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Stigmatization

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ON FAMILY SUPPORT AND CHILDREN'S MENTAL HEALTH

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Winter 2009

Vol. 23, No. 1

Save the Dates for The Building on Family Strengths Conference with a Focus on Youth Empowerment and Participation!

June 23-25, 2009

at the Hilton Portland and Executive Tower in beautiful downtown Portland, Oregon

The Research and Training Center on Family Support and Children's Mental Health is hosting the Building on Family Strengths Conference in Portland, Oregon. This year's conference will feature the latest developments in youth empowerment and participation in designing, delivering, and evaluating services, supports, and systems. The opening keynote is being presented by our Youth Summit leaders, and the research plenary, given by Youth in Focus, explores youth/professional research partnerships and youth-driven research. In addition, we anticipate numerous sessions with youth as presenters and co-presenters.

The conference also will feature a day dedicated to wraparound practice, supervision, fidelity measurement, outcome studies, and system support. And, as always, there will be exciting presentations on recent developments and innovations in the fields of family support and children's mental health.

For details, see the Conference section of our website:

www.rtc.pdx.edu/conference/pgMain.php

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Stigmatization

"That's crazy."
"He's insane."
"You're out of your mind."

These phrases are commonplace and demonstrate the pervasiveness of stigmatization of people with mental health conditions. But stigmatization is not just name-calling—it's also exclusion and discrimination. And when stigmatization is internalized, it can cause a person with a mental health condition to have feelings of shame and self-disgust.

Essentially, stigmatization is a form of prejudice. A person who stigmatizes makes negative or unfair

> *"I have learned to cope with my mental heath issues with and without meds… Now I'm a productive member of the community. I hope others can learn to do the same. It's not a limitation."*

judgments about others before really knowing enough to make a judgment. The person who is stigmatizing does not really perceive the "target" person as an individual, and instead forms expectations about that person based on limited information, such as knowing or suspecting that the person has a mental health condition. Parents and caregivers of children with emotional or mental health conditions may also be stigmatized. People learn about a child's emotional or behavioral condition, or observe the child's behavior, and make negative assumptions about the parents and/or other caregivers. Often, the assumption is that the child's condition has been caused

by poor parenting, household dysfunction, or inadequate discipline.

People with mental health conditions—and their parents and caregivers—are all too familiar with stigmatization, yet it is something about which the research community knows relatively little. Not much is understood about the sources, effects, and impact of stigmatization. Prevention programs are rare and lack rigorous evaluation. And most of what *is* known is based on studies of stigmatization of adults with mental illnesses. Far less is known about stigmatization of children, youth, and their caregivers. Yet despite the lack of empirical evidence, the President's New Freedom Commission on Mental Health[1] recognized the seriousness of stigmatization by making it a national priority in efforts to transform mental health care. This issue of *Focal Point* is intended to support this goal by providing state-of-the-art information about the causes and consequences of stigmatization, and about strategies and programs for alleviating it.

As we began work on this issue, the limited scope of existing research became clearer. Most existing studies focused on the general public's attitudes toward people with mental health conditions. This type of information is of course valuable, and forms the basis of a number of

the articles in this issue. Yet we knew that our readers would be equally if not more interested in knowing about how young people and their caregivers actually experience stigmatization. In what contexts do they experience stigmatization? Is stigmatization by the "general public" the biggest problem? What about stigmatization by relatives, service providers, or others? How big of an impact does stigmatization have on overall well-being? Do young people and caregivers internalize the assumptions that support stigmatization? We also wanted to explore whether or not there is a possible "flip side" to stigmatization: Do some people go out of their way to treat another person positively or to provide extra support because they know that the person has a mental health condition (or is a caregiver for a child with a condition)?

Because we could find so little information that would help us address these questions, we decided to conduct

> *"During my freshman year, my whole group of friends decided to ostracize me because I wasn't happy enough (their words) and they thought my self-harm was attention seeking. They also started numerous rumors about me. I eventually ended up switching schools, because I didn't have any friends."*

some informal research of our own. We created two anonymous, web-based surveys—one for youth and one for caregivers—to gather infor-

mation about experiences of stigmatization. The youth survey was open to young people aged 14 through 25 who experience mental health condi-

> *"In school I was secluded away from other students because of my disorders, which in turn made the other students believe that I was dangerous or a loner."*

tions. (We chose to only survey youth 14 and older because that is the age at which youth can legally consent to their own mental health services without consulting a legal guardian.) The caregiver survey was open to parents and other caregivers of young people who had been diagnosed with a mental health condition before age 18. The surveys were created with input from youth and caregivers, and were approved by the Human Subjects Research Review Committee at Portland State University.

Youth Survey

The responses for 90 youth were included in this analysis. Median youth age was 19 years, and just over half (56%) of our sample was female; 77% were White. Over half (55%) reported receiving either free or reduced lunch at school. One-fourth (25%) identified themselves as having bipolar disorder, another fourth (23%) stated they had depression, and 15% reported having anxiety/PTSD. Most respondents (85%) reported having taken medication for their mental health condition.

Negative Treatment. The large majority of these young people reported experiencing stigmatization—86% responded that there were times when people treated them negatively or unfairly because of their emotional or mental health condition. When asked who treated them most unfairly, the most common groups reported were peers, friends/people they socialize with, and teachers or school personnel (Figure 1). About half the young people reported being stigmatized by

adults in the community and by members of their immediate family.

Participants were asked to choose from a series of reasons why other people had treated them negatively or unfairly. The top response was "they assumed you were weak-willed or not trying hard enough to be 'normal'" (endorsed by 81% of the respondents). The second most frequently endorsed response was "they assumed that you had problems that would never get better" (78%). Half of the youth respondents (49%) stated that people treated them negatively just to be mean. Interestingly, the ways in which youth reported being treated negatively did not vary by diagnosis or by who was doing the stigmatizing.

Next, youth were asked a series of questions to assess their self-stigmatization. Most of the young respondents stated that they felt bad about themselves "often" (39%) or "sometimes" (44%) because of their emotional or mental health condition. Top reasons endorsed as to why youth felt bad about themselves re-

flect a sense of hopelessness: "I just felt bad for no reason I could define," "I felt that I caused problems for other people or let them down," and "I felt like I would never get better or wouldn't be able to have the kind of life I wanted."

Experiences with stigmatization seem to have large impacts on the lives of these youth. The vast majority stated that negative treatment from others had either a significant (53%) or moderate (33%) impact on their lives. Youth who said they were

> *"I was in a trial job. The boss and the employees went out of their way to make me feel comfortable and capable."*

more affected by stigmatization from others also reported more negative effects from self-stigmatization (r = .53, p < .01).

Positive "Stigmatization." When

FIGURE 1. PERCENTAGE OF YOUTH EXPERIENCING NEGATIVE TREATMENT BY GROUP
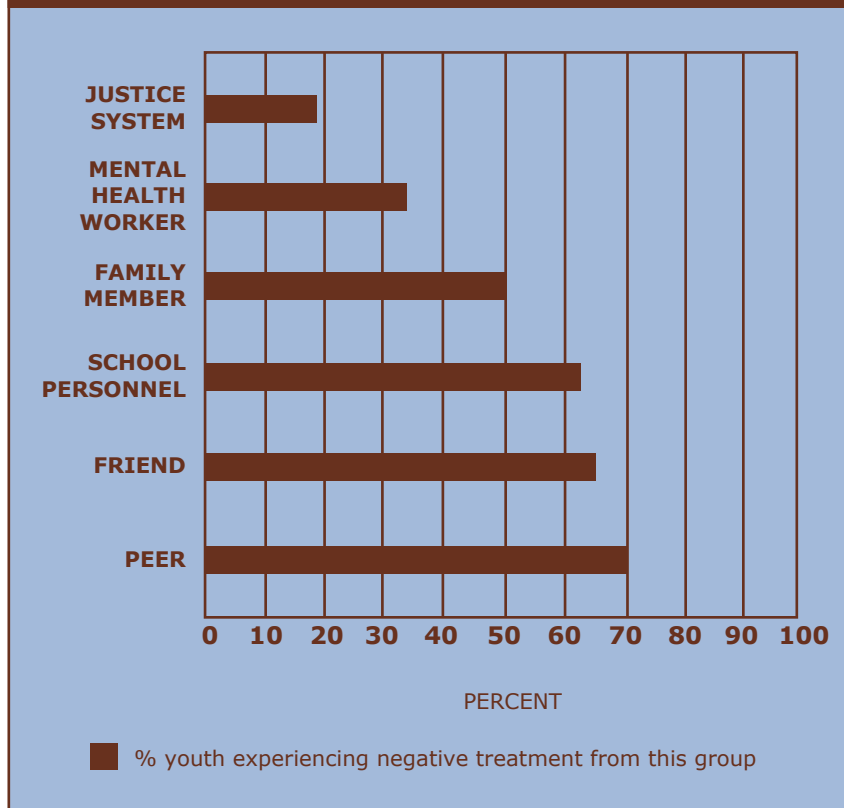
asked if other people treated them with extra care and understanding because of their mental health condition, 86% of the youth respondents said "yes." The people most likely to treat them positively were immediate family members and friends.

