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5. YOUTH ENCOURAGING SUPPORT

A Unique Youth Education/Advocacy Initiative to Reduce the Stigma of Mental Illness

Located in the frontier of central Nebraska, in the mid-Western United States, Youth Encouraging Support (YES) is an organization of youth who have diagnosable mental, emotional, and/or behavioural disorders. The development of this unique youth organization is a case study in dialogic leadership. A 14 year old with a mental illness conceived YES, but its development required that adults hear youth voices and foster the organization's growth. The burgeoning youth leaders in YES wanted to educate teachers, health care professionals, family members, peers and the public on mental health issues from their perspective. The youth worked collaboratively with adults who fostered leadership skills. This chapter examines the power of pooling the collective experiences of youth to create social change through the practical application of a strengths-based approach to developing youth organizations. The roles of youth leaders and adult facilitators are illustrated by the YES experience.

YES draws its members from a very rural area covering 22 counties in central Nebraska that includes small towns (Kearney, Grand Island and Hastings) as well as frontier areas (e.g., Blaine County has a total population of 675 persons). The area covers 38,762 square kilometres and has a population of 214,399 (fewer than six persons per square kilometre on average). The human inhabitants of the area are in the minority. In fact, twice a year during the Sandhill Crane migration and stopover along the Platte River, cranes outnumber humans in the region by a ratio of 3:1. Individuals generally must travel long distances for health care including mental health and substance abuse services. It is against this backdrop of wide-open spaces and limited professional service availability that the genesis of YES takes place.

The story of YES is portrayed by riveting personal stories told by the teens as they move from being subjects of treatment to serving on boards and advisory committees at the local, state, and national levels. Ultimately, the youth and adults learned from each other as YES transformed from a social/support group, to an advocacy group, and later to a voice at the policy level. YES boasted nearly 200 rural youth members who were unafraid to discuss their mental health problems. The three founding members of YES received the Youth Medal of Excellence from

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the United States National Mental Health Association for promoting awareness on childrens' mental health issues. Members presented at educator and mental health professional conferences across the country and were featured by Nickelodeon Studios, a national television studio focusing on children's programs, in a special broadcast highlighting the challenges youth face at home, school and in the community.

This chapter describes the experiences of youth and adults involved with YES to illustrate dialogic leadership principles. Practical application of lessons learned from this case study provide a roadmap of practical strategies to develop youth organizations that empower disenfranchised or marginalized youth, assist youth to develop the skills necessary to effectively organise, and address challenges and opportunities associated with building strong youth-adult collaboration. The chapter concludes with recommendations for the development of effective, sustainable youth organizations through youth-adult partnerships.

MENTAL HEALTH DISORDERS AMONG YOUTH

Serious emotional disturbances refer to a range of diagnosable emotional, behavioural, and mental disorders that severely disrupt daily functioning in home, school, or community (U.S. Department of Health and Human Services, 1999) and affect approximately 9–13% of youth in the United States during any given year (Friedman, Katz-Leavy, Manderscheid & Sondheimer, 1996). The most common emotional disturbances for youth include mood disorders, anxiety, and disruptive behaviour or conduct disorders (U.S. Public Health Service, 1999; Lewinsohn, Hops, & Roberts, 1993). As many as half of youth diagnosed with a mental health disorder also have a co-occurring substance abuse disorder (Greenbaum, Foster-Johnson, & Petrila, 1996).

Consequences of Mental Health Problems

Regardless of the type of mental health problem affecting the adolescent, all serious emotional disorders are associated with impaired functioning across important life domains, including home, school, peer, and community (Costello, Angold, & Burns, 1996). Studies reveal that youth with mental health disorders are at an increased risk for dropping out of high school, teenage parenthood, and substance abuse during adolescence; and experience higher rates of unemployment, marital instability, and criminal activity during adulthood (Kessler, Berglund, & Foster, 1997; Kessler, Foster, & Saunders, 1995; Kessler, Walters, & Forthofer, 1998; Vander Stoep et al., 2000). In fact, similar to findings among incarcerated adult populations (Ditton, 1999), the rates of mental illness for youth in the juvenile justice system are consistently found to be twice as high than in the general population (Otto, Greenstein, Johnson, & Friedman, 1992).

