

Smoothing the Transition to Successful Adulthood

Introduction

The National Fragile X Foundation (NFXF) receives phone calls on a daily basis asking about issues affecting young adults with fragile X syndrome (FXS). Young adulthood can be a challenging time. There is so much going on—the “children” are leaving school, finding and working at jobs, and living away from their parents—most likely for the first time. These are big changes for both the parent and the young adult, and there is not much written information available on how parents can help manage the transition, particularly for young adults with fragile X syndrome. These written materials and multimedia vignettes are a good starting place for parents to learn about the issues their children face as they leave the school environment. They provide ideas for parents to help their now-grown children become more independent in their lives.

Thanks from the NFXF go to the Project Team Members who developed these materials. In alphabetical order, they were: Elizabeth Berry-Kravis, MD, Marcia Braden, PhD, Jayne Dixon Weber (parent), David Hessel, PhD, Jane Jones (parent), Deborah Kwan, OTR/L (NFXF staff), Andrew Levitas, MD, Cindy Lunn (parent), Robert Miller (NFXF staff), Liz Porter (parent), Barbara Porterfield (parent), Phil Porterfield (parent), and Avis Primack (parent). All have many years of experience with fragile X syndrome as either parents of adolescent or adult children, or as professionals.

While the voices for the vignettes were provided by trained actors, the people appearing on camera are all either persons with FXS, parents of persons with FXS, or staff from the NFXF. They are, in alphabetical order: Jesse Avrahami, Olivia Barber, Tracy Barber, Deborah Kwan, Daniel LeCover, Greg Mishey, Teddy Palmer, Carrie Rose, Nick Rose, Cassie Weber, Ian Weber, Jayne Dixon Weber, Larry Weber, and Carolyn Ybarra. The only exceptions were Laura Bartell, friend of photographer Matt Carr, and Jeanette Baird, friend of Deborah Kwan, who both stepped in to fill last-minute needs.

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To all of the above: Thank you! Your efforts will help thousands of families in the years to come. To all parents and professionals: Transitioning to adulthood can be a challenge for those with FXS. We are confident that these materials will help you guide that transition in a productive way.

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