Understanding the Impact of Invisible Disabilities
Full Presentation

Understanding the Impact of Invisible Disabilities
“The People We Interact with as Individuals Living with Invisible Disabilities” Part 1 Zoom Presentation

Presented by Craig J. Phillips MRC, BA Second Chance to Live

My goal is not to affix blame on anyone — as that does no one any good – but to share what has helped me in my process.

My interest is to empower individuals who are also living with an invisible disability — due to a brain injury or due any other type of organic, medical, psychological or mental health condition.

May you find the hope and courage — by listening to and watching this presentation — to both love and accept your reality and yourself.

4 Groups that I Interact with as an Individual Living with an Invisible Disability

As a person with an invisible disability, I have interacted with four different groups of individuals over time.
The **first group** involves people who are completely oblivious to my being a traumatic brain injury (tbi) survivor or for that matter do not care.

The **second group** of individuals who hear that I am a tbi survivor, but because my disability is invisible believe that I am somehow using my invisible disability as an excuse. These individuals treat me with contempt, either overtly or covertly because I am unable to satisfy their expectations.

The **third group** of individuals knows that I have am a tbi survivor and that my brain injury has affected me in some manner, but still want me to function as an individual without a brain injury.

The individuals in the **third group** also believe that I use my brain injury as an excuse when I tell them I am unable to fulfill their expectations. The individuals in the **third group** refuse to accept that I have legitimate limitations and deficits.

When I state that I cannot do something because of my brain injury — or what some people refer to as a “head injury” — individuals within the **third group** blame me for reminding them that I have a brain injury.

The **fourth group** of individuals thankfully realize that I am a traumatic brain injury survivor and that my brain injury interferes with my ability to work with people, especially with those in the first three groups.
The **fourth group** understands that I am not making excuses for what I cannot do and accept and value me as a friend.

With the **fourth group** I do not have to be more than I am, nor do I have to continue to convince them that I have an invisible disability.

**Give me Lip Service**

The **second** and **third groups** of people give me lip service when they tell me they understand and accept that I am a traumatic brain injury survivor. Nevertheless, when I interact with the **second** and **third groups** of individuals, I feel less than because I cannot measure up to their expectations. Nothing I can say or do can convince them of my predicament – being disabled despite not appearing to be disabled.

When I interact with the **third group** of individuals, I feel like I am between a rock and a hard place.

The **second group** blatantly chides and ridicules me with disdain.

The **third group** has a degree of awareness and acceptance until individuals within the **third group** want me to be or give more than I am capable of giving.

In my experience, when members of the **third group** have an expectation of me — which I am unable to achieve — I also receive ridicule and covert contempt from them.
When I tell these individuals that I am unable to be more or do more they want me to buy back into their denial system.

**Denial Systems**

Their denial system includes manipulation through shame, guilt, and emotional coercion. I have spoken of this denial system dynamic throughout Second Chance to Live. The denial system wants me to believe that my invisible disability is all up in my head. That if I just tried harder then, I would not be impacted by my brain injury and invisible disability.

**In My Experience**

I have spent countless hours attempting to disprove the reality of my disability. For many years I internalized the impact of my disability as a reflection of my being.

I shamed, blamed, berated and criticized who I was because of my inability to perform as an individual without a traumatic brain injury. I allowed my Dad to treat me with contempt for many years because I did not know the significance of my invisible disability.

**Trying to Figure Things Out After Our Brain Injuries**

**Being Vulnerable**

Being vulnerable can leave or open us to up to being bullied. Being vulnerable can leave us susceptible to being bullied.
As a result, we may be led to believe that we cannot trust ourselves.

By not trusting ourselves we may be led to believe what other people want us to believe about ourselves.

**Through buying into those beliefs, we may find that we deserve to be mistreated and bullied.**

Such treatment and bullying can lead us to believe that we don’t deserve to be more than we are led to believe about ourselves by those individuals.

Individuals who then take advantage of our being vulnerable.

**Intimidation Defined**

**Merriam Webster** defines intimidation as: to make timid or fearful: frighten; especially: to compel or deter by or as if by threats.

