4. Parenting a Child with Fragile X
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Purpose: The purpose of this study is to understand different facets of parenting a child with Fragile X including mother-father roles, support systems, interaction with peers, changes in parenting style over time, problem behavior and how parents respond, how parents teach their children and what material they are teaching, and parents’ plans for their children in the future.

Methods: We are performing a qualitative research study of 54 different families. We read through transcribed interviews of mothers of children with Fragile X from all over the country from when the children were toddlers to adolescents. From the interviews we discovered trends and from those trends created a coding manual. We are in the process of becoming reliable and have yet to perform an in-depth analysis of the coded transcripts.

Results: Trends have appeared fairly consistent over transcripts with a few outliers. Mothers tend to be the primary caregiver while fathers are the ‘fun parent’. Religion is a typical form of support. Parents worry about their children having friendships outside of school. Parents have developed more realistic expectations of their children, whether they have lowered their expectations or raised them. Problem behavior strategies are similar across all interviews. Parents switch from teaching their children academic skills to teaching them life skills as they reach adulthood. Plans for the future are varied between staying at home or living semi independently or independently outside of the home.

Conclusions: Our next steps include becoming reliable and performing an analysis of all 54 interviews for Time 7. We would like to see the results of this analyses and extend it to later time interviews in order to study change over time.