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Leadership, Empowerment, Advocacy Project (LEAP): College Education for Recovery and Transformative Change in Community Mental Health

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Abstract

The Leadership, Empowerment, Advocacy Project (LEAP) students represented a heterogeneous groups of individuals commonly referred to as consumers/ peers who deal daily with severe and persistent mental health disorders and/or substance use disorders. They are often ostracized and marginalized and lack the same opportunities and supportive resources for advanced educational attainment as others. Over three semesters, LEAP prepared students with knowledge and tools to develop leadership skills as future leaders and volunteers within the mental health community and the consumer movement. This radical strategy created recovery and empowerment by producing an optimistic future for students that reflects personal goals of improved quality of life, a reduction in mental health symptoms, and the achievement of valued social roles.

Keywords: supported education; empowerment; recovery; leadership; advocacy; alternative models of mental health services; mental health stigma and discrimination; consumers and higher education

Introduction

Cultural Stigmatization Contributing to Self-stigma

"As long as a society's image is positive and flourishing, the flower of culture is in full bloom. Once the image begins to decay and lose its vitality, however, the culture does not long survive" (Polak, 1961, p. 19). Stigma and discrimination against consumers/peers challenged by mental health issues are symptoms of a diseased society. The history of stigma, so prevalent in Western culture, can be traced back to Ancient Greece from the 5th century B.C. to the 2nd century A. D. when "madness" was defined as a mark of shame, degradation, loss of face, and humiliation (Simon, 1992). Today, common toxic labels, such as crazy, insane, nuts, loco, wacko, psycho, off your rocker, out of your mind, mental case, schizo, lunatic, and deranged are embedded in our language and culture and express social ridicule and degradation of consumers/peers. These globally accepted terms support beliefs and attitudes that individuals with mental health challenges are to be feared, labeled, despised, misunderstood, and denied the same rights and opportunities as others.

The Americans with Disabilities Act (ADA) of 1990 claims that it recognizes and protects the civil rights of people with disabilities covering conditions such as emotional illness and learning disorders. Congress states within the ADA Amendments Act, which became effective on January 1, 2009, that "mental disabilities in no way diminish a person's right to fully participate in all aspects of society, yet many people with physical or mental disabilities have been precluded from doing so because of discrimination" (ADA Amendments Act of 2008, Section 2A). Individuals discriminated against in employment and education settings have often had little or no legal recourse. It is well documented that people with disabilities are disadvantaged socially, vocationally, economically, and educationally (e.g., Baron & Salzer, 2002; Drake, Skinner, Bond, & Goldman, 2009; Stein, Aguirre, & Hunt, 2013). In order for individuals in the mental health system to be healthy, they need opportunities, valued social roles, and equality. Empowerment means being fairly treated and having access to health care, education, employment, housing, citizenship, inclusion, civil rights, and social justice (Corrigan & Ralph, 2005). Equality is an essential ingredient for hope and recovery. Transformed identities are possible by being valued, included, respected, and heard.

Overview and description of the LEAP program

Program Development

The Leadership, Empowerment, Advocacy Project (LEAP) was developed to meet the needs of consumers/peers as an innovative supported education intervention for transformative change in community mental health services. Mowbray et al. (2005) reported that campus-based supported education models contribute to significant increases in educational enrollment and competitive employment, and significant decreases in hospitalization. In addition to these goals, LEAP aimed to promote recovery, empowerment, and hope for individuals living daily with mental health disorders within our communities, our service systems, our nation, and our world. According to Unger (1993), "The role of college student in our society is highly valued. The role of

mental health consumer is very devalued. With this change in role and identity, students realize they are not their illness, but functioning, productive members of the community" (p. 20).

The entities involved with LEAP are the State of Kansas, Wichita State University, and the Wichita State University Center for Community Support and Research (CCSR), (formerly known as the Wichita State University Self-Help Network Center for Community Support and Research). The collaboration had developed over many years of innovative projects serving Kansans with mental health disorders. CCSR believed in the opportunities that LEAP offered to individuals with mental health disorders and how the impact of being college students would transform their lives. A team of four visionary CCSR co-workers designed and developed LEAP. The team members included a professor of community psychology at Wichita State University who was also the Director of CCSR, the Assistant Director of CCSR, and two employees with Master degrees in Social Work. My role, as one of the team members with a Master's in Social Work and the only person with a mental health disorder, was to provide the perspective based on my experience dealing with my disability and managing the academic demands necessary to complete my college education. The team was an excellent mix of people and over time became very cohesive.

