

Training Overview



Background: The Heartland Genetics Services Collaborative is partnering with the Region 4 Midwest Genetics Collaborative to provide *Care Coordination: Empowering Families* training for the Heartland region. The *Care Coordination: Empowering Families* training curriculum was developed by the Region 4 Midwest Genetics Collaborative. It was created in partnership with representatives from public health, genetic and primary care providers and family members. They recognized that even when care coordination is provided within a medical home, the role of the family is an important one and there are few opportunities for formal training for parents on managing these tasks. With this information, a training curriculum was created to help parents work collaboratively with their child's physicians and care providers to better meet the needs of the child and family.

Training description: The purpose of the training is to provide parents with the skills, knowledge and resources they need to coordinate care for children with complex needs in partnership with a medical home. Parents will learn:

- How to identify a medical home
- Techniques to organize information and find reliable resources
- Tips to navigate health care and insurance systems
- Skills to increase communication and coordination between multiple providers
- The need to plan early for child's transition
- Ideas for coping with stress and finding support
- Advocacy skills

This one day, interactive training can be provided to up to 25 participants. Participants should be parents of children aged birth-18 who have been identified as having either a genetic condition or special health care need.

Take-home materials include a participant workbook with additional resources, Region 4 Midwest Genetic Collaborative's *Partnering with your Doctor: The Medical Home Approach* booklet and a personal journal.

Evaluation: The Care Coordination: Empowering Families training includes a comprehensive evaluation consisting of a pre- and post-training assessment as well as a one-year follow up. Evaluation data to date has demonstrated that participants have shown an increase in key knowledge areas such as care coordination, medical home, transition, advocacy, importance of self-care, evaluating resources, and navigating health insurance.