Additionally, three-fourths of the youth respondents reported feeling proud or good about themselves because of their mental health condition and/or how they are able to manage and cope with it; however, only one-fifth (22%) reported having these feelings "often," whereas half (52%) reported having these feelings only "sometimes." When asked why they felt good about themselves, youth most often reported it was because they felt proud for overcoming challenges that were part of their condition, they felt that having a mental health condition taught them things they could use to help others, and that their mental health condition made them a stronger or better person.

Most respondents stated that positive treatment from others had a significant (46%) or moderate (42%) impact on their lives. Youth who reported higher impact from positive "stigmatization" also tended to report more positive feelings about themselves, though the correlation was somewhat small (r = .29, p < .01). Surprisingly, youth who had more positive feelings about themselves (due to having a mental health condition) did not necessarily have less

> "In general, my mom has given me more support than I would have thought humanly possible to give. I know no matter what I do, she will try to support me in any way she can."
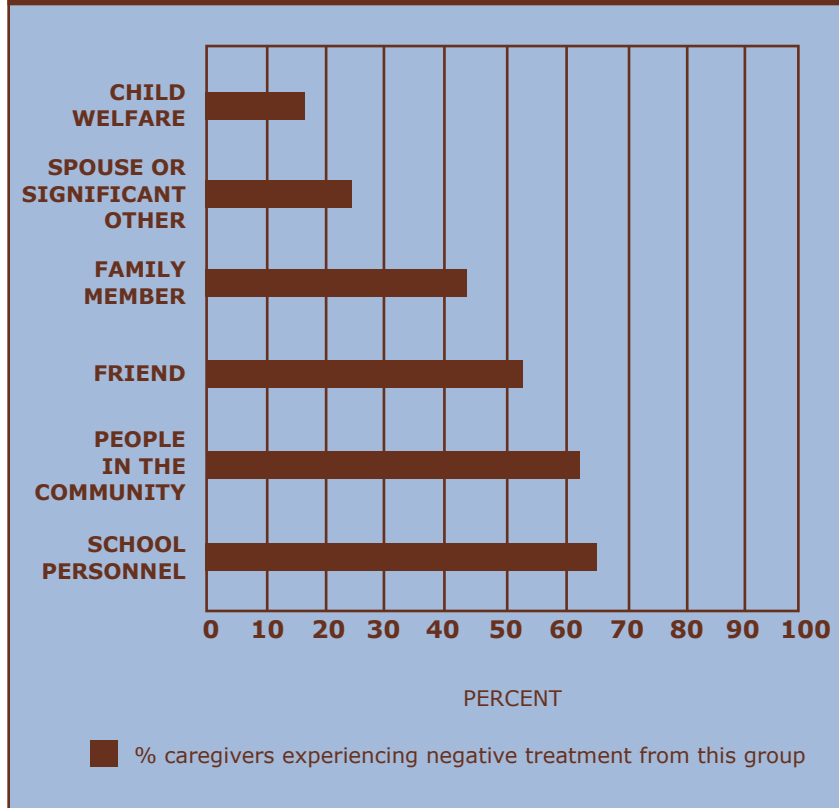
negative feelings about themselves (and vice versa); nor was there a significant tendency for young people who reported more negative impact from stigmatization from others to also report less positive impact (and vice versa). Thus it appears that posi-

FIGURE 2. PERCENTAGE OF CAREGIVERS EXPERIENCING NEGATIVE TREATMENT BY GROUP

tive and negative stigmatization—and self-stigmatization—are independent from each other and not opposite ends of a single spectrum.

Caregiver Survey

The responses of 454 adults were included in this analysis. The majority of caregivers were White (87%), female (88%), and the child's biological parent (71%). Half (52%) reported that their children received free or reduced lunch at school. The most common diagnosis they reported for their children was bipolar (33%), followed by ADHD (18%), and Asperger's/Autism (12%).

Negative Treatment. The large majority of the caregivers reported experiencing stigmatization—81% responded that there were times when people treated them negatively or unfairly because of their child's emotional or mental health condition. When asked from whom they experienced this treatment, the most com-

mon groups reported were "teachers or school personnel," "people in the community," and "friends or people you socialize with." (Figure 2)

When asked to choose from a series of reasons as to why respondents believed they were being treated negatively or unfairly, the top responses endorsed revolved around parenting issues: "[other people] assumed you were weak-willed or not trying hard enough to get your child to behave or act 'normal,'" "assumed your family was dysfunctional and/or that you were a bad parent," and "assumed that your child would be a burden or cause extra expense or work for them." In contrast, very few respondents believed that people treated them negatively just to be cruel or mean.

> "When we were around other folks who were like us... I felt that I had something to contribute."

Next, caregiver respondents were asked a series of questions to address self-stigmatization. Three-fourths (75%) stated that they felt bad about themselves because of their child's emotional or mental health condition or how they dealt with it. Top reasons

> *"When we got our daughter when she was 5 years old it was very obvious something was different from "normal." Our friends quit coming around or calling. We didn't socialize with friends due to the impact her behaviors had. When going to social events we would sit alone. I think people didn't know how to react so they just stayed away."*

endorsed were related to parenting: "I felt incompetent at helping my child cope with or manage his/her condition so he/she could stay safe and have a good life" (81% yes), and "I felt incompetent with disciplining my child or managing his/her behavior" (74% yes). Over half of respondents (51%) also stated that they felt bad for no reason they could define.

As with the youth, caregivers reported that experiences with stigmatization had an impact on their lives.

> *"I felt bad because I just wanted her to be like other kids and I felt guilty thinking that."*

The vast majority of these caregivers stated that negative and unfair treatment from others had an either significant (55%) or moderate (33%) impact on their lives. Similarly, three-fourths stated that their feelings of self-stigmatization had a significant or moderate impact on their lives. Caregivers

who reported more impact of stigmatization from others also tended to report higher levels of self-stigmatization (r = .38, p < .001).

Positive "Stigmatization." This survey also asked respondents to think about whether or not they were treated positively because of their role as caregivers of children with mental health conditions. Perhaps surprisingly, the large majority (84%) of respondents stated that people had treated them with extra support and understanding because of their child's emotional or mental health condition. When asked to choose who most often treated them positively, the most common groups reported were "friends/people you socialize with," followed by "members of your immediate family," and "your child's mental health providers."

Finally, caregiver respondents were asked if they ever felt proud or good about themselves because of their child's emotional or mental health condition or how they dealt with it. Only one-third (34%) stated that they felt this "often," though an additional 51% stated that they felt positively about themselves "sometimes." The top specific reasons endorsed by the caregivers as to why they felt good were: "I felt proud for overcoming challenges that were part of coping with my child's condition," "I felt that dealing with my child's condition made it possible for me to also help other children and families," and "I felt that dealing with my child's condition made me a stronger or better person, or taught me important things about life."

Almost all respondents stated that positive treatment from others had a large (56%) or moderate (37%) impact on their lives. Most, but somewhat fewer respondents stated that positive feelings they had about themselves had a strong (43%) or moderate (37%) positive impact on their lives. Caregivers who reported higher levels of impact from others' positive "stigmatization" also tended to report more positive feelings about themselves (r = .40, p < .001). As with the youth sample, caregivers who perceived more negative impact from stigmatization did not tend also to perceive less positive stigmatization. This was

> *"One powerful moment was when my children's therapist said, 'You ARE a good mother.' I broke down in tears because so many people had said the opposite."*

true both for stigmatization from others and for self-stigmatization.

