

Insights

NICHQ Employee Spotlight: Stacey C. Penny



Full name and title: Stacey C. Penny, MSW, MPH, Senior Project

Director

Years with NICHQ: 1

How has your background/experiences led you to join a national children's health organization?

“Supporting the health and well-being of young children and their families has been the primary focus of my career for the past 22 years. Before joining NICHQ, I was the Associate Director of Women’s and Infant Health for the Association for Maternal and Child Health Programs and served as the Executive Director for the National Healthy Start Association. I was most recently the Vice President for Individual and Corporate Foundation Relations for the March of Dimes, a role that focused on ‘bigger picture’ strategies, such as identifying transformational funding opportunities for children’s health organizations to carry out maternal and child health work. In March 2020, I joined NICHQ’s [National Network of Perinatal Quality Collaboratives \(NNPQC\)](#) as a Development Consultant and transitioned to Senior Project Director in August 2020. Joining NICHQ has allowed me to return to more direct work aimed to reduce infant and maternal mortality. Improving health outcomes for children and moms is in my blood, and I love being on a

project that's goal is to create measurable improvements in statewide maternal and infant healthcare and health outcomes."

As the coordinating center for the NNPQC, NICHQ provides resources and expertise to nationwide state-based perinatal quality collaboratives (PQCs) with the goal of deepening and accelerating improvement efforts for maternal and infant health outcomes. [Learn more](#) about the project.

Tell us about NICHQ's [Rare As One Network Workstream Facilitation Initiative](#).

"This is an initiative that really brings everyone to the table to create change. Patient communities, rare disease experts, and advocacy organizations are coming together to advance progress against rare diseases and scale these efforts through capacity-building services.

The Chan Zuckerberg Initiative (CZI) Rare As One project currently supports two dozen patient-led organizations working to improve the lives of people affected by rare diseases. Prior to NICHQ's involvement, grantees identified content areas of interest to potentially engage in collaboration with colleagues. This led to the development of five workstreams addressing specific topic areas for improvement:

- Natural History Studies and Patient Registries
- Centers of Excellence
- Drug Repurposing
- Engaging Researchers in Rare Disease
- Engaging Industry

NICHQ's role is to facilitate these five workstreams to support the development of goals, processes for collaboration, measures, and outcomes in key areas of need for the grantees. It truly is an opportunity for individuals who may not have otherwise worked together to figure out how they can learn from and support each other as they're determining how to address some of the toughest challenges that rare disease patients face."

What is the collective Impact framework and how will it be used to support the program's five workstreams?

"This project relies on effective communication between everyone involved, which is essentially the goal of collective impact. The five components of this framework are what guide NICHQ's approach as a facilitator of the five workstreams:

1. A Common Agenda: Participants are committed to working toward the same goal.
2. Shared Measurement: Participants understand the importance of measurement across the workstream and commit to shared measures to ensure accountability.
3. Mutually Reinforcing Activities: Participants bring their unique experience and expertise to support an aligned action plan.
4. Continuous Communication: Participants will participate in monthly webinars and have access to ongoing communication via the Rare As One online platform and slack channels for each workstream.
5. A Backbone Organization: To manage collaboration and ensure forward movement.

NICHQ has successfully used the principles of Collective Impact in a variety of projects as an organizing framework to drive change, including our [Early Childhood Comprehensive Systems Collaborative Improvement and Innovation Network \(ECCS CoIIN\)](#)."

How does this initiative stand out from other NICHQ initiatives? What makes this initiative unique?

"What makes it unique in general is the idea of bringing together 50 individuals, who represent 50 different organizations, focused on 50 different rare diseases. This project really demonstrates true collaboration. Everyone is bringing their individual goals, perspectives, and challenges to the table with their place on the spectrum of addressing their area of concern. We all want to accomplish the same goal but may have different ideas for achieving it, so this project really pushes everyone involved to support each other and take one step at a time."

What are you most looking forward to with this initiative?

"I'm really excited to move into the next half initiative because we're transitioning to a point where each workstream is ready to implement strategies to achieve their goals. True collective impact can take a long time to achieve, so for the last five months, each workstream has been solidifying their objectives, addressing their challenges, and organizing the best practices for improvement. From a facilitator standpoint, I'm looking forward to watching each network grow and accomplish their goals over the remaining seven months of the project."