiguity • Lack of anti-discrimination laws • Variance in disability related policies • Inequity in organ transplation legislation 	<ul style="list-style-type: none"> • Too much discretion • Lack of transparency • Wait list procedures • Inconsistency 	<ul style="list-style-type: none"> • Little disability competency education & training • Too much discretion • Attitude towards people with disabilities 	<ul style="list-style-type: none"> • Subpar information • Negative experiences 	<ul style="list-style-type: none"> • Bias • Discrimination • Stigma

Policy & Legislation

Several policy and legislative related gaps were highlighted in this focus area. Most comments related to anti-discrimination policies and the American with Disabilities Act (ADA). CDHPD Partners noted that many states do not have life-saving procedure anti-discrimination laws and instances in which laws do exist, they often do not protect all individuals with disabilities. CDHPD Partners also pointed out there is quite a bit of variance in the disability related policies implemented by organ transplant centers and the disabilities covered in those policies. Another gap discussed was a need to implement measures and national policies to guarantee equal rights to organ transplants for individuals with disabilities. CDHPD Partners also highlighted some ambiguity in the applicability of the ADA in organ transplant and other life-saving treatment situations and one person specifically noted that in organ transplant matters, the ADA is “rarely invoked in this context due to time-sensitive nature of organ transplant decisions.”

Healthcare System and Services

CDHPD Partners highlighted gaps in transplant centers, hospitals, and organ transplanting listing. The most commonly discussed gap was the high level of discretion granted to organ transplant centers in waitlist decisions. Other gaps discussed included a lack of consistency among organ transplant centers and a lack of transparency in hospital and organ transplant center decision making processes. CDHPD Partners also cited a lack of guidance from organ transplant networks.

Healthcare Professionals

CDHPD Partners mentioned that healthcare professional training, attitudes, and discretion all play a role in the medical treatment of people with ID/DD in the life-saving treatment focus area. Specially, CDHPD Partners noted that healthcare professionals receive little disability competency training. Additionally, it was mentioned that some healthcare professionals display attitudes towards and quality of life judgments about individuals with disabilities. Other gaps discussed included the level of provider discretion and the lack of consensus on medical terms and definitions such as “vegetative state.”

Patient

A few patient related gaps were mentioned by CDHPD Partners. It was mentioned that people with disabilities face a high rate of undiagnosed health conditions and are not always informed about all viable options for medical treatment. Another gap mentioned was the “lack of consideration of adaptive functioning.”

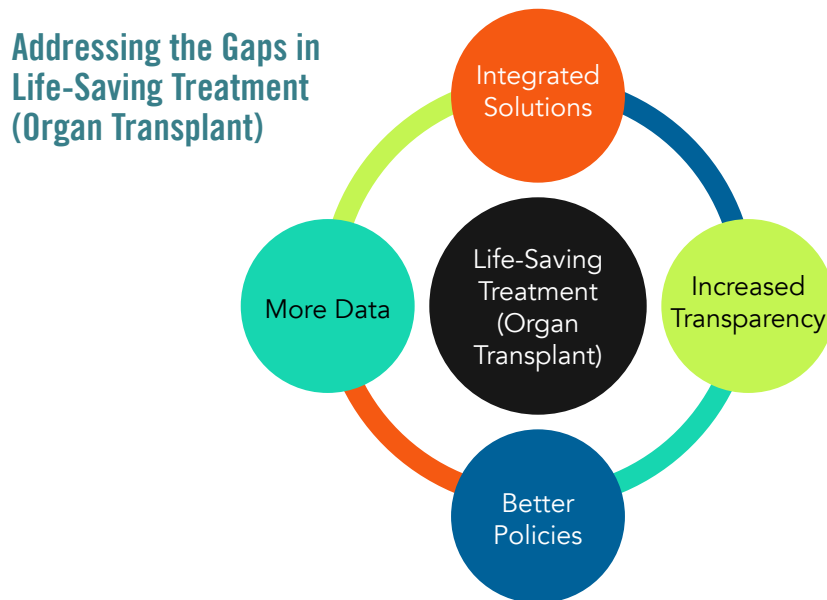
Ableism

CDHPD Partners commented on more gaps in this category than any category in this focus area. Issues of discrimination, bias, and stigma were highlighted. Instances of disability being used as contraindication for life-saving treatment and organ transplant discrimination were discussed. One noted gap was “the assumption that people with disabilities will not be able to comply with postoperative care has caused disability to be considered a contraindication to organ transplant at many transplant centers despite the fact that people with disabilities, when provided with necessary supports, are no less likely to comply than people without disabilities.”

Potential Solutions to Address the Gaps

CDHPD Partners provided suggestions for addressing the gaps in the life-saving treatment (organ transplant focus area. This information was recorded in the Gaps Highlighted field in the CDHPD Database. Potential solutions presented in this section represent a mixture of CDHPD Partners’ original ideas and ideas discussed in the documents they reviewed. This process led to the creation of four unique potential solution categories. Figure 5 displays the four categories aimed at addressing the gaps in this focus area.

Figure 5: Life-Saving Treatment (Organ Transplant) – Potential Solutions for Addressing the Gaps



Below are the potential solutions that were provided:

It recommends, all as options: (1) UNOS/OPTN to adopt specific guidance on the subject which transplant centers are recommended to follow; (2) Transplant centers themselves create a multidisciplinary advisory board that puts out guidelines; (3) Actual state or federal legislation; (4) Transplant centers be required, for every patient with ID they reject, to sign a statement which says that they did not discriminate.

The law review article suggests policy changes, including implementing HHS regulations creating uniform rules for how transplant centers consider psychosocial criteria when evaluating candidates for transplant, and/or additional HHS guidance to transplant centers on how to avoid including social worth determinations in their evaluations.

The need for legislation to make sure that individuals with disabilities have equal rights to organ transplants in every state.

The authors advocate that more data and greater transparency is needed to better understand the issues of ongoing access problems.

They further discuss how long-term solutions require changes at the healthcare professional, regional transplant center, and national levels.

...accommodations for optimizing the assessment and medical management suggestions: More data/ greater transparency to understand access problems, changes at the individual provider level, regional transplant center level, and national level

ASAN's toolkit on ending discrimination in organ transplantation provides resources for advocacy both on an individual and a system-wide basis.

Solutions discussed - policy changes, education/training among health care providers, health care promotion

Plan to Close the Gaps

CDHPD Partners met in focus area specific subcommittees in May and July with the purpose of developing a plan of action to close the gaps. During their July 16, 2020 meeting, the Life-Saving Treatment (Organ Transplant) Subcommittee members established a plan to identify and work towards three priorities. Listed below are the subcommittee's priorities and action plans to close the gaps in this focus area:⁷

A framework for transplant centers is necessary to ensure procedural consistency and transparency

Address biased assumptions that people with disabilities have a lower quality of life.
Consider the elimination of QoL in eligibility determinations

Medical decision-making related to life-saving treatments should be collaborative and person-centered but current systems rarely support this approach

⁷ Smith, L., (personal communication, July 23, 2020) discusses the Life-Saving Treatment (Organ Transplant) Subcommittee Action Plan.

Mental Health & Suicide Prevention

Current State

CDHPD Partners relied on a literature review to gauge the current state of mental health and suicide prevention within the population of people with intellectual and developmental disabilities (ID/DD). CDHPD Partners noted that people with ID/DD carry a higher risk for mental health issues as well as an elevated risk for suicidality. CDHPD Partners found that suicide screening tools are effective in predicting suicide risk but there are no screening measures designed for people with ID/DD. Furthermore, CDHPD Partners mentioned that people with ID/DD often face barriers in access to proper mental healthcare because of their disability.⁸

Ideal Future State

To conceptualize the ideal future state, CDHPD Partners envision a future in which quality mental health and crisis care services are easily accessible and provided in a way that is sensitive to the individuality of people with disabilities and the cultural context of disabilities, including their past experiences of mental health treatment and ableism. Mental health and crisis care services should be provided by highly qualified healthcare providers who are required to meet a baseline standard of education and training which enables them to deliver care in a manner that is free from bias and discrimination.

Gaps Identified

CDHPD Partners were tasked with reviewing diverse types of documents to identify gaps in mental health care and suicide prevention for people with ID/DD. A total of 26 documents were reviewed in this focus area. More than half of the documents (58%) were classified as manuscripts, 23% were other, and 19% were policy related documents. Please refer to Table 9 for more details.

Table 9: Mental Health and Suicide Prevention - Documents Reviewed by Type

Document Type	Frequency	Percent
Manuscript	15	58%
Other	6	23%
Policy-Related Document	5	19%

⁸ The Center for Dignity in Healthcare for People with Disabilities. Narrative, Grant Proposal to the Human Dignity and Civil Rights for People with Disabilities, Department of Health and Human Services Administration for Community Living. 2019. PDF Narrative.

Five separate groups reviewed documents related to this focus area. More than a third of the documents were reviewed by the Vanderbilt Kennedy Center for Research on Human Development (35%). Table 10 shows the percentage of documents reviewed by each CDHPD Partner.

Table 10: Number of Documents Reviewed by CDHPD Partners

CDHPD Partners	Frequency	Percent
Vanderbilt Kennedy Center for Research on Human Development	9	35%
Maryland Center for Developmental Disabilities at Kennedy Krieger Institute	6	23%
The Boggs Center on Developmental Disabilities	5	19%
Autistic Self-Adocacy Network	4	15%
University of Cincinnati Center for Excellence in Developmental Disabilities	2	8%

Every document was assigned an evidence score. Of the 26 documents reviewed in this focus area, 20 clearly identified evidence of disparity or discrimination and six somewhat presented evidence. Table 11 displays the number of documents in each evidence category.

Table 11: Evidence Scores – Mental Health and Suicide Prevention

	Clearly Evident	Somewhat Evident	Not Evident	Total
Mental Health and Suicide Prevention	20	6	0	26

Each document was assigned a utility score by CDHPD Partners. Thirteen of the documents in this focus area were considered useful in the development of protocols and 12 were somewhat useful. Table 12 to shows the number of documents in each utility category.

Table 12: Utility Scores – Mental Health and Suicide Prevention

	Clearly Useful	Somewhat Useful	Not Useful	Total
Mental Health and Suicide Prevention	13	12	1	26

Gaps were clustered in five areas, diagnostic and treatment, healthcare system and services, healthcare professional, patient, and research. The most frequently mentioned gaps were diagnosis and treatment related and included topics such as underdiagnosis of mental health issues and diagnostic challenges. Of the 26 documents reviewed, eight did not have any information recorded in the Gaps Highlighted field and one discussed aspects of the document

but did not list any gaps. Figure 6 highlights the categories of gaps identified in this focus area as well as the specific types of gaps classified under each category. The open ended CDHPD Partner responses provided in the Gaps Highlighted field for this focus area can be found in the Appendix A.

Figure 6: Mental Health and Suicide Prevention - Identified Gaps

Mental Health and Suicide Prevention – Identified Gaps

Diagnosis & Treatment <ul style="list-style-type: none"> • Underdiagnosis • Diagnostic overshadowing • Screening not cognitively accessible • Challenges 	Healthcare System/ Services <ul style="list-style-type: none"> • Poor communication w/ people with ID/DD • Gaps in healthcare • Inadequate care • Lack of access 	Healthcare Professional <ul style="list-style-type: none"> • Inadequate training • Little to no requirements for disability related training 	Patient <ul style="list-style-type: none"> • Increased risk of suicide for people with ID/DD • Elevated prevalence of mental health or co-occurring mental health issues • Lack of social support 	Research <ul style="list-style-type: none"> • Lack of research • Exclusion of people with low IQ from trials
---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------	-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------	-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------	-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------	---------------------------------------------------------------------------------------------------------------------------------------------

Diagnosis & Treatment

CDHPD Partners mentioned gaps related to diagnosis and treatment more often than any other gap category in this focus area. Issues of diagnostic challenges, underdiagnosis, and diagnostic overshadowing were discussed in terms of not identifying the mental health issues of patients with intellectual or developmental disabilities because issues of concern were attributed to a characteristic of the persons existing disability and not explored as a mental health condition. Additionally, CDHPD Partners noted that the type of psychiatric disorders can vary based on disability. They also noted that people with ID/DD are more likely than the general public to have mental health concerns such as depression and suicidality, are less likely to be diagnosed, and are often denied treatment. Another gap discussed was the disparity in substance abuse treatment for individuals with disabilities. Furthermore, it was noted that the mental health community needs to develop “nuanced mental health outcome measures.”

Healthcare System & Services

Gaps mentioned in relation to the healthcare system and services related to access and coordination of care. CDHPD Partners discussed fragmented systems of care, problematic care coordination, and lack of access or barriers in access to mental health services for people with disabilities. Communication problems between the mental health services system and the disability community was also sighted as major gap in this area.

Healthcare Professional

The driving theme for gaps discussed by CDHPD Partners as it related to healthcare professionals was inadequate education and training. The need for better preparatory training and continued education for healthcare professionals was discussed. CDHPD Partners specifically mentioned that at times healthcare professionals are not aware of and have negative attitudes towards people with dual diagnosis and mentioned that all of these issues “contribute to poor health outcomes for individuals with DD.”

Patient

CDHPD Partners found that people with ID/DD have a higher risk of suicide and co-occurring mental health conditions. The document review process revealed that there is lack of peer and social supports available for people with ID/DD and typical mental health support programs may not work for individuals with disabilities.

Research

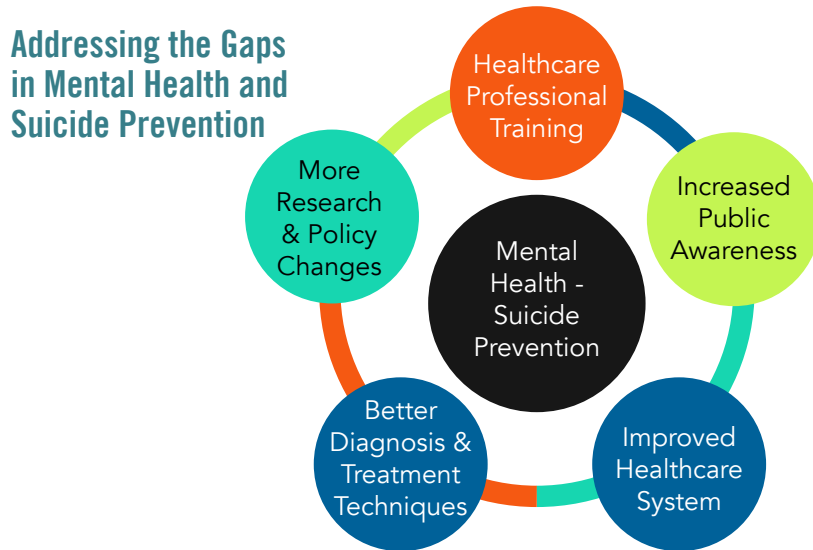
CDHPD Partners discussed a lack of research as it relates to the mental health conditions and treatments for people with intellectual and developmental disabilities. Furthermore, they noted that people with intellectual and development disabilities, particularly those with low IQs, are not included in the psychiatric research and development efforts.

Potential Solutions to Address the Gaps

CDHPD Partners provided suggestions for addressing the gaps in the mental health and suicide prevention focus area. This information was recorded in the Gaps Highlighted field in the CDHPD Database. Potential solutions presented in this section represent a mixture of

CDHPD Partners' original ideas and ideas discussed in the documents they reviewed. This process led to the creation of five unique potential solution categories. Figure 7 displays the five categories aimed at addressing the gaps in the mental health and suicide prevention focus area.

Figure 7: Mental Health and Suicide Prevention – Potential Solutions for Addressing the Gaps



Below are the potential solutions that were provided:

The Green Light Toolkit usage
... the development of evidence-based MH treatments for I/DD
further consideration of challenges experienced by persons with ID
... it is vital to consider the needs of individuals with ASD, and what he or she perceives to be important, when developing or recommending particular support programs
...system integration
... the development of quality MH regardless of whether public insurance is available
... developing better coordination between the MH and I/DD service systems
... public awareness campaigns and support for patients around dual diagnosis
Solutions discussed – policy changes, education/training among healthcare providers, healthcare promotion
Training be developed for practitioners and family members, nationwide and replicable, around ID and MH
...providers need training
further research is needed to better understand psychiatric differences in DS

Plan to Close the Gaps

CDHPD Partners met monthly in focus area specific subcommittees for since May with the purpose of developing a plan of action to close the gaps. During their July 16, 2020 meeting, the subcommittee members established a plan to identify and work towards three priorities. Listed below are the Mental Health/Suicide Prevention Subcommittee's priorities and action plan to close the gaps in this focus area:⁹

IDD Training Mandate for all Medical and Psychiatric Programs that are available. (mental health rotation that is usually a part of these programs, but not a disability rotation).

Determine if the Columbia -Suicide Severity Rating Scale (C-SSRS) Suicide Prevention Screening Tool is effective- Do we feel like this is sufficient? Language and format still effective?

Benchmark for training and effective performance around competencies. (i.e. an agency that traditionally serves I/DD should receive training on mental health and agencies that traditionally serve mental health should receive training on ID/DD.)
- Alliance for Disability in Healthcare Education

⁹ Smith, L., (personal communication, July 22, 2020) discusses the Mental Health/Suicide Prevention Subcommittee Action Plan.

Pre-Natal Genetic Testing

Current State

CDHPD Partners relied on subject matter expertise and an extensive literature review to gauge the current state of prenatal genetic testing. They found that prenatal and genetic testing is an area in which guidelines and protocols already exist, however the breakdown occurs in the consistency and implementation of guidelines and policies. CDHPD Partners note that while a vast array of genetic screening tests are currently offered, expectant parents have reported negative prenatal screening experiences and receiving inadequate educational materials; and clinicians have admitted to a lack of training and education in the field. Furthermore, CDHPD Partners note that societal stigma and discrimination against people with intellectual and developmental disabilities is pervasive in the United States and is a probable contributing factor to healthcare inequities.¹⁰

Ideal Future State

To conceptualize the ideal state for the prenatal and genetic testing, Stephanie Meredith (lead for the prenatal genetic focus area) developed an online survey and administered it to 10 CDHPD Partners. An additional three respondents answered questions via personal interviews. The respondents represented diverse backgrounds including a program director, a medical doctor, a genetic counselor, several professors, a self-advocate, and an attorney). Three people identified as a family member of someone with a disability and one person was a self-advocate. The survey asked the following open-ended questions:

1. In an ideal setting, what would you consider to be equitable policies surrounding the provision of prenatal screening?
2. In an ideal setting, how would expectant parents be consulted when offered prenatal screening in a way that would be equitable regarding people with disabilities?
3. In an ideal setting, how would medical providers deliver the news about a possible or confirmed diagnosis in a way that would be equitable regarding people with disabilities?

¹⁰ The Center for Dignity in Healthcare for People with Disabilities. Narrative, Grant Proposal to the Human Dignity and Civil Rights for People with Disabilities, Department of Health and Human Services, Administration for Community Living. 2019. PDF Narrative.

4. In an ideal setting, what type of information, support, and resources would clinicians provide at the moment of diagnosis to present disabilities in an equitable way?
5. Do you have any other recommendations for what an ideal scenario might look like in the provision of prenatal screening if expectant parents were being provided comprehensive support that included an equitable representation of people with disabilities?

Equitable Policies

Survey responses illustrated an ideal state in which policies would be in place to ensure that genetic testing is widely known as a choice guided by informed consent available and accessible to all who want it and complete education and counseling would be offered prior to screening to ensure that expectant parents have all the necessary information about what the screening can and cannot tell them. Respondents thought policies in an ideal setting, would be non-biased, flexible, consistently enforced, and inclusive of cultural, familial, and ethical considerations. The federal government would provide funding for prenatal screening education and require that every patient receive pre and postnatal education, information, and supports.

Equitable Counseling

Respondents expressed that in an ideal state, patients would be provided complete well-rounded information and education about prenatal screenings and the capabilities and shortfalls screenings prior to the actual screening. This information and educational materials would consider diverse perspectives and would be accurate and update. Information would be offered in a brochure form presented by the physician to facilitate discussion with the expectant parents. Lastly responses mentioned that public knowledge and disability awareness must be enhanced in the broader society to decrease misconception about people with disabilities.

Delivery of Diagnosis

Respondents describe an ideal state as one in which the results of a prenatal screening are provided in a medical office and presented to the patient by a healthcare professional in a comforting, supportive, and non-biased manner. One respondent mentioned that the prenatal

provider would team up with a genetic counselor to deliver results to ensure that the patient's questions about the diagnosis could be answered at the time of diagnosis in an ideal state. Additionally, respondents mentioned that patients be would be given ample time process the information and make decisions about how to proceed. Healthcare providers in an ideal state would be mindful of the language used when delivering a prenatal diagnosis to expectant parents and avoid the use of negative phrases such as "I'm sorry", "bad news" or "bad results." Another characteristic of the ideal state mentioned by respondents was referral of expectant parents to condition specific local or national support networks or organizations and connecting parents to individuals with a similar diagnosis and their families.

Information and Support Delivered at the Time of Diagnosis

Respondents mentioned that while it is important for clinicians to provide patients with information, in an ideal state, some information would be available in an online or paper form so that patients can continue to learn on their own. Information would be complete, factual, and include all patient options. One person mentioned that healthcare providers should use plain language to provide information instead of technical terms because jargon is "not as useful for people with a disability or a parent because they are not an expert or a professional." Healthcare providers would provide comfort at the time of diagnosis and support the patient's decision. Similar to the response with delivery of diagnosis, respondents state that in an ideal state, physicians would connect patients with communities of people that have a similar diagnosis including individuals with the condition, their families or related support groups and networks. Survey respondents indicated that ideally, patients would be fully educated about both the symptoms that could arise because of a specific condition as well as the possibilities of life with that specific condition. One survey respondent mentioned that the Lettercase materials provide an example of how to provide patients with "balanced information that frankly discusses symptoms and lived experiences of people with disabilities and their families."

Comprehensive Support Inclusive of Equitable Representation of People with Disabilities

Most respondents mentioned that in an ideal setting, healthcare providers would have training which includes topics such as empathy and patient centered care as well as a continuing education component that provides training on the various conditions inclusive of both the medical aspects and the lived experiences of people with disabilities. Consultation spaces would be less medical and more comfortable office spaces. Patients would be given ample time to process the information provided at a pace and volume they want and in format that is conducive to their decision making process whether that be faith based, fact based, data heavy, or in a more interpersonal way with connections to local condition specific organizations. Resources such as Lettercase would be available for a variety of conditions. Lastly, the respondents thought that in an ideal setting there would be a procedure for pre and postnatal patient follow-up to evaluate the patients experience with the information given and to inquire about the patients current situation and find out if they need additional supports.

Gaps Identified

CDHPD Partners were tasked with reviewing various types of documents to identify gaps in the prenatal genetic testing focus area. Because of the volume of documents, the analysis in this section was completed in two parts. Documents entered on or before June 3, 2020 were in the first round of analysis and documents entered between June 3, 2020 and July 17, 2020 were analyzed in the second round of analysis. The data from the two rounds of analysis was combined and reported in this section. There were 43 entries in the first round and 33 in the second. A total of 76 documents were reviewed in this focus area. More than half of the documents (57%) were classified as manuscripts and 18% were media reports. Please refer to Table 13 for more details about the types of documents reviewed.

Table 13: Prenatal Genetic Testing Number of Documents Reviewed by Type

Document Type	Frequency	Percent
Manuscript	43	57%
Media Report	14	18%
Other	6	8%
Policy-Related Document	5	7%
Organizational Statement	3	4%
Policy	3	4%
Curricula	1	1%
Legal Document	1	1%

Five different CDHPD Partner organizations reviewed the prenatal screening related documents in this focus area. Most of the documents were review by the University of Kentucky - Human Development Institute (82%). Table 14 shows the percentage of documents reviewed by each CDHPD Partners.

Table 14: Number of Documents Reviewed by CDHPD Partners

CDHPD Partners	Frequency	Percent
University of Kentucky - Human Development Institute	62	82%
University of Cincinnati Center for Excellence in Developmental Disabilities	9	12%
Maryland Center for Developmental Disabilities at Kennedy Krieger Institute	3	4%
Autistic Self-Advocacy Network	1	1%
American Academy of Developmental Medicine and Dentistry	1	1%

Every document was assigned an evidence score. Of the 76 documents reviewed in this focus area, 33 clearly identified evidence of disparity or discrimination and 18 somewhat presented evidence. Table 15 displays the number of documents in each evidence category.

Table 15: Evidence Scores – Prenatal Genetic Testing

	Clearly Evident	Somewhat Evident	Not Evident	Total
Prenatal Genetic Testing	33	18	25	76

Each document was assigned a utility score by CDHPD. Fifty-eight of the documents in this focus area were considered useful in the development of protocols and 18 were somewhat useful. Table 16 to shows the number of documents in each utility category.

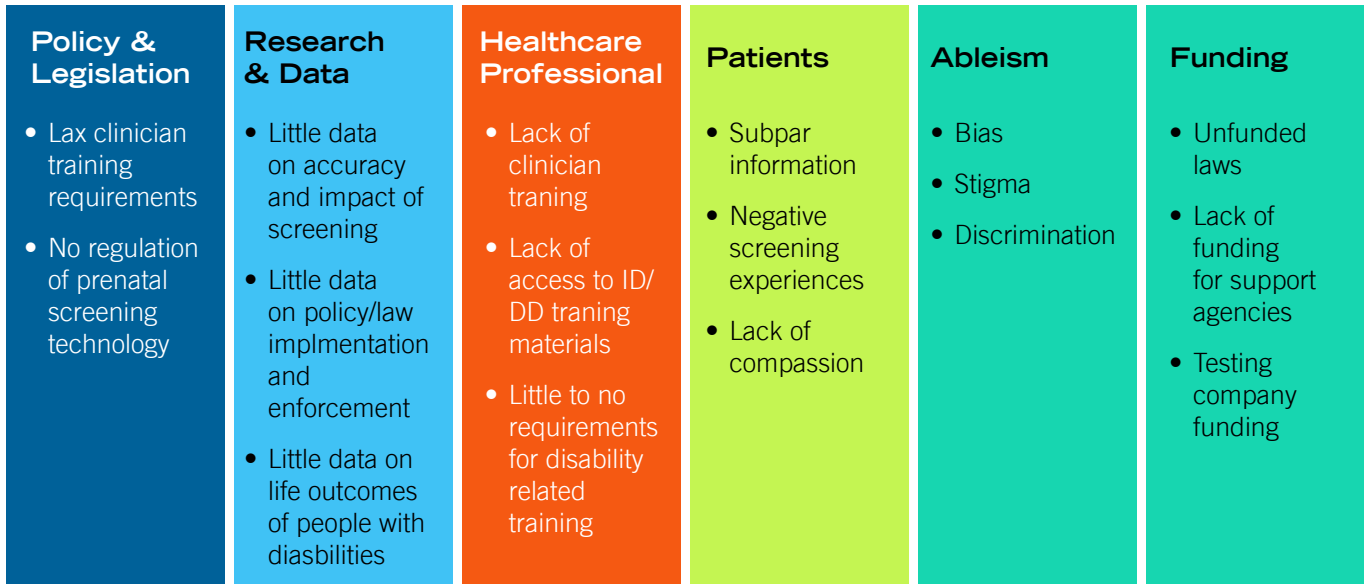
Table 16: Utility Scores – Prenatal Genetic Testing

	Very Useful	Somewhat Useful	Not Useful	Total
Prenatal Genetic Testing	58	18	0	76

Gaps were clustered in six areas, funding, policy/legislation, research/data, clinician related, patient related, and issues caused by stigma and ableism. The most frequently mentioned gaps were patient related and included topics such as patient information and education. Of the 76 documents reviewed, six did not have any information recorded in the Gaps Highlighted field and eleven discussed aspects of the document but did not list any gaps. Please refer to Figure 8 to view the categories of gaps identified in this focus area as well as the specific types of gaps classified under each category. The opened ended CDHPD Partner responses provided in the Gaps Highlighted field for this focus area can be found in Appendix A.

Figure 8: Prenatal Genetic Testing - Identified Gaps

Prenatal Genetic Testing – Identified Gaps



Policy & Legislation

Several policy related gaps were highlight by the CDHPD Partners. Many discussed little consistency in legislation and professional guidelines regarding disability awareness training for healthcare professionals. Additionally, CDHPD Partners discussed the lack of regulation for prenatal screening companies. They also mentioned that there are very few incentives

for governing agencies such as the FDA to regulate prenatal testing tools or for professional organizations to mandate disability training for healthcare professionals. Additionally, CDHPD Partners noted that in the instances in which these issues are regulated, they rarely include the disability rights viewpoint or a mandate for non-directive counseling. CDHPD Partners mentioned that laws such as the Down Syndrome Information Act (DSIA) focus on requiring that patients be provided with information but that becomes less clear when abortion politics are associated with DSIA's. Furthermore, not all states have DSIA laws.

Research & Data

Through the document review process, CDHPD Partners found that research and data is lacking in every aspect of the prenatal screening. Prenatal screening technology is a vastly growing field but there is little to no research on the impact of this technology. They also noted that while some prenatal testing companies do conduct research investigating the impact of their technology, there is no requirement to do so and no set standards for this research to follow according. Furthermore, the CDHPD Partners discovered that there is very little data tracking the implementation, use, or enforcement of laws and policies.

Healthcare Professionals

CDHPD Partners found that healthcare professionals have no mandated medical school or continued professional training requirements for disability training. They also mentioned studies that found that many practicing obstetricians and gynecologists felt they had inadequate medical training in disability related issues and medical students receive little to no clinical training pertaining to individuals with intellectual and physical disabilities or how to deliver pre or post-natal diagnosis to parents. Furthermore, CDHPD Partners commented that the healthcare professionals that did received training felt their training was inadequate.

Patients

Many different gaps involving the patient experience were mentioned by CDHPD Partners ranging from information and education received at prenatal appoints to negative experiences when receiving a diagnosis. The document review revealed that patients are not always

receiving complete, balanced, and up to date information from the medical providers or genetic testing sites. CDHPD Partners noted that this has led to patients choosing to terminate their pregnancy based on a misunderstanding or lack of information about the accuracy or capabilities of genetic testing. Also mentioned was the concern that in some cases patients are not aware that prenatal genetic testing is optional. CDHPD Partners also noted that patients have reported negative experiences in several different ways such as negative language used when prenatal screening results are presented and when patients receive condition specific medical information but no social support or information on life outcomes.

Issues Caused by Stigma and Ableism

The document review process exposed issues of ableism, bias, discrimination, and inequity. One CDHPD Partner noted that society is generally uneducated about the “historical stigma, trauma, and abuses endured by people with disabilities and how that historical stigma shapes current conscious and unconscious bias.” They also mentioned that negative stigma and stereotypes about the life and capabilities of individuals with Down Syndrome and other intellectual or developmental disabilities are common in society. Additionally, CDHPD Partners noted that the practice of prenatal screening is inherently biased because it is a practice of screened out disabilities.

Financial Issues

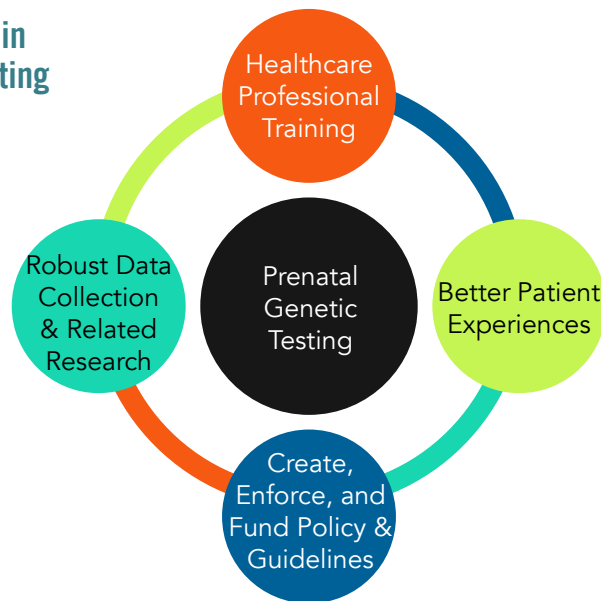
There were many different gaps related to financial issues discovered through the CDHPD Partner document review. CDHPD Partners found that some legislation such as the Prenatally and Postnatally Diagnosed Conditions Awareness Act have passed but are not financially supported. The document review process also highlighted issues of funding sources in prenatal genetic testing. CDHPD Partners found that some circulating free DNA (cfDNA) testing companies do have a practice of referring patients to patient advocacy groups (PAGs) which is a great outcome but it increases the demand for services that the PAGs must meet and they don't often have the funding to meet the demand. Also mentioned was the uncertainty in cost effective estimates of the use of non-invasive prenatal screening (NIPT) as well as inconsistencies in what insurance companies are willing to pay for items of counseling and testing.

Potential Solutions to Address the Gaps

CDHPD Partners provided suggestions for addressing the gaps in the prenatal genetic testing focus area. This information was recorded in the Gaps Highlighted and Notes fields in the CDHPD Database. Potential solutions presented in this section represent a mixture of CDHPD Partners' original ideas and ideas discussed in the documents they reviewed. This process led to the creation of four unique potential solution categories. Figure 9 displays the four categories aimed at addressing the gaps in the prenatal genetic testing focus area.

Figure 9: Prenatal Genetic Testing – Potential Solutions for Addressing the Gaps

Addressing the Gaps in Prenatal Genetic Testing



Create, Enforce, and Fund Policies and Guidelines

CDHPD Partners discussed a mixture of creating new policy and guidelines and funding and enforcing existing ones to address the gaps in the genetic testing focus area. The following policy and guideline related potential solutions were mentioned:

- Enact and enforce Down Syndrome Information Acts (DSIA): Keeping abortion politics out of the DSIA will ensure it stays true to its inception as not a pro-life or a pro-choice policy measure, but a pro-information law. The DSIA's intent is to ensure they receive the recommended information about Down syndrome and available support resources
- Federal roles could include mechanisms to provide condition-specific education,

mechanisms to facilitate collaboration and coordination between stakeholders to recognize genetic counselors as service providers

- Actively oversee the marketing claims and practices of prenatal genetic testing companies as more tests with questionable clinical validity and utility enter the market as part of the standard testing panels that companies offer.
- Develop enforceable Sunshine and Conflict-of-Interest laws that will bring transparency to any financial relationships among genetic counselors, providers, and commercial laboratories.
- Fund the Prenatally and Postnatally Diagnosed Conditions Awareness Act, Pub. L. No. 110-374, 122 Stat. 4051 (2008).
- Actively oversee the marketing claims and practices of prenatal genetic testing companies as more tests with questionable clinical validity and utility enter the market as part of the standard testing panels that companies offer.
- When a mistake is alleged about genetic testing there ought to be some sort of no-fault insurance scheme under the supervision of neutral mediators, not a courtroom slugfest that demeans the value of a life with disability and reeks of eugenics.
- insurers could ideally follow the recommendations by ACMG about the provision of patient education resources and/or ACOG could be more explicit in their directions about the provision of patient education about conditions detected by NIPT so that insurers are more likely to cover the costs of patient education and clinician training.
- We can hold more robust and diverse discussions to develop guidelines for deciding which conditions to incorporate into prenatal and carrier screening that are more measured, respectful, and ethically balanced. We need to teach a more honest assessment of our history.

