Experts Share

The Children of Everett House

The Adolescents of the UMass Continuing Care Units

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> “Listen, listen, and listen some more and when I feel heard, I will begin to heal.”

A thoughtful adolescent
at the UMass Adolescent
Continuing Care Units

Experts Share

In 2001, DMH undertook an initiative to promote strength-based care and reduce the use of S/R in licensed and contracted child and adolescent hospitals, Clinically Intensive Residential Treatment programs (CIRT's), Behavioral Intensive Residential Treatment programs (BIRT's), and Intensive Residential Treatment programs (IRTP's), as described in more detail in the *Overview* section of the *Resource Guide*.

As part of the process of creating the first edition of the *Resource Guide*, children and adolescents shared their thoughts about S/R and their ideas about how programs can further reduce their use of S/R in the future. In the second edition, the focus was expanded to people of all ages and families who were asked about their experiences in treatment programs and recovery.

Information included in this chapter came from direct interviews and materials that were provided for this project. Several adult experiences were taken from publicized accounts of people who have been involved in the mental health system.
A number of narratives are from people who participated in interviews or provided written accounts and explicitly gave permission to print their work for this *Resource Guide*. We are very grateful for all of these important contributions.

Former Residents of a Clinically Intensive Residential Treatment Program (CIRT)

Children ages 5-13

Thoughts offered during interviews

Andrew, age 11: "I used to beat up staff. Maybe they wanted to cry inside, too."

Andrew reported that staff members often restrained him when he was first admitted to the program. He stated, "I used to beat up staff. Maybe they wanted to cry inside, too." Andrew said that restraints were not helpful for him, but he was able to identify a number of calming strategies that he now uses to avoid using aggressive behavior. He listed calling his mother on the telephone, using the quiet room, listening to music, and using the swing in the sensory room as important settling strategies.

Robbie, age 12: "I'm the one that goes to the hospital."

Robbie said that he had been in treatment at the CIRT program for over two years. He stated, "I'm the one that goes to the hospital." Robbie said that he used to be restrained "a lot" by staff, but now it does not happen as often. He said that restraints are not helpful for him, and he listed a number of things that he tries to do when he is feeling upset, including

playing with toys, playing basketball, using the swings in the sensory room or outside, and playing catch with staff.
Robbie said that staff members remind him to use those settling strategies that are helpful for him. He made a number of suggestions of things he thinks the program needs to do to help kids, such as building a track and a swimming pool, because he enjoys physical activities.

University of Massachusetts,
Adolescent Continuing Care Units
Westborough State Hospital,
Westborough, MA
Adolescents ages 13-18

The adolescents at the UMass Adolescent Continuing Care Units shared their thoughts in several different ways. Two adolescents wrote down their ideas; a number of adolescents talked with program staff, who wrote down their comments; and, finally, several adolescents agreed to participate in interviews about their experiences with S/R.

Written thoughts

Jeff, age 19: “As time goes by, the stronger I am.”

“As time passes by I see all the pain
As time passes by I see all the rain
As time passes by I wish I was home
As time passes by I grow older
As time goes by time kills
As time goes by the more I sing
As time goes by the stronger I am.”

Kim, age 18: “… all we need to do is work as a team and think outside the box.”

“Restraint prevention is a very important thing that needs to happen in all hospitals. Restraints are painful and degrading. By putting a kid that has already been traumatized into a restraint is mortifying. There is a way around restraints; you have to think outside the box. Some things work well for one kid, but can be more damaging for another. To avoid restraints everyone needs to feel safe. For example: a sensory room, that is sound proofed, has sensory things, and relaxation equipment. I know in my times of suffering, being in the coat was a way to punish myself, but once that placement got a sensory room, that everyone took part in making, I found that I was restrained less. I also think that instead of giving treats after a certain amount of time restraint free, we should take all the kids that have been safe for one month or more and pick a place to go and enjoy the road to recovery. Most kids who have a hard time will see those who get the reward and will try harder. We should, as kids, start a group around restraint prevention. Like I said before, all we need to do is work as a team and think outside the box."

