

LESSONS IN LISTENING



**50 YEARS OF WORKING WITH CHILDREN
AND ADULTS WITH DISABILITIES WHO ALSO HAD
REPUTATIONS FOR DIFFICULT BEHAVIOR**

BY YEITER

Someone once said, “To find out, you gotta look in.” Yeiter has invited us to look inward in our search for ways to help people who engage in “difficult” behaviors. With decades of experience in the field of disabilities, he challenges us to examine our assumptions about why people act differently and to build communities where all people are welcome. Through personal stories and anecdotes, he describes his sometimes painful, often humorous journey of “looking in” and he shares important lessons about listening not only to the individuals served, but also to their entire community – family, friends, and caregivers. It’s almost always a gold mine.

*David Pitonyak
Imagine*

There are a handful of people in the field of disability services who “walk the talk” and Yeiter is one of them. Throughout his 50-year career he has often been the lone voice advocating for treating people with disabilities with respect and for getting to know the person behind the behavior. He understands the power of stories and readers will come away with a whole new way of looking at people with disabilities and the power of relationships instead of cookbook strategies.

*Cheryl M. Jorgensen, Ph.D.
Inclusive Education Consultant
Acworth, NH*

*I found Yeiter’s book, *Lessons in Listening*, a most enjoyable read, full of helpful ideas on how to support children and adults with so-called “challenging behaviors.” I highly recommend it to parents, direct support staff, and professionals. This honest account of his 50 years of learning from giants in the field of human services – Lovett, McGee, Gold, Wolfensberger to name a few – as well as the very people with disabilities he supported, shaped his values and practices in supporting people often forgotten or given up on. In a world that wants to engineer behavior change with operant conditioning, the lessons Yeiter offers are refreshing, humanizing, and respectful of the people being supported, because listening is the lesson!*

*Guy Caruso, PhD
Institute on Disabilities at Temple University
College of Education and Human Development*

In these gray days of covid fog, the array of bad news stories can drag you into a frightening sink hole. So don’t go there. Instead, take a few minutes and be inspired by the first hand wisdom of a man who has had the patience and the commitment to listen to folks many would ignore, and continue to learn life lessons from them. These ‘short stories’ are about the complexities of lives – including David’s – and the wisdom that emerges from genuine listening – from sharing life experiences – from being fully human.

These stories are an antidote to the mechanization and industrialization of ‘care’. There is an excess of rhetoric about care. Too often it is really about more forms and cost cutting. Personal care staff are over worked, underpaid and are typically unable to provide the supports they know how – and would actually love to provide. This glimpse into five decades of commitment unveils the wisdom and the rewards of taking the path less travelled. This book and the stories from are soul nurturing investments. I recommend both for your reading and your life.

*Jack Pearpoint
Inclusion Press*

Lessons in Listening is a must read for anyone who truly wants to offer good support to people who have “interesting “behaviors”. I have been in the field of disabilities for 38 years with my niche as a Direct Support Professional. I came into the field in 1984 ignorant (even with a BA in psychology) and needed all my stereotypes about people with disabilities challenged. Like Yeiter, I was exposed to and sought out some of the best minds in our field in order to support people to live a good life full of friends, family and purpose. After 25 years of both Yeiter and I practicing our craft in different parts of NH, we came together to teach a course to any human service worker and family members about many of the concepts in this book.

As a Direct Support Professional, I can attest that Yeiter is the real deal. Yeiter’s wisdom comes from a rigorous search for knowledge and then application of core values that are universal to us all. His insights are spot on as evident through the stories of real people he got to know, and all his suggestions are practical and doable. This book will certainly continue to advance the social justice movement for people with disabilities as we believe there are Lessons in Listening...

*Robin Carlson
Direct Support Professional, Rochester, NH*

“I could change the world if only I could get out of bed” I often say this because I want everyone to realize how important direct support work is. The hardest part about being disabled is not the disability at all. It is finding, training, and keeping that person who values your contributions to the world. The truth is most direct support workers and service agencies can manage “what is important for” but understanding “what is important to” is hardly ever considered even though what’s important to me makes me who I am. This book “Lessons in Listening” could help change all of that for individuals with disabilities.

*Kathy Bates
Institute on Disability, University of New Hampshire
Policy and training specialist*

This is a wonderful book. It is engaging and interesting. Yeiter shares insights that he has gained from 50 years of accompanying people with disabilities on their life’s journeys. He helps us to understand the assumptions that shape how we perceive and treat others – particularly people who are defined as having “behavior problems”. With sincerity and learned knowledge, Yeiter gently challenges us to slow down, learn by listening deeply, identify with people, and to see past the “diagnoses” that often define people who are marginalized.

As a professional and a parent, I highly recommend this book. Thank you, Yeiter.

Darcy Elks

It is a great honour to write a few words of endorsement for one of the most important books I have read about our interactions with people with disabilities who also had reputations for difficult behavior. This is a key issue in Australia right now as we grapple with the use of restrictive practices to “control” such behaviors. As a part of our National Disability Insurance Scheme, we are establishing a complex reporting structure on the use of restrictive practices and a not insignificant bureaucracy to develop the capacity of the Australian disability sector to implement “positive behavior support plans”.

Unfortunately, in many cases, we are dealing with these situations when they are presenting as full-blown crises, out of control, and requiring immense remediation. How might we have prevented letting things get to that state? Yeiter has the answer. Listen to people; learn from them; find out what they want; engage with them human beings with the same range of needs and aspirations as ourselves. If we would serve people we must learn from them!

*Richard Bruggemann
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Cover Photo: A snapshot of Yeiter (age 5) reading to his grandfather. The beginning of a life long commitment to supporting people to thrive and live full lives.



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50 years of working with children and adults with
disabilities who also had reputations for difficult behavior.

*"In the beginner's mind there are many possibilities.
In the expert's mind there are few."* —Suzuki

Acknowledgments

Thank you, Matthew Ertas, Cheryl Jorgensen, Robin Carlson, Guy Caruso, and
Darcy Elks for their support and wisdom in writing this book.

Sincerest thanks to my sister Diane Gittlen and Jack Pearpoint
for helping format this book.

Important Note:

If you (parent, direct support staff, teacher, paraprofessional, job coach, etc.) are directly involved in the life of a person with a disability who is exhibiting violent or destructive behavior towards you, themselves or others, you may not have the luxury of having the time/energy right now to read and digest this book, i.e., you may be in crisis mode. Thus, I have included a short one-page summary or framework in the Appendix as a guide to hopefully offering some initial direction in terms of what I have found to be critical focus points. When I am invited to provide consultation, this then is an overview of my mental framework and process.

If you have any questions, I am available via email at yeiter@gmail.com

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Foreword

People with intellectual and developmental disabilities who are seen and treated as presenting challenging behavior have a double risk of social exclusion and oppressive treatment. Misguided efforts to eliminate threatening behavior by asserting power over a person compounds social devaluation of their disability. Frustration at failure to enforce compliance escalates limitations on a person's opportunities and liberties, even to the point of bodily restraint, stupefying levels of prescribed drugs, and ruinously expensive levels of staff surveillance. A person's history shrinks to hypervigilant focus on behavior that evokes fear, disgust, and resentment. Their identity congeals into a stereotype of menace that justifies imposition of dehumanizing control.

In this book, Yeiter draw lessons from his own 50 years of personal commitment to supporting people who live in a status he names a "reputation for challenging behavior". He draws on a rich personal history. His time in the company of people defined by a story of challenging behavior begins in an unreformed back ward and continues through an attempt to reform the institution by implementing behavior analytic treatments, the move into local group homes and day programs, the implementation of integrated special education, and the development of individualized supports for work roles and establishing people in their own homes. In making a positive difference in people's lives he has taken many parts: ward attendant, behavior specialist, administrator, consultant, teacher.

That Yeiter has taken the time and trouble to reflect on and write about his experience is a gift. He reveals the depth in the lesson of the book's title with stories of his teachers among those who live with a reputation for challenging behavior and accounts of what he has taken from his study with Herb Lovett, John McGee, Wolf Wolfensberger and his associates, and Marc Gold. All of his experience comes to a clear point: if we are to be of help to people with challenging behavior, we must learn to listen and we will learn from our engagement in joining people to better their lives.

Like other lessons with moral power, “listen” is simple to state and hard to live. As he elaborates 14 practical lessons that each reveal a different facet of learning to listen, Yeiter returns repeatedly to identify the virtues that release the power of listening. The humility to not know the answer. The confidence that people can develop sufficient trust to communicate what matters to them and collaborate in efforts to experience more of what has meaning. The ability to support people to learn another way when listening shows what more is possible. The courage to take responsibility for one’s own part in creating and maintaining undesirable situations. The will to resist the dark undertow of dehumanization and distancing. The love to step empathically into the other’s shoes and take in the whole context of their life. The willingness to struggle through times when difficulty persists and empathy seems beyond reach. The capacity to offer and ask for forgiveness. The imagination to see a person as an active participant in their own life. The creativity to establish people in valued roles.

The force of these lessons is not diminished by the frightening extent to which current human services systems are aligned to make the relationships necessary to listen and act on what is discovered difficult if not illegitimate. More and more, even establishing the minimum conditions for authentic listening involves taking a moral stand for right relationship against the powers of mechanistic bureaucracy. Yeiter’s reflections on his work earns our gratitude for encouraging this stand.

John O’Brien

This book is dedicated to Herb Lovett who I got to know only briefly before his passing but who nevertheless impacted my life so deeply.

“Fundamentally, the most helpful thing I have found is to listen to what people have to say. By now, I suppose that by listening, I mean the act of attending carefully to what is said as well as to what is meant, to regard actions as communication, and, most profoundly, to possess the spirit of taking other people seriously.”

(Lovett, H.; Learning to Listen, p30)

Introduction

***Reputation:** the beliefs or opinions that are generally held about a someone or something; overall quality or character as seen or judged by people in general.*

—Webster’s Dictionary

Reputations for difficult behavior? After many years of being involved in the lives of people with disabilities who were labeled as behavior problems, I came to realize that such individuals were not the problem, we were. In my experience, clinical/diagnostic labels were not only misleading but useless and often harmful. This book is my best attempt to help you see this and less of what to do about it. My experience has taught me that how we come to define a problem will largely determine how we will approach it and solve it. “Treatment” must be informed by first listening to what the individual is trying to say through their behavior and in a greater context of what our relationship is with them.

I have debated for some time now whether

or not to write such a book, and if I were to write it, what form it would take, and to whom I might address it. I have decided to simply put it in the form of a ‘memoir’ or stories as opposed to some text book or how-to manual. I do not profess to be an expert on human behavior, but I do have some stories to tell where something was learned, mostly in my work with people with disabilities. My intended audience is primarily parents and support staff involved in the life of an individual who had gained a reputation for being a “behavior problem”, although it might be useful to anyone involved in the life of someone with a disability. Actually, although not my core intent, what I have learned from people with disabilities is applicable to dealing with non-disabled people as well. And as we shall see, oddly enough, it is the normal people, people like you and I, who are often at the bottom of it all. But more on that later.

It can be very trying and difficult, especially for parents, to experience the often long-term, day after day struggles of an individual who is exhibiting difficult behavior. It is my sincere singular purpose in writing this book that some of what I have learned will shed light on your struggles.



After graduating college and finding employment as a taxi driver, I happened to run into an old friend of mine, Rudy. He noted he had been working at Monson State Hospital (a human warehouse primarily for people with mental retardation) but was leaving and maybe I could take his place. The way he talked about it seemed quite awesome — to be the only man working in

a building with 150 women, I would be quite popular for starters! It seemed a bit strange for him to then show me the fireman's carry and the half nelson, wrestling moves. (I was told that Rudy later went on to become a semi-professional wrestler.)

Armed with a college degree in humanistic psychology, I entered the world of disabilities by taking that job at Monson State Hospital in the winter of 1971. I had never previously studied about nor even met a person with 'mental retardation' but it seemed like a good place to practice what I had learned in college. That was coupled to the fact that through a minor miracle I had escaped being drafted and seeing duty in Vietnam. I saw this work as some form of alternative service.

I applied for and was hired to be a male attendant in a building housing 150 adult women, all of whom were considered mentally retarded with varying degrees of reputations for very violent behavior. On my very first day, dressed in a white shirt and tie, I understood why Rudy had taught me those wrestling moves. It became clear that my job was to escort the women into an 8'x8' seclusion room if they had been attacking the staff and or other residents. I should note that as a general rule, they did not want to go into the seclusion room.

Again, I say '*reputations for violent behavior*' to make it clear right from the start what it took me many years to learn. Describing someone as a 'behavior problem' is often a huge misrepresentation of the locus or cause for such behavior. I will discuss this at length as we move into the text but suffice it to say that most of us would probably engage in some form of violent behavior (towards ourselves or others) if we were to be locked up on a ward with 40 other individuals with

nothing to do, little furnishings other than large wooden benches, and no hope of ever living in the outside world. This is not to justify such behavior but simply to suggest its rationale. To paraphrase Einstein, it is a good idea to be clear about the problem before we attempt any solution(s). And in brief, what I learned is that THEY were not the problem, I was/we were, not to mention the environment they were forced to live in.



During my early years in human services, I attempted to learn and master a number of approaches that would define the individual as the problem — that the problem was somehow "in" them. And what I can say about all of that is that the approaches worked or *seemed* to resolve the behavioral issue — but only for a time...enough time for me to ride off into the sunset as the behavioral expert I had worked very hard to become...and then things would often unravel and the individual would fall back into their previous patterns of behavior.

Let me therefore begin by introducing what I have taken the better part of my life to learn:

1. There are no experts on human behavior
2. Behavior is communication. Severe and violent behavior is often a desperate attempt to communicate, often a result of

not being listened to in the first place.

3. Relationship, relationship, relationship. Behavior always occurs in the context of relationship with another person.
4. It is never right to say “you must.” A relationship of trust is delicate but required and I cannot/will not enter in with the expectation that the other person must change.
5. People have fundamental needs for things like love, home, friends, belonging, security, a meaningful life. People do not do well when these fundamental needs are not being sufficiently met or addressed. My experience has shown me that quite often they are not being met very well if at all.
6. Human behavior is considerably complex
7. The core issue for most people with intellectual disabilities is how they are seen and thus treated. Oppression parades often unconsciously in the guise of many seemingly innocent and noble intentions.
8. Everyone including myself would like to know what to DO when confronted with someone who was trying to hurt me or make my life difficult. What I have learned to say when asked that question – What to DO – is “I don’t know.”
9. The “Way” out of the chaos of difficult behavior is to ask the right questions and then listen patiently for the answers you will be given.
10. My overarching assumption is that the individual AND everyone involved in their life, particularly staff and parents, are the true sources of the problem.

Most if not all of what we know has come by

way of how our parents raised us, what we learned in school, what our society has told us. For example, I have met a great many parents who believe in “spare the rod spoils the child” or conversely that their child should be given a free pass because they are disabled in some way. We have some ideas about punishment and rewards from BF Skinner. Books abound on how to deal with or treat difficult behavior. And it is not surprising that many of us become invested in a particular way of seeing difficult behavior. In a number of ways, we do not own these ideas, they own us.

I am not here to convince you of anything, only to offer up a few things that I learned the hard way. I would invite or encourage you to consider these alternatives, not that you necessarily agree but simply that you spend a little time trying to understand the ideas. This work is not easy. Ultimately, your own experience is the best teacher and it is my hope that this book will provide some directionality to your efforts.

The main idea of this book is that the real work and perhaps most reliable tool for understanding someone’s difficult behavior (and the people supporting them) is to listen. Listening seems like an easy thing to do but it is exceedingly difficult to master. If we are honest with ourselves, most of the time when we think we are listening, we are thinking about what we want to say in rebuttal or say next. Most of us would have a hard time repeating back to someone what they just said, to their satisfaction. Carl Rogers, a psychotherapist, put this practice to work in his form of therapy. Parker Palmer, author of the Courage to Teach, used this principle in dialogues between two parties who held opposing views to strive to find common ground.

One of the things I discovered is that real listening takes courage. Rogers would say *"If you really understand a person in this way, if you are willing to enter his private world and see the way life appears to him, you run the risk of being changed yourself... The risk of being changed is one of the most frightening prospects most of us can face."* Parker noted that through his experience of using this approach to true listening, that people with seemingly deeply rooted opposing points of view would often change sides!

If you doubt the difficulty of, but real power of listening, I would encourage you to read the exercise in the appendix and try having a conversation on an issue you are at loggerheads about with someone you are close to, if only for a few minutes at first.

The practice of listening to people with an intellectual disability can be far more challenging if they have limitations in their capacities to communicate or articulate what they are experiencing – if they cannot talk. But then this brings up another dimension of listening. Listening is not just with our ears but with our eyes and with our hearts, attending to body language (theirs and ours!!) And additionally, we need to consider people's backgrounds, the context of the behavior, and a deeper sense of curiosity as to WHO they are as individuals – their dreams, aspirations, and needs, what is important to them. Am I someone supporting them in those directions or am I an obstacle?¹

In my early days in human services, I saw myself as an aspiring behaviorist and worked primarily in large state institutions. The idea of listening was not even on the table. I believed that I could change people's behavior by manipulation

¹ I am going to assume for the remainder of this book that you understand that I am almost always talking about the individual who is seen as the problem as well as the parents, teachers and staff supporting him or her. This also includes me as I enter into the helping role.

of positive reinforcers to increase good behaviors and punishment to decrease bad behaviors. In my second year of work at Monson, I completed a 120-hour course in operant conditioning as part of the training for a grant project I had been invited to join. Skinner spoke of the "black box" (essentially our brains/minds) and that one can never really know what is going inside of that box only the person's observable behaviors. Thus, behaviorism focuses almost exclusively on external, observable, behaviors of the individual (and not the practitioner) not on what the individual is trying to say or express.

But, imagine if you will, trying to stop an adolescent with an intellectual disability from hitting other residents on a small, locked ward of 40 people with just two staff on duty, no furniture, nothing to do, many of the residents naked, defecating and urinating on the floor. I had a fairly good track record of getting people to stop hitting by rewarding positive behaviors and ignoring the problem (target) behavior but I began to notice that over time things would unravel. Of course, I blamed it on the two poorly paid and over worked direct support staff assigned to the ward for not following through with my carefully constructed protocols. What was I thinking!? Was I thinking at all? Somewhat but I would hasten to note, not unique. I came to realize that it was a bit like trying to do psychotherapy in a concentration camp. For the most part, what people needed was to be liberated from such a circumstance.

Now I will share a bit of a secret with you. I have recurring dreams, nightmares really, where I am involved in trying to support an individual with a reputation for being difficult and violent – and I fail – and fail miserably. I had one last night, and remembered it just

before I sat down to work on this book. and thought, I need to let people know about this. I think it is painful in some way to try to engage with someone who is seemingly all about hurting you, making life difficult for you — and worst of all, finding yourself defeated. Just as there are no experts, there are no quick fixes. Sometimes for years the challenging person has not been listened to, lived in a world where people talk down to them, not seen as fully human and labeled in negative ways. Their best attempts to communicate some of what they feel through behavior has fallen upon deaf ears — over and over and over again.

So, strap yourself in, armed with the understanding that this is very hard work. You may initially experience failure — but try to see failure as just one of the ways we learn. The hardest part of all for me was to (and continues to be) see my need to change, to grow, to learn, to listen. The sheer joy of discovering a way to support an individual out of their anguish and darkness has been immeasurably wonderful and are the stories I will share throughout this book.

I have decided that the best way for me to be of any value to you is to simply share those stories of some of the people I have come to know through my work. It is important to point out that the stories are provided to illustrate some foundational lessons but cannot begin to encompass the moment to moment complexity of the days, weeks, years of effort often involved in my working things out with them! I should have added to my list of 10 things that there are no quick fixes!

I would also like to acknowledge that the one person who has had the greatest influence upon my work was Herb Lovett,

who tragically died in a car accident in 1998 at a young age. His book, *Learning to Listen*, had a significant impact upon me both personally and professionally. Herb was one of those people, like [Marc Gold](#)², who was simply way ahead of his time. He possessed a capacity to cut through complex situations, often with great wit and humor, to put forth incisive and liberating perspectives, particularly for the people involved in supporting an individual with a reputation for difficult behavior. He really crystallized for me the notion that in order to address someone else's difficult behavior, we best begin by first listening and then taking a hard look at our own assumptions, expectations, and behavior. The first chapter of his book presents a brilliant critique of our tendency to label people, often without a fair trial. This frequently sets the stage for what he refers to as the hierarchy of control—techniques starting with behaviorism and sometimes, historically culminating in chemical, physical and or mechanical restraints all the way to behavioral surgery/ mutilation. The antidote he proposes is simply that we learn to listen, putting aside all labels, techniques and strategies, and begin by understanding what the individual is trying to communicate.

I would strongly encourage anyone involved in supporting an individual who has a reputation for being difficult, to get a copy of Dr. Lovett's book. It would also be useful to read more about Marc Gold's work via Google or [YouTube](#).\

² Marc Gold began his career as a special education teacher in Los Angeles in the 1960's. It was there that he formulated a values based systematic training approach, "Try Another Way." This approach was based on a few fundamental beliefs: Everyone can learn but we have to figure out how to teach; students with developmental disabilities have much more potential than anyone realizes; and all people with disabilities should have the opportunity to decide how to live their lives.



There is a story, I am told, on the back of an old Bob Dylan album about Frank and the Three Wise Men, who, as it so happens, were out looking for the Truth of the latest Bob Dylan album. They had finally figured out that a man named Frank had the answer, and soon came to Frank's door and knocked. "What can I do for you?" Frank asked. "We want to know the Truth of the latest Bob Dylan album" they replied. And so, Frank led them back to his bedroom whereupon he opened his closet door. Therein was darkness back into the closet as far as the eye could see. Frank then asked "Therein lies the Truth of the latest Bob Dylan album, would you like to venture in?" The three wise men consulted quietly with one another for several moments and then turned to Frank: "Yes we would like to venture in — but only far enough so that we can say that we have been there."

Much of my journey through life has been pushing myself — more often, being dragged — into the deeper regions of the closet of truth. Like the three wise men, I have certainly spent my fair share of time at the edge of it, at the threshold, being satisfied at just looking in. Sometimes it has been fear, sometimes just sheer laziness that I don't fully enter in. Life can be very comfortable with just saying "Yeah, I've been there!" but not venturing fully in — not really. And of course, being a truth seeker seemed like a great thing but then there is the whole difficult business of submitting to it once we found it! (I knew the truth that cigarettes were bad for my lungs but quitting was another story altogether.)

What does this have to do with listening you ask? I have learned that to really listen to someone, one must *stand in their shoes*-and to

do so with a person who has a cognitive and/or physical disability is easier said than done. It is easy to look at such an individual and say "Yeah that would be really difficult to be *them*." But then I am still standing outside the closet and risk becoming calloused or moving away, giving up. To truly listen to someone is to go far deeper, see the world through their eyes, through their emotions, feel the world through their skin, experiences, conditions. And if I were to truly be them, if only for an instant, what would it be like to look back at myself? Will you love me, will you shelter me, will you feed me, will you stand by me — are you even listening to me? Will you venture into the truth of my life? More importantly, will you act on what you find!? Our society has not historically been very nice to or welcoming of people with disabilities.³

This is not something done in a moment, but requires a level of commitment and thus sacrifice to hold such a question over time. If I am to truly help the other person, I need to know so much more about who they are, their life stories, stand in their shoes, imagine what it would be like to be disabled, to be looked down at, to not have a single friend, not belong — over and over again. This can be painful, not only in seeing their pain, suffering and woundedness, but perhaps more (and I will speak only for myself) to see my own shallowness, unwillingness to venture in too far, to become too vulnerable, to in short simply objectify "*them*" and return to my comfortable life outside the closet. But then this is to be human I have learned, and it is a place where I must find some forgiveness and

³ Jean Vanier, a Canadian philosopher and the founder of L'Arche communities once noted that when he walked across a street and saw a homeless person coming towards him, he would find himself averting his eyes. If he really looked into the eyes of the homeless individual he might see himself, gradually be drawn into taking the individual into his home. What would he, Jean Vanier, want if he was the homeless individual crossing the street? What would you want?

compassion for my moral weaknesses and imperfections, and then just humbly try my best to stay the course.

I have spent my entire adult life with that question and am not so certain that I have gotten more than a few inches further into Frank's closet. But that is not really the measure I am interested in as I sit down to write this book to you as someone involved in the life of someone with a disability who has a bad behavior reputation. For it is a **process** not an **outcome** that I want to explore with you. I say that first and foremost because as I have already noted, one thing I have learned is that one does not enter into a relationship with someone with the intention of changing them. This act of listening is NOT about changing or eliminating **their** difficult behavior(s). Behavior is communication and if I can stop and simply listen to and try to understand what is being communicated within the context of their life circumstances and stories, perhaps I might join with them in changing the conditions that have led to their expressing themselves so violently.

We have all experienced times in our lives when we have pounded our fist on the table when we have not felt listened to. When that fist gets pounded into our nose, it can be very difficult to not take it personally but instead, to practice listening. This can take time, will take tolerance, patience, forgiveness towards them and towards ourselves. I mean what do you do when someone punches you in the nose out of the blue. I truly don't know. I have been there as recently as just a few years ago and it hurt – and in that moment of pain, there seem to be only two courses of action – fight or flight neither of which would have proven helpful. Believe me when I say that I have searched long and hard for an answer to that

question of what to DO and still have no answer to offer.

In my life and work I have been particularly interested in understanding why in general terms, people with disabilities can come to behave so violently toward others, towards their environments, and towards themselves. I have felt it a calling to not only understand such violence but to help them to resolve what so often appears totally irrational. At the risk of repeating myself, what I gradually realized was that through working to **listen**, they were also teaching me things about myself – to come to grips with my own impatience, judgment, lack of tolerance and unwillingness to forgive. In so many words, I came to see that it was me/(us) who was often the problem in the relationship that I was being called into. It was me who needed to change, learn, grow – at least first. To learn to love, to be vulnerable, to become more forgiving, to have the courage to speak the truth in advocating for them. But first I needed to enter in and embrace their truth, to see beyond their clinical diagnoses, their reputations.

It is my sincere hope that, though I do not profess to have answers to what to DO, that this book provides some different ways of approaching “problem behaviors” which will prove beneficial, helpful and encouraging. In so doing, it is my deepest desire that I be a voice for the voiceless and honor what took me so long to hear, that is what they had to say to me – teach me.

A dear friend and colleague of mine, Robin Carlson, decided to invite a gentleman with a disability to live with her family which ended up becoming a 30-year life commitment. His name was Frank, and in short, he lived in an institution as a kid, experienced homelessness for 17 years as a man and at 52 his family

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sought services at the agency Robin was working for. It took Robin about a year to earn Frank's trust (typical for people who survive a harsh life) but a spark took hold despite Frank's highly unusual behaviors. Over the years, as Robin would often say, she had discovered that she really had a Buddha living in her home, sitting at her kitchen table.

I have been blessed and learned greatly at the feet of people with intellectual and physical disabilities, to have worked with and known

people whose intelligence and wisdom far surpassed my initial expectations and human service labels – to the heroes, who despite their disabilities and being labeled as “behavior problems,” have withstood the storms of oppressive treatment and professional strategies...

It is to those many truly wonderful people whom I also dedicate this book.

“I ask you, dear sir, to have patience
with all that is unresolved in your heart
and to try to love the questions themselves,
like closed rooms,
like books written in a foreign language.

Don't try to find the answers now.
They cannot be given anyway,
because you would not be able to live them.

For everything is to be lived.
Live the questions now.
Perhaps you then may gradually,
without noticing,
one day in the future,
live into the answers.”⁴

— Ranier Maria Rilke

Lesson One

Everyone is a suspect (including me)



Not that it is entirely relevant but I have a BS in Psychology and hundreds (perhaps 1000's!) of hours (over a period of 50 years) of training, workshops and conferences primarily regarding how to deal with people (children and adults) who have disabilities and, who also have a reputation for being "behavior problems." I say this only to make two points. The first is that whenever I started off with the assumption that the problem behavior was in the individual with a disability, or more generally, that he/she *was the problem*, I almost always ended up spinning my wheels and not being very helpful, especially in the longer run – in fact probably caused more harm than good. Secondly, the most important lessons about difficult behavior that I learned over 50 years has been not from professional/college training but directly from people who have disabilities and bad behavior reputations.



Michelle

As noted earlier, in 1971, after completing college, I started working at Monson State Hospital, Massachusetts, a very large state institution for people with mental retardation. I was hired to be the only male attendant on the second shift in a building of 150 women all of whom had reputations for severely violent behavior. My job, in short, was to “place” them in a seclusion room, hold them down while their clothing was removed by the female attendants, and then the nurse would inject their buttocks with a tranquilizer, often Haldol or Thorazine. After the nurse and attendants left the room, I would jump to my feet and race for the door before the individual could get a hold of me and then close/lock the door. Prior to regulations being put into place, people could be in a small seclusion room 24/7 for days on end, sometimes weeks if they had committed a serious offense.



(Seclusion room on Michelle's ward Monson State Hospital 1971.)