More Robust Data Collection and Research Efforts

CDHPD Partners noted several options for addressing the lack of data and research in the field of prenatal and genetic testing including increasing data collection on lived experiences,

researching patient and clinician attitudes and experiences, and funding research projects. The following potential solutions were mentioned:

- Research the relationship between women’s choices after receiving pre-test counseling and after undergoing genetic testing, and how choices are affected by the kinds of genetic counseling information provided, who delivers it, and who is paying for the counseling.
- Propose ways to achieve better data over time to determine the link between prenatal testing outcomes and various factors in the field of genetic testing such as counseling, cultural conditions, social expectations, and social determinants of health for particular disability communities.
- Improve research on the attitudes of genetic counselors regarding disabilities and the needs of individuals and families receiving a diagnosis.
- Where state Medicaid programs cover prenatal genetic testing, the state should ensure that it collects voluntarily provided information on patient demographics, including disability status, outcomes, and the quality of genetic counseling received before the testing, if any. This information will allow states and researchers to assess the use and results of prenatal genetic testing as a publicly insured service over time.
- if the testing is going to provide increasingly more genetic information, then the medical professionals and testing labs should be prepared to provide even more life outcome information about those conditions as well
- funding research on best practices for supporting patients receiving a Down syndrome diagnosis.
- We could conduct more studies on whether there are benefits to prenatal screening beyond pregnancy termination.
- Empirical studies will be helpful in determining the specific criteria (e.g., level of risk, conditions tested for, funding model) the Canadian public and stakeholders think satisfy the principle of equitable access.

Healthcare Professional Training and Accountability

CDHPD Partners mentioned that healthcare professionals need more and better education and should take responsibility for their own bias and awareness as it related to people with intellectual and developmental disabilities. The following potential solutions were mentioned related to healthcare professional training and accountability:

- Consult the disability community when developing training materials
- Clarify that disability education and cultural awareness extends beyond examining best practices for effectively communicating with patients with disabilities and includes a social and civil rights context for understanding disability.
- Medical, nursing, and genetic counseling students need a richer understanding about Down Syndrome, beyond the statistics cited in their texts.
- Comprehensive training on how to deliver a non-directive prenatal diagnosis of DS should be offered to all obstetricians, geneticists, midwives, genetic counsellors, neonatologists, family medicine physicians, and other healthcare professionals involved in prenatal care. Online simulation has already been developed for physicians to practice these skills.
- Incentivize the development of educational units on disability experience and exposure in genetic counselor education. Department of Health and Human Services (HHS), National Institutes of Health.
- ...it's imperative that genetic counselors, physicians, and all professionals who work with prospective parents reach out and partner with the disability community to strengthen the informed consent process connected with prenatal screening and diagnosis. Current, complete, and unbiased informational packets about a range of genetic disabilities should be assembled and distributed in consultation with advocates, parent support groups, and other representatives of the disability community.
- Introduction of a formal genetics curriculum, including the use of standardized patients, has been shown to improve residents' knowledge and confidence in applying genetics

concepts to patient care.

- Consideration should be given to using standardized patients to provide residents with more experience in Down syndrome counseling.
- Providers should strive to support families making these connections with other families with children who have the same diagnoses.
- Disability awareness within primary and continuing medical education that includes current information about Down syndrome is important. Health care provider knowledge base, communication skills, behaviors and attitudes should reflect current understanding of Down syndrome.

The following subset of potential solutions were pulled from the literature related to Genetic counselors and prenatal counseling. While they are specific to genetic counselors, these potential solutions can be applied to clinicians and other healthcare professionals:

- The Accreditation Council for Genetic Counselling (ACGC) must make disability education and cultural awareness mandatory and more consistent among genetic counselor programs, within a reasonable range of time and resources. The same holds true of professional ongoing education.
- Genetic counselors should examine their own conscious and unconscious biases about people with disabilities.
- Genetic counselors should build genuine relationships with the disability community
- Genetic Counseling student programs should recruit people with disabilities and family members; people with disabilities and families should be incorporated into the education and training of GCs; and disability studies should be incorporated into the curricula; and programs should develop measurable outcomes to evaluate methods.

Create Better Patient Experiences

According to the CDHPD document review process, so many gaps occur at the patient level and those issues include most of not all stakeholders in the prenatal genetic testing field, from testing companies, medical professions, disability advocacy groups and the government. CDHPD Partners mentioned potential solutions that included forging partnerships with the disability community and healthcare professionals and creating and disseminating better information. Below is a list of potential solutions mentioned by CDHPD Partners:

- ...it's imperative that genetic counselors, physicians, and all professionals who work with prospective parents reach out and partner with the disability community to strengthen the informed consent process connected with prenatal screening and diagnosis. Current, complete, and unbiased informational packets about a range of genetic disabilities should be assembled and distributed in consultation with advocates, parent support groups, and other representatives of the disability community.
- ...genetic counselors and disability advocates to work together to investigate this phenomenon and to help assure that appropriate medical and support services are available for these children and their families.
- Pretest and post- test counseling are essential and must be a part of any screening program. When a positive or negative screening test result is obtained, the patient should be counseled regarding the adjusted likelihood of carrying a fetus with the evaluated aneuploidies. The potential for the fetus to be affected by genetic disorders that are not evaluated by the screening or diagnostic test should be reviewed.
- Contact with local DS support groups should be offered
- Clinicians should schedule a follow-up appointment for additional questions and provide referrals to specialists as needed, such as a cardiologist.
- Prior to undergoing amniocentesis or CVS, clinicians should have a conversation with a patient about pregnancy preferences and whether or not the patient plans to proceed with the pregnancy, and clinicians should respect those wishes if patients have come up

with a conclusive personal decision.

- The medical professional on the team with the most expertise about Down syndrome should deliver the news.
- Discuss all reasons for prenatal diagnosis including reassurance, advance awareness before delivery of the diagnosis of DS, adoption, as well as pregnancy termination. Many of the mothers who responded to this survey never planned to terminate the pregnancy and were upset when their physicians provided detailed descriptions of pregnancy terminations without knowing whether they would like those options discussed.
- Patient education materials about conditions should be developed with input from multiple stakeholders including medical organizations and advocacy organizations.
- Information about tests and conditions should be available to patients in multiple mediums based on their needs, health literacy, language, and cultural preferences.
- Accurate, up-to-date, and balanced information about Down syndrome (or other tested conditions) should be provided.
- Physicians should discuss potential medical issues but also available supports and services and life outcomes for people with Down syndrome
- Should our recommendations possibly argue for requiring that positive information be given during prenatal testing for DS?
- Disseminating the Lettercase book.
- A “gold-standard” packet of information should be developed for all expectant parents who receive a prenatal diagnosis of DS. The booklet, “Understanding a Diagnosis of Down Syndrome Diagnosis” has now been created with assistance from all the organizations and is available for dissemination from the organization, Lettercase, Inc. (<http://www.lettercase.org>).
- Given these findings, an effort needs to be made on the part of health care providers to increase counseling rates to 100%, stressing the optional nature of the test to attain true

informed consent.”

- The document recommended that women be referred to local or national advocacy organization.
- To achieve consistency and accuracy in counseling, supplemental patient educational material may be helpful; more than half of the respondents provide patients with printed information, which suggests that they find this helpful. Complementary written or World Wide Web–based patient educational material designed by ACOG may assist physicians and ensure that patients are well informed about Down syndrome and the screening and diagnostic tests.

Plan to Close the Gaps

CDHPD Partners in the Prenatal Genetic Testing focus area began meeting monthly in May of 2020 for 3 months with the purpose of developing a plan of action to close the gaps. In their meetings they discussed issues such as developing protocols and guidelines to address the gaps and explored the various avenues to disseminate information. During their meeting on July 16, 2020, the subcommittee decided to use the completed gap analysis as to guide the development of protocols and guidelines to present to the CDHPD Community Advisory Board.¹¹ A research project was recently approved by the University of Kentucky’s Institutional Review Board. Through partnership with Down Syndrome organizations, surveys will be administered to expectant mothers and women who have recently given birth to babies with Down Syndrome. The surveys are designed to collect information about the type and amount of information parents or expectant parents of child with Down Syndrome receive. The study will also survey healthcare professionals to investigate the impact of medical outreach on healthcare professionals.

¹¹ Meredith, S. (personal communication, July 16, 2020) discusses the Prenatal Genetic Testing Subcommittee meeting agenda and notes.

COVID-19

Current State

The COVID-19 Pandemic began in the United States after the establishment of the Center for Human Dignity in Healthcare for People with Disabilities and was not within the original scope of the gap analysis project. However, when the COVID- 19 Pandemic emerged, it amplified disparities and discrimination unique to the healthcare people with intellectual and developmental disabilities which aligns with the mission of CDHPD.

Ideal Future State

To conceptualize the ideal future state for the COVID-19 focus area, CDHPD Partners envision a future in which equitable healthcare is guaranteed to individuals with disabilities in a manner that is free from bias and discrimination and delivered in a way that honors their autonomy and unique needs with the consistency and flexibility. CDHPD Partners also noted that in an ideal future state, during a crisis such as the COVID-19 Pandemic, levels of healthcare would remain intact.

Gaps Identified

CDHPD Partners reviewed a total of six documents to identify gaps in the medical treatment of people with ID/DD related specifically to the COVID-19 Pandemic. Of the six documents reviewed in this focus area three were policy related documents, two were policies, and one was a legal document. Please refer to Table 17 for more details.

Table 17: COVID-19 Number of Documents Reviewed by Type

Document Type	Frequency	Percent
Policy Related Document	3	50%
Policy	2	33%
Legal Document	1	17%

All of the documents in this focus were reviewed by CDHPD Partners at the University of Cincinnati Center for Excellence in Developmental Disabilities.

Table 18: Number of Documents Reviewed by CDHPD Partners

CDHPD Partners	Frequency	Percent
University of Cincinnati Center for Excellence in Developmental Disabilities	6	100%

Every document was assigned an evidence and utility score. All six of the documents in this focus area clearly identified evidence of disparity or discrimination and were considered to be very useful in the development of protocols. Tables 19 and 20 shows the evidence and utility ratings of the documents.

Table 19: Evidence Scores – COVID-19

	Clearly Evident	Somewhat Evident	Not Evident	Total
COVID-19	6	0	0	6

Table 20: Utility Scores – COVID-19

	Very Useful	Somewhat Useful	Not Useful	Total
COVID-19	6	0	0	6

Because there were few documents, the information recorded in both the Gaps Highlighted and the Briefly Describe the Document fields was also explored to collect additional commentary provided to include in the analysis. The CDHPD Partner comments mentioned that the impact of COVID-19 on persons with autism is unknown. Other gaps discussed were the issues the pandemic might cause such as ethical challenges in situations where resources become scarce and demands and surges on the medical systems becoming overwhelming. The “disability paradox” and disability-based distinctions in the delivery of treatment were also mentioned. Another gap discussed was the use of a person’s disability status as the basis for denial of care which is a violation the law. CDHPD Partners also mentioned that people with disabilities are not broadly represented in discussions and on committees related to the impact of pandemic or other scarcity situation will have on the disability community. Also noted was focusing illusions and how hard it can be to get patients to get patients to envision their ability to adapt to unfamiliar circumstances. The CDHPD Partner comments recorded in the Gaps Highlighted field can be found in the Appendix A.

Potential Solutions to Address the Gaps

CDHPD Partners provided several suggestions for addressing the gaps in the COVID-19 focus area. This information was recorded in the Gaps Highlighted and Briefly Describe the Document fields in the CDHPD Database. Potential solutions presented in this section represent a mixture of CDHPD Partners' original ideas and ideas discussed in the documents they reviewed. Below are the potential solutions that were provided:

An important first step is to identify and discuss the challenges and opportunities that the COVID-19 pandemic poses autistic adults, incorporating a variety of perspectives.

It is necessary to develop and test different ways to get people to imagine unfamiliar health states and to recognize the power of emotional adaptation.

This "nothing about us without us" approach to implementation of the crisis standards of care could help offset the presence of implicit bias in the judgment of nondisabled medical professionals.

Plan to Close the Gaps

The COVID-19 focus area is different from the 'other' focus areas because it addresses inequities and discriminatory practices in the healthcare of people with disabilities that were amplified by the pandemic. Shortly after the COVID-19 Pandemic came to the United States, CDHPD Partners assembled a workgroup to address the issues that COVID-19 has magnified. The COVID-19 workgroup began holding weekly meetings on April 10, 2020 and moved to biweekly meeting in June. The workgroup produced several tools designed to address the inequities exposed by the pandemic. One of the tools is a fact sheet titled 'Safeguard Against Disability Discrimination During COVID-19,' which is intended to provide healthcare providers with information and guidance for caring for people with disabilities in a manner to ensure equitable care. The COVID-19 Workgroup also produced the 'Do You Know Your Rights with COVID-19?' fact sheet designed to inform people with disabilities of the rights so they can advocate for themselves. Both fact sheets can be viewed in Appendix E. Additionally, the CDHPD issued a statement on the death of Michael Hickson and value judgments about the quality of life of people with disabilities.¹²

¹² Smith, L., (personal communication, August 8, 2020) discussed and shared the products produced by the COVID-19 Workgroup.

Legal Aspects for All Focus Areas

In order to examine legal issues related to all of the focus areas, CDHPD Partners included a focus area with the sole purpose of reviewing literature about the legal aspects of medical care and treatment for individuals with intellectual and developmental disabilities (ID/DD) in the various focus areas. The Legal Aspects for All focus area included 19 documents, three of which were 50 state surveys of the Down Syndrome Information Act and protections for organ transplant protections for people with disabilities created by CDHPD Partners.

Of the 19 documents in the legal aspects for all focus area, four also related to the aging end of life focus area, three related to the life-saving treatment (organ transplant) focus area, and one related to both the aging and end of life and mental health and suicide prevention focus areas. Four documents were originally categorized as other but were later reclassified as legal aspects for all during a review of the documents in the ‘other’ focus area. Documents pertaining to other existing focus areas were included and analyzed in the corresponding focus areas. Please refer to Table 21 to view the document focus area categorizations.

Table 21: Legal Aspects for all Focus Areas – Identified Focus Areas

Identified Focus Areas	Frequency
Aging and End of Life Care, Legal Aspects for All Focus Areas	4
Aging and End of Life Care, Mental Health and Suicide Prevention for people with ID / DD, Legal Aspects for All Focus Areas	1
Legal Aspects for All Focus Areas	6
Legal Aspects for All Focus Areas, Other	1
Life Saving Treatment (Organ Transplant), Legal Aspects for All Focus Areas	3
Other Reclassified as Legal Aspects for All	4

50 State Surveys

CDHPD Partners examined the laws in all 50 states and five U.S. territories to determine which states have enacted the Down Syndrome Information Act (DSIA) and organ transplant protections for people with disabilities. Table 22 displays the number of U.S. states and

territories that have enacted DSIA or organ transplant protection legislation. Please refer to the Appendix B to view a complete list of states that have enacted each type of legislation as well as notes about a few states that have not enacted legislation.

Table 22: United States and U.S. Territory Laws

Legislation	Yes	No
Down Syndrome Information Act	20 (36%)	35 (63%)
Organ Transplant Protections for People with Disabilities	16 (29%)	39 (71%)
Wrong Birth/Wrongful Life Legislation*	12 (22%)	43(78%)

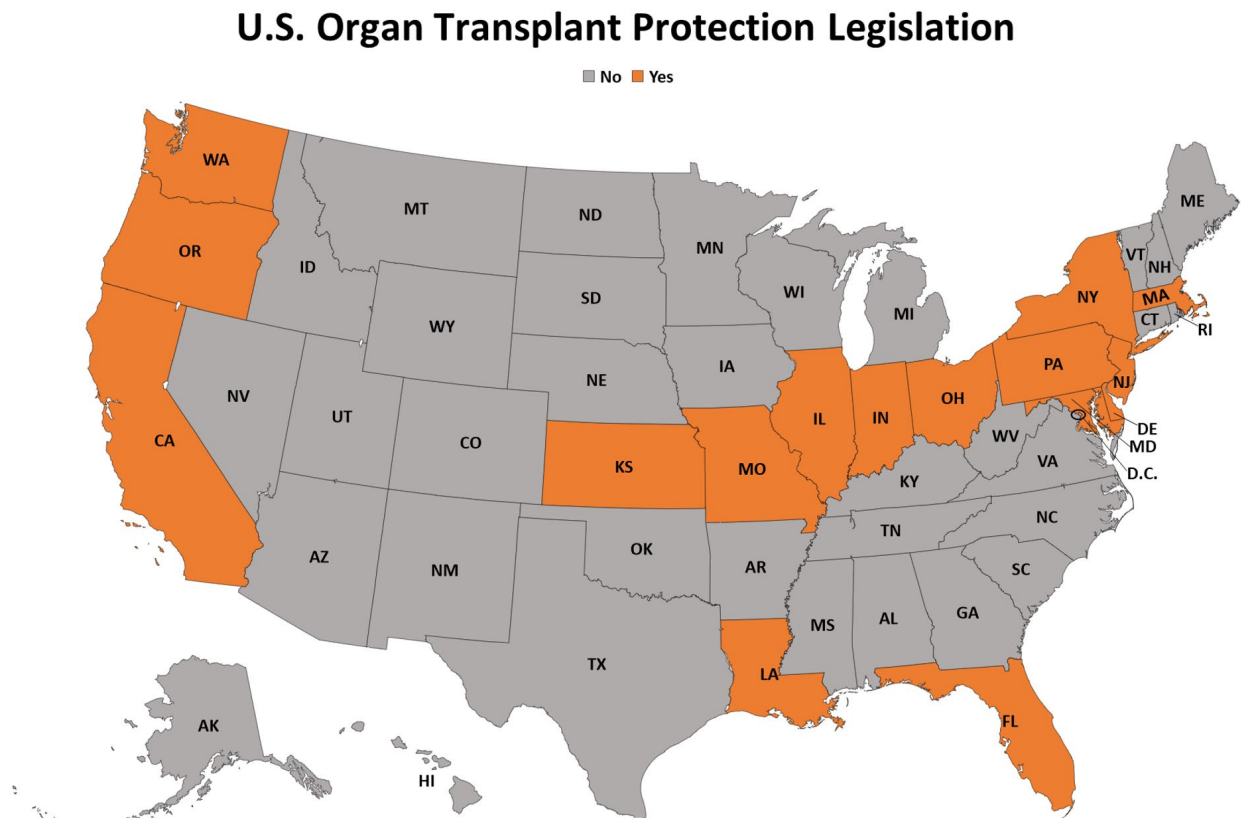
Notes: This table includes all 50 states, Washington D.C., Guam, Northern Mariana Islands, Puerto Rico, and U.S. Virgin Islands. American Samoa is not included.

*Of the 12 states that have enacted wrongful life or wrongful birth legislation, eight prohibit wrongful death claims and three allow them.

Organ Transplant Protections for People with Disabilities

Nearly one third (29%) of U.S. states and territories have some form of legislation that provides organ transplant protections for people with disabilities. The laws in each of the 16 states include language which prohibits the use of a person’s disability status as means to limit access to organ transplants or anatomical gifts. An additional nine states (Alabama, Arkansas, Georgia, Minnesota, Mississippi, New York, Tennessee, Texas, and West Virginia) have introduced but failed to pass organ transplant protection legislation.¹⁵ Figure 11 shows the states that have organ transplant protection legislation. Please refer to the Appendix B to view a complete annotated list organ transplant protection legislation in the United States and its territories.

Figure 11: Map of Organ Transplant Protections for People with Disabilities in the United States



Note: Guam, Northern Mariana, Puerto Rico, U.S. Virgin Islands, and Washington D.C. have not enacted DSIA legislation. American Samoa is not included in this report.

¹⁵ Waller, T. Organ Transplant Protections for People with Disabilities – States and Territories. Legislative Research Compilation. CDHPD Database.

Other

CDHPD Partners were concerned that the five existing focus areas; aging and mental health, legal aspects for all, life-saving treatment (organ transplant), mental health and suicide prevention for people with intellectual and developmental disabilities, and prenatal genetic testing) might not include all of the healthcare related discrimination and inequity issues faced by people with disabilities. In an effort to address this concern, CDHPD Partners created the ‘other’ focus area and reviewed documents outside of the subject matter of the original focus areas.

Recategorization

A total of 45 documents were reviewed in this category. To more narrowly define the documents categorized as ‘other’, open ended responses in the Briefly Describe the Document, Notes, and Gaps Highlighted fields for each document were reviewed to determine if the document could be recategorized into one of the five existing focus areas or if a new focus area needed to be created. The gaps highlighted and corresponding focus area recategorizations can be found in Appendix A. The recategorization process led to the creation of five new focus area categories:

1. **Intersectional Issues:** this category included documents that discussed:
 - **Cascading disparities:** instances where individuals had several issues or social situations compounded or connected to one another
 - **Social and racial justice issues:** disparity/discrimination based on race, gender, age, certain type of disability or another characteristic
 - **Compound health issues:** instances in which an individual had more than one medical condition or significant disability
 - **Stigma:** judgment or unfair treatment because of negative beliefs about a disability or another related characteristic
2. **Autism Spectrum Disorder:** included documents that discussed issues specific to Autism Spectrum Disorder

- 3. Health Insurance:** included documents that discussed issues pertaining to health insurance, managed healthcare, third- party coverage or other related issues
- 4. Healthcare Professional Training:** included a document that discussed inadequate medical training in disability related education/training and ways to address those deficiencies
- 5. Cerebral Palsy:** included documents that discussed issues specific to Cerebral Palsy

Eight of the documents were recategorized into one of the existing focus areas. Documents recategorized into existing focus areas were analyzed in their corresponding focus area sections of this report. Below is a list of the existing focus areas and the type of documents that went into each of focus area:

- 1. Mental Health and Suicide Prevention for People with ID/DD:** included documents that pertained to mental health issues, behavioral health issues or substance abuse
- 2. Aging and End of Life Care:** included a document that discussed the avoidable premature death of people with ID/DD
- 3. Life Saving Measures (Organ Transplant):** included a document that discussed cancer screening
- 4. Legal Aspects for All Focus Areas:** included documents that pertained to policy, laws, and health surveillance

Forty-four percent of the documents were recategorized as Intersectional Issues, followed by Autism Spectrum Disorder (18%), and Health Insurance (13%). Table 23 shows the number documents in each recategorized focus area. Table 24 displays the number of documents reviewed.

Table 23: Number of Documents in each Recategorized Focus Area (n=45)

Recategorized Focus Area	# of Documents
Intersectional Issues	20
Autism Spectrum Disorder	8
Health Insurance	6
Legal Aspects for All Focus Areas	4
Mental Health and Suicide Prevention for People with ID/DD	2
Medical Education	2
Aging/ End of Life Care	1
Cerebral Palsy	1
Life-Saving Treatment (Organ Transplant)	1

Table 24: Number of Documents Reviewed by CDHPD Partners (n=45)

CDHPD Partner	# of Documents
Family Voices	8
The Boggs Center on Developmental Disabilities	1
University of Cincinnati Center for Excellence in Developmental Disabilities	2
Vanderbilt Kennedy Center for Research on Human Development	33

Considerations for Development and Dissemination of Protocols

CDHPD hosted a Dignity in Healthcare Panel and Breakout Discussion entitled Practicing Dignity in Healthcare for Individuals with IDD: Addressing Inequities in Prenatal Diagnostics, Organ Transplantation, Mental Health, and End of Life Planning and Care. The panel was part of the American Academy of Developmental Medicine & Dentistry (AADMD) 2020 One Voice for Inclusive Health Virtual Conference, a conference for healthcare professionals. The facilitated discussion was conducted in focus area specific breakout groups. Conference attendees were asked to consider and discuss ideas related to the development and dissemination of protocols to address the gaps in the healthcare of people with disabilities. The results of those breakout sessions provide insight into the topics that should be addressed with respect to protocols. The break group session results can be found in Appendix F.

Protocol Platforms, Utility, and Other Considerations

In each breakout group, attendees were asked “What protocol platforms (like “UpToDate”) should we consider for our medical protocols? What do you as a healthcare provider use and/or find helpful?” Breakout session attendees shared information about platforms that they thought would be a good vehicle for protocol delivery and stressed the importance of information being easily accessible to healthcare professionals, using existing agencies and guidelines, and platforms that could be good options for dissemination. Also discussed were specific audiences to consider in the development of protocols, ensuring that protocols are available in platforms that are accessible and can reach all healthcare professions, and consider using care cards.

Platforms

While there was some uncertainty about whether or not it is a protocol platform, UpToDate (a medical information resource for healthcare professionals) was recommended as a good platform for dissemination because it used by healthcare professionals such as children’s specialists, genetic counselors, OBGYN, and women’s primary care doctors. This platform was suggested

because information can reach a large audience and it is current and comprehensive as opposed to some of the other existing platforms. It was also suggested the protocols should be linked to LexiComp (which is another medical information resource used by healthcare professionals), and other programs.

Protocol Integration and Other Considerations

Integrating protocols into existing systems such as the EMR (electronic medical records) was suggested because attendees thought protocols embedded in systems that easily accessible are more likely to be used if they are easily accessible. Below is a list existing guidelines, agencies, or platforms compiled by the breakout session attendees:

- AAFP Guidelines
- AAP Guidelines
- KDIGO is a guideline clearing house
- United Network of Organ Sharing
- DynaMed (used in Canada)
- John Hopkins Community Physician program SHARP (Small High Activity Risk Panel)
- Google
- State office of DD is where most Medicaid providers look for information
- DM-ID NADD
- MD Calc

Session attendees suggested that audiences to consider should include primary care healthcare providers specializing in women's care, healthcare professionals that provide counseling services, and families. Additional issues of consideration platform availability, the platforms used by each type of healthcare provider is known, the use of customized care cards (which are in a patients chart and provides the healthcare professional with details about the patient), using a push platform instead of a pull platform where information is provided as opposed to available it if one searches for it.

Protocol Components to Facilitate Good Healthcare Provider Decision Making

When asked “What do you think a useful protocol on the issue of TOPIC would entail to help healthcare providers to make good decisions/implement the appropriate treatment/intervention/next step as to not discriminate against people with I/DD?”, breakout session attendees mentioned that “any protocol should begin with a values exploration.” One should consider the patients point of view. Additionally, attendees discussed the importance of resource sharing as well as the need for communication and improved healthcare provider education. A person-centered approach was suggested as well as establishing a few key ethics review criteria. Addressing testing, diagnosis protocols, processes for referrals were also mentioned as ways to facilitate good decision making.

Patient- Healthcare Professional Communication

The breakout groups pointed out that a communicative relationship between the healthcare professional and the patient is important. To achieve the ideal healthcare provider-patient communicative relationship it was determined that the party responsible for speaking on the patients behalf should be known, whether it be the patient themselves, a guardian, conservator, other alternative for healthcare proxy. It was also mentioned that one must “create culture to facilitate communication of people with I/DD, similar to how interpreters used for non-English speakers” and ensure that the patient is included in the decision-making process. Protocols for communication should consider that the doctor appointment visits need to be longer than 15 minutes to facilitate meaningful patient-healthcare professional communication. It was also discussed that protocols should be developed that include parameters for patient dialogue that includes providing patients with resources and brings attention to tone of language.

Person Centered Approach and Ethics Reviews

According to the breakout groups, protocols should “establish a standard of care for people with disabilities” and should be person centered. It should be assumed that all patients have quality of life. Additionally, awareness of and sensitivity to intersectional issues should be

included in protocols in general and specifically, LGBTQ issues with respect to mental health. The groups also discussed criteria necessary in ethics review protocols. The consensus was that ethics review protocols should be transparent and significantly consideration should be used when deciding how to weigh ethics principals.

Education and Information/ Resources Sharing

Protocols for healthcare provider education, according to the AADMD breakout session attendees, should require learning components that require disability related education across all healthcare specialties. Starting the education protocols at the residency level which include providing care to people with disabilities as a was discussed as way to mitigate diagnostic overshadowing. They also discussed the need for protocols to help reduce implicit bias. Another protocol consideration discussed related to information and resources sharing. Attendees thought that protocols for information and resource sharing should ensure that resources are balanced, complete, and quickly and easily accessible to healthcare providers.

Testing, Diagnosis Protocols, and Referrals

Discussions concerning testing were focused on prenatal genetic testing aspect and attendees stressed that testing should be offered instead of recommended and there should be no automatic termination of pregnancy. In the event that testing is an option for patient, protocols should require that patients be equipped with sufficient information about the test including the sensitivity and specificity. The attendees thought protocols for diagnosing patients should “clearly identify target issues/ behaviors”, call for standardized evaluations and data tracking, use a systemic outcome measures, require that healthcare professions remain aware of common areas of underdiagnosis within the disability community especially as it related to mental health and depression and anxiety diagnoses. Protocol considerations for referrals should include a simplified process that readily connects patients with the proper outlets and services. Additionally, attendees felt that protocols should include a process for grievances and second opinions when patients do not get the referrals they want, specifically in issues related to organ transplant.

Strategies for Addressing Implicit Bias, Diagnostic Overshadowing, and Policy Violations

Breakout session participants were asked to consider “How can the issues of a) implicit bias, b) diagnostic overshadowing and c) policy violations be addressed in a non-adversarial way?” Responses provided for this question discussed the elements that should be included in protocols, increasing education and simulation opportunities, and the need to boost public relations and community involvement.

Protocol Elements

Breakout session attendees discussed several elements that should be included in protocols that would aid in addressing bias, diagnostic overshadowing, and policy violations. One of the elements discussed was acknowledgement of uncertainty in protocols. Additionally, it was mentioned that protocols should provide families with complete, up to date, and accurate information which provides patients with the all the information necessary for them to make informed decisions about their healthcare. Other necessary elements mentioned were ensuring that protocols include fieldwork elements and “include psychosocial research to help give the full spectrum.” Another protocol element discussed was differential diagnosis and treatment which allows for individual centered care.

Develop Curriculum

According to the AADMD breakout session attendees, curriculum should be similar to antiracism trainings in the manner in which the topic of implicit bias is approached. The curriculum should address common biases, misconceptions, and paternalism. Additionally, curriculum should include discussions of marginalized communities, utilize appropriate language, include the patient’s perspective, and recognize individual perspectives. Breakout session attendees also suggested that curriculum should recognize that people with disabilities are capable of more than their appearance may suggest. Two tools were suggested, one was a simulated decision making tools used help healthcare professionals understand the role that a patient’s disability plays in the decision-making process and the other was a “nuanced set of

tools to allow us to tailor to individuals and families, that is both medical model and social model of disability.” The attendees mentioned that the curriculum should address both the healthcare professional and the patient. It was also mentioned that the curriculum should be a mandatory part of the continued medical education (CME) for healthcare professionals.

Boost Public Awareness and Community Involvement

The breakout session attendees discussed public awareness campaigns as a way to mitigate bias by welcoming new people to the community, partnering with existing disability organizations, and raising awareness of implicit biases. Increasing exposure was also discussed in terms of ambassador programs that connect people with families that have experience with specific disabilities, developing videos intended to unmask implicit bias, introducing the medical to the lived experiences of people with disabilities, and patient panels which allow medical students to gain an understanding of the impact a diagnosis can have on a patient’s life. Another consideration discussed was open discussions which include the physician perspective.

Strategies for Gaining Healthcare Provider Buy-in for Supported Medical Decision Making

The AADMD breakout session attendees were asked to provide comments to the question “What are the best strategies for getting physicians to adopt a model of supported medical decision making for patients with I/DD?” Breakout group participants believed that making protocols easily accessible and a normalized part of the healthcare professional work environment are effective ways to get healthcare professionals to adopt a model of medical decision making. In particular, it was mentioned that a model or algorithm needs to be consistent and embedded in continued medical education curriculum (CME) or a part of hospital medical documents and included in medical billing coding. Additional avenues discussed were to include supported medical decision-making information in journals, conferences, and other educational resources so as to increase understanding of the purpose and need for supported decision making.

Ways to Improve the Quantity and Quality of Medical Data

The last question the AADMD breakout session attendees were asked to provide feedback on was “How can we increase and improve the quantity and quality of medical data about people with I/DD?” Attendees pointed out the much consideration needs to be given to protocols governing the collection of patient information. One key issue discussed was protocols to code a patient’s disability similar to the manner other medical issues are coded. While that would be an efficient way to collect information about a patient’s disability status, attendees noted that it proves to be a complicated task in situations where patients do not want to be labeled. Another issue discussed was the way to address transition of care. This was discussed in terms patient’s transitioning from one healthcare professional to another but also in terms of transition from pediatric care to adult care. An online resource, Got Transition <https://www.gottransition.org/>, was offered to aid development of pediatric to adult care transition protocols. Patient history and physical (H&P) was also mentioned a way to improve data collection but protocols should require that all H&P information follow the patients and be included in patient files. An additional protocol consideration discussed related to this topic was a requirement to a sheet inpatient files to collect information about patient preferences and communication styles.

Appendix A: Gaps Highlighted Comment Tables

Table 1: Aging and End of Life Document Review – Gaps Highlighted Comments

GAPs Highlighted – CDHPD Partner Comments
<ul style="list-style-type: none"> No clear, robust understanding of aging trajectory among individuals with IDD - A need for cross-training exists among both residential staff and palliative care and hospice providers. - The voices of adults with IDD are largely absent; and the extent to which they perceive and have self-determination in their own lives at their end of life is not well understood.
<ul style="list-style-type: none"> Well-designed research overall about adults with ASD poorly trained mental health and primary care providers
<ul style="list-style-type: none"> The trajectories of change in cognitive and social functioning in ASD in old age remain un- known. It may be that declines will follow the pattern observed in TD older adults or that certain functions may be spared or continue to improve in ASD. Future studies using prospective, longitudinal methods are needed in order to identify the nature of age-related changes in behavior, cognition, and neurobiology.
<ul style="list-style-type: none"> References gaps in service/access created by provider bias/attitude as well as other issues of access due to inaccessible equipment.
<ul style="list-style-type: none"> Lack of experience and low levels of confidence among ID staff and palliative care staff in caring for individuals with ID during end-of-life and in providing adequate care; though partnerships in palliative care are promoted as a solution to improve quality health care access, the increase in significant clashes of professional interest can derail quality health care efforts - urge for policy makers to recognize and improve the understanding of partnerships to effectively develop successful partnerships to alleviate gaps in health care for individuals with ID.
<ul style="list-style-type: none"> Identifies characteristics of aging particular to individuals with Down syndrome with specific guidance around screening/identification of Alzheimer's disease
<ul style="list-style-type: none"> Inability of some adults with IDD to express wishes re: end-of-life care -inability of guardians and providers to mindfully plan for end-of-life care with person with IDD with communication challenges
<ul style="list-style-type: none"> Person with IDD was often not involved in the decision-making process around end of life care - no clear process for making decision - guidance needed - role of guardian vs. doctor vs. person with IDD - lack of clarity

<ul style="list-style-type: none"> • Review of aging-related changes and age-associated health risk factors that identified some health-related conditions that accrue to older adults, establishing a bit of an evidence-base. however, more work is needed to address the gaps in knowledge about health risk and wellness factors related to adults with ID.
<ul style="list-style-type: none"> • Major gaps relate to health disparities due to underdiagnosis, misdiagnosis, less chance of receiving prompt treatment, limited access to providers, lack of research information, transportation barriers, and lack of accessible medical equipment.
<ul style="list-style-type: none"> • Factors contributing to health disparities experienced by aging adults with IDD: lack of research on aging with IDD, the lack of education/experience of primary care providers with this population, ageism, diagnostic overshadowing -Recommendations for nurses and clinicians in addressing these issues
<ul style="list-style-type: none"> • Addresses lack of resources for helping those with IDD to express loss or grief.
<ul style="list-style-type: none"> • The nature of quality-of-life judgments are often cited by healthcare providers as less subjective than science/disability community believes them to be. Little education or training in disability competency among healthcare providers. Many healthcare providers undervalue life with a disability. Physicians can't agree on the diagnosis of persistent vegetative state. Internal ethics committees are not an ideal forum. Lack of transparency in hospitals. All states have at least one law related to medical futility.
<ul style="list-style-type: none"> • Access to palliative care, issues related to consent
<ul style="list-style-type: none"> • "False assumptions about patients' quality of life can affect prognosis, the treatment options that we present, and the types of referrals that we offer. In this case, the physician equated complex disability with terminal illness. This common confusion can result in premature withdrawal of life-preserving care. Disability is not a disease. Persons with physical, mental, and cognitive disabilities can and do live rich, full lives. They are often healthy, even if they need support for basic activities of daily living. If well managed, secondary conditions such as aspiration, pressure sores, and osteoporosis can be prevented or minimized. With appropriate services and accommodations, persons with disabilities can make decisions, have relationships, and contribute to their community. This outcome is more likely when they are welcomed, supported, and valued. Despite a high prevalence of chronic medical conditions, the life expectancy of persons with developmental disabilities approaches that of the general population."
<ul style="list-style-type: none"> • Although we included representatives from many areas of the autism community, we were not able to directly include any autistic people currently living in residential care, although we hope that through this work their experiences will be centered in future research. In addition, we did not include the direct perspectives of autistic adults with high support needs (e.g., intellectual disability and communication difficulties) although these perspectives were conveyed by proxy representatives such as siblings and specialist service providers.