**Dictionary.com** defines intimation as: to make timid; fill with fear, to overawe or cow, at through force of personality or by superior display of wealth, talent, etc, to force into or deter from action by inducing fear.

**Vocabulary.com** defines intimidation as: You can see “timid” in the middle of intimidating, and to be timid is to be frightened or to pull back from something. When you intimidate, you frighten or make someone afraid. To frighten” or “make fearful” is at the root of the verb intimidate.
Intimidation can be mental, emotional, spiritual and physical or a combination of one or more ways.

**Challenged**

As a traumatic brain injury survivor, I struggle with a sense of inadequacy at times. At times I listen to messages that seem to challenge me for not being more than I am today. I am encouraged to be more, but for some reason, I simply do not believe I can be more.

Innuendos of shame — in these messages — trigger the notion that I am not enough, I don’t do enough and that I am unlovable.

**Controlled**

Unconsciously, shame seeks to discredit my desire to succeed in life through minimizing and marginalizing my best efforts.

Shame seeks to keep me distracted by a faulty notion that tells me that what I do and who I am is not enough.

**Shame seeks to keep me in denial.**

Shame seeks to rob my energy. Shame seeks to silence my efforts through criticism, minimization and marginalization.

As a person with a brain injury and an invisible disability, I allowed the message of shame to bully me for many years. The shame bully controlled and manipulated my every move.
Shame told me that I was not enough and that my best efforts were never quite good enough.

When I attempted to justify, answer, defend and explain myself to the bully, the bully would jeer at me.

Shame mocks me through patronization, minimization, marginalization, dismissing and discounting.

The more I attempted to appease the bully — through striving to do more to be enough — the more the bully would remind of the reasons why I felt inadequate and insecure.

With time and through my process I began to realize that no matter how much I did to appease the bully, the bully would still abuse me.

Essential

With time and through my ongoing pain I began to realize what the bully was doing to me.

With time and when I got tired of being bullied, I realized that if nothing changed, it would remain the same.

Consequently, I made the decision to examine why I believed that I deserved to be bullied.

With my decision, I made several other decisions. I realized that I needed to examine how the bully kept me distracted.
I Needed to Examine

Why I believed that I was a mistake?

Why I believed that my best efforts were never quite good enough?

Why I felt a need to justify, defend, answer and explain myself to the bully?

Why I had such a difficult time living in my own skin?

Through my recovery process and my pain, I found the motivation to confront the “shame bully”.

Through My Process

Through my recovery process I discovered the origins of the lies and how I had been set up to bullied.

Through my pain and my recovery process I discovered why I had so readily accepted what I was being told by the bully.

Through my recovery process I discovered why I felt minimized and marginalized by the bully.

Through my recovery process I discovered how the bully used shame to keep me in denial.

Through my process, I discovered that the shame bully echoed the voice of perfectionism — at my every move.

The voice of perfectionism crippled, devalued, minimized and marginalized who I was and what I had to contribute.
Through my recovery process and my pain, I discovered that my ability to heal and grow in my mind, body and spirit were hindered by the voice of fear of failure.

**Perfectionism**

Perfectionism cut with a two-edge sword — telling me my efforts were not good enough and that I should not try because I would probably fail.

Shame also stymied my efforts by threatening me with the fear that I would be abandoned physically and emotionally if I did not do things perfectly.

**The Bully created Drama**

At the core of my being the fear of abandonment kept me enslaved by the bully.

**Because the bully was unrelenting, I had no idea that there was life beyond the drama.**

I had no idea how much energy I was using to avoid being attacked by the bully.

**Energy Drained**

Through my recovery process and pain, I began to recognize that my internal energy was being drained in my attempt to avoid being attacked by the bully.

Through recognizing how shame was draining my life, I was motivated to look for solutions.

These solutions helped me to begin to heal emotionally, mentally and spiritually.
Three Rules

Through my recovery process and my pain, I discovered that there were three rules that enforced the power of the bully.

As I began to talk, trust and feel my eyes slowly opened. Through my recovery process and my pain, I discovered how the bully gained access to my life and to my world. I discovered how the bully perpetuated the lie.

Through my recovery process and my pain, I became aware of what was blocking the peace that I longed for in my life.

I found that I needed to work through the pain to get beyond the pain.