Thoughts offered to staff

Adolescents at UMass said the following to staff members on their units:

"Talk to me about my strengths"

"Ask us about our assets"

"We are ramping up our resilience"

"We are positive problem-solvers"

"Get to know all about me, not just my mental illness"

"I am so much more than a patient, I am a son/daughter, friend, relative and a youth in your community"

"We are restraint -free youth"

"Trauma can happen to anyone"

"The relationship I had with the staff person was what helped me the most"

"I have a positive future vision, please don't let stigma get in my way"

"Listen, listen, and listen some more, and when I feel heard, I will begin to heal"

Thoughts offered during interviews

Eight adolescents agreed to participate in interviews for the *Resource Guide*. They were all excited by the idea of having their thoughts printed in a book to help staff members reduce the use of S/R in treatment programs serving children and adolescents.

Tristan, age 15: "Restraints are no fun. You have to be held down on your hands and legs. You can't even move. It's very frustrating."

Tristan reported that staff members usually restrain him for hitting people and throwing things at people. He stated, "I get frustrated when things don't go my way and I flip out." Tristan said that staff members do not restrain him nearly as often as they did in the past. He cited several coping skills he uses, including talking, playing basketball, doing physical exercises in his bedroom, talking to his mother on the telephone, and listening to music.

Tristan said that he thought some staff members use the safety coat too quickly, without waiting to see if he was starting to calm down. He stated, "Staff should look for safe behavior." Tristan went on to say, "Restraints are no fun. You have to be held down on your hands and legs. You can't even move. It's very frustrating."

Tristan likes some of the items in the program sensory cart, and he said that he uses *Game Boys*, jump ropes, and stress balls. He also uses outdoor time with staff members "to shoot hoops." He said that physical activity helps him calm down, and there are usually staff members available to take him outside to engage in an activity when he feels he needs it.

Brianna, age 13*:* "They think the chart knows everything. No one knows everything unless you tell them."

Brianna said that she has been in the program for over a year. She stated, "I was restrained all the time when I came." Her suggestions for staff members to help prevent the use of restraints were: "Don't argue with us like we are little kids;" and "Don't talk to us like we are little kids." She added, "Some staff want to get the last word in." Brianna said kids often say *"forget it"* to staff members and walk away. She pointed out that means they do not want to talk anymore, and staff members should respect what they say or when they don't want to talk.

Brianna believes that when staff members do not speak English well, it contributes to misunderstandings. She stated, "They get offended." She also said that there are staff members who assume that they know kids because they have read their clinical records. She stated, "They think the chart knows everything. No one knows everything unless you tell them."

Brianna said, “Everyone here has their own problems. Some kids hit people and staff intervene quicker. They were worried about that when I first got here, but I haven’t hit anyone here.” Brianna said that she was physically assaultive at other hospitals and at DYS when she was there. She said she was restrained with handcuffs at DYS and locked in her bedroom until she calmed down. Brianna believes that the incentives in her current program, such as going home on overnights, help motivate kids to do well. She also said that trips to the hospital vending machines, the social center, and recreational trips every Sunday are good motivators, too.

Tiesha, age 16: “In the past, I never thought about the future.”

Tiesha reported that she was being discharged to a less restrictive program the following day, although she had been restrained by staff the previous day. She indicated that a peer was teasing and threatening her, and she “went after her.” Tiesha was able to calm down with staff assistance and this ended the physical restraint quickly. She said that a staff member asked her if her favorite stuffed animal, a large tiger, would help her calm during the restraint. Tiesha said yes, and the staff member put the tiger on her back at her request. Tiesha felt that, with the comfort of her stuffed animal, she was able to allow staff members to help her calm. They asked her to take slow, deep breaths, which she did.

Tiesha said that staff members also helped her by reminding her that she was leaving the next day, and they told her that they knew she did not want to hurt anyone and say goodbye in a sad or negative way.

Tiesha said that she was able to think about her future during the restraint and to remember that she always feels bad after she hurts someone. She stated, “In the past, I never thought about the future.”

Liz, age 16: “A few staff like to have the last word. That doesn’t help things.”

Liz said that she had been in the program for three years. She immediately stated, “This no restraint thing… it’s chaotic. Kids are flipping out and getting away with so much, like punching walls and swinging at staff. Three years ago you would go into the safety coat for anything or be in the quiet room permanently.” Liz went on to say, “If I had keys, I would not put up with punching walls and threatening. Kids would go to the quiet room.” She said that she believes the correct approach is a balance between the old way and the new way.

I asked Liz if she had suggestions for staff members to decrease their use of restraints. She stated, “Some staff do not know when to back off. It pisses me off. A few staff like to have the last word. That doesn’t help things.”

