Data Ethics

Preimplantation Genetic Testing

Persona

You are a disability rights advocate invited into the advisory panel. Many of your family have Down Syndrome and you have witnessed their joy, dignity, and social contributions. You worry that including Down Syndrome in early embryo screening implicitly sends a message that people like your loved ones are less valued or undesirable. You are concerned this could worsen stigma, reduce societal support, and undermine ongoing efforts toward inclusion and disability justice.

Objective

Regulate PGT in a Way That Protects Disability Rights, Human Dignity, and Social Inclusion

Talking Points

- A diagnosis does not determine a person's value
  - People with Down syndrome lead meaningful lives, form relationships, pursue education and employment, contribute to their communities, and bring unique perspectives to society.
  - Government policy should affirm that every person has inherent dignity regardless of genetic differences.
- Routine screening against Down syndrome can create harmful societal messages
  - When society routinely identifies and selects against embryos with Down syndrome, it may imply that these lives are less desirable or less worth welcoming.
  - This can reinforce stereotypes and deepen discrimination toward people currently living with disabilities.
- The impact extends beyond individual reproductive decisions
  - Individual choice is important and should be respected, but Congress must also consider the collective social consequences of widespread genetic selection.
  - A declining population of people with certain disabilities may reduce public awareness, advocacy, and commitment to services, accessibility, healthcare, and inclusive education.
- Disability rights history warns against a purely genetic definition of a "better" society
  - Historical eugenics movements used ideas of biological improvement to justify forced sterilization, institutionalization, and exclusion of people with disabilities.
  - Modern technologies are different in purpose and intent, but policymakers must remain vigilant that new tools do not revive old prejudices in new forms.

Talking Points

- Genetic counseling must provide balanced and accurate information
  - Counseling should include realistic information about medical challenges as well as the potential for meaningful relationships, education, employment, and community participation.
  - Families should have access to perspectives from individuals with Down syndrome and disability advocacy organizations—not only clinical descriptions of the condition.
- Protect reproductive autonomy while addressing disability justice
  - The goal is not necessarily to ban access to PGT or prevent families from receiving information.
  - Instead, regulations should ensure that the information is presented in a non-directive, balanced manner that does not pressure parents toward a particular choice.
- Medical technology should be accompanied by equal investment in disability support
  - Advances in reproductive genetics should not become a substitute for improving healthcare, education, accessibility, and social services for people with disabilities.
  - A compassionate society can support both medical innovation and the full inclusion of disabled individuals.
- People with disabilities must have a place at the policymaking table
  - Decisions about genetic screening should include individuals with Down syndrome, their families, disability scholars, and advocacy groups.
  - Policies affecting a community should be shaped with meaningful input from that community.
- Congress should establish ethical safeguards for future expansion of genetic selection
  - As genetic testing becomes more powerful, policymakers must consider whether the technology may eventually move beyond serious medical conditions toward selecting traits based on social preference.
  - Clear ethical frameworks can help prevent discrimination and preserve respect for human diversity.