I had to do the work to gain the awareness, to move beyond the awareness to a place of acceptance. A place of acceptance where I could stop losing myself.

Not Blaming Anyone – Including Myself

With my awareness, I realized that I had to move beyond the pain through the pain before I could accept what had occurred to me — without blaming anyone.

I found that I had to do the work to gain the acceptance before I could take the action to stop being bullied.

I discovered that I had to do the work before I could break free of the denial systems that contained the lie.
Through my recovery process and my pain, I began to realize that I had been living my life through vicarious demands.

Through my recovery process and my pain, I discovered that – over the years — I had willingly discarded parts of myself in an attempt to comply with the demands of the bully.

Finding Freedom

In my experience, I had to begin healing from the effects of shame that the bully foisted upon me.

I had to break free from the illusion of power that the shame bully had over me before I could hope to live life on life’s terms.

Through my recovery process and my pain, I have discovered that I am still susceptible and vulnerable to being exploited by the “shame bully”.

I have also found that my susceptibility and vulnerability — to being exploited by the “shame bully” — increases when I am hungry, angry, lonely, tired or sick.

Through recognizing when I am more susceptible and vulnerable to the “shame bully”, I am able to take the necessary steps to take care of myself.

Through being aware of the lies, distortions and illusion of power purported by the shame bully I was able to address a vital part of my recovery process — denial.
A vital part of my recovery process evolved because of my emotional, mental and spiritual pain.

**Because of my pain and anguish. I was motivated to address both my denial and the denial of family and friends.**

In my experience, I found that as I addressed my denial and the denial systems of family and friends, I experienced a new freedom. The freedom to accept my limitations, while not beating up on myself for them.

**No Longer have to be Held Hostage**

The good news is that I no longer need or have to be held hostage by the bully.

I no longer need to believe that I deserve to be bullied.

I no longer need to internalize the lie that I am not enough and that I do not do enough.

I no longer need to live in denial or defend other people’s denial. I no longer need or have to discard parts of myself.

I no longer need to stoop to the vicarious demands of other people’s expectations.

I no longer need to carry other people’s shame or sadness. I no longer need to be bullied by a fear of abandonment.

I no longer need to sit and be minimized, marginalized, discounted or dismissed by the bully.
By accepting that I am a work in progress — not a work in perfection — I have changed the way that I look at my process.

Consequently, I have had a change of perspective. I now look at myself and my experience in a different way.

I now realize that I no longer have to answer, defend, justify or explain myself to the bully.

I now realize that I no longer have to be accountable to the bully.

With my change of perspective — I now realize that my circumstances and experiences are meant to build me up, not to be used to devalue and shame me.

I now realize — as Eleanor Roosevelt poignantly stated — that no one can make me feel inferior without my consent.

“No one can make you feel inferior without your consent.”
Eleanor Roosevelt

In Conclusion

In my experience, I had to address how the bully (shame) crippled my life and my relationships. In my experience, I knew that something needed to change.

In my experience, I became willing to do whatever was necessary — because I no longer wanted to be bullied.
Because I no longer wanted to be bullied, I looked for solutions. 

Because I no longer wanted to be crippled by the bully (shame) I reached out for help.

**In my reaching out for help I found a new way of living.**

I found solutions for living life on life’s terms.

In my experience, I discovered solutions that help me to live life on life’s terms. A book that helped me understand and find solutions is *Shame and Guilt – Masters of Disguise* by Jane Middleton Moz. This book helped me to understand why I abused myself and allowed other people to abuse me through the “shame bully”.

For many years I did not know how to distinguish between guilt and shame.

Through my recovery process I learned something that changed my life and my world.

**Let me share what I learned with you.**

Guilt is different than shame. If you made a mistake, you can make an amends and thus resolve the guilt. 

Shame on the other hand is a being wound which leads the person to believe that they just don’t make mistakes, but that they are a mistake.

**Compensating for a Sense of Shame**
Shame can lead the individual to compensate by over achieving (develop a sense of grandiosity) or to under achieve (develop a sense of helplessness) can be seen in individuals who have been bullied by shame.