The team anticipated that the two major challenges would be university approval and funding. However, in 2002, the State of Kansas granted funding for LEAP, which paid for tuition, books, and supplies. For someone wanting to replicate the LEAP program in another university or community college setting, the challenges of university approval and funding may vary depending on the relationships between the state officials and the university administration.

At a great loss for Kansan consumers/peers, LEAP lost funding in 2007, after its last graduating class. The rationale for this decision by the State of Kansas and CCSR was to transfer funding from LEAP to a new program for consumers/peers which created income to CCSR for services provided. This exchange of funding was no reflection on LEAP as an innovative contribution for transformative change in community mental health services. Furthermore, although the LEAP program lost state funding, it nonetheless offers important suggestions for the advancement of supported education.

What LEAP Strived to Achieve

The development of LEAP started with a vision for how the quality of life for consumers/peers could be improved by providing a promising future. Next, it was identified that people with mental health challenges lack opportunities and supportive resources for educational attainment, ultimately hindering their prospects for employment. The solution began to form by asking what needed to happen and how to make it happen.

LEAP was a unique program that provided individuals with opportunities and supportive resources to compete and pursue equality for advanced educational attainment by being exposed to new and challenging ways of thinking about life and themselves. The shared challenges and life experiences among students created an academic environment rich with possibilities as students learned from each other about how to develop healthy boundaries to cultivate respectful and trustful relationships. As a result, students were empowered with increased options and choices that supported ownership and personal freedom. Many students dependent on the mental health system for all their needs never learned that having a sense of ownership means they have a duty to protect and defend their boundaries by taking control of how people treat them. Students acquired this knowledge and practiced these new skills, which resulted in the complex phenomenon of empowerment. Students gained self-respect as they learned they have the same inalienable rights available to people without mental health disorders. The LEAP students gained awareness as they explored advocacy as a dynamic process with the power to endorse the rights perspective based on the belief that advocacy is meaningless without rights.

Students experienced profound insights as they identified and committed themselves to their core values and passions. They learned that their fundamental beliefs acted as guided principles that created a reflection of the most inner description of their character. In addition, students discovered that their core values influenced every aspect of life, served as a guide to action, empowered and motivated, made it possible to take positions on issues, and assisted in resolving conflicts and making decisions.

LEAP provided peer support with warmth and positive self-regard. Friendships cultivated among students mutual support and built self-respect, acceptance, tolerance, and admiration for one another. In addition, LEAP taught students how to develop skills which promoted independence. Students gained or regained their feelings of humanity, which included personal worth, personal effectiveness, and personal value. The cohesiveness of the LEAP classes provided a safe place for mutual self-disclosure between students. This environment enabled students to identify with the same issues and concerns that produced emotional support and a sense of community. This experience taught

students about the importance of social skills. Students learned they could connect with people and overcome the fear of rejection that had forced some to live a life of isolation.

The fact that LEAP was completely campus-based promoted normalization and role transformation. With the focus on academia, students understood the boundary that I was their teacher and not a doctor, a therapist, or a case manager. LEAP followed some of the same principles and values highlighted in the supported education literature including: "hope" in which everyone was treated with respect and dignity; "normalization" by referring to consumers/peers as "students" and not as "patients" or "clients"; "self-determination" by providing information on campus resources and how to gain access; and "support and relationships" by encouraging students to take advantage of the opportunities to learn from each other and to form cohesive bonding between each other based on peer support (Mowbray et al, 2005).

The LEAP Process

LEAP was a three-semester college experience entirely located on the Wichita State University campus for individuals challenged by mental health disorders. I taught the classes solo beginning with the fall semester in 2004 to the last graduating class of 2007. During those three years, I reorganized the curriculum and methods of teaching.

The selection process used to recruit potential students was based on interviews and a point system with a (1) as unacceptable up to a (5) as very acceptable. The purpose was to measure strengths and deficits to determine if the consumer/peer was a good fit. The areas of concern included the following: communication skills, social skills, concentration skills, stage of recovery, coping skills with stress, coping skills with symptoms, medication stabilized, personal appearance, level of commitment, and how confident of being successful. The demographics of students were closely consistent throughout all of the classes. The majority of students were white and female with three to four males per class. All of the students were living below the poverty level and dependent on public transportation.