Every evening at 5 PM I would get a call from the charge nurse that Michelle needed to go into seclusion because she was attacking the attendants and/or other residents on her ward. Michelle would often already be naked and sometimes covered in feces. She lived on a ward with 39 other women, all of whom were considered severely/profoundly mentally retarded. She was a very petite, 19-year-old woman with blond straggly hair, crooked, broken sharp teeth, who had lived at Monson since she was a baby. The ward was roughly 30'x30' with 2-3 large heavy wooden benches and a broken television set 10 feet up in a corner with a screen door in front of it. The bathroom, which consisted of one showering sprayer (the women would be bathed in small groups) and several toilets without seats, toilet paper or stalls, was generally locked. This was Michelle's home.

The first time I *invited* Michelle to go into the seclusion room, my white dress shirt got shredded and covered with feces. She bit me several times and scratched my arms and face. She had very long fingernails that she would not let the attendants trim. From the ward to the seclusion room was about 20 yards, but it seemed like a mile. Every evening I lived in terror of having to do my duty and save the attendants and other residents from Michelle. Scratches became infected, and I was worried that she might seriously injure me. The female attendants would reward me with coffee, donuts and cigarettes after each bout, which became a routine every night for the better part my first month or two. Michelle terrified me and I almost quit because of her.

And so, I began to seriously question why this was happening every evening, and one night proceeded to go up to her ward a little after 4 PM and hang out to see if I could figure it out. I was not seeing any obvious causes

or “stimuli,” Michelle was just sitting quietly, naked, on a bench by herself. I decided to risk going over and talking to her, sat down next to her – nothing. So, although Michelle could not talk, only make sounds, I decided to strike up a conversation with her. “Hi Michelle, my name is Dave, how are you feeling today?” etc. And she would respond by making unintelligible sounds and then laughing almost like she was trying to tell me a joke. I sat there for quite a while, not being sure that she understood me or vice versa but she seemed to be enjoying our ‘conversation’ – and suddenly I noticed that it was 5:15! Time for dinner and she proceeded to calmly get up to walk with the other ladies down to the cafeteria. Michelle took my hand.¹

The following night, I again went up to her ward to observe and she came over to me and started “talking” to me again, laughing. And once again, 5 PM came and passed with no problems whatsoever. I did this for the better part of two weeks. The two nights that I was off, Michelle would continue her pattern of requiring to go into seclusion at 5 PM.

I was then told by the charge nurse that the attendant who had been managing dinner time had resigned and that it would be necessary for me to assume her role which meant that I would have to be down in the kitchen from 4 – 6:30 PM. There were several “higher level” residents who I would manage in putting all of

the food out on trays on the tables and then cleaning up afterwards. I asked if Michelle might be one of the people who helped me in the kitchen. (I am embarrassed to confess, an idea not born out of enlightenment but of fear of having to still put her in a seclusion room.) Michelle would actually get dressed and wear shoes for the opportunity to work with me. I did little things like ask the charge nurse if the women helpers could get some cool aprons and if they could sit and have an extra coffee, desert and cigarette after dinner with me.

I never had to put Michelle into seclusion again. And, as she was now “working” with the dinnertime crew, she was no longer requiring a seclusion room on my off nights. At the time it felt a little like a miracle. The Superintendent of the hospital actually came up one evening to shake my hand and congratulate me for my “innovations”!!! (I had asked the charge nurse if instead of 150 women come stampeding down the stairwells all at once into the dining hall (the resulting chaos beyond words), that they have one ward at a time come down. I had the maintenance department build me a divider using 1x12 pine boards to place on a table so that the major “food stealers” would sit, each in a little cubby and make it more difficult for them to steal food from their neighbors.) I was a Big Deal!! It felt “good”! And suddenly it occurred to me that this might also be what Michelle felt by my simply spending time with her. I strongly suspect that few if any other attendants had ever done that for her. At least I never observed it in the year that I worked in that building.

What did I learn? I learned that a simple act of human kindness was all that was required of me. I learned that as far as I knew, nobody had ever cared about Michelle, nobody had spent just a few minutes a day acknowledging

¹ This was quite humbling and still is, that clearly Michelle had forgiven me or at the very least did not hold it against me that I had dragged her kicking and screaming into a seclusion room many times over. I went back to Monson 12 years later hoping to find Michelle and some of the other women whom I had manhandled into seclusion rooms. Many had been discharged by then to community settings and I found only Alice, a 6’4” woman who sometimes required several other men to get her into the room. She remembered me. I told her that I had come to apologize for what I did to her. “Aw, Mr. Yeiter, that’s ok, you were just doin what you had to in your job.”

her as a human being. In order for her to live in this human warehouse, she had to be seen as less than human, as an animal, and an unpleasant one at that, naked, often covered in feces, inarticulate, and dangerous. I remember being a little overwhelmed when I first spoke with her, so seemingly eager to connect, her eyes communicating a gentle heart. She looked at me with such joyous intensity despite the horrors of her life circumstances. And I listened, just a little.



The short of all I have learned is this: In the process of trying to understand and treat difficult behavior, what I discovered time and time again was that it is often not (only) the “client” who is the problem but more likely (also) the people around him/her including parents, teachers, staff, doctors, psychiatrists, social workers – i.e., everyone is a suspect, including me. Moreover, I would have to include school systems and organized, formal human services. It took me a great number of years to understand how this could be true, and most of my 50 years to truly believe it. Seeing things this way had huge implications.

The facts are that when I entered into most consultations, the individual with a disability was certainly behaving poorly, sometimes quite violently which created a sense of urgency, concerns for safety, liability and the need to do something NOW. The people around the individual be it staff and or family were often exhausted, angry, fearful, and generally at their wits end. Every day for months sometimes years on end they had to experience frustrations and a strong sense of failure. For me to waltz in and suggest

that they were in fact the problem was never well received and often counterproductive. So somebody had to change and once again it was me in terms of how best I could drag them along with me into Frank’s closet.

First and foremost, this was quite the opposite from the way I saw most specialists who worked with people who had difficult behavior think and frame a ‘treatment strategy’. The fact that it often does not “work”, especially in the long haul, begins with blaming the victim, the “client”, and if need be, for others further up the food chain to extend the blame to the people closest to the individual (parents, aides or paraprofessionals at school, and/or Direct Support staff) for not following the behavior plan. If you are a parent or work in schools or human services, you will know that the focus of most attempts to quell difficult behavior is the student/client’s BEHAVIOR. It is customary for example to define the “target behavior(s)” and then keep data on its occurrence. This “evidence based practice” then has us consider ways to increase or accelerate good behaviors and decrease difficult (target) behaviors relative to baseline data accumulated prior to implementing treatment strategies.

It is critical to understand that I am not justifying the behavior of the individual who is often causing great harm to himself or others; but if I assume for a moment that behavior might be communication, perhaps they are trying to say something and I am not listening. Perhaps, just perhaps, I am driving the individual to act out in their increasingly desperate attempts to be heard. Perhaps the individual is in physical pain and has no way to express that other than their behavior. Perhaps they have been abused physically or sexually, perhaps they are lonely, deeply wounded by

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experiencing rejection from their peers at school. Perhaps they see everyone else going to the prom, getting a driver's license, dating, getting married, having children, having a career and financial independence, and they are sitting in a special ed classroom going nowhere. Maybe the very people there to support them in life, are not really listening, are overly protective or controlling, have low expectations, ...or are simply not nice.

What is interesting to me is that when the finger starts to turn from pointing just at the client to others, they would get at least a tad nervous if not indignant: "Moi!! But I love them, I have dedicated my life to helping people with disabilities, how dare you even suggest that I am remotely responsible for their bad behavior." Of course, talking about the individual in front of them (or often without them present) to scheme schemes and talk openly about their bad behavior, their noncompliance, selfishness, spoiledness, needing to learn a lesson is totally OK. To be clear, I am not suggesting that support staff, parents or teachers are bad people, but they have often been unwittingly caught up in a paradigm or set of understandings that are simplistic in portraying the individual as the problem; what they thought they really needed to do was just adopt strategies and techniques towards resolving the problem. We are not talking about a rat in a cage or Skinner box, we are talking about a human being in a set of relationships with other human beings. It is critical to look at and understand what is transpiring between people in those relationships. Not so simple especially when all of those people are misbehaving! ☺

What I have learned the hard way is that if I am to engage in helping resolve a behavioral

concern, it will be like playing a multiple level chess game. Everyone is a client, including me, actually starting with me. I must at the very least try to demonstrate leadership in modeling the postures, attitudes, expectations and behaviors that will lead to peace and not add to the chaos. This requires that I also have the courage to model failure, gentleness or being silly, leading the emotional dance with joy to counter the darkness and or violence. I must listen towards discovering and understanding unmet needs, to be thoughtful in how I invite the individual into a life where those needs can be addressed, and not get caught in being overprotective, authoritarian or callous. All of this is not something I turn on when I am working with an individual and then turn off when I leave. It is a life practice, a way of being, not just a set of strategies.

I will talk more about Gentle Teaching later but feel that this quote from John McGee, the author of the Gentle Teaching approach, is relevant here:

"One thing for sure is that we cannot think about gentle teaching and then talk about behavioral problems in the same breath. It is an intellectual and sentient incongruity to pose one issue in terms of the other. If we still worry about behavior problems, then we need a behavioral approach to deal with them."

Gentle Teaching is about teaching caregivers to teach marginalized people to feel safe and loved. It is in the pedagogical (teaching) process that caregivers need to find themselves. If we sit and talk about behaviors, then we are focused on the externals of the human condition. Love is internal. Life is internal. Death is internal. Hope is internal. Despair is internal. Feeling safe and loved is internal. Gentleness is internal.

Gentle Teaching is as much of a political

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movement as anything else in the sense that it is about forming a sense of community... caregivers and those served coming together and reflecting on safe and loved within their collective context. It is not a "behavioral change approach"! It is about the formation of a feeling of personal companionship and collective community.

If we wish to spread this to others, we have to see these dual purposes as the central issue. If not, we will not effectuate broader based change. This process requires a constant coming together and encounter with one another."

*—John McGee,
personal communication circa 1985*



And so, as I considered writing down all of what I have learned, this seemed a good place to start. And that specifically is this: as I enter into a struggle regarding difficult behavior, be it of a disabled person, my spouse, my child, friend etc. it is important to remember that it takes at least two to tangle, and the best place to begin in my experience is to, as much as possible, consider listening; and by that I am meaning a *standing in the shoes* of the person(s) with the problem, and seeing the world through their eyes. And of course, to really do that, it is critical to strive in every way to know WHO the people are in terms of demographic/facts, their life stories, and strive for an almost existential sense of who they really are deep down underneath what is observable. Concurrently, it is also helpful to start to look at the quality of my **relationship** with all involved. And above all, adopting a willingness to change, to learn and grow in my

understanding of not only the individual but first and foremost, myself, and then everyone involved in supporting the individual. These are the key components that are critical towards resolving almost all difficulties of behavior as we will explore in the following chapters.



Note: In almost all cases, I have changed the names of people in order to safeguard confidentiality.

Eliminating the Obvious



The “obvious” is a bit like “common sense” ...assumed but not always in play unfortunately. A great many children and adults with intellectual disabilities have issues with their capacities to communicate, often coupled with their inability to exercise control over their lives, especially if they are in human service programs. So, you or I may have heartburn and we can drive to the drugstore and get some Tums and take them straight away. Individuals with disabilities may not be able to tell the people supporting them that they are experiencing heartburn, they generally do not have a driver’s license or car, and if they are in a program, a doctor’s order is often required before they can even be allowed to take or be given Tums. In short, they feel pain — physical, emotional, existential — but have no idea why and/or no way to explain it to their staff or parents, and thus may become a bit grumpy. Over time, if they do not experience feeling listened to, they will (as most of us will) raise the ante, be it pounding their fist on the table or into someone’s nose.



What I have often seen in my own practice is that people in support roles **assume** right away that the individual's grumpiness, expressed by hitting themselves or others or breaking things, is yet another manifestation of a behavioral disorder requiring some sort of behavioral intervention often including various special control strategies including punishment/medications. In particular, what I hear most often is that the individual is engaging in a certain behavior just get attention, without any intent other than that. Historically, the behaviorists countered this by simply ignoring the "attention seeking" behaviors.

"I have many friends in the field of human services. Most, like me, have had training in behavioral shaping. From time to time, I find myself too bored to watch television or too restless to read. It's too early to go to bed, and it's still too close to dinner to eat again – so I start phoning. I have nothing in particular to say, but I do want to talk. Perhaps you yourself have never done this, but certainly someone you know has done it to you. The only point of the conversation is the company. I have never (yet) had any of my friends say to me, "This seems like you are just looking for attention. What I will do now is hang up, but you can call me (tomorrow/next week/next year) when you have something meaningful to say and I will talk with you then." (Learning to Listen by Herb Lovett, p49)



I once worked with a young man who was being released from a mental health institution into a community apartment program. Bob had spent his entire life, even as an infant, in institutional settings and was finally "free." Upon his discharge from the institution, we

were told that Bob would often feign difficulty walking "to get attention" – that he had had a complete physical at the institution and there was nothing physically wrong with him. Unfortunately, the community program that I was working with trusted that medical information.

After a couple of months in his first home in the community, Bob's 'refusing to walk' started to become noticeably more severe. He had always wanted to see the ocean, (he was 35 years old and had never seen the ocean!) and was very motivated to take a day trip there... and yet still his gait was extremely unsteady. He could not navigate across the beach to the ocean without his wheelchair. Finally, we insisted that he meet with his new community physician who ordered a series of x-rays and it was discovered that Bob had a huge mass on his spine. According to the physician, the mass could have been operable and removed had it been discovered earlier. The physician noted that the mass had been growing for at least several months and should have been detected by a routine physical. Bob died a few weeks later.

Bob had been labeled as attention seeking, non-compliant, stubborn, a behavior problem, mentally ill – with all the assumptions that go along with those labels and yet it suddenly became clear who had the behavior problem – not Bob. And Bob could talk, and he would say his back hurt and clearly demonstrate that he could not walk. Even the initial community physician had been convinced by the mental health system's label, that Bob's seeming inability to walk was just "attention seeking", and thus no need to investigate further.

A complete exploration of self-injurious behavior is beyond the scope of this book but

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suffice it to say that violence directed toward self is often the last and final place of trying to communicate the psychic pain of trying to make sense of a world that is not listening to you. On the other hand, I would quickly add that one psychiatrist noted that in the vast majority of self-injurious cases she dealt with, it was discovered that more than 70% of them had undetected physical pain. In one case, a young man had been hitting himself in the forehead to the point of getting a detached retina. The psychiatrist had some scans done and found that he had a large tumor in his forehead which when removed resulted in the cessation of hitting himself in the head. A couple of years later, this same young man was referred to her again for the same behavior. He lived in a group home where there was significant staff turnover and the new staff did not know about his recent past. Again, for months in fact, behavioral programs had been tried again and again — and failed. Upon referral she had him get another scan and indeed the tumor had grown back.

And so, lesson # 2 is learning to listen to behavior especially when the individual does not have words to express what is going on. 'Listening' is therefore not only with my ears but with my heart, with my powers of observation, for critical thinking, for valuing the person enough to do some difficult detective work, and not making assumptions without testing them first. It may also require some advocacy by me and hopefully the people closest to the individual with their staff, teachers, nurses, doctors, etc.



The following is not necessarily a complete listing of all possible things to consider in assessing difficult behavior but is simply

meant as an initial guide.

Medical / Health issues:

- Toothaches
- Sinus problems
- Headaches
- Earaches
- Seizures that are not obvious
- Joint pain/arthritis
- Muscle sprains/spasms/broken bones
- Intestinal (ulcer, heartburn, constipation)
- Rashes
- Sore throat
- Problems with vision/eyes
- Vertigo, tinnitus
- Undiagnosed medical conditions (heart, cancer, blood, high blood pressure)

Medications: Some drugs can actually exacerbate behavioral issues in terms of side effects

- Dilantin,
- Phenobarbital
- Mysoline
- H2 blockers (Zantac, Tagamet, Axid, Pepcid)
- Beta blockers

Mental Illness:

- Post-traumatic stress disorder (abuse, trauma...)
- Obsessive compulsive
- Depression
- Anxiety
- Fear
- Oppressive services or life circumstances,
- Physical/sexual abuse
- Loss (parents divorce, abandon, death of)

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- History of mental illness in family...

Diet/nutrition: food allergies, poor nutrition, too much sugar, etc.

Life worth living??

- Boredom,
- Maladaptive life circumstances,
- Day wasting programs
- No relevance of daily goals and objectives,
- Noninvolvement in one's life (learned helplessness)
- No social engagements, hobbies
- Fundamental needs not being addressed (belonging, home, work, \$, food, not feeling loved, insecurity, etc.)

Learned behavior:

- Parents not instilling discipline, etc
- Modeling/imitation (being placed in programs with others who have reputations for difficult behavior- mutual disturbance centers, limited social skills, etc.)
- History of punishment or aversives
- History of violence family, school (violence in our culture!)
- History of losses/death

Sleep patterns: nightmares, insomnia, poor sleep

Lack of physical exercise

Other possible "reasons" for behavior (from an adaptive viewpoint)

- To get control, to get something (power)
- To get our attention
- To escape or avoid a situation
- Self-regulation
- To have fun/play (actually the issue is often that the adults are way too serious)
- To get revenge (not justifying but quite

often people with disabilities are physically and or sexually abused)



It is sometimes useful to bring in an outside consultant or someone new with "fresh eyes" to the situation who might be able to see the obvious. It is easy for many of us to get emotionally entangled in someone's difficult behavior and lose perspective. Now this gets to the tricky but core implication of *we are all suspects*. If you understand that the individual with the behavior reputation may not really or entirely be the problem but instead, possibly the support people around him or her — how do you tell them that!? This requires a balance of some level of advocacy for the individual but fully recognizing the need to respect the other players. The point is that your target changes!! Behavior change needs to happen, at least first, in the people providing support.

For example, I often find with parents of children/adult children with disabilities, that because their child is labeled as having a disability, they will tend to see behavior issues as a clinical manifestation of that disability rather than realizing that most 6-year-old children will behave poorly at times. How many of us glided through our youth without a single shred of misbehavior? Very few of "us" have ever experienced having the people in our lives meet about those misbehaviors and then set up a behavior program for us. How many of us as parents have ALWAYS been successful in getting our children to wear a hat and coat when they went out to play? The reverse to this is that quite often parents will give their kids a free pass on behaving poorly simply because they are disabled. This pattern can extend into their teenage and adult years to the point where the individual has learned

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that it is ok if they punch someone in the nose. The behavioral issues can become so violent that now the parents are fearful, and to avoid confrontation, they will even condone their violent behavior. I once attended a lecture by a very prominent professor who addressed a group of 30 parents (all of whom had children with disabilities) with the above points. At least half of the parents walked out as they did not like what they heard — the truth hurts!

The Twilight Zone, for those of you old enough to remember had a great episode that illustrates this dynamic. If you are reading this on your computer, click [this link](#); otherwise go on YouTube and search for “*The Twilight Zone: It’s a Good Life*.”

I would add here, in the parent’s defense, that my other observation is that a great many parents of kids with a disability will be told by the experts that their child will manifest behavioral issues as a part of their disabling condition. A dear friend of mine and her husband took their daughter to her first day of school and were a bit taken back when invited to attend a meeting before their daughter could actually start first grade. There were a number of people at this meeting including a behavioral psychologist who proposed that the daughter start school with a strict behavior program. The parents noted that their daughter did not have behavioral issues. The psychologist and the team tried to convince the parents that children who had a label of Down Syndrome would of course have behavioral issues. Both parents were very well educated and experienced in the disability field. The mother called me that evening in tears of frustration because they could not convince the school to let their daughter attend without a behavioral protocol.

I worked with one family, a mother and her son, where the mother would massage the son’s head if he started hitting himself in the head. Her mandate to the teachers and aides at school was to do the same. This created strange scenes of her 19-year-old son sitting full lotus on the hallway floor between classes with the special ed teacher/aide massaging his head as students tried to get by. I later worked with a young man who would just randomly, “out of the blue²”, punch people in the nose. This created a problem for his staff and parents as well. However, when he hit his yoga teacher in the nose, his liability for going to jail etc. escalated. When he would do something destructive or violent, his parents would in fact praise him, ignore the damage and just buy him a new iPhone or almost ignore/blame the person who got punched in the nose because it was their fault somehow.

The elephant in the room in both of those cases had been the parents who were well educated, nice people. However, nobody at the team meetings I initially attended would even suggest that the parents had some part in the behavioral issue at hand. And yet, when I spoke with the team members individually, everyone saw them as the problem or at least a big part of it. I (and others) ultimately failed in both cases to get the parents to

2 “Out of the blue” is often used to explain away violent behavior as if the individual’s behavior is without cause or reason. There is a sense that it is almost “organic” in nature, typically “organic brain syndrome” or some label that suggests that the individual has no real control over their behavior and at any moment, regardless of context or situation, will just lash out. I have never found this to be true. What I have found is that when people use that expression, they are holding to some very negative assumptions about the individual’s capacities and not bothering to look deeper at the behavior as a form of communication. Both of these parents in particular wanted to see the behavior as some form of manifestation of disability rather than face their son’s communication and or their role as a potential cause for the problem behavior.

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move beyond their beliefs/fears. (I spent over a year in the first case working directly with the individual at school and at home, and three years in the second case working with the staff and parents.) All that we can do sometimes is to more clearly identify the source of the difficulty. In both of these cases, the parents were not getting along very well with each other, in the latter case resulting in divorce.

So back to the question of what strategy do you employ if you are an outsider working with such parents; or as a now enlightened wife see your need to change, but what about your husband who is wedded to the notion of corporal punishment? My experience has taught me that what you “do” with the parents (husbands or teachers or support staff) is the same as what needs to be done with the individual – listening. (A sort of corollary to the golden rule: Do unto others what you would have them do unto others). I have also found that **videotaping** (most people now have smartphones that can easily record video) can be extremely valuable in that a video simply tells the truth about a given situation without judgment.

Two quick stories regarding the power of video. The first story was in working with an 8-year-old boy with Down Syndrome who was reportedly eating paper, stripping and going to the bathroom in public places, and generally being non-compliant. He lived with his mother, Barbara on a mountain out in the Berkshires. As I sat with Barbara at her kitchen table, she told me that a year prior to my visit, her husband had shot himself, not once but twice, in the face on the rear deck of the house in plain view of her son Robert. A psychiatrist met with Barbara afterwards and convinced her that Robert did not possess the cognitive capacity to be impacted at all by what he

witnessed. He also confirmed to her that her son would never be capable of learning anything substantial and (because he had Down Syndrome) would probably die anyway within the next few years. Helpful?

Barb shared with me the school psychologist’s report and behavior plan noting that Robert’s major issue was non-compliance (another very demeaning label) not once mentioning that his behavioral issues might be related to witnessing his Father’s suicide. I then suggested to her that I would like to try conducting a simple experiment of her attempting to engage her son in doing a small task like washing dishes, and asked if it would be OK for me to videotape it. Mostly I just wanted to get some sense of the quality of their relationship. Barb was very rough and loud with Robert, to the point where I was beginning to feel a little uncomfortable. But we did the video and I was packing up getting ready to head home when she asked if she might see the video before I left. So, I hooked the camera up to her TV and after watching just a couple of minutes of the video, Barb ran out of the room without saying anything. A few minutes later as I started to wonder what had happened, she came back into the living room with a fistful of tissues in her face, sobbing. I said “Barb, what is wrong!” and she could barely speak but uttered “I did not realize what a horrible monster I had become!” I spent some time helping her to see that her real problem was that she had bought into the experts rendering of her son, how negative perceptions can lead to negative treatment, etc.

As I again packed up to leave, she told Robert that they were going to go out and get some ice cream at Friendly’s. It was Spring but there was still substantial snow in the mountains and a narrow, shoveled path out to our cars. I went out first and suddenly heard

Barb scream. I turned to see that Robert had pushed her into a snow bank. She was starting to stand up with her face encrusted in snow and I thought, Oh No, this is not going to go well – then she started laughing and pushed him into the opposite snow bank! A snowball fight ensued that I became a part of as well. At one point, with tears streaming down her face, she grabbed her son and hugged him telling him how much she loved him. Robert still exhibited problems at school but life at home improved dramatically.

I was invited to work with a 14-year-old boy, Jay, who had an Intellectual Disability and was almost completely segregated from his junior high school peers because of farting, swearing, burping and running in the hallways. Because of these behaviors, he had his own classroom with two aides and a full-time behaviorist taking turns working with him throughout the day. They had tried unsuccessfully for the better part of two years to eliminate his difficult behaviors and had failed. I asked them to send me a videotape sample of each of them working with him and possibly some video of him when he was misbehaving. They sent me over 20 hours of videotape!

I extracted some key scenes from all the video and 2 months later met with them and shared the footage. A great deal of the video showed them being angry, bored, frustrated and often ordering Jay around. All three of them immediately started crying. They had never watched the video before sending it to me, had never seen themselves working with Jay on video. There was still a bit of work to be done but the biggest hurdle had been removed.

One final point is that I have found learning to listen to be most fundamentally a process

of learning to identify with the individual, to imagine what it would be like to be that person, to stand in their shoes if only briefly. This is far more difficult and elusive than it might seem. What has helped me to make that effort is to understand as Albert Ellis (Rational Emotive Therapist) would say ‘...everyone is always rational’. We do not do things for no or bad reasons. This is not to go so far as to justify the individual’s behavior but simply to attempt to understand it. Nothing may justify an individual hitting their parents or teacher; but having at least a couple of theories as to **why** and how they came to do such a thing is important if we are to truly be helpful. Most situations I have found myself in as a consultant revealed that there had only been one single theory in play (spoiled brat, doing it for attention, brain damage, etc.) and it was not working. Doing the same thing over and over again when it is not really working is one definition of mental illness.

However, and I suppose that this is my bottom-line point, it is possible to come to a place of clarity in seeing the dynamics or circumstances of difficult behavior, but it is only through a relationship or partnership that we can possibly effect change. Parents of children or adult children still living at home for example, who are in the throes of a divorce, have mental health issues or who are holding tight and fast to corporal punishment have been a significant challenge in my work. It is beyond my purview to be a marriage counselor and I must respect that this is their child, their responsibility. The lines are often not bold and clear – and although I have worked quite hard to effect change, there are times when I simply must accept my limitations and move on. So it goes...



Lesson Three

Violence Begets Violence



Violence: the use of physical force so as to injure, abuse, damage, or destroy.

Force: coercion or compulsion, especially with the use or threat of violence.



Tim

I once worked with a young man (age 14) who was considered to have a very violent reputation including hitting, biting, and a degree of self-injurious behavior. Most of his difficulties occurred at school. He was at a team meeting with his mom at school and was playing with her car keys (which was totally fine with her), something he often did at home as well. In the middle of the meeting, the principal of the school asked Tim to return the keys to his mom and he refused. Things quickly escalated to the principle trying to grab the keys away from Tim. Tim ran out of the meeting room with the principal following him and eventually got Tim down on the floor in the hallway and sat on him, taking the keys away from him. Reportedly Tim head butted the principle in the face and almost broke the principal's nose. For a time, the principal was threatening to bring legal action against Tim but later dropped the charge. Tim needed to learn a lesson. What did Tim learn? How might we describe the relationship between Tim and the Principle? What did the principal do towards teaching other kids in the school how to think about/perceive Tim? Were the principal's actions helpful or hurtful?³

It is critical to look at the quality of people's relationship with the individual who is behaving violently, who is being seen as the behavior problem. Violence is often cyclical – violence of one individual will often trigger violence in return which often invokes more violence and on and on it goes. Tim was not being compliant and was refusing to do what he was told by the principal; the principal wrestled Tim to the floor and sat on him, and Tim head butted the principal in the face.

3 See Appendix: Punishment Fact Sheet

Without getting into who was right or wrong, just look at the nature of their relationship in terms of violence. What did the principal actually teach Tim? Perhaps something along the lines of if you don't do what I tell you to do, I am going to chase you, wrestle you to the floor, sit on you and make you do it? Comply or be punished. (I may have said this already, but compliance is the explicit goal of behavior management programs.)

This, for example, is one of the arguments against spanking children. Maybe the spanking actually stopped them from doing something bad. But more importantly what have we taught them – that when people don't do what we ask of them or behave poorly that it is OK to hit them? Oddly enough, this gets carried over into adult activities like war. (We kill people to teach them not to kill people, as I recall one bumper sticker saying.)



Perhaps it goes without saying but I will say it anyway...it is not easy to respond to someone in a loving/kind way when they have just hit you or spit on you etc. I remember someone telling me 'what is in our hearts will be revealed'. A large part of it being difficult to respond to violence with anything but violence in our hearts is due to probably a myriad of factors including a primitive survival instinct and the culture/world we live in. It is certainly not a simple matter to overlook pain or damage done to our bodies, and that is probably a very good thing for survival. Things get a bit more complicated in the human service system where hitting someone back is simply not permitted. Of course, the system came up with more "subtle" and legal ways of treatment (revenge) via seclusion, time out,

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mechanical, physical and chemical restraints. In one of the large institutions I worked at there was also Phillip, a 6'6" resident of the institution who would be promised an extra desert at night by a staff person for providing a "behavioral intervention" (a physical beating) behind the barn if someone hurt or disobeyed that staff person.