Being bullied by shame can lead the individual to develop a learned helplessness, which can in turn undermine the individual’s desire, ability and their motivation to succeed.

Illustration – The Pike Syndrome

Tank of water with a big fish at one end of the tank. Little fish at the other end of the tank. Pane of glass separating the big fish with the little fish. Big fish hits the pane of glass attempting to get to the little fish (food). Over time the big fish begins to associate pain with getting to the little fish. After a period of such conditioning the pane of glass is removed. Although the big fish can now readily get to the little fish, because of the learned pain associated with the little fish, the big fish gives up. The little fish can then swim around the big fish without a fear of being eaten. The learned helplessness results in the big fish going without food and starving to death.

Grandiosity and Learned Helplessness

Grandiosity (stiving to be more than so as to not feel less than) and a Learned helplessness (that I cannot do anything to change my situation and circumstances)

Both grandiosity and a learned helplessness perpetuates and gives power to the “shame bully”.
A learned helplessness occurs when an individual is subjected to what it perceives to be “adverse” stimulus that is believed to be inescapable. With this “stimulus” the individual is led to believe that they are helpless. Even when opportunities to escape or change are presented, this learned helplessness will prevent any action.

**Understanding the Impact of Invisible Disabilities**  
“Acceptance and Discovering a New Normal”  
Part 2 Zoom Presentation

Craig J. Phillips MRC, BA Second Chance to Live  
“Discovering a New Normal after Experiencing a Brain Injury”

**What I shared with a professional working with people living with brain injuries when asked about the term “new normal”**

**We are Not Our Brain Injuries – They Do Not Define Us**

**A New Normal**

I believe that life is likened to being on a train. The train runs down what I envision as the track of life.  
Along the track, I come to various places that look familiar to me.  
And then the day came when I experienced a brain injury.  
**A Switch Pulled**
On that day, unbeknownst to me, a “switch” was pulled and my life headed down a different track of the railroad. The railroad of my life.

The track that once looked familiar no longer looks familiar to me. Although being switched to a different track wasn’t my choice,

I now find my life traveling in a different direction.

**Accepting Something Does Not Mean I Like “IT”**

To be able to accept my “new normal” after my brain injury I discovered that I needed to grieve that I was no longer on the same “track”.

What I found was that I needed to confront what I could not do (my denial).

In my experience, I had to move through the stages of grieving (denial, anger, bargaining, depression and acceptance) to be able to begin the “re-birthing” process.

**Brain Injury, Re-birth and New Normal**

Re-birthing, re-framing and seeing my life’s experience in a new way after my brain injury

Re-birth in place of the term “a new normal”. I used the term “re-birth” to illustrate the need to own our power.

**Own our Power after Experiencing a Brain Injury. “Re-Birth”**
I shared the term “rebirth” with him because I believe new opportunities exist apart from the “old me”.

By framing my experience as a “rebirth” I am able to start fresh. I am able to start with a “clean slate” or a clean “canvas”.

I am able to “create in ways that work for me. Create in ways that work for me instead of being distracted.

**Owning Our Power**

Owning my power instead of feeling like I had been “cheated” out of something because of my brain Injury.

**Not “Why Me” but “Why not Me”**

Why not me gets me out of a mindset of merely being a “survivor” to accepting “what is” to be a “THRIVOR” in my life.

**To THRIVE in my Life, instead of surviving in my Life.**

**“What Is”**

Through owning my power, I am able to move forward with my life, instead of being stuck by comparing the “old me” with the “new” me.

**By re-framing (looking at “what is” instead of looking at “what isn’t”) I gain hope.**

Instead of comparing the “old me” with the “new me“, I am able to see my experience “what is” as an opportunity to create anew.
By owning my power and accepting what no longer “works” for me (after my brain injury) I no longer have to see myself as limited.

Limited by what No Longer works for me
Moving Forward with my Life after a Brain Injury
By re-framing, my experience and letting go of what cannot be changed I am able to move forward with my life.
Through seeing my experience as a “re-birthing” I am able to create with “what is”, instead of looking back to “what could have been”.

By building on “what is” I am able to create my dreams in ways that work for me.

“When one door of happiness closes, another opens; but often we look so long at the closed door that we do not see the one which has been opened for us.”