- | |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <ul style="list-style-type: none">• Eliciting information about a person's own end of life care wishes -determining capacity resolving disagreements around end of life decisions-supporting someone through end of life, particularly to age in place |
| <ul style="list-style-type: none">• Individuals with IDD are often not included in the usual conversations, cultural rituals, and other means of acknowledgement of grief and loss. |
| <ul style="list-style-type: none">• Death is a part of life. Too often death is a taboo in our society, and people avoid talking about or planning for it. This taboo is even more obvious when people with intellectual disability are part of these conversations. People with intellectual disability should learn about dying and death just as they learn about every other aspect of life. |
| <ul style="list-style-type: none">• Documentation of hospice care among older individuals with ID is incomplete and differs on the variables assessed. Although there are distinct barriers to hospice care in the general population, those barriers are even greater for those with ID. -Policies pertaining to hospice differ and there are misunderstandings about interpretation of those policies. |
| <ul style="list-style-type: none">• The number of research studies dedicated to investigating the physical health of autistic adults remains in the low single figures.⁴ This handful of studies has been conducted solely in the United States and has primarily relied on reviewing the health records of autistic people—a method the researchers acknowledge as having severe limitations. |

Table 2: Life-Saving Treatment (Organ Transplant) Document Review – Gaps Highlighted Comments

GAPs Highlighted – CDHPD Partner Comments
<ul style="list-style-type: none"> Wightman identifies that there are significant ethical considerations surrounding whether to transplant hearts into patients with intellectual disabilities, and that in the past ID was considered an absolute contraindication to transplant.
<ul style="list-style-type: none"> Discrimination in some states for organ transplantation for people with disabilities
<ul style="list-style-type: none"> has good strategies to encourage medication compliance and identification of pain.
<ul style="list-style-type: none"> No particular gaps are identified.
<ul style="list-style-type: none"> The entire structure of what happened to Lief and his Mom is a gap, but an additional gap is the fact that Lief wasn't told about the LVAD therapy, referred to as a "bridge therapy" in the article. It is highly likely people with disabilities elsewhere are not being properly informed of their options.
<ul style="list-style-type: none"> Real example of an individual with autism that has been rejected from a life-saving transplant for no apparent good medical reason.
<ul style="list-style-type: none"> The assumption that people with disabilities will not be able to comply with postoperative care has caused disability to be considered a contraindication to organ transplant at many transplant centers despite the fact that people with disabilities, when provided with necessary supports, are no less likely to comply than people without disabilities.
<ul style="list-style-type: none"> Disability-related policies vary greatly across transplant centers and across categories of disability. ADA and 504 are rarely invoked in this context due to time-sensitive nature of organ transplant decisions (medical time vs. legal time) The assumption that people with disabilities will not be able to comply with postoperative care has caused disability to be considered a contraindication to organ transplant. The ethical complexity of the shortage of organs and questions related to quality of life as measured in people with disabilities
<ul style="list-style-type: none"> The need for legislation to make sure that individuals with disabilities have equal rights to organ transplants in every state.

<ul style="list-style-type: none"> It is notable that the guidelines outright state that individuals with I/DD who have "severe cognitive-behavioral disabilities" or individuals who have "self-injurious behavior" or "the inability to ever understand and comply with medical care" should not receive heart transplants. The implication is that such individuals are per-se ineligible even with a sufficient support system! This gap relates to provider attitudes towards individuals with intellectual disabilities. Notably, there is a paragraph afterwards which does state: "It has been argued that patients with intellectual disability who have adequate social support may be deemed reasonable transplant candidates provided there are not any other contraindications after the full candidate evaluation." While this is more consistent with our opinions, this line is not in the recommendation, but rather in its explanation.
<ul style="list-style-type: none"> (1). Organ transplant centers' high discretion when deciding which patients, they will recommend to the national waiting list. (2). Physician discretion and its conflicts with the ADA. (3). The article highlights several specific, high-profile instances of organ transplant discrimination.
<ul style="list-style-type: none"> The entirely informal decision-making process used to recommend patients to the national waiting list is one gap. The consideration of I/DD as important to such decisions may be another, at least so far as it is based on a cutoff IQ score as a contraindication or a quality-of-life judgment. The article explicitly describes the former as a problem.
<ul style="list-style-type: none"> High discretion possessed by organ transplant centers when recommending patients to the waiting list. The ambiguity on whether and how the ADA and Section 504 apply to transplant listing decisions. Lack of substantive guidance directly addressing the issue from UNOS/OPTN. Children are being denied organ transplants because they have an intellectual disability.
<ul style="list-style-type: none"> The vast majority of liver transplant providers see merely having ID with high support needs or low recorded IQ as a contraindication to transplant. This means that it will be very hard for these individuals to get liver transplants.
<ul style="list-style-type: none"> The denial of a kidney transplant purely on the basis of an intellectual disability is a definite gap evidenced in the document. An additional barrier highlighted by the article is the high discretion that transplant centers possess, and the lack of transparency with request to the decisions they make. They claimed that Ms. Cargill's doctors said she lacked capacity, but neither doctor remembers saying this, for example.
<ul style="list-style-type: none"> None. The very existence of this law represents a gap - the lack of a legal prohibition against organ transplant discrimination - that has been rectified.
<ul style="list-style-type: none"> Gaps Highlight: barriers in organ donation experienced by individuals with NDD: physician referrals, center-specific decision making regarding wait-listing, accommodations for optimizing the assessment and medical management suggestions: More data/ greater transparency to understand access problems, changes at the individual provider level, regional transplant center level, and national level

- | |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <ul style="list-style-type: none">• Inconsistencies across centers lack of consideration of ADAPTIVE FUNCTIONING
conflicting priorities: high transplant success rate vs. negative media from discrimination
inconsistencies in using DD as social criterion vs. medical criterion |
| <ul style="list-style-type: none">• Many states do not have organ discrimination (or other life-saving procedure) laws.
For those that do, some of the laws are not comprehensive enough to prevent all
discrimination. |
| <ul style="list-style-type: none">• The nature of quality-of-life judgments are often cited by healthcare providers as less
subjective than science/disability community believes them to be. Little education or
training in disability competency among healthcare providers. Many healthcare providers
undervalue life with a disability. Physicians can't agree on the diagnosis of persistent
vegetative state. Internal ethics committees are not an ideal forum. Lack of transparency
in hospitals. All states have at least one law related to medical futility. |
| <ul style="list-style-type: none">• Gaps Highlighted: Health care disparities experienced by individuals with ID - high rates
of undiagnosed health conditions, exclusion in organ transplantation, lack of adequate
mental health services. Solutions discussed - policy changes, education/training among
health care providers, health care promotion |

Table 3: Mental Health and Suicide Prevention Document Review – Gaps Highlighted Comments

GAPs Highlighted – CDHPD Partner Comments
<ul style="list-style-type: none"> • Insurers have denied expensive, life-sustaining medical treatments but offered lethal drugs. Misdiagnoses of terminal disease can also cause frightened patients to hasten their deaths. People with the disability of depression are subject to harm where assisted suicide is legal.
<ul style="list-style-type: none"> • Four overarching challenges are presented: (1) what to call this subspecialty; (2) an inadequately trained mental health workforce with little motivation to work in this population; (3) establishing meaningful psychiatric diagnoses and developing nuanced mental health outcome measures; and (4) the systematic exclusion of people with low IQs in psychiatric research programs and clinical trials.
<ul style="list-style-type: none"> • Compared with adults without CP, those with CP have an elevated prevalence of mental health disorders, some of which may be more pronounced in patients with comorbid neurodevelopmental disorders. In the United States, care coordination and health care access are woefully inadequate to meet the complex lifelong health care needs of persons with pediatric-onset disabilities (including CP). This can lead to missed opportunities to properly diagnose and treat preventable noncommunicable diseases, such as mental health disorders. Even before the fourth decade of life, adults with CP have a prevalence of chronic diseases and a multimorbidity profile that is more than 4 times greater than those without CP.
<ul style="list-style-type: none"> • There are several major gaps identified: (1) Poor communication between the I/DD and MH service systems; (2) lack of doctors competent to treat dually diagnosed individuals on either I/DD or MH needs; (3) lack of social and peer supports available either to people with ID or their caregivers.
<ul style="list-style-type: none"> • The high risk of suicide among autistic people is a notable gap.
<ul style="list-style-type: none"> • Over the past five years, the suicide rates in autistic people - particularly women - have massively jumped up, particularly in Utah.
<ul style="list-style-type: none"> • Fragmented systems for serving people with IDD and systems serving people with behavioral health needs
<ul style="list-style-type: none"> • Diagnostic overshadowing (seeing mental health issues as inherent characteristics of IDD), higher rates of co-occurring mental health conditions among people with IDD, diagnostic challenges, lack of graduate preparation/training for psychologists

<ul style="list-style-type: none"> • There were no suicidality screening measures in 2012 specifically designed for people with I/DD. People with I/DD are more likely to have mental health disabilities - a risk factor for suicide - but less likely to actually be diagnosed with them or to have suicidal thoughts and behaviors detected as a result. Questionnaires and tests which screen for suicidal ideation in adolescence were largely not cognitively accessible to people with ID.
<ul style="list-style-type: none"> • Gaps in health care of individuals with dual diagnosis (DD): lack of awareness of DD among health care professionals and caregivers, negative attitudes of professionals towards individuals with DD, and lack of training of professionals in DD - all of which contribute to poor health outcomes for individuals with DD.
<ul style="list-style-type: none"> • Gaps Highlighted - barriers and enablers in accessing mental health services for individuals with ID within the following domains: utilization of services; service availability; relevance, effectiveness, and access; and equity and access.
<ul style="list-style-type: none"> • Adults with ASD are at an increased risk for suicidal ideation. "The finding that appraisal and belonging support may be less beneficial in terms of improving mental health outcomes in this population when compared to typical or other groups has practical implications for social support programs. These results suggest that it is vital to consider the needs of individuals with ASD, and what he or she perceives to be important, when developing or recommending particular support programs"
<ul style="list-style-type: none"> • Real lack of research investigating this idea, screening/identification of risk: no tools, providers need training!
<ul style="list-style-type: none"> • Gaps in mental health care services for persons with ID by examining the perspectives of both psychologists in the adult mental health field and those in the learning disability service field. issues discussed by psychologists in adult mental health care field: resistance to change; lack of confidence in ability to treat ID population; service restrictions, issues discussed by psychologists in learning disability service field: pessimism; diagnostic overshadowing, recommendations: additional training; system integration; recommendation 56 of the Bamford Review and Action Plan; The Green Light Toolkit usage; further consideration of challenges experienced by persons with ID.
<ul style="list-style-type: none"> • Differences in psychiatric disorders present in persons with DS compared to persons with ID
<ul style="list-style-type: none"> • Gaps Highlighted: Health care disparities experienced by individuals with ID - high rates of undiagnosed health conditions, exclusion in organ transplantation, lack of adequate mental health services. Solutions discussed - policy changes, education/training among health care providers, health care promotion

Table 4: Prenatal Genetic Testing Document Review – Gaps Highlighted Comments

GAPs Highlighted – CDHPD Partner Comments
<ul style="list-style-type: none"> The gap identified here is clearly related to historical and present-day ableism. Babies with Down Syndrome are "screened out" before they are born because of a lack of resources available to parents and systemic ableism. The authors do not wish to ban prenatal testing, but point out that testing for DS in the first place amounts to a statement that the lives of people with DS are "unworthy," and that in the face of societal pressure the "choice" about whether to abort the child is not really a choice at all. Should our recommendations possibly argue for requiring that positive information be given during prenatal testing for DS?
<ul style="list-style-type: none"> Discusses that research shows families want life outcomes about disabilities but among patients who learned about their child’s diagnosis of Down syndrome postnatally, 24% reported a negative experience while only 4% reported a positive experience. “This profound disparity between patient experiences clearly illustrates a gap between what is being communicated by clinicians about genomic medicine and what patients want to learn. (9)” This article talks about the evolving outcomes for people with disabilities based on access to supports and services and how medical professionals need resources that help them stay abreast of new information to provide an equitable view of disability and meet the informational needs of families. “Clinicians who do not provide accurate, up-to-date, and balanced information following a prenatal or postnatal diagnosis of Down syndrome and who focus exclusively on the genomic outcomes and medical issues run the risk of leaving parents feeling anxious and frightened. In contrast, if clinicians provide a full spectrum of information, patients likely still will undergo an adjustment process and some degree of grief, but they can make the transition to their new lives more smoothly and positively through immediate access to support and balanced information. (46)”
<ul style="list-style-type: none"> FUNDING LIMITATIONS LACK OF CONSISTENTLY IMPLEMENTED STANDARDS DIVERSE PERSPECTIVES AND QUESTIONS ABOUT NEUTRALITY LACK OF ACCESS TO TRAINING AND GENETIC COUNSELORS. Overall, members of the patient advocacy community have expressed appreciation that some cfDNA companies refer customers to PAGs, particularly after a screen-positive result; however, the success of these companies has driven more referrals and increasing workloads for PAGs without providing the needed financial support or other resources to meet this demand. A few cfDNA laboratories have allocated small amounts of funding, mostly for distribution agreements for educational materials. We maintain, however, that cooperative efforts should be undertaken to ensure that all patients who are offered cfDNA screening receive up-to-date and accurate information about screened genetic conditions and that patients receive consistent amounts and types of information, regardless of which laboratory’s test they use. Such a cooperative effort might take several forms: a suggestion emerged from the Stakeholders Symposium that a clearing- house organization might be developed to receive funds from multiple testing companies and distribute them to individual organizations and/or multi-organization collaborative efforts to support and inform

expectant parents. Patient advocacy organizations serve a vital role in providing support, community, and condition-specific information for families with a pregnancy affected by a genetic condition. As PAGs are on the front lines of actual patient experiences with cfDNA screening results and variably implemented screening protocols, all stakeholders would benefit from the inclusion of these groups in discussions about the most effective and ethical ways to implement this new technology. In order to facilitate informed and values-appropriate decision-making, we urgently need to bring all stakeholders together to discuss how best to ensure appropriate use of cfDNA screening and provide the requisite support services for parents who receive screen-positive results. As we continue to strategize the best ways to support families and PAGs impacted by cfDNA screening, we welcome and invite collaborations and connections with others engaged in this work from all sectors and encourage future efforts that will continue this dialogue between PAGs and other stakeholders.

- Resource needs to be updated, and references for expectant parents opting for termination are more than 25 years old and contain outdated information about genetic conditions. Overall, this resource serves as a template for what other medical and genetics organizations could be doing to equitably convey information about genetic conditions and available resources.

- It is possible to provide a balanced understanding of what it means medically and socially to have a child with a genetic condition, and what it means to live with a disability in the context of prenatal genetic testing. The necessity for doing so arises from the continued existence of deeply rooted social stereotypes and ongoing prejudice about disability, within and without the medical community. This paper's case study provides one example of how balanced, current medical and social education about disability can be achieved through provider and parent education. [Our Lettercase resources are the case study provided.] Unfortunately, there are no or exceedingly few incentives to promote such a balanced understanding in the current world of prenatal genetic testing. By extension, there are also few incentives to incorporate a disability rights viewpoint or understanding in the dawning world of prenatal genetic engineering, the first inheritable human incident of which made headlines all over the world at the end of 2018 when a scientist in China attempted germline editing on twin girl embryos to create resistance to HIV/AIDS, legally and socially recognized as a disability in the United States. From early manifestations of prenatal genetic testing in conjunction with preimplantation genetic diagnosis (PGD) to the latest NIPS tests, the impacts have been felt within disability communities, and are simultaneously difficult to trace given limited data collection on testing outcomes. Healthcare providers involved in prenatal genetic screening and diagnosis have little time to provide in-depth counseling about the tests and the outcome of those tests. Genetic counselors, who would typically stand on the front lines of providing sufficient relevant information to facilitate informed reproductive choices for women, are subject to few requirements when it comes to disability cultural or social awareness and are increasingly being potentially co-opted into the commercial genetic testing industry when they are directly hired by the industry. Prenatal and adult genetic testing laboratories have exploded in terms of number and profitability in the

United States, with very little regulation or oversight beyond the Centers for Medicare and Medicaid Services (CMS) ensuring that the laboratories function properly and the tests correctly measure the DNA components claimed. Over the last 10 years, industry has achieved technical leaps and bounds, developed sophisticated direct-to-market advertising materials and informational websites, and even coalesced into a lobbying arm that works with states to get Medicaid reimbursement for prenatal genetic testing. Genetic counseling, however, which is becoming more and more necessary as women and their partners receive commensurately greater amounts of unmediated test results, remains unrecognized by CMS as a profession that can independently bill, or that state Medicaid agencies will independently cover as “medically necessary.” The federal PPDCAA is one attempt to ensure that providers and parents receive current information about living with genetic conditions and available supports, but the act is unfunded. Nineteen states have enacted similar legislation, though these vary in sometimes important details. Anti-abortion groups could target these information-oriented laws and propose amendments that create barriers for termination of a pregnancy after a prenatal diagnosis of Down syndrome or another genetic condition. Most of these acts have no provision for data gathering after their implementation, so it is difficult to know if and how effective they have been since enactment, even if there were baseline data available for comparison. Unlike prenatal genetic testing, genetic information concerning adults is a more regulated area. The ADA and GINA have been used to address workplace discrimination based on individuals’ genetic information. While GINA has often been dismissed as responding to a nonexistent problem of discrimination based on genetic information, studies have repeatedly shown that such discrimination is not uncommon. The ADA has limited application to this type of discrimination, as an individual who may develop a genetic condition may not always meet the definition of a person with a disability protected by federal anti-discrimination laws. GINA, which addresses discrimination more directly, has been invoked in a relatively small number of circumstances to challenge adverse action taken by employers on the basis of employees’ or job applicants’ genetic information. GINA has been widely used, however, to address employees’ ability to keep their genetic information private or confidential from their employers. In an era where employers are increasingly seeking to make use of “big data,” those protections ensuring privacy of employees’ genetic information are important. Indeed, workplace wellness programs have increasingly been used as a way to collect employees’ health and genetic information. The ADA and GINA protect against the use of financial inducements to pressure employees to disclose such information, but in the past several years, Congress and federal agencies have made efforts to weaken those protections and allow large financial penalties for employees who choose not to provide that information. Those efforts have not been successful to date, leaving at least for now, the protections of the ADA and GINA in place. While state laws addressing genetic discrimination in the workplace are typically less protective than GINA, a state law proposal being considered by the California legislature has clear statutory language banning the use of financial inducements for employees to disclose health or genetic information in workplace wellness programs, and it may offer a useful model for states attempting to make their laws as clear as possible while maximizing protection for the confidentiality of genetic and health information in workplace wellness programs. Key

Recommendations Congress

- Develop enforceable Sunshine and Conflict-of-Interest laws that will bring transparency to any financial relationships among genetic counselors, providers, and commercial laboratories.
- Fund the Prenatally and Postnatally Diagnosed Conditions Awareness Act, Pub. L. No. 110-374, 122 Stat. 4051 (2008).
- Incentivize the development of educational units on disability experience and exposure in genetic counselor education. Department of Health and Human Services (HHS), National Institutes of Health
- Establish standing relationships with disability advocacy organizations and include individuals from them on genetic advisory panels.
- Encourage the attendance of advocates and representatives from disability communities at biomedical conferences by offering scholarships that reduce or cover fees and expenses. HHS, Food and Drug Administration
- End enforcement discretion and regulate LDTs, specifically, Noninvasive Prenatal Screening (NIPS), to establish and enforce standards for the accuracy of any claims made by prenatal genetic testing entities, and proactively work with the Federal Trade Commission to oversee marketing by genetic testing entities. HHS, Centers for Medicare, and Medicaid Services
- Recognize genetic counselors as health professionals who can receive reimbursement through Medicare and incentivize Medicaid payments for genetic counseling as an independent healthcare service rather than only reimbursing genetic testing. Federal Trade Commission
- Actively oversee the marketing claims and practices of prenatal genetic testing companies as more tests with questionable clinical validity and utility enter the market as part of the “standard” testing panels that companies offer. Equal Employment Opportunity Commission
- Leave wellness rules as they are now (May 2019) or, if EEOC does revise them, the agency should clarify that no financial incentives or penalties are permitted to induce employees to disclose health and genetic information. State Legislatures
- If genetic testing, and especially NIPS, is funded as a Medicaid service, the state should also ensure Medicaid funding for neutral genetic counseling before and after testing takes place.
- Where state Medicaid programs cover prenatal genetic testing, the state should ensure that it collects voluntarily provided information on patient demographics, including disability status, outcomes, and the quality of genetic counseling received before the testing, if any. This information will allow states and researchers to assess the use and results of prenatal genetic testing as a publicly insured service over time.
- Should consider enacting legislation, like that pending in California, that clarifies that no financial inducements are allowed for participating in or providing data to a workplace wellness program. Professional Organizations and Training Accreditation Bodies of Healthcare Providers Engaged in Genetic Counseling such as the Genetics Society of America (GSA); American College of Medical Genetics (ACMG); American Board of Medical Genetics (ABMG); American Board of Genetic Counselors (ABGC); and the Association of Professors of Human and Medical Genetics (APHMG)
- Clarify that disability education and cultural awareness extends beyond examining best practices for effectively communicating with patients with disabilities and includes a social and civil rights context for understanding disability.
- Ensure that the materials used for provider and patient education are passed through a consensus group of reimbursed stakeholders, including representatives from affected disability communities, to minimize the outsized influence of industry and investors in prenatal genetic testing.
- Professional standards of care for offering NIPS and other prenatal genetic tests should be

established through consensus negotiations that include genetic counselors, obstetrics and gynecology care providers, and representatives from affected disability communities. Genetic testing entities should not be allowed to market or provide specific genetic tests that have not been vetted through a professional organization using a consensus process.

- Ensure that online and printed materials used for provider and patient education are fully communication accessible to people with a range of disabilities and diverse linguistic and cultural backgrounds.
- The Accreditation Council for Genetic Counselling (ACGC) must make disability education and cultural awareness mandatory and more consistent among genetic counselor programs, within a reasonable range of time and resources. The same holds true of professional ongoing education.
- Genetic Testing Researchers
- Propose ways to achieve better data over time to determine the link between prenatal testing outcomes and various factors in the field of genetic testing such as counseling, cultural conditions, social expectations, and social determinants of health for particular disability communities.
- Research the relationship between women's choices after receiving pre-test counseling and after undergoing genetic testing, and how choices are affected by the kinds of genetic counseling information provided, who delivers it, and who is paying for the counseling.

- Only provides medical model of disability. Does not provide relative strengths or social support and services. "Down syndrome is the most common form of inherited intellectual disability, with approximately 6,000 affected infants born in the United States each year. It is estimated that 95% of cases of Down syndrome result from nondisjunction involving chromosome 21. The remaining cases result from translocations or somatic mosaicism (2). Although the clinical presentation of Down syndrome can vary, it is associated with characteristic facial features, learning disabilities, congenital heart defects (e.g., atrioventricular canal defects), intestinal atresia, seizures, childhood leukemia, and early onset Alzheimer disease. Fetuses affected with Down syndrome often do not survive pregnancy; between the first trimester and full term, an estimated 43% of pregnancies end in miscarriage or stillbirth (3). In economically developed countries, the median survival of individuals with Down syndrome is now almost 60 years (4). Factors associated with an increased risk of Down syndrome include higher maternal age, a parental translocation involving chromosome 21, a previous child with a trisomy, significant ultrasonographic findings, and a positive screening test result. After a prenatal diagnosis is made, prenatal assessment cannot predict the severity of the complications from Down syndrome." Recommendations for counseling and education are limited primarily to accurate information about testing and pregnancy options without any instructions for clinicians about the provision of condition-specific information or consideration for people with disabilities as marginalized populations. Moreover, no studies are cited about the information needs of families regarding the conditions; no accurate, balanced, or up-to-date resources are recommended as resources for clinicians; and no people with disabilities or their families are listed as being consulted in the development of these guidelines. "The intent of counseling for aneuploidy is to inform the pregnant woman about chromosomal disorders, provide information regarding her specific risk of carrying a fetus with aneuploidy, and review the available options so that she can make an informed choice regarding screening or diagnostic testing. After review and

discussion, every patient has the right to pursue or decline screening or diagnostic testing. Pretest and post- test counseling are essential and must be a part of any screening program. When a positive or negative screening test result is obtained, the patient should be counseled regarding the adjusted likelihood of carrying a fetus with the evaluated aneuploidies. The potential for the fetus to be affected by genetic disorders that are not evaluated by the screening or diagnostic test should be reviewed. In the event that a prenatal diagnosis of fetal aneuploidy is made, the patient must be counseled appropriately so that she can make informed decisions regarding pregnancy management. Counseling should include family education and preparedness as well as options regarding adoption, pregnancy termination, referral to a tertiary care center for delivery of the newborn if needed, and perinatal hospice care as appropriate for a child with a condition that is incompatible with life. Patients found to have a fetus with a chromosomal abnormality often benefit from referral to genetics professional for further detailed counseling.”

- In the assessment of women’s knowledge about Down syndrome, the study noted their knowledge was limited in some areas related to life expectancy, infantilization ideation, stereotypical traits, adult life, and prevalence in different ethnicities. Women also worried about the impact of a child with Down syndrome on family life and would have benefitted from education about life outcome information and psychosocial research. Women expressed that prior to testing, they wanted information about life outcomes, medical issues, birth prevalence, misperceptions, etc. about Down syndrome. This type of information is not cited by the medical organizations as information that should be included in posttest counseling, but women did express they wanted that information to be provided. Women expressed that following testing, they wanted more information on supports and services, life outcomes, development, and photos of people living with Down syndrome. This corresponds with the post-test recommendations of ACMG and NSGC and also the preferences expressed by families the research by Sheets et al. Women want access to printed and online information about Down syndrome and multi-media representations. “Findings from our study parallel the contents of a booklet that was recently developed for parents who receive a diagnosis of DS (www.lettercase.org). The booklet includes clinical information about DS, information about families with a child with DS, the degree of medical complications, resources for parents, among many other topics. The booklet also contains many photographs of children with DS engaging in everyday activities.”
- The document is helpful in actually stating that condition-specific education should be part of post-test counseling and naming examples of resources: “Accurate, up-to-date, and balanced information about Down syndrome (or other tested conditions) should be provided. There are a number of resources available (see Resources).” However, the document does not indicate who is responsible for the provision of this information: the clinician. the testing lab, advocacy organizations Some evidence of discrimination still exists in the connotation of the language used in this document: “risk,” “abnormality” In addition, pre-test counseling would also ideally include a discussion of the conditions for which the patient is being tested within the broader framework of disability rights.

- Current recommendations say that women should be offered testing and that it should be choice. However, in a society where 80-85% percent of women undergo testing-- are women actually being counseled about choice prior to testing and does not inertia of society lead to decisions that women might not otherwise make in isolation. The information in this article is somewhat misleading because it says only 2-3 babies with Down syndrome born in Iceland each year, but the population would only normally be expected to produce 7 people with Down syndrome per year if all babies were born. The doctor quoted, "We don't look at abortion as a murder. We look at it as a thing that we ended. We ended a possible life that may have had a huge complication... preventing suffering for the child and for the family. And I think that is more right than seeing it as a murder -- that's so black and white. Life isn't black and white. Life is grey." Research by Skotko et al. shows that people with Down syndrome do not live a life of suffering, so some of the variables impacting prenatal decisions may be based on implicit bias based on misperceptions about life with DS.

- Since the inception of prenatal testing for Down syndrome, concerns have been raised over whether it is ethically administered to respect a woman's autonomy and that it discriminates against those with the tested-for condition. Studies have reported negative experiences of mothers with how their medical professional delivered the diagnosis of Down syndrome. At the same time, prenatal testing has continued to evolve to allow earlier, more accurate assessments of a mother's likelihood for having a child with Down syndrome. In the face of these developments and the persistent challenge of having medical professionals fully follow the professional guidelines concerning prenatal testing, Down syndrome advocates have been introducing state measures called the Down Syndrome Information Act (DSIA). With each passing year since 2012, more and more states are enacting their versions of the DSIA with various levels of implementation. Future DSIA's can be expected given the broad bipartisan support and near unanimous passage the law has received no matter the politics of the given state. Going forward, implementation will increase, and more mothers can be assured of receiving the full information recommended to accompany a prenatal test result for Down syndrome, should states provide funding and the responsible agencies recognize the resources recommended by professional guidelines. Keeping abortion politics out of the DSIA will ensure it stays true to its inception as not a pro-life or a pro-choice policy measure, but a pro-information law. Expectant mothers accepting prenatal testing are seeking information. The DSIA's intent is to ensure they receive the recommended information about Down syndrome and available support resources.

- 35% of parents with a prenatal diagnosis reported a negative experience with their medical provider while only 11% reported a positive experience. 48% of parents with a prenatal diagnosis reported that other resources/supports were positive while only 9% reported those resources/supports were negative. though participants were not directly asked to describe their experiences with medical professionals, this was a primary theme reported by the participants. Participants in both groups reported both negative and positive experiences with their medical professionals; however, the negative experiences outnumber positive experiences 2.5 to 1. In the prenatal group, 35% (n 5 16) indicated

negative experiences. The reasons for the negative perceptions included: the medical professionals' insistence on terminating the pregnancies (n 5 11), the perpetuation of negative stereotypes of individuals with DS (n 5 7), the lack of information about DS provided by the medical professionals (n 5 5), and the perceived lack of compassion exhibited by the medical professionals (n 5 4). Fewer participants in both groups reported positive experiences with medical professionals. In the prenatal group, 11% (n 5 5) of participants described positive experiences with medical professionals; two participants expressed their experience as positive because the professionals discussed other options besides termination of the pregnancy, and one participant described how the medical professionals provided resources immediately after the diagnosis.

- Very few labs adhere to the guidelines for providing patient and provider education, and those who do are very limited in what they provide.

- Points out that prenatal screening itself may concern the disability community because the motivation for screening is often rooted in fear of disability, and there is no research yet showing that prenatal knowledge “improves medical, developmental, emotional, or adaptational outcomes. With a few exceptions, people with disabilities and their families usually do not derive direct benefit from prenatal testing.” The article also points out that there are disparities in access to screening and care by people of different socioeconomic backgrounds and that increased screening should also be accompanied by increased access to medical and support services for children with genetic conditions and their families. “The prenatal screening engine is fueled primarily by parents’ worries about having children with disabilities, a fuel that is economically cost-effective [Caughey et al., 2010]. Fear of disability runs deep and is difficult to uproot. Although some parents may undergo prenatal screening for emotional and medical preparation for the birth of their child, especially with Down syndrome there is very little empirical evidence that prenatal knowledge improves medical, developmental, emotional, or adaptational outcomes. With a few exceptions, people with disabilities and their families usually do not derive direct benefit from prenatal testing. Why should they favor it, other than on broader principles of reproductive freedom? Madeo et al. make some suggestions to encourage rapprochement between genetic counselors and people with disabilities, their families, and their advocates. I would add to their list that if we claim that prenatal knowledge of disability results in better outcomes then we are obliged to conduct studies to prove that assertion. Parents are putting a pregnancy at risk (albeit small) by undergoing amniocentesis or CVS; we must provide them with compelling justification to take that risk.” “Precisely the families that have the fewest social and economic resources to deal with disability are bearing the greatest proportion of children with developmental and physical conditions. This is an opportunity for genetic counselors and disability advocates to work together to investigate this phenomenon and to help assure that appropriate medical and support services are available for these children and their families.”

- The HRSA report discusses that the federal government has yet to provide funding for the development of educational materials about NIPS and genetic conditions and relies on health professional organizations, industry, and advocacy organizations to provide resources and education. However, the government has provided funding for the development of testing. There is a need for pre-test counseling so that women understand it's optional and what conditions are included in the screening panel, and obstetric medical providers need more training and resources to meet the needs of patients. The report also highlights that there are not enough genetic counselors who are equally accessible across the country geographically, and CMS does not recognize GCs as providers. Information about tests and conditions should be available to patients in multiple mediums based on their needs, health literacy, language, and cultural preferences. Professional organizations should provide standardized processes, like online training with sustainable and dynamic dissemination strategies. Patient education materials about conditions should be developed with input from multiple stakeholders including medical organizations and advocacy organizations. Provider education about prenatal screening needs to include input from an advisory committee that includes advocacy organizations and families. Educational resources for providers should include outreach through family groups, advocacy groups and community groups in multiple mediums. Educational materials about conditions should be available in multiple mediums, free to patients, and disseminated by all stakeholders, including health care providers, professional organizations, community service providers, family groups, advocacy groups, labs, and other. Federal roles could include mechanisms to provide condition-specific education, mechanisms to facilitate collaboration and coordination between stakeholders to recognize genetic counselors as service providers; health care provider and patient education and training; and research on the best ways to provide information and education about prenatal screening and conditions.
- This article highlights the tension in the genetic counseling profession (which could be extended to other medical disciplines) between “represent[ing] and advocat[ing] for the rights and opportunities of those affected by disabling conditions on the one hand; and offer[ing] parents reproductive opportunities to avoid having children with disabilities on the other.” Genetic counselors strive to be unbiased and non-directive, but the authors question whether that is possible when the profession is also tied very closely to reproductive rights. The authors also cite studies (10-20 years old) that show genetic counselors did not have a strong connection to the disability community and viewed information as overly positive about disabilities as compared to families who felt the information was accurate. Similarly, the authors cited studies (10-15 years old) that showed genetic counselors were more likely to discuss the medical issues associated with Down syndrome than the social and life outcomes, and they were much more like to mention pregnancy termination as an option following a prenatal diagnosis than continuing the pregnancy or adoption. Moreover, the authors indicate that genetic counselors may experience unconscious bias toward people with disabilities like the rest of society. Other gaps identified are that NSGC, the professional society representing genetic counselors, has an imbalance in funding received by abortion clinics as compared to advocacy groups; has a tendency to take public stands regarding abortion

rights and not disability rights; and does not provide leadership for disability education issues. The authors suggest the following solution to bridge the divide between the disability and genetic counseling communities: 1. Genetic counselors should examine their own conscious and unconscious biases about people with disabilities. 2. Genetic counselors should build genuine relationships with the disability community. 3. GC student programs should recruit people with disabilities and family members; people with disabilities and families should be incorporated into the education and training of GCs; and disability studies should be incorporated into the curricula; and programs should develop measurable outcomes to evaluate methods. 4. NSGC should be a leader in facilitating meeting between the genetic counseling community and disability organizations; The Journal of Genetic Counseling should highlight disability issues, and competencies in disability rights should be built into board certification and curricula. 5. Improve research on the attitudes of genetic counselors regarding disabilities and the needs of individuals and families receiving a diagnosis. Quote from Pat Bauer cited in article: Recent high profile mainstream media articles have included individual's descriptions of feeling judged as a direct result of the availability of prenatal testing that could lead to the termination of a fetus with disabilities (e.g., "Whenever I'm out with Margaret, I'm conscious that she represents a group whose ranks are shrinking because of the wide availability of prenatal testing and abortion [Bauer, 2005]." "Those who escape the net of screening are often viewed as mistakes or burdens. A tragic choice becomes a presumption— "Didn't you get an amnio?"—and then a prejudice [Gerson, 2008].") [Will, 2007].