Conclusion

The method we used for gathering data was not as rigorous as the methods used in other studies reported in this issue of *Focal Point*. Nonetheless, the surveys explored new territory and provided information that both supports and extends findings from existing studies. Studies examining stigmatization in the general public (see the articles in this issue by Walker, page 11, and by Pescosolico, page

> *"I feel sad that everyone can't treat everyone else like they want to be treated themselves."*

8) have found that stigmatization of young persons with mental health conditions is common. Our findings support this view, and confirm that this stigmatization has a large impact on young people's lives. Stigmatization also has a large impact on the lives of caregivers; in fact, caregivers and youth report a nearly identical magnitude of impact from negative stigmatization.

The pervasiveness of negative stigmatization toward young people from others points to a need to find strategies to prevent it—strategies like those reported in the articles by Quartly (page 24), and by Rafacz (page 21). However, in addition to strategies aimed at the general public—or in the case of young people, their peers and schoolmates—there is a clear need to explore stigmatization and antistigmatization strategies within other groups of people, such

as school personnel and family members. (The article on page 19 by Ryan about the Family Acceptance Project provides an example.). Similarly, caregivers also report high levels of stigmatization from school personnel and immediate family members as well as from the general public, and this suggests that strategies for addressing caregiver stigmatization within these groups are also needed.

Our survey also confirms that self-stigmatization is prevalent among both youth and their caregivers. These feelings are important to recognize, as they not only impact the well-being of these individuals, but also likely influence their willingness to seek treatment. (See the article by Biddle, page 26.)

A major finding from this research is that the impacts of positive and negative stigmatization experiences are not inversely related to one another. This is true for both youth and caregivers, and for self and other

stigmatization. Also, the impacts of self and other stigmatization experiences are only moderately correlated. This suggests that when researching the impact of stigmatization, it is important to recognize the separate contributions of stigmatization from internal and external sources, and to recognize that positive treatment is not an "antidote" to negative stigmatization.

Our findings related to positive treatment are encouraging. Most youth state that they have been treated with extra care and understanding due to their mental health condition, and that these experiences have a large impact on their lives. Youth also report feeling good about themselves, although this does not happen as frequently. There is clearly potential for services to build off and reinforce these positive feelings, and perhaps the most authentic way to accomplish this is through peer support (as discussed in the article by McWade,

page 15). Caregivers reported similar levels of positive treatment from others, but were somewhat more likely than youth to say they felt good about themselves. Continuing to listen to how positive experiences impact the lives of young people with mental health conditions and their caregivers may provide us with better solutions to combating the stigmatization they experience from others and the stigmatization they internalize.

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1. New Freedom Commission on Mental Health. (2003). *Achieving the promise: Transforming mental health care in America: Final report*. Rockville, MD: New Freedom Commission on Mental Health.

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PARENT/PROFESSIONAL THOUGHTS ABOUT THE USE OF THE TERM "SERIOUSLY EMOTIONALLY DISTURBED"

In a brief qualitative survey of 75 parents and professionals conducted by Oregon Family Support Network (OFSN), findings indicate that "Seriously Emotionally Disturbed" (SED) is no longer the preferred term to use when describing the symptoms of mental illness that children and their families experience. Instead, the most frequently recommended terms were:

   #1. "Emotional and Behavioral Challenges"

   #2. "Emotional and Behavioral Disorders," or

   #3. A specific mental health diagnosis

Most respondents indicated that their most preferred term was "Emotional and Behavioral Challenges." However, among those who considered themselves mental health professionals, there was more variety among secondary recommendations. Other terms suggested by this group were: a) "...Disorders," b) "...Diagnoses," c) "...Difficulties," d) "...Needs," and e) "...Issues." Family members overwhelmingly preferred the terms "Emotional and Behavioral Challenges" and "Emotional and Behavioral Disorders" as compared to other terms. Individuals who held dual roles as professionals and family members specified a clear preference for either "Emotional and Behavioral Challenges" or referencing a specific mental health diagnosis over using the term SED.

-Theresa Rice, Project Manager, Oregon Family Support Network

What Do American Adults Think of Children's Mental Health Problems? Findings and Lessons From the First National Study

Research over the last two decades has documented that the mental health problems of children and adolescents are profoundly under-recognized and under-treated. According to recent estimates, in any given year, one fifth of American children have a mental health disorder and one in twenty will experience severe functional impairment. The President's New Freedom Commission on Mental Health concluded in 2003, "No other illnesses damage so many children so seriously." (p.1)[1] Despite the serious consequences associated with childhood mental health disorders, fewer than one in three children and adolescents with recognizable disorders receive treatment.

Unfortunately, until now, we have had little concrete information about public perceptions of childhood mental health disorders and appropriate treatment. We did not know whether well-described symptom profiles, generally acknowledged to be prototypic of mental health disorders, were viewed as serious by the public; whether members of the public were able to recognize these symptom profiles as mental health issues; or, if they did, whether they attached the label of "mental illness" to them. Similarly, we knew little about what kinds of advice and treatment the public saw as appropriate for the emotional and behavioral challenges children and adolescents confront. Finally, there has been little information about the extent to which the public's reactions are shaped by stigmatizing beliefs.

In 2002, researchers from the Indiana Consortium for Mental Health Services Research designed and field-ed the National Stigma Study—Children (NSS-C). The NSS-C was explicitly developed to help close the gap in understanding American adults' knowledge and attitudes about children with mental health problems. (See box for more information on the NSS-C.) We used a series of short vignettes to describe children who met clinical criteria for ADHD, depression, and asthma. In addition, we described a child who had some problems of daily living but did not meet criteria for a childhood mental health problem. We used these stories because they are a more effective means of getting at individuals' responses than asking about ADHD or another problem directly. In addition, by only providing the descriptions, we were able to explore whether individuals recognize these behaviors as mental health problems in need of treatment. The analyses of these data, published in a series of peer-reviewed scientific publications, offered insights into what

members of the public think. Do they recognize mental health problems in children? What do they think causes them? What can be done? Will treatment help? What will happen to these children in the medical system and in the community? Here we offer an encapsulated view of American adults' attitudes, beliefs and sentiments.

What Does the Public Know?

Americans can distinguish between mental health problems, physical problems and "daily troubles" (Figure 1). However, the picture is clearer for "daily troubles" and asthma than it is for mental health problems, where respondents often endorsed several of these options at the same time. About half see behaviors that make up the symptoms for ADHD as a "mental illness," though most (80%) see them as normal "ups and downs." Most (over 90%) see asthma as a physical illness. Almost all (close to 100%) see "daily troubles" as the normal ups and downs of life. Figure 1 also shows that the public is more confused by depression. Almost equal numbers say that the behaviors that meet criteria for depression could, in fact, be depression, or they could be a physical illness, or they could be the normal ups and downs of life. This is curious because when asked how serious the situation described is, more respondents (over 83%) say that depression is very serious compared to the other conditions. (About 38% say ADHD is very serious; 58% for asthma; and only 3% for daily troubles.)

Perhaps the most interesting finding was that a substantial group (almost 20%) of the respondents who could correctly identify ADHD rejected the label of "mental illness," suggesting that we may want to consider language carefully when talking to and about children.

What Causes Mental Health Problems in Children?

Americans tend to see stress as the major factor underlying children's mental health difficulties (over 85% for ADHD, over 90% for depression), asthma (over 70%) and even their daily troubles (almost 60%). However, many individuals in our study also cited a lack of discipline, child-rearing techniques, and chemical imbalance as causes of ADHD, and reported that genetics, chemical imbalance, and child-rearing are likely underlying causes of depression. Genetics was most commonly seen as the cause of asthma (87%), but child-rearing was most often implicated in "daily troubles" (over 70%).

What Should Be Done?

Most Americans believe that treatment is required for ADHD (over 75%) and depression (almost 90%), but not "daily troubles," for which almost 80% of our respondents believed that the situation would improve on its own. Curiously, however, more than half (54%) agreed that ADHD would improve with better discipline, while almost as many (over 45%) reported that diet changes would help.