Helen Keller

“If you advance confidently in the direction of your dreams and endeavor to live the life that you have imagined…You will meet with a success unexpected in common hours.” Henry David Thoreau

Strategies that Have Helped Me in my Re-birthing Process

(Discovering my New Normal) after my Brain Injury

Through my recovery process, I became aware that I am much more than my brain injury. I am made up of a mind, body, soul, spirit, and emotions.

With this realization, I became aware that I needed to include my mind, body, spirit, soul, and emotions in my ongoing brain injury recovery process.

By examining how to involve my mind, body, spirit, soul, and, emotions in my ongoing brain injury recovery process I developed strategies.
Strategies for Discovering Our New Normal after a Brain Injury

Strategies that have Given me the Ability to Own My Power in my Ongoing Brain Injury Recovery Process

What Makes Me Who I Am in My Life

Mind – Growing in wisdom and understanding of how to relate to ourselves, other people and the world around us.

How We Learn — Understanding ourselves and how we learn after our brain injury. How we learned before our brain injury may now be different. As a result, we may find ourselves frustrated with learning. Consequently, the way people (teachers) may be trying to teach us may not be the way we learn.

Get tested to determine how you now learn.

Visually, Auditorily, Kinesthetically or a combination of these learning styles.

Body – Using the principles of neuroplasticity to improve your hand-eye coordination, balance, body awareness, coordination, focus, and agility. Create new neural pathways and brain reorganization through repetitive mirrored movements using both the dominant and non-dominant sides of our bodies.

Connections

Spirit – My connection to God. My connection to myself. The importance of making peace with God so that I can
learn to trust Him and His guidance. The importance of making peace with my past is so that my past does not spoil my present.

**Soul** – Growing in knowledge and wisdom of how to accomplish what I discovered through my process of acceptance. Learning to use my gifts, talents as I tap into my ability to live my purpose through my being.

**Emotions** – Learning how to talk, trust and feel with safe people. The power of identification. Coming out of the shadows of isolation and breaking free from feelings of alienation.

**Give Yourself Permission**

Give yourself permission to look at your life and your experience in a new way. In a way that empowers your process.

Begin to “paint” (if you have not already begun) on the canvas with your gifts, talents, and abilities in ways that work for you.

Begin to build on your lot in life (if you have not already begun to build) and don’t compare your lot to anyone else’s lot.

“Regardless of your lot in life, you can build something beautiful on it.” Zig Ziglar

**Brain Injury “Re-Birthing” is an Ongoing Process**

**Develop an Ongoing Recovery Process Strategy**
Develop an ongoing recovery strategy to include your body, soul, spirit, mind, and emotions in your ongoing recovery process.

**To Own Your Power**

Below is a link to several tools that have helped me to own my power in my ongoing “re-birthing” brain Injury recovery process.

You may find these tools to be helpful in the process of owning your power.

Click on the link to open these resources.

**Second Chance to Live Resources for Re-birthing**

**Understanding the Impact of Invisible Disabilities -- “Why do I Feel so Misunderstood and Shunned?” Part 3 Zoom Presentation**

Craig J. Phillips MRC, BA Second Chance to Live

**Comment and Question**

Recently I received a comment and a question. As an individual living with the impact of a brain injury and an invisible disability, I have asked the question many times.

The question I received was, “**Why do I feel so misunderstood and shunned?**”. In my experience and through many struggles the answer to the question became apparent to me. If you have asked this question too, I would invite you to read on to find out what became apparent.
What became apparent to me helped me to have peace in my life when misunderstood and shunned.

What became apparent to me helped me to grow in self-acceptance, despite being misunderstood and shunned.

What became apparent to me helped me to let go of the people who misunderstand and shun me.

What became apparent to me helped me to move across the bridge called hope and create a good life for myself.

What Became Apparent to Me

In my experience and through my own recovery process, I came to realize two realities.

The first reality is that many people do not want or do not know how to process their feelings.

The second reality that helped me to begin to have more peace in my life was that many people either do not know how to or do not want to change.

To face the reality that our lives have been forever changed because of our brain injury may be too painful.

Too painful for them to accept. Because accepting our reality may be too painful, individuals may stay in and defend their denial.