Youth who received residential care for mental health disorders are more likely to have at least one substance use disorder (Substance Abuse and Mental Health Services Administration, 2002), have difficulty gaining employment (Schwean, 1999), have

lower educational attainment (Best, Hauser, Gralinski-Bakker, Allen & Crowell, 2004), and experience residential instability or homelessness (Davis & Vander Stoep, 1997). Most importantly, the lifetime rate of suicide among youth who previously received inpatient mental health services is estimated at 6 times the community norm (Kjelsberg, Neegaard,,& Dahl, 1994).

Lack of community-based services. Many youth with mental health disorders do not ever obtain the professional help or appropriate services they need (U.S. Public Health Service, 2000; Weisz & Hawley, 2002). Kataoka, Zhang, and Wells (2002) suggest that about 7.5 million children have an unmet need for mental health services in the United States. A subgroup of youth, those with the most serious disorders, spend most of their adolescence disconnected from family, school, and peers as they move in and out of mental health, child welfare, and juvenile justice systems (Grisso, 2004).

We know from longitudinal research that youth with mental health disorders are also more likely to experience chronic or recurring disorders as they transition to adulthood (Newman, Moffitt, & Caspi, 1996). This means that youth with mental health disorders are less likely to meet important developmental markers of becoming an adult. These risks are assumed to be even greater among youth who do not receive appropriate mental health services (Grisso, 2004).

Often youth with serious emotional disorders experience difficulties because they are removed from their families when the service they need is only available far away from their homes. One YES member relates his story:

> I had to go [to a residential treatment program] because I wrote a bad note about somebody and got into trouble. I don't remember what the note said, but I couldn't stay at home with my family any longer. That was the worst thing about going there. While I was in the treatment home, I was liked by everyone. Some kids tried to get me to do bad things, but I never did what they wanted me to do. I learned a lot more bad stuff [that other] kids did than good stuff the staff was teaching. I got the most support from my family coming to visit me, my therapist, and conference calls for my wraparound team meetings. Being with my family was what really helped the most. If everyone would understand this, I would do better.

Another YES member discusses her experience in the foster care system:

> In my life I have lived in a lot of foster homes. By the time I was 8 I was in 5 different foster homes. I got adopted by my 5th foster family. I still live with them today. In the beginning the support I got from my family was very minimal and I got in a lot of trouble in the community. I got teased almost all the time too. Since I have been adopted things have gotten better because my parents are very supportive and I am not in as much trouble or teased as much.

Difficulty in school. Despite relatively high rates of mental health disorders among youth, schools generally lack the infrastructure to provide appropriate help. Research suggests that neither teachers nor administrators are equipped with the

basic training needed to handle the mental health issues of students (Doll, 1996). Youth often believe that teachers do not have time to devote to non-educational concerns and that they view emotional problems as separate from academic performance (Mowbray, Megivern, & Strauss, 2002). Teachers may, despite good intentions, assume that poor school performance reflects insufficient effort, rather than recognizing unmet mental health needs.

The lack of infrastructure and training can lead to inappropriate actions on the part of schools. Forness and Kavale (2000) found that students with mental and emotional problems were disturbing to teachers and that students were more likely to be expelled rather than be considered for special education services. More than half of all youth with an emotional disturbance do not make it all the way through high school (Jans, Stoddard, & Kraus, 2004). Youth with a mental health disorder are often labelled as troublemakers at school. High school students with emotional disturbances fail more courses, earn a lower grade point average, and miss more days of school than youth with any other disability (U.S. Department of Education, 1999, 2001).

The educational challenges faced by children with mental health problems are explained by one of the YES youth:

> My name is Sam. I am 10 years old. I am in the fourth grade. I should be in the fifth grade but I got held back in Kindergarten. I have a problem that has a funny name. It is called Aspergers Syndrome. In preschool, I wouldn't sit still when the teacher was reading books and I still don't. I like to walk around. That made the teachers mad. I don't need to sit still to listen. I remember the whole book word for word, even though it looks like I'm not listening. I am in Resource class. I hate it. They make me do stuff I don't want to do, and if I don't do it, I get a quiet room. I don't think I've improved much at school. I am in the 2nd grade level in reading and math.

Another member of YES relates a similar experience in school:

> I am 17 years old and live in central Nebraska. I have several different diagnoses including: posttraumatic stress disorder, delusional disorder, impulse control, and schizoid-affective disorder. I have trouble sleeping, they [the medications] make me feel tired, sometimes my hands start to shake and I get thirsty a lot. I used to hear voices, but not anymore. The worst thing is that my medicines make me so sick sometimes that I can't protect myself from the other kids. I am not sure when I got my first IEP, but my identified disability is emotional/behavioural. My emotional problems began when I was being teased and bulled in my school and in the neighbourhood. I received very little support from the school I was in. The teachers didn't help me with the bullies and teasing. They didn't give me enough time to do my work and got upset with me when I didn't get it done on time. They never listened to me and why I was having problems.

