

Waking Up Mental Illness

Taking Mental Illness Out from the Rug so We all Can Grow

Introduction

- Cargo Shorts and Sandals
- Doctor, Lawyer and Scientist
 - Better to have a husband or boyfriend
- Who we are
 - Family of five
 - Married 19 years
 - Wanted to be the perfect parents
 - At 3 found out son had cognitive development issues
 - Bell curve
 - Throw the kitchen sink at it
 - First 15 years
 - Programs for our son
 - Kids activities – sports and school
 - Happy family – doing everything together

Our Mental Health Journey

- November 25, 2016
 - “I can’t do this anymore”
 - Emergency room – 12 times
 - Ambulances – 10 times
 - Inpatient hospitalization – 8 times
 - Residential facilities – 3 times
 - Child protectives services – 3 times
 - Twice pulled out other kids out of school
 - Repeatedly accused by therapists of “causing” the illness

Our Journey

- Oldest daughter
 - Eighth grade
 - Counselor's office
 - No lunch room
 - Crying not to go to school
 - I don't fit in
- What do we do as parents
- Healthy Emotions Program
 - After school program for kids struggling

Healthy Emotions Program

- Seemed to be happy
 - Found her groove
 - Seemed like a good thing
- New and strange behaviors
 - Cutting
 - Constant talk of programs – acronym central
- Parent night
 - Similar stories
 - Cutting – where are they getting this
 - Social media as diaries
 - We're not alone

Post Healthy Emotions

- I want to go to PHP
 - Need to go to school
 - Swimming
- You're not listening
- Night after swim practice
 - Bottle of advil
- Poison control
- What to do next
 - Called therapist from Healthy Emotions

Emergency Room

- Only way to PHP is through emergency room
- Doctor; social worker
- No beds available
- Sent home
- Distraught
- Called everyday at work to multiple places
- Finally got through

PHP

- Intake
 - Met with psychiatrist
 - Diagnosis
 - Medication
 - Is this really how they do it
 - Met with therapist
 - Matter of fact; Firm
 - After you leave here I don't ever want to see you again
- Program
 - Half day at school – half day at PHP
 - Despised school; loved PHP
 - Joked with staff; new best friends
 - No sharing of information
 - Found connection
 - No clue at the time of how significant this was
 - Strange stories
 - We didn't know what to think or do

Post PHP

- Eighth grade ended
 - Summer regular routine
 - Explored different schools
 - Variety of schools
 - School with more diversity
 - Catholic school – big fish
- Freshman year
 - Fall semester – fabulous
 - Swim team
 - This is behind us
 - Spring
 - Strang behavior reappear

Freshman Year - Spring

- OCD, must write out every number
 - Refused to walk on cracks
- Disengaged in school
- Lost focus
- Seemed ok socially
 - With other kids who were struggling
- I don't want to go to school; I just want to die
- Please let me die
- What do we do?
 - I thought this was behind us

Private Therapy

- Engaged in private therapy
 - Helped at first
 - Each meeting; new illness
 - Is this where she was getting the OCD
 - Was the therapist suggesting new illnesses to try on
 - Getting worse
- Try DBT
 - No – dirty fishbowl
 - Healthy emotions
 - PHP
- Spiraling out of control

Mayo Clinic

- Fifteen minute conversation Dr. R.
 - 45 minutes with me
 - Described perfectly everything we were going through
- Finally, someone who understands what is going on
 - Going to be a long journey
 - Remember two things:
 - Keep her alive
 - Keep her out of the hospital

Keep Her Out of the Hospital

- Why Out of the Hospital
 - Connection
 - Comfort Zone
 - Revolving doors
 - Difficult to break cycle
- How do we find someone knowledgeable
 - Referrals
 - Referral from a referral
 - Very difficult to find someone knowledgeable

Dr. Z

- Meeting with Dr. Z
 - Described our situation to a T
 - Someone who understands
 - Liked him as much as Dr. R from Mayo
- Advice
 - Those with MI find comfort in chaos
 - Need to be firm and rigid
 - No easy resolution
 - Long and rocky journey
 - Be like Kobe Bryant
 - Recommended a few books
 - You are the quarterback
 - And “oh ya one more thing.”
- I can't imagine how anyone could deal with that