As a result, and because of the lack of acceptance, they may justify, in their minds, the way they treat us.

I Need to Remember
Defending their denial for what they do not want to accept is not our fault.

Justifying the way, they treat us, because of their lack of acceptance; is not our fault.

**Did Not Work**

In my experience and for many years (once I began to come out of my own denial) I attempted to get family members and friends to understand and accept my reality.

I tried to explain to them in many different ways that I was not “fudging” or “making excuses”.

I tried to convince them otherwise, but the more I tried the more I felt frustrated.

What was conveyed to me was, that if I just tried harder then, I would not be affected by my brain injury or by my reality.

But the reality was that I had tried “every which way”. Every way possible to prove that I was not affected or impacted by the open skull fracture and brain injury that occurred when I was 10.

**Ongoing Conflicts**

Instead of helping them to understand and convincing them of my reality, my efforts only created ongoing conflicts.
Conflicts in them because of what they could not accept and conflict in me for feeling that there was something wrong with me.

Conflicts in me for not being able to not be impacted by a brain injury. Conflicts in me by attempting to disprove my reality.

Conflicts in them that would leave them angry. Conflicts in me that would leave me frustrated.

Conflicts in me that left me with a sense of shame. A sense of shame for not being able to overcome the impact of my brain injury and my invisible disability.

Awakening

After much toil and cycles through the above-mentioned conflicts, I had a spiritual awakening.

A realization that I needed to do something different. A realization that I needed to do something to be able to accept myself to get different results.

A realization that what I was trying to change, was not changing the impact of my brain injury or helping my relationships...

Insanity – doing the same things over and over again expecting to get different results.

Making Choices

When I reached a point when I could no longer deny and defend my reality, I made some life changing choices.
I began to grieve my reality.

Grieving my reality helped me to get to a place of acceptance.

Acceptance provided the “bridge” to taking a different course of action. A course of action to create hope in my life.

A Bridge of Acceptance to Cross Over to Create Hope

Through my grieving process, I discovered that as I was able to face, confront and address my own denial. By facing, confronting and addressing my denial I started to walk across the bridge.

Finding Freedom from the Struggle
What I discovered was that by confronting my own lack of acceptance, I was able to let go of the struggle.

The struggle to get them to be OK with me, so that we could be OK, so that I could hope to be OK with me.

The struggle that convinced me that I needed to get “them” to understand and accept what I could not change.

The struggle that led me to believe that I needed them to accept my reality before I could get on with my life.

What I Discovered

I alone needed to accept the impact of my brain injury and my invisible disability.

I cannot wait for people to start or come across the bridge of acceptance.

I needed to and need to let go of what other people think of me because of their lack of acceptance.

I needed to cross the bridge of acceptance and keep walking to fulfill my destiny.

I needed to keep walking to create a good life for myself in my reality.

I needed to discover how to be effective in my reality despite my deficits and limitations.

Realization
I began to realize that being misunderstood and shunned was the “way” in which “they” coped with what they could not accept.

I began to realize that I needed to let go of the people. Let of the people who misunderstand and shun me to grow in acceptance.

I began to realize that I needed to let them believe what they need to believe, for whatever reason.

I began to realize that I needed to discover how to use my gifts, talents and abilities in ways that would work for me.

A Metaphor

Several years ago, I wrote an article and created a video presentation of the article to illustrate our great value. Our great value because of our reality.

“Living with a Disability and Rudolph the Red-Nosed Reindeer”

Click on the Links to Read or Watch the Presentation
Living with a Disability and Rudolph the Red-Nosed Reindeer

Living with a disability and Rudolph the Red-Nosed Reindeer Video Presentation

Acceptance

In my experience, as I grew in acceptance, I found a new freedom. A freedom to run my own race and stay in my own lane. A freedom to realize and use my great worth and value.

Hope
My experience may help you to let go of the people who misunderstand and shun you because of what they are unable to accept.

My experience may help you to find more peace in your life by accepting who you are as an individual living with a brain injury and an invisible disability.

My experience may help you to not feel less alone.

To read about my experience, process and journey click on this link.

Second Chance to Live Author’s Autobiography in Bullet Points