As part of the summer session for the first two years of LEAP, local agencies provided internships chosen by students and were not limited to mental health. Some students had good experiences with their agencies; however some students were treated like patients and not as interns due to stigma in the mental health system. It was decided by the team of instructors that the idea had not worked as planned, and it was discontinued. Furthermore, during the first two years of the LEAP classes before I started to teach solo, the desks were set up in a circle unlike traditional classrooms with the idea that it would encourage face to face communication. With the insight and control of decisions that affected LEAP, I decided to leave the desks in a traditional style to prevent the conclusion that LEAP was like group therapy.

Beliefs in the importance of praise, celebrations and fun were recognized in the LEAP program. Respect and sensitivity for confidentiality were the main ingredients that provided a safe environment for honest and open discussions. However, students were told that LEAP was a college class and that confidentiality could not be enforced. Students were encouraged to share information about themselves based on their comfort level. Students were informed of this on the first day of class along with a comfort contract developed by students. The lack of confidentiality enforcement did not hinder the openness shared in class discussions. LEAP students benefitted from peer support and mutual support as the focus remained on recovery. As students shared their recovery life stories, everyone was influenced to move beyond their challenges and to believe they could succeed in accomplishing more than they ever thought was possible.

Students earned a total of nine college credits in psychology and attended class for three hours per week over two days. They read the following five books with the assistance of audio recordings provided by the Disabilities Support Services: *The Four Agreements* (Ruiz, 1997); *Never Fear, Never Quit* (Tye, 2004); *The Freedom Writers Diary* (Gruwell, 1999); *Who Moved My Cheese* (Johnson, 1999); and *The Day the Voices Stopped* (Steele & Berman, 2001). In the fall and spring semesters, the students were required to write self-reflective, reaction papers related to the books on how the lessons impacted their attitudes about themselves based on past, present and future life experiences. As I tracked the quality of assignments, I was able to measure students' level of knowledge gained which I used as an indicator of my effectiveness as a teacher. Daily lesson plans were tailored from students' feedback. I incorporated daily lessons into power point presentations with paper copies of the slides available for students. Based on the students' feedback, they believed this new strategy helped them to better grasp the knowledge and tools. I considered this a major breakthrough, and it inspired me to write power points for all of the class lessons. Each semester of the LEAP classes followed a flexible syllabus. Students performed well and met the expectation to attend the LEAP classes regularly with as few absences as possible. The dropout rate of students for the first class in the series was consistent. The new group of students started with twenty-five and by two weeks into the semester, three

to five students would withdraw from the class. Students believed in the benefit from the same individuals present at each class which created opportunities to be more strongly bonded and committed to accountability with each other.

Some services I provided to students included the following: completing and submitting applications for Admissions to the University; enrolling students for the classes; securing accommodations for students from the Disability Support Services Office; and completing financial aid forms for students wanting to continue their education. Each new group of students started the first semester with a two-hour orientation facilitated by the Assistant Dean to the Liberal Arts College. The first class lesson included a discussion on important tips on how to survive the balance between college demands and their mental health. Students were taught the value of pacing themselves to avoid an over load of stress which could cause a relapse or hospitalization, even if it meant taking longer to complete a degree. Some minor tips included the amount of time students should spend studying per credit hour and the benefits of students exchanging phone numbers. The most important key to survival students learned was what to do about the class if their symptoms began to return. The first course of action students were instructed to take was to contact their mental health providers. Next, to inform me of the situation so arrangements could be made for extra support to avoid falling behind with their homework.

To satisfy the third and final semester of LEAP, students prepared and facilitated four workshop presentations at the 2007 Annual Kansas Consumer Recovery Conference. They used power point presentations on the following topics: "Learning, Thinking, Working Styles;" "Experience the Liberation of Learning how to Defend and Protect your Boundaries while Enjoying Healthy Relationships;" "People with a Personal Mission Statement Succeed in Reaching their Goals by Empowering them on a Journey of their Choice;" and "Mastering Servant Leadership takes a Life Time of Commitment to Serving Others Rather than Satisfying Individual Wants and Desires." This experience was the first time students had ever stood in front of people in a packed room and made presentations. I operated the laptop to change the slides, and students worked together in teams that were divided among the four workshops. In class, students worked hard as they studied the information on each slide and were able to speak confidently about the topic rather than just reading the slides to the workshop attendees. I was proud of their courage and how well all of the students performed.