Liz's coping skills include listening to music, playing with a hackey sack, and being outside and "just walking." She also said she has an incentive plan that helps her stay in control. She earns CDs and other items that she enjoys if she maintains safety for a period of time. She stated, "That's cool. It is something to look forward to."

Liz said she believes the program should make changes to their level system. She said that kids are penalized for not attending groups and that it is impossible to move up the level system if you don't go to almost all of your groups. She stated, "They should base levels more on safety than on groups. Sometimes isolating helps." Liz was in favor of being permitted to skip a group every day as a privilege for higher levels. She also suggested that staff members should provide kids with more activities to do in their rooms during quiet time. She stated, "Lots of kids can't stand being in their rooms during quiet time," and she said that she believes that kids get into more trouble during quiet time.

Julisa, age 17*:* "Kids get into trouble when they're bored. You start thinking about stuff and get anxious."

Julisa believes that staff would not use restraints if there were more activities at the program. She stated, "Kids get into trouble when they're bored. You start thinking about stuff and get anxious." Julisa wishes for more outdoor time, even in the winter. She stated, "It helps me calm down." She also said that she believes there are not enough activities during the evening shift or on the weekends. She stated, “We need more structure on the weekends.”

Julisa complained that when peers “flip out,” they get “too much attention” from staff members. She stated, “They don’t need seven staff members with them. It’s hard for the other kids with all of the staff gone.” Julisa went on to say, “When other kids are getting restrained, we need staff the most and they are not available.”

Julisa talked about her last restraint. She stated, “I lost my level and flipped out.” She added that kids typically lose their levels for unsafe behavior. She stated, “Staff got close and I kicked them.” She acknowledged that staff members probably needed to put hands on her to help her stop kicking. Julisa said that staff members helped her settle down by talking to her and encouraging her to take deep breaths.

Andrea, age 16: “Mostly staff do not know what it’s like to be in and out of hospitals since you were nine. If you want to help, just listen.”

Andrea stated, “I’ve been in a lot of restraints since I was ten.” She said that staff used the safety coat several times when she first arrived at the program because she was hitting people. Andrea said she has been restrained the least at her current program. She stated, “The older I get, the worse it is for my chart.” She proudly reported that she had not been restrained by staff for almost four months. Andrea said that she has an individualized incentive plan that is helpful for her. She earns points for safe behavior and school attendance and cashes in the points for special prizes. She stated, “My main goal was to not be restrained by staff, but I started small by not assaulting people.” Andrea stated, “Now my goal is about gaining hope. I am hopeful that I can do better than I used to.”

Andrea said she still feels “aggravated” and swears at people, but she emphasized, “no restraints.” She stated, “People in restraints need hope that they can do better.”

Andrea believes that staff members can make changes to decrease their use of restraints. She stated, “They should not get agitated as fast as they do. They should LISTEN. They should see things from our point of view.” She added, “Mostly staff do not know what it’s like to be in and out of hospitals since you were nine. If you want to help, just listen.”

Andrea said that she believes staff members should use some of the techniques themselves that they encourage adolescents to use, such as deep breathing and meditation. She stated, “They should listen and understand.” She added, “They should be strict but helpful. If they are too strict, kids get frustrated.”

Kelly, age 16: "Usually if they (kids) get restrained, staff have tried everything first."

Alison, age 14: "Staff members say helpful things to kids to help them remain in control."

Kelly and Alison are friends and asked to be interviewed together.

Kelly said that staff restrained her frequently during her first few months at the program. She proudly reported that she had not been restrained in "one month and one day." She said that she has been restrained less by staff because, "I got sick and tired of it." She did not have suggestions for staff members to help reduce restraints. She stated, "I would have kept hurting myself if staff did not stop me." She went on to say, "Usually if [kids] get restrained, staff have tried everything first."

Kelly said that she has an incentive plan to help her, and she explained that incentive plans are special plans for kids who are having a hard time. She stated, "You earn prizes like food, CDs, magazines. It keeps you motivated."

Alison said that she has an incentive plan too, which she thought was helpful. She and Kelly said that they worked with staff at the program to develop the plans and the rewards.

Alison reported, "Staff members say helpful things to kids to help them remain in control." She said that they frame these statements positively, such as saying, "Don't forget about the pass you have with your mother tomorrow. You are going to have so much fun together," instead of something negative and threatening, like, "you better behave or you'll lose your pass."

