**The Inclusive Pathways of Children with Fragile X Syndrome**

**Vitor Franco**

**Madalena Melo**

**Graça Santos**

**Heldemerina Pires**

**Ana Apolónio**

(Universidade de Évora- Portugal)

**Abstract**

Fragile X Syndrome (FXS) is a major disruption of development, a frequent genetic cause for mental disability and the best known cause of autistic spectrum disorders. In recent years, there has been increasing research on genetic and epidemiological aspects and the educational, developmental and functional characterization of these children. However, research on families of children with FXS is reduced and there is little information about the specifics of the lifecycle of these children in the Portuguese context. Our aim is to identify the difficulties, obstacles and challenges present in their inclusion pathway. The main objective is to identify the moments, persons and contexts most significant for family, school and social inclusion of these children and adolescents. A qualitative grounded theory approach was used to interview 40 families of children with FXS full mutation. Data were collected about the most significant moments of that trajectory to clarify the family dimensions and educational, social and professional inclusion. The results suggests that: a) very important difficulties are identified prior to diagnosis, which is also an important moment; b) early intervention is not very effective; c) educational inclusion is more effective in kindergarten than at the school level; and d) difficulties with school and social inclusion increase as the child is growing older. These results reinforce the importance of screening and diagnosis and the role of pediatricians and educators in that process, and also the need for more effective early intervention programs focused on family needs and child characteristics.

**Keywords:** Fragile X Syndrome, Inclusion, Disabilities