Facilitator Perspectives on LEAP's Success

If it had not been for the courage, commitment, and determination students invested in their battle against internalized self-stigma ingrained in their belief systems, the transformative change in their lives would not have happened. I credit LEAP's effectiveness to the fact that I know what it takes to be successful in completing my Master's in Social Work and licensure from the state of Kansas while being challenged by the diagnoses of Schizoaffective Disorder, a chronic roll-coaster ride of depression and anxiety; personality disorders; and a lifetime learning disability. In addition, my personal experiences with supported education for six years while completing my education influenced me to provide the necessary support and services for LEAP students to be successful. As a role model shaped by my lived experiences, I provided living proof, and this enabled students to believe that they too could succeed in fulfilling their academic goals and aspirations. This process promoted recovery and empowerment.

In the beginning of the LEAP program, students were fearful of being in a college class on campus because they did not know what was expected of them and where they would fit among the other students. At the root of their anxiety was the uncertainty of placing their trust in me as a leader on an uncharted journey. At this point, it was crucial for me to be sensitive and to validate with acceptance their fears and emotions as I assured them their reactions were common among all students in college for the first time. Although risky, students took the first step and faced their fears once they shared with each other about their painful lived experiences of isolation and being misunderstood. This interaction gave them peace with the knowledge they were not alone. After this major accomplishment, my intervention was to encourage and nurture students' courage wherein I stated my commitment to being trustful, caring, competent, self-confident, knowledgeable, and open to mutual communication. After students' anxieties decreased, they started to grasp the reality of being a college student rather than just a person with a mental illness. Gradually, students started to believe in themselves with the confidence they could be successful in college despite a life with a false self-image imprinted within their belief systems due to societal stigma of mental illness.

My next role was to support and encourage unconditional bonding between students and between students and myself. In the spirit of peer support, it was very important that I established the understanding that everyone would learn from each other which included myself as well. Students trusted and respected my leadership. On one occasion, a student approached me about me working full-time without Social Security Disability Insurance and asked if I was afraid of getting sick again. My response was that after I completed my

education I wanted to work, as it had been twenty years and I was willing to take the risk. Further, I told her that sometimes in life you have to take risks to reach your goals; if you never try, you will never know the accomplishments life offers. On another occasion, a student started a conversation about some personal issues unrelated to the class. I became aware that she was interacting with me as her therapist. My response was to set the boundaries as me as her instructor—not her doctor, therapist or case manager. Later, she approached me and stated she understood the boundary that made the interaction beneficial as a learned experience for her. The only situation that caused notable conflict was the first class of the first semester when a student I had known many years ago started talking down to the other students like he was their superior. I observed the other students' facial expressions; I knew this incident was about to blow up, and I had to take action so I asked him to leave the classroom. The student dropped the class the next day. Two days, later my car was vandalized. Despite this negative incident, the vast majority of students demonstrated appropriate boundaries and appreciated learning from me and from each other.

A psychiatric challenge can cause people to struggle because the illness attacks the very center of their sense of identity. People in the mental health system continue to be in the role of patient/client. This injustice is extremely damaging because individuals receiving mental health services are victims forced into defeating roles that affect the basic understanding of the self. As the LEAP students began their healing process, they learned that when people are forced to accept a role, they adopt self-meanings and expectations to accompany the role. Since society evaluates the role of students with positive regard when compared to a person labeled with a mental health disability, the person's self-esteem is healthier which can improve quality of life. Students were empowered by the self-verification that occurred and resulted in a transformation of their self-esteem and self-efficacy. Furthermore, as students continued to develop a strong commitment to their new identities as students, the roles associated with that identity reinforced their valued status within society.