Kelly and Alison said that staff members play lots of games with kids in the program, which they believe is good. Alison stated, "It distracts us and gives us other things to focus on." They talked about a program contest, where the entire unit earns a special prize, such as a pizza party or an ice cream party, when everyone is safe. Kelly and Alison also talked about a special weekend activity that all kids are permitted to participate in, no matter what level they are on. Staff members purchase a special snack for everyone, and all kids and staff members watch a movie together.

Kelly and Alison gave their ideas about important questions to ask staff members who are being interviewed to work at the program, such as:

> "How will you take it when kids get restrained?"
>
> "Will you get offended?"
>
> "Are you good with kids?"
>
> "Can you handle anything?"
>
> "Can you handle the stress?"

13 Reasons to Fly

Isabelle (Belle) Cole is a 17 year old former client of Cohannet Academy, an intensive residential program in Massachusetts contracted by the DMH. While at the program, Belle rejected the glorification of suicide and the stigma of mental illness. Instead, she created, *13 Reasons to Fly,* a Peer-to-Peer initiative that embraces life, positivity, self-acceptance, and recovery from mental illness. *13 Reasons to Fly* directly challenges the solution of suicide portrayed in *13 Reasons Why*. Belle's determination to embrace the best of herself and life with her peers was also the inspiration for a DVD.

The DVD, *13 Reasons to Fly*, is an educational video providing information about youth suicide and the stigma of mental illness. It also offers suggestions about what youth can do to think differently, accept themselves for who they are, reject the stigma of mental illness, and decide to choose a path of positivity by focusing on the good things in their lives. This film is the result of the efforts of many people who came together to embrace this message and share it with others.

13 reasons to Fly

1. **Even if everyone else has left you, I am going to stay.** I love you, and I care.
2. **Opportunities are waiting for you**; chances are waiting to be taken.
3. **There are years and years to fix everything**. You never know what things will look like in five years.

4. **It’s time to find your passion!** Try out new things and see what you like!
5. **People are waiting for you to inspire them, befriend them, and teach them.**
6. **All your cells are fighting for you** and sacrificing themselves every day to keep you alive. Don’t leave them behind!
7. **There are people in your life that love you,** even if it doesn’t feel like it.
8. **It gets better,** it can’t stay dark forever.
9. **You are so much more than what you’re facing right now**—you are infinitely complex and that is beautiful—your story isn’t over yet.
10. **You are not weak.** Your strength comes from accepting you are not okay and that is okay.
11. **Everything happens for a reason.** You may not see it right now, but what you’re going through now has a purpose.
12. **You are a work in progress.** You are a work of art; always changing.
13. **You are enough.** No matter what you think or what others may say, your worth is infinite and can’t be taken away.

By Isabelle Cole

For more information about 13 Reasons to Fly (DVDs, Discussion Guides): Janice.Lebel@massmail.state.ma.us

If you are interested in more information about *13 Reasons to Fly* or starting your own *13 Reasons to Fly Chapter,* contact Isabelle Cole: www.13reasonstofly.com

For more information about the Nan Project (peer mentors/school outreach): www.thenanproject.org

Isaac's Story

The Massachusetts Department of Mental Health, FableVision Studios, Express Yourself and the Walker School worked together to develop a public education campaign to raise mental health awareness and de-stigmatize mental health conditions experienced by children and youth. The goal of the campaign is to alleviate fear, stigma and establish a shared vocabulary for kids, their parents, and other adults, such as educators. The effort also underscores the power of friendship, support, and recovery from mental illness. The campaign I includes a short animated film of about "Isaac's Story," a picture book and collateral materials such as posters, teacher guides, a student coloring book/work sheet and other campaign materials.

For more information, visit the following website:
www.mass.gov/isaacs-story

Transition Age Youth & Young Adults (TAY)

Ages 16-25

The TAY Initiative at the Massachusetts Department of Mental Health was established to help young persons embark on a positive life path into adulthood toward the goals of obtaining personal stability, community housing, employment, and positive family/social relationships. One young adult involved with the TAY initiative shared her thoughts and recovery experiences in an essay included below.

Hannah, age 23:

“To write this essay on my experience with restraint and seclusion is an honor. What I am about to tell you is a true story on what I went through with restraints and seclusion.

