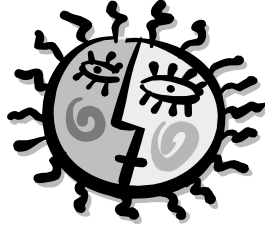


The OTHERS

Youth Taking Charge



Parent/Professional Advocacy League (PAL)
January 2009



Alone

I am alone
Alone in my corner
Fearing the sadness
The sadness within
That eats at my soul
I am lost
Lost in the darkness
Stuck in confusion
Avoiding the world
The people who judge me
The people who point at me
I am sad
Sad cuz' I' m angry
Angry at the world
The world that' s so stupid
So stupid it' s sickening
I am rejecting
Rejecting the help that I' m getting
The help from my family and friends
The ones that care for and love me
But they don' t know
The feeling I get
When I am alone

-- Chandra Watts

Respect yourself
Take care of yourself
Be important, be heard
You are valuable!

-- OTHERS group message

**The OTHERS
Youth Taking Charge**

**Lisa Lambert
Parent/Professional Advocacy League (PAL)
www.ppal.net**

January 2009

Acknowledgements

Parent/Professional Advocacy League (PAL) is a statewide family-run organization advocating for improved access to mental health services for children and youth. The youth group, the OTHERS, has amazed us with their energy and ideas. They have made us better partners and a better organization. We have been pleased and proud that they were a part of PAL for many years.

Over the years, many organizations have supported the OTHERS. Our thanks to the Department of Mental Health, SAMHSA, Community Healthlink, Central Mass Communities of Care and YOU, Inc. Special thanks go to Gary Blau and Elizabeth Sweet at SAMHSA who have funded and supported our youth initiative for a number of years.

Without the efforts of the following people and their willingness to nail down details, this project would not have been possible. Our thanks to Tina Adams, Rich Breault, Joanne Carey, Mark Carey, Rina Cavallini, Peter Metz, Joan Mikula, Meri Viano and Chandra Watts.

Special thanks go to Allison Bauer and the Boston Foundation for their belief in PAL and our ability to create materials such as this one, which help expands what we know is possible in children's mental health.

Youth Guided means that young people have the right to be empowered, educated, and given a decision making role in the care of their own lives as well as the policies and procedures governing care for all youth in the community, state and nation. This includes giving youth people a sustainable voice and the focus should be towards creating a safe environment enabling a young person to gain self-sustainability in accordance to their culture and beliefs. Through the eyes of a youth guided approach we are aware that there is a continuum of power and choice that young people should have based on their understanding and maturity in this strength based change process.

Youth guided also means that this process should be fun and worthwhile.

– from the web site of the Substance Abuse Mental Health Services Administration (SAMHSA)

Forward

Youth Guided Initiatives

The OTHERS, a group of teens in Worcester Massachusetts organized through a SAMHSA funded Statewide Family Network grant, was created in response to the expressed need for a social network and social activities for youth dealing with mental health issues. Once together, The OTHERS leapt into action. In one of their major activities, they yoked their street smarts and creativity to challenge the stigma of mental illness through a Public Service Announcement and an anti-stigma website. Through their work, the OTHERS have enriched our practical understanding of the benefits of Youth Guided Initiatives and how adults can best foster them. As Youth Guided Initiatives continue to be created by new groups of youth motivated to address their concerns, we hope this guide transmits the lessons we have learned to date in our very successful local project.

Youth Guided Initiatives are the community correlate of Person Centered Planning. Person centered planning, quickly becoming standard practice in mental health treatment planning, is based on the recognition that individuals know what they need. Planning for services and supports starts with the individual defining his/her goals, and then works back to identify the skill and strengths needed to reach those goals. Youth guided initiatives stem from the recognition that youth are also keenly aware of the strengths and needs of their community, particularly as it impacts them, and of the need for change to improve their own lives and those of others. The focus for such initiatives is identified by youth themselves, and youth, with adult guidance and support as needed, work together to create that change.

*Joan Mikula
Assistant Commissioner
Child/Adolescent Services
Department of Mental Health*

Background

America has been described as having a youth-obsessed culture. Our media is filled with images of young people talking, smiling, moving and listening to their ipods. Yet, teens continue to do what they have always done: they question things and seek to understand them. They find new ways to live and love and address the issues of their lives and times. Youth with mental health needs are no different. In fact, their questioning and desire to address the issues of their own lives may be more intense.

