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 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 Hessl, 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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Finally, special thanks to Kathy Elder and Greg Mishey of ThinkMedia, who produced all of the multimedia materials for the project; to their colleague, Matt Carr, who came from Brooklyn, New York and took over 3,200 photographs; to Andrew Hidas and Karen Ashton of Bridge Communications & Consulting, for their editing and design work on the accompanying materials, and, very importantly, to parent Jayne Dixon Weber and to Deborah Kwan of The National Fragile X Foundation, whose shared leadership and coordination of this effort “made the difference” between an interesting idea and a need fulfilled.

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.
The National Fragile X Foundation's Adolescent and Adult Project

Smoothing the Transition to Successful Adulthood

Table of Contents

1. BEHAVIOR, MENTAL HEALTH, AND MEDICATIONS
   - Medication, Behavior, and Fragile X Syndrome ........................................ 1
   - Additional Medication Information ............................................................... 3
   - Behavior Issues: Mood Disorders ○ ......................................................... 4
   - Behavior Support/Crisis Plan Hierarchy ...................................................... 6
   - When Agitation Occurs: Using the “3 Rs” ○ .............................................. 8
   - Reward Systems ......................................................................................... 11
   - Behavior at Home: A Few Simple Changes ................................................. 12
   - Resources .................................................................................................... 14

2. SOCIAL DEVELOPMENT
   - Social Development .................................................................................. 15
   - Socialization Survey and Results ................................................................ 16
   - Social Situations: Talking on the Telephone ○ ........................................... 19
   - Social Situations: Sensory Issues ○ ............................................................. 20
   - Social Situations: Anxiety Issues ○ ............................................................. 21
   - Tips for Making Social Outings Safe .......................................................... 22
   - Camps/Opportunities for Socialization ....................................................... 23
   - Other Types of Social Opportunities ............................................................ 25
   - Ongoing Social Opportunities .................................................................... 26
   - References .................................................................................................. 29

3. LIVING SETTINGS
   - Independent Living: Summary of Guidelines for Establishing a Private Home .......... 30
   - Other Living Options ................................................................................ 31
   - Living Settings Checklist .......................................................................... 32
   - Interview Questions for a Care Provider .................................................... 36
   - When Your Young Adult Moves Out ............................................................ 39
   - Various U.S. Living Settings ....................................................................... 40
   - Living Settings by State ............................................................................ 41
   - References .................................................................................................. 45

- Indicates there is a vignette on the DVD based on this material.
4. TRANSPORTATION

Walking to Work Independently .................................................. 46
Biking to Work Independently .................................................... 50
Riding a Public Bus Independently ........................................... 51
Car/Plane Travel Ideas ............................................................ 56
Transportation References ....................................................... 59

5. EMPLOYMENT

Finding a Job: Building on Strengths and Interests .......................... 60
Interview Form and Checklist .................................................... 63
Developing Appropriate Work Attributes ................................... 65
Behavior at Work: Modifying the Environment ............................. 67
Employment Opportunities—Nationwide Companies ....................... 70
Employment Opportunities—State and Local Resources .................... 71
Other Employment Options ..................................................... 75
National Employment Resources .............................................. 75

6. ISSUES IN SEXUALITY

Sexuality and Fragile X Syndrome .............................................. 76
Suggested Sex Education Curriculum ........................................... 78
For Women: A Strategy for Dealing With Sexual Advances .................. 79
Public vs. Private Behavior: Masturbation .................................... 80
Disability Solutions Magazine Article Reprint—Part 1 ....................... A-1
Disability Solutions Magazine Article Reprint—Part 2 ....................... B-1
Articles on Sexuality Education ............................................... 82
Resources .............................................................................. 83

7. DISABILITY ORGANIZATIONS, SERVICES, AND RESOURCES

Advocacy ................................................................................. 84
Colleges .................................................................................. 84
Community Safety Programs ..................................................... 85
Family Financial Planning ......................................................... 85
Guardianship ......................................................................... 85
Individual Support Planning (ISP) ............................................... 85
Supplemental Security Income (SSI) ............................................ 86
Transition Planning .................................................................. 86
Transportation ....................................................................... 86
General Disability Organizations/Websites .................................... 86
Books ..................................................................................... 87
Additional Resources ............................................................. 87