When I used to be in the hospital, I had out-of-control behavior that usually led to restraints. During my restraints, I did a lot of struggling when they were holding me down to get me into the restraint bed and to give me a shot so I could calm down, but being in restraints at the same time did not help.

I was in my teenage years when I was first restrained. I was angry at the time but being put in restraints made it worse.
I felt bad when my peers were restrained or secluded.

Things that would help me avoid restraint and seclusion:
When I was having a difficult time I would rock, listen to music, write in my journal, talk to staff or I would go to the sensory room. Those were the coping skills that helped me at that point and still help me today. I also used to calm down using a blanket wrap. When I used the sensory room, the main tools I used were the sound machine and the rocking chair. For me, rocking helped a lot. My social worker introduced rocking to me. She had me sit on the edge of the bed or on a mattress on the floor, I crossed my arms and just rocked. For awhile when I used to see people rocking, it scared me. But when I did it myself, it helped. I would rock until I calmed down.

The advice I give to children and transition-age clients is to use your coping strategies and if you are in the hospital, do what staff tells you to do. It keeps you out of trouble (restraint/seclusion-wise). It helps you with your goals to get discharged sooner than you think. Stay safe—hurting yourself only keeps you in the hospital longer.

Thank you for letting me share my experience with restraints and seclusion."

Parent experiences

Colleen Reed

Ms. Colleen Reed, a parent of a child diagnosed with a mental illness, presented at the Massachusetts Department of Mental Health's 6th annual Provider Forum on Restraint/Seclusion

Prevention. The theme of the forum was on "Consumer & Family Partnerships," and Ms. Reed spoke about the importance of collaborating and including families with all aspects of a child/youth's/young adult's mental health treatment and care. The following are excerpts from her presentation at the May 3, 2007 Provider Forum.

“For the most part, I think providers grossly underestimate the shock, strain, and apprehension parents experience when first immersed into a psychiatric setting for their child. Moreover, I think they are also less than mindful of the of the internal conflict parents experience about relinquishing control and entrusting the care of their ill child to what—at the time—are essentially ‘professional strangers.’ Given that, establishing trust with the parents at the outset of treatment should be a priority for providers. I see it as paramount. Ultimately, it sets a solid foundation for treatment to begin. From my experience, it cannot move forward without it.”

“Today we live in an “on-demand” society. When we want something, we want it NOW. Moreover, we have come to expect concrete solutions to problems. If something is broken, we want it fixed. Completely. In short, our expectations are high. Given that mindset, it’s natural for parents to expect their child to recover from mental illness. Quickly. And completely. But unfortunately, mental health is not available on-demand, and it appears to have total disregard for parental expectations. As painful as it was, I had to learn that my child’s recovery was not going to be six weeks long. I had to understand that it was not going to be over in four months. I had to accept that my child’s recovery time would not end in one year. Rather, I had to come to terms with the fact that my child’s recovery would be a process, not an end result. A continually evolving process. This was a turning point for me during my child’s treatment. Considering that, I think one of the most important things providers can do during the course of treatment is to help parents adjust their expectations. Help them to understand that mental illness is different than other medical conditions.”

“I think parents have a tendency to put off living during treatment when their child is struggling so. Instead, they wait for the difficulty to pass, and for that elusive guest named “Better” to arrive. Providers should strive to help parents accept that the situation “is what it is,” so they can learn to incorporate it into their lives, and learn to manage living with it, rather than waiting for the opportunity to live without it.”

“Parents are hard-wired to respond to a child’s needs. When they are hungry, we feed them. When they are sad, we want to make them happy. And when they are in pain, we want to comfort them and make it go away. Naturally, when they are struggling with a mental illness, we want to make it all better. But sadly, we can’t. As providers, one of the greatest things you can do is to help parents understand that they cannot make their child well. That instead, the child needs to do the work, not the parent. Quite simply, a shift needs to take place, and providers can help make it happen. To start, help them come to terms with the fact that it is not their battle. Help them understand that they can support their child, advocate for them, comfort them, and be there for them, but that they can’t do the work. But achieving this shift requires delicate balance. It is not about shutting the parent out, or abandoning the child, instead it's about changing their role. More than anything else, this was by far the most significant turning point in our course of treatment, and as my child continues to recover and mature, it continues to be so today."

Susan Ramsey

Susan Ramsey is a parent of a child who experienced restraint at home, in school, in residential care and in the hospital. Her son's last six years have been restraint-free. Susan has held the position of parent liaison at the Walker School in Needham since 2007.