In American culture, the teen years are also a time when youth prepare to leave high school and their family home in a gradual journey to productive adult life. During this period, they graduate from high school, build and experience a social life and develop new relationships; in essence, they prepare to launch into the adult world. What happens when such a “launching” is complicated by a young person’s experience of significant mental health needs, by having their early and mid-adolescence disrupted by challenges resulting from their illness? How do young people respond to the stigma that results from their illness and the pain and isolation it can cause?

A group of young people, in Worcester, Massachusetts, decided to come together to support one another and to respond to the stigma head on. They created an award-winning program, the OTHERS, a place where many teens became leaders and self-advocates, finding opportunities to be successfully heard. Along with their many other achievements, they created strong bonds and friendships with each other.

The OTHERS demanded to be seen as the experts on their own lives. They drew upon their experiences of what it’s like to be depressed, to be homeless, to be isolated, to fail in school, to be hospitalized, to lose friends, to be laughed or scorned. And they told their community how they had survived it all. And, along the way, they challenged all of us to change the way we partner with youth and view their role.

The Challenge

Building a partnership with youth is based on a willingness to move from seeing youth as recipients of services to partners who can initiate and direct projects and create systems change. The youth development movement was created to emphasize the positive outcomes that youth can create, rather than the negative outcomes that society hopes to prevent.

Youth development emphasizes developing skills and encouraging broader development for all young people, plus including young people as partners in decision making. A key feature is moving beyond seeing the young person as a *client* or a *patient* or being seen as *symptoms and behavioral problems*. Components of positive youth development include having a sense of competence, usefulness, belonging, and power.¹

In order to best support youth with mental health needs, the systems that serve them need to involve them fully in the process. When youth are engaged, they feel more able to take charge of their own lives in a meaningful way and their connection to the community is strengthened. Perhaps most importantly, it allows them to use their own experiences to help create meaningful change in the world around them.

Youth with mental health needs are challenged to demonstrate that they can not only manage their mental health disorder but prove they are people of worth, intelligence and strength.² Encouraging young people to share their stories, advocate for themselves and focus on change decreases stigma, empowers self and changes the way others see them.

¹ National Clearinghouse on Families and Youth, 1996

² Youth Involvement in Systems of Care: A Guide to Empowerment, Reflections from the Field. www.systemsofcare.samhsa.gov.

Moving to a system that is youth guided requires a retooling of our assumptions. We must begin to view youth as valuable partners and experts on their own needs. Youth are focused on the world they live in today and value projects that bring them a sense of accomplishment and visible impact. Youth coordinators play a key role in this process. Youth coordinators are able to both coach and challenge youth as well as create opportunities for youth leadership. They must be flexible, respect youth culture, share power, build a bridge between youth and professional world, reconnect youth to the community.

One youth group in Massachusetts, the OTHERS, moved those who knew them to view youth in a different way. They seized opportunities and helped adults see that they were the experts on their own lives. They took those opportunities and spun straw into gold. They turned their experiences of feeling depressed, isolated and unworthy into award winning anti-stigma initiatives and compelling and moving presentations.

The shift to a youth guided system requires that those who partner with youth commit to a new way of delivering services, involving the community and developing public policy. Young people have enormous energy, original ideas and an ability to focus on the desired outcomes. They can help us identify needs and demand that we respect their culture and beliefs. Moving to a youth guided system requires commitment and brings enormous rewards. Youth guided also means that all of this should be fun and worthwhile

Beginnings

In 2001, three Worcester parents gathered together a small group of ten teens, many with mental health needs to form a youth group. The first goal this group set for themselves was to create a message for the public about teen mental health needs. What began as a small goal led to a series of connections and to doors opening to further opportunities.

The teens decided to call their group Teens Help Everyone Respect Self, a “outsider” role the young people weekly and included an activity where “How’d your week go?” one came from diverse economic and cultural backgrounds but they shared a common experience of feeling isolated, shared experience became an under-over the next few years.

