

University of Texas Rio Grande Valley

ScholarWorks @ UTRGV

Counseling Faculty Publications and
Presentations

College of Education and P-16 Integration

9-12-2012

Living with a Disability : Finding Peace Amidst the Storm

Susan Stuntzner

The University of Texas Rio Grande Valley, susan.stuntzner@utrgv.edu

Follow this and additional works at: https://scholarworks.utrgv.edu/coun_fac



Part of the [Counseling Commons](#)

Recommended Citation

Stuntzner, S. (2012). Living with a Disability: Finding Peace Amidst the Storm. Counselling Association of India. <https://www.amazon.com/Living-Disability-Finding-Peace-Amidst-ebook/dp/B0096BGYX6>

This Book is brought to you for free and open access by the College of Education and P-16 Integration at ScholarWorks @ UTRGV. It has been accepted for inclusion in Counseling Faculty Publications and Presentations by an authorized administrator of ScholarWorks @ UTRGV. For more information, please contact justin.white@utrgv.edu, william.flores01@utrgv.edu.



Living
with a

DISABILITY:

FINDING PEACE AMIDST THE STORM

SUSAN STUNTZNER
PhD, LPC, CAC, ACC
UNIVERSITY OF IDAHO

Living with a Disability : Finding Peace Amidst the Storm

Susan Stuntzner PhD, LPC, CRC, NCC

Author Biography

Susan Stuntzner, PhD is an educator in the rehabilitation counseling program at the University of Idaho. She is also a Licensed Professional Counselor, a Certified Rehabilitation Counselor, and a Nationally Certified Counselor. She currently trains master level students to be counselors. Graduates are trained to work with persons with disabilities in a variety of settings: mental health, state and federal agencies, non-profit agencies, and private practice. Prior to her current position, Dr. Stuntzner worked as a psychology staff member at a state facility in the Midwest providing counseling and mental health-related services to persons with developmental disabilities and existing co-morbid conditions. She is a recent graduate of University of Wisconsin – Madison where she obtained her PhD in rehabilitation psychology. Her research interests include the role of forgiveness within rehabilitation counseling and psychology, adaptation to disability, and coping and adjustment strategies in women with acquired disabilities.

Dr. Stuntzner has presented at professional conferences on topics relating to forgiveness and adjustment to disability. Prior to her attendance at University of Wisconsin – Madison, Dr. Stuntzner was employed in the rehabilitation counseling profession in the Northwest.

Counselling Association of India

Copyright © 2012 Counselling Association of India & Susan Stuntzner. All rights reserved. No part of this publication may be reproduced or distributed, without the prior written permission of the publisher.

CONTENTS

Acknowledgement 7

Forward – Experiences Leading to the Development of this Book 9

PART I

DISCOVERING THE HURT THAT BINDS US

Chapter 1 – My Personal Journey of Living with a Disability 13

Chapter 2 – The Power of Other Peoples’ Words and Actions 40

Chapter 3 – Societal Attitudes & Disability: It’s Not About You 55

Chapter 4 – Making Choices: Appropriate vs. Inappropriate Social Behavior 76

PART II

MAKING THE CHOICE TO HEAL – FINDING PEACE

Chapter 5 – Understanding the Hurt that Binds You 97

Chapter 6 – Confronting the Obstacles that Prevent you from Living a Fulfilling Life..... 123

Chapter 7– Learning to Forgive Oneself and Others..... 145

PART III

STARTING A NEW LIFE – FINDING AND UTILIZING RESOURCES

Chapter 8 – Constructing A Life Worth Living: A Map to Creating a Better Life..... 157

PART IV

WORKING WITH PROFESSIONALS – BUILDING GOOD RELATIONSHIPS

Chapter 9 – Advocating For Yourself – When & How? 177

Chapter 10 – A Chapter to Professionals: Enhancing Your Effectiveness 195

Epilogue – Some Final Thoughts for Readers 214

ACKNOWLEDGMENTS

There are numerous people I would like to thank and acknowledge because without their help and encouragement this book would not have been possible. I would like to extend my gratitude to my psychology colleagues for their encouragement in the development of this book: Shawn, for encouraging me to pursue this book as a part of my professional development; Karla, Rob, and Beef for their time to listen and review parts of this publication in an effort to help me acquire clarity. Kristen is someone I am indebted to for taking the time to review parts of this book and for providing support in the completion of this book. My parents, for being instrumental in teaching me the importance of striving for what I believe in. Furthermore, they have instilled the value of believing I can accomplish what I set out to do through hard work. Trish is a dear and loyal friend who believed in me and the hope this might bring to others. I am indebted to her for being open to the many experiences I have had throughout the duration of my life. It is due to her caring friendship that I have been able to write this book. I would also like to thank her for helping me understand the importance of the message this book may provide to others.