Our respondents suggest that a range of formal and informal "advisors," including family and friends, teachers, medical doctors, and mental health professionals, should be consulted when mental health problems emerge. The lowest levels of endorsement are found for psychiatrists and hospitals, and then only for situations rated as very serious. In general, if individuals suggest consulting medical or mental health professionals, then they also indicate a willingness to take these professionals' advice on using medications for the children. However, if family, friends or teachers suggest using medications, respondents are much more skeptical, and the percentage of people willing to accept such advice drops by almost half. So, while members of the public indicate a willingness to consult others, many are circumspect about whose advice they would accept if medication was offered as a solution for depression or ADHD. In general, compared to our studies of public perceptions about psychiatric medications for adult mental health problems, Americans report greater suspicion about the use and efficacy of medications for children and adolescents.

When we asked whether legal means should be invoked to make sure that the child described receives care, a surprisingly large number of respondents (17% ADHD, 35% depression, 41% asthma, 7% daily troubles) supported coerced visits to a doctor. However, the highest levels of support for forced care were reported for asthma, suggesting that more than stigma may underlie the public's response. Rather, it appears that when there are known effective treatments, and perhaps in the face of a failure of responsible parenting, the public believes that the children must receive care.

Are There Stigmatizing Effects of Mental Health Problems for Children?

The plain answer is yes. Almost a quarter of our respondents indicated that they would not want their child to befriend the child with ADHD, and even more said so for depression (almost 30%). In fact, across four social situations (e.g., having the child as a neighbor, or as their child's classmate), the highest levels of rejection were consistently reported for the child with ADHD and depression. For these conditions, roughly one of every five Americans reported an unwillingness to interact with the child. In particular, the finding that more Americans see children with depression as dangerous than view depressed adults as dangerous signals the possible influence of media reports of school shootings and other events surrounding violence in adolescence. In fact, while we know that most adults with serious mental illness are no more dangerous than their neighbors, the research on violence, children and mental health problems

FIGURE 1. HOW RESPONDENTS CATEGORIZE VIGNETTE CHILD'S PROBLEMS
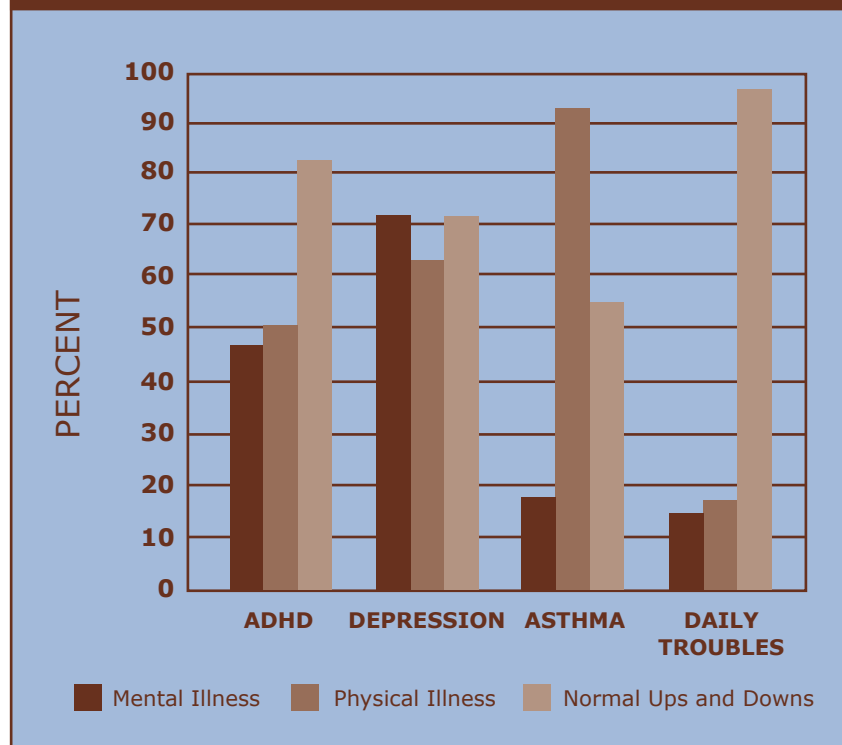
is thin and inconclusive.

The good news is that the levels of prejudice toward children that we see here are relatively low as compared to the much higher levels we have seen in our studies of attitudes toward adults with mental illness. Perhaps more importantly, many of our respondents believe that if children receive mental health treatment, it will have a positive impact on their lives. However, most respondents also believe that seeking treatment can not be kept confidential, and children who are known to have had treatment will be rejected in the community. Fewer respondents believe that the parents will be seen as failures if their children have mental health problems. Nevertheless, most report concern about the potential stigma that their children might encounter if they were to receive mental health treatment.

Why Do We Care What the Public Thinks?

Research tells us that individuals rarely make decisions about health care on their own. They consult family and friends, neighbors thought to have some relevant expertise, and those in positions of authority (e.g., bosses and teachers). Understanding the larger context in which parents and children/adolescents experience mental health problems, receive advice, and decide to seek or avoid treatment is an important first step in addressing the problem of the underutilization of mental health services.

This first study of public knowledge of and attitudes toward children with mental health problems suggests both opportunities and challenges. Overall, it appears that Americans can tell the difference between normal childhood variations in behavior, physical health problems like asthma, and mental health challenges like ADHD and depression. It is sobering, however, that Americans appear to stigmatize children's mental health conditions, particularly depression. Compared to children with asthma or daily troubles, the public sees children with depression and ADHD as much more likely to pose a danger to self and others. But overall the public sees depression as more serious, more in need of treatment, and more problematic even than ADHD.

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WHAT IS THE GSS AND WHERE CAN I GET MORE INFORMATION ON THE NSS-C AND OTHER STUDIES?

The NSS-C was fielded as part of the 2002 General Social Survey (GSS) administered by the National Opinion Research Center (NORC) at the University of Chicago. The GSS is one of the premier monitors of American public opinion that has been fielded since 1972. To ensure that the Americans who participate make up a nationally representative group, the GSS uses a stratified, multistage area probability sample of clusters of U.S. households. The GSS trains interviewers to visit the selected American households and conduct face-to-face interviews. The 2002 GSS included 2,765 non-institutionalized adults living in the contiguous U.S. and was conducted between February and June of 2002. Technically, the GSS segment that makes up the NSS-C is referred to as the "Children's Mental Health Module." It included 55 separate questions and occupied 15 minutes on one of the two samples of the 2002 survey for a total of 1,393 individuals who answered NSS-C questions. The response rate for the 2002 GSS was 70 percent.

Primary funding for the Children's Mental Health Module was provided by the National Science Foundation to the General Social Survey, Eli Lilly & Co., the Indiana Consortium for Mental Health Services Research, and the College of Arts and Sciences at Indiana University-Bloomington.

To see the full public report, American's Views of Children With Mental Health Problems, as well as the list of scientific publications on which this summary is based, go to

www.indiana.edu/~icmhsr/

or contact the

Indiana Consortium for Mental Health Services Research
Karl Schuessler Institute for Social Research
1022 E. Third St., Bloomington, IN 47405
Tel: 812.855.3841

The website also contains basic information from other studies on public beliefs about psychoactive medication for children; public knowledge and beliefs about the stigma attached to adult mental health problems, and public expectations of medical and mental health care.

Young People's Stigmatization of Peers With Depression and ADHD

In 2005, the influential final report from the President's New Freedom Commission on Mental Health identified a series of national priorities for transforming mental health care in the United States.[1] At the very top of the list was the need to reduce the stigmatization that people experience if they have mental health difficulties or if they seek mental health care. The report noted that stigmatization imposes further burdens on people even as they struggle to cope with mental health challenges, by reducing their opportunities to participate fully in social and economic life; contributing to low self-esteem, isolation, and hopelessness; and deterring help seeking.

Of course, designing effective strategies to reduce stigmatization requires first knowing something about how and why stigmatization occurs: What are the thought processes that result in avoidance, distrust, bias, and/or anger directed toward people who experience mental health difficulties? Recent research has helped make significant progress in answering this question with respect to stigmatization toward adults with mental illnesses. The growing knowledge base about the nature of stigmatizing attitudes and beliefs among adults has contributed to the development and evaluation of new theories to explain stigmatization processes, new strategies for reducing stigmatization, and new approaches to reducing barriers to help seeking.