The OTHERS is a place to see people that have, like, the same problem. Just seeing how they deal with problems, helps you deal with yours.
– Ashley

the OTHERS, an acronym for Other name chosen to convey the experienced. Meetings were held the group checked in with each other. youth would ask another. The teens tural backgrounds but they shared a marginalized or “different.” This pinning for their goals and activities

The OTHERS created a place where many teens became leaders and self-advocates. While seeking out opportunities to be successfully heard, they also supported each other in their shared efforts to reduce stigma and they created strong bonds of friendship. As Mark, one of the original members noted, “We supported each other during the presentations. We had each other’s backs if we needed help.”

Battling Stigma

The pervasive stigma associated with mental health disorders united members and became the OTHERS' primary target for action. They decided to focus a public education campaign "Stigma sucks," the common response of members when asked about the problem, became the catchphrase for sessions in which OTHERS members met with everyone from legislators to mental health professionals to civic groups.

Stigma! It's not a joke. Stigma keeps millions of people from getting the help they need. It's a barrier to treatment and it's about disrespect, judging and stereotypes.
-- Chelsea

with mental health disorders united members and became the OTHERS' primary target for action. They decided to embody the term "stigma sucks." response of members when asked about the phrase for sessions in which OTHERS legislators to mental health professionals

The group talked about how stigma had affected them personally and had affected other people that they knew. They collected facts about how many teens experienced mental health disorders and yet didn't get the treatment they needed. At their regular meetings, the teens researched mental health issues and stigma on the Internet for use in flyers, materials and their web site.

By 2002, the OTHERS were ready to undertake their first public action to combat stigma. The project began when Rina Cavallini, a parent who became group's passionate organizer, overcame the OTHERS' doubts that they could accomplish this task, saying: "My vision is bigger than your doubt. Dream big."

Realizing that the radio station WAAF, known for its hard rock edge, was a voice that teens hear every day, the OTHERS teens contacted Matty Blake, aka Matty B, the afternoon disc jockey for WAAF, and invited him to Worcester to share their vision. Matty B knew how to write and produce Public Service Announcements (PSAs). Under his tutelage, the OTHERS wrote, produced and recorded two 30 second spots. After many hours of brainstorming and hard work by the OTHERS, Matty B had the teens come into the WAAF radio station in January, 2002, to record the first of two PSAs to be aired on WAAF as well as placed on the WAAF website. OTHERS members described experiences they had had or knew that a friend had had. One teen wrote about drinking to get through the day, while another wrote about going to jail. Still another wrote about feelings of depression and thoughts of suicide and another wrote about teenage pregnancy. They then mixed up the stories, made up fictional names and created a message to go with each story.

The end of the PSA directed teens to *First Call for Help* at United Way. An adult coordinator of the group had asked United Way if the OTHERS could use their toll free number. The coordinators worked with United Way to develop a resource list for teens including resources for any teen in crisis or needing special information. The PSAs were sponsored by Community Healthlink, Worcester Communities of Care,

PSA written and recorded by OTHERS January 17, 2002

WAAF studio, Boston, MA with Matty Blake, WAAF DJ

At the United Way's First Call for Help Line, we're listening. Call 508.755.1233

I can't go to school without getting high.

I'm pregnant and afraid to tell my parents.

I'm pissed off all the time. I'm tired and I don't have anybody.

My boss is taking me to court cuz' I got busted stealing.

I've been living on the streets and I can't face my problems.

At the United Way's First Call for Help Line, we're listening. Call 508.755.1233

Hi, my name is Bob. I called 508.755.1233 and I got help. I've been drug free for a month now.

Hi, I'm Jessica. My baby is two months old and I'm doing better.

Hi, I'm Rich. I have a girlfriend now and I'm feeling much better about myself.

Hi, I'm Joe. I got a break and I'm doing community service.

Hi, I'm Dana. I'm off the streets and I'm starting to face my problems.

At the At United Way's First Call for Help Line, we're listening. Call 508.755.1233

Another program, the *Mistress Carrie* show, just happened to be doing a citizenship quiz on the air when the OTHERS were at WAAF and she asked Matty B to bring the teens into her studio to take the quiz live on her show. “ They all did a great job answering the questions, better than most of the adults calling in,” she said. Luke and Zach, just out of review-class, got all the answers right and Miss of today was renewed!