FOREWARD

Life is an interesting journey filled with hopes, aspirations, joy, happiness, undiscovered dreams, and dreams yet to be. Life is also a journey filled with unexpected turns and twists, sorrows, hurt, pain, and tragedies. Somehow, as a society, we often think and feel that if we do the “right” things nothing bad will ever happen to us. We often buy into the belief that “bad” things don’t happen to good people. As a society, we are too quick to engage in thoughts of judgment towards people who have had hard, gut-wrenching experiences. When people have not *yet* experienced painful, life-altering events, they automatically assume that the person must have done something to cause the pain which, by the way, is not always the case. We find ourselves engaged in thoughts of judgment and blame, consumed with feelings of anxiety and fear, perhaps wondering if something so terrible could ever happen to us. Even worse, when tragedies happen to us, we are prone to carry on the belief and legacy of self-blame and torment. Such beliefs further aggravate our own ability to cope and move through the event.

We must ask ourselves where these beliefs come from and whether or not these beliefs are really true. What is true is that most peoples’ lives are some combination of pleasant and unpleasant experiences. Sooner or later, if we all live long enough, we will experience some kind of deep hurt that rocks us to the core of our bones whether the hurt is due to divorce, death of a spouse or loved one, estranged relationships, tragic life-altering events such as a sudden, traumatic injury, or birth of a child who has a disability. Accidents and unforeseen events such as trauma are a natural part of life; thus, we cannot be assured that tragic events will not happen over the course of a person’s lifetime. Perhaps that is a part of what frightens people the most – their lack of power in being able to control the unknown and the reality that we are all mortal and vulnerable to such atrocities.

People forget to recognize that changes in physical functioning are also a natural part of the aging process. A typical, average person is likely to experience changes in her senses, mobility, internal organs, or physical functioning throughout her lifespan. Changes in bodily and physical functioning are a very natural part of the lifecycle. So why is it that some people have such an awkward time dealing with the concept of disability? Again, not an easy question to answer, but I believe the answer lies in a person’s ability to accept or not accept their mortality and vulnerability to unexpected change. People who are more anxious and insecure about themselves and their vulnerabilities are less likely to effectively handle other people’s differences.

When people’s lives are suddenly altered and forever changed due to a disability, people find the world a different, unfamiliar, and sometimes scary place. People who experience tragic, life-altering events (e.g., acquiring a disability) many times find themselves suddenly thrust into a new way of life with a “new set of rules”. Life according to this new set of rules is often unspoken, challenging, and confusing. Persons with disabilities must suddenly learn how to adapt and cope with many changes; changes for which there are no rules or handbooks. Changes experienced by persons with disabilities vary from person to person and

from disability to disability. For example, some people experience changes in memory and thinking while other people experience changes in their ability to move their hands or feet. Other times, the focus is on adjustment to the disability, “different” treatment by society and other people, or changes in family roles and relationships. Furthermore, each person’s experience and view of living with a disability is different. No one person views his or her disability in the same way and what this change means to them, just like no two people think or perceive any given event in exactly the same way. There are many factors (i.e., financial income, employment, social support, self-concept, family, age of onset, education) that affect a person’s perception and adjustment to disability process, all of which will vary from person to person.

Regardless of the disability-related changes experienced by each individual, persons with disabilities have many similar changes they must face. One common change relates to the way people are treated by the world around them. Everyone, including persons with disabilities, is given messages about themselves by other people. Persons with disabilities are given specific messages about themselves by society, well-meaning professionals, family members, and friends. Some messages are positive, but many messages are negative, invalidating, and hurtful. Messages may be clearly conveyed to people through a look or glance, non-verbal posture or behavior, facial expression, tone of voice, amount of physical distance between oneself and others, as well as by specific words used in conversation. To complicate matters further, people conveying these messages are often unaware of the effect they have on persons with disabilities, while others may lack common sense and sensitivity and have never taken a moment to consider the appropriateness of their behavior.

Social isolation is an issue sometimes experienced by persons with disabilities. Persons with disabilities often feel alone and isolated, because no one except others who have had similar experiences understands the journey a person is about to face and will continue to experience in the days and years ahead. Persons with disabilities may find others full of advice, yet continue to feel misunderstood, especially when they do not have anyone in their world who has had similar experiences. Family members and friends can be either a source of support or stress for the person with a disability. When strength and support is provided, family members and friends are able to nurture the fortitude in the person with a disability so she can move forward. Other times, persons with disabilities experience feelings of isolation and abandonment when the family is not able to be supportive. Some families and friends are temporarily distant due to their own grief and loss processes, while others remain distant over the long haul. It is during these times of change that families and friends find themselves unprepared for the days and years ahead, and the person with a disability finds herself coping with the disability and the changes that come with living with a disability the best she can.

