CASE WESTERN RESERVE UNIVERSITY
President's Leadership Development Program

Ethical Leadership Through Scholarship: An ELSI Analysis of Parental Declination in Optional Genomic Newborn Screening

Logan Tsukiyama

Leadership Action Project Executive Summary

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at Case Western Reserve University

Aaron Goldenberg, PhD
Professor and Vice Chair, Department of Bioethics
Mentor

Andrea M. Hauser, PhD
Executive Director, President's Leadership Development Program

Project Overview & The Social Issue

Optional genomic newborn screening (gNBS) programs present the promise of the early detection of rare genetic conditions, equipping families and medical teams with the knowledge for early intervention. However, screening for complex and rare disorders can introduce uncertainty and long-term implications, raising certain ethical considerations around the clinical integration of this technology.

In evaluating the success of gNBS programs, parental declination is often treated as a logistical barrier rather than meaningful data. Minimizing decliner data in this way risks reinforcing inequities, misrepresenting autonomy, and weakening public trust in medicine. This LAP aims to reframe declination as an ethically active decision that reflects how families interpret risk, responsibility, medical authority, cultural values, emotional burden, and trust in medical institutions.

The causes of this social problem operate on different levels. At an individual level, parents considering gNBS might face uncertainty and the psychological burden that comes with it. At a community level, decisions to participate in gNBS and research are often shaped by historical mistrust rooted in mistreatment and exploitation. At a systems level, the resources and infrastructure to support true parental autonomy have not kept up with the expansion of gNBS.

Project Type & Approach

This LAP was research-based and entailed producing a scholarly research paper for publication in a bioethics journal. The IRB-approved data focused on recruiter notes and survey data for parents who declined participation in ScreenPlus, a New York-based pilot program offering optional gNBS for 14 rare genetic disorders. The manuscript drafting process involved analyzing and integrating previously collected data and meeting regularly with a faculty mentor and secondary reviewers to clarify and refine contents.

Deliverable & Impact

The primary deliverable for the LAP was a complete scholarly manuscript that was ready for submission to a peer-reviewed bioethics journal. The first metric of success was academic rigor, defined as meeting the methodological and critical analysis standards required for a peer-reviewed publication. The second metric was practical translation, the ability to reach beyond simply describing why parents decline gNBS and articulate what the data implies for future program design. When an institution listens to those who are excluded from the group it serves and changes accordingly, it becomes more ethically sound and equitable, and this project seeks to contribute exactly that.

Leadership Reflection

At its core, this project was an act of advocacy for the voices institutional processes tend to overlook. The PLDP's four leadership assumptions of credibility, relationships, non-positional leadership, and values-driven leadership truly came to life throughout this process. Relationships undoubtedly shaped every phase of the project, whether it was my mentorship with Dr. Aaron Goldenberg who provided accountability and guidance or the ScreenPlus team in New York offering expertise and feedback.

Credibility had to be earned through the quality of the scholarship and deliverable themselves. I couldn't simply assert that decliner data mattered, but rather, I had to demonstrate it. The assumption of non-positional leadership was a prominent definer of my experience as an undergraduate student leading a publication in a group of senior academics and researchers. Where I lacked formal authority, I made up for in dedication and persistence. And lastly, putting values at the forefront of this project was ultimately what made it personal. I was drawn to this topic because of my belief that ethical innovation and progress in medicine requires highlighting the voices institutions most often overlook.

In the broader picture of the PLDP's mission to develop scholars who drive change toward a more just society, I hope that this project serves as a meaningful contribution to that mission. This project has been a manifestation of the conviction that ideas, when honestly developed and methodically disseminated, can fundamentally shape the way institutions translate values into practice and treat the people they are meant to serve.