"Those who cannot change their minds cannot change anything." -- George Bernard Shaw

"I approached motherhood with an open heart, hope, dreams and a rule book. All but the rule book have remained intact, although many times challenged. My rule book became obsolete by the time my son turned three. At this point I clearly knew something was different about my son. When compared to his classmates and peers, his behaviors and interactions in social settings and during transitions were markedly different. Too old for early intervention services, we were referred to our local public school. Six months later with IEP in hand we began to chart a course to navigate special education services.

When my son was in pre-school, I first heard the term restraint. "Your son was out of control this afternoon. I had to place him in a lap hold." Restraint was never discussed with me. I was never told who was trained and in what circumstances it would be used. I never gave permission for teachers to do it nor was I shown what it looked like. I took it on faith that the school knew the best practice. Honestly, I was thankful that my son was in school. During the prior six months he had been dismissed from four daycare centers, and babysitters, friends and family were beginning to pull away.

The fact that school staff would not show or teach me the method of restraint should have been a "red flag." Looking back, I think I didn't want to know. If he was not in school, where would he go? And, on some level, I began to repress the trauma I was experiencing by parenting this emotional and behaviorally volatile child.

My son was hospitalized for two weeks on a child development unit before starting kindergarten. He was five. Neither he nor I will ever forget the experience. Forever embedded in me is the sense of failure I experienced holding my out of control child and then feeling him go limp after the ER doctor shot him with Haldol. He can vividly recall being tied down, shot with a needle and left alone in a room on more than one occasion. I did not even entertain objecting. We were in a hospital that specialized in child development. With no other alternatives presented to me, I thought this was the only option.

Elementary school brought about more restraint experiences for my son but with a major difference. I knew at admission about the restraint policy and practices, and I had all my questions answered. I was confident staff members were trained and supervised and that oversight was in place. I had open and frequent communication with all staff, and they sought my input.

Restraint at this time in our life had become routine. It started to trump all strategies in the rule book. It became the norm, because I had lost my perspective of what was normal. I was concerned about the future.

The team at his school partnered with me, and my son slowly and incrementally made gains. This period provided me with a chance to rewrite my rule book, understand my son's disability and restore hope. As his ability to control his outbursts improved and his frustration tolerance increased, the need for restraint declined and disappeared, providing time to truly focus on his learning, social and developmental needs.

By now I had become a proponent of restraint. I was certain it had a time and a place. Like many parents I work with experience, "I couldn't know what I didn't know." What I do know and understand today is the high degree of risk and danger involved with restraint; it should never be the predominant practice in any setting. Equally important, I have come to acknowledge the trauma I experienced by having been involved or witnessing my son being restrained. Anyone involved with children who have been restrained should be provided support and time to heal. If I knew then what I know now, I would have sought a different course for my son and fine-tuned my rule book.

Fast forward to today. My son has blossomed into a handsome young man, and he is living at home and looking forward to his high school graduation in June. The future will not be without challenge, but it does warm my heart, it provides me hope and it allows me to dream of the day when I will no longer refer to the rule book."

Adult Perspectives

A Story of Survival, Courage, and Transformation—Anonymous

"I am a survivor, and I would like to share my story. At the age of 30 years, I had a major schizoaffective breakdown. Unfortunately, I was hospitalized, and given a long series of electroconvulsive shock treatments. The odds were against my survival. I had no home and no job. I had a four-year-old son to care for, a husband who had left me, and I was still very ill. I don't know to this day why I didn't just go on welfare, or move in with my parents, but the thought just didn't occur to me. I got a job a thousand miles away, moved, and I supported myself and my son with no assistance. Most of the time I felt terrible, but slowly, very slowly, I started to get better. It took me about ten years before I actually felt well again, but I did improve.

I am 55 years old now. My son has grown into a successful man, I have remarried, and I continue to teach school. I still take some medication, but I stay far away from psychiatrists.

I have survived! And not only have I survived, I have grown and developed strengths as a person throughout the ordeal. In fact, I never returned to the person I was prior to the breakdown. Instead I became a stronger, mentally healthier person. I have reached a level of development that I never would have attained without the experience of the illness. I feel blessed!