Back to PHP

- Struggling continued in school
 - OCD traits – nonfunctional
 - Spring semesters
- Therapist for OCD
 - She doesn't have OCD
- What do we do?
 - Something else or continuity
 - We chose continuity
 - PHP at same provider but a different location
 - Asked if Dr. Z could quarterback

New Therapist at New PHP

- New psychiatrist and therapist
 - Very different style from first therapist
- Daughter really liked her – very sweet and kind
- First family therapy
 - Need to start taking this more seriously
 - “I’m just going to say this”
 - “She was not born like this”
- Did she just say what I thought she did
 - She doesn’t even know us
 - She just met our daughter

Meeting with Psychiatrist

- Read multiple books about mental illness and therapists
 - Became knowledgeable
- Want to understand what therapist is getting at
 - Never met us
 - Doesn't know anything about us
 - Blaming us
 - Do you agree with her assessment of no biology
 - How is this helping our daughter
 - Searching for a new identity and you are handing her one
 - What they need is love and care
 - I don't agree with "rigid" and "tough" approaches
 - We need a new therapist

The Decision

- Did not change therapists
- Kathleen in Mexico
- Son's swim meet
- The day I will never forget
 - Multiple voice messages
 - Please don't send her
 - She has a plan
 - Where do you set the threshold?
 - I'm sorry – I'm sending her
- What do to
 - I called Dr. Z
 - That's unfortunate
 - Where did she set the threshold
 - Not much you can do now

Inpatient

- We want her out
- We will put her on a hold – Safety is paramount
- Stay until she stabilizes
- Demoralized
- Discussion of prior therapists
- What's your approach
- We are creating an identity for her
- You have to trust me

Prison

- Is this really happening
 - Metal detectors
 - No strings, sharp objects, markers.
 - No phones
 - Locked doors
 - Escorts
- Walked in and met with therapist
 - Handed me this

Camp

SKY Fall 2019							
	Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
7	Sleep In	Morning Routine	Morning Routine	Morning Routine	Morning Routine	Morning Routine	Sleep In
8	Morning Routine Breakfast	Breakfast	Breakfast	Breakfast	Breakfast	Breakfast	Morning Routine Breakfast
9	Morning Routine Hygiene	Hygiene	Hygiene	Hygiene	Hygiene	Hygiene	Morning Routine Hygiene
10	Cards and Games	Movement	Movement	Movement	Movement	Movement	Cards and Games
11	Running Group	Process	Process	Process	Process	Process	Tech Activity
12	Rec Therapy	Rec Therapy	Art Therapy	Rec Therapy	Rec Therapy	Rec Therapy	Rec Therapy
1	Social Skills Lunch	Lunch	Lunch	Lunch	Lunch	Lunch	Social Skills Lunch
2	Quiet Time	School	School	School	School	School	Quiet Time
3	Rec Therapy						Tech Activity
4	Expressive Arts Tech Activity or Choice Group (1st hour)						Process
5	Snack	Snack	Snack	Snack	Snack	Snack	Snack
6	Quiet Time	Team Time	Team Time	Team Time	Team Time	Team Time	Quiet Time
7	Community Meeting	Recess	Recess	Recess	Recess	Recess	Community Meeting
8	Break	Community Meeting	Community Meeting	Community Meeting	Community Meeting	Community Meeting	Rec Therapy
9	Tech Activity or Instant Mediated Dinner	Dinner	Dinner	Dinner	Dinner	Dinner	Coping Skills Dinner
10	Cards and Games	Quiet Time	Quiet Time	Quiet Time	Quiet Time	Quiet Time	Cards and Games
11	Community Night	Break Choice:	Break Choice:	Break Choice:	Break Choice:	Break Choice:	Movie Night
12	Evening Routine	Physical Activity Cards and Games Expressive Arts Evening Routine	Physical Activity Cards and Games Expressive Arts Evening Routine	Physical Activity Cards and Games Expressive Arts Evening Routine	Physical Activity Cards and Games Expressive Arts Evening Routine	Physical Activity Cards and Games Expressive Arts Evening Routine	Evening Routine
1	Snack	Snack	Snack	Snack	Snack	Snack	Snack
2	Relaxation	Relaxation	Relaxation	Relaxation	Relaxation	Relaxation	Relaxation
3	In Room	In Room	In Room	In Room	In Room	In Room	In Room