Stigma. There is a certain mark of disgrace or infamy associated with admitting you have a mental health problem in America. The word stigma is used to describe the negative perceptions that are commonly attached to the way people think about

mental health issues. Although many people experience stigma at some point in their lives, youth who have a mental health disorder face stigma on a regular basis. The stereotypes and stigma of a mental health disorder lead youth to experience strong feelings of isolation and marginalization. As one of the YES members illustrates: "When I first got diagnosed I thought I was the only one. I thought I was stupid and I didn't like it." Although youth may feel comfortable acknowledging that they have difficulties or that they experience negative emotions, the word 'mental' is much more threatening and is often a term of insult (Laws, 1998). Students who admit that they have a mental illness may be considered "weird" or "pitiful" by their peers (Mowbray, Megivern, & Strauss, 2002). One member of YES summed up the isolation of mental illness, "The worst thing about having [an emotional disorder] is not having friends." Psychological and physical bullying is a constant risk for these youth.

Stigma, and the reactions of others resulting from this, tends to flourish when the nature and causes of mental health disorders are poorly understood. As a YES member explains: "The kids with the hidden disorders are picked on the most." Their disorder is often viewed as reflecting personal weakness or a poor decision-making. This highlights the importance of adults and youth working together to use a strength-based approach rather than a deficit-based focus. The development of youth organizations such as YES is a monumentally important step toward decreasing stigma, empowering youth, and changing society. Through the work of these groups, youth with a mental health disorders learn that they are not alone. By sharing their stories and learning to advocate for change, youth are empowered to create change while decreasing the stigma and the isolation that surrounds them (Martarese, McGinnis, & Mora, 2005).

THE HISTORY OF YOUTH ENCOURAGING SUPPORT

The Vision for a Youth Organization

A young man named Brandon stood in front a room full of adults. He cleared his throat, took a drink of water, and began to describe what it felt like to hide from school bullies in the locker room, feeling alone and isolated. He talked about being labelled as mentally ill from the age of nine, and what this meant for a boy growing up in a small rural farming community. He explained the difficulty he had concentrating and sitting still in the classroom, and the problems that caused with his teachers. The adults in the room were silent as he spoke about growing up without friends and how he often thought of killing himself. Brandon's message was not one of despair, but rather of hope. He took another drink of water, looked into the eyes of his audience and shared with them how he gained friends, a purpose, and a new voice through a youth organization that has helped hundreds of rural kids just like him – kids who are alone, struggling with mental illness, coping with schools, doctors, and the well meaning adults trying to understand and help them.

Youth Encouraging Support (YES) is an organization of youth ages 10 to 21 that have a mental, emotional, or behavioural disorder. The inspiration for YES began in September of 2000 when Brandon was14 years old. His journey from

outcast to participant at the Surgeon General's children's mental health conference in Washington, D. C. served as an inspiration for other youth like him to band together and form YES.

Brandon grew up in rural Nebraska where he was often bullied and teased. He was identified as having a mental health problem which meant that the adults in his life met to discuss what was best for him. Brandon was allowed to attend these meetings and had always been vocal at them. While many kids are quiet during these meetings, Brandon actively engaged in discussions with the adults who were deciding his future. He stood out from the crowd and for this reason he was one of fourteen youth selected to travel to the nation's capital to attend the Surgeon General's Children's Mental Health conference. This would be one of the few times Brandon had travelled outside of Nebraska. He thought it would be great to get a free trip to Washington D.C., meet the country's Surgeon General, and most importantly, a chance to get out of school for a while.

The Surgeon General's conference was designed to address important mental health issues facing the country, highlighted in news stories about school shootings and the ballooning of prescription medications (such as Ritalin) for children with mental health challenges. Children's mental health had never received such prominent attention at the federal level, and youth involvement in conferences at this time was a relatively novel concept. At the conference, Brandon had an opportunity to meet other youth with mental health problems from across the country, but he found the sessions to be uninspiring. Because the number of youth attending was relatively small, Brandon felt that their role was a token one. Rather than continuing to attend sessions they considered dull and geared toward an adult audience, the youth participants decided to boycott the sessions and to meet with each other. In these meetings, the youth learned a great deal from one another about challenges they faced in each of their communities and ways in which they were trying to work with their peers. When the conference staff noticed the youth were absent and discovered their subversive meetings, they tried to re-engage the youth by inviting them to present their concerns to the 600 adult conference participants. Brandon helped organise the youth presentation, which was well received. This was one of the first times that the youth felt their perspectives were heard. They had discovered the power of their collective voice.