The greatest life-changing impact students gained from the LEAP experience was the authentic practice of peer support in action. The vital center of LEAP as a radical strategy of consumers/peers pursuing a college education was the supportive interaction made possible by the shared challenges that cultivated collective empowerment and recovery. This powerful energy acted as an inspiration of hope rather than a hindrance to class dynamics. The similar challenges gave students a transformed perspective of mental health services by the shifted focus from the deficit model of illness to the strengths model. This transformed perspective enabled students to be active participants possessed with the natural inclination and capacity for righteous anger and community activism. The overall LEAP experience created opportunities for formal and informal mentored relationships and role-modeled relationships that benefited everyone even in ways unknown.

The most inspired characteristic of the classes was the fact that although I planned the lessons, graded the homework, and assessed performance, the focus was on the commonality of the relationships where no one felt or believed they were better or worse than others. Students were taught about the importance of respecting diverse perspectives as they recognized the richness individual opinions contributed to a better understanding of the self and others. Consumers/peers try to cope by isolating themselves thinking no one could ever know what it means to live in their world. The burden was lifted as students learned they had more in common with each other than they could have ever imagined. The knowledge that they were not alone and isolated enabled students to take those first steps to exhibit leadership qualities, experience empowerment, advocate for self and others, protect and enforce their boundaries, listen to their inner voice, and learn how to trust and believe in their talents and gifts.

Program outcomes

Some examples of long-term effects related to LEAP include the following:

- One LEAP graduate completed her master's degree;
- Four LEAP graduates completed their undergraduate degrees;
- Four LEAP graduates completed the Peer Support Specialist trainings and are certified working in the mainstream of the mental health system;
- Five LEAP graduates as current or former directors/ officers on the Board of Directors for the Consumer Advisory Counsel for Adult Mental Health, Inc. (KSCAC);
- Six LEAP graduates completed the KSCAC Leadership Academy for Empowerment;
- Three LEAP graduates completed the KSCAC Leadership Academy for Action;
- Fifteen LEAP graduates became active in leadership roles at the local Kansas Consumer Run Organization and the Kansas Consumer Network; and

- Numerous students served as volunteers educating others about mental health in communities.

There are also many observations on the program's success based on conversations with LEAP students and observations of students' behaviors. Students enjoyed being on campus, and many visited the university even on days there was no class. Students interacted socially with other students without mental health challenges at the Student Center, played pool table games, and enjoyed the bowling alley. This indicates to me that students gained a sense of belonging and acceptance. Having the social support among the student population without stigma improved self-esteem, self-acceptance, and self-worth (Unger, Anthony, Sciarappa, & Rogers, 1991). I observed bonding, social support, and peer support among eight to ten students who gathered thirty minutes or more before class in an area with tables, chairs, and snack/soda machines across from the classroom. I joined the students and provided supported education support as I encouraged the formation of friendships.

Although we did not systematically track outcomes, future programs that replicate LEAP or conduct similar interventions should collect ongoing data about graduation rates, drop-out rates, recovery, social support, and community engagement. Systematic research related to program development, implementation, evaluation, and dissemination would be very valuable. In addition, research is needed to determine potential program outcomes by comparing students' assessments between semesters to detect any trends as related to the ability of LEAP to meet the expectations of the students.

The following quotes from LEAP graduates help to sum up some of the program's successes:

> "The LEAP class taught me many great things about education and leadership. I felt very comfortable working with an instructor in the LEAP class who also had a severe and persistent mental illness. The teacher was very dedicated to her work and taught me a lot about advocacy. It is important to get involved and to learn as much as you can about
>
> your goals in life to become a better person. It is never too late in life to do the things you want to do. You can accomplish anything you put your mind to."
>
> "What LEAP has meant to me: When I enrolled in LEAP I was not in recovery. I was in limbo. Through the LEAP class, I realized I did have potential as a human being. I began to feel empowered and worthwhile. LEAP taught me to reverse the drag of self-stigma. I am now off of disability and working full time as a Certified Peer Support Specialist. LEAP taught me how to be a leader and a role model working with individuals dealing with SPMI [serious and persistent mental illness]. All of us including the instructor had SPMI; but that did not stop us. I suffered from self-stigma so I had a difficult time getting through the classroom door. I made it and have forever been grateful."

Potential for Transformative Change in Students and Communities

LEAP encouraged students to embark on a journey of self-discovery and to believe in a future with challenging, meaningful, and rewarding goals. Students were exposed to the potential of self-examination which they hopefully could use to gain inspiration for action and a sense of determination in the face of opposition. LEAP aimed to teach students lessons about combining their passions and core values to begin their fight against internalized stigma and discrimination, thus improving their quality of life. The LEAP experience was designed to stimulate growth in students' leadership capacity by the enhancement and exploration of present and future skills, talents, and strengths. Students were encouraged to believe they could be high achievers regardless of their mental health challenges.