I have always found it extremely difficult to emotionally deal with being hit, bit – and yet not taking it personally. Fear of being hurt more would often render me unwilling to expose myself to further harm. I would listen to people like Jean Vanier, Gandhi, Martin Luther King, John McGee et al, talk about nonviolence, about absorbing⁴ violence and it all made such good sense. However, among my list of capacities or strengths, courage has never seemed to be one of them. And yet, for some strange reason, I continued to put myself in harm's way by focusing my work on people with reputations for difficult behavior. I mean, I knew that the people hurting me had often experienced hurt, trauma, oppression, etc. and also knew from experience that healing was their only way out of a vicious, downward cycle. Although ill-suited in many ways, I nevertheless felt a sense of calling to do the work of supporting individuals with such reputations. I did turn down some work with some pretty violent people, but that was often in institutional contexts where there was little hope for organizational change. I also

4 If violence indeed begets further violence and one wants to stop the vicious outward cycle of it, then absorbing the violence is a choice we can make. This requires that we forgive the person who hit us, not take it personally, and understand the deeper context for the individual's engagement in violent behavior...e.g., a form of communication. This does not mean that the individual gets a free pass, just that we do not return the violence or anyone else for that matter.

learned that being proactive, hitting the ground running and taking the lead in the relationship dance was critical. I would also quickly add that running away was a reasonable strategy when someone was trying to bite or hit me. I often noticed that direct support staff or parents would often stand toe-to-toe with a violent individual almost as if to say, "I dare you!" and then get hit in the face and of course blame the individual.

After some time struggling with this, I additionally began to realize that I needed to at least forgive the individual in my heart. I could understand on a rational level their life circumstances leading up to and culminating in physical violence but emotionally I still had difficulty, until I at least said the words to myself, "I forgive you ." It is also important however to say those words to the individual regardless of their capacity for receptive language. But most importantly, it is quite useful to teach forgiveness by role modeling it.

When I was quite young, probably in grade school, I remember hearing the statement that violence begets violence. For whatever reason, it caught my attention and has hounded me through all my years. So many times, I have questioned this statement, this belief, and wondered if it was in fact true – short of being good or bad.

It is important to consider the almost viral nature of violence. As noted earlier, it can become a vicious cycle between two people. However, it can also become generational, radiate to innocent others over time, and often operate in what is called the "herd mentality." If you have ever been involved in a protest or demonstration that went violent, you know what I mean.

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For example, children who are sexually abused are more likely to become sexual abusers. Corporal punishment by a Father upon a son can carry on when the son becomes a Father. Despite some years of “gentle teaching” and consciousness raising around the issues of violence, I suddenly found myself spanking my son at an early age. When I was a child, I vividly remember my parents breaking off willow branches from the tree in our front yard and using them to punish me. When I spanked my son, I found myself feeling so guilty, so full of deep remorse that I cried. I eventually told my father about that incident and he could not stop laughing.

I once had a discussion with a priest who taught nonviolence and he told me this story: He had been invited to dinner by one of his parishioners and during the meal his 5-year-old son spilled some food onto the table and the father severely admonished him. A few minutes later, the son knocked over his glass of milk and the father yelled at him, spanked him and sent him to his room. The priest was a bit taken back but said nothing. A couple of weeks later, the priest ran into the father at a store and the father started apologizing profusely. “I know you teach us to be nonviolent but I know my son was misbehaving on purpose and I needed to teach him a lesson.” The priest listened quietly, reflecting and turned to the father saying, “What else are you doing with your son?” The point is that sooner or later most of us may lose our cool and act out in a flash but then have deep regrets. The greater question however is to look at the overall picture of our relationship with our son/daughter/wife/husband...are the interactions mostly positive? or negative? Forgiveness is not only important to practice but important to teach by example.

In hitting another person, they may not hit you back, but they may “take it out” on someone else at some point in time. We all know the story of how the individual who has a bad day will go home and kick the dog. It is the nature of violence begetting violence that it continues to radiate out to other people over time. The men who flew the jet plane into the World Trade Center did not just wake up one morning and say to themselves, “I think I am going to blow up the World Trade Center today!” Certainly, what they did had very strong consequences and continues to radiate strong emotions some 20 years later.

Some people with a disability may in fact ‘take it out’ on themselves, becoming self-injurious. Upon first witnessing someone banging their head, sometimes hundreds/thousands of times a day, it simply does not make any sense. For some of the people I have worked with, I have come to see it as their last refuge of self-control, possibly their dignity. Roger lived in a program where they were utilizing electric shock in an attempt to stop his head banging. (Four electrodes⁵ were strapped to each of his limbs such that he would never know where the shock was going to occur. The staff had a unit on their belt that when pressed would randomly choose one of the electrodes.) One of the things I heard about Roger was that as an additional consequence for hitting his head, he would have to walk back and forth down a long hallway 25 times without hitting himself before he could resume his day. He would repeatedly be “compliant” for 24.5 turns on the hallway and then proceed to start banging his head again. Coincidence or Roger’s way of

5 Formerly the Behavior Research Institute, now The Judge Rotenberg Center, continues to utilize electric shock to this day despite several states attempting to shut it down over the past 30 or more years.

saying ____ - ____! (fill in the blank!!) ??

Violence can radiate through a crowd or through a country. Wars do not simply end. The individual and national repercussions of wars can extend through centuries. The origins of our country are deeply rooted in violence, especially towards the people who were already living here, native Americans. A quick review of American history will reveal an almost continuous stream of wars and violence since we got here starting with Mr. Columbus!

As mentioned above, it is not always obvious how violence begets still other violence – it is not always possible to track it through the hearts of its victims over long spans of time. The lesson here is not to enable that cycle and to as much as possible, stop it.

Our responses to having violence done to us be it in words or physical means, is often to strike back, or at least want to. When someone cuts you off on the highway, we can often almost instantly be caught up in rage towards that driver although we have never even met him or her. Maybe he or she is late for work or racing to the hospital because a family member was in an accident or perhaps they just have to go to the bathroom. We tend to just assume that it was intended as a personal attack upon us. I know all of this and yet how easy it is for me to start speeding after them and ride their bumper!!

At any rate, we are left with a problem when it comes to breaking the cycle of violence begetting violence. John McGee developed an approach to resolving behavioral issues back in the early 1980's called **Gentle Teaching**⁶.

I was fortunate enough to meet him and

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[See GentleTeaching.com](http://SeeGentleTeaching.com)

then spend a week with him at his clinic in Nebraska in 1983. In brief, he promoted a relationship-based approach to issues of behavior that emphasized unconditional valuing or love which has heavily influenced my work since then. That same year, I attended a workshop developed by Dr. Wolfensberger called "Normalization" (now **Social Role Valorization**⁷ if you are interested in looking it up) which began with understanding the deep woundedness (psychologically, physically, spiritually, emotionally) of people with disabilities. Again, he emphasized that one way towards healing those wounds was not some technical fix – but love.

One of the fundamental issues for people with disabilities, as for people of color, the mentally ill, senior citizens, the homeless, the poor, even women, is that they have historically been oppressed in our society. In Wolfensberger's language, they have been *devalued* by society at large, seen as "less than." We can see for example that for decades starting in the 19th century, the place for most people with intellectual disabilities was in large state operated institutions, human warehouses. Back then they were referred to as "idiots" or "imbeciles." When I first started working in the field they were often referred to as "low grades", "untrainables" etc. The wards were often locked, understaffed (2 staff: 40 residents), very little furniture consisting mostly of large wooden benches that some would be tied to, with a television high up out of reach and screened in with no access to the remote control; no curtains, the windows protected by large metal screens, no amenities, games, books, etc. and quite often no access to the bathroom given that for entertainment (my theory) some residents would often stuff articles of clothing into the

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[See SocialRoleValorization.com](http://SeeSocialRoleValorization.com)

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toilets and cause flooding which made the maintenance personnel quite angry with the staff – thus the bathrooms got locked. Part of my job at a large state school was to go around with a mop and bucket and clean up the feces and urine on the floors.⁸

Even though a majority of institutions- the bricks and mortar – have now been closed down, the ‘institutional’ mindset continues. We can certainly see this in the outcome of the civil war where African Americans were finally ‘free’ from slavery. After over a century and a half since then, despite protests, marches and civil rights legislation etc. racism is still rampant in this country. Despite the fact that people with disabilities are “out in the community”, the vast majority still do not have friends, a job, a sense of belonging, control and autonomy in their lives. As one writer put it (Dufresne- see Resources in Appendix), they still live in institutions, not of brick and mortar but in an ethereal, seemingly impermeable bubble where their primary contacts are only other people with disabilities and/or the staff paid to support them. We will talk more about this later.

My point is that how we approach people with intellectual disabilities is heavily influenced by our culture, by our upbringing, by our basic assumptions and beliefs. Learning to listen requires a true valuing of the individual with an intellectual disability which goes against the grain of the society we live in. It is not easy work and requires creativity, imagination and commitment to a willingness to often first change our own behavior, to challenge our assumptions and beliefs, and quite often to come to grips with the notion of “we have met the enemy and it is us” (Pogo).

If I am to march with people of color down

Main Street in Selma Alabama, I must be willing to risk having a brick thrown at me as well. If I am to stand in solidarity with people with disabilities, I must be willing to possibly experience at least a small degree of the oppression that they experience. Can I commit to loving people who are seen as unlovable, valuing people who are seen and treated as an economic burden upon our society, as people who will never be gainfully employed, have friends, get married and essentially have a right to the same piece of the pie as the rest of us? Am I about helping them to have the same piece of the pie as the rest of us? Or am I more or less just a functionary of the human service empire?

I raise all of this as a backdrop for thinking more critically when we find ourselves being violated by an individual with a disability. The inner work I must do if the cycle of violence is to be broken is emotionally complicated. If I am to stand WITH people, in addition to getting hit, I may often come under attack from peers and supervisors for being too soft or easy, for letting the person get away with murder, for not teaching them a lesson, for spoiling them, and making it difficult for others who have to work with that individual. Remember, the larger system is about “teaching” compliance. We might face the possibility of losing our job or being seen as an irresponsible parent. The bricks will fly!



There is much more to say about this dynamic of violence begetting violence and at this point I only ask you to consider it – not asking you to buy into it or agree with it. It is important not to externalize it as a good idea or a bad

8 See Christmas in Purgatory by Burton Blatt

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idea but simply to hold the idea and observe the questions or internal thoughts and feelings you experience from day to day as you witness the various forms of violence on the road, with family members, coworkers, etc.

Many parents and staff who are in support roles for people with disabilities will often want to know What to DO when confronted with violent behavior. What I have discovered through working with people is that this is not often the right question. The question really is more about How should we BE.



Lesson Four

Values, Beliefs and Assumptions

As noted previously, during the initial stages of understanding someone's difficult behavior, I would propose that it is far less about Doing and far more about Being. What I believe, my assumptions about what it means to be human, about the nature of human services, about disabilities, about the particular person I am working to support, even my assumptions about higher order things like is there a God etc. need to be considered and often challenged. I am not here going to advocate for a particular moral, ethical or religious belief system but just to say that, in short, our beliefs and values certainly impact how we see the world and how we act in it.



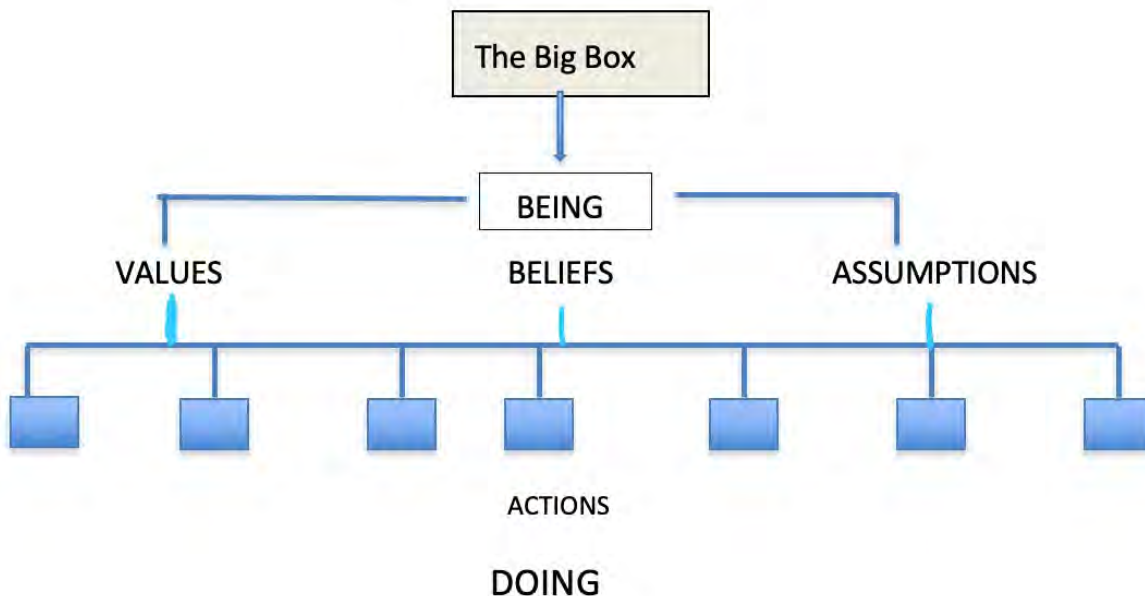
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Please take a look at the diagram below. The Big Box is your worldview, generally where you put your faith, e.g., in God (Nature, a cosmic intelligent creator, aliens) in Technology, in other people or a person in particular, or yourself. If for example you are a Christian and believe in God and the Bible, then this will often impact your values, beliefs and lower level assumptions about things. For instance, survival might not be an important value because you hold the belief that when you die you will have eternal life. So, when it comes to say a specific question of what would you DO (the small boxes at the bottom) if a nuclear missile was coming your way in a minute or two and you are in your bomb shelter with enough supplies to last a year but not enough space and supplies for anyone else...and there is a knock on the door with someone asking to come in. What do you DO? One theologian I heard answer this question stated that it was clear to him that he would open the door and let the other person in and he would step outside. Of course, in the actual moment of truth, who knows what they will do. But what we do will at least be influenced by our higher

order stuff.

Our Doing or actions stem from our values, beliefs and assumptions. If we believe that people with intellectual disabilities are not fully human our actions will be considerably different than if we believed they were fully human. We can turn that around and see how obvious it is in terms of the history of treatment for people with disabilities. What would people have to believe about children/ adults with disabilities in order to raise them in cages (as was the practice in the 19th century here in the US, and still practiced in places like Italy during the latter part of the 20th century!) or in human warehouses/large state-run institutions where they did not have access to bathrooms, no privacy, tied to benches often naked, etc.

When I started working with adults in a large state institution in 1971, we had a one-day orientation where the instructor, a former drill sergeant, Ozzie, gave us a tour of the various buildings. We were walking across a field between two buildings when Ozzie turned to



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me and said, “Ya know, these people would be better off if we took out into this field and shot them all⁹.”

Seemed a little strange for a staff person to say this during our orientation. We had just come from a building where there were 50 or more people referred to as the “pretzel people” because they were all twisted up and calcified from laying in beds for so many years. They would be fed and then picked up and placed on slabs, bathed and dressed in a diaper and then put back to bed. By the time the two staff on this ward had finished with the last person it was time to start all over again. The next building was CL building where 200 men with behavioral issues lived. This is where Ozzie worked. A young man came up to him smiling and Ozzie turned and said to us, “Now watch this!” as he told the young man to perform for us by banging his head against a concrete pillar as hard as he could. As a reward, Ozzie threw his soggy stogie on the floor where the man quickly grabbed it up and ate it. (I could not make stuff like this up.) The point once again is what must Ozzie have believed about these people to say and do the things that he did.

As stated earlier, although we closed the bricks and mortar institutions, we did not really address educating the staff who

⁹ One point worth consideration is that it is very hard to identify with people who are so deformed and severely disabled in terms of intellectual capacity. What would it be like to actually be them in the best of circumstances. Many would say that they themselves could not live or would not want to live that way. This also happens to people as they age and are terrified that they will end up in a nursing home. Enter Dr. Kevorkian and assisted suicide. This was actually a strategy of Hitler in Nazi Germany where he made films that depicted people with disabilities with the idea who would want to live a life like that. A film about this is available on YouTube: Selling Murder

continued to work with people. No small wonder then that these kinds of dehumanizing beliefs and assumptions carried over into community services.

I am raising all of this before we get into patience, tolerance and forgiveness just to lay a little groundwork. It is not my intent to dive deep into heady philosophical discussion about the meaning of life but just to point out that there is a problem in focusing just upon Doing without first understanding where our Doing comes from via some critical thinking.

Supporting people with disabilities who have reputations for difficult behavior is, as already stated, very difficult, complex and often emotionally laden work. My experience has been that the vast majority of staff/parents just want a behavior plan, be told what to do, and therefore think in terms of externals, behaviors. As Alfie Kohn states in his book Punished by Rewards regarding behaviorism “...we do not have the idea, it has us.”

I once asked John McGee (Gentle Teaching) what his thoughts were regarding behaviorism. In his own words:

“One thing for sure is that we cannot think about gentle teaching and then talk about behavioral problems in the same breath. It is an intellectual and sentient incongruity to pose one issue in terms of the other. If we still worry about behavior problems, then we need a behavioral approach to deal with them...If we sit and talk about behaviors, we then are focused on the externals of the human condition. Love is internal. Life is internal. Death is internal. Hope is internal. Despair is internal. Feeling safe and loved is internal. Gentleness is internal.”
(John McGee, personal communication, 2001)

Here are a few of my assumptions regarding

people with intellectual disabilities:

1. People with disabilities are people first, with the same kinds of reactions to and impacts from what happens to them in life; with the same kinds of needs for things in life like love, home, friends and a reason to get out of bed in the morning and therefore, the same kinds of things that work for people without disabilities will work for people with disabilities.
2. ALL people, no matter what their degree of impairment or level of functioning, can learn, change and grow.
3. There is a place in the world for EVERYBODY!
4. And one of my favorite assumptions, presume competence. As someone with an intellectual disability once said, "I may be mentally retarded but I am not stupid!"

Please note that assumptions are not like facts; they are often considered improvable thus involving a degree of faith. In attempting to support people with disabilities (or anyone for that matter), we may never fully live up to

our values, beliefs and assumptions. They are put up before us as ideals towards which to strive, a direction, a north star. We can test their importance by asking a simple question however: Are these things true for me? If suddenly we found ourselves in a car accident and woke up not being able to speak or use our body to communicate, or perhaps someday in a nursing home, would we want these things believed about us?

In short, education and consciousness raising are important in conducting the inner work of values, beliefs and assumptions. My experience has been that most of what has been considered mainline education on how to support people with disabilities (or more to the point, how to support people with a disability who are developing a reputation for being a behavior problem) lean towards mechanistic or simple externalized approaches that would have one focus on behavior and not the complex context of it. We could all benefit from learning how to think critically.



Lesson Five

Do No Harm

There is a most delicate balance to consider in supporting another human being. I support another person because they have need(s). But I too have needs. The other person may have good days and bad days. I have good days and bad days too. I must try to constantly remind myself that my best understandings or version of the other person being supported must be balanced by the fact that they (we) are always growing and emerging. Despite my best intentions to help, I will often fall short to the point of even causing harm. This is a very difficult idea for most people in support roles to accept.



Lesson Five

Human services, for example, would often have us see people as clients, neatly classified by labels and categories (autistic, permanently and totally disabled, behavior problems, schizophrenic, etc.) But behind all of that psychobabble sits an individual, more like us than they are different, regardless of their label or degree of impairment. Personally, I have experienced difficulty within myself, in transcending such labels to simply SEE the other person as I would want to be seen myself. The fact that they are ‘autistic’ becomes the most important thing about them, defines them.

I am now 72 years old, a “senior citizen” closing in on ‘geezer hood’. But that is not the most important part of who I am – in fact, I still find myself thinking that I am a 23-year-old, which often can lead to disastrous results when I try leaping over a guard rail – but you get my point. If I need you to support me and all you see is a senior citizen with all the trappings that go with that label, our relationship will not be off to a good start. (Just visit a nursing home and make note as to how staff address the residents with ‘goo goo gaga baby talk’! In other words, being talked to as if they were children once again, which is one of the negative role stereotypes that seem to come with old age in our culture.) . If you don’t believe me, for a very recent example, you might also take a look at this website care.coach.)

It is often because I find myself defining the other person by their labels that I can cause harm. The labels can become a wall and blind me to the humanity of the person. They are *just clients*, and so often I have heard it said that I as a staff person should not become friends with them lest I lose my *professional objectivity*. Rubbish. (Reminder: We are talking about a relationship-based approach

as foundational to any behavior change. Be prepared - you might experience some difficulty if you are working in an organization that puts strict boundaries on staff having a close relationship with a client or student.)

So how do I cause harm? Wolfensberger developed a list of the many ways we can cause psychological, emotional and physical harm to someone with a disability. His presentation of this typically took four hours of lecture to cover but I will only list them here and speak to a few of the more prevalent ones. He refers to them as *wounds* – not necessarily physical wounds but deeply psychological, emotional and spiritual wounds.

Some of the most common “wounds” of devalued (especially handicapped) persons:

1. Relegation to low social status (life defined by their label/deficit/impairment)
2. Cast into deviant role stereotypes (menace, object of pity, not human, etc.)
3. Rejection (a deeply painful wound often experienced daily)
4. Loss of freely given relationships and substitution of artificial or “boughten” ones
5. Loss of control, even autonomy and freedom
6. De-individualization
7. Involuntary material poverty
8. Life wasting (often “special” education or day wasting programs/sheltered workshops)
9. Death making (being made dead by medications, restraint practices, etc.)
10. Brutalization (Being treated like a brute via physical restraints etc.)

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11. Impoverishment of experience, especially that of the typical, valued world
12. Discontinuity with physical environment (being moved from place to place)
13. Discontinuity social / relationship (often consequence of #12)
14. Resentment, hatred of privileged citizens
15. Distantiation: usually via segregation and congregation

Before I dive into specifics, in order to understand how we might cause harm, often without realizing it, Wolfensberger put forth the following: When we see another person for the first time, we size them up (according to science) in less than 3-7 seconds. What Wolfensberger pointed out is that **perception is never neutral**, it is always positive or negative to varying degrees. We like or don't like a painting, a new food, a product or a person almost right away. Secondly, this is almost always **unconscious** – we are rarely aware of what transpires in those 3-7 seconds. Of course, what happens in our unconscious assessment is the sum total of all of our experiences (or lack thereof) with people in a wide variety of circumstances and more importantly what we have been taught via school, the media, our friends, parents, etc.. Third, and most importantly is the fact that positive perception of a person will most likely lead to positive treatment of that person and conversely, negative perception will most likely lead to negative treatment.

Wolfensberger then develops (in part) the whole construct of Social Role Valorization based upon this latter bit of psycho-social empirical fact: That in short, if we support people to be in valued social roles (employee, student, father, mother, banker, car driver, ad infinitum) and we leverage positive personal

appearance and behaviors in those roles, they are more likely to be perceived and thus treated more positively. Watch [Catch Me If You Can](#) with Leonardo DiCaprio for an object lesson on the power of roles.

Unfortunately, the vast number of direct support staff and parents I have worked with have not been made aware of Wolfensberger's work and thus often do not encourage people with disabilities to look and be at their best when on community outings or going to school etc.

But there are other ways we can cause harm, directly – or indirectly by collusion, or simply allowing ourselves to become functionaries of the human service system as was the case for me at Monson State Hospital.

Deviant role stereotypes (#2 listed above) include, being seen as nonhuman, an animal, refuse/discard, object of pity, a burden, eternal child, client, sick, dying or better off dead, menace or object of dread. One of the most common stereotypes of people with intellectual disabilities is being seen as a child, even when their chronological age is in the adult range. IQ testing has traditionally put forth the notion that adults may in fact have the “mental age” of a 5-year-old for example. (Marc Gold – look him up on YouTube – noted that this was an insult to 5-year-olds! That a five-year-old could learn to do just about anything if given the resources, time and instruction!!). At any rate, when an adult is seen as a child, serious harm is done in holding lowered or different expectations. Children for example do not get married or have sexual relations, children do not own their own home, have careers/jobs, etc. Support staff/parents can cause harm by seeing an adult as a child and not encouraging the adult to assume adult roles. Quite often

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when I visit adults with intellectual disabilities, I will find “age inappropriate” toys, games, videos, and almost always Mickey Mouse! Here again, harm can come not only by **not** encouraging them to have more adult interests and possessions, but in some cases, after learning of this role stereotype, proceeding to take all of their childish possessions away from them. This is a huge perversion of this particular notion in that we are then causing harm by violating their capacity to have some degree of autonomy and control over their life. It is an attempt at a quick fix that can lead to great harm to the individual.

Another common role stereotype for people with intellectual disabilities is to be seen as a menace or object of dread. These are the people who are being accused of being behavior problems with all the colorful labels that go with that: non-compliant, psychotic, manipulative, spoiled, attention seeking, self-injurious, feces smearers, biters, dangerous, etc. It is interesting in my work over many years that some of the nicest and most courageous people I have met have been labeled as behavior problems. If you even begin to understand the oppressive nature of our society and the human service system, a deep appreciation for some people’s spirited refusal to buckle under it will come into view. Truly heroes.

Finally, people with disabilities are often seen as non-human or less than human. I mentioned earlier about how we forced them to live in dehumanizing institutions. Additionally, they can be seen as “sick.” “Mental Retardation” was seen as a medical condition and of course (one might think) medical conditions would as a matter of course seek to be resolved by medical treatment or cures. Thus, many of the large state institutions were called state *hospitals*

often managed by doctors and nurses. The medical model of treatment continues to this day although not as blatant. The critical point to be made here is that if your primary role is a client or patient and there is no medical cure, Hmmmmm?

Wolfensberger accumulated a vast amount of data, articles, and evidence from around the world on how much harm was being done to people with disabilities by human services, and often by people with the best of intentions. In a monograph entitled The New Genocide of Handicapped and Afflicted People, he estimated at the time that more than 150-200,000 people/year with disabilities were being *made dead*. He developed the concept of *deathmaking* because “...in addition to direct or overt killing, there was no word for the many forms of concealed and indirect killing that may take a long time to accomplish and may be very difficult to trace; and it can include active participation as well as silent, unobjecting collusion.” By the term *deathmaking* I mean to refer to “...any actions or pattern of actions which either directly or indirectly bring about, or hasten the death of a person or group.” (Wolf Wolfensberger. The New Genocide Handicapped and Afflicted People, 1987, p 1). The monograph explores this in great depth and if you are a serious student of human services, I would strongly recommend reading it. Examples of deathmaking would be abortion as result of amniocentesis, infanticide, child abuse, physical restraint, or the life-impairing use of psychoactive drugs.

We may not therefore harm someone directly but do so simply by colluding in the harm being done, following orders, turning a blind eye, simply by giving someone their psychotropic medications (Wolfensberger referred to these as ‘neurotoxins’ . Direct

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support staff are particularly vulnerable to this given that they can lose their jobs and even be “blackballed” in terms of seeking employment with other agencies if they are disobedient/non-compliant in not being willing to follow orders, for example to attend physical restraint training.

If I am in a support role with someone with a disability, I will cause harm; it is not an issue of “if” but “when.” I may have not intended it, not meant it, perhaps did so but was not even conscious of it, but it will happen. This holds true for anybody engaged in human services but is possible in families as well.

Going back hundreds of years, over the archways of entrances to hospitals would be the axiom, often in Latin, ***Primum non Nocere, First Do no Harm***. Why was it there? It was clearly recognized back then that human beings were not infallible, mistakes had been and would continue to be made. The point being that we should all hopefully aspire towards excellent care but with a sharp sense of humility as to our human capacity for harm.

The example cited earlier of Bob who died

from a spinal mass which should have been detected via a routine physical – there were a number of staff including myself who had serious doubts about the mental hospital’s claim that his feigned inability to walk was Bob just doing it for attention. We talked about the issue frequently after assuming support responsibility for him. But we did not act soon enough – not until the “beach” experience did we begin to consider taking him to a community doctor. We did not kill Bob but we colluded in his being made dead, even if only to a small degree. I would add that the community doctor was quite vehement that the institutional doctor overlooked what should have been obvious. We will never know (this was 35 years ago now) but it does raise the possibility of the institutional doctor not valuing Bob enough to have done a more thorough physical. Of course, again I also strongly suspect that the psychiatric professionals had convinced the doctor that Bob was faking it, just seeking attention. Just as I had been led to believe that I was doing the right thing in placing women into seclusion because it was always with a doctor’s order and a charge nurse telling me to do it.¹⁰

14 See Stanley Milgram Experiments in appendix. Stanley, in trying to understand what happened in Nazi Germany, did an experiment where subjects were told to deliver electric shocks to an individual in another room who they could not see but hear. If the individual (an actor) gave the wrong answer to questions, the subjects were told by a man in a white lab jacket to deliver the shock. Despite the individual’s pleas for mercy, the subjects continued to deliver the shocks at increasing intensity simply because the man in the white lab jacket insisted they do so. Milgram referred to this dynamic as blind obedience to authority.