In contrast, the knowledge base about the stigmatization experienced by children and adolescents with emotional and behavioral difficulties is far less developed. One large-scale national study examined stigmatization of children by adults (see page 8), but until very recently there had been no similar research examining the stigmatization of children and adolescents by their peers. In 2006,

the Research and Training Center on Family Support and Children's Mental Health collaborated with the polling firm Harris Interactive to explore this topic. The result was the first-ever national survey examining children's stigmatization of peers with depression and attention-deficit hyperactivity disorder (ADHD), two of the most common mental health disorders of childhood. Our survey instrument was developed collaboratively by children's mental health researchers, staff from Harris Interactive, and young people who had experienced emotional and behavioral disorders.

The survey was administered online by Harris Interactive. The survey participants—1,318 young people between the ages of 8 and 18—reflected the demographic characteristics of the broader US youth population in the same age range. Survey participants received one of three versions of the survey, focusing on depression, ADHD, or asthma. Participants read a brief story about Michael, a fictional peer who was described as having one of the three conditions. Participants then answered questions focusing on

- positive and negative attributions about Michael (i.e., assumptions about Michael's personality or character),

- the causes of Michael's condition,

- their family's attitudes about a

child with Michael's condition, and preferences for social distance from Michael (i.e., how willing participants thought their peers would be to interact with Michael in different ways).

Participants were also asked whether or not they had ever been diagnosed with the same condition that Michael had, and what sorts of help they would seek if they thought they had Michael's condition.

Levels of Stigmatization

Our survey examined stigmatization through the questions about attributions, social distance, and family attitudes. A relatively positive message to emerge from the survey findings on attributions was that only a minority of respondents thought that Michael with ADHD or depression was lazier, more violent, or more likely to get into trouble than the average peer (Figure 1). However, the comparison with asthma shows that negative attributions were significantly more common toward Michael with depression or ADHD.

In fact, differences with asthma on the questions about "is more violent" and "gets into trouble more often" were some of the most significant effects we found when analyzing the survey data. This is potentially important, since studies on stigmatization of adults have found that people who see the mentally ill as dangerous in some way are much less willing to interact with them.[2] In reality, the rates of dangerous, antisocial acts committed by people with mental illness are relatively rare, and most antisocial acts are committed by people without mental illness.[3] Our study found that, for Michael with depression, participant ratings of likelihood of violence were far higher than the "real world" association of depression and violence. However, for ADHD, par-

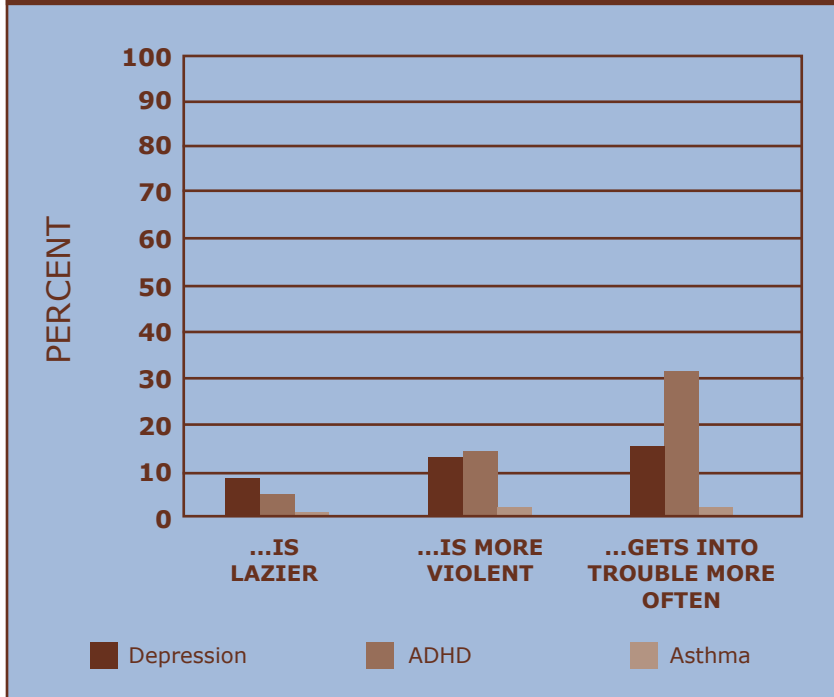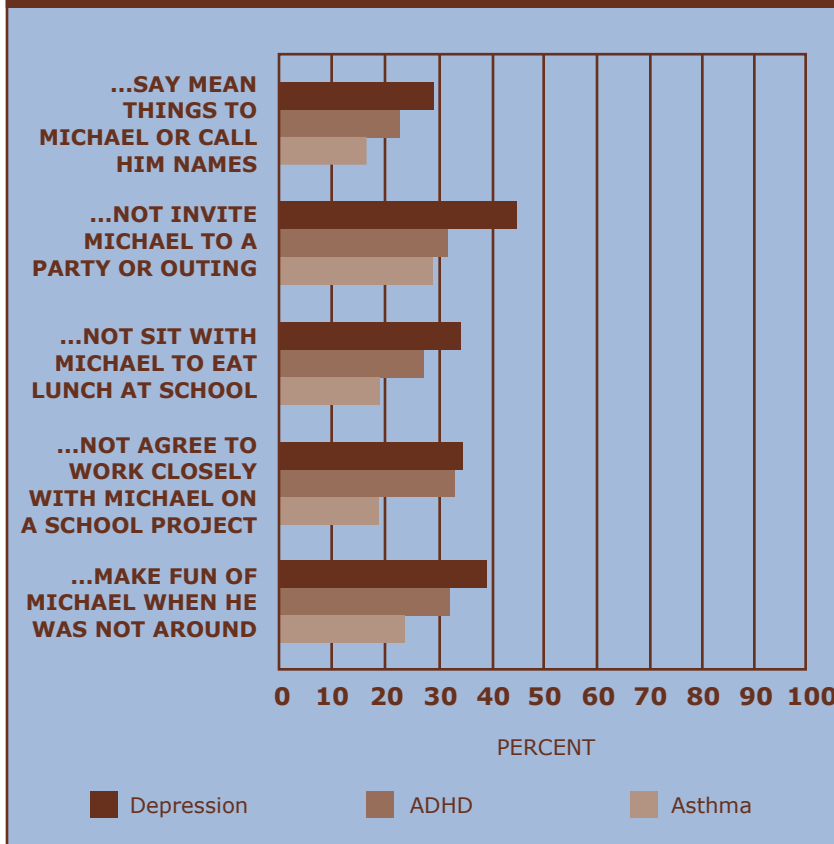## FIGURE 1. PERCENTAGE OF RESPONDENTS WHO THINK THAT, COMPARED TO AVERAGE PEER, MICHAEL...

FIGURE 2. PERCENTAGE OF RESPONDENTS WHO THINK THEIR PEERS WOULD...

ticipant ratings of the likelihood of violence or getting in trouble were at a level similar to the real world association of ADHD and these types of behavior problems.

The findings regarding positive attributions provided some contrasts to the general pattern of the negative attributions. For example, though Michael with asthma was slightly more likely to be seen as smarter than average and much more likely to be seen as more caring, Michael with ADHD or depression was thought to be more creative. Michael with ADHD was seen as more likely to have a good sense of humor, on par with Michael with asthma; however Michael with depression was not as likely to be seen as having a good sense of humor.

The most common way that researchers have assessed stigmatization is by measuring social distance. In our survey, overall social distancing was much larger for Michael with depression—and somewhat larger for Michael with ADHD—as compared to asthma (Figure 2).

With regard to family attitudes, only about 10-15% of our participants thought that their families perceived young people with depression and ADHD negatively; however both of these conditions were perceived more negatively than asthma, with depression the most negatively perceived.

Overall, we found no significant differences when we examined attributions, social distance, or family attitudes by sex, and only a few when we looked at differences by race. For example, as compared to White respondents, Hispanic respondents reported somewhat more negative attributions towards peers with ADHD. The largest differences were found for Asian/Pacific Islander respondents who, relative to other respondents, reported more negative attributions toward a peer with depression and more negative family attitudes towards a child with ADHD or depression.

Causes

On the survey, participants were given a list of possible causes and were asked to rate how likely it was that each one might actually be a cause of Michael's condition (Figure 3). Respondents' ratings for three of

the causes—Michael's fault, bad parenting, and substance abuse—were correlated with each other and with stigmatization (as measured by social distancing). Thus, people who endorsed these causes appeared to have a moralistic and blaming view of the causation of mental health difficulties. These causes were more likely to be endorsed for depression than ADHD and more likely for ADHD than asthma.

