
CENTER FOR DISABILITIES AND DEVELOPMENT

Possibilities in Education and Training

A quarterly publication of the Center for Disabilities and Development, Iowa's University Center for Excellence on Disabilities at University of Iowa Stead Family Children's Hospital, Iowa City, Iowa 52242-1011

My Story of Growth and Independence

By Shane Fetui



I was 16 years old in November 2000, a sophomore in high school, when I suffered my traumatic brain injury by falling off the hood of a car. My mom was working and had a feeling something was wrong with me so she came home early and found me lethargic and thought I was on drugs. She called 911. I was air lifted by helicopter to Dubuque, Iowa to Mercy hospital. Six to nine men had to hold me down, as I was combative. I was then air lifted to Iowa City to University of Iowa Hospitals and Clinics. I was placed in a medically induced coma and they took my left bone flap out of my head.

When I woke up from my coma, I asked where my tongue pierce was. My mom said, "If you get thru this, I will buy you 100 tongue rings." I was in recovery at the University of Iowa Hospitals and Clinics for three to four months, where the doctors asked me pretty common questions such as "What year is it?" and "When is your birthday?" I had to relearn how to walk and talk, and they had me do some memory work. I returned home eventually.

We tried to have services in our home, but it was difficult to find services. My struggles included mood, anger, anxiety and depression. Because I was aggressive with people and out of control with my anger, 24-hour



care services were found at a facility in Dubuque, Iowa. I was at this facility for seven months. I was then transferred to a facility in DeWitt, Iowa, which was also a 24 hour service. I was not at this placement for very long as I was moved to Camanche, Iowa into hourly Home and Community Based services (HCBS).

All of these years I struggled with taking my medications. I did not want to take meds. My hourly services failed due to lack of support, having the wrong support and my unwillingness to stay healthy. The agency discharged me. I then moved to Des Moines, Iowa into a rehabilitation group home that specialized in brain injury. I was there for two years when I tricked my mom into taking me back home to Clinton, Iowa, where she was living. I was there for a week and a half and then was transported to Brookhaven Hospital in Tulsa, Oklahoma. At Brookhaven I achieved a lot of goals such as becoming my own guardian. I had a job coach and a job working maintenance. I made it to the transitional living center program. I became in control of my moods, anger and behaviors. I learned the importance of medications and how to deal with my anxiety. I stayed at Brookhaven for about two and a half years and was ready to move out/graduate from the program.

In June 2016, with help from REM of Iowa and Money Follows the Person (MFP), I was able to move back to Iowa and into the community. REM provided me with 24-hour Home and Community-Based Services (HCBS) under the Brain Injury Waiver and MFP offered me enhanced case management services, household set up items, rent deposits, and specialized employment services. I lived with two other men in a three bedroom apartment. While I was at REM, I became my own med manager with doctor's approval, passed my National Careers Readiness Certificate test, passed the Math Assessment/Placement test and was accepted into Des Moines Area Community College to get a culinary arts degree. I was also successful in taking my medications on a regular basis and in controlling my anxiety, anger and frustrations. With my success and goal achievement, I moved out to my own apartment where I receive hourly community services.

I am grateful and thankful to the following services and supports that helped me achieve my successful journey: MFP, REM of Iowa, HCBS/IFA housing, Iowa Vocational Rehabilitation Services (IVRS), Iowa Workforce Development (IWD), Evelyn K Davis Center for Working Families, Premier Payee and Iowa Family Assistance.

(The Money Follows the Person (MFP) demonstration program is a collaborative partnership between Iowa Medicaid Enterprise (IME), a division of the Iowa Department of Human Services (DHS), and the Center for Disabilities and Development (CDD) at University of Iowa Health Care. This program, funded through the Centers for Medicare and Medicaid Services (CMS) provides opportunities for individuals with intellectual disabilities, or other related disabilities, to move out of intermediate care facilities for individuals with intellectual disabilities and into their own homes or apartments in the community of their choice. Individuals living in nursing homes may also qualify. MFP grant funding provides for transition services and enhanced supports needed for the first year after an individual moves into the community. Under a contract with IME, eight Transition Specialists from CDD are deployed throughout the state to provide transition planning services, community options awareness, training, advocacy, employment supports and ongoing support and care coordination to individuals with disabilities, their families and facility-based and community-based providers.)

When Life Gives You a Handbook ...from the DRL

The essential guide to safe travel-training for children with autism and intellectual disabilities. Desirée Gallimore. Jessica Kingsley Publishers, 2017.

“For people with autism or an intellectual disability, safe and independent travel can be a serious challenge – once mastered, it’s also a vital gateway towards freedom, fulfilment, and equality within society. For the first time, this book offers a simple step-by-step system that can be used to teach travel skills to children of any age or ability.”-synopsis

Every child welcome: a ministry handbook for including kids with special needs. Katie Wetherbee and Jolene Philo. Kregel Publications, 2015.

“Because children’s ministry workers are volunteers who may or may not have training in the field of special needs education, one goal of *Every Child Welcome* is to encourage quality teaching. The goal is accomplished when volunteers assess and understand each child’s strengths and needs rather than focus on the child’s diagnosis.”-introduction

The survival guide for new special education teachers. (2nd ed.).

Catherine Creighton Martin and Clara Hauth. Council for Exceptional Children, 2015.

“This all-new edition offers practical guidance on such topics as roles and responsibilities, school environment and culture, classroom organization and management, collaboration with other professionals, and individual professional development.”-synopsis

The autism playbook for teens: imagination-based mindfulness activities to calm yourself, build independence & connect with others. Irene McHenry and Carol Moog. Instant Help Books, 2015.

“This book offers a unique, strengths-based approach to help teens on the autism spectrum to develop social skills, communicate more effectively, and thrive.”-synopsis

Mindfulness for teens with ADHD: a skill-building workbook to help you focus & succeed.

Debra Burdick. Instant Help Books, 2017.

“This book is designed for the teen with a short attention span. For the teens who are reading this [book], you can dip in for a few minutes and get a few reminders that immediately set your track in a new direction.”-foreword

Relationship building & sexual awareness for kids with autism: S-T-A-R-S 2. Susan Heighway and Susan Kidd Webster. Future Horizons, 2015.

“Many of the problems in the area of sexuality and sexual abuse that adults with disabilities currently face could be lessened by early education and prevention; this publication is an essential tool that provides information and assistance in this field. This edition focuses on understanding relationships, social interaction, sexual awareness, and assertiveness.”-synopsis

What does consent really mean? Pete Wallis and Thalia Wallis; illustrated by Joseph Wilkins. Singing Dragon, an imprint of Jessica Kingsley Publishers, 2018.

“Learn more about consent and what it means for you by following a group of teenage friends chatting on their way home from school. Confronted by the myths and taboos surrounding sex and consent, they talk about their own experiences and debate what’s okay and what’s not, as they explore what consent really means.”-synopsis

Is it you, me, or adult A.D.D.? Stopping the roller coaster when someone you love has attention deficit disorder. Gina Pera. 1201 Alarm Press, 2008.

“Until now, no books existed that combined both a scientific understanding of adult ADHD with pragmatic recommendations to guide these adults and their partners in coping, problem-solving, and otherwise addressing the difficulties they face in sharing a life and a home. Gina Pera’s book does so with an admirable balance of current scientific information mixed with sage advice and wise, practical strategies based on current science.” –foreword, Russell A. Barkley, Ph.D

“MFP is such a great program for people coming out of institutions.”

–Shane Fetui

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