







Family Functioning

- Financial**
 - Cost of medical insurance
 - Life insurance
 - Stuck with current clinic
 - Medical foods and formulas - Cost out of pocket
 - Retirement with the responsibility of a disabled adult
 - Prescription glasses, tutor, mileage
- Transition to Adulthood**
 - Strong communication between parent (child) critical
 - Typical teenager stuff
 - Sex
 - Drinking
 - Family planning
 - Self care
 - Diet
 - Medication
- Education**
 - Food
 - Transition to adulthood
 - Educating family, school, everyone child comes in contact with
 - From early intervention to regular education
 - Center-based inclusion vs. general education
 - Lack of timely help
- Guilt**
 - What have I missed?
 - Am I doing enough?
 - Did I cause it?
- Development**
 - Bullying and Threats
 - Concern
 - Social Stigmas
- Siblings**
 - Care for siblings when parents can't (take over as care giver)
 - "Genetic Labeling" - Insurability
 - Lost Opportunities
 - New Opportunities
 - Expected to "pick up the slack"
- The Disease**
 - Limited health care resources for disorder
 - Optical
 - Therapy
 - Dental
 - Pharmacy
 - Can't handle orphan drugs
 - Lack of treatment options

- Job**
 - Transfer = fewer benefits?
 - Employers willing to hire/work with parents
 - Flexible scheduling
- Information Gathering**
 - Getting information
 - Cures from the child (patient)
 - Parents have info - not listened to
 - Lack of/failure to give parent the information
- Strain on resource of time - travel, phone, follow-up**
 - Feel like you're on your own
 - Divorce
 - Marriage
 - Vigilance - constant
 - Stress
 - Siblings
 - Food
 - Not enough time for everything - some things drop off
- Extended Family**
 - Genetic testing?
- Ongoing Care**
 - Educate care provider
 - Require longer than the average family "functioning age"
- Social Understanding**
 - "That's so sad"
 - Well meaning, unsolicited advice
 - Lack of understanding of effect on family
- Legal Issues**
 - Difficulty getting protective services involved when D
 - Threat of Protective Services
 - Register with service at age 18
 - Power of Attorney? Independent? Durable power of attorney over medical care and finance.
- Medical**
 - Secondary complications
 - Surgery
 - Getting and passing the reports
 - Do carriers have latent symptoms yet to surface?
 - Loss of providers, little sharing information
 - I am the medical home
 - Parent carriers/extended family

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