

Family Center Workgroup on Inclusion

“Diversity is being invited to the party. Inclusion is being asked to dance.” ~Verna Myers

Scope of Work

I. Workgroup Background

[Expecting Health](#) has a cooperative agreement with the Maternal and Child Health Bureau ([MCHB](#)) of the Health Resources and Services Administration ([HRSA](#)) to serve as the National Genetics Education and Family Support Program ([NGEFSP or Family Center](#)). The purpose of the Family Center is to increase access to genetic services by promoting and strengthening engagement of individuals and families with, or at risk for, genetic conditions in the genetic health care delivery system.

Family Engagement is one of six core outcomes that define a comprehensive and coordinated system of care for children and youth with special health care needs. Actively engaging families as equal partners in their child’s health care and decision-making has been associated with reduced unmet health needs, fewer reported problems accessing specialist referrals, lower out-of-pocket expenses, and improved physical and behavioral outcomes in children.

As a leader in healthcare information, Expecting Health continues to work toward meaningful change by striving to eliminate inequities in the delivery of genetics healthcare to improve outcomes for families. We know that to truly achieve these changes it is essential that the culture of our organization, leadership, and workgroups is diverse, equitable, and inclusive. We recognize that there is much work to be done – and that this work is critical to ensuring that we are able to most effectively address the complex challenges facing families as they interact with the genetics delivery system.

II. Purpose

The Family Center Workgroup on Inclusion (FCWI) is tasked with asking hard questions and having difficult conversations to identify inequities and barriers to inclusion so that we can address them and achieve a more inclusive and vibrant community. The FCWI’s role is to support the Family Center in ensuring strong family-professional partnerships and that families are central to genetic health care delivery systems around the nation and U.S. Territories through the development of products, resources, and trainings.

III. FCWI Composition

The FCWI will consist of eight to ten family representatives from around the U.S. and U.S. territories. The membership will be reviewed annually in May to ensure diverse, underserved, disadvantaged, and geographically isolated representation and lived experiences and to assess if additional members and perspectives are needed.

Recruitment for the FCWI will come through the various channels of Expecting Health and SPAN Parent Advocacy Network ([SPAN](#)) along with outreach to our partners.

IV. Responsibilities

The FCWI meets via video conference call twice annually to discuss ongoing projects and relevant Family Center updates with additional opportunities to participate in relevant projects, if interested. The main duties of the FCWI consist of:

- Bi-annual meetings to receive and discuss updates to the NGEFSP activities and identify unmet needs and possible solutions
- Creation of resources and products that are generated from the needs identified by the FCWI
- Create and deliver two webinars annually and host a Regional Genetics Network (RGN) Office Hours
- A member of the FCWI will serve on the Family Center Advisory Committee to provide cohesion between the two groups
- Review and provide input to NGEFSP and RGN projects (as requested)

VI. Compensation

All FCWI members will be compensated \$35/hr with all employment recordkeeping and payments to be administered by SPAN.

VII. Governance

Code of Conduct

FCWI members are expected to exercise professionalism, diplomacy, and discretion when conducting their responsibilities. When topics of discussion arises on which FCWI members disagree, members are expected to treat one another with respect and dignity. FCWI members should be able to see beyond their own personal experiences and represent the needs of other families.

If any FCWI member feels that this code of conduct was breached, they should bring it to the attention of Expecting Health or SPAN.

Term of Service

- (1) Term. The committee will be in effect for the full-term of the NGEFSP Cooperative Agreement which runs from 6/1/2020 thru 5/31/2024. Individual membership will be reviewed annually in May to ensure the committee represents a broad range of diverse experiences and perspectives. A member may resign by delivering or sending (via mail or email) a written letter of resignation to Expecting Health or SPAN.
- (2) Removal. FCWI members may be removed at the discretion of Expecting Health and SPAN.
- (3) Vacancies. Any vacancies will be filled as soon as possible.

Oversight

The FCWI is a workgroup for the Family Center. It is at the discretion of Expecting Health staff to utilize input given to them by the FCWI. The committee does not serve as an authorized decision maker for the Family Center's programs and services.

Oversight of the workgroup will be a joint venture between Expecting Health and SPAN.

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