- The response to the Madeo commentary highlights efforts by NSGC to build relationships with the advocacy community that were not recognized in the first commentary: including developing a position statement on disability and a position statement on reproductive freedom; featuring people with disabilities and giving discounts to nonprofit disability organizations at the annual NSGC education meeting; publishing practice guidelines on communicating a diagnosis; funding research on best practices for supporting patients receiving a Down syndrome diagnosis; disseminating the Lettercase book; and developing cultural competency groups to examine diversity issues, including disability.

- Bauer discusses how the medical literature does not adequately capture the robust, diverse, and meaningful lived experiences of people with disabilities, specifically her daughter with Down syndrome and friends. She also talks about how most Americans, including medical providers, are unaware of the historical stigma, trauma, and abuses endured by people with disabilities and how that historical stigma shapes current conscious and unconscious biases. She also talks about how people with disabilities have made progress thanks to the legal protections put in place through the Americans with Disabilities Act and IDEA; however, she says: "Young people with disabilities today have never known a time when they lacked strong legal protections. Even though they still sometimes struggle with social attitudes and lack of access to services, they don't view their lives as tragic or pitiable, and feel that society's negative myths, fears, and stigmas needlessly complicate their lives. They are eager to take their rightful places

in society, proud that they have something to contribute. But first they must get past the old stereotypes and open people's eyes to the possibilities—a task that is made immeasurably harder by the confidential conversations about prenatal testing and diagnosis that are going on in the offices of genetic counselors and physicians across the land.” Key passage about how medical bias by medical professionals can affirm stereotypes when delivering a diagnosis unless clinicians also provide a more balanced view that reflects current outcomes for people with genetic conditions. “Depending on where you stand, the words “Down syndrome” can mean many things to many people. The term could be a description of somebody you've spent time with, maybe a friend or family member, somebody who laughs at your jokes and brightens your day. It could be a description of a community of people, citizens who have legal rights, personal challenges, abilities, and a capacity for joy and friendship. Or it could be a clinical description of a bunch of cells accompanied by a lengthy list of potential health problems and frightening uncertainties. Each of these meanings has a basis in fact. But it seems that only one is being communicated during the conversations that surround prenatal screening and diagnosis. In the absence of culturally sensitive context, these conversations are having the effect of legitimizing and amplifying negative attitudes toward people with genetic differences. What we're hearing is that professionals are providing information to prospective parents that sounds a lot like what I found in medical texts a generation ago: scientific data presented in a reductive and sterile fashion, lacking any mention of quality of life, family or social relationships, or personal satisfaction. I'm not suggesting that the data as presented is inaccurate, but it does seem to me woefully incomplete. How can couples make informed decisions that truly reflect their values when they haven't been given information about the lives of those they've historically been taught to fear? I worry that professionals within the prenatal testing world, often without even being aware of it, are shading their messages in such a way as to transform the right to terminate into something that feels more like an obligation to terminate. Again, I don't think physicians and genetic counselors are sending this message deliberately. But regardless of intent, the effect is the same. These subliminal messages support a climate in which disability discrimination can flourish unchallenged. People with what are seen as “preventable” disabilities are coming to be regarded by many not as good neighbors and potential friends or coworkers, but inconveniences to be avoided. Errors. Potential burdens. Objects of pity. It's obviously not acceptable for a counselor or a physician to urge a course of action on a prospective parent, whether it be continuation of a pregnancy, termination, or giving a child up for adoption. But over the years, the non-directiveness cherished by genetic counselors seems to have become reason not to share information that might portray people with Down syndrome in something other than a negative light. I've heard genetic counselors say they hesitate to tell patients that many people with Down syndrome are beloved by their families because such information wouldn't be supportive of their patient. It might make the patient feel bad if they decide to terminate. From my vantage point, such logic is pernicious. Are we really saying that discriminatory old biases and stereotypes should be left unexamined so patients can be spared discomfort during their counseling sessions? What is the purpose of the counseling process, if not to provide patients with up-to-date, accurate, and balanced information? Can we truly call it “informed

consent” if we are deciding up front that certain kinds of information—information that acknowledges respect for a historically vulnerable and stigmatized population—shouldn’t be shared? Over the past 40 years, as educational and political advances have been improving outcomes for Americans with disabilities, the prenatal testing industry has exploded into a billion-dollar business that annually offers millions of people insight into their odds of carrying a fetus with a genetic difference. Yet, ironically, the voices of people with disabilities are only beginning to be heard within this industry and have not yet been heard in a comprehensive way. As a result, it seems, an entire generation of young parents is being subjected to an impoverished consent process in connection with prenatal screening and testing, one that lacks acknowledgement of the value and dignity and possibilities of people living with the conditions that are being diagnosed and discussed behind closed doors. The public health consequences of this omission extend far beyond the counseling room to affect the collective future of everyone in our society who may have a disability now or could become disabled in the future—which to me sounds like just about everybody. What is said in those rooms matters, not just to the patients who may be present, but to all of us. It’s important that we work together to get it right. What’s to be done? First, it’s imperative that genetic counselors, physicians, and all professionals who work with prospective parents reach out and partner with the disability community to strengthen the informed consent process connected with prenatal screening and diagnosis. Current, complete, and unbiased informational packets about a range of genetic disabilities should be assembled and distributed in consultation with advocates, parent support groups, and other representatives of the disability community. Training should be developed, also in consultation with the disability community, in how to counsel patients in ways that promote respect both for the patients and for the people who live with unexpected diagnoses. And most of all, I would urge that genetic counselors, physicians, and others in the field consider developing genuine friendships—not caretaker relationships—with people on my side of the disability divide. With luck, you’ll get a glimpse of some of the fascinating people I have come to love: People whose lives are complex and messy, to be sure, but rich and satisfying, too.”

- “From the clarity in which mothers described their experiences, this does not seem to be the case, suggesting that receiving a prenatal diagnosis of DS is a true flashbulb memory, accurate, complete, and immune to forgetfulness.” (676) Therefore, the attitudes, support, and information provided in the first moment of the life course are critical in how families perceive a future with a disability. Recommendations for how clinicians should deliver a diagnosis: Clinicians should use sensitive and neutral language when delivering a diagnosis and not convey unconscious bias by using phrases like, “I’m sorry.” “Discuss all reasons for prenatal diagnosis including reassurance, advance awareness before delivery of the diagnosis of DS, adoption, as well as pregnancy termination. Many of the mothers who responded to this survey never planned to terminate the pregnancy and were upset when their physicians provided detailed descriptions of pregnancy terminations without knowing whether they would like those options discussed.” “Up-to-date information on DS should be available. Respondents requested clinical information on the health concerns for infants with DS and “success stories’ that demonstrated the potential and possibilities for children with DS. Contact with local DS support groups

should be offered, if desired. Respondents appreciated providers who gave them the contact information for local DS support groups. One mother reported that after talking to other parents, “I felt 100% better and positive about having my daughter.” Another mentioned, “I regret that I didn’t get involved with any support groups in the beginning. I thought everyone would sit around and cry on each other’s shoulders, and I wasn’t ready for a pity party. I only wish that physicians, nurses, and hospitals were better informed about the wonderful opportunities that are out there to help parents.”

- Mothers from the USA, Spain, and the Netherlands who have received a prenatal diagnosis of DS and chose to continue their pregnancies have indicated that their physicians often provided incomplete, inaccurate, and, sometimes, offensive information about DS.^{38–41} Mothers in the Netherlands who have terminated their pregnancies after receiving a prenatal diagnosis of DS mostly based their decisions on an understanding that DS was “an abnormality too severe” and a “burden” that was “too heavy” for the child.⁴² As a result, some have even questioned whether mothers are making informed clinical decisions about their pregnancies.⁴³ Physicians’ training and personal opinions might underscore this conclusion. “Are today’s physicians competently trained? In a survey conducted in 2004 of 2500 medical school deans, students, and residency directors in the USA, 81% of medical students report that they “are not getting any clinical training regarding individuals with intellectual disabilities”, and 58% of medical school deans say such training is not a high priority.⁴⁴ In a questionnaire completed by 532 ACOG fellows and junior fellows in 2004, 45% rated their training regarding how to deliver a prenatal diagnosis as “barely adequate or non-existent”, and only 28% felt “well qualified” in general prenatal genetic counselling.⁴⁵ A survey of 507 ACOG fellows and junior fellows conducted 4 years later showed little progress – approximately 40% thought their training was “less than adequate”, and only 36% felt “well qualified” in counselling an expectant mother whose prenatal screen suggests a high chance for DS.⁴⁶ Taken together, these studies suggest that today’s and tomorrow’s physicians are not adequately prepared. “The only known study, to date, examined 499 physicians and 1084 genetic professionals from the USA who were involved in presenting a prenatal diagnosis of DS to expectant couples.⁴⁷ On anonymous surveys, 63% of physicians and 86% of genetic professionals claim that they try to adhere to non-directive counselling. By contrast, 13% of physicians and 13% of genetic professionals admit to overemphasizing the negative aspects of DS in hopes that pregnant women would seek a termination. Further, 10% of physicians said that they actively “urge” mothers to terminate. On the flip side, 10% of physicians and 2% of genetic professionals indicate that they overemphasize the positive aspects of DS in hopes that pregnant women will continue with their pregnancies. An additional 4% of physicians said that they actively “urge” mothers to continue. With data showing that pregnant women often make pregnancy decision with inadequate information and showing that clinicians often receive little training about genetic conditions and sometimes convey biases, it’s important that clinicians follow the guidelines below to work toward equity in discussions about disability:1. “Obstetric, midwifery, and genetic professional organizations across the world need to develop guidelines on how their country’s health professionals should deliver a prenatal diagnosis of DS to expectant parents.” 2. “Current and accurate

informational packets on DS need to be assembled by a collaborative of medical organizations and parent support organizations. 3. “Comprehensive training on how to deliver a non-directive prenatal diagnosis of DS should be offered to all obstetricians, geneticists, midwives, genetic counsellors, neonatologists, family medicine physicians, and other healthcare professionals involved in prenatal care. Online simulation has already been developed for physicians to practice these skills.” 4. “Medical, nursing, and genetic counseling students need a richer understanding about DS, beyond the statistics cited in their texts. Some schools are now inviting people with DS and their families to give lectures, and others are offering creative opportunities for students to interact with people who have DS. What we have seen is that these recommendations have been implemented in pockets of the US, but they are not followed consistently or required. Therefore, the population has not begun to dwindle as it has in countries like Iceland, but families are still reporting negative diagnosis experiences in many areas.

- “One of the largest challenges participants reported was finding time to educate patients on their prenatal screening and testing options. The initial pregnancy visit encompasses a wide variety of screens, baseline health assessments, and patient education.” “Finally, provider time constraints are also an issue. There is little current guidance on the level of detail that should be provided to patients about each condition for which they are being offered screening. As the number of conditions on screening panels increases, providers are faced with a trade- off between providing patients with in-depth information about every condition for which there is an available test or more pretest counseling about the spectrum of clinical severity of microdeletion syndromes and aneuploidies, while preserving more detailed counseling for the event of a high- risk finding. “One gap identified was limited time and compensation for adequate pre-test counseling about disabilities for patients to truly understand the conditions for which they are being tested. This can be particularly problematic when other documents show that families often interpret screening as a method for detecting “something bad.” “In addition, many organizations provide patient support materials around cfDNA screening and specific genetic conditions. Proactively partnering with these organizations so that materials, or references to materials, are immediately available when a high-risk result is received may greatly improve conversations in this space.” While it is clear that this meeting included a limited discussion regarding education about genetic conditions, the conversation did not seem robust in exploring how the provision of that information can provide an equitable representation of disabilities following prenatal testing.

- Quote: “Now, and increasingly so in the future, clinicians will need to provide expectant parents with accurate information about family life when a member has DS. Extensive training is needed, but, thus far, the education of healthcare professionals has placed scant focus on what to say about DS to new and expectant parents. When 2,500 medical school deans, students, and residency directors were surveyed in 2005, 81% of medical students reported that they “are not getting any clinical training regarding individuals with intellectual disabilities,” and 58% of medical school deans said such training is not a high priority [Special Olympics, 2007]. When 532 ACOG fellows and junior fellows were questioned in 2004, 45% rated their training regarding prenatal diagnosis

as “barely adequate or non-existent,” and only 28% felt “well qualified” in general prenatal genetic counseling [Cleary-Goldman et al., 2006]. When a separate group of 507 ACOG fellows and junior fellows were questioned some four years later, little had changed—approximately 40% thought their training was “less than adequate,” and only 36% felt “well qualified” in counseling an expectant mother whose prenatal screen suggests a high chance for DS [Driscoll et al., 2009]. A consensus statement, written in 2009, from ACOG, ACMG, NDSGC, NDSS, and NDSC calls for four areas of collaborative change in anticipation of these forthcoming non-invasive prenatal diagnostic tests [American College of Obstetricians and Gynecologists, 2009]: (1) A “gold-standard” packet of information should be developed for all expectant parents who receive a prenatal diagnosis of DS. The booklet, “Understanding a Diagnosis of Down Syndrome Diagnosis” has now been created with assistance from all of the organizations and is available for dissemination from the organization, Lettercase, Inc. (<http://www.lettercase.org>). (2) Practice guidelines should be written on how best to deliver a prenatal diagnosis of DS. Since this recommendation, a 29-member Down Syndrome Diagnosis Study Group has now published an evidence-based review, which can serve as a blueprint for the academic societies as they develop their own practice guidelines [Skotko et al., 2009b]. (3) A public awareness campaign should be initiated to educate pre-pregnant couples about life with DS. Addressing this urgency is a new online patient simulation, available for free, with evaluation already published in peer-reviewed journals (<http://www.brighter-tomorrows.org>) [Ferguson et al., 2006]. At the core of the recommendations in the consensus statement is the need for a more informed understanding of family life when a member has DS. This study provides further information that can be incorporated into informational booklets, public awareness campaigns, and professional trainings. Additionally, the study provides evidence-based information from our sampled population that can now be shared with expectant couples during prenatal counseling, whether done in the offices of obstetricians, family practitioners, geneticists, and genetic counselors or in one of the many DS clinics across the country (<http://www.ndss.org>): * The overwhelming majority of parents who have children with DS report that they love their son or daughter and are proud of them. * The overwhelming majority of parents who have children with DS report that their outlook on life is more positive because of their son or daughter with DS. * Parents who have children with DS mention that while there are struggles and challenges, their children with DS bring them much joy and many rewards. They cite life lessons in acceptance, patience, and purpose. * The overwhelming majority of parents who have children with DS say that their other children have good relationships with their brothers and sisters with DS. * The majority of parents who have children with DS report that their other children are more caring and sensitive, as a result. * A very small percentage of parents who have children with DS say that they are embarrassed by their son or daughter or even regret having them altogether. The majority of these parents had children with significant medical and learning challenges. * Slightly more than half of parents who have children with DS say that they have found non-profit DS organizations helpful. Delivering a diagnosis of DS will remain difficult for providers and parents alike, but clinicians now have even more tools to deliver such news in a more complete and accurate manner.”

- 1. Outline differences between different tests and not phrase screening in terms of “positive” or “negative” 2. Prior to undergoing amniocentesis or CVS, clinicians should have a conversation with a patient about pregnancy preferences and whether or not the patient plans to proceed with the pregnancy, and clinicians should respect those wishes if patients have come up with a conclusive personal decision. 3. The medical professional on the team with the most expertise about Down syndrome should deliver the news. 4. Ideally, a diagnosis should be given during a personal visit or pre-scheduled phone call. 5 & 6. Physicians should discuss potential medical issues but also available supports and services and life outcomes for people with Down syndrome. They should also convey that outcomes cannot be predicted prenatally, and they should provide contact information for local and national Down syndrome organizations. 7. “Physicians should use nondirective language during their counseling. Instead of saying “I’m sorry . . .” or “Unfortunately, have some bad news to share . . .,” physicians should be careful to use sensitive language that does not proscribe value on people with DS.” (2365) 8. Provide a bibliography of resources about Down syndrome, including national organizations. 9. Clinicians should schedule a follow-up appointment for additional questions and provide referrals to specialists as needed, such as a cardiologist. There is currently no training required for medical professionals on how to follow these instructions for delivering a diagnosis sensitively, particularly obstetricians, and they further receive very little training on the conditions themselves and current outcomes, particularly as the prenatal screening panel has extended to additional conditions.

- “These data can now be incorporated into informational prenatal booklets about DS, such as the one created by Lettercase, Inc. (www.lettercase.org) in collaboration with the national organizations issuing the 2009 consensus statement. Our findings can also be incorporated into educational opportunities for medical students, genetic counseling students, nurses, and the public, at large. Health-care professionals might use the study as a point of discussion during conversations about forthcoming non-invasive prenatal diagnostic testing for DS, and policymakers might consider these self-reflections as a way to better inform legislation about people with DS. Perhaps more importantly, these reflections of people with DS can be shared during prenatal counseling sessions. When an expectant couple receives a prenatal diagnosis of DS, healthcare professionals can now share evidence-based statements from actual people with DS, with the understanding that these statements are based on the population we sampled: (2368)
 - * The overwhelming majority of people with DS are happy with their lives.
 - * The overwhelming majority of people with DS like who they are and how they look.
 - * The overwhelming majority of people with DS love their families, including their brothers and sisters.
 - * The majority of people with DS feel they can easily make friends.
 - * The majority of people with DS feel that they help other people.
 - * Only a small percentage of people with DS feel sad about their lives, which appears to be associated, in part, to transition points of adolescence.”

- This survey highlights the similarities and disparities between what genetic counselors’ value as essential information at the moment of diagnosis. As it pertains to a prenatal diagnosis, both clinicians and expectant parents found printed information and

factsheets or brochures to be very important. Genetic counselors tended to rank the provision of information about the variability of intellectual disability, health issues, genetics, and the provision of information about reproductive options more highly than parents even though they also ranked the life outcomes important as well. Parents also valued the genetic and health issues information, but they placed the highest value on non-medical information such as available supports and services, therapies, information resources, and life outcomes, such as employment, inclusion, independent living, and friendships. Moreover, nearly half of parents were dissatisfied with their diagnosis experience. Many parents also indicated that the negative messages were often conveyed by obstetric medical providers instead of genetic counselors, and obstetric medical providers rarely receive training specific to life outcomes for genetic conditions. The author indicates that this gap between what parents and clinicians and value may lead to that dissatisfaction when parent needs are not met at the moment of diagnosis. Specifically, this gap arises from the medical model focus of the medical community and the social model focus of the disability community where clinicians value more medical/genetic information, and families want to know more about life outcomes. Additionally, the author suggests that many parents perceive that an offer of reproductive options at the moment of diagnosis undervalues the life of their child.

- "... the Food and Drug Administration (FDA) is not empowered to require testing companies to produce evidence of clinical utility before receiving marketing approval, companies have been free to build consumer demand for cfDNA testing by aggressively marketing the tests, emphasizing data that do not answer key questions. As a result, cfDNA testing seems to be drifting into routine practice ahead of the evidence. "The article highlights the aggressive marketing of the testing labs to reach pregnant women both directly and indirectly with little oversight by the FDA so that testing is being widely used without educational and equitable practices being put into place. "The evidentiary gaps concerning cfDNA testing, aggressive marketing, and rapid diffusion into routine practice can be traced, at least partially, to our country's regulatory scheme for laboratory-developed tests. Under FDA regulations, commercial test kits — which are distributed to multiple laboratories and health care facilities — are subject to both premarketing assessments of analytic and clinical validity and post marketing reporting of adverse events. No similar requirements exist for tests, like the cfDNA tests, developed for in-house use by a single laboratory. Laboratory-developed tests are governed, instead, by the Clinical Laboratory Improvement Amendments of 1988. Laboratories must demonstrate such a test's accuracy, precision, specificity, and sensitivity — but not its clinical validity or utility. Although companies offering noninvasive prenatal tests have chosen to perform studies in the targeted population, they aren't obliged to do so, nor must they design studies so as to provide robust evidence about clinical utility."
- Current cost justifications for the coverage of screening depend on a certain number of pregnancies being terminated and also rely on estimations about the cost of the life of individuals with genetic conditions. This is ethically problematic toward the equitable treatment of people with disabilities at several levels: 1. If termination is relied upon to justify cost-effectiveness, then there is an implicit leaning toward termination

in the process. According to Bronfenbrenner’s ecological theory, the overall financial framework of the macro impacts the clinical practice at the mezzo level and individual decisions at the micro level. Moreover, the idea that a certain percentage of terminations must be performed to justify the cost-effectiveness is counter to the notion of non-directive counseling. 2. The idea that people with disabilities can be reduced to a QALY assessment of their lives is reductionist conveying a purely economic/utilitarian viewpoint of human life and ignoring the societal contributions made by people with disabilities. 3. This model completely ignores the cost of provider training and patient education about both testing and genetic conditions which would be necessary for the equitable administration of prenatal screening and testing. Therefore, the enumeration of the cost-effectiveness is based on a flawed model that does not incorporate the cost of training, education, and support services for providers and patients.

- Report found that the tests had been released without oversight, and some patients were terminating pregnancies because the clinicians and patients were largely misunderstanding the accuracy of the tests. “And at Stanford University, there have been at least three cases of women aborting healthy fetuses that had received a high-risk screen result. ‘The worry is women are terminating without really knowing if [the initial test result] is true or not,’ said Athena Cherry, professor of pathology at the Stanford University School of Medicine, whose lab examined the cells of the healthy aborted fetuses. In one of the three Stanford cases, the woman actually obtained a confirmatory test and was told the fetus was fine but aborted anyway because of her faith in the screening company’s accuracy claims. ‘She felt it couldn’t be wrong,’ Cherry said.” Another “Natera study found that some women are ignoring that advice and having abortions without getting a confirmatory diagnostic test. In its study, 22 women out of 356 who were told their fetuses were at high risk for some abnormality terminated the pregnancy without getting an invasive test to confirm the results. “The article indicates that the initial marketing of NIPS was overly aggressive and misled doctors and patients with the advertising making claims like “near diagnostic.” This author says this has been particularly difficult to reign in because of the lack of regulation by the FDA. “The companies have done a very poor job of education [and] advertising this new technology, failing to make clear that it is screening testing with very good but inevitably not perfect test performance . . . and that doctors are recommending, offering, ordering a test they do not fully understand,’ said Dr. Michael Greene, director of obstetrics at Massachusetts General Hospital and a professor at Harvard Medical School. “One mother who received a false positive said that “enormous heartache could have been avoided in her family if companies advertised more scrupulously, and if her doctor had understood the limitations of the screen. “The article author also uses alarming biased about genetic conditions such as the “horrors” of Edward’s syndrome and says that children who do not have genetic conditions are “perfect” and “healthy” when many children with genetic conditions are also health and loved by their families as “perfect.”

- Implies that NIPT can tell if a fetus has a “chromosome abnormality” (without indicating that confirmatory testing would be necessary) and that expectant parents could use that information to decide whether to continue or terminate the pregnancy. Indicates that

prenatal whole genome sequencing is coming and would be able to detect many more conditions, and companies are eager to market the expanded prenatal screening panel. In these articles, there is always an assumption that testing for the trisomy conditions is always appropriate for the trisomy conditions and conditions that cause intellectual disability, but then the author indicates that testing for other more minor conditions is more morally ambiguous and may cause more anxiety during pregnancy. However, research has shown us that, in many cases, prenatal screening for families learning about Down syndrome is also anxiety-ridden and often a negative experience when families are not provided adequate information and support. In addition, intellectual disability as a litmus test also reflects the biases of society against people with cognitive disabilities because the research about people with Down syndrome suggests their life satisfaction is actually higher than that of the typical population. The article indicates that NIPS is the most rapidly adopted genetic test ever and has very little regulation. “But the rise of NIPT has been both incendiary and chaotic, in part because there’s so much money to be made, and in part because the technology innovations that make the increasingly sophisticated tests possible have far outpaced the research community’s ability to assess both their clinical utility and their impacts on society. “If you look historically at prenatal genetic testing, there’s a very clear ratcheting effect,” says Ben Berkman, a bioethicist who studies NIPT at the National Human Genome Research Institute. In the US, no single legal authority dictates requirements or limitations on prenatal genetic testing. Professional societies of genetic counselors, medical geneticists, and ob-gyns provide guidelines for what should or shouldn’t be included in the screens and who should be eligible to take them. But, says Berkman, no matter what those groups actually recommend, there’s always some company offering a little more, marketing to families who want to be just “extra secure.” And, as his own research shows, wherever the upper limit of information is, most people want that.” The experts in the article also indicate that many people use these tests to terminate a pregnancy when they might be making inaccurate assumptions just because the testing itself suggests that a condition is bad news. “Even more surprising was what women intended to do with that information. In every category at least some respondents said the primary reason they wanted the data was to make a decision about potentially terminating the pregnancy. While that has been the underlying purpose of prenatal genetic testing since the beginning, the results—while hypothetical—indicate a shifting set of criteria for what might inform such a serious decision. And with that comes profound ethical implications. ‘Everyone thinks they’re going to have a perfect baby but if you test any genome, you’re going to find a large number of things that each confer a little bit of risk,’ says Berkman. On average, each individual carries several hundred potentially harmful genetic variants, and for the vast majority of those variants, it’s unknown exactly how severely they impact human health. “My worry is that people will panic and make these reproductive decisions that maybe aren’t in line with their values based on information that’s not quite ready for prime time.”

- Leach claims that Kaplan’s objections to the Down Syndrome Information Acts are based in ignorance about the laws. He says the laws do not require families to contact local Down syndrome organizations as Kaplan claims. Rather, the laws require that “contact information for those organizations be provided to the patients, but it is up to the patients

whether to contact them.” Leach argues that these laws do not require that patients be provided a “positive spin” about Down syndrome. Instead, he says the laws require a more neutral presentation of Down syndrome that includes both the challenges and strengths, as recommended in the guidelines from the national medical organizations. Leach asserts that Kaplan’s own limited, medical model description of Down syndrome is what constitutes spin when it does not also acknowledge their relative strengths. “Not sharing this fuller picture of a life with Down syndrome is what is “spin.” Focusing on only the medical aspects is a biased portrayal of a life with Down syndrome precisely because it is incomplete. The Down Syndrome Information Act, by requiring the provision of “accurate, up-to-date, and balanced information,” in fact brings the advice given to patients back to neutral and in compliance with the same guidelines that recommend the offer of prenatal testing. Caplan’s critique is wrong on what these laws require and why they are needed.”

- Dr. Kaplan argues that the state laws requiring the provision of information about Down syndrome and genetic conditions are misguided because he claims the laws are driven by families who want to reduce the abortion rate of babies with Down syndrome, and he claims the laws inordinately require that expectant parents receive positive information about Ds.

- This article reveals that the motivation to pass Down syndrome Information Acts largely stems from parents who had negative diagnosis experiences. Heather Sachs, a mother who testified on behalf of the Down syndrome Information Act revealed that when she learned about a diagnosis as recently as 2006, “she was simply handed a pamphlet, entitled “So You’ve Had a Mongoloid: Now What?” [a pejorative term that had been considered offensive for decades at that point] On the audio of the Senate Finance Committee hearing where she testified, the gasps from lawmakers and attendees are audible.” Another mother, Kathleen Wachter, testified about her frustration at receiving no information following a diagnosis.

- “It’s very good news for pregnant women,” says Diana Bianchi, a pediatric geneticist at Tufts Medical Center who led the study. “It’s very important because it means a significant proportion of women are not being made anxious by being told they have an abnormal test result.” “Others have more concerns. Abortion opponents fear the test could prompt more women to terminate their pregnancies. And advocates for people with Down syndrome have their own worries. ‘People with Down syndrome are artists. They’re poets. They’re athletes. Their lives are happy ones and fulfilling ones. I have a sister with Down syndrome who certainly is a life coach for not only myself but for my entire family,’ says Brian Skotko, co-director of the Down Syndrome Program at Massachusetts General Hospital in Boston. ‘If the new tests become a routine offering, then we have to start to ask: Will babies with Down syndrome slowly start to disappear? ‘And that’s not all. The technology the test uses can quickly and relatively inexpensively scan the entire genetic code of a fetus. So, it could be used to screen fetuses for all sorts of things, such as whether the fetus is male or female, much earlier in a pregnancy. ‘In the near future you could imagine people testing for your risk of getting Alzheimer’s when you’re 70 years

<p>old or diseases that don't strike until the middle of life, like breast or ovarian cancer, or something as minor as color blindness,' says Hank Greely, a bioethicist at Stanford University." "I think regulators, legislators, doctors, will have to make some hard decisions about what kind of information they want give parents that parents could then use to terminate a pregnancy," Greely says.</p>
<ul style="list-style-type: none"> • Lack of training of medical school students in providing a parent with a post-natal diagnosis of Down syndrome, and the fact that families often do not receive balanced, supportive, and accurate information at the point of diagnosis
<ul style="list-style-type: none"> • These researchers found in a survey of 532 practicing obstetricians and gynecologists, that 45% rated their training regarding prenatal diagnosis of DS as barely adequate or nonexistent.
<ul style="list-style-type: none"> • The need for both OB/GYN and pediatric residents to receive training in providing balanced, accurate and supportive information in delivering either a prenatal or post-natal diagnosis of Down syndrome
<ul style="list-style-type: none"> • Resident physicians' preparation and training (or lack of preparation and training) for providing accurate, balanced, and supportive information to parents at the point of receiving a new-born diagnosis of Down syndrome, and one approach to helping to alleviate that gap.
<ul style="list-style-type: none"> • The need for vs. the likelihood parents receives balanced medical AND social education about disability in the context of prenatal genetic testing. The few incentives to promote such a balanced understanding of disability in the current world of prenatal testing. The healthcare professionals who are most likely to interface with parents during prenatal testing have few requirements to further their own disability cultural or social awareness. The co-opting of the commercial genetic testing industry. The Prenatally and Postnatally Diagnosed Conditions Awareness Act passed but is unfunded. Whether the ADA and GINA provide the promised protections in practice
<ul style="list-style-type: none"> • This law requires that clinicians who are involved in delivering a prenatal diagnosis of Down syndrome (or screening results that suggest a high probability) must also provide: (a) Up-to-date information about Down syndrome that has been reviewed by medical experts and Down syndrome organizations. The information shall be provided in a written format and shall include the following: (i) A clinical course description, including possible physical, developmental, educational, and psychosocial outcomes; (ii) Treatment and therapy options; and (iii) Life expectancy; and (b) Contact information for Down syndrome organizations that are nonprofit and that provide information and support services for parents, including first-call programs and information hotlines specific to Down syndrome, resource centers or clearinghouses, and other education and support programs for Down syndrome. These recommendations follow what was found to be valuable in the Levis study. This information follows the more progressive social model of disability. The fact that these laws exist provides some evidence of medical disparities as the laws were passed because women were testifying that they weren't getting the support they needed following test results.
<ul style="list-style-type: none"> • One gap is our understanding of how often these types of documents are being accessed by clinicians and influencing clinical practice in the provision of a more balanced presentation of Down syndrome.

Table 5: COVID-19 Document Review – CDHPD Partner Comments

GAPs Highlighted – CDHPD Partner Comments
<ul style="list-style-type: none"> • "The document provides guiding principles for avoiding disability discrimination in treatment rationing and interpretations for the Dept of Health and Human Services' bulletin, " "Civil Rights, HIPAA, and the Coronavirus Disease 2019 (COVID-19)."
<ul style="list-style-type: none"> • WHILE THIS DOCUMENT PROVIDES A VERY THOROUGH ANALYSIS OF HHS'S GUIDANCE FOR CRISIS STANDARDS OF CARE, IT DOES NOT MAKE ANY RECOMMENDATIONS REGARDING THE COMPOSITION OF TRIAGE COMMITTEES AND HOW THEY MIGHT BE STRUCTURED IN A WAY TO INCLUDE VOICES FROM THE DISABILITY COMMUNITY. THIS 'NOTHING ABOUT US WITHOUT US' APPROACH TO IMPLEMENTATION OF THE CRISIS STANDARDS OF CARE, COULD HELP OFFSET THE PRESENCE OF IMPLICIT BIAS IN THE JUDGEMENTS OF NONDISABLED MEDICAL PROFESSIONALS. "
<ul style="list-style-type: none"> • "The Florida Bioethics Network provides alternatives to medical or hospital standards; in addition to ethical standards for: triage, rationing and crisis standards of care; ventilator allocation and re-allocation guidelines; Cardiopulmonary Resuscitation; and decisions regarding use and allocation of blood, dialysis and drugs.
<ul style="list-style-type: none"> • While it is of critical importance that they recommend including a person with a disability on triage committees, there is very little discussion that justifies why this is important or what qualifications this person should have, risking this recommendation being reduced to a form of tokenism. Further, no discussion of why intersectionality should also be a factor (there is no singular disability experience and so it is important to have diversity within diversity). "
<ul style="list-style-type: none"> • "Early evidence suggests that it is very difficult to help people to do a better job of imagining how chronic illness and disability will affect their lives. People often overestimate the emotional impact of chronic illness and disability, through focusing illusions and through a failure to consider adaptation. Focusing illusions are extremely difficult to eradicate. And although people are open to the idea that they will adapt to their circumstances, it is doubtful that they fully appreciate how much they are likely to adapt. These misestimates could cause people to make inappropriate decisions in their lives. It is necessary to develop and test different ways to get people to imagine unfamiliar health states and to recognize the power of emotional adaptation."
<ul style="list-style-type: none"> • "This document was written in 2010 and revisions were made in 2016 to bring the plan up with the latest thinking, which still makes this document over 4 years old. This is especially troublesome because the document was written prior to the Robust public discussion of triage guidelines that happened after the beginning of the COVID crisis.

- This document uses exclusion criteria that denies care to patients based on the presence of a disability rather than contextualized medical facts about their particular circumstances or chances of responding to treatment.
- One of the exclusion criteria used in the document states that patients should be denied care if they require assistance with activities of daily living, which has no bearing on whether they will respond to treatment and maximize the efficiency of resource allocation.”
- Requires a “best reading of the ADA, the Rehabilitation Act, and the Affordable Care Act” to reach the conclusion that the denial of life-saving treatments to individuals who have a distinct pre- existing disability violates the law.
- Roundtable discussion limits the discussion to the expertise and knowledge of the participants, rather than a broad-based sample of the disability community in all of its diversity. Further, this conversation was held during a snapshot of time during an ever-evolving pandemic.