The road ahead for the person with a disability is an individualized journey that is full of both blessings and difficulties. Many people will have similar experiences to their peers who also live with disabilities, yet no two people will have exactly the same experience. This is because each person is unique and has a different way of viewing and interpreting these experiences. Nonetheless, it has been my experience that people find peace and comfort when they know others who have had similar trials and tribulations and have someone with whom they can check things out. Furthermore, it seems persons with disabilities experience a sense of hope and freedom when they hear and identify with another who has had similar experiences to them. Somehow this “identification” serves as a source of strength and hope that given time, life will work out.

In an effort to find peace and happiness, persons with disabilities must learn to accept and cope

with changes in functioning due to their disability, other peoples' perceptions of them, and feelings of isolation. Living with a disability does not mean a person's life is over. Rather, a person is presented with the opportunity to learn and grow in ways probably not foreseen or anticipated. Living with a disability offers a person the opportunity to discover her inner strengths and abilities, to learn what she is made of, and to focus on what is truly important! Because people must learn to do things differently and make adjustments which may include the way they do things physically or mentally, they are provided the opportunity to learn more about themselves. Likewise, they may find over time that some activities or values are just not as important. So, a change in values and focus is likely to occur.

Persons with disabilities are blessed and provided with the opportunity to experience personal freedom, grace, and love. Persons with disabilities have the ability to find a freedom that will allow them to be secure and content and to discover the grace and love of God in ways not expected. Learning to live with a disability can provide many blessings and joys not initially anticipated. Some people may find they would not want to change their life post-disability because living with a disability has helped them become more aware, empathetic, and caring, or it has helped them realize they have so much to offer the world in ways they had not previously foreseen.

Living with a disability is not always easy. There are likely to be ups and downs, as well as good days and bad days many years down the road, but a continuous pursuit of peace, joy, and contentment can provide a person the opportunity to live a well-balanced, fulfilling life. For this to occur, each person must be willing to examine her barriers and own issues that prevent her from achieving the life she wants and then take the action necessary to develop the life she 'imagines'.

The heart and soul of this book was written to be a guide and to assist people who have encountered hard, gut-wrenching experiences, such as the acquisition of a disability, in finding peace and happiness amidst the changes taking place in their lives. It may also be used as an educative resource for family members and professionals whose lives are intertwined with persons with disabilities. The content of this book is a composition of my own personal journey of living with a disability, experiences I have had both personally and professionally, along with some formal knowledge I have acquired over the years.

Stories and events discussed throughout are intended to either illustrate a point or to further demonstrate the prevalence of situations to which persons with a disability are sometimes exposed. The stories are not meant or intended to imply blame or to finger point toward another for his or her hurtful words or actions. Rather, my intent is to bring to light the event. For it is the event or situation and the meaning, positive or negative, a person has ascribed to it that has long-lasting power. It has been my experience that other people are simply characters we encounter in the road of life. Furthermore, the characters will often change from situation to situation and the persons involved often have little or no awareness of the power and influence their words and actions had. Some may be ignorant to this fact and others may simply not care. Some may care but simply not be enlightened or 'in-tune'.

Throughout this book, I have used pseudonyms in an effort to protect the identity of various persons discussed. As just mentioned, the person is not the salient feature of the story. Rather, it is the effect and how the event affected me that is of value. I have also included these stories because I believe they represent a sampling of situations to which I have had repeated exposure. Therefore, some statements and comments may represent a composite of experiences.

Some of the stories presented may be ones to which people can relate. Others may not, as the

experience of living with disability is very individualized. Similarly, the experience of living with a visible condition differs in some aspects than that of invisibility. In addition, persons born with a disability may perceive their situation different from those who acquired it later in life. While I wish I could cover and encompass every possible situation a person may encounter based on life situations, that task is very diverse and beyond the scope of this book. Yet, I believe that many of us can relate to some of the thoughts and feelings we have experienced in living with a disability. Therefore, it is my hope that the chosen stories help provide readers with a place to identify and check out some of the experiences they have had and then decide how they want to proceed and move beyond them.

A second reason I decided to write the book is related to resource availability. Over the past 26 years I have lived with a visible, physical disability. During this time, I have come across few 'hands-on', practical resources that were readily available to persons with disabilities. Much of what I have learned about living well with disability came through the school of hard knocks. I had to learn through my own experiences how to make sense of my situation and the experience of disability. It was not until I found myself in a wheelchair, followed by leg braces, that I began to waken to the fact that there are societal attitudes and expectations toward persons with disabilities by persons without disabilities.

Twenty-six years ago, our society did not have Internet, chat rooms, and blogging for people to check out their experiences post-disability. It was not until 10 years post-injury I began to realize that journal articles and text books talked about the general experience of disability and societal bias. I also realize many people reading this book may not have accessed these resources for whatever reason. Thus, it is my hope that this book will provide people with a practical resource and the opportunity to realize there is a solution. It is my hope people realize they are not alone in their coping process, and there is hope for the future.