The next success occurred In May *Celebrating Strengths* annual dinner, dio public service announcements be- and providers. Matty Blake attended OTHERS received a certificate of rec-

At the dinner was Paul Carey of YOU, He was so impressed with the public ranged for the OTHERS to work with tion to working as a White House videographer/editor of the *Emmy Our Times*, on WHDH-TV, Boston. make their WAAF scripts into visual ground music. On the hottest day of the OTHERS at locations selected by

The final video PSA was aired on local munications, and later the national sta- ESPN.

The OTHERS presented their PSAs at Washington DC in July 2002. The fed- on ways of developing and operating systems of care for children and youth participants attended this conference, clinicians, case managers, researchers,

As the OTHERS’ work became bet- awards. These included national rec- Mental Health Services award for Ex- tion and Outreach which was given to Family Strengths Conference

In 2004, the OTHERS helped design sit Authority buses. They selected captions to highlight the message. One can’ t deal with anything, I just want a way out.” Another showed a teen with a drink in her hand while the caption read, “ I can’ t function without alcohol.’ A friend saw the picture on a bus and said, “ I did- n’ t know you had a drinking problem.”

It was important that teens did the whole project from beginning to end. Teens are more likely to listen to other teens. If you hear it from someone your own age, it’ s going to have a different effect. Going to the WAAF studio was the greatest. It was important for me to do this because I want my peers to know there’ s help if they need it and I can relate to my peers. It was a privilege to do this. The highlight of my day was when we got yelled at for playing hackey sack in the lobby by DJ LB!

– Molly

It was a great experience. I didn’ t expect it to go this far. It showed me how a radio station works and that you can actually make a difference when you’ re on the air. It was awesome. All my friends think I’ m so lucky and that it was a once in a lifetime thing.

– Steve

It was a great experience. I hope it reaches a lot of needy ears. It was a lot of fun too. I got to meet a lot of cool people making of this PSA..

– Tom

ing American History in their 8th grade tress Carrie said her faith in the youth

2002 at the *Honoring Families*— when the OTHERS presented the ra- fore a crowd of hundreds of families and both he and the members of the ognition from the Governor’ s Office.

Inc., a non-profit agency in Worcester. service announcements that he ar- photographer J. Dolan Barry. In addi- news photographer, Barry was the Award-winning news magazine show, His expertise helped the OTHERS re- skits, for which they also chose back- the summer, Barry filmed members of the youth.

cable access, owned by Charter Com- tions, MTV, Comedy Central and

the Georgetown Training Institutes in erally-funded Training Institutes focus high-quality, effective community-based with mental health needs. Nearly 2000 including state and local policy makers, and educators, as well as families.

ter known they received additional ognition from SAMHSA’ s Center for cellence in Community Communica- them for the PSAs at the Building on

posters for Worcester Regional Tran- shots from the video PSA and chose picture of a youth was captioned, “ I

Another showed a teen with a drink in her hand while the caption read, “ I can’ t function without alcohol.’ A friend saw the picture on a bus and said, “ I did- n’ t know you had a drinking problem.”

Stigma Sucks

The OTHERS, like most youth, found that social stigma was the most painful form of stigma they experienced. Media stories often feature youth with mental health needs as crazy, dangerous, unpredictable or unworthy. These stereotypes reinforced the way many had felt and contributed to feeling isolated from peers at school, in their neighborhoods or in their communities.

Continuing their work to battle stigma, in 2005 the OTHERS created a web site, www.stigmasucks.org to talk about their perspective on the effects of stigma. The group wrote about stigma and its effect on their lives and the lives of others they knew. They collected facts showing how many teens were affected by mental health disorders and the large numbers that didn't get the treatment they needed.

At their regular meetings, the teens researched stigma on the Internet. The website included "stigma busters" and "stigma solutions" and offered a list of The Top Ten Things You Can Do to Relieve Stress. They advocated for respectful language and against terms like "crazy, lunatic, manic depressive, retarded, slow."

Stigma, they wrote, keeps millions of teens from getting the help they need. And some of them are people I know. Stigma isn't just about using the wrong word or action, it's also about disrespect, judging and stereotypes! So you need to decide. Are you going to be part of the solution or part of the problem?