Lesson Six

Patience and Forgiveness

I originally encountered the importance of practicing the qualities of patience, and forgiveness as put forth in a one-week workshop I attended with John McGee on Gentle Teaching in 1983. I find this lesson particularly important for any of us engaged in supporting people with intellectual disabilities or afflicted people in general. Just to be clear, I feel a need to speak about these qualities, but make no claim to mastery, that is for sure. However, in the intimate work of supporting people, I find at least an awareness of the importance of them being essential. And yet this topic is rarely on the agenda for staff orientation/training.



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If we are involved with an individual who has a reputation for difficult behavior, it is very likely that we might get hit, bitten, spit at or have to 'endure' the individual in one way or another. Conversely, as noted in the previous chapter, we will more than likely make errors of judgment, lose our tempers, our patience, and often unconsciously cause harm to the individual. And again, all of this also applies to our work with the staff, teachers, support staff or spouses etc. who are trying to support the individual with us. There will be disagreements, arguments, sabotage, passive-aggressive behavior and not following agreed upon protocols.

First of all, we need to remember that *relationship* is the critical component of supporting an individual who has a reputation for difficult behavior. There needs to be trust, equity, and ebb and flow of interaction, mutual respect, and reciprocity. This does not always happen naturally from the beginning and requires time in any relationship. Additionally, in working with an individual who has experienced (and probably still is experiencing) life defining wounds as noted earlier, they may not have a strong experience base of how to be in a relationship. In fact, they may not see themselves as lovable and may not have yet learned how to be loving in return. And given their past experiences of mostly being told what to do, they may not feel particularly safe in a new relationship. As John McGee would say, we need to begin by **"teaching"** people that they are safe and loved as well as how to be engaged and reciprocal. **We** need to take the lead on this score.

Two of the most ancient and time-tested effective teaching strategies are role modeling and imitation. We see this with animals, we certainly see it with small children especially. But this is also true for adults. Personally,

showing me how to do something is often more effective than reading a manual. I would sometimes find myself speaking with the parents in their home with their son/daughter present and the phone will ring. It is the special ed teacher calling from the school. In front of the child, the parents will get into an argument with the teacher and after hanging up, will speak quite unkindly about him/her. And I see this in the school as well where the teacher or aid will speak poorly of the child's parents in front of them as if they were not there, not listening, not able to understand what is being said. I have also seen some pretty terrible role modeling at team meetings.

Granted, there is often a need for working through conflict and having difficult conversations. My point is that as far as the child is concerned, there should be "peace and love" flowing between the people around them, on their team.



Dick

When I first met the staff working to support Dick, they were standing about 50 yards away from the house with his two housemates, Michael and John in the cold and dark whilst we could hear Dick screaming and breaking things in the house. They were all terrified because at one point, Dick had threatened to stab one of the staff people with a butter knife. As the Residential Director, I had just that very day been told that our organization was assuming responsibility for this particular program and had not even had the opportunity yet to formally introduce myself to the staff. In any event, the staff were scared and saying horrible things about Dick in front of Michael and John. They were not terribly nice to me

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either. And when I spoke with Dick's mother the following day, she was quite angry and had nothing but criticism for the support staff.

Dick was a large 24-year-old man with autism and had been beating up his two much smaller and older roommates Michael and John, the house and the staff for some time. It reached a state of crisis and we had to request emergency respite for him. With the help of outside consultation from a friend of mine, it came to light for everyone involved how difficult and barren Dick's life had been for a great many years. Within the next month, he was no longer a problem. The vision from a meeting of the team including the mother, was to give him a daily social calendar similar in intensity to the President of the USA! We filled it with the have to do's but with a generous amount of choice and fun activities and breaks. One of the staff volunteered to invite him to be a roadie for his rock band. Dick was ecstatic with this paying gig.

The other thing we did because Dick had been beating up on his roommates was to find a way to move toward some form of forgiveness in action. Saying "I'm sorry" had become a thing that he had learned to say after he hit someone, and then he would hit them again. What the team arrived at was to have him do nice things for Michael and John and vice versa. Dick would occasionally buy each of them a present or offer to help them in some way. They had lived together for several years but rarely if ever did things with or for each other, which seems to happen a lot in group homes etc. And within these strategies we needed to teach Dick in particular how to be hospitable, patient and forgiving as Michael and John were not the easiest people to get along with either. It was truly beautiful to see the three men learn these ways of being nice to each other. What was previously a program

evolved into a beautiful, small community.

When an individual is gaining the reputation for being a severe behavior problem, it was not uncommon for me to find the people around him/her behaving badly as well. To a certain degree, this was understandable as they were quite afraid of getting hurt or seriously injured. Sometimes people had already experienced a fair amount of physical abuse, often had experienced months or years of difficulty. And so, much of my initial work was in simply sitting down with the individual people and or the team privately without the child/adult present, listening and allowing people to vent. Very often people would get angry or impatient with me, just wanting to know what to DO and I would have to tell them that I did not know, but we would figure things out together.

One of Dick's more concerning behaviors was grabbing women by the breast. During his job as a roadie, he was at a rehearsal with the band in a bar one evening and the band member's wives were sitting at a table having drinks. Dick went over to their table and started to grab one of the women's breasts. The husband/band leader jumped off the stage and ran over, spun Dick around, grabbed him by the shirt collar and told him in no uncertain terms that if he ever touched his wife again he would beat the _ _ _ _ out of him and he would no longer have his job as roadie. Dick never did this again. It is important to note that this was not a planned or pre-arranged consequence. Some will say that what people like Dick needed was a "natural consequence" and often mean that all he really needed was one good punch or talk of arranging one. Caring about someone does not include wishing him or her harm. I am not advocating that at all. But I do believe that all of us learn what works and what doesn't

by living in community with other people. Unfortunately, many children in special ed classrooms never get the opportunity to be “bad” because they have an adult aid attached at the hip all day; in short, they do not get opportunities to play with other kids and be bad, and learn the social mores.

This raises another dynamic that is frequently in play when there is difficult behavior at hand, and that is **Control**. I am primarily referring to this in terms of the individual who is being seen as the problem, but it also applies to everyone around them. Giving Dick greater substance and control over his schedule, routines, his life in valued roles was a core strategy. Oddly, it is perhaps a fundamental need that all of us have which can get lost in our supporting people with disabilities. Giving Dick more control was certainly not first on people’s list of how to better support him, quite the opposite in fact.



Rick

I once worked with a young man, Rick, who was purportedly “severely autistic with *extreme behavior problems*.” I was directing a small employment program and because the other staff were very fearful of Rick, I decided that I would work with him, find him a job and support him in that job. He was offered a 30 hour a week position at a Taylor Rental store which mostly rented power tools, but also rented out dishes for weddings. The staff at Taylor Rental loathed having to wash dishes and so we definitely had an easy time getting this job. My pitch was that I would work with Rick and assure Taylor Rental that the dishes would be clean and ready to rent out before the next weekend. We will discuss his work in

more detail later.

At any rate, the agency office provided to me was on the second floor of a bank building amidst high end lawyer offices and there was only one men’s bathroom which could only accommodate one person at a time. Before work one day, Rick let me know that he needed to use the bathroom. This was after roughly two months of working through a fair amount of difficulty between us and I had just begun to have his trust.

One of the lawyers stopped by the office to let me know that “one of your people” had been in the bathroom for some time and expressed some urgency in his needing to use the men’s room. I went to the bathroom and knocked on the door letting Rick know that he needed to finish up as someone else needed to use the bathroom. After a few minutes of no response, I opened the door just a crack (I had a key) and saw that Rick was in front of the mirror singing. I entered and immediately Rick started to pull his pants down and head for the toilet. “No way Rick! You have been in here for almost 45 minutes and your time is up. Someone else needs to use the bathroom.” I got in between him and the toilet and told him again in no uncertain terms that he had been in the bathroom long enough and we needed to leave as I grabbed hold of his pants and with some force buttoned them up and started using my body to usher him out of the bathroom. As we got closer to the door, Rick suddenly walked out into the hallway on his own initiative, zippered up his fly, looked at me with tears streaming down his face walking very fast towards our office. He refused to speak with me or even look at me for over a week.

I apologized to him right away, and again repeatedly over the next several days. I also would get him small presents that he would

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initially refuse, try to do favors for him, and in general talk with him about what a bone head I had been. I sincerely did not feel good about how I had handled the situation, and should have been more proactive in supporting his efficient utilization of the bathroom. I felt terrible.

Two weeks later: One part of the dishwashing job at Taylor Rental was to pull large plastic bags off of a perforated roll on the wall and then pull them over each tray of cleaned dishes. Rick seemed to have a hard time with this which I was trying to teach him by doing hand over hand, manual prompting. It was awkward and Rick seemed to struggle even with my support. Once the bag was off the roll, his job was to hand me the bag and I would put it over the tray. I had just put a bag over a tray and was turning around to help Rick get another one. He was standing there with this huge grin on his face holding the bag up in front of himself as if to say, "I was just screwing with you, I knew how to do this all along!" I said something like "you son of a gun!" and he started laughing (I had never heard him laugh so hard before) and so did I, now with tears streaming down my face. He had forgiven me.



One final note: quite often when we are asking to be forgiven, what we are actually asking for is a free pass, to be excused. Being excused is the polar opposite of forgiveness. If we are excused then there is nothing to be forgiven about. If we did something wrong we need to apologize and be serious about the fact that we wronged the other person. (I think I mentioned

this already regarding Dick) Where do disabled people get the idea of just saying "I'm sorry" as a sort of mechanistic resolve to something nasty they just did!? And then they do it again. I think we teach them this, otherwise where do they get that notion!? I see it in marriages sometimes (never my own of course) where the husband will get yelled at for not putting the proverbial toilet seat down and he will say he is sorry and then an hour later do it again and so on. Was he really sorry or did he just want to be excused? Worth thinking about?



Learning to be patient is important in my work with people. I found that the best way to find patience is to stand in the other person's shoes after learning some of who they are via their life stories. Prior to discovering the importance of people's stories, I had a much harder time being patient with them based purely on their labels, diagnoses and human service records.

Stephen Covey, in his book **7 Habits of Effective People** (highly recommended reading) talked about how our perception of a person or situation can change in an instant when we know something more about them. He tells the story of his taking a subway home one peaceful evening, few commuters in his car, reading the newspaper. Suddenly a man with several children boards the car and the children are screaming, running around, banging into Stephen, fighting etc. He is almost ready to tell the father to get his kids under control or else, when the father leans over and apologizes for his children's behavior; that he had just come from the hospital

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where his wife died from cancer and he was on his way home. In an instant, Stephen's whole perspective shifts 180 degrees to now wanting to offer help in any way he can. This is technically called a paradigm shift and for me it is what so often happens between the time I get a call to consult with a child who is purportedly a 'terrible monster' and after getting to know them, see that they are actually little heroes, not buckling under the oppressive forces of the system.

When I am in the rear of a long check-out line and I see an elderly person slowly counting out pennies to pay for her groceries, it is so easy for me to become impatient, grumbling and wishing someone would just knock her over so I could pay for my groceries and get back to my life! And so, I remember Steven's story and wonder what the elderly person's story is all about. Would my attitude change if I found out that she had just lost their spouse after 50+ years of marriage, or that she was struggling to survive cancer, barely able to afford food, at risk of becoming homeless? And worse yet, someday not far down the road, I might be an old man counting out his pennies.

I have found that in many ways, we can all get hooked into being the victim, complaining, whining, *oh how hard my life is*, etc. I am far from being healed of that state of mind, but I strive to become mindful of the choices I am exercising when in it...giving my power to others for "making" me miserable, choosing to have others feel sorry for me rather than take full responsibility for myself.

The point here is that patience and forgiveness are important qualities to hold in any relationship, let alone our work in helping/supporting others. I did not mention this previously, but it is my hope by laying out some of these ideas for you that you will give them continued thought and even have discussions about them with your coworkers, spouse or people you support. We could all benefit from more encouragement in these realms!

I did not talk about love...Do I really need to!?



Lesson Seven

Fundamental Needs

*You've got to have something to eat and a little love
in your life before you can hold still for anybody's
sermon on how to behave.*

Billie Holiday

We know that humans have *survival needs* such as food, shelter and clothing. But humans also seem to be universally in need of things like “home”, friends, belonging, autonomy/control, love, which we might label as “Fundamental Needs.” When any of these needs are unmet — well, in short — we may not do so well.



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When people lived in large dehumanizing warehouses, the state schools, they most certainly did not do so well. I was there – 1971. The conditions were beyond my wildest imagination, dismal, bleak, rancid. And that was where people “lived” – that is what they woke up to everyday. Life made absolutely no sense there. But humans have an amazing capacity to adapt. Of course, their adaptations were to do things that seemed so utterly bizarre like stuffing shoe strings up their nose and somehow pulling them out through their mouths, biting the ears off of other residents, smashing themselves in the head repeatedly, sitting in a corner curled up in a fetal position for hours on end. (Burton Blatt was one of the first people to have photographs taken of these conditions and put them into a monograph entitled *Christmas in Purgatory*. You should be able to find these images on Google or YouTube. See Resources)

Around this same time, behaviorism developed initially in a laboratory with rats by BF Skinner was coming into vogue. Behavior consultants like Azrin and Foxx, Whaley and Malott were going around the country into these human warehouses, using behavioral techniques to address the behaviors noted above. This was definitely better than nothing or so it seemed, but as a rule a short time later, the individuals would return to engaging in the same behaviors that existed prior to treatment. Why? Because the conditions did not change, the context for their behavior, the environment and the staff, did not change. Their fundamental needs remained unmet.

I also know this because after a year as a male attendant, I was chosen to work on a million dollar Federal grant along with 14 other people to learn behavioral techniques and then demonstrate how they could be effective in teaching self-help skills like toilet training,

dressing, eating with a fork and spoon (many people would eat with their hands only, had never learned how to eat with a fork), as well as addressing severe behavioral issues like head banging and ear eating. My experience? Over a period of three years I would say that we got absolutely nowhere. Of course, the team of 14 “behavior specialists” that I worked with would blame the direct support staff for not following the behavior plans, or the psychiatrists for changing the individual’s medications repeatedly without notifying us in advance.

Imagine a very large room, roughly 40x60 with 20 beds in it, a few wooden benches and 20 adolescents who were considered severely/profoundly mentally retarded. No dividers or stalls in the bathroom, just 6 toilets without toilet seats, no toilet paper, the bowls often cracked and broken. And by the way, the bathrooms were often locked because the residents would stuff the toilets with socks and underwear requiring the maintenance department to have to come and clean them out, and they would yell at the direct support staff for allowing the residents to do this. The solution? Lock the bathroom door. This is where 20 young men lived, slept, ate and went to the bathroom on the floor. And I was there with 4 other trained behavior specialists to teach self-help skills and modify behaviors. What were we thinking!!?? Were we even thinking at all? Seems crazy, right? A million dollars.

In hindsight, to believe that anyone could learn anything in such a barren, dehumanizing context is inconceivable. And yet, nobody including the project director who had a PhD, the consultants that we brought in nor the management of the institution – nobody even suggested that this project was utterly crazy, including me.

Funny aside: I can still remember having a beer with one of the consultants and he said, "You know, someday, maybe 20-30 years from now, we are going to look back and think that all of what we are doing today was barbaric." I remember nodding my head in agreement but not really believing him. Behaviorism was amazing, we were doing ground-breaking cutting-edge work!! How could it get any better!?

And my guess is if he were here to say that again today in 2021.... well, what do you think? (I will let you run with that one.)

So back to fundamental needs, sort of obvious right? Well, maybe not. Today, 2021, I know I can still pick some individuals with a disability at random to go visit and they will more than likely not have a job, not have any friends, not have a sense of belonging or community membership and not have "home." And when I say "home" I mean a home like you and I have, that we can call our own, decorate it as we please, have privacy, a sanctuary away from the world, raise a family, invite people over for dinner, plant a garden. Maybe we just live in an apartment but it is still our home. Smells like a home, looks like a home, feels like a home. Is there not something sacred about Home?

Ok, yes, people today certainly have it better than¹¹ people back in 1971 – but the question remains, do they truly have a HOME. Do they truly have friends, meaningful employment, belonging, a reason to get out of bed in the morning? At planning meetings that I used to conduct with organizations, I would ask Who loves ____? Many staff would often say that they did, but when they left their jobs, often

¹¹ Over the past 50 years, I repeatedly heard this expression that people had it better than they used to in the dark days of institutions. The problem here is that as Wolfensberger would often note, on a scale of 1-10, institutions were not even on the scale! Bottomless.

without even really saying goodbye, the love stopped.

In the years since I finally abandoned behaviorism and came to understand this business of fundamental needs, I worked with a number of people where all I really did to address behavioral difficulties, was to assess and then address their fundamental needs. The story told earlier of Dick did not involve a 20-page behavior plan; we helped him to get a life! And the behaviors just sort of disappeared...Really!!

The fact is that people with disabilities are often unloved, lonely, bored, homeless, having little to any real control over their lives, often not participating in their own lives – paid staff are doing everything for them. And when they engage in strange and difficult behaviors, we call the psychiatrist or behaviorist. And once again, things go well for a while but not for long if the fundamental needs have not yet been fully addressed which may have been the basis for the problem behavior to begin with.



Glen

I was once asked (about 15 years ago) to do a behavioral consult on an older gentleman, Glen. Glen was reportedly throwing trash cans at passing cars on a side street near the downtown area, peeing on the bathroom floor, punching holes in the walls, refusing to get out of bed or engage in chores etc. He also had a reputation for going up to women he found attractive and talking to them about his bowel habits and therefore was considered to possibly be a sex offender.¹² The first time

¹² The label of sex offender is truly a life sen-

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I visited Glen, I was knocking on the door with an elderly woman sitting at the kitchen table reading the newspaper seemingly ignoring me (she had been “warned” that I was coming). So, I opened the door and let myself in and asked her if Glen was home. She pointed to his bedroom at the other end of the apartment without uttering a word. I soon learned that she did not really like Glen from the ways she spoke to or about him. Glen also had a “roommate”, a staff person who was supposedly “sharing” the apartment with him, but he was only there to sleep at night and his door was always locked. He did not really like Glen either. This was Glen’s home.

I went through the living room to Glen’s bedroom and knocked (there was no door to his bedroom) lightly to announce my arrival. He pulled the blanket further up over his head and basically told me in no uncertain terms to get out. I went back and tried to engage the staff person in her understanding/experiences about Glen. It was a relatively short conversation. I then sat in the living room, hoping that Glen might come out to visit with me at some point, which he eventually did. He of course played his cards close to the vest, but would ask me pointed questions over and over again, like “Who are you!?”, and “Why are you here?” I explained why I was there, apologized for possibly disrupting his day (nobody had told him that I was coming!) and left.

tence, often in my experience, based upon a single incident. The fact that people with disabilities are not seen as sexual beings is fairly evident. In short, they do not learn about the many nuances of dating and sex and yet grow into adulthood with this basic need unmet. Staff are not trained or prepared for the possible moment of serendipity when a young woman might ask Glen to come over to her place for a drink. How does that work when he is in a program that mandates 24/7 staff coverage?

Long story short, after several meetings with his staff and brother, Glen moved in with a family that I knew and had worked with previously. Glen became part of the family, was invited to participate in all family outings, daily chores, caring for their dog, watching TV with them, playing “Uncle” with their two children, etc. Glen continued to be a bit of a curmudgeon but the serious behavioral issues disappeared in short order. He finally had Home, belonging, a reason to get out of bed in the morning, and valued roles — Glen found love and family.

I would note that HOME is an important fundamental need that often gets overlooked in the human service world, often being replaced by a *Program*. Glen had lived in a *program*, a staffed apartment *program* to be exact. It did not feel like Home, did not look like Home, and it certainly was not his Home. If we stop and think for just a moment about the importance of Home, we would start to see how obvious and sacred Home is for most of us. We could also begin to describe the important components of Home, such as privacy, control over who lives there or visits, how we decorate it, a sanctuary away from the world, a place where we can have a dog, raise a family, do what we want to do when we want to do it, invite people over for dinner.

My one failure with Glen is that over my 10 or more years of involvement with him, I could not convince program managers or his brother (who was also his legal guardian) to consider opportunities for him to meet women. The brother simply did not even want to talk about it, and the people working with Glen did not believe that he was really interested in women. I began to have some doubts myself until a female staff person told me about an evening where she took Glen to a dance. A woman asked him to dance (Glen at that point was

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61 years old) and there was a slow dance and she had her hands on Glen's rear end and vice versa. Unfortunately, the woman had a little too much to drink and her husband was there – and well – quite simply Glen did not get to finish that dance. When I spoke with the staff person she was terrified that she would lose her job if the agency or guardian found out. But something significant was learned.



Most human service organizations tend to focus on people's impairments not their capacities. In some ways, this should be obvious given how funding works. Money is given to organizations to address special needs and problems. Very detailed and lengthy documents called Individual Education Plans (for children) or Individual Service Plans (for adults) are developed to address these special needs and to also document progress in order to justify continued funding. I am vastly oversimplifying a complex system/dynamic but the major point is that the human service system is therefore less concerned (if at all) about the fundamental needs being addressed for belonging, friends, meaningful activities/jobs, home or autonomy and control. There are some enlightened education programs or adult service programs that will attempt to address more fundamental needs but more the exception than the rule in my experience.

In some ways I wonder if people are truly better off today than when they were living on the back wards of institutions. Ok, I am cynical but only because I have spent time with people living in the midst of community who are terribly lonely, feeling like they do not belong, without a true Home or a real job,

without any sense that they are accomplishing or contributing anything to the world, etc.?

In 1983 I was the Director of a large residential program for 40 residents with intellectual disabilities, employing close to 150 full and part time staff. I did a series of open discussions for staff to attend during their off hours on various topics. During the first such forum, I will never forget one of the staff noting that the people we served *had it made in the shade*. They had their food prepared for them, a nice group home to live in, people to help them bathe, do laundry, clean etc. One by one other staff started to agree. The staff sincerely believed that people living in the group homes had it made in the shade! They didn't have to pay bills, cook, or do their own laundry - everything was done for them. It took me several meetings to even begin to get some of them to see that group homes were programs, certainly not HOMES and to begin to imagine what it would really be like to be one of the residents.

On the other hand, discussions I had with parents reinforced all of this – their son or daughter was SAFE and that was paramount. One can witness this same set of dynamics with the nursing homes of today...SAFE, well cared for, Done! I however pray that I will never live in one. For a time, I evaluated nursing homes in MA and CONN and some of the supposedly best ones at that. Nope. Not for me thank you.

The service system solutions work best if there are few if any other alternatives. Given a choice between living in a group home or in an institution, group home will win every time. Given a choice of living in a nursing home or living on the street, nursing home wins.

Early on in my work, especially in the institutional settings, most mission

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statements would focus upon Care, Custody and Control of individuals in their charge. I discovered this when I was hired to be a unit director of two wards, one female the other male, of 32 adolescents with labels of IDD and severe behavior problems at a new institution in Ohio. The wards were locked which was customary in those days (circa 1974). One night, I received a phone call from Kevin, the overnight staff for the boy's ward telling me that he had locked himself in the staff office because the residents had taken over the ward with baseball bats, brooms, etc. When I arrived on the unit, it felt a bit like a prison riot with broken furniture in the hallways and the residents running around screaming. I cannot remember his name, but one of the residents who was the biggest, strongest and most articulate, approached me and in short told me that they were sick and tired of being treated like animals, especially in terms of being locked up.

That next morning, I met with the Superintendent who had recruited me to come to Ohio and manage the adolescent units. My recommendation was that the units no longer be locked and he agreed to allow me to present my case to a full interdisciplinary team meeting later that day. This is when I first heard those words, *Care Custody and Control*, as the head psychologist told me that it was the institutions responsibility to keep people safe, not to mention protecting the surrounding community from the residents attacking their homes. It was a heated discussion to say the least but I somehow managed to win their confidence and was given a two-week trial period. I met with the "men" on the unit, discussed some ground rules and proceeded to unlock the doors. Two weeks later I got the team to agree to unlock the female unit as well. This was perhaps

the first time ever that these young men and women were given back a fundamental right. They were not criminals or animals.

One of the principal arguments of the psychologist against the doors being unlocked was that I would be rewarding 'bad' behavior (unit takeover) by giving them what they wanted. I wish I still had my notes from that meeting but I know that I told him that if you treat people like animals or criminals, that is what you will get. Secondly, I felt strongly that the deinstitutionalization movement was a civil rights movement for people with disabilities who had been locked up and treated like criminals for years simply for the *crime* of being born with a disability. There was not a single mishap or incident.

What I began to see and continued to see in my consulting work over the next 3-4 decades was that control was often at the heart of seeming behavioral issues, often a form of protest by the individual. The antidote was not to take away more rights and privileges or punish, but instead, to listen to people and formally address their expressed needs, often for greater autonomy and control over their lives. It was not about giving people control or more to the point, freedom, but recognizing this as a fundamental right that all of us would probably fight for if we thought we were at risk of losing it. Too often we have *clinicalized* what is more fundamentally a civil rights protest. Where there has been great courage, we have taken away people's dignity with a diagnosis/label of *behavior problem*. It may seem a form of exaggeration to say that the issue here is political and not clinical, but in my experience, it is not a bad assumption to start with and explore.



Lesson Eight

Goals: Participation vs Compliance

“The label of noncompliance not only dismisses any good reasons people might have for their behavior, it also sets us up to manage people in automatic and unthinking ways. Obviously, if someone’s problem behavior is noncompliance, then compliance reflexively becomes the programmatic objective. As a result, there are therapeutic programs to “teach” compliance. People are told to stand up and sit down, simply because they are told to, and then rewarded with a piece of sugar or treacly verbal praise.”

— Learning to Listen, Herb Lovett



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Quite often people think of goals as things to do like learning how to tie your shoes or brush your teeth. What I learned from John McGee, the author of *Gentle Teaching*, was that for people with reputations for difficult behavior, one needs to begin with goals of teaching the basics of feeling safe, feeling valued or loved, being engaged in one's own life, and learning how to be reciprocal in a relationship. As previously noted, such goals are also explicitly stated in working with the people involved in supporting the individual with an additional goal of their learning the essentials of teaching. Tasks such as brushing teeth or tying one's shoes are then framed as vehicles towards relationship. Knowing how to teach effectively is critical to this process. After all, we want the individual (and the teacher) to experience success. Over and over again I was surprised to find that many special education aides and even teachers did not know how to teach effectively. Whatever is being taught needs to be a vehicle to relationship, not an obstacle. Is the student failing to learn or is the teacher failing to teach?

Traditionally, behavioral consultations focus on the individual with compliance being the explicit goal in behavior plans that are often given to supporters without any training. In a great many cases I have been told that there is a behavior plan for the individual but nobody seems to know where it is and/or have not even read it. Because compliance is emphasized in our public education systems it is very difficult for most people to wrap their heads around participation as the primary goal.

When I first learned this concept, it seemed so obvious and yet in practice I would get lost. I have had the same experience in teaching it. I will provide practical hands on examples,

repeated explanations from different angles and students almost seem insulted when I ask them if they really got it. And yet a couple of weeks later, like me, they are scratching their heads on how exactly to implement it in real life situations. Again, I think this is because we have been so indoctrinated with the compliance paradigm.

So, strap yourself in and put on your thinking caps again because I am going to do my best to shake up your belief system. This is a lengthy "lesson" but perhaps the most important one in this series of lessons.



Compliance: The action or fact of complying with a wish or command; obeying, submission, docility, acceptance

Participation: The action of taking part in something. Involvement, engagement, contribution, sharing.

Compliance means that when I ask or tell you to do something you do it. If you do not do it, you are therefore noncompliant. The vast majority of behavior plans I have read over the years will often cite "noncompliance" as a big part of the individual's problem behavior. Quite often, if the individual does not comply, they may be punished or placed in time out. Compliance becomes the goal and the strategies for attaining this goal often become the central focus of the practitioner. Herb Lovett in his book ***Learning to Listen***, suggests a hierarchy of control becoming increasingly punitive if the client does not comply:

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- **Positive Reinforcement:** giving the student edibles, tokens, privileges, praise, etc. when they comply, increasing the likelihood that they will continue to comply. (Alfie Kohn in his book Punished by Rewards, makes the point that rewards and punishment are opposite sides of a coin but of the same coin which is fundamentally about control. For example, you are told you will get to go to the circus on Saturday if you are a good girl which is offered as a positive reinforcer; however what happens if you are not a good girl – not going to the circus becomes a punisher.)
- **Overcorrection:** Overcorrection is punishment. It is the application of a negative event or the removal of a negative event. ... It combines the reductive effects of punishment and the educative effects of positive practice. Restitution is based on requiring the person to do what a normal individual might do to correct a situation.
- **Ignore and redirect:** Simply stated, ignoring the problem or target behavior and redirecting the individual to some alternative task or behavior.
- **Time-out:** Often framed as “time out from positive reinforcement. Removal of the individual from their social context, often into another room often referred to as the “time out room.” This is essentially on the spectrum of the old seclusion rooms of institutional days.
- **Physical restraint**
- **Mechanical restraint**
- **Chemical restraint**
- **Aversives:** use of pain to control behavior, e.g., electric shock, ammonia spray, pinching, slapping, etc.
- **Behavioral Surgery and Mutilation**
- I would strongly recommend Lovett’s book to anyone seriously interested in wrestling with traditional approaches to resolving

behavior problems.

