



Children & Youth with Special Health Care Needs National Research Network

CYSHCN Advisory Committee Information for Potential Members

CYSHCN is a national research network, funded by the Health Research and Services Administration's (HRSA) Maternal and Child Health Bureau (MCHB). The Network is governed by two committees: The Steering Committee (SC), which is the rules-making and voting committee, comprised of the member site leads, and the Advisory Committee (AC), the outward-facing committee that provides advice to the Leadership Team (LT) and the SC on the network's direction. The Advisory Committee consists of representatives from different disciplines, including members of the children and youth with special health care needs (CYSHCN) community, individuals with lived experience (including youth), and other experts, who are interested in guiding the research that enhances the lives of CYSHCN.

Roles and responsibilities: The AC plays a crucial role in guiding the Network's efforts to better serve the needs of the CYSHCN community by advising the leadership team and steering committee. The AC helps the Network understand the needs of CYSHCN, their families, and their providers; explores new possible research and partnerships; participates in lively conversations about the CYSHCN community and their interests; and provides their thoughts to help the leadership team and SC make decisions about the future direction of the Network. People interested in the AC should be dedicated to improving systems for CYSHCN and possess values aligned with the goals of the network.

Experience and/or knowledge in at least one of the following areas are helpful but not required:

- dissemination
- research
- caregiving
- policy work
- health care financing
- program development
- clinical care for CYSHCN
- legal skills,
- public relations, or communications.

Once the Advisory Committee is formed, members will choose two co-leads – one who represents the clinical, or professional in systems change perspective, and one who represents the lived experience perspective. Co-leads will report to the CYSHCN Steering Committee and will share information with the Advisory Committee. Co-leads will be paid a stipend to perform these tasks.

Compensation: AC members bringing the lived experience perspective will be offered a stipend of \$600 annually to participate in 12 hours of committee business. AC Members who are participating as clinical or systems-level professionals (i.e. clinicians, organizational representatives, state or federal employees, or others who are employed in the CYSHCN field) will be asked to participate as volunteers. The two co-leads will each receive an additional stipend of \$300/year for 6 hours of work to lead the committee.

Expectations of AC members:

Specific tasks of Advisory Committee members may vary based on the needs of the Network, interests, and time available of the members. The table below outlines basic tasks that may be asked of members:

TASK
Advise on various specific topics as appropriate, including but not limited to content expertise, dissemination, DEI, cultural practices, language translation/interpretation, research methods, etc.
Help the Network gain new insights into the needs of CYSHCN and their families
Help the Network gain new insights into the needs of providers who care for CYSHCN
Explore new opportunities for research, funding, collaborations, and connections
Provide critical thinking and analysis to help the leadership team and SC make decisions about the trajectory of the Network
Explore ideas for leveraging the National Research Agenda (https://cyshcnet.org/national-research-agenda/) and/or the MCHB Blueprint
Provide input on potential projects/proposals, including being reviewers for proposals
Support research by being on research teams in some capacity
Talk to others about what the network is doing.
Help recruit lived-experience research partners
Help support lived-experience research partners
Help share work and news from the Network
Participate in equity activities
Advise SC & LT based on individual expertise or interests
Assist with study participant recruitment: who, what, where, how
Outreach for Emerging Investigator/Pathways applicants
Help the network create and maintain relationships with other communities of practice and individuals/ systems that impact CYSHCN such as: <ul style="list-style-type: none"> ○ Policymakers ○ Education ○ Title V ○ Public health ○ Medicaid programs ○ Research specialties e.g. measurement, care integration, home health, finance, etc.
Review Network by-laws
Mentor new Emerging Investigators
Lead projects

Tasks of the Co-chairs

TASK
Serve as the connector between the AC and Steering committee
Run quarterly AC meetings
Represent AC at SC and annual meetings as non-voting “visitors”
Recruit members for tasks such as proposal reviews, lived-experience partner recruitment, etc.
Work with Cores to determine tasks appropriate for AC members
Meet monthly together to plan for the following quarter
Help with planning annual meeting

Other Information

<p>Compensation and time commitment</p>	<ul style="list-style-type: none"> ● Committee members with lived experience will receive \$600/year for participation at \$50/hr X 12 hrs to be broken down as follows: <ul style="list-style-type: none"> ○ Quarterly meetings: 4 hours ○ Network business such as reviewing study proposals, recruiting research partners, working with the dissemination and/or health equity core, etc.: 8 hours ● Co-Leads are required to commit to an extra 4 hrs/year for leadership activities ● Family lead will receive \$900/year (\$600 + \$300 lead stipend) ● Clinical/systems lead will receive \$300/yr ● Members will be asked to verify their hours quarterly ● For people working on projects, they may be compensated separately from project funds when appropriate
<p>Working on a research team project</p>	<ul style="list-style-type: none"> ● Members who work on a research project as a co-investigator in any capacity will be paid separately as part of the research team.
<p>Application</p>	<ul style="list-style-type: none"> ● An application is required for new members to inform us about skills, interests, ideas.