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9/3/2019

The Schedule – Connection

- 7-8 Sleep In/Morning Routine
- 8-9 Breakfast
- 9-9:15 Hygiene
- 9:15-10 Cards and Games/Movement
- 10-11 Nursing Group/Process
- 11-12 Rec Therapy/Art Therapy
- 12-12:30 Lunch
- 12:30 – 3 School/Rec Therapy/Art/Tech Activity
- 3 – 3:15 Snack
- 3:15-3:45 Team Time
- 3:45-4:15 Recess
- 4:15 - 5 Community Meeting
- 5 – 5:30 Dinner
- 5:30 – 6 Quiet Time
- 6 – 6:15 Break
- 6:15 – 7 Choice/Physical Activity/Cards and Games/Expressive Arts
- 7 – 7:15 Snack
- 7:15 – 8 Relaxation
- 8:00 In Room

Camp

- Recalled words of Mayo Dr. and Dr. Z
 - Keep her out of the hospital
- It's just like camp
- Creating a magnet for her
- Only one hour of therapy
- What's the plan for making this too enjoyable
- Is there an orientation process for parents

I'm a Big Deal in Here

- I then got to visit our daughter
- I'm the most popular kid in here
 - And please bring me Starbucks next time
- Then met with psychiatrist
 - Only have a few minutes
 - I rambled about it being like camp
 - Want her out – It's like a prison in here
 - Is it a prison or a camp
 - We laughed
 - The system is not perfect; we are keenly aware of revolving doors
 - It's a very difficult path to navigate
 - Safety always is always paramount and that creates holes in the system

Feeling Bad and Sad

- Kathleen's visit with Lucy
 - Expecting her to be sad
 - Mom, let me introduce you to the staff
 - Next time you come please bring me Noodles and Starbucks
- What should we do
 - Should we be feeling bad or sad
 - We had no idea what to do
 - Kathleen wanted to make it comfortable
 - I wanted to make it uncomfortable
 - Hard to know what to do – emotional

That Night

- Back from hospital
 - Son was with our au pair
 - Son - Where were you dad?
 - Had to do some stuff for your sister
 - Didn't say a word, walked over to cabinet grabbed markers and canvas board

What lies ahead



The Note

- Kathleen in our daughter's room sobbing
- Found a note on her computer
- What has happened – Our lives turned on a dime
- What are we going to do?
- Like living in another universe
- Where is everybody
- Crickets were deafening
- We didn't open up

Did we cause this

- Maybe the dr. was right to send her
- We lost complete confidence in ourselves
- What did we do wrong
- Were we just really bad parents

The dirty fishbowl effect

- Loving the new environment
- I'm the most popular kid in here
- Nicknames with all of the staff
- We inadvertently made it comfortable for her
 - We need to be there for her
 - Instinct it to comfort
- Running the place

New Home

- We expressed that she was liking it a little too much
 - Stopped talking to us
 - “She’s” not ready to talk to you
 - “She doesn’t want to see you”
- When she did talk to us
 - Not interested in discussing plan to get better
 - Stories of other kids struggles
 - Acted like therapist to other kids

We've lost our daughter

- Sole focus in on making friends
- Dr. T didn't know what to do
 - Working every angle
 - Packets
 - Intensive care unit
- Unrecognizable
 - Left that night even more distraught
 - We've lost our daughter

Allegations and CPS

- Next day even worse
 - Stories to staff
- Staff mandatory reports
- Don't worry – CPS won't investigate
- Call from CPS
- Twilight zone continues
- Obvious that stories are false
- We see this a lot; I'll keep the file with me
 - You need to protect yourselves
 - Her stories will better the longer she is in the hospital

Train Wreck

- Dr T.
 - We don't know what to do
 - We try everything and she just escalates
 - Extinction Burst
- Stabilized and released home
 - Now what
 - School
 - Needs more structure
- PHP with original therapist
 - Different medications
 - Different approaches
 - Nothing working
 - Escorts
 - Just let me die; please let me die