Table 6: Other Document Review – Focus Area Recategorization

Recategorized Focus Area	Gaps Highlighted
Aging/ End of Life Care	Premature deaths of individuals with ID are most commonly attributed to causes amenable by improved quality of health care. Contributing factors to premature deaths among individuals with ID: problems in advanced care planning, adherence to the mental capacity act, living in inappropriate accommodations, adjusting care as needs changed, and caregivers not feeling listened to.
Autism Spectrum Disorder	While the preponderance of evidence suggests that physical health varies widely across the population, and particularly for individuals and groups who are otherwise disadvantaged by society, we know relatively little about health disparities in ASD. Although evidence of decreased life expectancy and poorer physical health in adulthood in ASD has only recently emerged, this evidence coupled with the rapidly increasing population of adults with ASD signals the need to better understand physical health, and factors that promote physical health, in ASD.
Autism Spectrum Disorder	There are three critical emerging issues in disability and health: 1. The first is the need for better disability health data to inform policy and program development regarding critical issues of health disparities and health equity. A solution is to ensure that standard disability items are included in all public health surveillance instruments and that data is analyzed for individuals with disabilities where disability is in the data source. 2. The second is the need to increase the implementation of evidence-based health and wellness programs that have been demonstrated to be effective among people with disabilities in community settings, including adequate strategies for preparedness and response for individuals with disabilities. Related to this is the need to translate existing evidence-based interventions demonstrated to be effective in clinical settings for people with disabilities to community programs. A solution is to add individuals with disabilities to community-based health promotion efforts where possible. 3. The third is the need to improve environmental designs and public infrastructure. Solutions include: Ensuring the accessibility of technology, health information technology tools and systems, broadly defined, for people with physical, sensory, and cognitive disabilities. This includes electronic health records and personal health records as well as wearable technologies and home monitoring systems. Designing homes and community spaces that are fully accessible to individuals with disabilities. Ensuring that professional degree programs offer coursework in disability and health.

Autism Spectrum Disorder	unmet healthcare needs of children with autism: delayed identification of autism diagnosis -this article highlights the use of the ECHO project as a way to educate healthcare providers in treatment for patients with autism
Autism Spectrum Disorder	Researchers say: "We have virtually no data on health, mental health, and health care for young adults with autism. The richest source of nationally-representative data we currently have on these topics is surveys of the parents of teens."
Autism Spectrum Disorder	1. Disruption in provider relations. 2. Network inadequacy 3. Problems with case management 4. Service cuts and denials 5. Limited consumer engagement. 6. Lack of oversight
Autism Spectrum Disorder	In recent studies, a majority of health care providers themselves reported needing more training in autism spectrum disorder (ASD) and having "poor or fair" knowledge and skills in providing care to adults with autism. Researchers did in-depth interviews with nine of those primary care doctors. "With the exception of one physician trained both in pediatrics and internal medicine, all others indicated they had little or no autism training during medical school or residency," according to the study.
Autism Spectrum Disorder	disparities in health care for children with ASD and specific areas of unmet needs, implications for policy: insurance coverage for autism treatment, access to health care insurance, and issues with Medicaid service caps.
Autism Spectrum Disorder	Factors associated with the unmet need for therapy services: the child being female, being uninsured, having greater functional limitation, not receiving a well-child visit in the past year, and surveyed in 2009.
Cerebral Palsy	unmet health care needs of children with CP and children with other special health care needs that are more severe
Health Insurance	disparities in health care service for children with ID due to lack of primary care providers adherence to AAP guidelines - implications: ways to alleviate these disparities include education of physicians and families, ongoing review of the AAP 2011 health supervision, guideline adherence rates, and summaries/reminders to simplify screening recommendations.
Health Insurance	disparities in health care transition services for individuals with ASD compared to youth with other special health care needs - highlights the need for education and training among healthcare providers, caregivers, and youth in order to ensure proper HCT services are provided
Health Insurance	discrimination and barriers to accessing health care services for persons with ID - implications: more widespread implementations of WHO recommendations

Health Insurance	Recommendations based on gaps identified: 1. Improve access to health care and human services. 2. Improve data collection and use it to advance public health standards. 3. Strengthen the workforce. 4. Include people with disabilities in public health programs and practices. 5. Prepare for emergencies with people with disabilities in mind.
Health Insurance	The current health care system is fragmented and does not provide uniform access to a comprehensive array of health services and supports. These barriers include: Access, Discrimination, Affordability, and Communication and personal decision-making.
Health Insurance	lack of sexual health services provided and available to persons with IDD through HCBS waivers. lack of sexual health services focused on proactive services (promotion of healthy sexuality and sex education)
Intersectional Issues	The need for additional training for adult providers of primary care.
Intersectional Issues	Physician participants identified themes of “operating without a map,” discomfort with patients with intellectual disability, and a need for more exposure to/experience with people with intellectual disability as important content areas. The authors also identified physician frustration and lack of confidence, compounded by anxiety related to difficult behaviors and a lack of context or frame of reference for patients with intellectual disability. Primary care physicians request some modification of their educational experience to better equip them to care for patients with intellectual disability. Their request for experiential, not theoretical, learning fits well under the umbrella of cultural competence (a required competency in U.S. medical education).
Intersectional Issues	Parents’ discussions emphasized (a) loss of relationship with provider and lack of support transitioning from pediatric to adult care, (b) providers’ lack of knowledge about Autism Spectrum Disorder, and (c) concerns about losing guardianship. Youth emphasized their confusion and anxiety around (a) medical providers’ role, especially in the transition to adulthood; and (b) managing their medical lives independently.
Intersectional Issues	Disparities individuals with ID experience: higher rates of comorbid, complex health conditions, inadequate attention to health care needs, inadequate focus in health care promotion, and low-quality health care services.
Intersectional Issues	Numerous focus areas noted. Overall theme: "all treatment-based medical decision making should be derived without the consideration of a co-existing consideration"

Intersectional Issues	Differences in access to services, quality of services, and family support when comparing caregiver perceptions of children with ASD with perspectives of caregivers of children with DD, MH conditions, or both.
Intersectional Issues	Physical accessibility, Communication challenges
Intersectional Issues	Physician responses revealed inadequate training in the care of adults with an ASD and physicians' interest in obtaining additional training. The ability to provide a medical home for adults with autism will need to address effective strategies to train current and future physicians.
Intersectional Issues	Health disparities and secondary conditions can be the result of inaccessible health care facilities and equipment, lack of knowledge among health professionals about specific differences among people with disabilities, transportation difficulties, and higher poverty rates among people with disabilities.
Intersectional Issues	Compared with children with PHC, those with all three conditions (PHC, MHC, and DD) had the lowest odds of access to medical home (61% decreased odds (DO), community services (67% DO), and adequate insurance (26% DO); MHC and DD had the lowest odds of partnering in decision making (51% DO); DD had the lowest odds of healthcare transition service (66% DO).
Intersectional Issues	Gaps Highlighted: disparities in the unmet service needs experienced by adults with IDD who are on service waiting lists: poor health, from minority backgrounds, and non-verbal were characteristics of persons with IDD discovered to have greater amounts of unmet service needs
Intersectional Issues	Health disparities for individuals with Down syndrome: Secondary health conditions, lack of healthcare provider comfort in treating DS population, low rates of subspecialty referrals, limited insurance, racial health disparities
Intersectional Issues	--- no gaps highlighted used the notes and briefly describe the document fields to identify gap category. --
Intersectional Issues	Interactions and roles of stigma/discrimination Creating a new framework for nursing related to addressing stigma/discrimination and ID
Intersectional Issues	postpartum health disparities experienced by women with IDD: higher rates of medical complications during pregnancy; higher rates of postpartum hospital admissions; higher risk of hospital utilization for psychiatric reasons. -suggestions: changes in guidelines for more frequent postpartum visits; modification in Medicaid reimbursement policy for postpartum visits for women with IDD
Intersectional Issues	These guidelines outline standards of care for which there is a good basis in current knowledge.

<p>Intersectional Issues</p>	<p>We found that Latino and Black adults with IDD had worse health outcomes compared to White adults with IDD, and Latino and Black adults with IDD had worse health outcomes than nondisabled adults from the same racial and ethnic group. Worse outcomes were found on all four measures for Latino adults with IDD: health, mental health, obesity, and diabetes, and for health and mental health for Black adults with IDD. This study offers new evidence, using nationally representative data of important racial and ethnic disparities in the health of individuals with IDD. Further, this study showed disability-based health disparities of an alarming magnitude. Assertive policy measures are necessary to improve the health and well-being of Latino and Black adults with IDD.</p>
<p>Intersectional Issues</p>	<p>1. Health Care Insurance 2. Third-party Coverage of Health Programs and Services Most Needed by Americans with Disabilities 3. Lack of Health Care Provider Training and Awareness 4. Structural and Communication Barriers</p>
<p>Legal Aspects for All Focus Areas</p>	<p>Takes the evidence of health disparities experienced by persons with ID and provides ways to take action - Provides ideas on how to approach health inequities in practice</p>
<p>Legal Aspects for All Focus Areas</p>	<p>Therefore, our findings show that even if their medical provider had a proactive response, having any passive/reassuring responses may negatively impact on Latino family's specialty service receipt</p>
<p>Intersectional Issues</p>	<p>Researchers found significant disparities in stillbirth among non-Hispanic Black and Hispanic women with IDD compared with their non-Hispanic White peers. Also, the average labour and delivery-related charges for non-Hispanic Black and Hispanic Women with IDD (\$18 889 and \$22 481, respectively) exceeded those for non-Hispanic White women with IDD (\$14 886) by \$4003 and \$7595 or by 27% and 51%, respectively.</p>
<p>Legal Aspects for All Focus Areas</p>	<p>"[P]olicies that base triage decisions on quality-of-life judgments or exclude patients with specific conditions that constitute disabilities."</p>
<p>Legal Aspects for All Focus Areas</p>	<p>Difficulties include how to define cases of intellectual and developmental disabilities, how to find cases, and how to obtain accurate information.</p>
<p>Life Saving Treatment (Organ Transplant)</p>	<p>gaps in screening due to disability over-attributing health concerns to disability rather than underlying health conditions poor referral behavior of providers</p>
<p>Intersectional Issues</p>	<p>Racial disparities in health care (mammography) among African American women with ID - Implications: interventions and public health campaigns that have shown success in reducing racial disparities (in mammography) among African American women in general, haven't reached African American women with ID; all but one participant in study had health insurance suggesting that lack of insurance was not a barrier in this case</p>

<p>Medical Education</p>	<p>disparities highlighted: lack of education/training of healthcare professionals in ID - implications highlighted: strategies to reduce barriers require better educating medical personnel by: including ID within medical curricula, provide exposure of medical students to persons with ID, using specialized training programs in ID, provide continuing education credit in ID, and collaboration between the individual, network, and healthcare providers</p>
<p>Medical Education</p>	<p>health care check disparities of persons with ID in the UK - assesses the effectiveness of initiatives implemented to improve health checks - recommends potential policy change into requiring more than one educational session in ID for healthcare providers</p>
<p>Mental Health and Suicide Prevention for People with ID/DD</p>	<p>Disparities in substance abuse treatment for individuals with ID and substance abuse compared to individuals without ID - authors highlight the need for improvements in health policy, the need for cross-system collaboration in the use of treatment approaches, and service delivery patterns.</p>
<p>Mental Health and Suicide Prevention for People with ID/DD</p>	<p>Although they have higher rates of chronic diseases than the general population, adults with disabilities are significantly less likely to receive preventive care. Mental distress such as depression or anxiety is a common concern for people with disabilities who are also less likely to report receiving adequate social and emotional support. Although public insurance provides coverage for many people with disabilities, it does not cover all people, and the greatest gaps are felt by people with emotional disabilities; 28% are uninsured. Even with insurance, people with disabilities are much more likely (16% vs 5.8%) to miss getting needed care because of cost. National data are not available, but a recent survey of almost 2400 primary care facilities serving Medicaid patients in California noted that fewer than half of facilities were fully architecturally accessible; only 8.4% had accessible examination tables, and less than 4% had accessible weight scales. Every major report addressing the poor health of people with disabilities has called for improvements in training of health care providers about adults with disabilities.</p>

Appendix B: 50 State Legislative Surveys

Prenatal Care – Down Syndrome Information Acts¹⁷ - States and Territories

*Note: This information was exported from the CDHPD Database. The U.S. legal research information was prepared by Tracy Waller, Esq., Maryland Center for Developmental Disabilities at Kennedy Krieger Institute.

Alabama: No Down Syndrome Information Act.

Alaska: No Down Syndrome Information Act

Arizona: No Down Syndrome Information Act.

Arkansas: No Down Syndrome Information Act.

Notes: Other relevant statutes: 2019 Ark. SB 2 Enacted, April 1, 2019; Ark. Code Ann. § 20-16-2103 (2020). Prohibition – Down Syndrome.

(a) A physician shall not intentionally perform or attempt to perform an abortion with the knowledge that a pregnant woman is seeking an abortion solely on the basis of:

(1) A test result indicating Down Syndrome in an unborn child;

(2) A prenatal diagnosis of Down Syndrome in an unborn child; or

(3) Any other reason to believe that an unborn child has Down Syndrome.

California: No Down Syndrome Information Act.

Colorado: No Down Syndrome Information Act.

Connecticut: No Down Syndrome Information Act.

Delaware: Del. C. tit. 16, § 801B (2019-2020). "Provision of information relating to Down Syndrome" requires genetic counseling to parents who receive a prenatal or postnatal diagnosis of Down Syndrome, evidence-based information, and contact information for support services.

District of Columbia: No Down Syndrome Information Act.

Florida: Fla. Stat. Ann. § 383.141 (LexisNexis 2020). "Prenatally diagnosed conditions; patient to be provided information; definitions; information clearinghouse; advisory council" requires that when a developmental disability is diagnosed based on a prenatal test, the patient shall receive information about the nature of the developmental disability, the accuracy of the test, and contact information for support services.

Georgia: No Down Syndrome Information Act.

¹⁷ Down Syndrome is capitalized in the title of the document and appears throughout the document as the title "Down Syndrome Information Act." The "s" in syndrome may be capitalized throughout this document depending on each state's statute.

Guam: No Down Syndrome Information Act.

Hawaii: No Down Syndrome Information Act. But under Haw. Rev. Stat. Ann. § 321-331 (LexisNexis 2020). “Prenatal health care; authority,” the department of health is granted authority to adopt rules pursuant “to ensure that all pregnant women in this State are offered appropriate information, quality testing, diagnostic services, and follow-up services concerning neural tube defects and other disorders amenable to prenatal diagnosis. . . Nothing in this section shall be construed to mean that prenatal screening and testing are mandatory.”

Notes: 2015 Bill Text HI H.R. 24 Introduced, February 26, 2015; House Resolution Urging the Department of Health to require that medical care professionals provide information on prenatal screening and testing for down syndrome to all pregnant women. Measure Deferred March 24, 2016.

Idaho: No Down Syndrome Information Act.

Illinois: Under the “Down Syndrome Information and Awareness Act,” 410 Ill. Comp. Stat. Ann. §§511/1 – 511/15 (LexisNexis 2020), for a woman receiving a positive prenatal diagnosis of Down syndrome and for the family of a child receiving a postnatal diagnosis of Down syndrome, the Department of Public Health is required to make available up-to-date, evidence-based written information about Down syndrome that is culturally and linguistically appropriate.

Indiana: Under the “Down Syndrome and Other Conditions Diagnosed Prenatally,” Ind. Code Ann. §§ 16-35-9.-1 – 16-35-9.2-3 (LexisNexis 2020), “the state department shall identify current, evidence based, written information that concerns the prenatal diagnosis of Down syndrome and any other condition diagnosed prenatally” and “when a positive result from a test for Down syndrome or any other condition diagnosed prenatally is received, a health care facility or health care provider shall provide to the expectant parent or the parent of the child diagnosed with Down syndrome or any other condition diagnosed prenatally the written information approved and made available by the state department.”

Iowa: No Down Syndrome Information Act.

Kansas: Kan. Stat. Ann. § 65-1,259. “Prenatal and postnatal diagnosed conditions awareness programs” authorizes the secretary of the department of health and environment to oversee activities, including the awarding of grants to establish information and support systems for women and spouses of women who receive a diagnosis of Down syndrome or other prenatally or postnatally diagnosed conditions for their child.

Kentucky: Under Ky. Rev. Stat. Ann. § 211.192 (LexisNexis 2020). “Information to be provided concerning Down syndrome and spina bifida – By whom – When,” “[t]he Cabinet for Health and Family Services shall make available to any person who renders prenatal care, postnatal care, or genetic counseling to parents who receive a prenatal or postnatal diagnosis of Down syndrome or spina bifida and to any person who has received a positive test result from a test for Down syndrome or spina bifida” up-to-date written information and contact information for support programs

Louisiana: Under La. Stat. Ann. § 40:1109.2 (2020). “Public information concerning Down syndrome,” “the Department of Health and Hospitals shall identify current evidence-based” information and provide the information to healthcare facilities and healthcare providers that furnish prenatal care, postnatal care, or genetic counseling to expectant parents who receive a prenatal test result for Down syndrome and parents of a child diagnosed with Down syndrome. Additionally, “C. (1) Upon receipt of a positive result from a test for Down syndrome, a healthcare facility or healthcare provider shall provide to the expectant parent or the parent of the child diagnosed with Down syndrome the written information provided or made available by the department pursuant to Subsection B of this Section. (2) All information . . . shall not engage in discrimination based on disability or genetic variation by explicitly or implicitly presenting pregnancy termination as a neutral or acceptable option when a prenatal test indicates a probability or diagnosis that the unborn child has Down syndrome or any other health condition.”

Maine: Under 22 Me. Rev. Stat. Ann. § 1642 (LexisNexis 2020). “Down Syndrome,” “The Department of Human Services shall establish, maintain and operate an information service for Down syndrome. . . A hospital, physician, health care provider or certified nurse midwife who renders prenatal care or postnatal care or a genetic counselor who renders prenatal or postnatal genetic counseling shall, upon receipt of a positive test result from a prenatal or postnatal test for Down syndrome, offer the expectant or new parent information provided by the department” including up-to-date evidence based information and contact information regarding support services and resource centers.

Maryland: Under Md. Code Ann., Health-Gen. §§ 20-1501, 20-1502 (LexisNexis 2020), the Maryland Department of Health is required to identify up-to-date and evidence-based information about Down syndrome and make the information available on the Department’s website. The Department is required to provide the information “(b)(1) to health care facilities and health care providers that provide prenatal care, postnatal care, or genetic counseling to expectant parents who receive a prenatal test result for Down syndrome and parents of a child diagnosed with Down syndrome.” “(c)(1) On receipt of a positive test result from a test for Down syndrome, a health care facility or health care provider may provide to the expectant parent who receives a prenatal test result for Down syndrome or the parent of the child diagnosed with Down syndrome the written information provided or made available by the Department.”

Massachusetts: Under Mass. Ann. Laws ch. 111, § 70H (LexisNexis 2020). “Down Syndrome Test – Information for Parents,” the department of public health “shall make available to a person who renders prenatal care, postnatal care or genetic counseling to parents who receive a prenatal or postnatal diagnosis of Down Syndrome,” up-to-date, evidence-based information about Down Syndrome, and contact information for programs and support services. And “[t]he department may also make such information available to any other person who has received a positive test result from a test for Down Syndrome.”

Michigan: No Down Syndrome Information Act.

Notes: 2015 Bill Text MI H.B.5509 introduced, March 23, 2016, Synopsis: “Requires provision of information regarding Down Syndrome to certain patients by directing the patient to

the department’s website and requires the department to include certain information on its website.” Failed upon introduction.

Minnesota: Under Minn. Stat. § 145.471. “Prenatal Trisomy Diagnosis Awareness Act,” the commissioner of health shall make available “up-to-date and evidence-based information about the trisomy conditions that has been reviewed by medical experts and national trisomy organizations” and post the information on the Department of Health website. And “[a] health care practitioner who orders tests for a pregnant woman to screen for trisomy conditions shall provide [this] information . . . to the pregnant woman if the test reveals a positive result for any of the trisomy conditions.”

Mississippi: No Down Syndrome Information Act.

Missouri: Under Mo. Rev. Stat. § 191.923 (2020). “Prenatally diagnosed conditions, patient to be provided information – definitions – clearinghouse of information to be established,” “[t]he general assembly of the state of Missouri hereby finds and declares that pregnant women who choose to undergo prenatal screening should have access to timely and informative counseling about the conditions being tested for, the accuracy of such tests, and resources for obtaining support services for such conditions.”

Montana: No Down Syndrome Information Act.

Nebraska: Under the “Down Syndrome Diagnosis Information and Support Act,” Neb. Rev. Stat. Ann. §§71-4101 – 71-4104 (LexisNexis 2020), Neb. Rev. Stat. Ann. § 71-4104. “Department; duties; Down syndrome organization; include information on web site,” the Division of Public Health of the Department of Health and Human Services is required to make up-to-date information available about Down syndrome, contact information and support services and post the information on their website.

Nevada: No Down Syndrome Information Act.

New Hampshire: No Down Syndrome Information Act.

New Jersey: Under N.J. Rev. Stat. §26:2-194 (2020). “Information available relative to Down syndrome,” “The Department of Health shall make available on the department’s Internet website, to any person who renders prenatal care, postnatal care, or genetic counseling of parents who receive a prenatal or postnatal diagnosis of Down syndrome” up-to-date, evidence-based information, and information for support services. And Under N.J. Rev. Stat. § 25:2-195 (2020). “Provision of information upon positive test result for Down syndrome,” “Any physician, health care provider, nurse midwife, or genetic counselor who renders prenatal care, postnatal care, or genetic counseling shall, upon receipt of a positive test result from a test for Down syndrome, provide the expectant or new parent with the information that is provided by the Department of Health.”

New Mexico: No Down Syndrome Information Act.

New York: No Down Syndrome Information Act.

Notes: 2017 Bill Text NY S.B. 7345 Introduced January 8, 2018, failed in 1st Committee; Purpose: “To require information on Down syndrome be provided to a pregnant woman, parent, or expectant parent of any infant or fetus diagnosed with Down syndrome.” 2019 Bill Text NY S.B. 197 Introduced January 9, 2019; Purpose: “To require information on Down syndrome be provided to a pregnant woman, parent, or expectant parent of any infant or fetus diagnosed with Down syndrome.”

North Carolina: No Down Syndrome Information Act.

North Dakota: No Down Syndrome Information Act.

Notes: Under N.D. Cent. Code, § 14-02.1-02 (2020). “Definitions,” “‘Genetic abnormality’ means any defect, disease, or disorder that is inherited genetically. The term includes any physical disfigurement, scoliosis, dwarfism, Down syndrome, albinism, amelia, or any other type of physical or mental disability, abnormality, or disease.” And under N.D. Cent. Code, § 14-02.1-04.1 (2020). “Prohibition – Sex-selective abortion – Abortion for genetic abnormality – Penalty,” “a physician may not intentionally perform or attempt to perform an abortion with knowledge that the pregnant woman is seeking the abortion solely [b]ecause the unborn child has been diagnosed with either a genetic abnormality or a potential for a genetic abnormality.”

Northern Marianas: No Down Syndrome Information Act.

Ohio: Under Ohio Rev. Code Ann. § 3701.69 (LexisNexis 2020). “Down syndrome information sheet distribution,” the department of health is required to create a Down syndrome information sheet with evidence-based, up-to-date information and provide the information on its website. “(B) If a patient under the care of any of the following health care professionals or facilities receives either a test result indicating Down syndrome or a prenatal or postnatal diagnosis of Down syndrome, the health care professional or facility shall provide to the patient or the patient’s representative a copy of the information sheet.”

Oklahoma: No Down Syndrome Information Act.

Notes: 2015 Bill Text OK S.B. 9 “An Act relating to genetic counseling . . .” Failed in 1st Chamber.

Oregon: No Down Syndrome Information Act.

Pennsylvania: Under the “Down Syndrome Prenatal and Postnatal Education Act” 35 Pa. Cons. Stat. §§ 6241 – 6244 (2020), 35 Pa. Cons. Stat. § 6243 (2020). “Dissemination of information on Down syndrome,” “A health care practitioner that administers, or causes to be administered, a test for Down syndrome to an expectant or new parent shall, upon receiving a test result that is positive for Down syndrome, provide the expectant or new parent with educational information made available by [the Department of Health of the Commonwealth]” website. The department is required to maintain up to date, evidenced based information about Down

syndrome including contact information for programs and support services.

Puerto Rico: No Down Syndrome Information Act.

Rhode Island: No Down Syndrome Information Act.

South Carolina: No Down Syndrome Information Act.

South Dakota: No Down Syndrome Information Act.

Notes: 2015 Bill Text SD H.B. 1155; Passed House Committee on State Affairs to Senate Committee on Health and Human Services, February 9, 2015; Tabled February 20, 2015; “An Act to require that information be provided to a pregnant mother whose child tests positive for Down syndrome.”

Tennessee: Under the “Down Syndrome Information Act of 2018,” Tenn. Code. Ann. §§ 68-1-1301 - 68-1-1304 (2020), the department of health is required to make available online up-to-date, evidence-based information about Down syndrome, including information and support programs. This information may be made available on this department’s website. Healthcare providers may make this information available to expectant or new parents.

Texas: Under Texas’ “Information Regarding Down Syndrome,” Tex. Health & Safety Code Ann. §§ 161.651 – 161.653 (LexisNexis 2020), the Department of State Health Services is required to make available current evidence-based information regarding Down syndrome on the department’s website and may make it available in writing to health care providers. Health care providers are required to provide the information to “expectant parents who receive a prenatal test result indicating a probability or diagnosis that the unborn child has Down syndrome; or a parent of a child who receives: a test result indicating a probability or diagnosis that the child has Down syndrome; or a diagnosis of Down syndrome.”

Utah: Under Utah Code Ann. § 26-10-14 (LexisNexis 2020). “Down syndrome diagnosis – Information and support,” the Department of Health “shall provide contact information for state and national Down syndrome organizations that are nonprofit and that provide information and support services for parents, including first-call programs and information hotlines specific to Down syndrome, resource centers or clearinghouses, and other education and support programs for Down syndrome.” The department is required to post this information on its website and create and informational support sheet. “Upon request, the department shall provide a health care facility or health care provider a copy of the informational support sheet . . . to give to a pregnant woman after the result of a prenatal screening or diagnostic test indicates the unborn child has or may have Down syndrome.”

Vermont: No Down Syndrome Information Act.

Virgin Islands: No Down Syndrome Information Act.

Virginia: No Down Syndrome Information Act; However, under Va. Code Ann. § 54.1-2403.01

(2020). "Routine component of prenatal care," "[a]s a routine component of prenatal care, every practitioner . . . who renders prenatal care . . . upon receipt of a positive test result from a prenatal test for Down syndrome or other prenatally diagnosed conditions performed on a patient, the health care provider involved may provide the patient with information about the Virginia Department of Health genetics program website and shall provide the patient with up-to-date, scientific written information concerning the life expectancy, clinical course, and intellectual and functional development and treatment options for an unborn child diagnosed with or child born with Down syndrome or other prenatally diagnosed conditions."

Washington: Under Wash. Rev. Code Ann. § 43.70.738 (LexisNexis 2020). "Down syndrome resources – Development," the department of health is required to develop up-to-date, evidence-based information about Down syndrome, including support services. "(2) The department shall make the information described in this section available to any person who renders prenatal care, postnatal care, or genetic counseling to expectant parents receiving a positive prenatal diagnosis or to the parents of a child receiving a postnatal diagnosis of Down syndrome."

Under Wash. Rev. Code Ann. § 18.46.150 (LexisNexis 2020). "Down syndrome – Parent information," "A birthing center that provides a parent with a positive prenatal or postnatal diagnosis of Down syndrome shall provide the parent with the information prepared by the department under RCW 43.70.738 at the time the birthing center provides the parent with the Down syndrome diagnosis."

West Virginia: No Down Syndrome Information Act.

Wisconsin: No Down Syndrome Information Act.

Wyoming: No Down Syndrome Information Act.

Organ Transplant Protection for People with Disabilities - States and Territories

*Note: This information was exported from the CDHPD Database. The U.S. legal research information was prepared by Tracy Waller, Esq., Maryland Center for Developmental Disabilities at Kennedy Krieger Institute.

Alabama: No current organ transplant protections for people with disabilities.

Notes: 2020 Bill Text AL H.B. 58: failed in 2nd Committee; AL S.B. 225 Failed 1st Committee; Known as Exton's Law, "Relating to health care; to prohibit discrimination against an individual with a disability in receiving an anatomical gift or organ transplant based on his or her disability; and to require health care providers and organ transplant centers to provide reasonable accommodations to individuals with a disability in medical need of an anatomical gift or organ transplant."

Alaska: No current organ transplant protections for people with disabilities.

Notes: Under Alaska's Health Care Decisions Act, Alaska Stat. § 13.52.135, "Discriminatory treatment prohibited: When determining the best interest of a patient under this chapter, health care treatment may not be denied to a patient because the patient has a disability or is expected to have a disability."

Arizona: No current organ transplant-specific protections for people with disabilities.

Notes: However, under Title 36 Public Health and Safety, Chapter 5.1 Developmental Disabilities (Arts. 1-5), Ariz. Rev. Stat. § 36-551.01(A) (LexisNexis 2020), "Persons with developmental disabilities; rights guaranteed: A person with a developmental disability in this state shall not be denied as the result of the developmental disability the rights, benefits, and privileges guaranteed by the constitution and laws of the United States and the constitution and laws of this state. The rights of persons with developmental disabilities which are specifically enumerated in this chapter are in addition to all other rights enjoyed by such persons. The listing of rights is not exclusive or intended to limit in any way rights which are guaranteed to persons with developmental disabilities under state and federal laws."

Arkansas: No current organ transplant protections for people with disabilities.

Notes: 2019 Bill Text AR S.B. 317 introduced February 13, 2019, "an act to prohibit discrimination against individuals with disabilities regarding access to organ transplantation" failed.

California: Under California's "Uniform Anatomical Gifts Act," Cal. Health & Safety Code § 7151.35 (Deering 2020), "Potential recipient's mental or physical disability," a person with disability has extensive protections including, "(c) A person with a physical or mental disability shall not be required to demonstrate postoperative independent living abilities in order to have access to a transplant if there is evidence that the person will have sufficient, compensatory support and assistance."

Colorado: No current organ transplant protections for people with disabilities.

Connecticut: No current organ transplant protections for people with disabilities.

Delaware: Under Del. Code Ann. tit. 16, § 2741 (2020). "Legislative Intent," "(5) Delaware

residents in need of organ transplants are entitled to assurances that they will not encounter discrimination on the basis of a disability.” See Del. Code Ann. tit. 16, § 2743 (2020). “Discrimination prohibited.”

District of Columbia: No current organ transplant protections for people with disabilities.

Florida: Fla. Stat. Ann. § 765.523 (LexisNexis 2020). “Discrimination in Access to Anatomical Gifts and Organ Transplants Prohibited.”

Notes: Newly enacted by the Legislature of the State of Florida; Effective July 1, 2020.

The statute added Fla. Stat. Ann. §§ 627.64197, 627.65736, 641.31075 (LexisNexis 2020)

“Coverage for Organ Transplants,” prohibiting the denial of coverage for organ transplants on the basis of disability.

Georgia: No current organ transplant protections for people with disabilities.

Notes: 2019 Bill Text GA H.B. 842: Failed in 1st Chamber. Known as Gracie’s Law, “To amend Chapter 1 of Title 31 of the Official Code of Georgia Annotated, relating to general provisions regarding health, so as to prohibit providers from discriminating against potential organ transplant recipients due solely to the physical or mental disability of the potential recipient. . .”

Guam: No current organ transplant protections for people with disabilities.

Hawaii: No current organ transplant protections for people with disabilities.

Idaho: No current organ transplant protections for people with disabilities.

Illinois: Under the “Illinois Anatomical Gift Act,” 755 Ill. Comp. Stat. Ann. § 50/5-15 (LexisNexis 2020). “Disability of recipient,” “(a) No hospital, physician and surgeon, procurement organization, or other person shall determine the ultimate recipient of an anatomical gift based upon a potential recipient’s physical or mental disability, except to the extent that the physical or mental disability has been found by a physician and surgeon, following a case-by-case evaluation of the potential recipient, to be medically significant to the provision of the anatomical gift.”

Indiana: See Ind. Code Ann. § 16-32-5 (LexisNexis 2020). “Anatomical Gifts and Transplantation.” Burns Ind. Code Ann. § 16-32-5-3 (LexisNexis 2020), “Prohibited actions of a covered entity,” and § 16-32-5-5, “Inability to comply with medical requirements not medically significant if assistance is available” prohibit discrimination by covered entities in organ transplants. But see Ind. Code Ann. § 16-32-5-4 (LexisNexis 2020), “Disability as medically significant,” (similar to discrimination statutes in other states).

Notes: Effective July 1, 2019, Ind. Code Ann. §§ 5-10-8-21 and 27-13-7-24 (LexisNexis 2020) prohibits denial of coverage solely on the basis of disability for anatomical gifts, transplantation, or related health services.

Iowa: No current organ transplant protections for people with disabilities.

Kansas: Under the “Revised Uniform Anatomical Gift Act,” Kan. Stat. Ann. § 65-3276.

“Nondiscrimination on organ transplants,” prevents discrimination in organ transplants based on a person’s physical or mental disability.

Kentucky: No current organ transplant protections for people with disabilities.

Louisiana: Organ transplant discrimination is prohibited under La. Stat. Ann. § 40:1170.3 (2020). “Discrimination against potential organ transplant recipients based on disability; prohibition.”

Maine: No current organ transplant protections for people with disabilities.

Maryland: Under Md. Code Ann., Health-Gen. “Nondiscrimination in Access to Anatomical Gifts and Organ Transplantation.” §§ 20-1601 – 20-1606 (LexisNexis 2020), discrimination based on disabilities in anatomical gifts and organ transplantation is prohibited.

Massachusetts: Mass. Ann. Laws ch. 111, § 236 (LexisNexis 2020). “Nondiscrimination in Access to Organ Transplantation” prohibits covered entities from discriminating against people with disabilities in organ transplantation and related services.

Michigan: No current organ transplant protections for people with disabilities.

Minnesota: No current organ transplant protections for people with disabilities.
Notes: 2019 Bill Text MN H.B. 3078, introduced February 11, 2020 and 2019 Bill Text MN S.B. 3035, introduced February 13, 2020, both failed upon introduction. Synopsis: “A bill for an act relating to human rights; requiring nondiscrimination in access to transplants; prescribing penalties; proposing coding for new law in Minnesota Statutes, chapter 363A.”

Mississippi: No current organ transplant protections for people with disabilities.
Notes: 2020 Bill Text MS H.B. 414, introduced February 3, 2020, failed in 1st Chamber. Synopsis: “An act to enact Cole’s Law to prohibit discrimination against recipients of an anatomical gift or organ transplant based on disability; to define certain terms for the act; to provide requirements for covered entities; to provide for the relief provided by the act; to provide certain requirements of insurers; and for related purposes.”

Missouri: Mo. Ann. Stat. § 194.320 (LexisNexis 2020). “Prohibition on discrimination based on disabilities in anatomical gift process” prohibits discrimination against people with disabilities in each part of the organ transplant process.

Montana: No current organ transplant protections for people with disabilities.

Nebraska: No current organ transplant protections for people with disabilities.
Notes: 2019 Bill Text NE L.B. 994, Introduced, January 14, 2020 (Low chance to pass next stage); “A bill for an act relating to health; to adopt the Organ Transplant Fairness Act.”

Nevada: No current organ transplant protections for people with disabilities.

New Hampshire: No current organ transplant protections for people with disabilities.