Back to participation. Let me begin by having you imagine you are working with an individual – John – to teach him how to wash his dishes after dinner. And let us assume for the moment that he is not highly “compliant” with your verbal request to do so. Repeated requests or commands to do so might even result in his throwing the dishes at you or breaking them. OK.

I would quickly note that participation, which we will get to in a moment, is not meant to be THE ONLY strategy or way of supporting the individual in isolation of other considerations. I always need to be careful of falling into the trap of seeing behavioral change as a matter of simply employing strategies and techniques. I am putting forth a bunch of ideas separately to illustrate the components of support. In practice, I often need to remind myself here and there that there is no quick fix or simplistic way – that the practice of all the “lessons” I am putting forth will take time and patience to integrate...and there is always more.

If **participation** is the explicit goal of working with John, what does that really mean, how is it different from having the goal be compliance. So, we have a task, say washing dishes, and the task can become an obstacle to our continued relationship or it can become a vehicle for our continued relationship. My overall approach is relationship based and thus our relationship is of primary importance for several reasons. The first is that John probably has no friends, only staff/ boughten relationships in his life aside from maybe some other people with disabilities. My experience is that staff have come and gone, and that John has learned to be anxious or

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suspicious of new staff coming into his home. What John has most likely learned is that staff are people that make him do stuff. They may have told John that they really care about him, but then often have left without even saying good-bye, never to be heard from again. That hurts. If I am to work with John towards finding equity, trust and fairness between us, I need to understand that he may not be all that eager to work with me. Fair enough. So, from the outset I need to be clear about my role and that is not to necessarily become John's friend but to put forth a vision of bringing other people, peers not paid staff, into relationship with him.

Secondly, John may need to learn how to be in a relationship that is built upon a foundation of his feeling safe, valued/loved, and for him to experience a sense of fairness about moving through his day with me. Third, I need to be someone who John looks forward to seeing and hanging out with. The mantra I learned from John McGee is "What does the onset of my presence signify to John?" Wow here comes Yeiter!? Or Oh no, here comes Yeiter!?

Fourth, I need to discover and understand what is important to John and become his ally in creating a pathway with him towards actualizing what is **important to** him. An entire lesson, Lesson 11, is devoted to this. In brief, there is what is **important for** and what is **important to**. Important For is health and safety, brushing your teeth, taking your medications, going for doctor visits, the kinds of things that most agencies and parents will prioritize. Important TO is about what you really want out of life, things that are fun and fulfilling like dating, learning how to drive a car, travel, playing sports. If I am helping you to get what is important To you, which sometimes requires some advocacy on my part, then

there can be a greater sense of a partnership.

And fifth, it is John's life not mine, his dishes not mine, and I need to find a way for him to see that and to find the meaning and satisfaction in participating in his own life. All too often staff think that their job is to do everything for the individual. This creates a huge problem over time in that people with disabilities grow up seeing staff as their slaves rather than as their teachers and supporters. Case in point:



Dan

I worked with one older gentleman, Dan, who would "take" his staff to the grocery store and walk around pointing out items he wanted whilst the staff person pushed the cart and took the items off the shelf and put them in the cart etc. When we got to the checkout counter, it was the staff's job to put the items from the cart onto the conveyor belt while Dan paid for the groceries. Then he simply walked out of the store towards the car expecting the staff to bring the groceries out to the car. This manifested in almost every aspect of Dan's life in his home as well. Staff did the cooking, cleaning, mowed the lawn, took the garbage out, etc.

Dan was perfectly capable of doing all of those things himself without any support. However, the problem came to be that if staff refused to comply with Dan's mandates, he would start yelling at them and become quite violent and destructive. So now Dan is seen as a behavior problem requiring some massive behavior plan along with medications to control his "mood swings."

In essence the staff/program had created the

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problem by doing everything for Dan to the point where he was no longer participating in his life. From his perspective staff were not doing their job and he would get quite upset about that. To exacerbate matters further, he would often call his mother and let her know that he was out of tissues for example and that the staff were refusing to go to the local store to get him some more. She would in turn be upset with the staff for not doing the simple business of supporting her son effectively. The behavior plan was to address Dan's being violent but did not address the underlying cause or set of dynamics set into play unwittingly by the staff.

So often in human services, staff get this idea that they are there to "serve" the individual versus teaching them. This is actually a huge problem in that not only does the individual learn that staff are more or less "slaves" but robs the individual of their proper roles in living their own lives and having responsibilities. At the very least they should be participants in their own lives.

The final point I would make here is that whatever happened to the idea/expectation that individuals like Dan, could learn how to do things. Marc Gold, demonstrated back in the 1960's that people who appeared to have severe retardation, could learn to drive cars, do their own laundry, dress themselves, etc. given effective teaching. Rarely in all of my years did I find direct support staff, Special Education teachers, aides or parents who knew how to teach effectively. By and large the service system including Special Education did not hold this expectation or provide the training. It always seemed to me, long before I became enlightened via Social Role Valorization and Gentle Teaching, that people who were labeled with mental retardation would obviously require people in their lives who knew how

to teach - that this notion seemed to be a foundational component given the nature of their disability.

Back to the dishes. If we are going to teach Dan how to do the dishes we first need to get our act together beginning with knowing how we are going to teach him how to do the dishes in a way that will ensure his success. We must get organized and prepare by first constructing a step-by-step plan. This is called a Task Analysis. Basically, I could take a video of someone like a friend or my wife doing the dishes and then simply write down the steps I see in the video. This will take some guesswork initially to gauge how small or large the steps will need to be. I have seen toothbrushing task analyses that have been 100 steps and some with only a few steps. A recipe is a good example of a task analysis.

I enter into this with the understanding that my plan will more than likely need to be revised. What I learned was called the Plan, Do and Review process of teaching. I need to embrace failure and see it indicative of the need to always be prepared to refine and not get hung up in being too invested in my beautiful and perfect initial plans. I need to do all of this with some idea as to what it is all going to look like when I am done, the vision. Perhaps a vision might be for Dan inviting someone over for dinner, they prepare a meal together, enjoy the meal and then one washes, one dries the dishes. How often for example had Dan ever invited anyone over for a meal? Never, not once.

Knowing Dan, I also need to consider how I am going to initially support him in the task, what sorts of prompts will I use: verbal, gestural, visual printed or pictorial guides, or physical hand over hand prompts. It is often helpful to have the process laid out in print or pictures

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so as to reduce the chances that Dan will see me as the giver of demand. I need to think about the teaching environment in advance to ensure I have everything organized in terms of materials. The task needs to have a clear beginning and ending such that the individual knows when he/she is done. Initially, the task might be of shorter duration. How is this teaching session going to be part of a “flow” of what happens before and after the dishes. The dishes are his and I am there to help him learn how to wash them in a way that gives him a sense of accomplishment and success. Most importantly we need to do the task together. This is not about independence but interdependence.

And lastly, I need to carefully consider my posture. Is this going to be fun, interesting, maybe a little silly...Will Dan experience being successful, feeling good about himself, have a good time? I need to keep the focus on relationship, the goodness of being together and not allow the task to become an obstacle between us when it should become a vehicle for us to be in relationship – Dan washes, I dry and we talk about how his favorite sports team the Red Sox are faring in the season not just about the dishes. (Imagine doing the dishes with a friend or your spouse and the only conversation is about the dishes.)

The key element in all of this will be carefully understanding how important it will be to replace compliance with participation as the goal. I have done all my homework and now I am eating dinner with Dan and it is time for him to bring his dishes to the sink. I know from past experience that staff have done this for him and he will just sit there and refuse to do what is asked. And why should he? Hmmm. Maybe if I ask him real nicely. Nope that didn't work. What if I say, 'Dan why don't you bring

your silverware over to the sink and I will get the rest.' That seemed totally fair, right. But Dan just sits there, now starting to show some anger and possibly throwing his plate against the wall. Now what?

Here is the moment when I must be clear in myself. What is participation...it is Dan doing the task WITH me. What is the smallest way that he could do the task with me? I mean really the smallest way. What if when I ask him to do the dishes, I ask him if he wants to bring his dish up or if he wants me to do it for him. If he says “you do it”, what is that???? Is it participation? YES!! What if he says nothing... maybe he looks at me when I ask...is that participation, YES!!

The key is to continue to shape participation in the direction of Dan doing the task with me every step of the way from bringing all of the dishes over to the sink to washing, drying and putting them away. I essentially require him to participate. He needs to know that he is not off the hook. I will be fair about the process but I am looking for him being able to do all of the steps of the task WITH me. I will do my best at making it fun and interesting, I will give him constant positive feedback and make participation powerful and I will continue to review my teaching sessions, ideally on videotape/smartphone etc. and refine the plan.

- I want the task to be a vehicle to our having a relationship, not an obstacle.
- And what is most important here, the task or our relationship? (Hint: not the task)

When the task does become an obstacle to relationship, what might we do then? In short, I put the task to the side and just sit with Dan and enjoy the goodness of being with him. But I continue looking again for participation.

An example might be that we tell him what an awesome sweater he has on, and he smiles or looks at me or says “yeah, I know” ...what is that? Participation! And again, I make sure that I make a big deal out of that moment. I lead the emotional dance. If Dan gets irritated and is starting to behave like a thundercloud, I do not follow him down that rabbit hole emotionally, I do not let him lead. I smile, use any touch gently, avoid giving demand or correction, I help him feel valued, safe and good about himself.

If I can get to a place where we are actually having a fun time, then maybe we can get back to the dishes and say something like I did before, “Hey this list says that we need to do the dishes and then we can watch some TV or we can go outside and I can whoop your butt in basketball!” I try to not ask simple yes or no questions because we can get stuck there if he says No. The specifics of what I might say will vary with the individual, where they are at in the moment and this requires some judgment. It is also a skill that I gradually master over time and so expect to make mistakes and learn from them. This requires a very different mindset for me and it may feel a bit awkward — that is natural and totally ok.

As an outsider observing this, it will look crazy. “What are you doing telling Dan he did a great job doing the dishes — you did the dishes!” But if he did .5% of the task he is participating, right? ... that is our goal. Dan did the dishes!

This approach is also effective regardless of place. Dan could run off to another room and he can still participate in doing the dishes.



Rick

My maiden voyage with Gentle Teaching

I already mentioned my work with Rick at a Taylor Rental Store. Our first day on the job he sat full lotus near the door leading out of the basement (I had it closed) and the dishwasher was about 30 feet away on the other side of the room. I would bring a dish and a washcloth over to Rick and ask him if he wanted to wipe the dish or wanted me to do it. I held the washcloth out and he took it and threw it at me. AWESOME! (participation!) After a few hours of this in a hot steamy basement, Rick was taking the wash cloth and handing it back to me nicely. “Rick, you are so freaking AWESOME, you gotta let me give you a hug!” And so, he stood up and let me give him a hug. I thought maybe just maybe he might walk over to the dishwasher with me...but as soon as he realized we were heading in that direction, back down in the corner in his full lotus again.

It took several weeks, 30 hours a week but Rick eventually was doing the dishes with me, and he was doing the majority of the tasks involved. The critical point is not independence with him doing it all by himself; the critical point is doing it **together**, interdependence. More fundamental is that Rick learned that he could trust me, that he felt safe with me and we looked forward to and enjoyed working together. There were certainly bumps in the road, days when I thought I had lost him, but on those days, we just backed up a bit and I would need to remember why I was there.



Participation as a goal is a means to an end — an end that we now need to discuss at some length as well. Participating with me

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as his staff person was necessary to lift Rick out of the deep hole he was in where he was reportedly hurting people and/or himself on a daily basis. His eligibility for this employment grant project was predicated on his being considered to have a severe intellectual disability as well as severe “behavior problems.” In other words, he was considered incapable of being competitively employable. The documentation provided to me indicated that Rick had a number of “undesirable behaviors.” These behaviors had purportedly led to Rick being in very controlled behavior programs both residentially as well as a day habilitation program established mostly for other individuals with reputations for being difficult. Rick had never had the opportunity to hold a job. The grant was funded as a trial balloon with the firm belief that there was a place in the world for everyone. Rick was employed full time at Taylor Rental for 3 years.

There was previously little chance that any Jane or John Doe citizen would be interested in hanging out with Rick. It certainly had not happened thus far and he was at that time 24 years old with no future to speak of. And so, in the next chapter I want to get into the real goal of our work which is to help people permeate the disability bubble that imprisons them and to have a relationship with a citizen/ a regular “neurotypical” person in the real world, which requires, as noted earlier, holding the belief that there is a place in the world for EVERYONE.



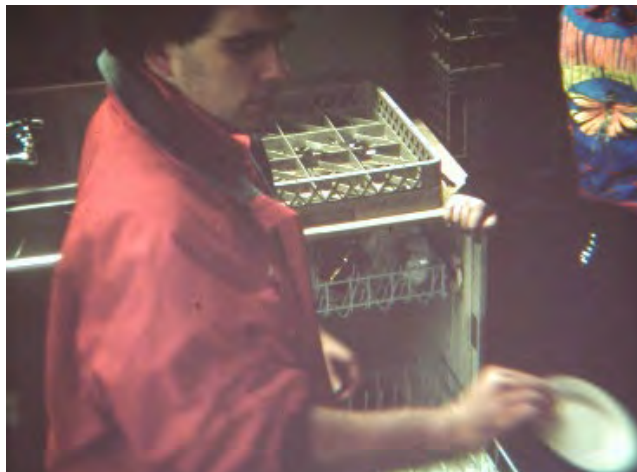
Lesson Nine

What's the Point or Why Bother

Friendship is a thing most necessary to life since without friends no one would choose to live, though possessed of all other advantages.

—Aristotle

We can master the whole notion of participation where Rick can finally do the dishes, but sometimes I have to wonder, so what? I have often been relatively successful in the short term of addressing significant issues of behavior only to have this gnawing sense of a deeper failure. I think I learned this lesson a long time ago when I was working as a behaviorist in the institutions as I mentioned previously. People can finally dress themselves but what does it matter if they are not going anywhere but the inside of a 40'x60' ward? Rick can do the dishes but is anyone coming over for dinner? Jay is no longer burping, farting or swearing out loud in school, but he is still spending his entire school day in his 1:1 classroom.



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To finish the story about Rick at Taylor Rental, as he began to experience success in his work washing dishes, I sought out other opportunities for him to learn how to do other jobs in the store and to start to draw the other employees into a working relationship with him. Actually, this kind of happened by accident. I was attempting for the first time to “teach” Rick how to help me load some long conference tables into the truck for delivery. I would have him put his hands under the end of the table to prepare to lift it, but by the time I got to the other end, his hands were by his sides. It was a bit like a Laurel and Hardy skit. However, in the midst of trying to figure this out with Rick, Eric, the boss’s son, walked by and said, “Hey Rick I need you to help me load these tables so that I can get out and deliver them.” I think I was probably standing there with my mouth open as Rick, without hesitation, now helped Eric load 24 long tables into the truck. And then to top it off, Eric asked me if Rick could go on the delivery run with him to unload the tables. There was only room in the truck for two people. Conclusion: LIFE happened and I needed to get out of the way. We had been working at Taylor Rental for 2-3 months and had never been apart. I was Rick’s staff, Rick’s teacher. Eric was the real world. I knew that I was simply a bridge to where the action was for Rick!

Rick’s treatment plan required 24/7 1:1 support; I am almost certain that if the management of Rick’s residential program or worse, the service coordinator, had found out that I did not go with Rick and Erik, I would have lost my job. There is a principle that has gotten lost over the years called the **dignity of risk** (by Bob Perske). In an increasingly liability driven system, this is often seen as a dangerous idea. The other important consideration is our judgment as to it being a

“reasonable risk”. . Rick really liked Erik who was a responsible and mature employee at Taylor Rental. More importantly, Rick made the decision to help Erik load the tables and agree to go on the delivery with him. I just knew that Rick would not engage in difficult behavior or attempt to run away; I also knew that Erik was not the type of person that might irritate Rick to do so. But yeah, there was a risk. (I was sweating bullets until they returned an hour later!!) Erik stopped at Dunkin Donuts and got Rick a Diet Coke and a donut on the way back.)

After this incident or “teachable moment” for me, I started to work harder at connecting Rick with other employees in a variety of tasks and fading out of the picture. I also did a couple of other things. I really wanted Rick’s parents to see that Rick was capable of employment. With the approval from Rick and the owner (Max), I arranged for them to visit. When I had met with them at the outset of this project, they were very skeptical – had essentially been convinced by the system that Rick would never be gainfully employed because of the severity of his autism and behavioral issues. This had the added bonus of Max becoming even more personally invested in Rick’s success at Taylor Rental which gave me the idea of inviting the local newspaper to do a personal interest story about Rick at Taylor Rental.

Taylor Rental was (is) a franchise and there were many other stores within this area of Massachusetts. The owners of all the stores would meet monthly to discuss a variety of business-related topics. After the article came out, Max returned to the store from a corporate meeting so excited because the other stores had seen the article and wanted to know more from Max as to how they might be able to employ people with a disability.

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Photo/article in Leominster, MA newspaper circa 1996 headline reads: **WORKER WITH AUTISM DOING WELL ON THE JOB**

When Rick was hired to work at the store, I noticed that everyone there had on red Taylor Rental polo shirts, black pants and black steel toed shoes. I purchased a set of clothes for both Rick and myself as his job coach. Max purchased the jacket for Rick as a gift. This may seem obvious, especially in looking at the above photo, but I have seen many employment sites where the person with the disability and the job coach were dressed differently from everyone else. Rick was also very attached to his Star Wars lunchbox but I managed to convince him to use a more age appropriate lunchbox for his work at Taylor Rental.

The other lesson learned was that I needed to get out of the way, as just noted. The general public did not know that I was a staff person and Rick a client, but the staff certainly knew this. I did not want Rick to be in the role of a *client* at his job. It is very hard to break that perception once established in the minds of the other employees or in Rick's self-image. I am not sure how Rick could have moved beyond his behavioral issues without my involvement; but with the above 'table incident' with Erik, I knew it was time for me to get out of the way. I worked with my Executive

Director and Max to work out a financial arrangement between my organization and Taylor Rental where Taylor Rental would hire an additional employee (see previous photo – man in background) who would be paid via funding from both Taylor Rental and the funds provided in the contract for Rick by the MA Department of Mental Retardation. I would provide some initial training for this individual (who was interviewed and hired by Max) and then turn him over to Max as a full-fledged Taylor Rental employee. There were times when he would do certain jobs with Rick but his primary role was to coordinate Rick's working on different jobs with the other employees there. It was not perfect but it worked much better for Rick in terms of him coming to see himself not as a client but as an employee.



Rick's first day on the job at Taylor Rental



I have worked with a lot of people in community services over the years. I cannot think of a single one of them who had a friend outside of a staff person or another person

with a disability. This was often true when people lived in institutions however. One writer, Dufresne, refers to it as the disability bubble or service land. In that bubble, which floats in the very midst of community, there are only staff and clients.

When I would meet individuals with a disability and ask if they had a friend, I would then also ask the staff and parents around them why the individual did not have a friend outside of staff or others with a disability — sadly, the answer would often be “Who would want to be a friend with someone like Glen?” Typically, people would say this almost apologetically, as if to say they did not personally believe it, but that it was just a fact.

In almost all cases, be it in school or in adult services or with children living at home with their parents, the idea was that despite the above belief, people with a disability needed to get out into the community a minimal number of times per week. This was a good start, but what I observed was what this often meant was going for a walk in the park, stopping at McDonald’s for lunch, maybe a trip to the grocery store, or driving around town. Sometimes this would be individually, sometimes this would be with several other people with disabilities. The focus was not on trying to connect with individual citizens in the community but just a broad shotgun approach of exposure. Staff in general often saw their job as being the individual’s friend and did not see their mission as facilitating individual relationships, and in fact had not been educated or supported to do that kind of social work. It was not stated (e.g., job descriptions) as being the focus of their work. Instead, the focus of their work was often (unstated) care, custody and control, as it had been in the bad old days of institutions. Keep people safe and healthy, protect them from harm.

I remember working with one child, Brian, in the first grade who had significant physical and cognitive disabilities sitting at lunch at a table with several neurotypical children. He was having a difficult time opening his bag of chips and his aide was a short distance away getting her lunch. The girl sitting next to Brian noticed his struggle and offered to open his bag of chips but hesitated as the aide approached the table to also sit next to him and asked the aide if she could open Brian’s bag of chips. The aide’s response was ‘*no, but thank you, that is my job*’. None of the children at that table interacted again with Brian during the half hour lunch period.

One family I worked with had a son, Nathan, who loved to take photographs in his backyard. In meeting with the family, we were discussing the fact that Nathan, now 18 years old, did not have any friends, so we started to explore how and where and with whom he might connect with who also enjoyed photography. After considerable struggle to get a few ideas up on the board, the father noted that their next-door neighbor, who lived less than 50 yards away, was the manager of a photography store in town! They knew of this but had never met him despite the fact that they had been neighbors since before Nathan was born. Hmmmm? So, we discussed how Nathan might come to at least meet the neighbor and landed upon the idea of him baking some cookies and bringing them over as a gift as a way of introducing himself. We even role-played it in terms of Nathan mentioning that he was a photographer and inviting the neighbor to maybe take some pictures together some time.

When the mom and Nathan finally got up the courage several weeks later, they knocked on the neighbor’s door armed with brownies that Nathan had made. The neighbor was

thoroughly delighted and immediately noted that he frequently would see Nathan out taking photographs. And, as both the manager of a local photography store and an avid photographer himself, he wondered if Nathan would like to go out 'shooting' with him someday soon! He did not invite the mother to join them.



I did some work with a mom and her son Jay (previously mentioned) many years ago. Jay was 14 years old and gaining a major reputation for being a behavior problem in school. One of the things I suggested was to invite people that the mom and Jay knew to meet for pizza once a month, mostly socialize but also discuss if anyone in the circle had need of help. For example, one woman noted that she needed help moving a refrigerator in her kitchen. One of the mothers who attended who also had a child with a disability asked if she could open the gathering up with prayer and a Bible reading. Jay had apparently never been exposed to religion and in his talking with her about it, she mentioned that she attended the Catholic church on the island. Jay wanted to see that and so his mom brought him to church the following Sunday. Part of the Catholic tradition is to have an altar boy walk down the aisle from the back of the church holding up a pole with a cross on it. Jay asked what that was all about and his mom told him that this was the altar boy. He quickly noted that he wanted to do that and be the altar MAN.

His mom called me that night noting that Jay loved the Catholic church service but was laughing when she told me that he wanted to be the altar Man. I said something like

'well, why not?' and she proceeded to try to convince me that it would never happen given his behavior. I asked her if he had been at all inappropriate during the church service (not at all!) and that maybe we could ask to meet with the priest and discuss this possibility with Jay. So, she contacted her friend from the support group and the two of them along with Jay met with the priest who was delighted that he wanted to be the Altar Man. He noted that Jay would first have to take the course to become a Catholic and on top of that come to the church every Thursday evening to learn the routine of being an altar man. That in fact, there would be an altar boy vacancy that Spring (this was in the Fall). That following Easter, Jay became the Altar Man at the only Catholic church on Nantucket.¹³



A RADICAL IDEA

What if staff and parents were given the opportunity to discuss and explore their beliefs, what if instead of community outings, there was more of a focus on meeting specific people on their outings (e.g., the man at the Deli Counter, the woman at the check-out counter), and what if people had at least one such opportunity daily to engage with a person as opposed to simply a community outing? What if the staff or parent were thoughtfully prepared to facilitate, to the degree necessary, such meeting opportunities and were to keep track of people's names/conversations? What if the staff or parent discussed the outing with the individual afterwards and noted if they liked the person and wanted to see them

¹³ Important to note that Jay attended the Catholic classes and Altar Man sessions without his mother and never exhibited a single behavioral issue at church. I have the first occasion on video!!

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again? What if the individual with a disability had 365 such outings a year and could learn with the staff or parent what worked and what didn't work?

My experience has been that life for the individual changes significantly when they make a genuine connection with someone outside of the disability bubble, when they permeate that membrane that seems so often like a wall – life happens!

Parents and human service workers have been talking about this for over a half a century and some progress has been made for sure. But by and large we have failed. We need to start paying attention to the math, the frequency of thoughtful ventures into the greater community. Additionally, we need to educate ourselves and our staff in the basic social skills involved in facilitating relationships; we need to hire staff who have social skills of this order and be clearer about their fundamental role.

Perhaps the greatest fear of parents is expressed in a major question: What will happen to my son or daughter when I am/we are gone? My answer is that the sooner they get to work challenging their own beliefs and making the above practice standard operating procedure, the closer they will move towards The Answer, which is having other people in the individual's life. The time to start that kind of work is when the individual is a baby, but as the saying goes, the best time to plant a tree is now.

I worked with the Community Membership Project in western Massachusetts for a couple of years back in 1996 or so. The specific intention of that project was to address the above question for families with an adult child with a disability. One family I worked with was a Japanese mom whose husband

had just passed away and she herself was over 80 years old with a 50-year-old son with a disability. She was worried sick that her son might end up homeless or be institutionalized when she passed away. After meeting with the mom and her son, she agreed to my facilitating a family meeting of relatives, friends and neighbors including her other two sons to discuss her fears and work to develop some strategies and safeguards. At the very outset of this meeting, after she was invited to express her fears, both of her other sons vehemently stated that they would **of course** take care of their brother when she passed away. They immediately shut her down when she tried to talk about not wanting to burden them. The experience of this project for the three of us that worked on it was that quite often when we brought people together and posed the problem, they solved it.

A friend of mine who does a great deal of relationship building work calls this "gentle arm twisting." It does not always work but it works enough to warrant consideration. It takes a bit of encouragement, courage, and boldness, but nothing ventured, nothing gained. As Aristotle pointed out over 2000 years ago, not having a friend can be quite painful to the point of questioning whether life is worth living, even if you have everything else life has to offer.

One pointed example of gentle arm twisting: Glen, mentioned earlier, was out in his local community at the post office one day with his staff person, Emilee. Emilee had been a student in one of my classes about how to support people with a disability. While at the post office, an older man, Butch, who had retired from working at the town recycling center (one of Glen's favorite places to go) remembered Glen, said Hi to him and in the course of their conversation, noted that he

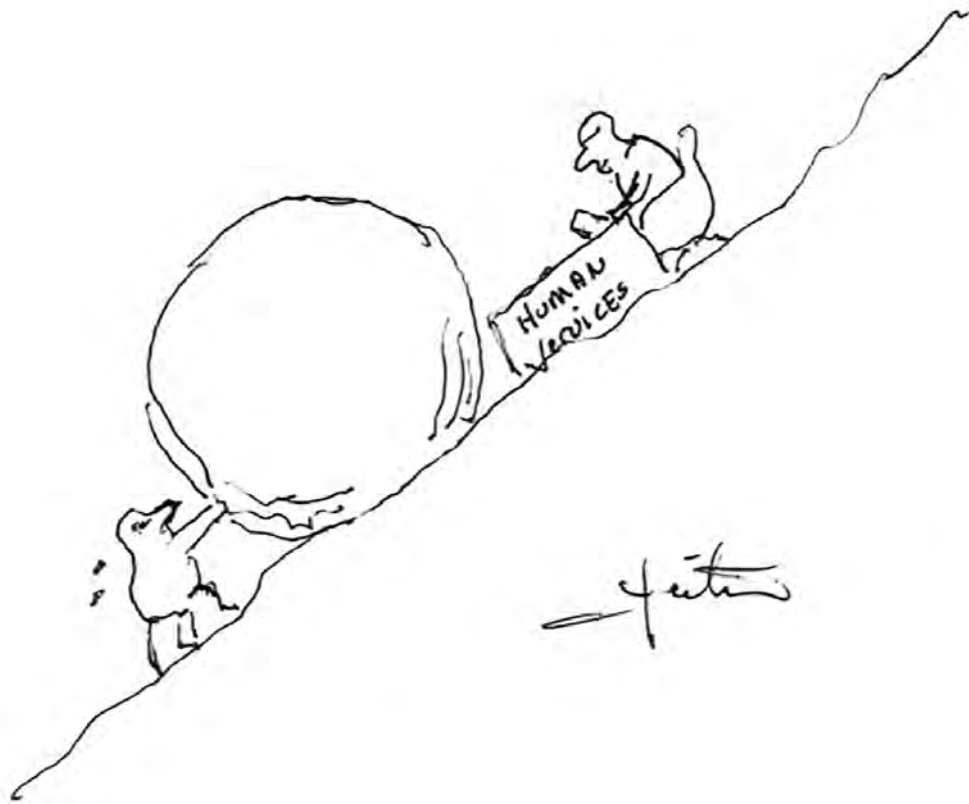
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often had cookouts at his home on Saturday nights and that he should come over some time. I suspect it was stated similarly to how people often say Hey, Let's have lunch someday, but don't really mean it. Glen did not respond but Emilee did and asked for Butch's phone number, noting she would talk to Glen about the idea and that he would get back to him. That following Saturday, Glen went over to Butch's house for a cook out. During that time, Butch invited him to go fishing with him. Glen loved fishing. In short, Butch and Glen became good friends. This was by all accounts, Glen's first real friend in his entire 62 years. The personal transformation in him was amazing. Perhaps Butch was sincere in his invitation but had it not been for Emilee's boldness and gentle arm twisting, it would never have happened.