Anything to Keep Her Out of Hospital

- Desperately wanted back in the hospital
- Plan to keep her out
 - 911 – paramedics
 - Letter
 - Buzz words
- Impossible to get all on same page
- Back at hospital
 - Behind the glass
- Back to inpatient

More of the same

- Inpatient, release, php, inpatient – caught up in tornado
 - Always found someone to believe her
 - Buzzwords, stories, sympathy
 - Nurses and tech's rubbing her back
 - Food and movies in the hospital
 - Maintained control through chaos
- She needs long-term care

Residential

- Search for “right” one
 - Specialized in personality disorders
 - DBT focused
- Unique model
 - Separate family therapist from daughter’s therapist
- Told them our concerns with desire for peer connection and stories
- Family Therapist
 - Will teach us skills
 - 24 year old
- You can’t see her “because of the abuse”
 - Excuse me, what abuse
 - You know the abuse
- There has been no abuse – These are stories she fabricates to fit in

Family Therapy

- Family therapist, her boss and us
- We trust you; we will look at everything
 - 9 months searching behind each stone
- After 9 months of looking at everything at home, nothing
 - Why don't we look at peer issues
- I don't think that's it
- Little was uncovered in family therapy
 - Daughter was telling friends and her therapist she was abused

Transitioning Home

- Stability and home visits - Optimism
- Spring break in Duluth
 - Home early
 - Kathleen in office crying
- Made an allegation against you
- Therapist called CPS
- Called the Therapist
 - Why did you not call us
 - There was a mark
 - Do you believe what she has been telling you

Meeting with Administration

- How can this happen
- We are mandatory reporters
 - Don't you owe it to her treatment to discern more
 - Don't you owe it to her to ask for more information
 - Don't you owe it to her to dig deeper
- You have been giving her an identity
 - You are in the middle of the storm and can't even recognize it
- We are breaking off contact
 - Don't do that – she needs support and love
- You have not listened to us
- We changed course

Child Protective Services to Schools

- While we were meeting with staff, Kathleen got a text
 - WTF – I just got pulled out of class
 - She is on the way to see V
- Middle daughter (8th grade) distraught
- Son confused; teacher attended “meeting” with him
 - I’ll keep in confidential
- The file had been closed and reopened by someone new
- How can this happen; you are destroying out other kids
- What can we do to make sure it doesn’t happen again
 - I’ll meet with team to make sure it doesn’t happen again

Daughter Opens Up

- Three days later, admitted stories were made up
 - Letter
- Discharge meeting
 - See how much better she is
 - Successful
- You've got to be kidding me
- Why are you saying these things
 - Don't worry about it
- Everyone had a story and I didn't
- I wanted my therapist to like me; I didn't want her to think I was a loser

Post-Residential

- Slow progress
 - PHP
 - New school - options
- PHP – psychiatrist
 - Need a “reprieve”
 - Please don’t send her
 - More inpatient
- The cycle restarted
 - She can’t make it at home and the hospital makes it worse
- Very short stays at inpatient
 - Keep at it; we will break this
 - Home is her best option

Turning the corner

- Inpatient “kicking her” out
- More stability at home
 - Job as a swim instructor
 - Stability with alternative school structure
- Stable few weeks – Then phone call from suicide hotline
 - In parking lot; Swallowed pills
 - Back in ER
 - Strange stories continue
 - Wouldn't see us
 - Nurses rubbing her back
 - She was in charge at the hospital

Back to Inpatient

- Hospital would not release her home
- Back to inpatient
 - Immediately scheduled for release
 - Kathleen to pick her up
 - She wouldn't leave
- Dr. T called – made another allegation – don't think anything will come of it
- Later that day a new guy from CPS called Kathleen

CPS Round 3

- New guy – very aggressive
- Serious allegations
- Called Kathleen while he was at our daughter's school
- Daughter bawling and broken
- Social media in a frenzy – why was C pulled out of class
- Haven't you review the file; what are you doing here
- Drove to our house to interview Kathleen
 - Very aggressive with Kathleen; daughter looked at Kathleen and said: "I'm sorry he's being so mean to you."