Battles4ACause

In 2004, the OTHERS turned their attention to creating change through a new medium – music. During a casual conversation at her regular coffee spot, Rina Cavallini heard one day of a group begun in Worcester called Concerts4Charity. The organization's founder, Kaleem Clarkson, conceptualized Concerts4Charity to engage youth through philanthropy by various means including music, sports and performing arts. Through a personal connection, Rina Cavallini contacted Mr. Clarkson and invited him to partner with the OTHERS to create a concert designed to attract local teens.

In the meantime, Wilfredo, one of the OTHERS members, had a conversation with his history teacher about his dream of a concert for teens in Worcester. The teacher told Wildredo about Concerts4Charity, where he directed education and outreach programs. The information excited the OTHERS, who came up with the idea for Battles4ACause.

Between 2004 and 2006, the OTHERS worked with Kaleem Clarkson to produce a two day concert. Local bands were recruited and invited to sign up and all teens were invited to attend. Among the group, members had different tastes in music and wanted to reach out to a variety of bands. The concert was designed to get the attention of other teens to promote mental health awareness, "not just for May, but for every day."

The OTHERS were concerned that even the minimal ticket price might exclude some teens, so fees were waived when needed. This concert, which took place for three consecutive years, was the group's answer to fighting the stigma of mental health disorders, while raising money for youth development.

In 2005, seeing the growing popularity of rubber wristbands for cancer awareness and other causes, the OTHERS ordered green wristbands of their own. The wristbands read "Healthy Minds, Healthy Youth" and were sold to raise money for youth activities at the concert and throughout the year.

Educating the Community

The OTHERS also expanded their activities to creating presentations and workshops that combined their personal experiences with a message about the impact of coping with mental health challenges. They created and presented a workshop called *Everything You Wanted to Know about Teens (But Were Afraid to Ask)*! The teens offered this presentation as a way to let the general public ask questions and what works for teens with mental health needs and what doesn't. Many of the youth had been involved with juvenile justice and child welfare.

The young people also described the experiences each had had. All the youth stigma and desire to create change.

Teens are often afraid to ask for help from parents or doctors or don't necessarily realize the kind of help they need. Teens need people they can count on with their problems and worries .
– Chris

parents, providers, policy makers and receive honest, practical answers about health needs and what doesn't. Many mental health, special education, juvenile different services, placements and ex-could identify with feelings of isolation,

As well, they educated people who might be in a position to help others like themselves, talking about what works and what does not work in adolescent mental health. For four years they provided input to child psychiatry fellows at UMASS Medical School. " They talked about their experiences with mental illness and especially with child psychiatrists--what they liked, what they didn't like. We valued the input greatly." noted Peter Metz, MD. They presented at the Massachusetts Behavioral Health Partnership (MBHP) Recovery Conference in May 2006 about who and what helped them achieve what they had achieved. Over three years, OTHERS did a presentation at Worcester State College for students in a community health class. An example of their message: "If you are going to include me in a med visit with my mother, then please talk with me, too, or at least make eye contact. If you just talk/look at my mother, it makes me not even want to be there..."

Mentoring other teens, the OTHERS Worcester Public Schools. They organized video nights for the boys. Although OTHERS found opportunities to mentor the teens, "This was one of the most important things we had learned and make a difference." They visited with youth at the IRTP at Worcester State Hospital activities. During the holidays, some members of the OTHERS volunteered at a local food shelter. They also held a food drive for the shelter, and brought gifts for local charities.

During the summers the OTHERS met which involved recruitment from other teens to events such as the Worcester nights, and " arcade night." At Hal-house party for area teens. Social activities drew the group together and offered an opportunity for youth in the community to come by and try a meeting.

