

Region 4 Genetics Collaborative Family Functioning Discussion Groups

The Region 4 Genetics Collaborative conducted discussion groups in each of the seven Region 4 States (IL, IN, KY, MI, MN, OH, & WI) from March to May of 2009. Only caregivers (e.g., parents, grandparents) of children age birth to eighteen and those who have a child with a genetic condition were invited to participate. The purpose was to learn from parents and caregivers about the impact of having a child who has a genetic condition on family functioning. The number of parents participating in each discussion group ranged from 3 to 16 with a total of 56 participants. Each discussion group lasted approximately ninety minutes.

The information below was collected and organized during the discussion through a mind mapping process. Mind mapping is a strategy to help participants organize their thoughts and allows ideas to be displayed in a diagram. Themes are discovered and participants are able to visualize how their ideas connect. After completing all of the discussion sessions, Region 4 staff compiled the information to look for emerging themes in the participants' discussions.

Major themes were discovered surrounding family functioning and the impact of having a child who has a genetic condition. The themes range from Child's Health to Financial and Insurance Issues and encompass all aspects of life. Some themes are recurrent and came up during all seven discussions, while many others were new but related ideas. Marital Stress was the most repeated theme, particularly the stress of divorce. Other major recurrent themes are accessible social activities for children, emotional issues concerning siblings, child's emotional health, support groups and peer socialization.

CHILD'S HEALTH

- Medical Equipment
- Medical Research
- Medical Support
- Newborn Screening
- Medical Care Coordination
- Surgery
- Legal Medical
- Medical Stress
- Medical Insurance
- Medical Finances
- Medical Care
- Medical Organizations
- Support groups
- Education about condition
- Peer Socialization
- Child's perspective on family functioning
- Child Development with extraordinary situation

CHILD'S EDUCATION

- School's Awareness
- Choice of School
- Services
- Activities
- Transition
- Advocating

SIBLINGS

- Social Support
- Genetic Issues
- Emotional Issues
- Greater responsibilities

CAREGIVER'S HEALTH

Self Care
Propensity for Crisis
Relationships
Family Stress
Social Support
Increased Quality of Life
Guilt
Relief
Grief and Acceptance
Shock and Denial
Depression
Stress
Anxiety
Single parenting
Support
Career
Spirituality
Physical Health

CAREGIVER'S EDUCATION

Educating Self
Advocacy

COMMUNITY

Accessibility
Social Activities
Physical Accessibility
Education
Travel
Educating Others

FINANCIAL/INSURANCE

Savings/Planning
Increased costs
Extra non-covered costs
Financial Stress
Insurance

GENETIC ISSUES

Family Planning

TRANSITION

Communication between parent and child
Mentors
Inclusive Community
Fear
Death of parent(s)/caregivers
Child Care
Guardianship
Educational Transition
Sex, Tobacco, Drugs, Alcohol
Housing
Self-care
Registering for service/draft

FOOD

Educating Family and Friends

CULTURAL ISSUES