I believe that there are many factors that have enabled me to successfully survive my illness:

1. The love I had for my young son kept me going. His father had little interest in him, and I was all that he had. I had the choice of either killing both of us (which I considered), or to keep on going no matter what. I couldn't justify killing my little boy, so I had to keep trying to get better.
2. I read a book about a survivor of a Nazi concentration camp. In the book, the author explained why he had survived whereas others had not. He explained that a person can not always control the circumstances of life, but a person can control the attitude with which the circumstances are met. Because of what I learned from this author, I chose to regard my condition as a challenge rather than a disability. That made a big difference.

3. I had a lot of personal resources. Because of the late onset of my illness, I had a personality that was already formed; I had a good education and the means of supporting myself. Also, I was blessed with above average intelligence and insight.
4. I learned early not to believe everything that a psychiatrist said, and instead, to keep myself informed, and to make my own decisions." (Successful Schizophrenia, 2003)

Laura Prescott

Laura Prescott is the Executive Director and Founder of Sister Witness International. She described herself as a recovering addict, psychiatric ex-patient, and survivor of childhood abuse. Her comments were taken from her keynote address given at the International Society of Psychiatric Mental Health Nurses convention in April 2000 (Prescott, 2000).

Ms. Prescott speaks and writes about her own experiences in psychiatric hospitals. On the topic of restraint, she stated:

"Rather than deterring anything, these episodes perpetuated a vicious cycle. There more I was restrained, the more humiliation I felt. The more shame and humiliation I felt, the more I dissociated, self-injured, and was restrained. This level of containment is not only traumatizing, but it is also a costly proposition. Research shows a correlation between the use of restraints and increased length of stay in a facility

(Philips & Nasr, 1983). This disruption to the milieu could have been avoided had people been willing to take some risks well in advance, assisting expression and witnessing pain."

Ms. Prescott went on to say: "Violence only teaches violence and indifference; it never teaches kindness and compassion. It is the antithesis of healing and true recovery. I believe that recovery is only possible in the absence of attack, force, and coercion, that health happens when the greatest dignity and respect is afforded to each human life." (Prescott, 1998)

An Elder recounts her experiences in treatment

Dorothea Buck is a ninety-year-old woman who has written and spoken about her experiences in five different psychiatric hospitals in Germany between 1936 and 1959. Her experiences, and those of other patients who were considered to have psychoses, included having buckets of cold water poured over her head, sitting in long-duration baths in a tub covered in canvas with her neck fixed in a high, stiff collar, and being wrapped tightly in cold wet sheet packs where she could not move at all. Ms. Buck was one of many psychiatric patients who was sterilized during a time period when many treatment providers believed that hereditary carriers of "social inferiority" should be excluded from procreating. At the time, patients were told that the sterilization surgery was an appendectomy. Ms. Buck learned that she had been sterilized from another patient, after the operation had already occurred.

In her keynote speech at the World Psychiatric Congress in Dresden, Germany (June, 2007), Ms. Buck reported that what she calls “decades of backwardness of this kind of psychiatry” still influences practices today. She stated, “It remains devoid of conversation and uses medication also under coercion and restraints, only fighting the symptoms, instead of understanding.”

Ms. Buck also stated: “Many people are afraid of psychiatric institutions with their forced medication and complete lack of help to understand either the psychosis or the self. From their very first contact with a patient onwards, psychiatrists should prove themselves to be helpers and not opponents. My wish would be that the patients could, right from the start, present their disturbing experiences in group sessions, that they could talk about them, write about them, paint and draw them, that they would be taken seriously with their experiences, without needing to fear unwanted psychiatric interventions. During this process it would be very valuable to have the aid of those who have experienced psychoses and have overcome them and have understood their meaning for their lives and have been able to integrate them into their normal lives.” (Buck, 2007)

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"…The World Health Organization and European Commission have [also] stated the need for the development of new non-stigmatizing and self-help approaches for people in emotional distress. Organizations of people who have experienced psychiatric treatment have taken the lead in developing self-help programs that are based on quality and choice, rather than on coercion, and have been successful in helping people lead integrated lives in the community. We know that healing can only occur when people are respected as humans with free will and when there are alternatives beyond psychiatry which are based on ethical approaches, which see the whole person, and which support recovery, while force makes recovery impossible…"

Signed by:

European Network of (ex-) Users and Survivors of Psychiatry (ENUSP)
World Network of Users and Survivors of Psychiatry (WNUSP)
MindFreedom International (MFI)
Bundesverband Psychiatrie-Erfahrener (BPE)

Experts Share

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