One of the things I really loved about being part of the OTHERS was having the opportunity to talk to and help teens that I could identify with. The message that I always tried to get across to teens is that even though you have a mental illness, that's not who you are – YOU are not your mental illness.
– Chandra

reached out to local students in the organized activity nights for the girls and the activities were the initial draw, the most important things we did. It was a chance to make a difference." They visited with youth at over the winter holidays to do holiday members of the OTHERS volunteered their annual Holiday party, did a food drive for local charities.

weekly, participating in fun activities local youth groups and inviting these Tornados baseball games, movie loween, the OTHERS held an open and offered an opportunity for youth in

Impacting Policy

For more than 50 years, May has been recognized as Mental Health Month. The first full week in May is National Children's Mental Health Awareness Week. This awareness week was first celebrated in Massachusetts in 1996 and brought to Worcester in 2000. Beginning in 2003, the OTH-City of Worcester for the May is tion. Throughout the month, events

The highlight of Children's Mental Health Month was organized by the OTHERS. Each May, a group of teens would go to city hall, where the mayor would read a proclamation to recognize the challenges faced by youth with mental health needs and help promote awareness. During the city council meeting, youth would pin the ribbons of awareness and one OTH-ERS member would speak very briefly for the group. Afterward, the OTHERS would have an ice cream social and celebrate their success.

It's important to understand what a partnership means. We build a plan to address the needs of youth and we need to be respectful of what they think of the services and check in with them to find out how we can improve.

—Tina Adams, DMH

By 2007, the OTHERS had accomplished two other policy milestones. In 2006, they joined with other teens to form a coalition called Teens Leading the Way which was sponsored by Health Care for All, the Public Policy Institute and the United Teen Equality Center in Lowell. Twenty-three high school students from all over Massachusetts worked together to promote their own legislation to establish teen drop in centers. Chris, a 14 year old, ended his testimony by saying, "As legislators, you know how important these issues are. As a teen in Massachusetts, I know that this proposal would really make a difference for me and my friends."

In early 2007, several OTHERS members spoke at the Statehouse Legislative Advocacy Day for the Children's Mental Health Campaign, that made the bill's provisions identification by school staff would

The OTHERS, a group of teens coming fronting mental health challenges during their teen years, with its associated stigma and daily difficulties in school and community, had, with their own initiative, organized a widely disseminated effectiveness in community education of a supportive group which brought them friendship and peer support. Most importantly, they harnessed their experiences and passion to impact their world.

The OTHERS is really about focusing on the talents and strengths of teenagers. A bunch of teens have come together to make a difference. And they have.

—Rina Cavallini

telling their personal stories in a way come alive and describing how earlier have made a difference in their lives.

fronting mental health challenges during stigma and daily difficulties in school and community, had, with their own initiative, organized a widely disseminated effectiveness in community education of a supportive group which brought

Conclusions

Youth groups such as the OTHERS are an untapped source of energy and creativity to raise awareness of the challenges faced by youth and the capacity to overcome them. Youth are the experts when it comes to their own lives and experiences. They are articulate spokespersons for change that can transform the mental health system. When youth are our partners, the stigma around mental health needs is reduced.

Youth groups require several key ingredients to be successful. They need a safe environment to connect, brainstorm and create the bonds that define any group. They need a passionate, dedicated coordinator who can coach, mentor, respect and support them. They need opportunities to be heard and they want to be heard in a way that reflects their beliefs, values and culture. And most of all, they need a commitment from funders, providers and policymakers that supports their sustained involvement.

The OTHERS are a shining example of what youth guided work looks like. They questioned the world around them and recommended new ways to meet mental health challenges for the media, for their peers and for the community. They drew on their experiences to explain their world to us and, in return, they asked us to partner with them to create a better one.

Resources

1. SAMHSA has created an excellent guide to creating and sustaining youth involvement. Youth Involvement in Systems of Care: A Guide to Empowerment, Reflections from the Field. January 2005. <http://www.systemsofcare.samhsa.gov/headermenu/docsHM/youthguidedlink.pdf>
2. Rhode Island's youth group is considered to showcase a best practice by Georgetown University National Cultural Competence Center. Engaging Youth to Create Positive Change. <http://www.l1.georgetown.edu/research/gucchd/NCCC/documents/pprhodeisland.pdf>
3. In 2000, Focal Point devoted an entire issue on youth in systems of care. Focal Point: A National Bulletin on Family Support and Children's Mental Health: Roles for Youth in Systems of Care, 14(2), Fall 2000. (ENTIRE ISSUE)
Caplan, E. (Ed.) <http://www.rtc.pdx.edu/pgFPF00TOC.php>
4. Youth Move is a national, youth-led organization devoted to improving systems that support youth. Their web site has many excellent resources. <http://www.youthmove.us>

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