Developing a Research Protocol for a Pilot Study of Children with Special Healthcare Needs

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Purpose:
Collaborated with Maine Developmental Disabilities Council staff in designing and implementing a pilot study on the healthcare needs of Maine children with special healthcare needs.

“Just because a man lacks the use of his eyes doesn’t mean he lacks vision.”
~ Stevie Wonder

Learning Objectives:
• Reviewed literature related to measuring the quality of healthcare for children with special healthcare needs;
• Learned about conducting interview research by taking the lead on all phases of the development of a research plan;
• Collaborated with other organizations to develop a research plan;
• Developed and field-tested a questionnaire;
• Gained insights into the healthcare needs of children in Maine.

Leadership Activities:
• Took the lead in a collaborative effort of the Maine Developmental Disabilities Council and Children with Special Health Needs, in developing a research protocol for a pilot study of the healthcare needs of children with special healthcare needs in Maine.
• Increased practical research skills by the following: (1) conducting a literature review; (2) developing a questionnaire for the pilot study; (3) collaborating with other researchers to improve the questionnaire; (4) successfully submitting an IRB proposal for the research; and (5) conducting initial interviews with families in the pilot study.
• Collaborated with other stakeholders including the Maine Parent Federation and the UMaine Center for Community Inclusion and Disability Studies in refining the research protocol and in the recruitment of participants.
• Gained knowledge and understanding of health issues impacting Maternal Child Health populations.