Seeing mental health difficulties as caused by "brain differences" appeared to reduce stigmatization (although this effect was small). Seeing mental health difficulties as caused by stress or by God's will was consistent with higher levels of stigmatization, though these effects were modest. Children who said they had been diagnosed with a condition were more likely to endorse stigmatizing causes. Asian/Pacific Islander and Hispanic youth were more likely than others to endorse "bad parenting" as a cause, and African American and Hispanic were more likely to endorse "God's will."

Coping and Help-Seeking

We are still working on analyzing the data about coping and help-seeking; however, even the preliminary analyses have yielded some interesting findings. For example, respondents reported that they would be far less willing to talk to their parents, talk to a doctor, or take medication if they thought they had depression (versus asthma) and somewhat less willing if they thought they had ADHD (versus asthma). Respondents were much more likely to say they would "try harder to act normal" and somewhat more likely to pray if they thought they had depression or ADHD (versus asthma). More respondents in the depression condition predicted that they would "wait for it to go away" or try to change their habits (as compared to ADHD and asthma). Finally, more respondents in the depression condition said they would talk to friends (as compared to ADHD and asthma). Generally, our analyses also showed that respondents with higher scores on the social distance scale (i.e., respondents who reported that peers were less likely to interact with Michael than with an average peer) were also less likely to report they would seek help.
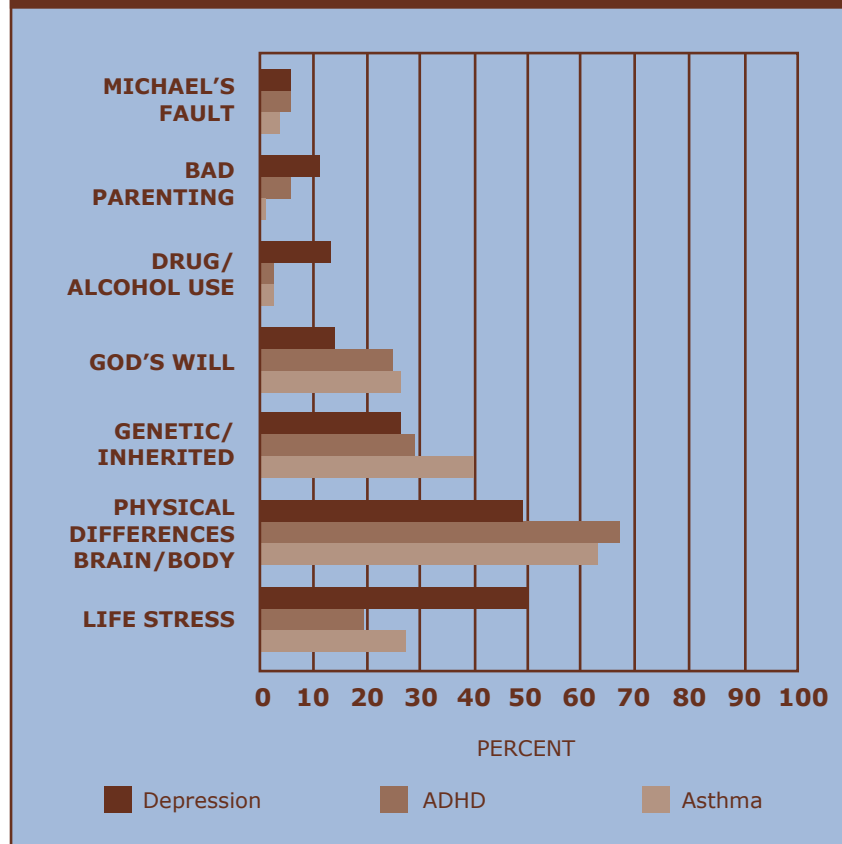
Implications

Our analyses of the survey data have consistently found that both depression and ADHD are more stigmatized than asthma, and that depression is overall even more stigmatized than ADHD. These findings highlight a particular need to develop strategies for reducing the stigmatization of depression among children and adolescents. Our analyses further suggest that many young people believe that peers with ADHD and depression may be dangerous. For depression, these fears appear to be out of line with real-world risk, though for ADHD these beliefs more closely reflected actual rates of problematic behavior among children with ADHD. Of course, this does not justify stigmatization of ADHD, since the great majority of children with ADHD do not develop antisocial behavior and even among those who do get into trouble, for the large majority the trouble is relatively minor.[4]

Thus, for both depression and ADHD, our findings suggest that strategies for reducing stigmatization should address young people's fear that their peers with emotional or behavioral difficulties are dangerous. The link between mental health difficulties and dangerousness is reinforced in children's media, which depict characters with mental illnesses as violent, criminal, and unattractive.[5] It may thus be worthwhile to explore these depictions further, to develop strategies for changing depictions, and to determine whether changing how children's media portray characters with mental health difficulties can impact stigmatization. In England, a novel anti-stigmatization effort called Shift is taking exactly this approach. Project staff provide training to journalism students and work with the Royal College of Psychiatrists and

FIGURE 3. PERCENTAGE OF RESPONDENTS ENDORSING POSSIBLE CAUSES FOR MICHAEL'S CONDITION

STIGMA VS. STIGMATIZATION

The word stigmatization *has twice as many syllables and more than twice as many letters as* stigma. *In addition, using* stigmatization *leads to relatively more complicated phrases such as "the* stigmatization *of people with depression" (versus "the* stigma *of depression"). And* stigma *is far more commonly used by advocacy groups, researchers, and the media. So why have we at the RTC made the decision in our own writing to use the longer word with the more complicated constructions?*

Our current thinking about this issue began with an angry email we received a few years ago. The writer was firmly opposed to the use of stigma *in connection with mental health conditions, though he was not very specific about why or about what an acceptable alternative would be. My own first reaction was essentially to ignore his comments—why make a change on the basis of one complaint? There did not seem to be any broad-based movement objecting to the use of* stigma *and promoting an alternative.*

As a writer and editor, however, it seemed that the least I could do was to check its definition. The dictionary says that stigma *is a stain, mark, or brand of shame. With this definition in mind, it became easier to see why someone might object to a phrase like the* stigma *of depression. The phrase could be interpreted as saying that depression is a mark of shame. Even though this is clearly not what many people mean when they use* stigma, *the RTC eventually decided that our own policy would be to avoid the word. Instead, we use* stigmatization, *which is the act of casting shame onto others. We feel that this difference, though perhaps subtle, is an important one, and that using* stigmatization *is more consistent with our Center's mission and values.*

Putting together this issue raised the question for us once more, since most of the articles submitted for the issue used stigma. *Ultimately, we decided not to ask our contributors to change their wording, and we were left wondering whether the distinction we were trying to make was meaningful to anyone besides ourselves.*

We hope to gain some insight into this issue from our readers. If you have thoughts on stigma *vs.* stigmatization, *go to the Featured Discussions page on our website (www.rtc.pdx.edu/FeaturedDiscussions/pgFD00main.php), where you can vote for your preference and leave comments. We look forward to hearing from you and we'll let you know what we find out.*

- Janet S. Walker, Editor

leading mental health charities to change how news is reported when people with mental health difficulties commit violent acts. The project's intention is to have news stories stress that most people with mental health problems are not violent and do not pose a risk to others.

Our findings regarding the moralistic and blaming beliefs about the causes of mental health difficulties provide further evidence of stigmatization. They also demonstrate how beliefs about causation are related to young people's willingness to interact with peers who experience emotional or behavioral difficulties. These findings too have implications for stigma reduction programs, suggesting that it may be productive to target beliefs about causation, particularly the beliefs that having emotional or behavioral difficulties results from bad parenting, substance abuse, or not trying hard enough to get better.

Anti-stigmatization efforts should be careful not to overlook the need to address possible self-stigmatization among young people who have actually been diagnosed with a mental health condition. Our findings indicate that self-stigmatization may be significant, and that, for example, professionals and family members should be aware that children with ADHD or depression are even more likely than their peers to hold stigmatizing beliefs about the causes of their own conditions.

Both self-stigmatization and the fear of stigmatization by others appear to deter young people from seeking help for mental health difficulties. Our findings support the idea that strategies to address these barriers to help-seeking are needed. For depression in particular, it may be fruitful to build on the finding that talking to a friend was the avenue for help-seeking or coping that most respondents predicted they would use.