Although inviting youth with serious emotional disturbances to the conference was laudable and a significant step by adults to include the youth perspective in decision-making, the adults planning the conference had little experience in how best to include youth. Traditionally, these types of meeting were planned and conducted by adults for an adult audience. The Surgeon General's conference was typical in that presenters used technical jargon and assumed a high level of knowledge about mental health policy. There was little effort to tailor the meeting so that youth could productively participate (e.g., special briefings to help youth understand key concepts, special meetings with youth to obtain input apart from adult participants). It took action by the young conference participants to reveal these deficiencies. To the credit of the adult conference organisers, they were willing to make changes to the agenda and provide the opportunity for the youth to be heard.

Brandon left the conference feeling that the policy makers had actually listened to their perspectives. His new friends had told him that youth in other areas of the country had formed support groups to help adolescents cope with mental illness and the accompanying stigma. Brandon returned to Nebraska determined to create such a group.

Prior to his conference experience, Brandon was the young man hiding in the locker room. But now he had hope. He aspired to develop a local network of youth with similar problems so he could share with them the experience of being accepted, heard, and empowered. Brandon developed his vision for a group led by youth that would recreate the power and voice he found in Washington D.C. His vision expanded to include ideas he was gathering from other adolescents across the United States. He wanted the group to be a social support network for youth to develop precious friendships without fear of teasing or bullying. He researched other groups and decided that they could also serve in an advocacy role, providing adults with information about what it is like to be a kid with emotional problems. He also decided that it was important that the organization be governed and run by a council of youth that determined the direction and activities of the group.

Brandon subsequently attended several other national mental health conferences and continued to interact with youth from other states. During one of these meetings, the director of the central Nebraska family organization heard him speak and asked him to present his ideas to her organization. When Brandon presented to this group, the adults were receptive, but his ideas remained a vision. He felt empowered, but was still alone in a world of adults. Although he had developed friendships with other youth with mental health problems from around the country, he lacked a local social network of peers. But this was about to change.

After hearing Brandon speak, another adult asked him to talk to her staff as part of a panel of youth who had received services through that program. Participation on this panel introduced Brandon to Mary and John, both of whom had mental health issues and neither of whom had presented to a group before. Like Brandon, they felt empowered by the experience. The three soon became friends, and all adopted the vision for a youth-driven organization that would be supportive for youth while changing the way people thought about and acted toward kids with mental illness. Finally, Brandon discovered that there were other youth nearby who had experiences very similar to his own. This fledgling group, in partnership with adults, organised and held a rally that brought kids together who were receiving services through a local community mental health program. Adults, primarily parents of these youth, provided transportation to the event and encouragement to organise and meet children with similar needs. The number of youth in the group swelled after the rally. The first priority for the kids in the informal group headed by Brandon was to get together regularly so they didn't feel alone anymore. The adults in the family organization helped them find a place and a time to meet. In adult terms it was a support group, but for the youth it was a social time when they didn't have to constantly be guarded about the challenges they faced. It didn't take long in the rural areas for word to spread to neighbouring towns that there was a

time and a place where kids with mental health problems were accepted and supported. The group became so successful, that youth in three surrounding communities started their own groups, modelling them after Brandon's vision.

The support of other YES members is in direct contrast to the teasing and bullying from other youth. The support groups focused on the strengths of each child, rather than her or his deficits. YES members determined early on that a strength-based approach would be key to their success. Children and adolescents who participated in these meetings had experienced so much negativity in their lives: from other children teasing and bullying them, teachers admonishing them, schools expelling them, and treatment professionals focusing on what was wrong with them. A positive atmosphere where youth could discover and build upon their talents and skills would be essential to develop and sustain a youth organization. This perspective was reinforced by adults, both parents and professional, who were advocating a wraparound or strengths based approach to services (see VanDenBerg & Grealish, 1996; Kutash, Duchnowski, Sumi, Rudo, & Harris, 2002) expressed by one YES member:

> My strengths are: working with my hands, being friendly and helping others, building things and repairing electronics. My friends at YES tell me that I am kind, caring, and always happy and smile a lot. Currently, my goal is to finish high school and get a job afterwards.