Lesson Ten

The System



I sort of bumped into “the System” within my first few weeks of working in human services. As noted earlier, I had taken a job as the only male attendant on the second shift in a building with 150 women all of whom were considered too violent to live anywhere else.





Life on the four wards was pretty awful, beyond words actually. There were no decorations, not enough wooden benches for everyone to sit down, the windows all had metal screens to prevent the residents from breaking the windows and the bathrooms were often locked, again because they would try to stuff all sorts of things down into the toilets to create a flood. One television up in the corner of the room so that people could not reach it, screened in barely audible for all the noise on the ward. The wards all smelled of urine and feces, everything felt and looked dirty and dark. No place to hide. Nothing to do.

I cannot remember where I got this idea, but one day I brought in several cans of Barbasol shaving crème at my own expense and invited several of the residents on this one ward to go down to the (also barren) activity room in the basement and make shaving crème sculptures. I did tell the female attendant on that ward what I was doing. However, I had not gotten formal, official permission from the Charge Nurse, a very large and formidable woman. Suddenly the door blew open and it was her yelling at me, “Mr. Yeiter, what the hell do you think you are doing!!! Ladies, get back up the ward right now!! And Mr. Yeiter, if you want to keep your job here, don’t let me ever find you doing something like this again!” She could scare the hell out of someone just by looking at them let alone her fierce voice. Without realizing it, I had apparently bumped into the system.

I think one of the things that happens when you work inside the system is that you find yourself having to compromise, and often wondering if you just sold out! More times than I care to admit, I chickened out or

rationalized my way out of taking a stand. When you do that, it eats away at your liver. It is not a good feeling. Cowardice, shame, guilt, betraying the people you purport to be supporting – all feelings that well up and make you want to quit the job. I often felt like I had sold my soul to the devil. Always hard to discern when to take a stand and when to let it go. I have taken my share of stands and been fired just once, come close many times, but over the years I know I lost a chunk of myself. You do learn to pick your battles, but it is never easy.

The system is not all bad. I think quite often we tend to blame the system’s badness on individuals, typically the executive directors, but others as well. I worked for a large regional agency, let’s call it the ABC agency and a good friend of mine would often criticize it severely. I reminded him that I worked there – was he talking about me?

I think that the problem with most human service systems is that the people who promulgate (love that word?) the rules and regulations, are the farthest away from the individuals and families being served/ supported. Always great intentions, but we know where that road leads.¹⁴ A great deal of it tends to lean in the direction of avoiding liability. Despite all of that, the system does provide a mechanism for good people to do good work or at least try to.

In terms of “burn out” or the high rate of turnover in human services, I think it fair to say that it is not the fault of the clients or students but of the systems that are funded to support them. Paperwork, regulations, mismanagement (or often No management),

¹⁴ The road to hell is paved with good intentions.
Corollary: The road to hell is lined with billboards with human service mission statements.

no leadership, liability, typically poor pay and benefits (unless you happen to be the CEO) and very little if any substantive training/education for 'front line' staff to name a few.

The smaller an organization, the more it has an explicit and shared values system, the more involved the administration and management are in the daily operations of actually working with the people served, the better chance that it has for being somewhat morally coherent... living the values and beliefs that it espouses.



Brian

The very first consulting job I had was working with a child labeled with Autism and behavioral difficulties in a large public school system. Brian was a 6-year-old boy supposedly raising hell in the first grade and because of all his behavioral issues, the school was "encouraging" the parents to have Brian stay back in the first grade with a much more restrictive behavior plan the following year. I spent the better part of a day observing Brian at school and meeting with the aid who supported him.

The aide was a single mom with two children of her own living in a trailer, barely able to make ends meet. She was a high school dropout, and beyond a basic overview of personnel policies and school rules had not received a stitch of orientation or training or education about how to support people with autism let alone people with autism who had behavioral difficulties. The school year was half over and she had never (NEVER) received any supervision from her supervisor, the Special Education Teacher, assigned to Brian. Nor had she received any support despite the

fact that Brian was turning over chairs and desks in his inclusionary classrooms. What was happening were weekly meetings of the Inclusion specialist, special ed teacher, the classroom teacher and the SPED director to purportedly discuss Brian's recent behavioral incidents and come up with strategies for the aide to implement.

When I arrived at the school I was taken to Brian's classroom where all the students were engaged in taking turns reading a Disney story whilst Brian sat in the middle of the classroom with his aide, matching words to pictures, e.g., picture of pants to the word "pants." When I met with the aide she noted that she had been up late the previous night cutting out pictures and making up cards with the words, an assignment given to her by the special education teacher assigned to Brian. Brian was included right in the middle of the classroom but he may as well have been in another part of the building.

At recess, EVERYONE went out to play EXCEPT for Brian who stayed in the classroom and was supported hand over hand to place the next period's work assignment on each child's desk. The aide noted the needed to use the bathroom and wondered if I might hang with Brian for a few moments. During that time, some of the children came back into the classroom. Immediately 4-5 of them got Brian out of his chair and took him by the hand to the front of the classroom where they helped him pick out a book to read and then assisted him back to his desk where they took turns reading aloud to him and asking him to point to the pictures on the page when relevant. (Inclusion!!!) All was fine until the classroom teacher suddenly entered the scene and very loudly ordered the children to return to their seats and leave Brian alone. (Exclusion!!)

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The reason I am telling you all of this is that the most important organizational person in this whole equation was the aide who was poorly paid, unsupported, not supervised, untrained, and of course, blamed when anything went wrong in the classroom. In my experience, this was the norm, not the exception. When I tried in various organizations to advocate for more education for direct support staff, the answer I invariably got was 'Why waste our resources on people who are just going to leave anyway?' Staff turnover was and remains a major issue. My experience has been that genuine and valuing educational and support opportunities is in fact the antidote to the turnover issue and to the notion of staff burn out in general. (As one writer put it, people are not burning out, the problem is that they never caught fire in the first place.)



I want you to imagine the very large system of human services and think about all of the various college programs geared towards preparing social workers, psychologists, administrators and managers for it. Consider the millions upon millions of dollars that pour into it for those positions, the cost of office space, computers, photocopiers, technology; and then imagine way down the pipeline, the direct support staff person, who gets maybe a one-day orientation, a minimum wage without benefits who goes to work with a young man who has a complex disability and severe behavioral issues. If he/she does not know how to teach, how to support the individual effectively, has little involvement in the decision making around goals and vision for the individual (which are often made by the people who know the least about him/her),

the whole system above that direct support worker is rendered almost useless. In short it just does not make any sense!! It is an elaborate design for failure.

Many of the individuals I have worked with who had reputations for difficult behavior, were supported by service contracts with a budget between \$150-250,000/year. Clearly, money was not the answer.¹⁵

After 12-15 years of this, Brian will be no more ready to enter the world with the rest of us than he was at the outset of his education. In fact, he may be even more "disabled" by the system by not being included with neurotypical children, by experiencing failure over and over again not because of his disability but because the people supporting him did not know how to teach or value him as a learner. What he will be ready for is the adult system of services.

In 2011, a good friend of mine, Robin Carlson, heard of a course for direct support staff that had been developed and was experiencing strong success down in GA. The course was developed primarily by Joy Eason Hopkins but with a great deal of collaboration/input from people like John O'Brien, Beth Mount, Rick Strickland and David Pitonyak. In short, Joy agreed to give the course to NH via Robin and myself. Robin and I taught this course several times at community colleges in NH. One of the major requirements of Joy was that the course be taught **outside of** the human service system in a higher educational setting.

Our experience in teaching this course (4 hours/week for 20 weeks) was that when direct support staff were given the opportunity to be educated in the basic components

¹⁵ The average cost for securing a bed at Monson State Hospital back in 1971 was well over \$100,000/year.

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of providing good support, amazing things happened, good stories abounded.

“Even the shy and the self-conscious among direct support workers have communicated powerfully when they are part of a group of learners invited, assisted, and celebrated for seeing beauty in those they support, walking in beauty with those they support into new opportunities, and communicating with beauty that which they have learned.”

John O’Brien, “An Ethics of Possibility” 2007

The point of this discussion is not to discourage direct support staff or families from working in and/or with the human services system but to provide some foundation for understanding why it is often so frustrating to do so. It is not that the people working in the system, including the highly paid CEO’s, are evil people/the enemy, but they are so often unconsciously colluding in a broken system and simply do not see it – and if they do, they are afraid to challenge it lest they lose their jobs.

A German Philosopher, Friedrich Nietzsche once noted: *“Beware that, when fighting monsters, you yourself do not become a monster...for when you gaze long into the abyss, the abyss gazes also into you.”* In other words, as it often becomes necessary to fight the system, be careful and guard your heart. It is easy to become embittered and blame it for all your troubles in supporting someone served by it. It is helpful to stay mindful of the fact that the people in it are often good people who may be trying to make it work too.

However, advocacy with a passion for social justice is its necessary medicine. Just be aware (and beware) that advocacy can incur a cost.

Taken from: Closing the Gap Between Vision and Reality: Building Person-Centered Organizations, Bruce Blaney “

The defining patterns of the (organizational) model (for most human services) include:

- A top down and segmented hierarchy
- The marginalization of direct support staff in roles as sitters, attendants, aides, and skills trainers.
- The exclusion of direct support staff and people supported from empowered roles in supports planning, design and implementation.
- Mid-level staff formulate and write plans of support, assign plan objectives to direct support staff and monitor direct support staff in carrying out objectives.
- Plans of support focus on health, safety and skills training.
- Plans of support do not focus on the Five Accomplishments (Community Presence, Community Participation, Choice, Contribution, Valued Roles)”

I am less certain about our capacity to change the system but convinced that we can still manage to do good for the “consumers” of

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that system one person at a time, lest they become “consumed” by it. Education is the key in my experience. As I think I noted earlier, we do not have to be victims of this failure of the system to educate us. The resources of the internet let alone our local libraries, are readily available to all of us. This monograph is in part an attempt to put forth some of the more critical elements of providing good support. On this foundation there are books and resources listed in the appendix as a solid starting point for educating yourself.

There is a great article among the resources listed in the appendix entitled Lao Tsu, Entropy, the Coroner, Problem Clients and Lost Dreams by Richard Brueggemann. In it he notes that organizations are subject to entropy (2nd law of Thermodynamics) which indicates that a glass of boiling water and a glass of ice cubes, if left over night, will be at the same temperature the next morning. In order to get the water back to ice or boiling requires energy. For organizations, entropy means that “...growth, development and

expansion are often followed by a period of complacency and comfort followed by decline, decay and defeat.” (p2) What is needed to stay or return the original state is energy, and for human service organizations that tend towards cooling off to a level of comfort, this would involve applying heat in the form of advocacy, critique and a willingness to engage in conflict. Most of us require a loving kick in the pants during our lifetime, some (like me) more than others.

I have not been all that successful at engaging in systems change but believe that one person can make a difference one person at a time. There is of course the Gandhi saying “Be the change that you want to see in the world”, a belief that says that change begins within each one of us.



Lesson Eleven

Important To

One of the things I did not learn until relatively recently is this idea of what is important TO the individual you are supporting. Before I go any further, just let me say that we spend the vast majority of time and resources supporting individuals in what is important FOR them, which boils down to health and safety. This is of course a good and necessary practice especially for individuals who have complex medical needs and limited capacities to tell us when they have a stomach ache etc. Also, important, of course to support them so that they do not get run over by a car or try to leave their home without clothes on, etc. Liability usually gets intertwined with this class of needs, in particular the liability of the staff or caretaker if something bad happens like taking the wrong medications, eating handfuls of donuts when they have a swallowing issue and the like. What is important TO the individual is not health and safety typically but the things, people and dreams that make our lives meaningful, our reasons for getting out of bed in the morning. It may be family, your home, a hobby like fishing, or things like having control over your life, feeling safe, being loved, having friends, having a job and some financial security. It is very individual and will change over time. Sometimes what we think is important turns out to not be so important when we get there. Nevertheless, it is an area that rarely gets addressed in the lives of people with disabilities.



Henry

I was asked to consult with a middle-aged man a few years ago who lived in a group residence. Reportedly he was doing a great deal of screaming, pinching the rear ends of female staff, throwing things around and generally being quite miserable to support. I met briefly with the program manager and direct support staff who worked with Henry, who both confirmed that he was frequently violent and stubborn. I then met with Henry over a cup of coffee in their sun room and proceeded to ask him some questions about his life story.

Henry had formerly been a practicing attorney in Massachusetts up until the age of around 30 when alcoholism started to take its toll and he found himself facing legal charges and possibly being disbarred. He left the country and went to China where he met a young lady, got married and had a couple of kids. Somewhere along the line he had a motorcycle accident (his drinking continued) that resulted in some serious injuries and some degree of brain damage. Later, riding a bicycle he was hit by a car and ended up in a wheelchair with more significant brain damage. His parents back in Massachusetts heard of this and had him flown back to the US and placed in a nursing home, despite his clear protests. He exhibited severe depression and behavioral issues which resulted in him being kicked out of the nursing home and transferred to this particular behavioral group home where he had now resided for almost two years. I asked him if he missed being with his family and tears rolled down his cheeks. He became so upset that it seemed he would burst, could not speak and made a fist and shook it at me.

What was important TO Henry? It took me

less than a half hour in conversing with him to figure it out, and I remind you I am not some genius. I simply tried to imagine my wife and two sons being taken from me and thinking I might never see them again; and not being able to find anyone who might understand and or support me in some way to do so. Most people I have had imagine this happening to them would fight very hard to see their wives and children. What happens however when we or Henry doth protest is that the focus comes to be on the others perceptions of our behavior and of course, nothing justifies hitting, pinching, yelling at the people trying to care for you. But we forget that from our or Henry's perspective, this can become seemingly necessary because nobody is truly listening to us/him. We think we are trying to communicate more clearly our needs, our pain, our fears. Others just see unjustifiably violent behavior towards them and generally take it personally as well. Everybody involved in supporting Henry knew his story but nobody could have been truly identifying with him.

When I had finished meeting with Henry, I again met with the program manager and direct support staff to give a summary of my recommendation. In short, buy Henry a plane ticket back to China. They laughed and of course said that they did not have the authority to do such a thing, certainly not against the wishes of Henry's parents who had also become his legal guardians. I spoke with the Program Director, the Service Coordinator and finally the Regional Director, all who claimed that it was not in their "purview" to support Henry in getting back together with his wife and children. I was told that I could not be given confidential contact information for his parents and I never heard anything further. The Service Coordinator told me that she would discuss my recommendation with the parents. (I seriously doubt that she did.)

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This is a tough issue; and it illustrates I think the tension that often arises in supporting people with disabilities when we stumble upon the real problem at the root of what is being portrayed as their behavior problem. How would you define listening if I took you away from your children and/or spouse?

I would add that maybe it was unrealistic to think Henry could hop on a plane and fly back to China. The real point here is that we listen, not ignore his perhaps most important life need, side with him and try – that is all, just try and not give up.



Wolfensberger once noted that sometimes the wounds that are inflicted upon people with disabilities can run so deep that healing may never be possible. Many people with disabilities and severe reputations who I have met are so seriously wounded by rejection and the constant turnover of support staff, that they cannot trust, cannot open themselves up to once again being vulnerable to yet another relationship ending in rejection, abandonment, betrayal. Many staff I have worked with will often say to the individuals they supported upon leaving: “Of course I will call you, visit you, send you letters etc. after I leave. I love you!” –However, my experience has repeatedly been that they are never to be heard from again.

Some people with disabilities will often put forth a “test” that support people or parents need to pass: If I spit at you, will you still love me; if I hit you in the face will you still love me; if I burn your house down or hurt your child, will you still love me. Sometimes the costs

of passing these tests are just too steep or difficult for the parent or support person.

As hopeless as that may seem, it certainly would not be considerate of the individual for us to design and implement a behavior program in lieu of truly listening to their need(s) for getting back together with the wife and children. There just may not be a fix. Staff who often ask me, “So what do we do?” are quite frustrated with my response: Love them. Don’t give up in keeping their stated need, what is most important to them, front and center.

In my small sphere of practice, although over a long period of time, I have found few staff or parents who were aware of what was most important to the individual they supported. It is not always obvious what the answer is to this question, even for ourselves if put on the spot. But not asking the question can lead to great harm, from imposing behavioral programs on people to the individual experiencing a world that does not care to truly hear or listen to them.



Carlos

Carlos was a young Hispanic man with an intellectual disability who worked in a vocational program in Boston and lived with Roberta, a home provider, and Mark, another young man with a disability. I was invited to consult with the organization that supported Carlos, particularly with his vocational program. In brief, I was told that Carlos was constantly going to the bathroom in his pants. There were mountains of laundry at his home, and when he went to work, he carried a backpack with typically several changes of clothing. This had been an issue for some time despite a number of efforts to correct his behavior as

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well as medical evaluations to determine if the problem was physiological in nature.

I drove into Boston early one morning to meet Carlos and his support staff as they entered the offices of his vocational program. He was a spirited young man of small stature with a great deal of machismo I suspect to compensate for both his disability and his stature. He could not speak but had a communication book that had pictures or icons with him at all times.

Right away, the staff had to take Carlos into the men's room to change his wet and soiled clothing. As a consequence, he was told he would now have to sit in the agency conference room for the remainder of the day. Initially I was told that I would not be able to sit with him since he was being punished; but I persisted and was finally allowed to join him in the conference room.

Carlos did not currently have a job but would spend his days doing some volunteering, going for walks, riding around Boston. Despite the fact that he had some very wonderful people working to support him in life, his repeated soiling behavior was clearly beginning to wear them down. (If my memory serves me correctly, this had been going on for a matter of years.) It was particularly troublesome in that not only would he soil his clothing but the furniture at home and at work and the seats of people's vehicles. Staff had learned to cover everything with absorbent pads etc. but it was not foolproof. And so, the staff were at times rather short with Carlos, being at their wits end. To make matters worse, Carlos was not the least bit apologetic for this behavior despite the fact that he seemed intelligent and capable enough to know how to use a bathroom. So why was he

doing this?

I sat with Carlos alone in that large conference room for several hours. Initially he seemed quite angry and not interested in speaking with me and so I just sat and pretended to read a magazine. Gradually we struck up a conversation. After about an hour, I could tell that he had once again gone to the bathroom in his pants (the smell being quite overwhelming), and took a short break to go to the bathroom myself and told the support staff what had happened. I was told that by the staff that he had no more "back up clothing" and would just have to "sit in it" until he went home.

When I returned to the conference room, I asked Carlos if he ever had a job and he pulled out his communication book and almost violently opened it to a page where he pointed to an icon for money (dollar bill symbol). He then madly flipped pages to a picture of a store, then to an item (I think it was a boom box), and just sat there staring at me. I asked him where was he going to get the money to buy the boom box and with even greater vehemence, struggled to find the page where he pointed to an icon for JOB! And then he just stared at me with a look that said "Don't you get it!!?" I vaguely remember asking him various questions about what kind of job, or how me might get a job and he just kept pointing with increasing force upon that job icon!! Playing a little dense, I said, so you just want a job so you can make money to buy a boom box? He looked at me like I was a complete idiot and once again pointed at the icon for job.

After Carlos was taken home, I spent some time with the organizational staff discussing what they had been doing to support him. They noted that they had told Carlos that they

would get him a job once he stopped going to the bathroom in his pants. It seemed plain to me that Carlos had told me that he wanted a job, period! — and, although unspoken, that until he got one, he was going to continue to go to the bathroom in his pants. This seemed to be a classic example of a stand off! Neither side was going to give in.

I cut to the chase and told the staff what Carlos had told me via his communication book and suggested that maybe he was trying to say something via his behavior. What might that be? It took some discussion but they seemed to finally get it. I recommended that they meet with Carlos immediately, apologize for their behavior, and tell him that they would get him a job whether he continued soiling his clothing or not. Although this was quite a bitter pill for them to swallow, to their credit, they agreed and followed through in meeting with Carlos the very next day. They also immediately started a job search with Carlos — and the soiling issue ended that day. Case closed!

What was important TO Carlos was being a MAN. And men had jobs and made money so that they could buy things and have some degree of control over their lives. I think that this was also somewhat cultural for a Hispanic man, particularly of small stature to be so driven to express his machismo if you will. He would NEVER have given in or conceded and in fact may have continued to soil his pants and people's furniture even more if he had not gotten "his way."

I have often encountered other examples of this where people are desperately trying to tell us what is important TO them and because we do not hear them (or want to hear them) they get to the point of self-abuse. We also can get

stuck in thinking the person needs to learn a lesson, to be punished, to obey our demands. Carlos was a kind and gentle soul and would never have hurt anyone but himself. The staff were also well educated, thoughtful and caring people and had gotten caught up in a vicious cycle with Carlos, a very emotional one at that.



Why is knowing "What is Important To" important? Imagine supporting Henry and no matter what you do, he is beating the heck out of you day after day. In essence, he wants to be with his wife and children and you are possibly the *enemy* keeping him from them. Now suppose you suddenly realize what is important TO Henry and team up with him to support him reuniting with his family or at the very least let him know that you understand his situation and will do the best you can to support him. At the very least he will see you as being "WITH" him, a partner, an ally, and not a guard.

It is very powerful to be supporting an individual towards what is most important TO them when they need your support to get to it. The traditional roles of direct support staff have been all about doing the important FOR health and safety stuff. The system requires it. Certainly important, no argument there. But as a rule, people with disabilities like the rest of us want more, want to have the same piece of the pie as the rest of us in terms of autonomy/control, friends, belonging, Love, meaningful work, an income, etc. Again, traditionally, direct support staff are not hired for such purposes, and certainly not educated or supported in how to support individuals towards meaningful community goals.

Lesson Eleven

I know at some point that I will need help with the important FOR issues in my life as I increasingly lose control over my body/mind; someone to wipe my butt, feed me, help me brush my teeth, get dressed, take my medicines, etc. But it would certainly be nice if whoever was supporting me knew about my love of music, photography or making sure I didn't lose touch with old friends.

There is a simple process that we can employ in conducting some detective work towards figuring out what is truly important to an individual called *Discovery*.



Lesson Twelve

Discovery

First of all, Discovery is an adventure not a technique. It is full of risks, perils, the unexpected, excitement, challenges, successes and failures. In our support roles, this often requires judgment in terms of not exposing the individual to unnecessary danger on the one hand but not being overprotective on the other. Generally, most of us in our support roles will experience a learning curve here. It begins with a simple question: Who is _____? It starts with basic demographic info but requires us to then strive to identify with the individual in terms of their fundamental needs, visions, what is most important TO them and working to dig deeper behind the various labels and stereotypes the person has been saddled with - to gain an almost existential sense of the individual.



Lesson Twelve

Sometimes our own best adventures involve a little pain and suffering, the hero's journey! We can become lost, lose hope, fail, experience great hardship, but we move forward. Our role as a **guide** therefore is the one who holds the map, to support the adventurer with advice, encouragement and hopefully celebration.

There are a couple of levels to this work of *Discovery*. The first is to figure out with (not for) the individual what is most important to them. There are usually clues we can work with at the outset of this process. What is the individual good at (even if it is considered "bad" – an example in a moment), what do they like to do, where do they like to go, do they have any friends or people who might become friends, what are their capacities, gifts, skills, past experiences that they loved and often mention, and what are their stories.

What is the individual good at, even if it is bad? What does that mean? A couple of examples may suffice:

I once worked with a very progressive agency that explicitly encouraged staff to support people in meaningful ways beyond health and safety. They had been trying to find a job for Fred. Fred was quite articulate and physically capable but he had this one thing about him that kept getting in the way: he swore constantly and loudly, and with the strongest swear words he could muster. Finding him jobs at McDonald's, Filene's basement, or Walmart, had not succeeded simply because he would sooner or later swear in public. Even when he agreed that he would not swear, it just kept happening and the staff were stumped.

They held a brainstorming session¹⁶ with

¹⁶ Brainstorming with a team of people is a great way to solve problems. The only rule is that no idea is too bizarre or impossible – the point is to get what comes up in people's minds on chart paper and discuss them with a willingness to be a little crazy! In my experience,

someone familiar with the process of Discovery, as well as understanding the concept of *capacities and deficits* which I will speak to at greater length. But for the time being, just know that quite often a capacity can be a deficit and vice versa. The consultant asked the staff why Fred kept getting kicked out of jobs and they told him about his swearing. Swearing was clearly in the deficit column – but could it be a capacity sometimes in some places as well? Where might that be? In short, this led to the vision of Fred working on a fishing pier. Swearing was not only not an issue but a highly valued form of communication! It took a bit of work finding a job in that industry but it finally came to pass and Fred was an instant hit with the other fishermen where great swearing was considered a gift!



In a booklet on **Friends** listed in the Appendix (strongly recommended reading), there is a story of a young man who was quadriplegic and could not move or speak. He wanted a job and so his team gathered to explore where someone like Fred could actually be useful. In the process of exploring the young man's gifts and capacities, someone noted how beautiful his hands were. Hmmmm? where might that be welcomed or useful? This led to the team coming up with the idea of his being a model for an art class. The team realized that in addition to having cool looking hands,

people, especially professionals, need help with this as they will immediately throw liability or some hurdle in the way. Imagination, creativity and boldness are often what have led to mankind's greatest discoveries.

the individual could not move (deficit), which would be a huge advantage (gift) in becoming a model for art students.



Strategies of Discovery

This is a fairly straightforward but often challenging shift in process for most staff and parents. It requires some thinking, some imagination, a willingness to throw up crazy ideas and not immediately dismiss them. It takes time, patience, and a little courage. First, we need to make some notes about what the individual has as interests, skills, gifts, deficits, capacities, etc. and then start thinking about activities and places to explore and visit where those traits would be welcomed, needed, helpful.

The individual watches NASCAR on TV, has NASCAR posters, articles of clothing, but has he/she ever been to a NASCAR event or similar race car event? Are there any race tracks within driving distance, and if so, when are they open, how much would it cost to go, who might want to go with him/her. All of this is discussed with the individual. You speak with them even if they cannot respond and/or you are not sure they are understanding you. You speak with them about the idea and make note of their response. And if it feels like they are interested, you begin to make plans with them, involving them as much as possible. (remember our discussion about the goal of participation?) Quite often, your biggest hurdle may be the system which may say NO because of liability, you can't drive the individual in your car, they require a nurse with them at all times, etc. Trust me, the system will throw obstacles in the path requiring at

times some rigorous advocacy, judgment and creativity.

If you run into a brick wall, back up, discuss this with the individual and try to come up with another strategy of discovery. Maybe instead of going to a NASCAR race, trying to find someone who knows someone who knows someone who is big on NASCAR, possibly an actual race car driver. And you may need to make or support the individual in making some phone calls. "Hi, my name is Bill and I love racing and my friend Betty said that you have a very cool race car, wondering if I could stop by and meet you and see your car some time?" Perhaps you can script it better than that, but you get the idea.

And so maybe you are taking Bill over to that driver's home or garage next Saturday. I often encourage parents/staff to keep what is referred to as a Learning Log. It is not to be viewed as some formal or required form (although I find it helpful) but just as a guide for some of the kinds of information you want to record and keep track of. The important bits are:

- **What did the Person do?**
- Who was there? (Names, phone numbers and or email address if possible),
- What did you learn in terms of **What Worked well**; What did the person like about the activity, thus what needs to stay the same if a return visit is considered?
- What did you learn that **did not work** so well? What did the individual not like about the activity? What needs to be done differently the next time.

It is important that ALL of the above questions get discussed with the individual. Your job is to record his/her answers. If you are to have input you need to ask them first, "I noticed

that maybe you had a hard time with all the loud noise at the race? And if so, anything we could do differently the next time? Rule #1 is that you discuss ALL of this with the individual and make note of their responses, ideas, comments, etc. You may have observed things like they covered their ears when the cars went by, but you do not record anything in the learning log without first verifying why they covered their ears...was the noise really a problem?

The point here is to start. I have a well-worn sticky in my Day Timer: *Just do it; just do it badly; just do it afraid; just do it now!* Come up with several strategies for discovery, review them with the individual and pick one to get started with. This will become a very powerful tool of support if you keep good notes of the individual's experiences and your conversations with them about their experiences.

I once supported a young man with autism who would often start screaming and beating his head which overall could be kind of scary to witness if you didn't know him. I took him to a Gold's Gym to teach him how to swim... they also had a jacuzzi next to the pool where he liked to hang out after swimming. One day he was in the jacuzzi and an elderly lady got in as well. He started banging his head and screaming and she immediately got out and went into the swimming pool. The next time we went to the gym, she was in the pool and I went over and introduced myself and apologized that she had been frightened off. It turned out that she was formerly a special education teacher and had not been frightened at all but just wanted to give me space for working with him. I got her name, Betty, and introduced her to the young man. What was amazing to me was that the next time they were in the jacuzzi together, he started hitting

himself and she told him to stop it and he did!!

