

2. Genetic Information and Privacy

Prelims Syllabus: Rights Issues

Mains Syllabus: GS-II Government Policies and Interventions for Development in Various Sectors and Issues Arising out of their design and implementation.



Why in News?

- Recently, the Supreme Court has ruled that children have the right to protect their genetic information from being revealed in Deoxyribonucleic Acid (DNA) Tests without their consent.

About the News:

- The judgment came in a petition filed by a man who questioned his second child's paternity while accusing his wife of an adulterous relationship.
- The apex court concluded on the facts of the case that no adverse inference could be drawn on the ground that the mother declined to subject the child to a paternity test.

What is the Judgement?

- Genetic information is personal and intimate. It sheds light on a person's very essence.
- It allows individuals to make informed decisions about their health, privacy, and identity.
- Children have the right to protect their genetic information from DNA testing in divorce proceedings, as it is part of their fundamental right to privacy. This is guaranteed under Article 21 of Indian Constitution.
- It is imperative that children do not become the focal point of the battle between spouses.

- Rights of privacy, autonomy and identity are recognised under the United Nations' Convention on the Rights of the Child.
 - ✓ The Convention acknowledges the control that individuals, including children, have over their own personal boundaries and the means by which they define who they are in relation to other people.
 - ✓ Children are not to be deprived of this entitlement to influence and understand their sense of self simply by virtue of being children.

What is the Status of Genetic Information in India?

Genetic Data and Privacy:

- Genetic data privacy is a term that seeks to prevent a third party or anyone else from using a person's genetic data without his permission.
- Technological advances have made it easy to extract personal information from DNA samples, violating privacy rights.
- While genetic research holds promise for the future, misapplication can have negative consequences. Due to the significance of genetic data as the blueprint for a person's physical being, privacy protection is crucial.

Advantages of Genetic Information:

- Genetic information can reveal details about disease, health, and ancestry.
- This knowledge can increase a person's awareness of their own health, be used in medical research, and enable early intervention for disease prevention.

Disadvantages of Genetic Information:

- Genetic data consists of a person's DNA and chromosomes and can reveal personal information about health and ancestry. Direct-to-consumer genetic tests are not always reliable and can result in unintended exposure of private information. Unauthorized access to genetic data can result in negative impacts, such as unwelcome responses from employers, insurance providers, and the government, affecting a person's privacy and life.

Status of Genetic Privacy:

- In 2018, The Delhi High Court ruled against United India Insurance Company's discrimination in health insurance against a person with a heart disease that was thought to be a genetic disorder.
- Genetic discrimination is a breach of Article 14, which guarantees that everyone is treated fairly under the law.

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- The Supreme Court of India unanimously stated that the Right to Privacy is a Fundamental Right under Article 21 in Justice KS Puttaswamy (Retd.) & Anr. v. Union of India. Genetic discrimination is illegal in almost all countries. In 2008, the United States passed the Genetic Information Non-discrimination Act (GINA), a federal law that protects people from genetic discrimination in health care and jobs.

Way Forward:

- From a legal standpoint, there is a need to develop more comprehensive privacy laws and regulations specifically tailored to genetic information.
 - ✓ It may include stricter requirements for obtaining informed consent for genetic testing and data sharing, as well as penalties for unauthorized access or use of genetic information.
- Technologically, there may be opportunities to enhance privacy protections through advancements in encryption, secure storage, and data sharing protocols.
 - ✓ For example, homomorphic encryption techniques could be used to allow computation on encrypted genetic data without revealing the underlying information.
- From an Ethical perspective, it will be important to continue to engage in public dialogue and education around the value and risks of genetic testing and data sharing.
 - ✓ It may involve efforts to promote transparency, openness, and accountability around how genetic data is collected, used, and shared, as well as initiatives to promote equitable access to genetic testing and benefits.