Another YES youth discusses her strengths:

> My name is Sheila and I am 15 years old and currently in the 9th grade attending High School in Central Nebraska. My strengths and hobbies are: drawing, art, singing, reading, knitting, crocheting, and my family. I am very determined, friendly, funny, kind, caring, and good at listening. I am learning how to be a good leader in my YES group. I am a representative on the youth council. I am passing most of my classes now. In the future I plan on attending college and getting a degree, probably in cosmetology. Then I plan on getting a job, get married and have kids. Beyond that I don't know what I'm going to do.

The Role of Adults in YES

Brandon's mom, Brenda, always did what she thought was best for Brandon. She took him to specialists; made sure he took the many drugs that were supposed to help him, and followed the directives of teachers and doctors. None of this seemed to be as helpful to Brandon as the self-discovery he was making. Brandon was empowered and had a new purpose to his life through his quest to help other children and adolescents with problems similar to his. Brenda marvelled at the change:

> I remember the first time I heard Brandon share his story. I had never thought of it from his perspective. I'm his mom; I was trying to help him. I thought I was advocating for him. And when he said, 'You know, I've been on at

> least 20 medications, I've seen at least 10 different doctors,' it was that one sentence, 'Seeing 10 different doctors, seeing that many counsellors, and at least 20 different medications and nobody once asked me if any of it was helping.' And I went, oh my God, we never did. We sat in all those team meetings with the schools and the therapists and the doctors and we didn't ask him once. And why weren't we asking him? So when that came up, it made me realize, he's right. We have to have youth start talking. He's 14 now, and he's not a little boy. I don't need to talk for him and he can't be the only one [youth who are not consulted about their treatment].

As Brandon's youth-led support/social groups expanded, the regional family organization decided to support the youth organization by providing a paid part time staff position who shared the vision of a youth-directed organization. The family organization was a non-profit corporation organised about 10 years earlier to provide support and advocacy for caregivers of children with mental health disorders. Parents and other adults who parent youth with mental health disorders had felt marginalized, in a manner much like the youth themselves. Family members, neighbours, teachers and mental health professionals often had blamed the child's behaviour on poor or inadequate parenting. Much like the children and youth were doing now, family members had come together to support each other, to inform community members about children's mental health in an effort to reduce stigma, and to advocate for policy changes. Now these caregivers were witnessing the same type of group initiative by their children.

The youth needed an adult who could be guiding but not controlling. The board, based on its experience in developing the family organization, selected Brandon's mother, Brenda, to assume the position. Brenda was considered ideal because she had experience raising children with mental health disorders, had a strong interest in developing a successful organization that would benefit other children in the way her son had been helped, and had an interpersonal style that would fit well with the task. Since Brenda had been involved in development of the family organization, she knew that providing gentle guidance, rather than rigid direction, would help ensure youth were successful. She understood that children with serious mental health problems, like her son Brandon, had been both blamed, and dictated to, by adults. The youth organization provided an opportunity for youth to exercise their own self-determination for a change.

The small office serving as YES headquarters vibrates with activity. As the energy in the room picks up, Brenda's smile widens. This mother of three beams with pride and purpose as she talks about the YES organization and the youth who find purpose there, but it's not the boasting of a parent one hears. Brenda's approach to youth-adult partnerships in the YES program is far from parental. The youth are intuitively aware of this, but can't really articulate this difference. Brenda sees herself as a catalyst rather than a partner or friend. The youth view her as bridge to resources as well as a resource herself.

Brenda believes her age and experience are assets when working with youth. She believes there are major advantages in finding someone who is mature and philosophically aligned with youth empowerment through dialogue rather than

depending on common interests. The temptation for those with common interests is that they may defend their position rather than enter into dialogue with youth. Brenda believes that it is vital for adult partners to suspend their own position long enough to really listen:

> What has worked for us is not what a lot of youth organizations are getting – they get adult leaders who are kids who've been in the system or right out of college. It wouldn't work for us the way we do our stuff because most of the time young adult leaders want to be friends with the kids and then there's no sort of authority figure. The other problem is then when that youth coordinator wants to go in to talk with other professionals, they're not respected as much. You've got to have somebody who can get, and be respected by, adults and the kids.