New Jersey: N.J. Rev. Stat. § 26:6-77 (2020). “Revised Uniform Anatomical Gift Act,” under § 26:6-86.1, “Findings, declarations relative to anatomical gifts,” prohibits discrimination on the basis of disability of New Jersey residents in need of organ transplants.

New Mexico: No current organ transplant protections for people with disabilities.

New York: 2017 Bill Text NY A.B. 9630, introduced January 26, 2018 and failed upon introduction; 2019 Bill Text NY A.B. 2123, introduced January 22, 2019 and failed upon introduction; No known current additional protections.

North Carolina: No current organ transplant protections for people with disabilities.

North Dakota: No current organ transplant protections for people with disabilities.

Northern Marianas: No current organ transplant protections for people with disabilities.

Ohio: Under the “Revised Uniform Anatomical Gift Act,” Ohio Rev. Code Ann. §§ 2108.01 – 2108.99 (LexisNexis 2020), § 2108.36, “Definitions; nondiscrimination in transplantation services,” prohibits discrimination on the basis of disability.

Oklahoma: No current organ transplant protections for people with disabilities.

Oregon: 2017 Bill Text OR H.B. 2839, Enacted – June 20, 2017; “An Act relating to anatomical gifts; and declaring an emergency,” prohibits a covered entity from considering an individual ineligible to receive an organ transplant solely on the basis of disability. Section 2 of the 2017 act was added to and part of Title 10 Property Rights and Transactions, the Revised Uniform Anatomical Gifts Act (ORS §§97.951 – 97.983).

Pennsylvania: 20 Pa. Cons. Stat. § 8613 (2020). “Manner of executing anatomical gifts,” provides that, “[a]n individual who is in need of an anatomical gift shall not be deemed ineligible to receive an anatomical gift solely because of the individual’s physical or mental disability.”

Puerto Rico: No current organ transplant protections for people with disabilities.

Rhode Island: No current organ transplant protections for people with disabilities.

South Carolina: No current organ transplant protections for people with disabilities.

South Dakota: No current organ transplant protections for people with disabilities.

Tennessee: No current organ transplant protections for people with disabilities.
Notes: 2019 Bill Text TN H.B. 2609, introduced, February 5, 2020, failed upon introduction. If passed, the Act would have prevented discrimination on the basis of disability of a qualified recipient of an anatomical gift.

Texas: No current organ transplant protections for people with disabilities.

Notes: 2013 Bill Text TX S.B. 1112 introduced, March 5, 2013 and failed. If passed, it would have amended the Health and Safety Code to prevent the denial of a person with a disability otherwise eligible for an organ transplant solely on the basis if the person’s physical or mental disability.

Utah: No current organ transplant protections for people with disabilities.

Vermont: No current organ transplant protections for people with disabilities.

Virgin Islands: No current organ transplant protections for people with disabilities.

Virginia: No current organ transplant protections for people with disabilities.

Washington: See Wash. Rev. Code Ann. §§ 68.70.010 - 68.70.030 (LexisNexis 2020). “Organ Transplants.” Under Wash. Rev. Code Ann. § 68.64.210 (LexisNexis 2020), “Prohibition of discrimination,” a covered entity may not deny an anatomical gift to a person with a disability otherwise eligible for an organ transplant, solely on the basis if the person’s physical or mental disability.

West Virginia: No current organ transplant protections for people with disabilities.

Notes: 2020 Bill Text WV S.B. 257, Introduced, January 10, 2020, failed upon introduction.

Synopsis: “A bill. . . relating to prohibiting discrimination based on an individual’s mental or physical disability in access to organ transplantation; and providing enforcement mechanisms.”

Wisconsin: No current organ transplant protections for people with disabilities.

Wyoming: No current organ transplant protections for people with disabilities.

Wrongful Birth and Wrongful Life – States and Territories¹⁸

*Note: This information was exported from the CDHPD Database. The U.S. legal research information was prepared by Tracy Waller Esq., Maryland Center for Developmental Disabilities at Kennedy Krieger Institute.

Definitions:

Wrongful birth claim: A malpractice claim brought by the parents of a child born with a birth defect against a physician or health-care provider whose alleged negligence (as in diagnosis) effectively deprived the parents of the opportunity to make an informed decision whether to avoid or terminate a pregnancy.¹⁹

Wrongful life claim: A malpractice claim brought by or on behalf of a child born with a birth defect alleging that he or she would never have been born if not for the negligent advice or treatment provided to the parents by a physician or health-care provider.²⁰

Wrongful pregnancy/conception claim²¹: “[I]n a wrongful pregnancy action, the parents of a healthy child claim that negligence in the provision of contraceptives or the performance of a sterilization or termination of pregnancy operation has led to the birth of an unplanned child.” *Haymon v. Wilkerson*, 535 A.2d 880, 883 (D.C. 1987).

Alabama

No wrongful birth, wrongful pregnancy, or wrongful life legislation.

Relevant case law

Wrongful birth in Alabama: Claims are recognized as medical negligence malpractice cases and parents must be able to prove their damages. *Keel v. Banach*, 624 So. 2d 1022 (Ala. 1993). In *Keel*, parents filed suit against the doctors for medical malpractice in failing to discover fetal abnormalities that would have caused them to terminate a pregnancy. Although no cause of action for wrongful birth or damages for wrongful birth are recognized in Alabama, “the court held that an action for wrongful birth was in reality a medical negligence malpractice case.” “[T]he parents were allowed to maintain an action claiming that the birth was the result of the negligent failure of the doctors to discover and inform them of the existence of fetal defects.” *Id.* at 1023. **The parents must be able to prove their damages and they can then recover medical and hospital expenses incurred as a result of the doctors’ negligence, the physical pain suffered by the wife, loss of consortium, and for the mental and emotional anguish they had suffered.**

Wrongful pregnancy in Alabama: The court found that damages are recoverable “including: (1) The physical pain and suffering, and mental anguish of the mother as a result of her pregnancy; (2) the loss to the husband of the comfort, companionship, services, and consortium of the wife during her pregnancy and immediately after the birth; and (3) the medical expenses incurred by the parents as a result of the pregnancy.” *Boone v. Mullendore*,

¹⁸ Statute of limitations are not included in this summary, but note that claims will be dismissed should the statute of limitations expire.

¹⁹ www.merriam-webster.com/dictionary/wrongful%20birth

²⁰ www.merriam-webster.com/dictionary/wrongful%20life

²¹ While these claims are not specifically applicable to I/DD, they are often intertwined with wrongful birth and wrongful life legislation and case law, and therefore included for some states.

416 So. 2d 718, 719 (Ala. 1982).

Wrongful life in Alabama: *Elliott v. Brown*, 361 So.2d 546 (Ala. 1978). “The father of the child went to the doctor for a vasectomy because of the medical condition of his wife, which could not support a pregnancy. . . . Despite the vasectomy the wife became pregnant and the child was born with deformities. . . . The child brought an action for wrongful life.” The court dismissed the action for failure to state a claim because it held that there was no legal right not to be born and the child therefore had no cause of action for wrongful life. **(Alabama permits no relief under this claim).**

Alaska

No wrongful birth, wrongful pregnancy, or wrongful life legislation.

Relevant case law:

Wrongful birth in Alaska: No relevant case law.

But see Poor v. Moore, 791 P.2d 1005 (Alaska 1990). In *Poor*, a child was conceived as the result of a tortious sexual relationship between a therapist and a client. The court held that inappropriate sexual conduct resulting in the birth of a child would not allow the victim to recover damages as a wrongful birth medical malpractice case. *Id.*

Wrongful pregnancy/conception in Alaska: No relevant case law; although, courts have discussed in peripherally, no cases have dealt directly with this claim.

Wrongful life in Alaska: No relevant case law.

Arizona

No wrongful birth, wrongful pregnancy, or wrongful life legislation.

Relevant case law

Wrongful birth in Arizona: *Walker by Pizano v. Mart*, 790 P.2d 735 (Ariz. 1990). “A mother sought medical treatment during her pregnancy from two doctors. The doctors failed to adequately test the mother and therefore she was unaware that she had contracted rubella. She gave birth to a child who suffered from severe birth defects including cerebral palsy, deafness, and cardiac abnormalities” *Id.* at 736. “[I]f parents establish that a physician’s negligence prevented them from exercising their right of choice to terminate the pregnancy, they may bring a wrongful birth claim to recover damages in accordance with the principles established in *Univ. of Ariz. Health Scis. Ctr. v. Superior Court*, 667 P.2d 1294 (Ariz. 1983). *Id.* at 738.

But see Arbors Health Care Ctr. v. Superior Court, 1994 Ariz. App. LEXIS 15, at *1 (Ct. App. Jan. 27, 1994). The court held that the **adoption statutes prevented adoptive parents from**

a claim of wrongful birth because they did not suffer any injury from the wrongful birth of a child.

Wrongful pregnancy in Arizona: *Univ. of Ariz. Health Scis. Ctr. v. Superior Court*, 667 P.2d 1294, 1295 (Ariz. 1983). A husband and a wife had a healthy unwanted child after a doctor had performed a failed vasectomy on the husband. The husband and the wife filed a wrongful birth action against the hospital for medical malpractice. The court held that the **parents could present evidence to collect future costs of rearing and educating the child** offset by the benefits [also known as the “benefit” doctrine] to the parents of receiving a healthy child, but that the term “wrongful pregnancy” is used to “describe an action brought by the parents of a healthy, but unplanned, child against a physician who negligently performs a sterilization or abortion.” *Id.* at 1295. This is distinguished from a “wrongful birth” claim brought by the parents of a child born with birth defects.

Wrongful life in Arizona: The court held that **children suffer no legal injury when a parent, doctor, or other practitioner fail to prevent their birth.** *Walker by Pizano*, 790 P.2d at 735.

Myers v. Hoffman-La Roche, Inc., No. 1 CA-CV 06-0137, 2008 Ariz. App. Unpub. LEXIS 857, at *1-2 (Ct. App. May 22, 2008). In *Myers*, claimant, through her mother, sought damages for personal injuries she sustained after her mother took Accutane. The court held that the claims were not barred by “wrongful life” (which is not recognized in Arizona) because they were for **damages sustained in utero.**

Arkansas

Ark. Code Ann. § 16-120-902 (2020). “Wrongful birth claims – Wrongful life claims.” Prohibits civil actions for wrongful life and wrongful birth claims whether or not a child is born healthy or with a birth defect; however, it “[d]oes not apply to a civil action for damages for an intentional, reckless, or grossly negligent act or omission, including without limitation an act or omission that violates criminal law.”

Relevant case law

Wrongful pregnancy/conception in Arkansas: Parents cannot recover the expenses of raising a normal, healthy child; however, “damages connected with the operation and connected with the pregnancy [are recoverable] inasmuch as these are valid damages.” *Wilbur v. Kerr*, S.W.2d 568, 569 (Ark. Sup. Ct. 1982).

California

No specific wrongful birth legislation; however, under Cal. Civ. Code § 1714 (2020). “Responsibility for willful acts or negligence; Proximate cause of injuries resulting from furnishing alcohol to intoxicated person; Liability of social host; Provision of alcoholic beverages to persons under 21 years of age,” “if defendants’ negligence was the proximate cause of plaintiff’s present medical expenses, then the basic liability principles of Cal. Civil Code § 1714 would hold defendants liable for the cost of such care.” *Turpin v. Sortini*, 643 P.2d

954, 955 (Cal. 1982).

No wrongful pregnancy/conception legislation.

Cal. Civ. Code § 43.6 (2020). “Wrongful life action.” “(a) No cause of action arises against a parent of a child based upon the claim that the child should not have been conceived or, if conceived, should not have been allowed to have been born alive.” This statute, “relieves the parents of any liability in this situation and also provides that the parents’ decision shall neither be ‘a defense in any action against a third party’ nor ‘be considered in awarding damages in any such action.’” *Turpin*, 643 P.2d at 959.

Relevant Case Law

Wrongful birth in California: In *Turpin*, a child was born with hereditary deafness, after doctors misdiagnosed her sister’s hereditary defect, thereby depriving her parents the choice to conceive her. “**Parents have regularly been permitted to recover the medical expenses incurred on behalf of such a child.**” *Id.* at 965.

Wrongful pregnancy/conception in California: The court found that “plaintiff should be permitted to recover all the damages to which she is entitled under ordinary tort principles. Under those same principles the defendants may prove any offsets for benefits conferred and amounts chargeable to a plaintiff under her duty to mitigate damages.” *Stills v. Gratton*, 127 Cal. Rptr. 652, 659 (Cal. Ct. App. 1976).

Wrongful life in California: “[W]hile a plaintiff-child in a wrongful life action may not recover general damages for being born impaired as opposed to not being born at all, the child -- like his or her parents -- **may recover special damages for the extraordinary expenses necessary to treat the hereditary ailment.**” *Turpin*, 643 P.2d at 966.

But see Alexandria S. v. Pacific Fertility Medical Center, Inc., 55 Cal. App. 4th 110 (Cal. Ct. App. 1997). **Although courts recognize wrongful life claims by “impaired” children, the court does not recognize wrongful life claims by children born without any mental or physical impairment.**

Colorado

No wrongful birth, wrongful pregnancy, or wrongful life legislation.

Relevant Case Law

Colorado recognizes “wrongful birth” claims but not “wrongful life” claims. *Lininger v. Eisenbaum*, 764 P.2d 1202 (Colo. 1988).

Wrongful birth in Colorado: In *Lininger*, Plaintiffs [the Liningers] had one blind child and were unwilling to have a second blind child. Defendant physicians failed to properly diagnose the first child’s blindness as hereditary, and plaintiffs had a second child, also born blind. Both children were later diagnosed with a hereditary form of blindness. The Liningers allege that

“but for defendant’s act of negligence, plaintiff would have avoided conception of their second infant [Pierce], which was diagnosed with the same blindness.” *Id.* at 1203. “[T]he Liningers’ complaint sufficiently states a cause of action upon which relief may be granted, and they are **entitled to prove and to recover at least the extraordinary medical and education expenses they have incurred, and will incur, in raising Pierce, if they are able to establish that those expenses were proximately caused by defendants’ negligence.**” *Lininger v. Eisenbaum*, 764 P.2d at 1208.

Wrongful pregnancy/conception in Colorado: No relevant case law; although, courts have mentioned the claim, they have not opined on the action.

Wrongful life in Colorado: “[A] person’s existence, however handicapped it may be, does not constitute a legally cognizable injury relative to non-existence.” *Lininger v. Eisenbaum*, 764 P.2d at 1210.

Connecticut

No wrongful birth, wrongful pregnancy, or wrongful life legislation.

Relevant Case Law

Wrongful birth in Connecticut: “Connecticut recognizes a cause of action for wrongful birth.” *Chamberland v. Physicians for Women’s Health, LLC*, Docket No. CV010164040S, 2006 Conn. Super. LEXIS 451, at *8 (Conn. Super. Ct. Feb. 8, 2006). “[T]he law in Connecticut permit[s] **damages for emotional distress in wrongful birth cases where, as in the case at bar, the emotional distress was a direct and proximate result of the defendant’s negligence.**” *Id.* at 1. “Connecticut has adopted the so-called ‘benefit rule’ which permits the trier of fact to deduct from the parents’ damages the value of the joy which the child brings to the parents.” *Id.* at 20.

Wrongful pregnancy in Connecticut: The court in **Connecticut allows “parents to recover for the expenses of rearing an unplanned child to majority when the child’s birth results from negligent medical care.”** *Ochs v. Borrelli*, 445 A.2d 883, 885 (Conn. Super. Ct. 1982).

Wrongful life in Connecticut: *Donnelly v. Candlewood Obstetric-Gynecological Associates, P.C.*, No. 30 20 96, 1992 Conn. Super. LEXIS 1682, at *1 (Conn. Super. Ct. June 8, 1992). The court **declined to recognize the wrongful life claim** because it requires a calculation of damages dependent on a comparison of the “choice of life in an impaired state [to] nonexistence.” *Id.* at 4.

Delaware

No wrongful birth, wrongful pregnancy, or wrongful life legislation.

Relevant Case Law

Wrongful birth in Delaware: *Garrison v. Med. Ctr. of Del., Inc.*, 581 A.2d 288 (Del. 1989). “[T]here is an actionable claim under Delaware law, rooted in common law, for negligence in performing a medical testing procedure and for negligence in failing to timely report the results of testing. The cause of action need not be characterized as ‘wrongful birth’ since it falls within the realm of traditional tort and medical malpractice law.” *Id.* at 290. **“If the health care provider deprives the parents of the ability to choose not to carry an unwell fetus to term, the provider may be held liable for the resulting extraordinary expenses of the parents for child care.”** *Id.* at 292. The expenses include: “maintaining and educating the child exceed the usual costs of raising an unimpaired child.” *Id.*

Wrongful pregnancy in Delaware: In a failed sterilization procedure, the court does not allow damages for support of a healthy child; however, plaintiffs **may be allowed provable damages associated with the procedure, pregnancy, and birth.** These damages are limited to: “1. The pain, suffering and discomfort of Doris Mae Coleman as a result of her last pregnancy; and 2. The cost of a tubal ligation; and 3. The loss to Leroy B. Coleman of the comfort, companionship, services and consortium of Doris Mae Coleman; however, the loss of consortium is limited to the loss arising from pregnancy and immediately after birth; and 4. The medical expenses incurred by Mr. and Mrs. Coleman as a result of the 1968 pregnancy of Mrs. Coleman.” *Coleman v. Garrison*, 327 A.2d 757, 761-62 (Del. 1974). “[P]laintiff must allege and prove not only that the representation was false, but also that it was made with fraudulent intent.” *Coleman*, 327 A.2d at 763. In *Coleman*, the court refused damages to the plaintiffs because there were risks involved in the procedure, and plaintiffs did not prove false representation or intent. *Id.*

Wrongful life in Delaware: The court in *Coleman*, in dicta, adopts the view of many other jurisdictions, denying wrongful life claims, due to the “impossible task of identifying damages based on comparison between life in the child’s impaired state and nonexistence.” *Id.* at 293. The court also distinguishes the claim in *Garrison* from other wrongful life claims when a child was born with Down’s syndrome, because the condition of the child was not caused by action or inaction (or a negligent act) by the defendants. *Id.* at 288.

Washington, D.C.

No wrongful birth, wrongful pregnancy, or wrongful life legislation.

Relevant case law

Wrongful birth in Washington, D.C.: *Dyson v. Winfield*, 129 F. Supp. 2d 22 (D.D.C. 2001). Plaintiff Dyson filed a suit alleging defendant Winfield “negligently prescribed the drug Provera to her while she was pregnant, causing her child to be born with numerous birth defects and eventually die.” *Id.* at 23. “[A] plaintiff may recover for extraordinary child rearing expenses under a common law cause of action for wrongful birth.” *Id.* at 24. *Haymon v. Wilkerson*, 535 A.2d 880, 884-86 (D.C. 1987) (parent of Down’s syndrome child has cause of action for wrongful birth where physician failed to properly advise amniocentesis). But see *Cauman v. George Washington Univ.*, 630 A.2d 1104, 1109 (D.C. 1993) (D.C. allows recovery for extraordinary expenses for child rearing, but does not recognize a claim for negligent infliction of emotional distress resulting from a wrongful birth).

Wrongful pregnancy in Washington, D.C.: “In *Flowers v. District of Columbia*, 478 A.2d 1073 (D.C. 1984), **this court refused to recognize a wrongful pregnancy action**, holding that shifting the financial burden of raising an unplanned but healthy child to a physician would be wholly disproportionate to the culpability involved. *Id.* at 1077.” *Haymon*, 535 A.2d at 883.

Wrongful life in Washington, D.C.: No explicit bar; however, in *Haymon v. Wilkerson*, 535 A.2d 880, 883 (D.C. 1987), the court reiterated that **most courts have refused to recognize a wrongful life action because of an impossible calculation between the “choice of life in an impaired state and nonexistence.”**

Florida

Florida has established the Birth-Related Neurological Injury Compensation Plan under Fla. Stat. Ann. § 766.303 (LexisNexis 2020). The Plan provides “**compensation, irrespective of fault, for birth-related neurological injury claims.**” The rights granted by this plan prevent other claims by the parents or on behalf of the child related to medical negligence, but not bad faith, malicious purpose, or willful and wanton disregard of human life. Awards are calculated under Fla. Stat. Ann. § 766.31. “Administrative law judge awards for birth-related neurological injuries; notice of award.”

Relevant case law

Wrongful birth in Florida: In *Kush v. Lloyd*, plaintiffs Lloyds had one son with an inherited genetic condition. 616 So. 2d 415, 417 (Fla. 1992). They received genetic testing and were advised that their son’s impairment was not a genetic defect. The Lloyds went on to have a second child with the same condition. A test disclosed the condition was inherited. The court “extend[ed] the tort of wrongful birth **to encompass all extraordinary expenses caused by the impairing condition for the duration of the child’s life expectancy.**” *Id.* at 424; *Ramey v. Fassoulas*, 414 So. 2d 198, 200-01 (Fla. Dist. Ct. App. 1982) (limiting liability in damages for the special medical and educational expenses associated with raising a child to the age of majority).

Wrongful pregnancy and wrongful conception in Florida: Florida does not allow “rearing expense damages in ‘wrongful birth’ cases where the child born is otherwise normal and healthy.” *Ramey*, 414 So. 2d at 200.

Wrongful life in Florida: “In common with the other courts to have considered the issue, we decline to recognize a cause of action for general damages for **wrongful life.**” *Lloyd v. N. Broward Hosp. Dist.*, 570 So. 2d 984, 989 (Fla. Dist. Ct. App. 1990); *See, e.g., Moores v. Lucas*, 405 So.2d 1022, 1024-26 (Fla. Dist. Ct. App. 1981); *Viccaro v. Milunsky*, 551 N.E.2d 8, 12-13 (Mass. 1990).

Florida does not recognize specific damages for wrongful life for special care and maintenance expenses before and after the age of majority, ascribing these as claims of the parents and not the child. *Id.*

Georgia

No wrongful birth, wrongful pregnancy, or wrongful life legislation.

Relevant case law

Wrongful birth in Georgia: *Etkind v. Suarez*, 519 S.E.2d 210, 211 (Ga. 1999). “After their child was born with Down’s [s]yndrome, plaintiff parents brought a wrongful birth suit against defendant doctors claiming that, but for the treatment or advice provided by defendants, plaintiffs would have aborted the fetus and prevented the birth of their child.” *Id.* at 211. “The court said that **because the General Assembly had not enacted any legislation authorizing a recovery for wrongful birth, plaintiffs had no viable claim.**” *Id.* (upholding *Atlanta Obstetrics & Gynecology Group v. Abelson*, 398 S.E.2d 557 (Ga. 1990), that that Georgia courts cannot recognize wrongful birth claims absent legislative authorization).

Wrongful pregnancy and wrongful conception in Georgia: “The plaintiffs in a wrongful pregnancy action never wanted to become parents, and their suit is based upon the alleged negligent performance of an actual sterilization or abortion procedure.” *Id.* at 213. “[W]rongful pregnancy will not authorize a recovery of the expenses of raising the child, but only a limited ‘recovery of expenses for the unsuccessful medical procedure which led to conception or pregnancy, for pain and suffering, medical complications, costs of delivery, lost wages, and loss of consortium.’” *Fulton-Dekalb Hospital Authority v. Graves*, 314 S.E.2d 653, 654 (Ga. 1984) in *Etkind*, 519 S.E.2d at 213.

Wrongful life in Georgia: A claim for wrongful life is not recognized in Georgia. *Atlanta Obstetrics & Gynecology Grp. v. Abelson*, 398 S.E.2d 557, 558 (Ga. 1990).

Guam

No wrongful birth or wrongful life legislation.

No relevant case law.

Hawaii

No wrongful birth or wrongful life legislation.

No relevant case law.

Idaho

Idaho Code § 5-334 (LexisNexis 2020). “Act or omission preventing abortion not actionable” prohibits actions for wrongful birth, wrongful pregnancy, and wrongful life. However, it does “not preclude causes of action based on claims that, but for a wrongful act or omission, fertilization would not have occurred, maternal death would not have occurred or disability, disease, defect or deficiency of an individual prior to birth would have been prevented, cured or ameliorated in a manner that preserved the health and life of the affected individual.” *Id.*

Relevant case law

Wrongful birth in Idaho: Although allowed in *Blake v. Cruz*, 698 P.2d 315 (Idaho 1984), the Idaho Legislature enacted Idaho Code § 5-334 to overturn *Blake*. *Vanvooren v. Astin*, 111 P.3d 125, 127 (Idaho 2005).

Although **negligent infliction of emotional distress is prohibited within wrongful birth claims** under Idaho Code § 5-334 (LexisNexis 2020), the court in *Vanvooren*, left the potential for a claim of negligent infliction of emotional distress open, should a plaintiff amend the claim without specifically relying upon wrongful birth allegations. 111 P.3d at 128.

Wrongful pregnancy/conception in Idaho: No relevant case law.

Wrongful life in Idaho: The court held in *Blake*, that **wrongful life was not a cognizable action in Idaho**. 698 P.2d at 315.

Illinois

No wrongful birth, wrongful pregnancy, or wrongful life legislation.

Relevant case law

Wrongful birth in Illinois: “Plaintiffs who succeed in wrongful birth claims are entitled to recover extraordinary damages, including the medical, institutional and educational expenses that are necessary to properly manage and treat their child’s congenital or genetic disorder.” *Williams v. Rosner*, 7 N.E.3d 57 (Ill. 2014). However, “[b]ecause the common law and statutes of the State of Illinois do not require the plaintiff parents to support their child after he reaches the age of majority, **they may not recover his extraordinary postmajority expenses as an element of their damages.**” *Clark v. Children’s Memorial Hospital*, 955 N.E.2d 1065 (Ill. 2011).

Wrongful pregnancy/conception in Illinois: Parents are generally permitted to recover damages for the cost of the unsuccessful operation, pain and suffering, any medical complications caused by the pregnancy, the costs of the child’s delivery, lost wages, and loss of consortium. Parents may not be awarded the expenses of raising a normal, healthy child born following the negligently performed procedure.” *Cockrum v. Baumgartner*, 447 N.E.2d 385, 387 (Ill. 1983).

“[W]here the pleadings establish that the birth of a diseased child is a foreseeable consequence of a negligently performed sterilization procedure, then wrongful pregnancy plaintiffs should be able to obtain an award of extraordinary damages. *Williams v. Rosner*, 7 N.E.3d 57, 67 (Ill. App. Ct. 2014).

Wrongful life in Illinois: *Goldberg v. Ruskin*, 499 N.E.2d 406 (Ill. 1986). In *Goldberg*, “[t]he parents filed a wrongful life action on behalf of their child against the wife’s obstetrician, alleging that he failed to diagnose the presence of Tay-Sachs disease in the fetus and alleged further that had the diagnosis been made, they would have aborted the fetus.” *Id.* The court

held that **“a child may not recover, in an action for wrongful life, damages for pain and suffering associated with the disease or condition that underlies the action.”** *Id.* at 410. **“[N]o right not to be born, even into a life of hardship, has ever been recognized in our judicial system.”** *Siemieniec v. Lutheran General Hospital*, 512 N.E.2d 691, 700 (Ill. 1987).

Indiana:

No wrongful birth legislation.

Burns Ind. Code Ann. § 34-12-1-1 (LexisNexis 2020). “Action based on failure to abort.” “A person may not maintain a cause of action or receive an award of damages on the person’s behalf based on the claim that but for the negligent conduct of another, the person would have been aborted.”

Relevant case law

Wrongful birth in Indiana: *Bader v. Johnson*, 732 N.E.2d 1212 (Ind. 2000). In *Bader*, Plaintiffs sued a doctor for failing to disclose the results of prenatal testing—where the ultrasound showed abnormalities. “The child died several months after birth due to congenital birth defects. Plaintiffs alleged plaintiff wife would have terminated the pregnancy had plaintiffs known the test results.” *Id.* at 1214. The court declined to recognize the tort of wrongful birth, but held that **wrongful birth claims such as these should be addressed as “any other medical malpractice claim.”** *Id.* If the parents proved negligence then they were “entitled to damages proximately caused by the tortfeasor’s breach of duty.” *Id.* at 1220.

Wrongful pregnancy and wrongful conception in Indiana: “The costs involved in raising and educating a normal, healthy child conceived subsequent to an allegedly negligent sterilization procedure **are not cognizable as damages** in an action for medical negligence.” *Chaffee v. Seslar*, 786 N.E.2d 705, 706 (Ind. 2003). However, the **parents can recover costs directly incident to the pregnancy and child bearing expenses.** *Id.* at 708.

Wrongful life in Indiana: Wrongful life damages are not cognizable in Indiana. *Cowe v. Forum Group, Inc.*, 575 N.E.2d 630 (Ind. 1991).

Iowa

Iowa Code § 613.15B (LexisNexis 2020). “Wrongful birth or wrongful life case of action – prohibitions – exceptions.” Iowa prohibits wrongful birth and wrongful life claims except civil actions “for damages for an intentional or grossly negligent act or omission, including any act or omission that constitutes a public offense.” Or “for the intentional failure of a physician to comply with the duty imposed by licensure pursuant to chapter 148 to provide a patient with all information reasonably necessary to make decisions about a pregnancy.”

Relevant case law

Wrongful birth in Iowa: *Plowman v. Fort Madison Cmty. Hosp.*, 896 N.W.2d 393 (Iowa 2017).

In *Plowman*, the court held that wrongful birth claims “**fall within existing medical negligence principles.**” *Id.* at 401.

Wrongful pregnancy in Iowa: *Nanke v. Napier*, 346 N.W.2d 520 (Iowa 1984). In *Nanke*, a failed abortion procedure led to the birth of a healthy child. *Id.* at 521. The court held the parents could not recover. *Id.* at 522-23.

Wrongful life in Iowa: No relevant case law.

Kansas

Kan. Stat. Ann. § 60-1906 (LexisNexis 2020). “Wrongful life or wrongful birth claims; prohibited.” The statute prohibits wrongful life and wrongful birth claims except for those claims where, “the death or physical injury of the mother would not have occurred, or the handicap, disease or disability of an individual prior to birth would have been prevented, cured or ameliorated in a manner that preserved the health and life of such individual.”

Relevant case law

Wrongful pregnancy in Kansas: Kansas courts have parsed out wrongful conception and does not permit the projected cost of rearing a normal, healthy child. *Johnston v. Elkins*, 736 P.2d 935, 938 (Kan. 1987). In Kansas, the court has defined wrongful pregnancy as “cases where parents of a healthy child bring a claim on their own behalf for the monetary and emotional damages they suffered as a result of giving birth to an unwanted child.” *Bruggeman v. Schimke*, 718 P.2d 635 (Kan. 1986) in *Johnston*, 736 P.2d at 938. The court in *Johnston* held that upon proper proof, **damages are recoverable** for: the expense of the unsuccessful vasectomy; the physical pain and suffering of the patient for that surgery; the cost of prenatal care, delivery, and tubal ligation; the physical pain and suffering sustained in connection with the pregnancy, childbirth, and tubal ligation, and during a reasonable recovery period thereafter; loss of consortium at the time of vasectomy, during the later stages of the pregnancy, and during a reasonable recovery period thereafter. 736 P.2d at 940.

Kentucky

No wrongful birth, wrongful pregnancy, or wrongful life legislation.

Relevant case law

Wrongful birth in Kentucky: “Where parents allege that their injury was in being deprived of accurate medical information that would have led them to seek an abortion, the Kentucky Supreme Court is **unwilling to equate the loss of an abortion opportunity resulting in a genetically or congenitally impaired human life, even severely impaired, with a cognizable legal injury.**” *Grubbs v. Barbourville Family Health Ctr., P.S.C.*, 120 S.W.3d 682, 684 (Ky. 2003).

Wrongful pregnancy/conception in Kentucky: No relevant case law.

Wrongful life in Kentucky: “[W]rongful life claims. . . must fail for lack of a cognizable injury.” *Id.*

Louisiana

No wrongful birth, wrongful pregnancy, or wrongful life legislation.

Relevant case law

Wrongful birth in Louisiana: “[A] doctor who negligently fails directly to prevent the conception or birth of an unwanted child, as by negligently performing a sterilization or abortion procedure, or by failing to diagnose or inform the parents that the child might be born with a birth defect - because of a disease or genetic condition -- breaches his duty of care owed to the parents.” *Pitre v. Opelousas Gen. Hosp.*, 530 So.2d 1151, 1157 (La. 1988).

Wrongful pregnancy/conception in Louisiana: Because of the foreseeable consequences of the doctor’s alleged negligent acts and omissions, “the parents upon proper proof may recover for the expenses incurred during pregnancy and delivery, the mother’s pain and suffering, the father’s loss of consortium, service and society, and their emotional and mental distress associated with the birth of an unplanned and unwanted child and the unexpected restriction upon their freedom to plan their family.” *Pitre v. Opelousas General Hospital*, 530 So. 2d 1151, 1161-1162 (La. 1988).

Wrongful life in Louisiana: The court does not recognize these claims in Louisiana. *Davis v. Bd. of Supervisors of La. State Univ. & Agric. & Mech. Coll.*, 709 So.2d 1030 (La. 1998).

Maine

Me. Rev. Stat. Ann. tit. 24, § 2931 (LexisNexis 2020). “Wrongful birth; wrongful life.” The statute limits damages for the birth of a normal, healthy child—and prohibits an award for damages for rearing a healthy child. The statute also limits damages for the birth of an unhealthy child born as the result of professional negligence.

Relevant case law

Wrongful birth in Maine: *Anastosopoulos v. Perakis*, 1995 Me. Super. LEXIS 504 (Me. Super Ct. January 27, 1995). In *Anastopoulos*, plaintiff mother filed a complaint against her physicians for failing to recommend an HIV test, and had she known she was positive, she would have avoided pregnancy or had an abortion. *Id.* at 10. The court found that if she “had brought a timely action, she would have had a cause of action for damages related to Christopher’s illness under subsection 2931(3).” *Id.* at 13.

Wrongful pregnancy and conception in Maine: “A person may maintain a claim for relief based on a failed sterilization procedure resulting in the birth of a healthy child and receive an award of damages for the hospital and medical expenses incurred for the sterilization procedures and pregnancy, the pain and suffering connected with the pregnancy and the loss

of earnings by the mother during pregnancy.” Me. Rev. Stat. Ann. tit. 24, § 2931 (LexisNexis 2020) in *Musk v. Nelson*, 647 A.2d 1198, 1199 (Me. 1994).

Wrongful life in Maine: A child should not be precluded from recovery because his cause of action was titled wrongful life or that his mother failed to bring a timely claim.

Anastosopoulos, 1995 Me. Super. LEXIS 504 at *14. In *Anastosopoulos*, the court found that the child was seeing damages not from being born, but for the effects of the illness the child was born with. *Id.* at 13-14. “The title of the statute itself, ‘wrongful birth/wrongful life’ suggests that the statute envisions actions brought by the child as well as -the parents and does not distinguish between them.” *Id.* at 14.

Maryland

No wrongful birth, wrongful pregnancy, or wrongful life legislation.

Relevant case law

Wrongful birth in Maryland: The State of Maryland **recognizes a tort cause of action for wrongful birth** when the doctor does not inform the patient about an available diagnostic test to determine the nature and extent of any fetal defects, and when the plaintiff asserts she would have aborted the child had she been aware of the fetus’s deformities. *Reed v. Campagnolo*, 630 A.2d 1145 (Md. 1993).

Wrongful pregnancy in Maryland: “In Maryland, a **wrongful pregnancy action is nothing more than an action in negligence and is decided properly by applying the same legal analysis employed in any medical negligence claim.**” *Dehn v. Edgecombe*, 865 A.2d 603, 610 (Md. 2005).