It is especially important to write down **people's names** you come across, especially if they engaged in a conversation with the individual. You are sitting in the bleachers at the race next to a guy who is clearly into NASCAR – NASCAR shirt, hat, etc. – and at some point, during the race he leans over and extends his hand towards you and says, "Hey I am Burt, is this your first time at the races?" Let's say he totally ignores the individual you are with, Bill. So, you field the fly ball and say something like, "Yes, our first time, my name is Yeiter and this is my friend Bill. Bill, this is Burt, etc. Again, I suspect you can do better than this given that my social skills would fit on the head of a pin. The important part is to get the name and write it down. If you go back to this particular race track in hopes of running into Burt again, you may want to perhaps freshen up your memory as well as your partner's before getting there. Why? Because returning to the track and running into Burt again could be the start of something huge, a friendship. Maybe down the road, Burt offers to pick up Bill and take him to the races without you.

Much of this comes with experience but you need to be ready for life to happen. Suppose I am at the race track sitting next to an attractive lady who seems to be around Bill's age and they start hitting it off? What if she invites Bill over to her house for a drink after the race? Remember I opened this topic up as being an adventure with risks, challenges, etc.? Serendipity does not fall upon us every day. This could someday be Bill's wife! On the other hand, I have no idea who she is, where she lives or if perhaps she might take advantage of Bill or expose him to alcohol and or drugs that could be dangerous given Bill's current medications. If one of the things that is important TO Bill is to meet a woman, I need to be ready, I need to have worked through

some possible scenarios with other staff, my supervisor or my spouse if I am Bill's parent, and then discuss this issue with Bill now and then.

Other strategies of discovery might include people to interview (with the individual) such as former teachers, relatives, former staff, friends, acquaintances, former employers, etc. What you are looking for are **stories** about the individual, not necessarily facts, data or evaluations. It is stories that provide a rich perspective, a deeper sense of WHO the individual is. During the interviews, you may ask to see photographs, videos, newspaper articles etc. that are relevant.



If you have not seen the movie Catch Me If You Can with Leonardo DiCaprio, it is well worth viewing in terms of one more core strategy. In addition to thinking about going to the race track as an activity, it is also important to view it as an opportunity to consider the individual's role. In the movie, DiCaprio plays the real-life character of Frank Abagnale, well known for his career as a forger, imposter and con man who before his 19th birthday, successfully performed cons worth millions of dollars by posing as a Pan American World Airways pilot, a Georgia doctor and a Louisiana parish prosecutor. Frank was able to succeed in those roles mostly by only having the appearance and some of the technical lingo of those professions.

It is thus worthy of some research and thought to support the individual going to a NASCAR race to be seen in the most positive and valued light. Our goal after all is not just for the individual to be in the community (as

discussed earlier) but to support them in connecting to specific people. How do people dress who go to a NASCAR racetrack? The one time that I went, I noticed that many people had some item of clothing on that indicated that they were NASCAR fans, mostly hats. Some people also had coolers of food and beverage with them that were either NASCAR coolers or regular coolers with NASCAR stickers on them. What are the important terms to know when you go to the race track? Here is a [list](#), put forth by NASCAR of 20 terms **you need to know** when you go to the race track. You might need to help the individual learn these. . (If you are reading a printed version of this book, simply Google NASCAR glossary.)

There is scientific, empirical evidence that there is a correlation between how people are perceived and how they are then treated. As most of us have heard, we tend to size up a stranger within 3-7 seconds. Perception (through all of our senses of taste, touch, smell, sound and sight) is always either positive or negative. Even as a baby, when Mom puts a spoon full of baby food in our mouth we will either go yum or yuk! Furthermore, this perceptual activity is generally unconscious. What has been proven is that negative perception will typically lead to negative treatment of the thing or person. Positive perception leads to positive treatment.

Historically, people with a disability have been cast into negative role stereotypes, clearly perceived and treated in very negative ways (institutionalization, seen and treated as less than human, rejected, etc.) and so it is even more important for them to be seen in a positive and valued light.

My experience has been that people with a

Lesson Twelve

disability will often go out in public dressed in frumpy clothing, messy hair, body odor, bad breath and age inappropriate lunch boxes or backpacks. Aubrey, a 40-year-old woman would carry a Tinker Bell backpack. Marcelle, a 17-year-old girl would attend high school with Winnie the Pooh sneakers, pink sweatpants and a pink Winnie the Pooh sweatshirt.

Staff and parents will often shoot back and say that it is Marcelle's **choice** to wear a Winnie the Pooh outfit. When I attended her school, she spent most of her day in a room with other people with disabilities who dressed in a similar fashion. There is also a very strong tendency for a negative feedback loop of being seen as a child, being treated as a child, and the individual then acting like a child which reinforces being seen as a child, etc. If given the opportunity to engage in the adult goods of life, such as dating, going to the race track or having a job where there is a required uniform or dress code, the individual may need some encouragement, as was the case of my work with Rick at Taylor Rental. This is not about taking away but replacing. Most of us put away our toys as we grow older to make room for the adult goods and toys! Why this is not true for people with disabilities is less about them and more about us – our continuing to see them and treat them like children, low expectations in general. If you want to discover this for yourself, just try starting a conversation about dating or sex with the parents of a teen age girl with a disability.

Given the very dark history of people with a disability, it is even more imperative for us to bend over backwards in how we support them in the various valued roles of community life. When Rick went to work, it was important for him to look GREAT.

After making sure that Rick had purchased the red Taylor Rental Shirts, black pants and black shoes along with a manly man's lunchbox, he came out of his group home on his very first day of work dressed in a Peanuts sweatshirt and pants, sneakers and a Superman lunch box. I asked the staff why Rick was not dressed in his "uniform" and they told me that this was his **choice**. Rick and I spent the better part of an hour helping him to understand that he had to wear the shirt and pants if he was going to work at Taylor Rental. We were late, but miraculously, we made it. Never an issue after that. (Rick would have been fine had the staff laid out his Taylor Rental uniform as I had instructed the house manager to do. But somehow that communication got lost. Once Rick was dressed, it was almost impossible for him to consider changing.) The photograph below of Rick entering Taylor Rental with his black lunch box was taken that very morning.



Lesson Thirteen

Vision

The notion of “vision” became quite big in the human service world shortly after our country started closing the state institutions and moving towards a community-based system in the 1970’s. A number of planning tools, some independent (ISD, PATH, MAPS) and some state regulated (ISP, IEP) came into existence with the intent of more effectively supporting individuals with disabilities to become more independent in addressing both their special and fundamental needs as well as their visions and dreams.



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What I began to notice was that the vision statements, ranging from maintaining good health to visiting the Vatican in Rome, often did not happen. The reasons for this are considerably complex and beyond my intent here to explain. But I will say that over a period of many years, I began to realize that we were engaged in a process of thinking about dreams for people with disabilities when in fact we were not so adept at actualizing dreams and visions in our own lives. There is something innately difficult about becoming a rock star or an astronaut, writer, artist, or just losing a few pounds. We all know this dynamic as when we engage the idea of the New Year's resolution.

When it comes to supporting other people's dreams and visions, things may get considerably more complicated. Moving towards accomplishing a dream is not a linear, mechanistic process. Moving towards a dream requires a consistent degree of commitment, passion, and an understanding or acceptance of failure as a learning opportunity, a willingness to get back up, learn from mistakes and try again. It also requires some degree of sacrifice.

When I asked a classroom of parents and direct support staff what their dreams were, one of them said that they wanted to visit the pyramids of Egypt. They then immediately noted that they would never be able to afford to do that. I asked them how much it would cost to visit Egypt and they did not know. But suppose, for sake of argument it would cost \$5000 to fly over and visit for a week or two? I knew that they smoked cigarettes and asked them if they would be willing to quit smoking and thus save an average of \$60/week, which would mean that they would have saved enough in less than 2 years. No comment.

A friend of mine has a daughter who wanted to play the violin, one of the more difficult instruments to master. Her teacher challenged her to practice for just 30 minutes a day for one week. The daughter was 6 years old at the time. She successfully managed to practice every day for a week and was then challenged to practice 30 minutes a day for a month. The young lady succeeded and then on her own, raised the bar to 6 months...and then to a year. Every single day, 30 minutes no matter what, she practiced.

One day, she was having a small birthday party for her dolls, lit a candle and accidentally caught her hair on fire. She was rushed to the emergency room with pretty severe burns on her head and neck. When she returned home that evening, the first thing she did was to practice despite the pain she was in. She is now, after several years, playing in a high school orchestra even though she is just starting the 6th grade.

If she had been told at the outset that she would have to practice 30 minutes a day every day for 5 years in order to successfully learn the violin, I am not sure she would have agreed. The sacrifice to forego doing things that might have been more immediately gratifying often needs to be doled out in smaller chunks.

One of my favorite films is What About Bob, with Bill Murray and Richard Dreyfuss. In it Bill plays a man with mental health issues who seeks help from Dreyfuss, a psychiatrist who had just written a book entitled Baby Steps. Essentially the book's premise is that patients can overcome their phobias etc. one day at a time, one tiny step at a time. Baby stepping.

So, for the woman who wanted to go to Egypt, the question then becomes what would baby

steps look like for her in terms of going to Egypt. The first step might be to ask Google, how much would it cost to go to Egypt for two weeks. The next step might be for her to then start to explore how much could she afford to put into a piggy bank on a daily or weekly basis, what would she be willing to sacrifice, what external supports might she want to recruit to help her, what further research, in small bits, might she want to conduct in terms of planning out the specifics of her trip? Putting things down in writing is also important in terms of what is called “concretizing” the goal.

In the work that I did with children and adults with a disability, I began to employ the notion of “mini-visions”, small, achievable, simple and short-term activities or roles. For example, Marcelle, a junior in high school was vomiting to the point where the medical/surgical solution of a J tube was being considered. She had been vomiting daily, especially in school for 2-3 years. Numerous gastroenterologists, medical evaluations, and behavioral programs had failed find a medical basis for the vomiting or effectively address this as a possible intentional behavior. (She would frequently put her hand in her mouth to make herself vomit.)

What I observed in my first-time observing her at school was a hunch that she was bored and not having fun. When I asked the team including the parents what Marcelle liked to do or might have fun doing, they really did not have much to offer. I had visited Marcelle at home and noticed that she seemed to enjoy sitting (in her wheelchair) next to her mom when baking or cooking. So, I asked the team if maybe Marcelle would like to learn how to cook or bake. The team was not overly enthusiastic about this idea but I could see that Marcelle’s face lit up when I suggested it. I proposed that I spend one hour with

her in the home economic kitchen baking something simple. Given Marcelle’s reputation for vomiting, it took me close to a month to get clearance from the Home Economics teacher, the assistant principal, the principal and finally the special education director to utilize the kitchen for one hour. (Had to sign in blood that I would leave it as clean as when we found it.)

I talked with my wife about what would be easily baked in a one-hour framework and we landed on the idea of blueberry muffins. As per her instructions, I went to the store and bought enough ingredients for two sets of muffins, one for me to practice on and the other to make with Marcelle. I wrote down the steps and gave some thought to how I would support Marcelle given that she was in a wheelchair and could only use one hand and could not talk.

That following week we successfully baked muffins and Marcelle was ecstatic! I told her I would be back the following week and we would make cookies. When I returned that following week, the special ed teacher informed me that Marcelle’s vomiting behavior had decreased by 50%! I developed a plan with the paraprofessional to do a baking project with Marcelle on a weekly basis to which she and the team and of course Marcelle agreed and asked that she videotape each of the sessions. I should note that the paraprofessional was actually my primary “target” – during the first session I simply asked her to hold the camera while we made the muffins. The second week we took turns supporting Marcelle in the baking of cookies. The third week I could not attend the baking session but agreed to meet with the paraprofessional a couple of days later to watch the video together.

During this time, I also worked on Marcelle

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getting a part time job outside of school and being involved in the determination of a job coach who would support her. The job was just a couple of hours a day at a Salvation Army store but the job coach knew how to make it FUN and focus not on the tasks as much as working to introduce Marcelle to the other employees and volunteers who worked there. Within a month, Marcelle stopped vomiting. I followed up on her for 4 years and she never threw up again.

There was no behavior plan or even focus on her behavior. One hour a week baking cookies, muffins, etc. with a focus on making it fun. Actually, the behavioral focus was on the aid working with Marcelle, to support her to see that teaching could be fun, that Marcelle could learn and that they could both be successful together.



“
Our deepest fear is not that we
are inadequate. Our deepest
fear is that we are powerful
beyond measure. It is our light
not our darkness, that most
frightens us.

”

– Nelson Mandela

Jay *(Introduced earlier p.29)*

Jay lived on an island and was one of a very few noticeably disabled individuals attending school on that island. He had gained a reputation for being exceedingly stubborn, non-compliant and difficult including such behaviors as spitting, running in the hallways,

farting and burping (many of which I myself fully enjoyed as a young man). The school was considering kicking him out to a residential school on the mainland and the mother was not ready to send her son away. The school contacted me and asked if I might be willing to consult with the teachers and help out in some way. I told them to make video tapes of the times when he was being particularly difficult and send them to me to look at so I could hit the ground running when I flew over there in a month or two.

The school had already hired a full-time behaviorist to work with Jay. His daily supports at school also included two female aids. Most of his day was spent in a separate, small “classroom” for academics and all of his gym, arts and vocational programs were also separate but in different locations. He did not spend any of his school day with regular kids. This was 1998.

When I received and watched the videotapes it was abundantly clear that a few things were happening. The aids and behaviorist were totally fried. Jay was almost totally isolated from the regular school population even at recess. The aides were nice people but quite ineffective as teachers which was not hard to imagine given that they had no formal training or support from the special education department in how to teach. His curriculum was truly boring and designed for failure albeit unconsciously. The administration of the school clearly wanted Jay gone.

He was a spirited, fun loving and very intelligent teenager. In school they were reading aloud with him books like Dick and Jane. At home, outside of school, he was reading books like Moby Dick, The Yearling, The Scarlet Letter, etc. And he loved, absolutely loved to read out loud to anyone

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who would listen changing his voice to portray the different characters.

When I arrived on the island I had two major goals. The first was to have the aides and the behaviorist watch themselves on video (although they sent me over 20 hours of videotapes, they had not watched any of it themselves.) When they saw themselves on video, (which never lies or judges), they cried – my hoped-for response. They realized how awful they had become with Jay and to their credit rose to the occasion.

The next goal was to craft a small tiny vision for Jay with his staff's involvement. Sitting at a very large meeting of administrators, school psychologists, the behaviorist, both aides, Special Ed Director, and Jay's mother I suggested that Jay really loved to read and might we create a small trial balloon of him benefiting other people with his gift/capacity. Mom noted that every Friday morning, the First Grade Teacher would have guests to read a book or story to her students. Of special significance was the fact that the First Grade Teacher at one time had Jay in her class loved him, and had continued contact with Mom and Jay over the years. Immediately the assistant principal emphatically noted that he was not going to be liable for parents calling him and threatening legal action because Jay might burp, swear or fart in that class. I then further proposed that we do a series of roughly ten rehearsals, video recording them and evaluating them with the assistant principal afterwards. Jay would pretend to be reading to the first grade, his behaviorist would be his assistant, sit next to him and do whatever he asked of her which was primarily to hold a copy of the book up to the children and point to the pictures as they came up in the story. And we would do our best to find another

student to be the video man and record each practice session. If Jay could conduct himself in a "civilized manner" throughout the rehearsals, then the assistant principal might "allow" him to do this.

The first three rehearsals started with me acting as the Principal and introducing Jay and the behaviorist to the first graders. I was there simply to role model for the behaviorist and aides how to make the rehearsals fun and to have as they say, some 'skin in the game'. We found a student who agreed to be the videographer. There were ten rehearsals recorded to share when the team reconvened the following month. The behaviorist and the aides essentially convinced the assistant principal to support Jay reading to the first graders.

I wish you could see the video of Jay reading to the first graders. He dressed up for the occasion and got a standing ovation from the kids. He sat straight and tall and clearly filled the role of a teacher. He sat in front of the classroom by himself without the behaviorist or aides.

If you will also recall the story told earlier as to how Jay later went on to become the Altar Man at the only Catholic Church on the island. Again, never a single burp, fart or swear in the church or in the first grade classroom. No behavior plan, no behaviorist or isolation from others in the church. One factor worth noting here is that creating a valued social role for Jay was instrumental in the success of this mini vision. Teachers do not burp, fart or swear generally. Jay was invited back several more times to read to this class over the school year. The other student filmed all of these occasions.



Don

In one of the courses I taught some years ago on how to provide support, a course primarily designed for Direct Support Professionals, I asked the students to come up with a small mini vision for the people they supported. Roxanne worked with Don, a middle-aged man, in a group home and could not think of a good vision for him. Don had been seriously injured in a motorcycle accident when he was 19-years-old which resulted in some brain damage and difficulty walking to the point he needed a wheelchair. I asked Roxanne if maybe Don might still have an interest in motorcycles. She told me that she thought he might have PTSD as a result of the accident but was not sure. So as a baby step I suggested that she invite Don to visit a motorcycle shop, perhaps there might be one near the group home? She told me that there was a Harley dealership within a mile of the home! In terms of the PTSD theory, we decided that first she would discuss the idea with him and if OK, they would at least drive by the Harley Davidson (HD) store. If Don started feeling uncomfortable, keep going – if not pull into the parking lot.

The following week, Roxanne was quiet and although I did not probe, suspected she had not followed through on our plan. A couple weeks more went by and finally Roxanne raised her hand. She reported that she had run into a disagreement with the group home manager who told her she could not use the house van for driving just one individual for an outing (something about cost effective?). But she persisted because Don said he would like to visit the store and she finally got approval. Then with tears in her eyes, she said that

when they pulled into the HD parking lot, Don could not get out of the van fast enough to go into the store!! That when he got inside, he was laughing and yelling, touching all the motorcycles. It was a Tuesday morning and there were no other customers in the store. He attracted the store manager's attention, a woman, who came over to see what all the commotion was about. She instantly fell in love with Don given his passion for motorcycles and invited him to be a volunteer at a fundraising event coming up soon. Don was ecstatic! Such a simple story but the entire class and myself were in tears listening to Roxanne tell it. Don got a free HD t-shirt and Roxanne made sure he got to the event and in short, took a number of photographs of Don sitting on a Harley, several with a female Harley owner sitting on his lap.

The cool thing is that this works for us as well! And the most difficult bit is to just do it. Success, even in tiny tiny bits breeds success! And the overall lesson here is that if we learn how to do this with our often-discouraging selves, we can perhaps have a huge impact on the people we support including our children. So many of us, but definitely a vast majority of people with intellectual impairments, ever have someone in their life who believes in them, who encourages them to live larger, blow off the limits that we so often impose upon them. I have had a couple of great teachers in my life, one of whom 52 years ago convinced me that I was in fact a great writer even though I was flunking English. . He believed in me when I didn't. In my heart then, I thank him for his gift and for my being able to write this book even though I have long forgotten his name.





I would strongly recommend a book by John O'Brien and Beth Mount: ***Making a Difference: A Guidebook for Person-Centered Direct Support*** from Inclusion Press. It is a wonderful book written to and for Direct Support staff and parents filled with very useful planning tools/worksheets.

Lesson Fourteen

Effective Teaching

In a 1987 short film, titled Then Came John,¹ about a young man with Down Syndrome, his mother is told by the experts that her son would never read. In short, she takes a box of index cards and writes in bold letters the names of things like CEILING, REFRIGERATOR, FLOOR, WALL, STOVE, SINK, TELEVISION, etc. and tapes them to each item in the home... She leaves them up for a month or two, spending a little time each day stating the word for each card/item and having John repeat the word. By the end of the two months or so, John was able to read every single index card in the home...and thus able to start reading books. So much for the experts.



¹ Have not been able to find this film which used to be on YouTube. The man with Down Syndrome's name is John McDonough

Lesson Fourteen

There is much to be said about effective teaching starting with the work of Marc Gold back in the late 1960's who was teaching people considered "untrainable" to successfully engage in complex assembly tasks like circuit boards, bicycle brakes, as well as drive cars, make their bed, brush their teeth, etc. Given how groundbreaking and way ahead of his time he was, it still amazes me how few people have ever heard of him or his teaching methods. It is certainly worth a brief internet/YouTube search to watch a few of his videos.

It seems to me that the primary ingredients of effective teaching are presuming competence, preparation of the environment, task analysis prior to each session and making it fun, which includes ensuring that whatever the task, that the individual experiences success. An overriding factor is to do the task WITH the individual, together – you wash I dry. As success builds introduce the opportunity for a brother or sister and then a neighborhood friend to replace you. You can be a friend even in a parental role, but the goal is to bring other people into the individual's life who are not paid to be with him. The individual's motivation to learn increases, moving toward interdependence in all relationships. Most of us (and the rest who aren't honest) know the pain of rejection and the longing to belong, to be valued for who we are.

One of the helpful teaching expressions I learned is *What do we want this to look like when we are done?* The trap that many fall into is thinking that "independence" is what we are striving for; that Rick will be down in the basement by himself doing the dishes independently. Our work should always be pointed towards creating connections between the individual and the greater community, albeit one person at a time.

The general framework for our teaching process will be Plan- Do – Review – Refine Plan. You sit down and make a plan including the task analysis, considerations for prompting, give some thought to the environment (arrangement of tables and chairs; materials to be utilized and how arranged to facilitate teaching, prevent the onset of problems; and generally, create a positive, valuing atmosphere) and give some thought to modes of reward/motivation. Note that one way you value and to a certain degree, motivate the student is through thoughtful preparation. The opposite of this is quite true as well. Finally, you conduct a short teaching session to see what works and what doesn't towards almost always needing to refine your plan.

The reason for the plan-do-review is: All plans always fail all the time. Aspects of your plan may be quite successful but there is always room for improvement is the basic assumption here.

Another very useful tool is to have someone videotape your teaching sessions and review them afterwards. This is perhaps the greatest teaching tool of all! Video shows the truth of what is going on, and without judgment.

I found it critical to write out the plan and review it prior to a teaching session.



Just stop for a moment and consider how many really great teachers you have had in life so far. Include coaches, parents, grandparents, friends, supervisors along with school and college teachers. I have had maybe 10 in my

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70 years and one really stands out. This is actually worth pondering more deeply. What was it about that one or more teachers that made them great. And after you have a short list of qualities, ask yourself if you have or even strive to have those qualities in your role as a teacher. As Parker Palmer points out in his book, The Courage to Teach, what we most fundamentally teach is not the task but who we are. Thus, who you are as a teacher is perhaps the most important teaching strategy of all.



Homework

Assuming you have a son or daughter with a disability or you are working in providing support to an individual with a disability, the assignment is simple. Think of something to teach the person. Ideally pick something that they might enjoy learning, simple enough to teach over a period of maybe once a week for several weeks. Making muffins, a peanut butter and jelly sandwich, a salad, how to vacuum a floor, how to use a washing machine, toothbrushing, etc. Come up with at least three good ideas and talk it over with the individual and have them pick one. Inform them that they are going to be your teacher as you learn how to teach effectively.

Do not make it too complicated such that you become overwhelmed trying to think of every possible variable. The complexity of necessary considerations will fill in as you go along. The most important thing is to Do It. Again, do it with a partner and give each other feedback and/or videotape yourself.

Additional considerations:

1. Sometimes it is helpful to use a checklist of words, pictures or icons to outline the steps of any given task. One reason for doing so is that this may be useful given that most of us learn to refer to recipes or instructions on how to put things together etc. Secondly, it enables the individual to see their progress through the task. As a general rule it is important to engage the individual in a task that has a clear beginning and a clear ending. (One of the things that many people with disabilities have experienced is that tasks can seemingly go on forever, or when they do a good job, they get more to do.) Third, it provides a built-in support for independence. As they begin to master the steps of the task, they can use the list as a reference. It is often hard to fade verbal prompts where the individual needs to rely upon the teacher for directing the sequence of steps to a given task. Having the task listed out in words and/or pictures enables the teacher to step away from being the “giver of demand” to a more neutral role of supporting the individual through the sequence. The list becomes the voice of what needs to be done and you are just there to assist/support the individual through it.
2. Transitions.
 - Many people with disabilities have some difficulty with transitions from doing one thing to doing another. The problem here is quite often that the individual does not experience a level of control over the flow of their day or even the basic routines that compose the flow of their day. For example, I have a morning routine. When that

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routine gets interrupted, I get irritated.

- » Quite often, for an individual living in a residential program, the staff will determine the sequence and even content of the morning routine. And the individual may have several staff each of whom has a different idea of what the routines should be. This can be quite irritating and set the individual up for having a “bad” day.
- » Therefore, it may be a good idea to first determine what the individual’s preferred morning routine actually is, then to write it down as standard operating procedure for the staff to adhere to in supporting the individual every morning on a consistent basis. It furthermore may be a useful guide for the individual in moving through their morning routine as well as other routines throughout the day (e.g., meals, chores, bedtime, after school or work, etc.)
- Returning to the notion of the “flow of the day”, it is important again for many of us to have a degree of control over what we do through the course of our days. For most people this includes things we have to do but almost always includes places of choice and/or things we like to do or want to do, like taking a break. We might even build in “rewards”; for example, I will work on writing this book for an hour and then take a break and play a video game or go for a walk or watch TV. And what I want to consider as a reward, may change from one day to the next – so choice is important. Most of us also have calendars or appointment books/ day timers so that we can remember things or plan out our weeks. It is helpful, therefore, to have a mix of have to do’s, hard activities, fun activities, easy things to do, time for ourselves, time with other people, time to rest, and above all, feeling good about our accomplishments, owning our own lives.
- The essential or core idea here is that the individual has a fair degree of **control** over their life. Our role as teacher or staff is to support the individual through their routines and days, not to dictate or control.
 - » I use an Oral B toothbrush with a built in 2-minute timer. If I am in a hurry I may not brush my teeth for a full two minutes and sometimes 2 minutes can seem like an eternity but I keep going until the signal that the 2 minutes is up. If I had to rely on someone telling me that I still have another minute to go, they would quickly not be my favorite person. It is also important to note that many people with disabilities may not know how to tell time – how long is 2 minutes or an hour? (It is a good idea to have a large clock or timer handy but to also have the sequence of any given task as a measure of the progression of time through the task.)
- And finally, in the support role, the teacher or support person would refer to the steps of the routine or the schedule-of-the-day to inform the individual where they are at. “After we

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eat breakfast (pointing to the schedule) it says here that WE are going to wash the dishes (interdependence) and then you will have a half hour to play a game on your iPad and then we will get in the van and go to work. Remember, participation means that WE do things together and the individual gets full credit for doing the task even if she only does a small part of the task or sequence and continues to participate in some small way.

3. One final word is to make the task fun and maybe even a little silly. Even vacuum cleaning can be fun: "Our schedule says it is time to vacuum the living room. Why don't we have Brenda (the paraprofessional) show us how it's done first. Brenda is told that she will do 5 sweeps of the vacuum then it will be Bob's (the student) turn. Let's count together each time Brenda does a sweep. One, two, three, four, four and a half, four and $\frac{3}{4}$'s, 5. (Brenda acts a little disgruntled and we laugh)." Then I would ask for it to be my turn and Brenda would make the count even longer, again inviting Bob to count with her. I complain but do the task. Typically, Bob will want to have his turn without even asking him. Sometimes we can make the task a little clearer by saying, in this case, throwing some dots of paper on the floor (from those 3-hole puncher). This makes it clear when the vacuuming task is complete.

We need to continue to stay clear about our primary goal – PARTICIPATION (the real goodness of being together) – especially as we work to support people out of established behavior patterns of violence, withdrawal, self-abuse, etc. And why would we want to

initially participate in something arduous and boring under a mandate from an overly serious and controlling master? No! We are going to take on the day and have a great time, you are going to experience success, and have fun doing it, pure and simple. There will always be bumps in the road but I will assume the lead role in figuring those out as we continue to move forward.



I would strongly recommend if you are a parent or teacher to read Cheryl Jorgensen's book: ***It's More Than "Just Being In": Creating Authentic Inclusion for Students with Complex Support Needs***. It is excellent in laying groundwork for effective teaching, and extremely useful as a resource towards individuals finding genuine community in school.