With Brenda's help, the youth began to seek out opportunities to educate adults and make life more bearable for other kids like them. In part, this meant sharing their stories with any adults who would listen. One group of particularly interested adults was the "lunch ladies" from local schools, who interacted with youth frequently as they prepared school lunches and monitored cafeteria behaviours. These women had observed the isolation youth with mental health problems experienced and the teasing they endured. Often, the lunch ladies tried to help these youth by shielding them from the taunting and bullying; they tried to include the kids in activities and befriended them. The lunch ladies initially requested a presentation from one of the youth who had an eating disorder, an area of particular interest for those responsible for the nutrition of school children. The young woman was uncomfortable presenting alone and asked if she could bring her friends to present on other types of behavioural health disorders. The panel presentation was so well received that soon lunch ladies from across the state were requesting presentations, and the youth were invited to speak at the state-wide lunch lady conference. The youth were not interested in making money from their efforts and were willing to speak to any group who would offer them gas money and a meal, which lunch ladies do well.

In the wake of this overwhelming success, other organizations and mental health provider agencies began to ask the youth to present on the challenges of having a mental illness and what works to address these challenges. Soon, the youth were speaking at state-wide, regional and national conferences, association meetings, and university classes. At first, speaking in front of adults about highly personal issues was difficult for many of them. Brenda helped them be effective speakers and choose appropriate messages to communicate. Her philosophy was that kids often learn best from direct experience. She suggested that they develop an evaluation form to obtain feedback from the adults they presented to so they could improve their presentation styles. They asked for constructive feedback and often received very positive remarks on these forms. The adult audience members were surprised and impressed with how articulate the speakers were and how well organised the presentations were. Many of the adults felt that the presentation was "eye-opening" and extremely valuable for them to have the opportunity to hear the

youth voice "direct from the source". They reported feeling that the presentations greatly bolstered their understanding of the youth experience and that because of the information they learned, they would "be more understanding in the future and not take labels at face value". This positive feedback provided valuable encouragement for the youth who had struggled in school and seldom received positive comments on their efforts.

There were times Brenda was tempted to move the YES group in a given direction. She knew through experience that there was an easier way to do things, but it is not her experience that is important in this partnership. Instead, creating experiences for youth guides her in this partnership. She tried to balance this need with her instinct to protect the kids from world. While others may seek to share power equally in a youth-adult partnership, Brenda knows that she holds a certain authority by virtue of being the adult with greater access to resources. Thus, her task is to tip the power balance in the direction of youth whenever she can. Sometimes this means letting them make decisions and choices that are not the ones she would choose.

As the youth effort began to grow, they realized they needed an organizational structure to help coordinate their activities, assist in making decisions, and to set direction. In response, the youth established by-laws, a logo, and a name – Youth Encouraging Support (YES). Although Brenda provided gentle guidance during this organization, the major decisions were made by the youth themselves. They developed a board and a code of conduct that the board enforced. YES also began to plan and implement other activities. One activity was a summer camp, since many of the youth had never attended camp like other children. They worked with adults to find a location and organise the camp activities. Some parents enjoyed the days of respite while their children were away at camp having fun, while others volunteered to help supervise activities at the camp.

Another activity that received national media attention was a "stigma busting" campaign at a local shopping mall. YES youth invited people shopping in the mall to write their impressions of mental illness on a graffiti wall. This activity generated discussions between the YES youth and community members about the nature of emotional disorders and the stigma associated with them. The event was filmed and broadcast by Nickelodeon Television, a national studio specializing in children's programming, to a national audience. Youth were also included in a project by Nebraska's public radio station about the issues surrounding behavioural health in the state. YES youth were interviewed and included in the radio program that featured a segment on youth with serious emotional disorders. The graffiti wall idea was expanded for use in a number of area schools as a way to inform students about mental health and to help reduce bullying and the social stigma attached to mental illness. These events allowed YES youth to practice being effective advocates and successful communicators. The YES organization also collaborated with other organizations to tap expertise in related areas, such as school bullying.

From its inception, YES grew to include almost 200 members in central Nebraska. The three founding youth each won Youth Medals of Excellence from the national Mental Health Association for their work in combating stigma and

promoting mental health. These three members of YES are now young adults. They each continue to struggle with mental health challenges, but are living healthy, active lives. They continue to be leaders (and now legends) for the young new members of YES.

Brandon describes his journey from struggling with the challenges of mental illness to helping others cope with their own emotional disorders.

