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Fragile X Syndrome: An Examination of Family Occupations

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Fragile X Syndrome (FXS) is the most common form of inherited Intellectual Developmental Disorder and a genetic model for Autism Spectrum Disorder. Those living with FXS face, emotional, social, intellectual, and physical challenges that impact engagement in occupations, yet to date, there has been limited qualitative research examining family occupations in FXS. In this research, twelve interviews were transcribed, coded, and analyzed for common themes anchored in the Person, Environment, Occupation (PEO) model. Results indicated that while children with FXS exhibit strengths, there are certain occupations that families find difficult to engage in. A new model was created for consideration of family occupations and FXS. This model depicts family occupations as a complex and ever changing, dynamic interaction between the child and family engaging in varying environments, and activities. This model can further inform clinical reasoning when designing a comprehensive child and family-centered approach supporting participation in occupations.