Wrongful life in Maryland: “Because it was impossible to calculate damages that would require a comparison between an impaired life and no life at all, **a wrongful life claim was not recognized.**” *Kassama v. Magat*, 767 A.2d 348, 350 (Md. 2001).

Massachusetts

No wrongful birth, wrongful pregnancy, or wrongful life legislation.

Relevant case law

Wrongful birth in Massachusetts: *Yanjun Li v. Davidson*, 2015 Mass. Super. Lexis 154 (Mass. Super. Ct. Oct, 19, 2015). **The court allows parents of a child born with “a genetic defect” to recover against a “physician whose negligent preconception counseling led the parents to decide to conceive children.”** *Id.* at 6. Parents can recover the extraordinary medical, educational, and other expenses that are associated with and are consequences of the disorder, during the child’s minority. “Under Massachusetts law, the parents of a disabled child must continue to support her in adulthood if the child is physically or mentally impaired and incapable of supporting herself.” *Id.* If parents prove they must continue to support the child;

they will be entitled to recover for the extraordinary expenses they will incur during the child's majority. "The parents may additionally recover for emotional distress and for physical harm caused by that emotional distress and, in some circumstances, for wages they lost or will lose in providing extraordinary care to the child." *Id.* at 6-7.

Wrongful pregnancy in Massachusetts: "[D]amages properly would include the cost of the unsuccessful sterilization procedure and costs directly flowing from the pregnancy: the wife's lost earning capacity; medical expenses of the delivery and care following the birth; the cost of care for the other children while the wife was incapacitated; the cost of the second sterilization procedure and any expenses flowing from that operation; and the husband's loss of consortium; the wife's pain and suffering in connection with the pregnancy and birth and with the second sterilization procedure. . . and emotional distress they sustained as a result of the unwanted pregnancy." *Burke v. Rivo*, 551 N.E.2d 1, 3-4 (Mass. 1990). If the reason for not wanting the child was for economic reasons, the parents "may recover the cost of rearing a normal, healthy but (at least initially) unwanted child. . . the trier of fact should offset against the cost of rearing the child the benefit, if any, the parents receive and will receive from having their child." *Id.* at 6.

Wrongful life in Massachusetts: The court in Massachusetts does not recognize wrongful life claims, finding a comparison of existence to nonexistence beyond the task of the judicial system. *Payton v. Abbott Labs*, 437 N.E.2d 171, 190 (Mass. 1982) in *Doolan v. Ivf Am.*, 2000 Mass. Super. Lexis 581 *6 (Mass. Super. Ct. Nov 20, 2000).

Michigan

Mich. Comp. Laws Serv. § 600.2971 ([LexisNexis 2020](#)). "[Wrongful birth or wrongful life claims; prohibitions; exceptions.](#)" This statute prohibits civil actions for wrongful birth and wrongful life claims; but does not apply to a civil action for damages for an intentional or grossly negligent act or omission.

Relevant case law

Wrongful birth, wrongful conception, and wrongful life in Michigan: "[T]he Legislature has spoken in no uncertain terms, and those terms state that **wrongful birth and wrongful life claims are actionable in Michigan for damages for an intentional or grossly negligent act or omission** Mich. Comp. Laws Serv. § 600.2971(4) ([LexisNexis 2020](#)). Further, **wrongful conception claims remain actionable in Michigan, and damages related to the costs of raising the child to the age of majority may be recovered on a showing of an intentional or grossly negligent act or omission.**" *Cichewicz v Salesin*, 854 N.W.2d 903 (Mich. 2014).

Minnesota

Minn. Stat. Ann. § 145.424 ([LexisNexis 2020](#)). "Prohibition of Tort Actions." The Minnesota statute prohibits claims for wrongful life and wrongful birth where plaintiffs claim that "but for the negligent conduct, an abortion would have been sought." But, it does not prevent wrongful contraception/wrongful pregnancy claims for intentional or negligent malpractice of a contraceptive method or sterilization procedure.

Relevant case law

Wrongful birth and wrongful life in Minnesota: Claims for wrongful birth and wrongful life are prohibited under Minn. Stat. Ann. § 145.424, where “but for” the doctor’s negligence, the child would have been aborted.

Wrongful conception in Minnesota: Minnesota classifies (and allows) all cases where a claim is based in a failed contraceptive method or sterilization procedure as wrongful conception, regardless of whether the child was born healthy or with “genetic abnormalities.” *Sherlock v. Stillwater Clinic*, 260 N.W.2d 169, 172 (Minn. 1977); *Molloy v. Meier*, 660 N.W.2d 444 (Minn. Ct. App. 2003), *aff’d*, 679 N.W.2d 711 (Minn. 2004).

Mississippi

No wrongful birth, wrongful pregnancy, or wrongful life legislation.

Relevant case law

Wrongful birth, wrongful conception/pregnancy, and wrongful life in Mississippi: *Miss. State Fed’n of Colored Women’s Club House for the Elderly in Clinton, Inc. v. L. R.*, 62 So. 3d 351, 364 (Miss. 2010). Other than L.R., Mississippi does not have any wrongful birth, conception/pregnancy, or wrongful life cases. While the court did not address wrongful birth or wrongful life specifically, it followed the majority of jurisdictions, holding that **Mississippi does not recognize a claim for the “wrongful birth” of a healthy child.**

Missouri

No wrongful birth or wrongful pregnancy legislation.

Mo. Rev. Stat. § 188.130 (2020). “No cause of action for wrongful life.” Missouri prohibits wrongful life claims by statute.

Relevant case law

Wrongful birth and wrongful life in Missouri: Missouri does not recognize the torts of wrongful birth or wrongful life. *Wilson v. Kuenzi*, 751 S.W.2d 741, 746 (Mo. 1988), cert. denied 488 U.S. 893, 102 L. Ed. 2d 219, 109 S. Ct. 229 (1988); Mo. Rev. Stat. § 188.130 (1986) in *Williams v. Van Biber*, 886 S.W.2d 10, 12 (Mo. Ct. App. 1994).

Wrongful pregnancy/conception in Missouri: Missouri recognizes wrongful conception as a form of malpractice. *Miller v. Duhart*, 637 S.W.2d 183, 188 (Mo. Ct. App. 1982). If plaintiff can prove injury, this claim allows for compensatory damages that are measurable. “Such damages might include prenatal and postnatal medical expenses, the mother’s pain and suffering during the pregnancy and delivery, loss of consortium, and the cost of a second, corrective sterilization procedure.” *Id.* In addition to these, plaintiffs can recover damages “subject to appropriate proof, emotional distress, loss of wages, pain and suffering associated

with the second corrective procedure, and any permanent impairment suffered by the parents as a result of the pregnancy, the delivery, or the second corrective procedure.” *Girdley v. Coats*, 825 S.W.2d 295, 298-99 (Mo. 1992).

Montana

No wrongful birth, wrongful pregnancy, or wrongful life legislation.

Relevant case law

No wrongful birth or wrongful life case law.

Wrongful pregnancy/conception in Montana: Montana does not recognize wrongful pregnancy claims. *Martin v. Fife*, 1996 Mont. Dist. LEXIS 837, *8 (Mont. Dist. Ct. September 25, 1996).

Nebraska

No wrongful birth, wrongful pregnancy, or wrongful life legislation.

No wrongful birth, wrongful pregnancy, or wrongful life case law.

Nevada

No wrongful birth, wrongful pregnancy, or wrongful life legislation.

Relevant case law

Wrongful birth in Nevada: *Greco v. United States*, 893 P.2d 345 (Nev. 1995). Plaintiff Sundi Greco gave birth to a child with “severe anomalies” who she would have aborted had doctors made a timely diagnosis of the “anomalies afflicting” the child in utero. *Id.* at 347. The court held that should plaintiff mother be able to prove them; she should be able to recover **extraordinary care expenses associated with the doctors’ negligence.** *Id.* at 350. “Nevada law requires the parents of a handicapped child to support that child beyond the age of majority if the child cannot support itself.” Nev. Rev. Stat. Ann. § 125B.110(1) (LexisNexis 2020); see, e.g., *Minnear v. Minnear*, 814 P.2d 85 (Nev. 1991).” *Id.* Therefore, the court held that plaintiff could “recover extraordinary medical and custodial expenses associated with caring for Joshua for whatever period of time it is established that Joshua will be dependent upon her to provide such care.” *Id.*

The court also held that “a mother who is denied her right to abort a severely deformed fetus will suffer emotional distress,” and permitted damages for emotional distress. *Id.* at 351.

Wrongful pregnancy/conception in Nevada: “[T]he mother of a normal, healthy child **could not recover in tort** from a physician who negligently performed her sterilization operation

because the birth of a normal, healthy child is not a legally cognizable injury.” *Szekeres v. Robinson*, 715 P.2d 1076 (Nev. 1986) in *Greco v. United States*, 893 P.2d 345, 348 (Nev. 1995).

Wrongful life in Nevada: Nevada does not recognize a claim by a child for harms the child claims to have suffered by virtue of having been born. *Greco*, 893 P.2d at 348.

New Hampshire

No wrongful birth, wrongful pregnancy, or wrongful life legislation.

Relevant case law

Wrongful birth in New Hampshire: *Smith v. Cote*, 513 A.2d 341 (N.H. 1986). Plaintiffs claim that the mother “contracted rubella early in her pregnancy and that, while she was under the defendants’ care, the defendants negligently failed to test for and discover in a timely manner her exposure to the disease,” that the child was born with multiple impairments, and plaintiff mother would have aborted had she known. *Id.* at 342. The court found that “New Hampshire recognizes a cause of action for wrongful birth.” *Id.* at 348. And that plaintiff mother could seek compensation for “the extraordinary medical and educational costs, extraordinary maternal care . . . damages for her ‘emotional distress, anxiety and trauma.’” *Id.*

Wrongful pregnancy/conception in New Hampshire: New Hampshire permits a claim for wrongful conception. *Kingsbury v. Smith*, 442 A.2d 1003 (N.H. 1982).

Wrongful life in New Hampshire: New Hampshire does not recognize a cause of action for wrongful life. *Smith*, 513 A.2d at 355.

New Jersey

No wrongful birth, wrongful pregnancy, or wrongful life legislation.

Relevant case law

Wrongful birth in New Jersey: *Canesi v. Wilson*, 158 N.J. 490 730 A.2d 805 (1999). The court in New Jersey has emphasized that wrongful birth is not about proving the doctor caused the birth defect, but that the doctor failed to provide parents an appropriate diagnosis and therefore, the option of whether to terminate the pregnancy. *Id.* at 502-03. New Jersey permits recoverable damages for this claim beyond the normal costs of raising a child for the duration of the child’s life, “the special medical expenses attributable to raising a child with a congenital impairment.” *Id.* at 502. And if parents can prove proximate injuries suffered by the doctor’s negligence, **parents can also recover for** emotional and economic injury suffered. *Id.*

Wrongful pregnancy/conception in New Jersey: “We distinguish between the application of the rule in wrongful pregnancy cases that involve damages for the birth of a *healthy* child. We have permitted recovery for **wrongful pregnancy** and have followed the same reasoning as *Berman v. Allan*, applying the concept of the benefits rule to preclude recovery for the normal cost of raising the child, rather than applying it to reduce the emotional distress damages. 404 A.2d 8 (N.J. 1979); See *P. v. Portadin*, 432 A.2d 556 (N.J. Super. Ct. App. Div. 1981); *M. v. Schmid*

Labs., Inc., 428 A.2d 515 (N.J. Super Ct. App. Div. 1981).” *Lodato ex rel. Lodato v. Kappy*, 353 N.J. Super. 439, 447 n.2 (N.J. Super Ct. App. Div. 2002).

Wrongful life in New Jersey: Child can recover extraordinary medical expenses attributable to birth defects as special damages, but could not recover general damages for emotional distress or for an impaired childhood. *Procanik by Procanik v. Cillo*, 478 A.2d 755 (N.J. 1984).

New Mexico

No wrongful birth, wrongful pregnancy, or wrongful life legislation.

Relevant case law

Wrongful birth and wrongful life in New Mexico: No case law on wrongful birth or wrongful life. *But see Provencio v. Wenrich*, 261 P.3d 1089, 1092-93 (N.M. 2011) (defining the meaning of both while comparing them to wrongful conception).

Wrongful conception in New Mexico: “New Mexico remains one of very few jurisdictions to permit **complete recovery for the costs of raising a child to the age of majority** in a wrongful conception case . . . with no offset to the doctor for any benefits that the child might provide the parents over the course of their lives.” *Id.* at 1096 (referencing *Lovelace Medical Ctr. v. Mendez*, 806 P.2d 603, 612, 616-17 (N.M. 1991)).

New York

No wrongful birth, wrongful pregnancy, or wrongful life legislation.

Relevant case law

Wrongful birth in New York: “[T]he child’s parents may seek to **recover their past and future ‘extraordinary financial obligations relating to the care’ of that child during his or her minority.**” *Foote v. Albany Med. Ctr. Hosp.*, 944 N.E.2d 1111, 1114 (N.Y. 2011) in *B.F. v Reproductive Medicine Assoc. of N.Y., LLP*, 136 A.D.3d 73, 77 (N.Y. App. Div. 2015). “The parents must establish that malpractice by a defendant physician deprived them of the opportunity to terminate the pregnancy within the legally permissible time period, or that the child would not have been conceived but for the defendant’s malpractice.” *Mayzel v Moretti*, 105 A.D.3d 816, 817 (N.Y. 2013) in *B.F.*, 136 A.D. 3d at 73.

Wrongful pregnancy/conception in New York: While the court does not permit recovery for raising a healthy child, [i]f that pregnancy was the result of medical malpractice, established law permits the parents to **recover damages for the medical expenses for the care and treatment . . . during pregnancy and delivery of the baby and for the loss of her services and consortium and it permits . . . recover[y] for the physical injury and pain occasioned by [the] unanticipated pregnancy.**” *Sorkin v Lee*, 78 A.D.2d 180, 184 (N.Y. App. Div. 1980).

Wrongful life in New York: **Wrongful life is not legally cognizable.** *Alquijay v St. Luke’s-*

Roosevelt Hosp. Ctr., 473 N.E.2d 244 (N.Y. 1984).

North Carolina

No wrongful birth, wrongful pregnancy, or wrongful life legislation. However, see N.C. Gen. Stat. Ann. § 14-45.1 (LexisNexis 2020). “When abortion is not unlawful.” In the case notes, the statute cites to several cases on wrongful birth, wrongful pregnancy, and wrongful conception.

Relevant case law

Wrongful birth and wrongful life in North Carolina: Claims for relief for wrongful life and wrongful birth are not cognizable. *Azzolino v. Dingfelder*, 337 S.E.2d 528, 532, 537 (N.C. 1985), cert. denied, 479 U.S. 835 (1986).

Wrongful conception/pregnancy in North Carolina: Wrongful conception and pregnancy claims are recognized in North Carolina—and treated as medical malpractice claims. *Jackson v. Bumgardner*, 347 S.E.2d 743, 749 (N.C. 1986).

North Dakota

No wrongful birth or wrongful pregnancy legislation.

N.D. Cent. Code § 32-03-43 (2020). “Wrongful life action prohibited – Definition.” **This statute prohibits wrongful life actions.**

Relevant case law

No wrongful pregnancy/conception case law.

The only case with a wrongful birth claim brought in North Dakota was barred by the two-year statute of limitations for malpractice actions. *B.D.H. v. Mickelson*, 792 N.W.2d 169 (Sup. Ct. N.D. 2010).

Northern Marianas

No wrongful life, wrongful pregnancy, or wrongful birth legislation or case law.

Ohio

No wrongful birth, wrongful pregnancy, or wrongful life legislation.

Relevant case law

Wrongful birth in Ohio: Ohio does not allow recovery for this claim. *Schirmer v. Mt. Auburn Obstetrics & Gynecologic Assocs.*, 844 N.E.2d 1160, 1162 (Ohio 2006).

Wrongful conception/pregnancy in Ohio: Ohio does not recognize this claim. *Johnson v. Univ. Hosps. of Cleveland*, No. 53192, 1988 Ohio App. LEXIS 228, at *8 (Ohio Ct. App. Jan. 14, 1988).

Wrongful life in Ohio: This claim is not actionable in Ohio. *Flanagan v. Williams*, 623 N.E.2d 185, 187 (Ohio Ct. App. 1993).

Oklahoma

Okla. Stat. tit. 16, § 1-741.12 (2020). “Wrongful Life Action – Wrongful Birth Action – Limitation on Damages.” This statute prohibits recovery for wrongful life and wrongful birth actions.

No wrongful pregnancy legislation.

Relevant case law

Wrongful pregnancy/conception in Oklahoma: Damages are not recoverable for this claim. *Morris v. Sanchez*, 746 P.2d 184, 185 (Okla. 1987).

Oregon

No wrongful life, wrongful pregnancy, or wrongful birth legislation.

Relevant case law

Wrongful birth in Oregon: This claim is actionable if plaintiff “establishes a cognizable negligence claim, [and] damages are recoverable to the extent necessary to make the plaintiff whole.” *Tomlinson v. Metro. Pediatrics, LLC*, 412 P.3d 133, 146 (Or. 2018). Damages may also include “the parents’ emotional distress, subject to offsets for emotional benefits the parents may gain in having the child.” *Id.* at 147.

Wrongful pregnancy in Oregon: Plaintiff is entitled to present evidence for damages in a claim for negligence for all alleged harm, including: “damages in the form of expenses of raising the child and providing for the child’s college education.” *Zehr v. Haugen*, 871 P.2d 1006, 1011-1012 (Or. 1994).

Wrongful life in Oregon: This claim is not actionable. *Id.* at 156.

Pennsylvania

42 Pa. Const. Stat. § 8305 (2020). “Actions for wrongful birth and wrongful life.” The statute prohibits wrongful birth and wrongful life claims.

No legislation for wrongful pregnancy.

Relevant case law

No relevant case law for wrongful pregnancy.

Puerto Rico

No wrongful birth, wrongful pregnancy, or wrongful life legislation.

Relevant case law

Wrongful birth in Puerto Rico: There may not be any wrongful birth cases. *But see DOMINGA SOTO CABRAL Y OTROS v. estado LIBRE ASOCIADO DE P.R., UNIVERSIDAD DE P.R., Y OTROS*, 138 D.P.R. 298, 330 (P.R. 1995) (assessing a wrongful pregnancy claim) (“A child’s right to the development of his or her life and the indelible parental obligations arising from it cannot be regarded as compensable damages”). Damages would be recoverable if there is a causal link between the congenital condition and negligent medical act. *Id.* at 315.

Wrongful pregnancy in Puerto Rico: *RAMÓN TORRES ORTIZ y OTROS v. DR. FRANCISCO J. PLÁ y OTROS*, 123 D.P.R. Dec. 637, 648 (P.R. 1989). In *Ortiz v. Plá*, the doctor incorrectly performed a sterilization procedure. “If negligence and a causal relation are established, compensation should be awarded for the medical expenses incurred in the [pregnancy,] delivery and in the sterilizations, the mental anguish, physical sufferings, loss of earnings, and other damages.” *Id.* at 648.

Wrongful life in Puerto Rico: “We simply cannot consider a child’s right to live and develop as ‘compensable damages.’” *DOMINGA SOTO CABRAL Y OTROS*, 138 D.P.R. at 315.

Rhode Island

No wrongful birth, wrongful pregnancy, or wrongful life legislation.

Relevant case law

Wrongful pregnancy/conception in Rhode Island: “Plaintiffs would be entitled to recover the medical expenses of the ineffective sterilization procedure, the medical and hospital costs of the pregnancy, the expense of a subsequent sterilization procedure, loss of wages, loss of consortium to the spouse arising out of the unwanted pregnancy, and medical expenses for prenatal care, delivery, and postnatal care. However, no recovery would be allowable for emotional distress arising out of the birth of a healthy child.” *Emerson v. Magendantz*, 689 A.2d 409, 414 (R.I. 1997). “[T]he public policy of this state would preclude the granting of rearing costs for a healthy child whose parents have decided to forego the option of adoption and have decided to retain the child as their own with all the joys and benefits that are derived from parenthood.” *Id.* at 413.

Wrongful birth in Rhode Island: In the event of the birth of a child who suffers from congenital defects, which birth is a result of an unwanted pregnancy arising out of a negligently performed

sterilization procedure, special medical and educational expenses beyond normal rearing costs should be allowed. *Id.* **Parents would be permitted to recover costs beyond the age of majority** as well as compensation for emotional distress. However, the damage award should be “[o]ffset against such liability would be any economic benefits derived by the parents from governmental or other agencies that might contribute to defraying the costs of caring for the child or its support in adult life.” *Id.*

Wrongful life in Rhode Island: This claim is not permitted in Rhode Island. “If the negligence of the defendants in this case was the cause of injury to the child plaintiff, which resulted in extraordinary medical expense, his parents will be able to claim such damages.” *Schloss v. Miriam Hosp. & DR., C.A. No. 98-2076, 1999 R.I. Super. LEXIS 116, at *16 (Super. Ct. Jan. 11, 1999).*

South Carolina

No wrongful birth, wrongful pregnancy, or wrongful life legislation.

Relevant case law

Wrongful birth in South Carolina: No relevant case law.

Wrongful pregnancy in South Carolina: No relevant case law.

Wrongful life in South Carolina: Following a majority of courts, South Carolina does not recognize an action for wrongful life. “[W]e find [the argument] untenable. . . that a child who already has been born should have the chance to prove it would have been better if he had never have been born at all.” *Willis v. Wu, 607 S.E.2d 63, 71 (S.C. 2004).*

South Dakota

S.D. Codified Laws § 21-55-1 (2020). “No cause of action based on wrongful life – Conception defined.” South Dakota prohibits wrongful life actions by statute.

No wrongful birth or wrongful pregnancy legislation.

No relevant wrongful birth or wrongful pregnancy case law.

Tennessee

No wrongful birth, wrongful pregnancy, or wrongful life legislation.

Relevant case law

Wrongful pregnancy/conception in Tennessee: Plaintiffs cannot recover for the cost of raising a healthy child. *Smith v. Gore, 728 S.W.2d 738 (Tenn. 1987).* However, **damages are**

recoverable “related to the pregnancy and delivery would be recoverable, such as the costs of prenatal care during pregnancy, the expenses of any medical complications arising from the avoidance technique itself or caused by the pregnancy and delivery, as well as pain and suffering from the time Plaintiff discovered she was pregnant until she has recovered from childbirth. In addition, lost wages during pregnancy, delivery, and some period of postnatal recovery of the mother are recoverable. In the appropriate case, loss of consortium would be an element of damages as well.” *Id.* at 751.

Wrongful birth and wrongful life in Tennessee: No “on point” case law; however, courts have dismissed several cases for plaintiff’s failure to allege that any act by the doctors or hospital caused the child’s injuries/disabilities. *Glasner by Glasner v. Howick*, 1997 Tenn. App. LEXIS 766, *1, 1997 WL 677955 (Tenn. Ct. App. November 3, 1997). “Tennessee does not recognize ‘wrongful birth’ as anything other than a claim for ordinary negligence.” See *Owens v. Foote*, 773 S.W.2d 911, 913 (Tenn. 1989).

Texas

No wrongful birth, wrongful pregnancy, or wrongful life legislation.

Relevant case law

Wrongful birth in Texas: “In *Jacobs v. Theimer*, 519 S.W.2d 846 (Tex. 1975), we approved a cause of action for ‘wrongful birth,’ under which **parents may recover the expenses reasonably necessary for the care and treatment of their child’s impairment from a physician who has negligently failed to inform the parents of the risk of that impairment.**” *Nelson v. Krusen*, 678 S.W.2d 918, 923-24 (Tex. 1984).

Wrongful pregnancy/conception in Texas: These claims are not recognized in Texas. Although the action is called “wrongful birth” in *Hickman v. Myers*, the court found that “the cost of raising a healthy child born as a result of the negligent performance of a sterilization operation on the mother is not recoverable from the physician.” 632 S.W.2d 869, 872 (Tex. App. 1982).

Wrongful life in Texas: There is no cause of action in Texas for wrongful life. *Nelson*, 678 S.W.2d at 925.

Utah

Utah Code Ann. § 78B-3-109 (LexisNexis 2020). “Right to life — State policy — Act or omission preventing abortion not actionable — Failure or refusal to prevent birth not a defense.” The statute prohibits a cause of action for wrongful birth and wrongful life.

Relevant case law

Wrongful pregnancy/conception in Utah: “[D]amages [are] recoverable for medical and hospital expenses, compensation for physical and mental pain and damage suffered by the

mother, lost wages, and punitive damages, if applicable. . . [T]he projected costs of rearing a healthy, normal child [are] not recoverable.” *C.S. v. Nielson*, 767 P.2d 504, 505 (Utah 1988).

Vermont

No wrongful birth, wrongful pregnancy, or wrongful life legislation.

No relevant case law for wrongful birth, wrongful pregnancy, or wrongful life.

Virgin Islands

No wrongful birth, wrongful pregnancy, or wrongful life legislation.

No relevant case law for wrongful birth, wrongful pregnancy, or wrongful life.

Virginia

No wrongful birth, wrongful pregnancy, or wrongful life legislation.

Relevant case law

Wrongful birth in Virginia: Virginia recognizes a wrongful birth claim in accordance with traditional tort principles. *Naccash v. Burger*, 290 S.E.2d 825, 829 (Va. 1982). Parents are entitled to recover damages for the care and treatment of a child. *Id.* at 830. Parents are also permitted to recover damages for emotional distress. *Id.* at 831.

Wrongful pregnancy/conception in Virginia: Virginia applies traditional tort principles in a wrongful pregnancy or wrongful conception claim “where the child is reasonably healthy, both physically and mentally.” *Miller v. Johnson*, 343 S.E.2d 301, 304 (Va. 1986). The costs of raising a healthy child are not recoverable because those damages are too speculative. *Id.* at 302. However, [t]he mother . . . may recover damages, if proven, for medical expenses, pain and suffering, and lost wages for a reasonable period, directly resulting from the negligently performed abortion, the continuing pregnancy, and the ensuing childbirth. The mother is also entitled to recover damages for emotional distress causally resulting from the tortiously caused physical injury.” *Id.*

Wrongful life in Virginia: A wrongful life claim cannot be maintained in Virginia. *Glascovk v. Laserna*, 30 Va. Cir. 366, 369 (Va. Cir. Ct. 1993).

Washington

No wrongful birth, wrongful life, or wrongful pregnancy legislation. Although not directly on point, the court has cited to Wash. Rev. Code Ann § 4.24.010 (LexisNexis 2020) to inform damages for wrongful birth claims.

Relevant case law

Wrongful birth in Washington: Recovery may include “those expenses in excess of the cost of the birth and rearing of . . . normal children. In addition, the damages may compensate for mental anguish and emotional stress suffered by the parents during [the] child’s life as a proximate result of the physicians’ negligence. Any emotional benefits to the parents resulting from the birth of the child should be considered in setting the damages.” *Harbeson v. Parke-Davis, Inc.*, 656 P.2d 483, 494 (Wash. 1983).

Wrongful pregnancy/conception in Washington: Child-rearing costs cannot be recovered. But, if proven, “damages for the expense, pain and suffering, and loss of consortium associated with the failed tubal ligation, pregnancy and childbirth may be recovered.” *McKernan v. Aasheim*, 687 P.2d 850, 856 (Wash. 1984).

Wrongful life in Washington: A “child may maintain an action for wrongful life in order to recover the extraordinary expenses to be incurred during the child’s lifetime, as a result of the child’s congenital defect. . . [T]he costs of such care for the child’s minority may be recovered only once. *Wooldridge v. Woolett*, 96 Wn.2d 659, 666, 638 P.2d 566 (1981). If the parents recover such costs for the child’s minority in a wrongful birth action, the child will be limited to the costs to be incurred during his majority.” *Harbeson v. Parke-Davis, Inc.*, 656 P.2d 483, 495 (Wash. 1983).

West Virginia

No wrongful birth, wrongful pregnancy, or wrongful life legislation.

Relevant case law

Wrongful birth in West Virginia: Parents may “recover the extraordinary costs for rearing a child with birth defects not only during his minority, but also after the child reaches the age of majority if the child is unable to support himself because of physical or emotional disabilities.” *James G. v. Caserta*, 332 S.E.2d 872, 882-83 (W. Va. 1985).

Wrongful pregnancy/conception in West Virginia: Wrongful pregnancy claims are recognized in West Virginia. *Id.* at 876. The ordinary costs of raising a healthy child cannot be recovered. *Id.* at 878. The court held that damages could include: “(1) any medical and hospital expenses incurred as a result of a physician’s negligence, including costs of the initial unsuccessful sterilization operation, prenatal care, childbirth, postnatal care, and a second sterilization operation, if obtained; (2) the physical and mental pain suffered by the wife as a result of the pregnancy and subsequent childbirth and as a result of undergoing two sterilization operations; and (3) recovery for the loss of consortium and loss of wages.” *Id.* at 877.

Wrongful life in West Virginia: This claim is not recognized in West Virginia. *Id.* at 881.

Wisconsin

No wrongful birth, wrongful pregnancy, or wrongful life legislation.

Relevant case law

Wrongful birth in Wisconsin: Plaintiffs must prove the doctor was negligent in not diagnosing a condition that would have led them to seek an abortion—and that one was legally available to them. *Dumer v. St. Michael's Hospital*, 233 N.W.2d 372, 377 (Wis. 1975). “If they obtain a favorable finding as to all of these facts, they then are **entitled to the damages they have sustained because of the deformity and defects of the child**. Their damages must be limited to those expenses which they have reasonably and necessarily suffered, and will to a reasonable medical certainty suffer in the future by reason of the additional medical, hospital and supportive expense occasioned by the deformities of the child as contrasted to a normal, healthy child.” *Id.*

Wrongful pregnancy/conception in Wisconsin: Using the term “negligent sterilization,” **Wisconsin permits parents to recover the full costs of raising a healthy child to majority.** *Marciniak v. Lundborg*, 450 N.W.2d 243, 244 (Wis. 1990).

Wrongful life in Wisconsin: This claim is not recognized in Wisconsin. “The damages claimed cannot be measured by any standards recognized by our law.” *Dumer v. St. Michael's Hosp.*, 233 N.W.2d 372, 376 (Wis. 1975) (ruling on the claim as a wrongful birth claim of the child—which is a wrongful life claim in almost every other state).

Wyoming: No wrongful birth, wrongful pregnancy, or wrongful life legislation.

Relevant case law

Wrongful pregnancy/conception in Wyoming: If parents can prove fault, parents can “recover damages for any medical expenses associated with the unsuccessful ligation, medical expenses for the birth of the unplanned child, wages for lost time due to the pregnancy, and costs of abortion, together with pain and suffering.” *Beardsley v. Wierdsma*, 650 P.2d 288, 289 (Wyo. 1982) (using “wrongful birth” and “wrongful pregnancy” interchangeably for a failed sterilization procedure leading to the birth of a healthy child).

Wrongful birth in Wyoming: There are no specific wrongful birth cases. In *Beardsley*, the terms “wrongful birth” and “wrongful pregnancy” were used interchangeably for negligent sterilization procedures leading to healthy children. *Id.* However, in awarding damages, **the court expressly rejected the “benefit-rule” or offset concept** (“with fact finders first assessing the expense and damage incurred because of a child’s life, then deducting the value of that child’s life”). *Id.*

Wrongful life in Wyoming: There are no specific wrongful life cases. In *Beardsley*, the court dismissed the wrongful life claims of healthy children; however, no cases exist in Wyoming for wrongful life claims of

Appendix C: CDHPD Database

CDHPD Database Data Entry Screen Example

Gap Analysis

[Gap Analysis Tables](#) [Add Document](#)

*****You must click the Submit Button (at the bottom of the form) to save your data*****

Add Gap Analysis Document

Lead Partners *

- University of Cincinnati Center for Excellence in Developmental Disabilities
- Human Development Institute
- American Academy of Developmental Medicine and Dentistry
- Maryland Center for Developmental Disabilities at Kennedy Krieger Institute
- Vanderbilt Kennedy Center for Research on Human Development
- Family Voices
- Autistic Self-Advocacy Network
- The Boggs Center on Developmental Disabilities

Focus Area *

- Prenatal Genetic Testing
- Life Saving Treatment (Organ Transplant)
- Aging / End of Life Care
- Mental Health / Suicide Prevention for people with ID / DD
- Legal Aspects for All Focus Areas
- COVID-19
- Other

Team Member 1 *

First Last

Role (Team Member 1)

- Self-Advocate
- Family Member
- Project Staff
- Medical Provider
- Other

Document Title *

Briefly Describe the Document

Document Type *

- Curricula
- Policy
- Policy Related Document
- Manuscript
- Media Report
- Organizational Statement
- Legal Document
- Key informant interview highlight
- Other

Evidence Score *

- Not Evident
- Somewhat Evident
- Clearly Evident

[Review Evidence Scale](#)

Utility Score *

- Not Useful
- Somewhat Useful
- Very Useful

[Review Utility Scale](#)

Notes

Gaps Highlighted in this Document

Gaps Missing (Not Addressed) in Document

APA Citation for Document

Document Link

Please Upload the Document Below

Upload Document

No file chosen

Appendix D: Gap Analysis - Document Review Bibliography

*Note: The bibliography was exported from the CDHPD Database. Only 46% of the documents had APA citations in the database.

Ackson, L., Cichon, M., Kleinert, H., & Trepanier, A. (in press). Teaching medical students how to deliver diagnoses of Down syndrome: Utility of an educational tool. *Patient Education and Counseling*.

Ali, A., Scior, K., Ratti, V., Strydom, A., King, M., Hassiotis, A., & Ginsberg, S. (2013). Discrimination and other barriers to accessing health care: Perspectives of patients with mild and moderate intellectual disability and their carers. *PLoS ONE*, 8(8), e70855.

Allyse, M., Aypar, U., Bonhomme, N., Darilek, S., Dougherty, M., Farrell, R., ... & Otto, L. (2017). Offering prenatal screening in the age of genomic medicine: A practical guide. *Journal of Women's Health*, 26(7), 755-761.

American College of Obstetricians and Gynecologists. (2007). ACOG Practice Bulletin Number 88. *Obstetrics and Gynecology*, 110: 1459-1467.

Becker, AJ. Prenatal Diagnosis of Down Syndrome: What Would You Choose? *Christianity Today*. <https://www.christianitytoday.com/amyjuliabecker/2015/february/prenatal-diagnosis-of-down-syndrome-what-would-you-choose.html>.

Benevides, T., Carretta, H., & Lane, S. (2016). Unmet need for therapy among children with Autism Spectrum Disorder: Results from the 2005–2006 and 2009–2010 National Survey of Children with Special Health Care Needs. *Maternal and Child Health Journal*, 20(4), 878–888.

Bishop, K., Robinson, L., & Vanlare, S. (2013). Healthy aging for older adults with intellectual and development disabilities. *Journal of Psychosocial Nursing and Mental Health Services*, 51(1), 15–18.

Boardman FK. The expressivist objection to prenatal testing: The experiences of families living with genetic disease. *Social science & medicine* (1982). 2014; 107:18-25. doi: 10.1016/j.socscimed.2014.02.025.

Brasington CK. What I Wish I Knew Then...Reflections from Personal Experiences in Counseling about Down Syndrome. *J Genet Counsel*. 2007;16(6):731-734. doi:10.1007/s10897-007-9116-1

Bryant LD, Green JM, Hewison J. The role of attitudes towards the targets of behaviour in predicting and informing prenatal testing choices. *Psychology & Health*. 2010;25(10):1175-1194. doi:10.1080/08870440903055893.