> Most of us at one time or another have ridden on a roller coaster. We have enjoyed the thrill of the ride. It may be the anticipation during the ascent or the excitement when the coaster soars downward. Living with bipolar disorder for me has been much like that experience. In the beginning, however, it was not an enjoyable feeling. My roller coaster was going much faster than normal. Sometimes I felt invincible; other times I lived in constant fear of it crashing as it sped downward. My life was out of control. My ride began shortly after kindergarten when I was diagnosed with ADHD and was placed on Ritalin. By the time I was in third grade, I had been diagnosed with learning disabilities. I had to endure the constant teasing and bullying of my classmates. All the while the teachers discarded or ignored my feelings about the treatment I received from them. Teachers felt it was justified since "I CHOSE to act this way." When I entered the sixth grade, the roller coaster was speeding out of control. The teasing not only continued, it got worse. Kids were using me as their personal punching bag. Some days I was so angry that I would destroy things, hurt my little sister or myself. Some days I just cried. That was the first time that I tried to kill myself. After changing schools, and finding the proper medications and support, I have been able to better get my life on track. I became a roller coaster engineer. I can control the roller coaster so it doesn't go so fast. I still have my good days and bad days, but not as bad anymore because I'm better able to manage my illness. I don't want to kill myself anymore. Instead, I want to help others to become roller coaster engineers.

DIALOGIC LEADERSHIP IN ACTION

One of the practical lessons learned from the YES experience relates to the leadership role and style of the key adults in youth-adult partnerships. The type of leadership that Brenda instinctively models has been called dialogic leadership. William Isaacs (1999) argued that there are lessons from dialogue theory that can be applied to the field of leadership. Dialogue can be used to create an environment that minimizes fragmentation while tapping into the collective wisdom of the group. Rather than adopting a defensive stance related to one's own position and trying to sell one's point to others, dialogue involves being open to ideas that others propose. Isaacs describes the difference between dialogue and discussion by highlighting the roots of the words. The Greek root of dialogue is related to "flow of meaning" whereas the word discussion comes from a root that means "to break apart." The practical difference is that dialogue involves greater give and take, and openness to others' ideas. Dialogue builds on the collective wisdom by tapping into

the creativity of the entire group through conversation that demonstrates openness and values differences. According to Isaacs, an effective dialogic leader is someone who can elicit the true voices from group members by actively listening and assuming that all opinions are valuable and can contribute to the whole.

Dialogic leadership encourages people to dynamically assume different positions in conversation. At different times, it may be appropriate to actively share an opinion, to represent an opposing viewpoint, to advocate for one position or the other, or to simply hold a neutral position while taking in information. The dialogic leader models this balanced dance and fosters the ability of group members to do the same. The adult leaders who encouraged the formation of YES had to engage in dialogic leadership to make it successful. This in turn led to development of similar skills for the youth leaders of that organization through observation of their adult partners as role models, and through their successful experiences interacting positively with adults in the community, reinforcing and refining these skills. Isaacs identifies four practices of dialogic leadership based on this model of balanced conversation.

The first and most difficult leadership practice is to encourage others to find and express their true voice. This is difficult because that voice may not be correct, easy to listen to, or in line with the opinions of others. Based on their own experiences in developing a successful family organization, learning from both positive and negative experiences, the adults working with the YES project understood that direct experience was a more powerful teacher than anything they could impose. They allowed youth to make mistakes that probably could have been avoided if adults ran the group. The experience of making those mistakes was instructive for the youth leaders. Finding their true voice involved making mistakes. These mistakes were reframed as positive learning opportunities by the adults. Youth who were used to being ridiculed for making mistakes were now encouraged to take risks, voice opinions, and safely test their own leadership skills by adult partners. As Brenda explains:

> If he wants to eat a chocolate donut instead of a strawberry one, that's okay. And if he mildly breaks out from strawberry donuts then maybe he'll learn not to eat those. Now if it's not life or death, I'm all about letting them learn from their mistakes.

The second practice is to model and encourage others to listen to all voices. Listening is equated with following because it entails opening up to another's opinion or direction. The first example of this in the YES model was Brandon's treatment team. They took a chance by actively including him as a member of his own team. An adult in the group believed his opinion was important and thought that others may benefit from hearing it. The ultimate result was the youth panel presentations that stimulated formation of the YES group. The youth who were marginalized by their peers were empowered to tell their stories by adults who listened. Brenda's role as a partner rather than leader with YES youth further exemplifies the role of listening adults. She guided but did not impose her ideas on the youth. Her philosophy and practices placed youth in control of their

organization. She listened to them and helped them clarify their goals, and helped them listen to each other:

> Brenda would be there to write it but she was always like, this is your group you guys. She was there, but we ran it.
>
> YES member