Appendix

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 - [Beyond Accreditation: Five Star Quality, by Derrick Dufresne](#) Download [HERE](#)
https://www.communitylivingbc.ca/wp-content/uploads/2018/05/Beyond_Accreditation_Five-Star_Quality.pdf
 - [David Pitonyak](#) Takes you to his website with a number of great articles re difficult behavior.
<http://dimagine.com>
 - Greece: keeping people in cages <https://www.youtube.com/watch?v=d5KPcv007mg>
 - [Judge Roenberg Center](#) <https://youtu.be/PUhPMNdnOW8>
 - [Behavior Research Institute using electric shock](#)
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Fact Sheet on Punishment

A few things I have learned over 50 years

1. Punishment addresses only simple behaviors, not complex human problems.
2. Emotional components of the behavior such as inner turmoil and feelings are disregarded
3. Quality of life issues such as trusting other human beings and enjoying oneself are disregarded
4. In their interactions with others, individuals subjected to punishment imitate the aggression to which they have been subjected. (And those who witness)
5. Children get the wrong message that might is right. (And those who witness)
6. Escape or avoidance of appropriate settings (e.g., school) occurs in anticipation of punishment.
7. If you punish behaviors that are inappropriate in one setting (e.g., talking to peers in class), the behaviors also will decrease in settings in which they are appropriate (e.g., the lunch-room) New inappropriate behaviors take the place of ones that have been punished to extinction.
8. There is no longitudinal evidence that punishment is more effective than non-aversive approaches.
9. Punishment does not bode well towards a mutually valuing and trusting relationship
10. Anger or aggression toward the punisher often occurs. Other individuals subjected to punishment withdraw and can become clinically depressed.
11. Punishment can lead to ritualistic and inflexible behaviors (e.g., excessive handwashing from punishment for masturbation).
12. Punishers too often abuse their authority and punish behaviors that could and should be ignored.
13. Punishment too often is used before all other avenues have been exhausted.
14. Punishment is too easily applied for the convenience of staff. Individuals being punished miss out on positive learning opportunities that are taking place while the punishment is being administered.
15. Punishment reduces human dignity and is harmful to an individual's self-esteem.
16. Punishment is painful. (See Amnesty International definition of Torture)

On Punishment

17. Most forms of punishment would be considered assault and battery if used on non-disabled adults.
18. Increasing amounts/intensities of punishment are necessary to maintain the desired effect over time.
19. Punishment does not enable people to learn acceptable behaviors as an alternative to their inappropriate behaviors.
20. Even with training, punishment rarely is administered consistently by different staff members across shifts, etc.
21. Punishment fails to consider how the individual's environment affects his/her behavior and mood and therefore offers no relief to the individuals.
22. Punishment used on people with disabilities usually reflects the results of behavior control experiments that originally studied the behavior of laboratory animals.
23. There can often be undiagnosed physiological reasons for people's self abuse, aggressive behaviors (e.g., brain tumors/headbanging)
24. As long as we think it is acceptable to hurt other human beings, particularly those who are most vulnerable, we cannot call ourselves a civilized society.
25. Behavior is often a form of communication, especially for people with disabilities who may not be able to express themselves verbally. Punishment may therefore be directed at people's only form of communicating their needs and concerns.



Lao Tsu, Entropy, the Coroner, Problem Clients and Lost Dreams

Richard Brueggemann, July 2010

Getting older and becoming more acutely aware of my mortality, I have increasingly begun to think about how “it” all fits together. God, physics, the way we live our lives, are they all bound together by some rules that apply universally no matter what topic or discipline we are discussing? Was “The Hitchhiker’s Guide to the Universe” correct; that the answer really is 42?

For some time, I have been attracted to the work of Lao Tsu who, many years before the birth of Christ, endeavored to understand the power of the universe and how it affected our everyday lives. He called this power and its set of rules the “Tao” and demonstrated how opposites-hot and cold, hard and soft, male and female- complemented each other to create a universe that could be understood.

Recently I have been trying to apply some of his thinking, together with some of the laws of physics, to the work of supporting people with disabilities.

I want to start with the concept of entropy. Entropy is the phenomenon by which a glass of boiling water and a container of ice will both be at the same tepid temperature in the morning after we have left them out overnight. This is dictated by the laws of thermodynamics. The only way we can restore them to their previous state is by the application of energy; to get our boiling water back we apply direct energy (heat); to restore the ice we would need to use energy to power a refrigerator to freeze it. Moving away

from the equilibrium state in either direction requires energy!

Historians, in their work on the various empires that have come and gone over the millennia, have described a process that contains some of the elements of entropy. For some of the glorious empires of the past, growth, development and expansion were followed by a period of complacency and comfort followed by decline, decay and defeat and perhaps their eventual reconstruction as a lesser society.

It is my view that the same process occurs within the organizations providing services to people with disabilities. These have often been built through the energy and enthusiasm of a small group of entrepreneurial people who share a vision and have the will to see it implemented to meet the needs of a particular group of people. There is often a process of growth and expansion perhaps through new funding or strategic mergers. Usually the original entrepreneurial leaders are involved, pouring their energy into this growth and development.

Usually at the time that an emerging organization develops its first strategic plan, we might start to see the genesis of a process that significantly corrupts organizations- the emerging difference between the espoused culture as set out in vision and mission statements and the dominant culture. Because organizations are composed of people, it is not hard to understand that the

dominant culture usually reflects the human needs reflected in Maslow's hierarchy. The values of dominant culture will therefore be more influential than those stated or implied in visions and mission statements. One of our human needs is for comfort and I believe this is one of the most powerful forces in determining how organisations behave.

Incidentally, I am reminded of A.J. Shaddock's assertion "If the road to hell is paved with good intentions, then the advertising billboards along the way will be mainly Vision and Mission statements of human service organizations."

All organisations have a propensity to move towards an equilibrium of comfort that no one wants to unbalance. Only energy will change the entropy of organizational culture.

In the private sector this is theoretically kept in check by the marketplace and the energy that it brings to bear on comfort- people well understand that the mediocrity that leads to sloppy goods and higher prices will be punished. This competitive energy regenerates and reinvents businesses to ensure they can keep up with and hopefully surpass others in their particular industry.

However, as we have recently seen this system doesn't even hold up in the private sector and it is salutary to briefly look at the Toyota Motor Corporation.

Its vision is to be the "most respected and admired company."

Its mission is to "deliver outstanding automotive products and services to our customers, to enrich our community, partners and environment."

Its core values are "customer first, respect

for people, international reputation and continuous improvement and innovation."

Yet recently, Toyota has been embroiled in controversy and litigation after many customers have been killed because of serious defects in their vehicles and many thousands of cars have been recalled.

One can only contemplate the corrupting corporate culture that caused the current crisis in customer confidence.

Of course, we have set up our service system for people with disabilities without any reference to the competitive forces that supposedly keep private enterprise on its toes. Notwithstanding the recent move to competitive tendering, disability organizations are usually funded by government and offer the range of services that they have been contracted to provide. These contracts may be quite complex but are often more concerned about such issues as occupational health and safety, governance, financial requirements and service excellence goals rather than positive outcomes for the clients it serves. Furthermore, any competitive forces basically cease once you've got the contract.

Inevitably, a comfort level is then reached which is more about what the organisation wants to offer than what people with disabilities, their families or agents want. In essence they can take what is provided or not take it. In a market where the services are scarce, there is great pressure on the part of people with disabilities and their agents to take the offerings that are before them. That these offerings do not necessarily correlate with what people want is largely irrelevant and I will return to this point later. Not only does comfort dictate what is offered but it also shapes how it is provided.

No where is the commitment to organizational needs rather than the needs of individuals more obvious than in the use of restrictive practices. Historically such practices have been for the convenience of the organization and staff rather than for any benefit for the individual. In saying this one must not be too critical only of the organization; we must remember that the “purchaser” of services- the government- wants to spend as little as possible. Despite the rhetoric of government statements that people with disabilities should have opportunities for citizenship, the reality is that they are treated as “problems to be solved” and the major consideration is cost!

To justify their approach to the way people with disabilities are treated in their systems, CEO’s and professionals gather, at government expense, in exotic locations (from which the subjects of their deliberations are largely excluded by the cost) to tell others how they are achieving “world best practice”, to listen to their peers tell similar tales and mainly to reinforce that they are professional and doing good things! It would be interesting to do a rigorous analysis to discover if all of this made a scrap of difference to the people they are meant to serve.

The equilibrium of comfort that is reached by organisations and indeed the wider service system could be described as one where nothing bad happens but equally nothing good happens.

It is not difficult to understand why this is the case. In Australia the requirement that organisations provide a safe environment for the people they serve is underpinned by common law and legislation. So if you have your arm broken, your money stolen or your pajamas go missing from the laundry, the individual or their agents could assert that the

organisation did not fulfill its duty of care and could take legal action. This is the “energy”- fear of being sued- that keeps the bad things from happening.

As well as common law a major force that has seen this duty of care taken seriously within South Australia and other jurisdictions has been the involvement of the coroner. It is probably timely to reflect on some history in looking at the role of the coroner.

If you have read “From darkness to Light” by Professor Bill Cramond or read the personal stories of people living in large residential services you would start to get a rough idea of the scant regard that was given to the lives of people with intellectual disability. It was highly likely that the doctor whose negligence or lack of interest might have contributed to your death would be the person signing your death certificate. It would be filed, never to be seen again let alone examined and queried. You were truly “A nameless number on a list that was then lost.”

Some years ago this changed in South Australia and the coroner now investigates the deaths of all people who live in institutions and group homes. He also regularly investigates the deaths of people with intellectual disabilities where it appears the death was caused when services or systems have stuffed up. The coroner has rightfully not been slow to direct criticism to organisations and individuals who have not fulfilled their duty of care to individuals who have died.

To receive criticism from the coroner is rightly embarrassing and if repeated a CEO sacking offence. It is my view that meeting your duty of care so that you don’t get sued or get a thrashing from the coroner has contributed more to preventing the “bad” things happening

than much of the training in service philosophy and values. Incidentally when you don't get a thrashing from the coroner for the death of a person with intellectual disability in your care it is not an occasion, as has occurred, for celebrating with champagne. Someone is still dead and we should use the report to learn and ensure that it doesn't happen again!

So if common law and the coroner have largely kept the "bad" things in check, why are the "good" things not happening? Firstly, I need to justify my assertion that largely the "good" things are not happening.

What constitutes the "good" things? Of course this will be a very personal question that some of us take a lifetime answering as we grapple with desires, fears, relationships, aspirations, careers, guilt – a pot pourri of factors that make us who we are. Most of us seek happiness through the things that are important to us – our relationships, our accomplishments, our work, our status, our contributions, our talents or our possessions. Often, we find that some of these are not the source of happiness we had thought they would be – that the Porsche and the penthouse are but two additional places where we can reflect on the emptiness of our lives. For others, the acquisition of material things is indeed a source of great happiness.

A common theme though is, whatever it is that we desire, our chances of success will be enhanced if we have opportunities to gain skills and if we are truly in control of our own lives. Richard Trudgeon, in his book "Why Warriors Lie Down and Die", cites lack of control as the major cause of the malaise of the Yolnu people in the Northern territory. I believe that developmental opportunities and personal sovereignty are the keys to all the "good" things that are important to us. The

two are of course inter-related; it is though our acquisition of skills as we grow and develop that we are able to take more control of our lives.

Indeed the importance we place on these two "good" things in our own lives is reflected in the principles of the United Nations Convention on the Rights of People with Disabilities. Oh! And not to mention the vision and mission statements of hundreds of disability organizations!

Ironically and sadly duty of care is regularly referenced to prevent learning and its inherent risks. Learning is a risky business but that is no reason to deny people with intellectual disabilities opportunities to learn and develop. Furthermore, I am unaware of any case where an organization has been sued for failing to provide developmental opportunities.

It is my belief that within many organizations these two "good" things are missing. You are not in charge of your life and largely you will not have opportunities to gain new skills. If this is the case why is it so?

Personally I don't think it is through malice; I think we must put it down to organizational entropy! It is easier to feed everyone at the same time; it is easier to prepare meals than to assist individuals to prepare their own meals; it is easier if everyone goes on the same excursion. It doesn't take much imagination to add to the list. Despite what is written in vision and mission statements, the dominant culture will prevail. Like Toyota, the reality of our practices bears little relationship to what we espouse as our values. The dominant corporate culture instructs new employees "this is how we do things around here."

Within an institutional setting, "how we do things" often includes getting client chores

done as quickly as possible so that staff can then spend time socializing. If residents are ambulant, their activity for the day is often to “mill” until the next meal or intervention. This was dramatically demonstrated by Prof Jim Mansell and Prof David Felce in the UK, who discovered that in a four hour block for an individual resident in a large residential service, there were only twelve minutes of interaction with staff and only four minutes of that positive.

The “energy” created by the Mansell/Felce revelation saw the development of the active support model, based on person centred planning and a developmental approach to supporting residents.

But the question must be asked “Why was this necessary?” If we read their mission statements one could assume that active support and its commitment to skills development was already the *modus operandi* of organizations. Well yes it was a part of the documented way of doing business, but like Toyota, the real way of doing business was about ensuring comfort levels for staff. You could imagine how well received a new staff member in this environment would be who, through his/her training or intuitively, wanted to do “developmental” things! In my recent discussions with students, most of whom have worked in providing hands-on support, I heard many stories of how they had tried without success, to enthuse colleagues to work developmentally.

Furthermore one would want to question how enduring the commitment to active support and person centred thinking will prove. Will it long succeed the manager/CEO who introduced it when he/she leaves the organization? Of course one could argue that it is the role of the board through its

governance processes to continue to provide this energy but if we look at Toyota we find the board asleep at the wheel or complicit.

I would like to suggest that any future disability legislation might include a requirement of disability service organizations to ensure that their programmes support skill development. Where it could be demonstrated that an organization had not fulfilled its developmental responsibilities and that, as a result a person’s learning had been impaired, there could be a case for legal action. (As I mentioned there might well be such a case now but I know of no legal action based on a person not being given the opportunity to learn new skills.)

Another trait of organizations is not to ask the second order questions. Dr Lorna Hallahan of Flinders University, in a talk to a group of leadership students, made the point that organizations grow in the direction of their questions.

It is interesting to note the changes the South Australian Department of Families and Communities made some four years ago to deal with the issues facing disadvantaged people in the state including those with disabilities. There was an emphasis on restructuring, a burgeoning of bureaucracy with new executive positions, the establishment of a learning college and a customer service branch, name badges and generally all the trappings of “professional culture.” One could question if any of this made a nanogram of difference to the people the department was meant to serve.

There has been no commitment to community development and the true involvement of people in determining their own destinies. The department acted in effect, using the

analogy of John Bunyan's "Pilgrim's Progress", as a "giant social worker" loftily dispensing professional help to the needy.

What is most galling to people with disabilities and their families is that, four years after this highly publicized change which was to have so greatly improved services to people with disabilities in South Australia, the Government has recognized that the system is failing and has seen the need for a further major disability service reform that will led by the Social Inclusion Commissioner. All the architects of the change, including the Minister, have moved on and the lives of people with disabilities are not a jot improved. One could imagine how we might view a doctor who embarked on a radical plan for a patient and then walked away from his/her ongoing treatment. If unethical is too strong a word perhaps cavalier might suffice. Some people with disabilities talk disparagingly of the "tourists" in their lives who come in, talk a good game, enhance their reputations and move on to bigger and better things. Apres moi la deluge! Let us all hope that some second order questions will be asked by Monsignor Cappelletti and his team!

Only recently has a second order change been made- a commitment to pilot self managed services which might enable some people to control their own service provision. Descriptions of how this has liberated people with disabilities and their families in the UK have made this reform most welcome in South Australia. One could only wonder "If we were starting from scratch, would we ever invent the current system?"

I also want to examine the responsiveness of organizations and the wider community from the perspective of people with disabilities and families.

Let us consider John Citizen, a 20-year-old man with moderate intellectual disability who lives with his mum and dad. John has Down Syndrome, an easily identified syndrome, and a process began almost at birth that put him on a completely different path to that of Fred Doe, who is the same age and lives next door.

Fred will be graduating in economics next year, is mapping out his "brilliant career", and has an active social life. John is at special school, doesn't know what he's doing next year, has few friends (and all of them are people with intellectual disability) and is socially isolated. Fred's use of services is an occasional visit to the dentist or doctor. For John and his parents, services are an all-consuming part of life.

Understanding these differences is much more than just understanding the nature of John's impairment. It also requires an understanding of a handicapping process that probably began with his visit, at three months of age, to a doctor's surgery, where his parents were told "to enrol him immediately with Strathmont Centre."

*It is that **first** assumption (that a child with Down Syndrome will have intellectual disability and will always be dependent) that places the child (and the parents) on a path that in the past would almost invariably have delivered the child to the gates of some residential service.*

In the past, children with intellectual disability (or conditions such as Down Syndrome that pre-supposed intellectual disability) were denied an education due to an assumption that they could not learn. Largely, this was rectified in the seventies and eighties, although it is only within the last two decades that all children, irrespective of their intellectual disability, have been guaranteed an education.

Secondly, children with intellectual disability will have additional needs which require extra effort for families – a different effort for a

different outcome. The lack of valuing of this different outcome is a major factor for families as it may act as an emotional barrier and a deterrent to their acceptance of the child as a member of their family.

Thirdly, *many of the natural supports that exist within our community and neighbourhoods break down when these assumptions are made. Whereas neighbours and other family members might be important in providing the "break" that all families require, for children with intellectual disability there is less reliance on these natural networks and more reliance on formal service models and indeed the invention of a new service type- respite. Kids with intellectual disability often don't get to play in backyard cricket competitions or get invited to birthday parties or sleepovers. "Difference", being feared, is avoided.*

Fourthly, *these services in themselves can be institutional and isolating, and can reinforce "difference." Institutions occur in our minds rather than in buildings, and they happen when we treat a group of people homogenously rather than individually. So, many programs in the past have been aimed at dealing with people as a group and doing this in ways that are most economical (at least in the short term) or most convenient to service providers or the community.*

Fifthly, *there is the risk that many issues in the lives of people with intellectual disability will be defined more by the professionals than by individuals and families themselves, and more in terms of services required than around the aspirations of the person.*

Sixthly, *all of these combine to slowly continue the process of isolation, use of special services and separation from the things that are important to the person's peers and neighbours.*

By the time John reached the age of 20, this

process of segregation and institutionalisation was so complete that John's choices were very limited. So limited, in fact, that he does not think in terms of "future" and "career" as his neighbour Fred does, but rather he (and more likely his parents) would be thinking of his future in terms of where he might live and what services he would require.

When they look back on their lives, his mum and dad would also identify a segregating and isolating process that, for some parents, is all-consuming and utterly debilitating. They have also arrived at a point that Julie Simpson of Parent2Parent in Queensland has described as "resigned acceptance."

Whatever dreams they might have had for their son have been long extinguished. During those 19 years they probably couldn't count the number of times they have heard such organizational responses as "We don't offer that type of service", "What you want is inconsistent with our policy", "There's no precedent for what you want to do." Each response has chipped away at their sovereignty and slowly passed the power to organizations.

Unfortunately over the years I have met hundreds of families in this state, so subjugated by the system of which I was a key part that their dreams for their sons or daughters no longer exist and who have been taught to see only the solutions that the system wants them to see.

And if you are a parent who doesn't "accept resignedly?" Well the system can really give you a hard time! From my observations you will be invited to abandon your vision for your daughter or son and take what's offered. If you don't you will be "unrealistic" or perhaps even a "problem parent." Eyes will roll at

the mention of your name and you will hear things like “everyone else thinks it’s a good programme”, “you think you have difficulties; you should see Mrs Bloggs down the street” and “as a social worker/psychologist/etc.... I think you’re wrong.” Your file will be 6 inches thick and a succession of workers will be assigned the task of getting you to see reason.

The message is clear- “Give up your dream; be reasonable.” However I am reminded of George Bernard Shaw’s warning- “All progress is brought about by the unreasonable man (and woman!), as the reasonable man accepts the status quo.” Of course the status quo is the end result of organizational entropy. It is interesting to note that in the past fifty years progress in the field of intellectual disability has largely emanated not from organizations or conferences but from “unreasonable” individuals.

If it sounds overly pessimistic then I want to offer a way forward. Nearly all organizations deal well with the one thing that governments are most concerned about-money. It is now time for governments to make some statements about the outcomes they seek for people with disabilities. The United Nations Convention on the Rights of Persons with Disabilities gives considerable direction and could be used as the starting point of developing outcomes that have a human rights focus. Boards would be required to report on these as rigorously as the financials.

Some governments already do parts of this and use their disability legislation as a key tool in that process. In Victoria for example, the use of restrictive practices is now subject to a rigorous reporting and educative regime.

In the absence of government leadership, I

believe it is up to boards of organizations to set up reporting mechanisms that monitor the outcomes for the people they serve which reflect the UN Convention and their own vision and mission statements. These should be scrutinized as rigorously as the “financials.” In the absence of external forces, boards offer the only “energy” to combat the comfort that delivers nothing bad but nothing good.

Finally I would like to paraphrase chapter 17 of Lao Tzu’s immortal Tao Te Ching.

Evil organizations are those which abuse and hurt those in their care.

Bad organizations are those which use their power and influence to control those in their care.

Good organizations are those which are lauded for their good practices.

The best organizations are those whose support is so attuned to the needs of those they serve that their presence is barely detected.

Organisations will have been most successful when those they serve can say-

“We did it ourselves!”

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Listening Exercise¹

Fairly simple but very difficult in practice. Next time you have a dispute or disagreement with someone, institute this rule:

- Each person can speak up for himself only after he has first restated the ideas and feelings of the previous speaker accurately, and to that speaker's satisfaction.
- Essentially you summarize what the other person has said and ask them if you have understood them properly to which they will agree and or offer a small correction. However, it is OK to discover that you were completely wrong. That is important to know.
- When you are the listener, you are forbidden to speak in any way except if necessary you may ask honest questions of clarification.
- The basic idea of listening and not expressing your thoughts until you have summarized back to the other person what you thought they said, is in general, a good practice.

"The great majority of us cannot listen; we find ourselves compelled to evaluate, because listening is too dangerous. The first requirement is courage, and we do not always have it. If you really understand a person in this way, if you are willing to enter his private world and see the way life appears to him, you run the risk of being changed yourself. You might see it his way, you might find yourself influenced in your attitudes or personality. The risk of being changed is one of the most frightening prospects most of us can face."

"Fundamentally, the most helpful thing I have found is to listen to what people have to say. By now, I suppose that by listening, I mean the act of attending carefully to what is said as well as to what is meant, to regard actions as communication, and, most profoundly, to possess the spirit of taking other people seriously." (Lovett, H.; *Learning to Listen*, p30)



¹ Taken from Rogers, C.R. (1952) "Communication: its blocking and its facilitation" *ETC: A Review of General Semantics*, 9, 83-88.

Framework

Before going any further, please
see the checklist on p 24.

In supporting an individual who is exhibiting violent, aggressive, self-abusive or destructive behavior, the place to begin to effect change is with ourselves. As a culture and particularly in the world of human services in this country, we have been led to believe that compliance/control of people with disabilities is necessary and desirable. The mindset of behaviorism has been indoctrinated into us often without our even being aware of it. Compliance (the explicit goal of behaviorism) and various practices of positive reinforcement, time out, physical restraint and psychotropic medications have evolved from that mindset put forth by BF Skinner over half a century ago. It is a longer conversation, but in essence, behaviorism as an approach is not what we would want for ourselves. We do not typically like being told what to do and then having to do it or else. We would not want someone grabbing and physically restraining ourselves if we tried to raid the refrigerator for a snack at 2 in the morning.

The following is a list of 9 things that we need to begin practicing if we are to effectively resolve someone's difficult behavior. And this framework applies to anyone, not just someone with a disability. The basic core idea of this book is that we need to learn to listen better. We need to change, at least first in the process of addressing behavioral change in others. Although it is not rocket science, it is not easy.

The first thing I would recommend is that you find someone to work with you in adopting this mental framework. And the second thing is that you use a smartphone or camera

to record video of yourself as you begin to practice it. Although we would like to believe that we are always conscious, my experience of myself and in my work with others is that we often are not fully aware of our tone of voice or our body language. And so please consider utilizing video occasionally as one of your primary teaching tools towards personal growth and change.

And so for starters, you need to put aside you're current framework or mindset including the use of physical restraint, contingencies, time out, punishment, and compliance. You need to understand that such practices, although offering short term control over behavior, do not lead to long term resolution and can often exacerbate behavioral issues, harm relationships, and cause deep emotional, mental and psychic wounds — certainly not in a direction of healing. I am not here however asking you to abandon your belief system or convince you otherwise — just that you put it to one side for a trial period.

This framework is taken from what I learned from a man by the name of Dr. John McGee back in 1983 at one of his Gentle Teaching workshops in Omaha Nebraska. If you have access to a computer, there are numerous websites and YouTube's available about Gentle Teaching.

The central purpose of our presence in the lives of others (not just people with disabilities) is to teach, nurture and sustain the experience of connectedness, companionship and community.

1. **SAFE:** you are safe with me always. I am not going to hurt you, restrain you or make you do anything. Nor will I allow/tolerate anyone else to treat you in those ways. It will take time to build your trust in me.

2. **LOVED:** I will work to love you unconditionally regardless of your behavior; it is a fundamental assumption that ALL persons hunger for connectedness and human companionship. Quite often people with disabilities experience rejection and not being valued as who they are. Their behavior in some ways may in fact be their best effort to express their need to be loved because they have come to believe that they are unlovable.
3. **LOVING:** You can learn to become loving towards yourself and others, we can teach that. We must recognize however that you cannot give what you don't get...that you need to learn that you are loved before you can become loving. I will teach you that relationships need to be reciprocal
4. **ENGAGED:** The primary goal of our relationship is not your compliance for me but your coming to see that it is good to be with me and good to DO things with me – good for yourself, me and others. I want to do things WITH you and want to teach you the goodness of being engaged with others.

I will teach you that you are safe, loved and how to be loving and engaged through:MY WORDS: speak only kindly including tone of voice

5. **MY EYES:** look only warmly (what is in our heart shows thru our eyes)
6. **MY HANDS:** touch only gently and respectfully. Touch is not hurtful physical intervention. I want you to learn that my touch will not harm and for you to learn through my example, how to touch others.
7. **PRESENCE:** I will be there with and for the person, be present to and for them. This is where it is important to learn to LISTEN, to be a reader of the person's heart. I need to

be mindful of what the onset of my presence signifies for him/her...that I am someone that they look forward to being with. I need to learn to stand in their shoes. (what would it be like to be them?)

As noted previously, it is **Being** that typically determines or at least influences what we will Do in any given situation. Adopting the above set of understandings will go a long way in reducing difficult behavior. However, because some individuals are so deeply entrenched in their behavioral patterns, it is important to note a couple of strategies that Gentle Teaching puts forth.

The first is that we do not want to give the difficult behavior any more power by attending to it. The Gentle Teaching approach puts forth the idea that we Ignore, Redirect and Reward. In essence we ignore the behavior problem as much as possible and in the meanwhile, redirect the individual to the task at hand (with the goal being participation as noted in Lesson 8) and immediately make participation powerful by rewarding it! To be clear, ignore the behavior but not the person.

Thus, the second strategy of sorts is to make sure that you have the individual's day organized with a schedule or flow as to what they are doing throughout it. What is the task at hand that you are attempting to engage them with? At the very least, you strike up a conversation about how cool their shirt of blouse is and when they acknowledge that, you reward them. When I first learned about Gentle Teaching in Nebraska in 1983, we were given a nut and a bolt as the task to engage an individual with a difficult reputation in. It almost does not matter what the task is, but you need them to be engaged in more than just breathing.

One final word is that you learn to not react

with fear or anger etc. when the individual engages in a violent or self-abusive behavior. It is a relatively safe assumption for you to understand and embrace that they are already filled with a great degree of fear and woundedness. This is not easy. What I found is that you need to learn to simply be silly and to give up any idea that you are the authority figure, the staff person or parent. Sing a silly song, be playful, whatever, but lead the emotional dance in a positive direction and work to avoid getting pulled into their drama... and do not expect this to work instantly! This will take practice and time and effort for you to learn. Keep watching yourself on video and involve others in supporting your work.



About the Author - Yeiter

This book is primarily written to put forth a relationship-based approach to supporting an individual with a reputation for being difficult, aggressive, violent and often labeled as a “behavior problem”. I wrote this mostly for direct support staff and parents. First and foremost, a relationship-based approach calls into question the behaviors and assumptions of the caregiver. Listening, in the broadest and deepest sense of the word with both our heads and our hearts, listening to what the other person is trying to say through their behaviors and words is the central process for the caregiver to engage and practice. This is not a one-time strategy but an unfolding exploration over time...perhaps a lifetime.

For people with intellectual disabilities, I have always believed that it was my role to be a teacher. Over the years, I realized that through teaching - most fundamentally - we teach who we are. If you think back upon the great teachers you have had in your life (be it parents, coaches, friends, schoolteachers, etc.) you remember qualities that made them great, not so much what they taught. Caring, encouraging, their believing in you when you did not believe in yourself, patience, kindness, passion, rigor, love – these and other qualities are the work of a great teacher.

So, the change process begins with us, within our souls, not with the externals of another person’s behaviors. This involves a different kind of listening - a listening to our spirit, muse, or conscience, and furthermore submitting to it which can often involve some courage. I accomplish this through solitude, reflection, meditation, walks in the woods or finding a good friend to have conversations with.

I have spent most of my life engaged as a teacher, and although the work has been difficult on many levels, I have been blessed by getting to know and be in relationship with some magnificent human beings.



*Yeiter age 5 reading
to his Grandfather*



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