Finally, our studies show some apparently culture-based differences in various attitudes and beliefs that are related to stigmatization. These findings caution against adopting a "one size fits all" approach to anti-stigmatization efforts. Instead, strategies should be developed and tested with possible cultural differences in mind.

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My Experiences With Stigma, Self-Worth and Roles

Peer Support was buried. Before I was introduced to the idea of peer support, I believed my diagnosis was something to get over and then toss away. I believed my diagnosis (currently paranoid schizophrenia) was something to manage and then mention two years into a committed relationship as a skeleton of my (anticipated) ancient experience, something nowhere near me, something gotten past (if even worth mentioning at all). Prior to peer support, all my beliefs about my diagnosis hinged on the fundamental assumption that I could not live as a person with paranoid schizophrenia, personally or socially, for a single extra second longer than was necessary. Before peer support, I was paying tithes to the church of shame, attending every sermon, and waiting for that pure moment when I would be "saved" and would no longer have to admit to society that I was someone with paranoid schizophrenia; instead, I'd be blending myself into the crowd, lost to any distinction. I planned for such a day because of my shame. I needed such a day because of stigma. I felt that my diagnosable experiences, and therefore the majority of my life had no value, and therefore I needed to be born again. Before peer support, I was not in touch with any community consisting of mental health consumers, and because I never experienced one, I did not believe they existed—anywhere. I believed that I had to recover from the various diagnoses I had experienced over the years. My ideas about mental health and recovery were completely wrong.

When I first heard about peer support, I was faring very well, having moved out of the Transition Age Youth (TAY) residential group-home I had been in for a little over two years into a subsidized apartment. I was working the closing shift at a fast food restaurant, and my girlfriend and I, who shared the subsidized apartment, acquired most of our income from SSDI (we each got a separate monthly check). Right around this time I was truly lamenting the lackluster life of which I had been forced to be the central character and its relationship to my fast-food job and the unfathomable amount of credits necessary to finish my college education due to the equivalent of twenty months of hospitalizations in a three-year period (before the residential). Then my social worker called me and said that a TAY peer mentoring position was opening up with a local provider and that I had to apply.

"Peer mentor?"

She explained to me that a peer mentor's job was to utilize his or her experience with transition and recovery to help bring hope to other TAY, not so accustomed to recovery, by sharing each other's experiences with mental health diagnoses. The peer mentor would also help the TAY mentee navigate the local and state mental health system.

After two interviews I was called and offered the position.

Originally the position consisted of networking with young adults throughout our area, attending conferences, and doing some suggested reading. I was also immediately placed in a group of peers (The Peer Leadership Meeting) who were also providers and who met monthly to discuss peer issues and how to assist the peer movement. I was very amazed to find a group of consumers blended into the provider world, keeping their consumer status, and talking about how to assist the peer movement.

Even at that point in time, now a consumer-provider, I felt my peer status had its place: nowhere near anybody I knew who did not have a diagnosis (including my family and everyone I met everywhere unfamiliar to me). But, I guessed, my mental health status was helpful in my role as a peer support worker.

As the networking with young adults continued I became more and more comfortable saying, "I work for such-and-such an agency, and I'm a consumer." When they asked what I did I replied, "I'm a peer mentor." And as I began saying this sentence more frequently I began noticing, specifically from older adult consumers, that I would often receive some casual approval exclaiming my equality with a PhD-carrying doctor—me, a consumer who was hired and not just treated. And on certain providers' parts, there was an air of expectations met, like this move (accepting peer support) was not something amazingly unexpected but it's good we came along (thumbs up).

I continued working as a TAY peer mentor for about a year and a half until my SSDI was pulled and my Medicare and Masshealth (state-funded health insurance) began to charge a fee. Not able to survive financially, I decided to look for another job. By this point in time I was back in school to become a social worker. I

figured as a social worker I would still be employed in a similar role; I would just have to toss the peer label aside (which I would have had no trouble doing at that time).

I enjoyed working as a peer. The aspect of my mentoring position that I cherished most was the one-to-one work I did with other male consumers. I felt valued, and in the majority of the cases the individuals I worked with helped me just as much as I helped them. Within the peer community and within my work as a peer in the mental health field I saw my di-

at the Metro-Sub RLC that I learned what it really meant to be a peer. Regardless of any assistance I may have provided to anyone I worked with in my paid peer role it was the compassion and openness I experienced with my fellow peers, employees and supervisors that truly offered me a scenario appropriate for my character to walk out of the closet and claim myself as a consumer without shame. Now I'm not saying that I introduce myself to every random Joe I meet on the street as "Matthew McWade, Mental Health Consumer," but by meeting

where I now work as the DMH Statewide Youth Coordinator, is funded by DMH to provide the Certified Peer Specialist training to Massachusetts. The goal of this training is to provide a technical, systematic approach to peer support. Those who complete this training will be able to be hired by traditional providers and become a part of a community of peers. Ideally, if peer support becomes widespread enough, all consumers will have access to peer support. It took me years of being a consumer before it was ever even mentioned to me that there was

> *Before peer support, I was not in touch with any community consisting of mental health consumers, and because I never experienced one, I did not believe they existed—anywhere.*

agnosis doing great things, but looking out to society and the larger world I still did not feel there was a place there for me to be a "peer" without having the word surrounding my diagnosis spread the cotangent of stigma. I felt quick judgments and faulty hearsay would plague me everywhere I went. I felt I would never be able to face even my extended family in complete honesty.

The new job I found was a Coordinator position at a newly opening peer organization, The Metro Suburban Recovery Learning Community. The Department of Mental Health planned to establish six Recovery Learning Communities (RLCs) strategically placed across Massachusetts, and this would be one of the first active RLCs. The mission of the RLCs is to provide peer support and advocacy as well as establish communities of consumers who could know one another as peers. In addition to providing advocacy, support, and outreach as peers, the RLCs also function as a structure for peers, living within the community, to come together and find other peers in a setting that promotes their worth. Consumers from all walks of life came together to assist the RLCs in their work.

It was only when I began working

other individuals who were so open, pure, personal, and unique about their own mental health experiences I finally had a good example to help stimulate the inkling I had always had that my diagnosis did not make me a bad person, nor was it something necessary to hide as a personal policy.

As I continued to work in a strictly peer setting I became more and more comfortable with myself and my diagnosable experiences. I began to see the value of my experiences not simply limited to assisting other consumers, but also the entire mental health system as it stands, and hopefully the general public. This process of dignity through mutual experience was the catalyst and essential fuel for my current recovery.

Peer support's message is "hope" unbridled. That hope translates into consumers, who seek or find peer support, discovering through the experience of another peer that they may not only take control of their relationship with traditional providers, but also they may take control of their diagnosis. They can also seek life in the community at a level they are most comfortable with, and be this hope for other peers as well as themselves.

The Transformations Center,

a thing called peer support, and that was by accident and for monetary reasons. Even being a peer support worker myself, originally, I did not know that consumers were organized and helping each other, calling me out to join them.

"All the work of Patrick Corrigan supports the idea that the best stigma-buster is contact with people with psychiatric diagnoses," says Lyn Legere, Director of Education at the Transformation Center. "Anything we do in the community breaks stigma because we are out there assuming new and different roles. For example, when peers work in traditional agencies both the providers and the people receiving services get a new image of the possibilities of recovery." Consumers as peers (mental health workers) validates a diagnosed individual without forsaking the diagnosis. Peers and mental health workers must know that recovery is not about casting aside symptoms, but discovering their appropriate place in one's being.

The stone that the builders cast aside was the most important stone of all.

- Jesus Christ

Everything in its right place.

- Thom York

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A Young Adult Discussion on Stigma Had By the Massachusetts DMH Statewide Youth Advisory Council

The Massachusetts Statewide Youth Advisory Council (SYAC) serves primarily as an advisory board to the Massachusetts Department of Mental Health, and was created to provide youth and young adult consumers in Massachusetts a voice in helping shape the mental health system for young adults. SYAC includes youth and young adults from across the state, some of whom are also members of their local area councils. In addition, SYAC reaches out to youth and young adult consumers, inviting them to its meetings and into its community to bring them hope and the possibility of recovery. SYAC has made a concerted effort to reduce stigma by providing real and candid presentations featuring youth who experience mental health challenges. We make this material available through various media including, but not limited to, a YouTube channel (www.youtube.com/user/voiceofSYAC), a website (www.transformation-center.org/communities/youth/index.html), and a SAMHSA/CMHR-sponsored documentary.