CPS – Round 3

- Kathleen texted me:
 - This guy is going to try to take our kids
 - He said he is going to call you next
 - He is on his way to see our daughter at the hospital
- Kathleen then called me:
 - X just called and said she told the guy she made the whole thing up
- CPS guy then called me at work
 - Asked if he was at hospital and my daughter indicated she made the whole thing up
 - Didn't answer
 - Proceeded to interrogate me
 - Have you reviewed the file
 - Did you consider the effect on our other kids
 - Why are you doing this
 - Standard Protocol

The Call with My Daughter

- Biking home and daughter called me
 - I'm so sorry
 - Do you understand how many people are getting hurt by your stories
 - I told them I made the whole thing up
 - What are they going to do to me
 - Why do you keep making up these stories
 - It's the only way people will listen to me. I told them I was not ready to discharge and they would not listen to me. I didn't know what else to do.

Moving Forward

- Periods of stability and many hospital stays
 - Blocked from PC “inpatient”
 - Two additional residential programs
 - Many, Many ER visits
 - Essentially addicted to hospitals
 - Same behavior as drug or alcohol addiction
 - Gets reinforced by hospital staff
 - Don’t bother to read the file
 - Rub her back; watch movies
 - Then to inpatient
- Recent ER visit sums up the cracks in the system

Summing Up the Cracks

- Fourth of July weekend
 - Woke up and she was gone
 - Tracker said she was at Children's hospital
 - Walked to store, bought pills and ubered to the ER
 - Social worker called
 - Dr's. are saving her life
 - Please have psychiatrist call us – we do not want her send to inpatient
 - Inpatient is like a drug for her
 - She will do anything to get back to inpatient
 - She won't talk to you – nothing you can say that would change her mind
 - PC inpatient won't accept her we said
 - They just did and she is on her way there
 - The next morning – PC inpatient psychiatrist called us; I'm sorry she should not have been admitted. We are sending her home.
 - I went to pick her up and she wouldn't leave – Her favorite psych. tech was working that weekend
 - Finally, she discharged that next Monday

Summing Up

- Picked her up; went to family get together for Fourth of July
- Three days later she took a handful of pills and was back at the Children's ER
 - They send her to Mayo inpatient
- Mayo called us
 - Why does the file say she was discharged from inpatient AGAINST MEDICAL ADVISE
- Kathleen emailed Dr. T
 - Dr. T sent an email confirming never released AMA
- We asked to see the file
 - Patient released AGAINST MEDICAL ADVICE by parents urging so she could spend the weekend at a cabin
 - Parents are separated

Summing it up

- Kathleen send a long email to Children's
 - Your records are incorrect
 - Never released against AMA
 - Been married for 19 years
 - File replete with assumptions that are patently wrong
 - Psychiatrist refused to call us bc nothing we could say would change her mind
 - Psychiatrist refused to call our treating psychiatrist
 - Social worker refused to listen to our concerns about inpatient
 - It is this behavior that is largely responsible for our journey over the last three years
 - Assumptions
 - Predetermination
 - Condescension
 - Failure to read the file
 - Failure to ask questions
 - Not knowing what you don't know
 - We would like a response regarding how this happened, and would like to meet with your team to discuss how we can improve the process
- Three weeks later we received a letter
 - We are sorry. The team typed in the file what they were told by your daughter
 - Everything we do is in the best interest of the patient

Best Interest of the Patient

- The standard we all try to meet
- What does this mean?
- Not on my watch
- Slow spiral of contraction
- Short term vs. long term

Best Interest of the Patient

- Goal
 - Functioning for growth
 - Individual
 - Contribution to the world
- Not without risk
- Easy Path – Difficult Path – Courage
- How to Foster Functioning for Growth

Functioning for Growth

- Long-term thinking
- Ask questions
- Read the file
- Team approach
- Know your role/limits
- Recognize the unwitting nature of compassion
- Tough love
- No easy answers
- Where is connection being fostered
- Are programs inadvertently removing natural consequences
- What does the “fish bowl” look like
- Adult programs as models