Burke, M., & Heller, T. (2017). Disparities in unmet service needs among adults with intellectual and other developmental disabilities. *Journal of Applied Research in Intellectual Disabilities*, 30(5), 898–910.

Caplan, A. Disclosing Down Syndrome to Pregnant Patients: Must You Give an Upside? *Medscape*. March 25, 2016. <https://www.medscape.com/viewarticle/860611>.

- Carroll, C., Carroll, C., Goloff, N., & Pitt, M. B. (2018). When bad news isn't necessarily bad: recognizing provider bias when sharing unexpected news. *Pediatrics*, 142(1).
- Cernat, A., De Freitas, C., Majid, U., Higgins, C., & Vanstone, M. (2019). Facilitating informed choice about non-invasive prenatal testing (NIPT): a systematic review and qualitative meta-synthesis of women's experiences. *BMC pregnancy and childbirth*, 19(1), 1-15.
- Chauhan, U., Kontopantelis, E., Campbell, S., Jarrett, H., & Lester, H. (2010). Health checks in primary care for adults with intellectual disabilities: how extensive should they be? *Journal of Intellectual Disability Research*, 54(6), 479–486.
- Cheak-Zamora, N., Xuejing Yang, Farmer, J., & Clark, M. (2013). Disparities in transition planning for youth with autism spectrum disorder. *Pediatrics*, 131(3), 447–44754.
- Chiri, G., & Warfield, M. (2012). Unmet need and problems accessing core health care services for children with autism spectrum disorder. *Maternal and Child Health Journal*, 16(5), 1081–1091.
- Cleary-Goldman J, Morgan MA, Malone FD, Robinson JN, D'Alton ME, Schulkin J. Screening for Down syndrome: Practice patterns and knowledge of obstetricians and gynecologists. *Obstet Gynecol* 2006;107:11-17.
- Cohen, A. B., Wright, M. S., Cooney, L., & Fried, T. (2015). Guardianship and end-of-life decision making. In *JAMA Internal Medicine* (Vol. 175, Issue 10, pp. 1687–1691). American Medical Association. <https://doi.org/10.1001/jamainternmed.2015.3956>.
- Complex Moral Issues: End-of-Life Decisions for Adults with Significant Intellectual Disabilities. <https://ucedd.georgetown.edu/complex/index.html>.
- Constantino, J.N., Strom, S., Bunis, M. et al. Toward Actionable Practice Parameters for “Dual Diagnosis”: Principles of Assessment and Management for Co-Occurring Psychiatric and Intellectual/Developmental Disability. *Curr Psychiatry Rep* 22, 9 (2020). <https://doi.org/10.1007/s11920-020-1127-8>
- Cook, M. Oregon: “wrongful birth” of Down syndrome child. *BioEdge*. March 16, 2012.
- Dley, B. (2014). Oversold and Misunderstood. *Boston Globe*.
- Driscoll, D. A., Morgan, M. A., & Schulkin, J. (2009). Screening for Down syndrome: changing practice of obstetricians. *American journal of obstetrics and gynecology*, 200(4), 459-e1.
- Dupras, C., Birko, S., Affdal, A., Haidar, H., Lemoine, M. E., & Ravitsky, V. (2018). Benefits, challenges, and ethical principles associated with implementing noninvasive prenatal testing: a Delphi study. *CMAJ open*, 6(4), E513.
- Dykens, E., Shah, B., Davis, B., Baker, C., Fife, T., & Fitzpatrick, J. (2015). Psychiatric disorders in adolescents and young adults with Down syndrome and other intellectual disabilities. *Journal of Neurodevelopmental Disorders*, 7(1), 9.
- Ebert L, Bellchambers H, Ferguson A, Browne J. Socially disadvantaged women's views of barriers to feeling safe to engage in decision-making in maternity care. *Women and Birth*. 2014;27(2):132-137. doi:<http://dx.doi.org/10.1016/j.wombi.2013.11.003>.

- Edwards, J. G., & Ferrante, R. R. (2009). *Toward concurrence: understanding prenatal screening and diagnosis of Down syndrome from the health professional and advocacy community perspectives*. Columbia, SC: University of South Carolina.
- Estreich, G. (2019). *Fables and Futures: Biotechnology, Disability, and the Stories We Tell Ourselves*. MIT Press.
- Faragher R. Research in the Field of Down Syndrome: Impact, Continuing Need, and Possible Risks from the New Eugenics. *Journal of Policy and Practice in Intellectual Disabilities*. 2019;16(2):130-133. doi:10.1111/jppi.12305.
- Ferguson, J., Kleinert, H., Lunney, C., & Campbell, L. (2006). Improving resident physicians' competencies and attitudes in delivering a postnatal diagnosis of Down syndrome. *Obstetrics and Gynecology*, 108, 898-905.
- Frank, S. (2014). Eligibility Discrimination of the Intellectually Disabled in Pediatric Organ Transplantation. *Journal of Health and Biomedical Law* 10, 101-136. <https://heinonline.org/HOL/LandingPage?handle=hein.journals/jhbio10&div=8&id=&page=>.
- Friedman, C., & Owen, A. (2017). Sexual health in the community: Services for people with intellectual and developmental disabilities. *Disability and Health Journal*, 10(3), 387–393.
- Krahn, G., Hammond, L., & Turner, A. (2006). A cascade of disparities: Health and health care access for people with intellectual disabilities. *Mental Retardation and Developmental Disabilities Research Reviews*, 12(1), 70–82.
- García-Pérez, L., Linertová, R., Álvarez-de-la-Rosa, M., Bayón, J. C., Imaz-Iglesia, I., Ferrer-Rodríguez, J., & Serrano-Aguilar, P. (2018). Cost-effectiveness of cell-free DNA in maternal blood testing for prenatal detection of trisomy 21, 18 and 13: a systematic review. *The European Journal of Health Economics*, 19(7), 979-991.
- Gill, M. (2015). *Already doing it: Intellectual disability and sexual agency*. U of Minnesota Press.
- Hall, I., Soni, S., Razza, N. J., Dayan, L. S., Tomasulo, D., & Ballan, M. S. (2014). Intellectual disability and mental health: is psychology prepared?. *Advances in Mental Health and Intellectual Disabilities*.
- Haveman, M., Heller, T., Lee, L., Maaskant, M., Shooshtari, S., & Strydom, A. (2010). Major health risks in aging persons with intellectual disabilities: an overview of recent studies. *Journal of Policy and Practice in Intellectual Disabilities*, 7(1), 59-69.
- Hedley, D., Uljarević, M., Foley, K. R., Richdale, A., & Trollor, J. (2018). Risk and protective factors underlying depression and suicidal ideation in autism spectrum disorder. *Depression and anxiety*, 35(7), 648-657.
- Hedley, D., Uljarević, M., Wilmot, M., Richdale, A., & Dissanayake, C. (2017). Brief report: social support, depression, and suicidal ideation in adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 47(11), 3669-3677.
- Heslop, P., Blair, P., Fleming, P., Hoghton, M., Marriott, A., & Russ, L. (2014). The Confidential Inquiry into premature deaths of people with intellectual disabilities in the UK: a population-based study. *The Lancet*, 383(9920), 889–895.

- Ho, C. (2017, May 16). Insurers help make genetic testing widely available. San Francisco Chronicle. <https://www.sfchronicle.com/business/article/A-new-era-for-genetic-testing-especially-in-11148178.php>.
- How, B., Smidt, A., Wilson, N. J., Barton, R., & Valentin, C. (2019). 'We would have missed out so much had we terminated': What fathers of a child with Down syndrome think about current non-invasive prenatal testing for Down syndrome. *Journal of Intellectual Disabilities*, 23(3), 290-309.
- Jackson, K., Krishnaswami, S., & Mcpheeters, M. (2011). Unmet health care needs in children with cerebral palsy: A cross-sectional study. *Research in Developmental Disabilities*, 32(6), 2714–2723.
- Johnson, C. (2019, February 8). Our concerns about non-invasive prenatal testing (NIPT) in the private healthcare sector. Nuffield Council on Bioethics. <https://www.nuffieldbioethics.org/blog/nipt-private..>
- Johnston, J., Farrell, R., & Parens, E. (2017). Supporting women's autonomy in prenatal testing. *The New England journal of medicine*, 377(6), 505.
- Kaplan, A. (2016). Disclosing Down Syndrome to Pregnant Patients: Must You Give an Upside?. *Medscape*. Retrieved from <https://www.medscape.com/viewarticle/860611> on March 28, 2020.
- Kaposy, C. Non-invasive prenatal testing makes it simpler than ever to detect the condition, but does it amount to discrimination? *Policy Options Politiques*. April 22, 2019.
- Kleinert, H.L., Lunney, C.A., Campbell, L., Ferguson, J.E. II. (2009). Improving residents' understanding of issues, comfort levels, and patient needs regarding screening for and diagnosing Down syndrome. *American Journal of Obstetrics and Gynecology*, 201:328, e1-6.
- Kripke, C. (2017). Patients with Disabilities: Avoiding Unconscious Bias When Discussing Goals of Care - Curbside Consultation - *American Family Physician*. *American Family Physician*. <https://www.aafp.org/afp/2017/0801/p192.html>.
- Leach, M. (2016, April 1). Breaking news: prenatal testing for Down syndrome done right from now on. *Down syndrome Prenatal Testing*. <http://www.downsyndromeprenataltesting.com/breaking-news-prenatal-testing-for-down-syndrome-done-right-from-now-on/>.
- Leach, M. (2016, April 14). Down Syndrome Prenatal testing. Site name. <http://www.downsyndromeprenataltesting.com/response-to-art-caplan-provide-all-the-recommended-information-with-prenatal-testing-for-down-syndrome/>.
- Leach, M. W. (2015). Unjustified: the imbalance of information and funding with noninvasive prenatal screening. *AJOB Empirical Bioethics*, 6(1), 21-30.
- Mazurek, M., Brown, R., Curran, A., & Sohl, K. (2017). ECHO autism: A new model for training primary care providers in best-practice care for children with autism. *Clinical Pediatrics*, 56(3), 247–256.
- Mcnally, P., & McMurray, K. (2015). Exploration of the dynamic barriers to adults with intellectual

- disabilities accessing mainstream mental health services. *Advances in Mental Health and Intellectual Disabilities*, 9(6), 352–362.
- Mello, M., Persad, G., White, D.B. (May 19, 2020). Respecting Disability Rights — Toward Improved Crisis Standards of Care. *NEJM*, 1-4. Retrieved from <https://www.nejm.org/doi/pdf/10.1056/NEJMp2011997?articleTools=true>.
- Mindy B. Statter, Garey Noritz and COMMITTEE ON BIOETHICS, COUNCIL ON CHILDREN WITH DISABILITIES *Pediatrics* May 2020, 145 (5) e20200625; DOI: <https://doi.org/10.1542/peds.2020-0625>
- Mitra, M. (2017). Postpartum health of women with intellectual and developmental disabilities: A call to action. *Journal of Women’s Health* (2002), 26(4), 303–304.
- Mollison, E., Chaplin, E., Underwood, L., & McCarthy, J. (2014). A review of risk factors associated with suicide in adults with intellectual disability. *Advances in Mental Health and Intellectual Disabilities*.
- Molteni, M. (2019). How Much Prenatal Genetic Information Do You Actually Want? *Wired*. Retrieved online March 27, 2020.
- Morain, S., Greene, M. F., & Mello, M. M. (2013). A new era in noninvasive prenatal testing. *The New England journal of medicine*, 369(6), 499.
- Murray SA, Kendall M, Carduff E, et al. Use of serial qualitative interviews to understand patients’ evolving experiences and needs. *BMJ*. 2009;339. doi:10.1136/bmj.b3702.
- Naaldenberg, J., Banks, R., Lennox, N., Ouellette-Kunz, H., Meijer, M., & Lantman-De Valk, H. (2015). Health inequity in people with intellectual disabilities: From evidence to action applying an appreciative inquiry approach. *Journal of Applied Research in Intellectual Disabilities*, 28(1), 3–11.
- “Nelson Goff, B. S., Springer, N., Foote, L. C., Frantz, C., Peak, M., Tracy, C., ... & Cross, K. A. (2013). Receiving the initial Down syndrome diagnosis: a comparison of prenatal and postnatal parent group experiences. *Mental Retardation*, 51(6), 446-457. Chicago ”
- Ohno, M., Allen, A., Cheng, Y., Shaffer, B., Blumenfeld, Y., Norton, M., & Caughey, A. (2013). 547: A cost-effectiveness analysis of using non-invasive prenatal testing as a screening tool for Down syndrome. *American Journal of Obstetrics & Gynecology*, 208(1), S235.
- Organ Procurement and Transplantation Network (OPTN). 42 C.F.R. Pt. 121 (2018). <https://www.law.cornell.edu/cfr/text/42/part-121>.
- Overby, K., & Fins, J. (2016). Organ transplantation for individuals with neurodevelopmental disorders. *Cambridge Quarterly of Healthcare Ethics*, 25(2), 272–281.
- Parish, S., Swaine, J., Son, E., & Luken, K. (2013). Receipt of mammography among women with intellectual disabilities: Medical record data indicate substantial disparities for African American women. *Disability and Health Journal*, 6(1), 36–42.
- Ploeg Booth, K. (2011). Health disparities and intellectual disabilities: Lessons from individuals with down syndrome. *Developmental Disabilities Research Reviews*, 17(1), 32–35.

- Pond E, Dimond R. Reproductive decision making: interviews with mothers of children with undiagnosed developmental delay. *J Community Genet.* 2018;9(3):315-325. doi:10.1007/s12687-017-0354-0.
- Portocarrero, M. E. L., Garvelink, M. M., Perez, M. M. B., Giguère, A., Robitaille, H., Wilson, B. J., ... & Légaré, F. (2015). Decision aids that support decisions about prenatal testing for Down syndrome: an environmental scan. *BMC medical informatics and decision making*, 15(1), 76.
- Resta, R. Selective Amnesia, Part 3: We Are Judged On Our History. *The DNA Exchange.* July 6, 2020. <https://thednaexchange.com/2020/07/06/selective-amnesia-part-3-we-are-judged-on-our-history/>.
- Rubeis, G., & Steger, F. (2019). A burden from birth? Non-invasive prenatal testing and the stigmatization of people with disabilities. *Bioethics*, 33(1), 91–97. <https://doi.org/10.1111/bioe.12518>.
- Ryan, K. Law could change how parents are told about Down Syndrome. (2014, May 4). *WTOP News.* <https://wtop.com/news/2014/05/law-could-change-how-parents-are-told-about-down-syndrome/>.
- Ryan, K., Mcevoy, J., Guerin, S., & Dodd, P. (2010). An exploration of the experience, confidence, and attitudes of staff to the provision of palliative care to people with intellectual disabilities. *Palliative Medicine*, 24(6), 566–572.
- Sanborn, E., & Patterson, A. R. (2014). Disability training in the genetic counseling curricula: bridging the gap between genetic counselors and the disability community. *American Journal of Medical Genetics Part A*, 164(8), 1909-1915.
- Schwartz, M. and Vellody, K. (2016). Prenatal Risk Assessment and Diagnosis of Down Syndrome: Strategies for Communicating Well with Patients. *AMA Journal of Ethics*, 18(4), 359-364. Retrieved from <https://journalofethics.ama-assn.org/sites/journalofethics.ama-assn.org/files/2018-06/joe-1604.pdf>.
- Shapiro, Joseph. (2006, December). Dispute over Mental Competency Blocks Transplant. *NPR.* <https://www.npr.org/templates/story/story.php?storyId=6665577>.
- Sheets, K. B. (2009). Defining essential information in a balanced presentation of Down syndrome (Doctoral dissertation, University of South Carolina).
- Sheinis, M., Bensimon, K., & Selk, A. (2018). Patients' knowledge of prenatal screening for trisomy 21. *Journal of genetic counseling*, 27(1), 95-103.
- Simpson, J. (2010). "What do you expect? She is mentally retarded!": on meeting the health challenges of individuals with intellectual disability. *The Internet Journal of Health*, 11(1).
- Skotko, B. G. (2005). Prenatally diagnosed Down syndrome: mothers who continued their pregnancies evaluate their health care providers. *American journal of obstetrics and gynecology*, 192(3), 670-677.
- Skotko, B. G. (2009). With new prenatal testing, will babies with Down syndrome slowly disappear?. *Archives of disease in childhood*, 94(11), 823-826.

- Skotko, B. G., Allyse, M. A., Bajaj, K., Best, R. G., Klugman, S., Leach, M., ... & Gregg, A. R. (2019). Adherence of cell-free DNA noninvasive prenatal screens to ACMG recommendations. *Genetics in Medicine*, 21(10), 2285-2292. Chicago.
- Skotko, B. G., Kishnani, P. S., Capone, G. T., & Down Syndrome Diagnosis Study Group. (2009). Prenatal diagnosis of Down syndrome: How best to deliver the news. *American Journal of Medical Genetics Part A*, 149(11), 2361-2367.
- Skotko, B. G., Levine, S. P., & Goldstein, R. (2011). Having a son or daughter with Down syndrome: Perspectives from mothers and fathers. *American Journal of Medical Genetics Part A*, 155(10), 2335-2347.
- Skotko, B. G., Levine, S. P., & Goldstein, R. (2011). Self-perceptions from people with Down syndrome. *American Journal of Medical Genetics Part A*, 155(10), 2360-2369.
- Slayter, E. (2010). Medicaid-covered alcohol and drug treatment use among people with intellectual disabilities: Evidence of disparities. *Intellectual and Developmental Disabilities*, 48(5), 361–374.
- Song, K., Musci, T. J., & Caughey, A. B. (2013). Clinical utility and cost of non-invasive prenatal testing with cfDNA analysis in high-risk women based on a US population. *The journal of maternal-fetal & neonatal medicine : the official journal of the European Association of Perinatal Medicine, the Federation of Asia and Oceania Perinatal Societies, the International Society of Perinatal Obstetricians*, 26(12), 1180–1185. <https://doi.org/10.3109/14767058.2013.770464>.
- Stein, R. Blood. (2014, February 26). Test Provides More Accurate Prenatal Testing For Down Syndrome. NPR. <https://www.npr.org/sections/health-shots/2014/02/26/282095202/blood-test-provides-more-accurate-prenatal-testing-for-down-syndrome>.
- Tracy, J., & McDonald, R. (2015). Health and disability: Partnerships in health care. *Journal of Applied Research in Intellectual Disabilities*, 28(1), 22–32.
- Treatment Advocacy Center (July 2018). Emergency Hospitalization for Evaluation Assisted Psychiatric Treatment Standards by State. 1-13. Retrieved from https://www.treatmentadvocacycenter.org/storage/documents/Emergency_Hospitalization_for_Evaluation.pdf.
- Treatment Advocacy Center (July 2018). State Standards for Civil Commitment, 1-50. Retrieved from <https://www.treatmentadvocacycenter.org/storage/documents/state-standards/state-standards-for-civil-commitment.pdf>.
- Treatment Advocacy Center (July 2018). State Standards for Initiating Involuntary Treatment, 1-29. Retrieved from <https://www.treatmentadvocacycenter.org/storage/documents/state-standards/state-standards-for-initiating-involuntary-treatment.pdf>.
- Tuffrey-Wijne, I. (2012). *How to break bad news to people with intellectual disabilities: A guide for carers and professionals*. Jessica Kingsley Publishers.
- Vohra, R., Madhavan, S., Sambamoorthi, U., & St Peter, C. (2014). Access to services, quality of care, and family impact for children with autism, other developmental disabilities, and other mental health conditions. *Autism*, 18(7), 815–826.

- Wagemans, A. M., Van Schroyen Lantman-de Valk, H. M., Proot, I. M., Metsemakers, J., Tuffrey-Wijne, I., & Curfs, L. M. (2013). End-of-life decisions for people with intellectual disabilities, an interview study with patient representatives. *Palliative medicine*, 27(8), 765-771.
- Werner, S., & Stawski, M. (2012). Mental health: Knowledge, attitudes, and training of professionals on dual diagnosis of intellectual disability and psychiatric disorder. *Journal of Intellectual Disability Research*, 56(3), 291–304.
- Whittle, E., Fisher, K., Reppermund, S., & Trollor, J. (2019). Access to mental health services: The experiences of people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 32(2), 368–379.
- Williams, K., Wargowski, D., Eickhoff, J., & Wald, E. (2017). Disparities in health supervision for children with Down syndrome. *Clinical Pediatrics*, 56(14), 1319–1327.
- Zaraska, M. The problems with prenatal testing for autism. *Spectrum*. August 14, 2019. <https://www.spectrumnews.org/features/deep-dive/the-problems-with-prenatal-testing-for-autism/>.
- Zigman, W. B. (2013). Atypical aging in Down syndrome. *Developmental disabilities research reviews*, 18(1), 51-67.

Appendix E: CDHPD COVID- 19 Tools

Do you Know Your Rights with COVID-19? - Fact Sheet

Do You Know Your Rights with COVID-19?





The COVID-19 virus has made many people with disabilities scared. You might worry you will get sick and not get treatment. People with disabilities know that discrimination affects who gets medical care. The National Disability Institute reports that 60% of adults with disabilities worry about being treated unfairly at hospitals.

You should feel comfortable advocating for your rights when you are sick.

Know Your Rights

-  You have a right to get care just like everyone else. You cannot be denied care just because you have a disability and may need extra help.
-  State Medicaid Programs must now pay for any help you need from attendants while you are in the hospital.
-  Hospital policies for visitors have changed to stop the spread of the virus. Hospitals may not allow visitors. They can make an exception if you need help with advocating, communicating, understanding or self-care.
-  Your civil rights have not changed. This includes the right to be treated fairly in the hospital. Treatment should not be denied because of your disability.

Act with Care

-  Hand washing can be difficult for some people. Do your best. Remember to clean equipment like wheelchair rims and canes. Wash, then wipe! Post-it notes or timers can help you remember.
-  Try to change how you do things to expose yourself to less germs. Look at your routines. See if there are things you can change to stay away from crowds. Stay home and stay safe.
-  Try to touch surfaces less often. If you have to touch things to get around or communicate, wash your hands or use sanitizer. You may need to try new ways to do things during this time.
-  Avoiding others may not always be possible. You may need to have close contact with your caregivers. Talk to you caregiver about how you can both stay healthy. If you have masks and gloves, they may help.



Follow us
@ThinkEquitable

The Center for Dignity in Healthcare for People with Disabilities aims to identify and reduce life-limiting healthcare inequities for people with disabilities

Safeguard Against Disability Discrimination During COVID-19 - Fact Sheet

CENTER FOR DIGNITY IN HEALTHCARE FOR PEOPLE WITH DISABILITIES



Safeguard Against Disability Discrimination During COVID-19

Including individuals with disabilities in the COVID-19 response to ensure equitable care



THINK EQUITABLE CARE - TAKE ACTION!

- **Inform key medical personnel** immediately that individuals with disabilities have equal rights to COVID-19 testing and treatment.
- **Make equitable decisions** to ensure that allocation of COVID-19 resources, supplies, and care are not based on inaccurate assumptions about life with a disability.
- **Provide accommodations** to make sure all individuals can access COVID-19 testing and treatment. This requirement includes accommodations for behavioral, intellectual, or physical disabilities that may impact someone's ability to comply during testing and treatment.



KNOW THE BEST PRACTICES - TAKE ACTION!

- **When communicating with individuals with disabilities:**
 - Talk directly to them.
 - Ask permission before speaking with their caregivers, if possible.
 - Ask the caregiver for assistance if you need help communicating with a patient.
 - Use plain language to tell individuals and caregivers about COVID-19 test results and anticipated procedures.
 - Keep in mind that you may have difficulty understanding the patient, however, in most cases they understand you.
- **Make these accommodations:**
 - Allow a caregiver to go with a patient to ensure adequate support for decision-making and treatment.
 - Provide ramps and rooms with enough access for a wheelchair.
 - Provide qualified interpreter services for the deaf or hard of hearing.
 - Use prompts, such as picture cues, for those with limited use of verbal communication.
 - Provide the time needed for individuals to speak, respond, and understand.

THINK EQUITABLE!

This information is based on guidance from the Department of Health and Human Services Office for Civil Rights. For more information, visit [HHS.gov/ocr](https://www.hhs.gov/ocr) and bit.ly/2WXEscv

Appendix F: AADMD Conference Notes

The American Academy of Developmental Medicine & Dentistry (AADMD) Dignity in Healthcare Conference - Panel Breakout Discussion Session Results Notes

What protocol platforms (like “UpToDate”) should we consider for our medical protocols? What do you as a healthcare provider use and/or find helpful?

UpToDate (III III)

- I use UpToDate all the time, but is it a protocol platform?
- UpToDate is a good general platform for the 4 audiences:
 - o Women’s Primary Care
 - o OBGYN
 - o Genetic Counselors/ Children Specialists
 - o Families
- Easy to get out to a large population
- More comprehensive than DynaMed and updated more than Dynamed
- Linked to LexiComp and other programs
- Who is the Target audience for UpToDate?

Professional society (III)

- a. **American Academy of Pediatrics (II)**
- b. **ACOG (II) , ACMG (II), Society of Maternal/Fetal Medicine (for OB Topics)**
 - i. ACOG was developing EMR platform and was asking about patient education
- c. Mental health- APA and Academy of Child and Mental Health
- d. Society for American Genetics
- e. AHA

Protocols should be built into the EMR (III)

- If resources are not tied directly into EMR then they won’t be used bc it’s not quick and easy.
- But don’t always have the time and capacity to use it

- AAFP Guidelines
- AAP Guidelines
- KDIGO is a guideline clearing house
- United Network of Organ Sharing which develops protocol would be best platform to use - Holds transplant centers accountable for their policies and procedures.
- DynaMed (used in Canada)
- **John Hopkins Community Physician program SHARP (Small High Activity Risk Panel):** Helpful for people with disabilities and those with chronic healthcare needs. Helps coordinate care between multiple different providers when the patient has complex medical needs. Involves assigning a special RN for each patient, and during emergencies on-call doctor has a “cheat sheet” that provides an action plan for caring for the patient using best practices individualized for that patient. However, this is not

a widely used platform and is only available at a PCP office, and can't be shared with hospitals/other providers

- Google
- State office of DD is where most Medicaid providers look for information
- DM-ID NADD as a resource
- MD Calc
 - - Free- medical students are more likely to use MD Calc rather than UpToDate)

Audiences to Consider:

- people doing primary care for women
- Ob/Gyn
- people providing counseling (geneticists, child specialists on the receiving end of the child)
- Families

Other Thoughts/Concerns:

- Does the platform have to be somewhere people would actually go or is it a place where people would be held accountable?
- Need to make sure that the referring providers are aware of the protocols because if we don't get referrals then the patients won't get the transplant.
- Making psychiatrists aware of the protocols could make it easier for patients to get referred or for psych to know what to do
- Need to find out what EM physicians use because that is a setting in which it would be helpful to have an easy-to-access and easy-to-use resource
- Where would it be available if someone were searching? My understanding during the presentation was very shocking-that people aren't searching? I think finding some sort of push platform rather than a pull. In a targeted way, select people on LinkedIn by job title and *push* ads to their feeds; twitter?
- This/That tool: This is normal for this patient vs. That is not normal. User-friendly tool for individualized information that is easy for families/patients to provide info and easily accessible to providers.
- Customized Care Communication card: a tool that patient has in chart/on file that addresses who their point-of-contact is, what their communication strategies are, etc. Allows providers to better their care and individualize care
- Health Passport: similar tool to customized care card. Having more details is helpful to providers.
- Many tools from self-advocacy groups that help patients, families, and medical providers integrate and collaborate. Many groups are active to improve two-way communication between patient/families and providers. One such group is Self Advocates Being Empowered (SABE), which has developed protocols to help people with I/DD speak from their own point-of-view.

What do you think a useful protocol on the issue of TOPIC would entail to help healthcare providers to make good decisions/implement the appropriate treatment/intervention/next step as to not discriminate against people with I/DD?

- Any protocol should begin with a values exploration
 - ← How would patient feel about the test? What would patients do with the test? (Gets lost when we present the test as a standard of care rather than a choice)
 - ← Test should be applied based on prevalence of issues for that specific population

Resources/Information Sharing

- Resources need to be required to review and shared quickly and efficiently
- Information should talk about medical challenges and a bigger picture of what life would be like
- Information available to healthcare providers should be complete and balanced (II)

Communication

- needs to be outlined in the protocol at all stages in prenatal diagnostics
- Biggest challenge?- prolonged and in depth discussion that doesn't fit well into a 15 minute doctor visit
- Develop a communicative relationship with the patient
 - Need to know who is speaking for the patient—such as guardian, healthcare proxy, conservator, consentor, self-advocate? Oftentimes, decision-making happens without the right person in the room.
 - Include patient in decision making process
 - Create culture to facilitate communication of people with I/DD, similar to how interpreters used for non-English speakers
- Awareness of the connotation of the clinician's dialogue
 1. Avoid somber tones; remain hopeful
 2. Provide them with resources
 3. Pre/post protocol dialogue with the patient

Education

- for all healthcare providers to know that people with I/DD can do well
- Increased education for those that give prenatal diagnosis information
- More education for inpatient psychologists/psychiatrists
- educating physicians at the residency level to avoid or minimize diagnostic overshadowing
- Establish a caseload (for residents) criteria with a minimum number of patients with I/DD
- residents/medical students must be sensitive and aware of possible judgmental language
- Healthcare providers often do not feel that they have received enough training in this area and deny I/DD patients because they do not feel properly equipped
- The I/DD Toolkit
- Providers should initiate investigation for other causes for behaviors rather than MH. MH, medical illness, communication difficulties, environmental issues (prompted support; included medical issues) that can be misconstrued as BH.

Person Centered Approach that is individualized

- Assume quality of life. Providers make assumptions that patients with I/DD have poor quality of life when it may be just the opposite. It's important to go into medical records (as well as person-centered plan) to include that patient has high quality of life
- Establish a standard of care for people with disabilities

Ethics Review Criteria

- Transparent
- Lots of gray areas when it comes to what the criteria are. Seems to differ from center to center
- Ethics principles can be weighted in a biased manner, depending on the situation

Testing

- Don't recommend testing, offer it.
- People need to understand what the results will mean
- Not automatic termination of pregnancy? not binary
 - ← May learn things about how to treat baby at birth
 - ← May learn how you can prep for baby's birth
 - ← New protocol needs include this step
 - ← More information on the benefits of testing (many assume you wouldn't be getting tested if you weren't going to terminate)
 - ← Once the testing option is chosen, present the kinds of tests, what they test for, sensitivity, specificity, etc.

Referring

- Emphasize to err on the side of referring (from specialist POV). An organ transplant specialist can decide better than I can if they are a good candidate. (II)
- Genetic Counselors- often have family groups they refer patients to
- If primary providers decline to refer for transplant, there should be readily available option for patients to ask for other opinions.
- Protocol to refer and protocol of who gets the transplant. It doesn't have to be complicated about who to refer to

Intersectionality

- I/DD and biases of race, nationality, primary language, LGBTQ when assessing for MH issues.

Diagnosing Protocols

- MH providers need to consider the under diagnosis of depression/anxiety projecting an immediate need for a protocol that is NOT antipsychotics. SSRIS anti-anxiety meds may be more appropriate
- Clearly identify target issues/behaviors we're looking to improve on and regularly assess for actual improvement, support intervention; medication management instead of leaving them on things forever? Use systematic approach to measure treatment outcomes.
- Spread sheets to print out to track data might be helpful
- Standardized evaluations (for organ transplant)

How can the issues of a) implicit bias, b) diagnostic overshadowing and c) policy

violations be addressed in a non-adversarial way?

Protocols

- Should be case based with a field/work practice element
- Protocol for discussing this problem with women and their partners, including how we measure this as an informed decision
- Must acknowledge uncertainty in any protocol that comes out (need that humility)
- Have to give families the full spectrum- avoid taking either end of the bias spectrum (III)
- Include psychosocial research to help give the full spectrum
- Protocols to ensure we are conveying that accurate, up to date view of these conditions
- Protocols that allow for individual treatment, rather than this is how you treat the diagnosis (III)
- Implement a one page 'know the person' document in patient files that allows physician to see the whole person

Communications/Public Relations

- Awareness Campaign
- Address issues to advocate for education
- Partner with different disability organizations
- Include photos with quotes/statements from each organization
- Raise awareness of biases individuals may not even know they have
- Partner with The National/International Association of Dual Diagnosis
- Strong need to develop new narratives
- Approach aimed at welcoming people into a new community

Develop Curriculum

- Training aimed towards both providers and patients (III)
- Must recognize broad range of people's values
- Provide information about patient advocacy groups
- Curriculum similar to anti-racism material that addresses implicit bias. Perhaps there's a parallel curriculum [that can be made around I/DD.] (III)
- Simulating how someone might make different decisions based on the patient's perceived disability
- Teach the history of disability
- Disability is about more than just the medical issues
- Training for the spectrum of support
- Teach about marginalized populations
- Information given should not be a 'terrible' thing- but welcoming into a new community
- Nuanced set of tools to allow us to tailor to individuals and families, that is both medical model and social model of disability.

- Provide CME and test certifications with educational materials to make the knowledge mandatory that follows adult learning principles, simulations (III)
- Identify implicit bias in medicine, emphasizing biases that are commonly seen to help evade misconceptions (III)
- Curriculum should use proper language
- Teach physicians to listen to each individual as a person, considering them an expert on their disability.
- Curriculum that addresses patients are often more capable than they look
- Curriculum to address the paternalistic approach to medicine and how it can be harmful to patients
- ECHO Model and Project TEACH

Simulations/Community Involvement

- Would love to have prenatal families meet with other families with children with disabilities
- Simulating how someone might make different decisions based on the patient's perceived disability.
- Discuss physician perspective- talk about physician encounters to give family a good sense of everything
- Ambassador program that allows parents to meet adults with same type of disability
- Patient panels for medical students- to learn what it's like and how their lives changed once they received a diagnosis
- Exposing people to simulations and lived stories- they need more than guidance documents. Need to see it through the lives of real people sharing their stories.
- Develop videos similar to the ones regarding racial biases- that show one patient with I/DD and one without, but presenting with same symptoms. Shows clinicians how they make mistakes because of biases they're unaware of

What are the best strategies for getting physicians to adopt a model of supported medical decision making for patients with I/DD?

- Model or algorithm for tools regarding informed decision making
- Needs to be modeled consistently
- Put this into a CME protocol
- Incorporate into hospital medical documents that are in front of decision maker/clinician working the case
- Grand Rounds
- Conferences
- Journals
- Explore intersectionality of I/DD in relation to other diagnoses and use to this to an

advantage to provoke interest

- Raise awareness on number of people with disabilities
- Educate on what supported medical decision-making is and that we all need this
- Make SMD a billing code to give providers more time to interact with patients

How can we increase and improve the quantity and quality of medical data about people with I/DD?

- When people are coming to a hospital, they are coded for things like stroke, GI bleed, or whatever the chief complaint is, but not for I/DD. Unfortunately, this is a challenge because some self-advocates are uncomfortable with being labeled in that way.
- When a patient is not known to an office, and is starting as a new patient or transitioning from a provider, the very first H&P is not included, but rather the most recent H&P. Family members and patients will fill out their own history, but collaboration needs to increase, particularly in the transition of care.
- The system is broken with regards to transition of care, particularly from pediatrics to adulthood care ? gottransitions.org has multiple resources for this.
- Doctors should make a separate sheet included with the screening/intake form you give to gather info about patient's likes/dislikes, communication style, and everything else providers should know about the patient. However, this may be difficult to accomplish in a waiting room. Perhaps, should be offered to patients/families in advance.