> They told me youth were incapable of making decisions.... I said, "Really? So if I set a plate of chocolate donuts and liver and onions, do you think he could make a choice?" And he says, "Well that's different." I said, "No, it's not, because you aren't allowing him to make decisions."
>
> Parent of a YES member

The third practice involves respecting opinions and voices that are opposing or unacceptable to you. One problem faced by the youth of YES was that the illnesses they had were generally unacceptable to society. It was not okay to admit you had a mental illness. It was particularly frightening and unacceptable to their peers and parents. The voices and opinions of these youth were hard to listen to for many people. The kids talked about not feeling safe, wondering why they were not accepted by teachers, peers, and parents. They questioned the way adults were trying to help them and in an outright rebellion at the Surgeon General's conference, they discounted the motives and rhetoric of those around them. It was not easy for some of the adults to hear what these youth had to say. Adults engaging in youth-adult partnerships must be prepared to listen, even when it is hard to hear. Marginalized youth who have found their voice will invariably have harsh realities to share that may run counter to the image that adults wish to project. Dialogic leaders expect to encounter opinions that differ from their own and try to incorporate that voice rather than hide from it. One YES member talked about a disconnect that he sees with adults who say they want to work with youth, yet don't seem to incorporate youth voices in their work: "I said, 'You are working with the youth. Don't you want to know what they have to say'?"

The fourth practice is suspending opinions long enough to really listen to others. This may require taking a deep breath and allowing others to speak without trying to defend a position. Some adult partners are chosen specifically because they can still 'relate' to youth. Brenda's observation about the need to have mature adult partners work with youth reflects her concern that many young adults may still be too close to the maturity level of the youth to be an effective adult partner. The value of adults modelling dialogic leadership principles in adult-youth partnerships may be that the young adults who matured under that leadership style are equipped earlier to embody both youthful thinking and the ability to effectively be an adult partner at an earlier age.

Most of the literature available on youth-adult partnerships in children's mental health discusses the roles of adults and youth in an organization, and describes how adults can form youth adult partnerships, foster growth and leadership among youth, and demonstrate to adults the viability and benefits of

a youth voice (e.g., Martarese, McGinnis & Mora, 2005; Keller, Bost, Lock, & Markenko, 2005). The lessons from YES enhance this framework by highlighting how an adult's leadership style can strongly influence whether the youth can assume leadership roles themselves. In other words, YES moves beyond the roles of adults and youth and demonstrates the importance of the personal characteristics and demeanour exhibited by the youth leader in facilitating successful youth endeavours.

Jones and Perkins (2004) view youth-adult partnerships on a continuum. At one end are groups led by adults in which youth inhabit a participant or follower role. At the other end are groups without any adult guidance. An example of the 'adultless' group is a youth 'gang', but it would also include the group of youth who boycotted the United States Surgeon General's conference on children's mental health. These youth banded together and took collective action without adult guidance or partnership. However, this group was ad-hoc and short lived, as many of the purely youth led groups are.

At the centre of the continuum is a balanced youth-adult partnership in which power is shared equally by youth and adults. The Nebraska YES group is best described as a youth-led collaboration. The adult served as a bridge to other adult groups and provided the youth with guidance and assistance in acquiring resources. Without this bridge, the work of the youth might not have been considered important enough to integrate into the adult institutions, thereby perpetuating the marginalization of youth with mental illness.

LESSONS LEARNED

There are a number of leadership lessons embodied by the YES project that can enhance adult-youth partnerships. The style of leadership that moved YES forward from vision to action can best be described as dialogic. The leadership style of adults working in partnership with youth was more important than their formal or informal role in the organization. Practical leadership lessons for adult partners include the following:

- Adult partners serve as a bridge to resources and opportunities that help youth find their own voice
- Adult partners model active listening for youth and allow them to safely explore and experience the results of expressing their voice
- Adult partners encourage tolerance and model empowerment by encouraging diversity of opinion and consideration of marginal views.
- Adult partners are mature enough to recognize that empowerment is more beneficial to youth than wielding power over them.
- New adult partners blossom from youth who have been exposed to adult partners who have modelled dialogic leadership principles.

> You can do all the research you want, but if you forget who we are and what we need as people, and if you don't respond to our needs in the system and in

> our individual treatment, you will fail, the system will fail, and we will bear the burden as we do now. You must include youth, bring us to the table, and when we show up, you must listen.
>
> Youth Statement written by eleven youth at the 2000 Comprehensive Community Mental Health Services for Children and their Families Program.

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