Functioning for Growth

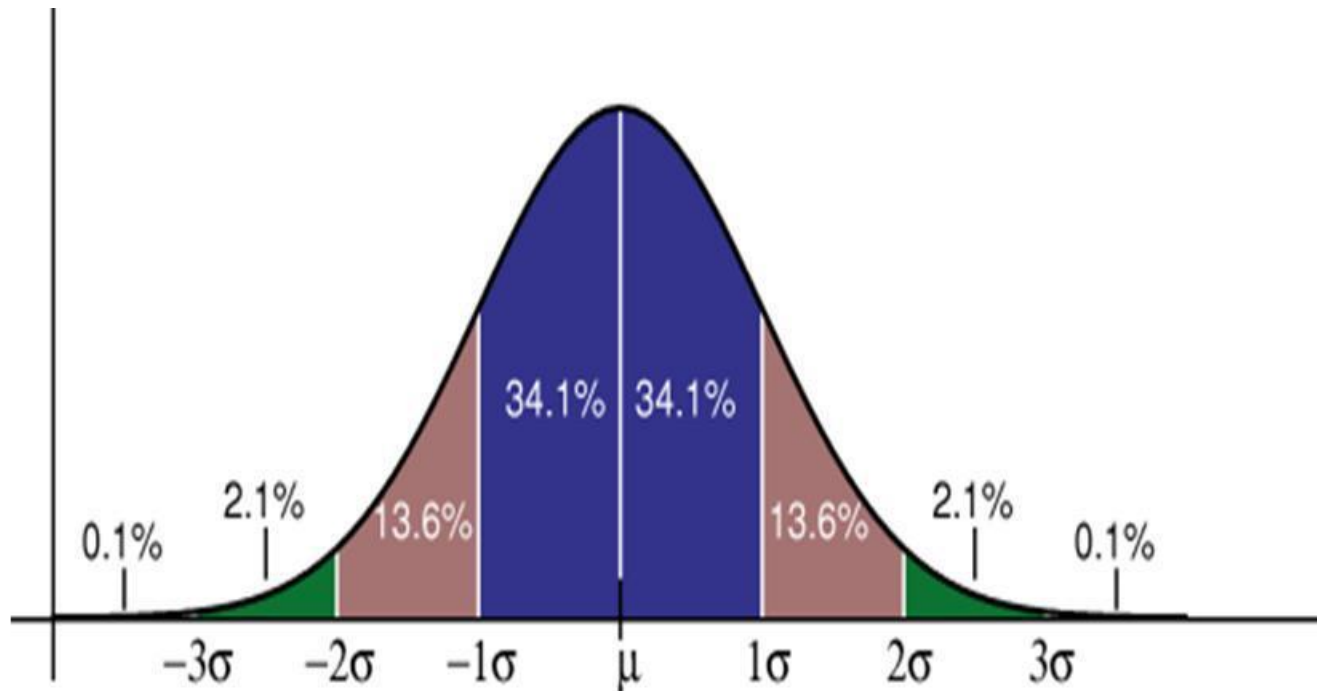
- Actions that lead to contraction
 - Thinking the answers are clear or easy
 - “I’m going to teach you”
 - Not reading the file
 - Not asking questions
 - Not listening to parents
 - Not orienting parents and siblings
 - Not questioning the patient’s stories
 - Ask questions
 - Read the file
 - Not adequately training staff
 - Social workers
 - Psychiatrists
 - Not adequately considering the mental health connections and identity
 - Not having a trained psychiatrist on staff
 - Commonality – Canned approach

What did we do wrong

- We have asked repeatedly over the last three years
 - What did we do wrong?
 - Did we cause this?
 - What could we have done differently?
- Was this inevitable?
- Why does this happen to people?
- What's the meaning behind the mess?

Meaning and Purpose

- MI is life at the edges
- Purpose:



Live Long and Proper

- Spock and Society
 - It's society's unwritten goal
 - It's what most of us unconsciously work towards
- It's why we get so upset and why it is so difficult
 - Anything outside of the bell curve causes havoc

Growth

- What if instead the goal is growth
 - Life at the edges is a catalyst
- Our journey
 - A gift to experience life differently
 - Rocket ship to a “new world”
 - Wouldn't trade it for anything
- Storm at Sea – Strong Sailors

Meaning Behind the Storms

Blessed are the weird people, the poets, the misfits, the artists, the writers and music makers, the dreamers and the outsiders.

For they force us to see the world differently.