

5 **STOPS** on the Road to writing a Job Description for Families in a Health Related Project

If you are reading this, you are likely part of a project or group (workgroup, advisory, research etc.) that seeks to include families in various aspects of your work. Beyond simply inviting someone to join in your effort, partnership with youth and families requires planning to ensure their engagement is meaningful and authentic. Just as a proposal or project requires written plans, outlines and role descriptions, successful engagement of youth and families as partners also takes planning, which includes providing a description of your partners roles, responsibilities, time commitment, and compensation.

The following are stops along the road to partnership that will assist teams to articulate commitment to engaging youth and families in health systems change work. Planning your route will ensure the ride along the road is smooth, that everyone enjoys the journey, and reaches the desired destination!

NOTE: Each **STOP** on the road is critical. Youth and Family partnership can transform projects, people and the health care system. However, it will fail unless teams start with, and continue to nurture, commitment. Seeds of mistrust exist for many in all types of public health and health care delivery transformation work based on past experiences, history, miscommunication and misunderstanding. Partnership and teamwork must be intentional to build trust and succeed. The pace of life and work in any aspect of health care is fast and often unforgiving. It is akin to a racetrack- 500 laps of the Indy500 with no pit stops unless fuel is nearly empty or the tires need to be changed. Growing health disparities and health inequities for CYSHCN and their families demand that we make time for regular pit stops throughout the race, before the fuel tank is completely empty.

FIRST STOP

STOP Before You **START**

Before you write a project plan or proposal, start a project or invite a youth or family to join a project, ask some key questions:

- WHY does your team want to include the voices, experiences and skills of youth and families?
- WHAT gains does your team anticipate or expect from the contributions of youth or family with lived experience as part of your team?
- WHAT specific lived experience, skills, or characteristics would be helpful to the work of the team?
- HOW do these specific experiences, skills and characteristics inform overall project goals and outcomes?

Consider using [Worksheet: Planning for Meaningful Family Involvement](#) by the Oregon Center for Children and Youth with Special Health Needs as a roadmap for planning at this stop and the next few to ensure a smooth ride on the road to partnership.



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NEXT STOP

How will you articulate this commitment to youth and family partnership in your work?

You started with your why, so now this stop requires focus on the what, how, when and who of articulating the commitment to youth and family partnership to ensure that you move beyond inspiration to meaningful action. Below are just a few questions to consider:

What type of commitment will you articulate?

- Do you have or will you write a statement of commitment to youth and family partnership?
- Do you have or will you develop a Diversity, Equity, Inclusion and Belonging statement for this project or workgroup?
- Do you have or will you develop description of roles for youth and family? Do all members of the team or workgroup have similar role descriptions? Why or why not?
- How will these commitments be articulated? In writing? In video? In more than one language?
- How will these commitments be shared with the team or workgroup?
- What roles will these commitments play in the project or workgroup? For example, will it be done as part of the proposal? Will it be the first phase of the project or workgroup? What will be done to ensure the commitment is woven throughout the project or work of the group?

Who will be involved?

- Is this a process that should involve everyone?
- Are you including youth and families?
- Who will lead and/or co-lead the writing process to ensure it travels the entire road and makes it into the project?

NEXT STOP

Maybe not a **STOP**, but rather a critical **PAUSE** to consider

The act of involving youth and families in systems level work is described in many ways (engagement, partnership, inter-professional, team-based etc.) and youth and families are referred to by many names or titles (partners, advisors, leaders, advocates etc.). Many boil it down to the following description: “the family voice at the table.” This PAUSE is to encourage you to commit to more than just a single voice or a seat at the table. Instead, plan for multiple voices, in multiple roles, and more than just sitting. Involving families in a project or workgroup requires the same intentional planning as with the other members of the team. How you use the worksheet linked above or follow the questions below with regard to outlining of tasks and types of time or budget required will help you discern the details to move beyond singularity to a rich

Outlining each role description?

NEXT STOP

It is important to approach writing a role description for a youth or family in a project or workgroup with the same consideration as you would another team member. Youth and families who partner in health systems transformation work are colleagues. Their lived experience is an expertise that is critical to eliminating disparities, achieving equity, and improving a system of care for all children, families, and individuals served. Many youth and family have education, training and skills in addition to the expertise of their lived experience. Many also have challenges with receiving or providing health care and accessing basic needs such as housing and food for themselves or a loved one in addition to your project or workgroup and other work. Do not assume anything about a youth or family in terms of their willingness or ability to participate. Instead, be clear in your commitment and the role description. Do not be afraid to ask questions and have a conversation.

The following is a list of considerations for writing a youth or family role description. It is not exhaustive but intended to provide a starting point and offer ideas. In all written documents, language should be plain and accessible to all.

- What tasks does the role involve? Be specific. Are they all required or are some optional?
- What is the time requirement? Is it a number of hours each week? Is it a monthly meeting? Can you link time requirements to specific tasks?
- What is the project or workgroup timeline? Can you provide an overview of how the tasks fit into that timeline? Are there specific deadlines for the tasks in this role?
- Will there be in-person, virtual and hybrid meeting requirements?
- How will accommodations be made? If there is a health issue that disrupts ability to participate, what is the procedure for communication and accommodation?
- Is there team structure to be noted with regard to organization, supervision and mentorship? How will the different youth and family interact or work together? Will there be a mentorship structure?
- What is the budget? Is there compensation for the role? How will it be provided? Will compensation be linked to completion of a task or hourly?

LAST STOP

Pit STOP to pick up any additional help, guidance or resources as frequently as needed!

Consider all types of sample job descriptions:

- ◆ Are role descriptions for other members of the team or past projects that provide examples of how to articulate a skill or needs for a skill? Or to how to identify a project or advisory role expectation? NOTE: Role descriptions that may inform your team's process of articulating commitment are not limited to health care; think outside the box.
- ◆ The MA CMC CoIIN team developed this [Family Leader](#) and [Family Advisory role](#) descriptions
- ◆ Download the FESAT Family Engagement in Systems Toolkit for addition strategies and resources [here](#).

Locate and contact the Family-to-Family Health Information Center (F2F) in your state. Funded by MCHB, these family-led organizations are staffed by highly skilled professional families with lived experience. F2F staff support families and assist providers, state and federal agencies, legislators, and other stakeholders to better understand and address the needs of CYSHCN. [Find the F2F](#) in your state or territory.