LEAP equipped students with insight to take back their power from the political system, the social system, the civil system, the labor system, the legal system, the educational system, and the mental health system. LEAP educated about how rights and their enforcement empower consumers/ peers. Rights are at the heart of advocacy and the force that drives the advocate. Lessons about "Self-Advocacy" provided students opportunities to learn about the process of speaking or acting on their own behalf in pursuit of their own needs and interests. Students were taught that an increase in their knowledge would improve their ability to advocate for peers who are underserved and underrepresented. In addition, LEAP educated students about "Citizen Advocacy," which hopefully equipped them with the necessary competence to pursue and protect the same civil rights available to people without mental health issues. Finally, LEAP aimed to demonstrate the value of peer support and the capacity of others to strengthen people's will, to supply the means to achieve, and to express optimism for the future. Students were challenged to never underestimate the collective power of peers who are otherwise considered voiceless.

As part of the evening celebrations at the 2007 Annual Kansas Consumer Recovery Conference, the LEAP graduates were honored for their academic accomplishments on stage and received an engraved

plaque. I gave a speech to the audience, which was primarily consumers/peers, and shared in detail that recovery is all about self-determination and how the graduates were living proof of this. In my speech, I emphasized that LEAP was not just about grades and completed assignments; it was an experience that changed lives. Furthermore, LEAP gave students the tools to take back their life when they faced the personal barriers that posed the greatest challenges to their self-determination. I praised the graduates for their courage to walk that journey of self-discovery and personal growth. They faced their fears without surrender; they worked to improve their self-esteem and self-confidence; they replaced negative self-talk with positive self-talk; they developed their coping and social skills; they became knowledgeable about their civil rights; and they changed their feelings of hopelessness into a life with purpose.

My aspirations associated with what I have written in my own words testify to my beliefs about self-worth, self-respect, self-acceptance and humanity for individuals dealing with mental health disorders worldwide. Being passionate about social justice in the face of stigma and discrimination is what drives me. The LEAP model can produce transformative change in community mental health by helping our communities gain a better understanding of the potential within individuals receiving mental health services to achieve more than was thought possible. The academic achievements of LEAP graduates disproved the myths that individuals living daily with mental health disabilities are so disabled that they are mentally impaired and limited in major life activities such as learning, reading, writing, concentration, thinking, communicating, and working. The LEAP graduates are the evidence that if given the opportunities and supportive resources for higher education attainment, they can do as well as people without mental health issues. Over the years, many LEAP graduates have been encouraged to continue their college education.

Conclusions

Before LEAP, students' common experience as individuals receiving mental health services had provided them with little insight regarding their rights and self-worth. LEAP taught students about social justice and how society is to be blamed for the injustice. As advocates with the tools and skills for leadership, the LEAP program inspired students to be agents for transformative change in the mental health system. Through the process of healing and rebuilding, students were taught the skills to become empowered; the ability to reject how society justifies the practice whereby consumers/peers have been denied the right for consumer-driven mental health services based on recovery; the right for an adequate income from competitive employment; the right for decent housing in safe neighborhoods; the right for affordable health care; the right for inclusion to citizenship with social opportunities; the right to be informed and involved with equal power to enable them as contributors to their communities; the right to cast their vote with a voice to be heard; the right for opportunities to attain valued social roles ; and the right for participation in society on equal terms.

While there have been some improvements, traditional mental health services offer persons with disabilities little to dream of, aspire to, or hope for. Mental health advocates have fought hard for recovery-based services, but many providers and programs seem to believe that lifelong disability maintenance is a proper therapeutic goal. Society's beliefs are changing in a positive direction by challenging stigma and discrimination and by believing that a life of disability without hope for recovery is an unacceptable long-term view for any human being. In the hopeful words of Stephen P. Hinshaw (2007), "Success rates for mental health treatments already rival those for heart disease and cancer in physical medicine, meaning that there is reason for considerable optimism. Views of mental disorder that emphasize its hopelessness and immutability may eventually become relics of past ignorance." (p. 228).

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