On September 16th, 2008, SYAC met at a local bookstore in Westborough, Massachusetts. Our main agenda item was to discuss the concept "stigma" in relation to our personal experiences. This article is a product of our discussion. I attended as council chair and coordinator, alongside about 20 additional members whose ages ranged from 16 to 29. Some of us worked in paid peer roles, while the rest either lived in the community or were residing in a nearby state hospital.

To start the conversation, I suggested that everyone speak generally about stigma. Some responses were that stigma manifests as a "judgment," a "label," a "biased prejudice." We all agreed stigma is "not always based on fact," or "not founded on any truth or on minimal truth." (But even when founded on minimal truth, stigma is a "stereotypical exaggeration.") By "pop-logic" processes stigma can cause personal shame in the stigmatized individual, and can also cause discrimination against the stigmatized individual or party. Our conclusion was that the main problem was: "You can be judged but the problem is you're being treated differently. More than being judged—being treated differently." As one member said: "My experience with stigma has been that people expect less out of me because of my diagnosis. People think that I can't do things that 'normal' people can do such as work a full-time job or go to school because it is too much stress."

Some of the ways that stigma made us feel are "ashamed," "fear(ful)," and "helpless." We sense that other people "feel they may be better than [us]" when they stigmatize us. One council member said that because of his diagnosis and his experiences with his symptoms he felt "like an easy target." Other comments included, "The biggest problem with stigma: people don't listen to you. If you're being judged you don't get listened to," and the "little mistakes we make are considered [to be caused by] our mental illness. These are the same mistakes other people make too."

One young woman iterated what we all had felt at one time or another: that others believe that "just because she's in a mental hospital she must be crazy." She says that is "a miscommunication—just because we're in a hospital they think we're going to harm people. We're common people who just need a little more help. We can get jobs—do anything we want to.

Help is okay." She said, "I'm okay the way I am."

At one point the conversation became passionate; a true lash-back, illustrating our discontent with being so casually judged:

• "If they're judging me, that's their issue."

• "Judging is a mental process. Everyone has a mental problem."

• "I am trying not to get caught up in what other people think of me, just what I think of me."

• "I know who I am and I am certainly not my diagnosis."

Some of us decided it would be important to share how stigma has manifested itself in our lives:

• One member was "blamed for being in this place [a psychiatric hospital]."

• Another said, "Ever since I've been in the hospital, my stepmom won't accept me for who I am. She won't let me come home for visits with my dad. My siblings accept me but my stepmom can't. The hospital said I can go home for visits. But my stepmom won't allow me to live there. Actions speak louder than words: I'm getting better and working hard at getting better, but when I do she still takes the rug out from under me. People make you who you are—you're made who you are."

• Another member said he "didn't feel like they [staff at hospital] paid attention to me until I started taking my meds." He felt they were "covering up the problems."

Other people in the group talked about their experiences with stigmatization:

• "One time I went to the hospital because I got an infection from a bee sting and I had to tell the nurse my diagnosis. Her immediate response was, 'That's a hard diagnosis, it must be hard.' This woman doesn't even know me and she is telling me that my life is hard. She heard my diagnosis, lumped me into a category and responded to that."

• One participant was "denied informed consent in the past," and did not always get "a say in what my diagnosis is."

• "My entire junior high career I was called 'freak' and 'crazy,' because I was depressed and dressed differently, listened to different music. Sometimes large groups of kids would stare at me obnoxiously, walking down the halls. Sometimes kids would follow me around, making me anxious and making fun of me. Eventually the anxiety around school got so much that I couldn't go and I was allowed to be home-schooled for the remainder of junior high."

• A young woman from the group said she was "belittled by staff. The staff [at her treatment center] said they were in charge of my treatment, not me. They're a bureaucracy. They hurt the people they're trying to help. I haven't done anything I used to do before at other programs. I say I don't need to be there, but because of bureaucracy they have to keep me there for a certain amount of time." As a group we all agreed that, generally, treatment is not individual enough.

Wisdom we wanted to pass on to individuals without any firsthand experience with a diagnosed individual was: Don't judge others, because it's just a reflection of yourself, not the

diagnosed individual. One member quoted Lewis Carroll: "We're all mad here. I'm mad. You're mad. We wouldn't be here if we weren't."

At that point we went on a quoting spree of our favorite sayings, the two most relevant to this article being "rock bottom is good solid ground," and "a dead end street is a good place to turn around."

We do not feel less or worse because of our diagnosed experiences, but stronger of character and more open in general. We feel and hope for the same things everybody else does. "I try to live a life of meaning, purpose and fun," said one council member. He also said, "the most valuable thing for me was to feel connected to other people." Our pursuit of happiness is only deepened by our experiences with mental illness: "I needed a lot of self-care in those days and after I got back on my feet I started to want to get better and get healthier. This drive was strong in me and as the days went by it got stronger."

As a group we agreed that stigma "needs to be eradicated!" We "need to educate on mental illness to help stop stigma." Stigma does no one any good, but we feel that we cannot force anyone to cease perpetuating stigma. As a group, the most we can do is actively pursue an effort to present the truth about young persons with mental health conditions. It is ultimately up to those we educate to embrace this truth and increase their own awareness.

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The Massachusetts Statewide Youth Advisory Council is a group of transition age youth (TAY) consumers who come together to voice themselves in relation to issues pertaining to TAY consumers in Massachusetts, affiliated with both the Massachusetts Department of Mental Health and the Transformations Center.

The Family Acceptance Project:
Understanding the Experiences of LGBT Youth

Lesbian, gay, bisexual, and transgender (LGBT) adolescents face the same social and developmental challenges as their peers. Yet most grow up in environments where families, parents and other adults, and institutions that nurture children and adolescents have limited or no information about supporting a child's sexual orientation and gender identity. Even providers who help families with child and adolescent development are often unable to answer questions and concerns on how to support the positive development of LGBT young people.

Social stigmatization remains a primary barrier to helping families and communities support and ultimately accept LGBT children and youth. Family members, peers and the media typically convey very negative messages about children who are "different" in this way. These messages are internalized and contribute to feelings of shame and low self-worth, leaving children fearful of revealing their real feelings and identities to others as they age.

LGBT youth must learn to manage this stigmatization (a complex task regardless of age) and to cope with social, educational and community environments where victimization and harassment are normative. This stigma has social, health and behavioral consequences. Internalized as self-stigmatization or in the extreme as self-hate, stigma can be acted out behaviorally and contribute to high risk behavior.[5]

Overall, the literature on LGB (there is little research of any sort on transgender youth) adolescents emphasizes the increased risks these youth face. Most of what is known about LGB youth focuses on victimization, substance use, depression, attempted suicide, sexual health risks, and overrepresentation of LGB youth

among out-of-home youth, with little attention to positive youth development, strengths, and well-being. The purpose of our research, therefore, was to study how families adjust and adapt to their children's LGBT identity and to examine how family acceptance and rejection affects LGBT young people's health, mental health and well-being.

Protective Role of Families

Parents and key caregivers play a vital role in an adolescent's health and well-being and have a central, enduring influence on a child's life. Research has shown that connection to families is protective against major health risk behaviors, including alcohol and other drug use, emotional distress, suicidality, unsafe sex, and violence towards others.[2]

However, a significant gap in the research literature and in community and professional practice on helping families support their LGBT children led us to develop the Family Acceptance Project (FAP) in 2002, with funding from The California Endowment. Our experience working with LGBT youth over a period of years showed that even though LGB youth were coming out at younger ages compared with adults from prior generations (The latest research shows that LGB adolescents are becoming

aware of sexual attraction at an average age of 10 and coming out, on average, between ages 14 -16,[1,3] few providers or community agencies offered any services or support for families with LGBT youth. And surprisingly, the research literature included few studies that explored family reactions to disclosure of sexual orientation, and only from the perspective of the adolescent.

So we started FAP to conduct high level, community-based research to develop effective interventions, educational materials and approaches to: 1) strengthen families to increase support for their LGBT children; 2) improve the health, mental health and well-being of LGBT children and adolescents; 3) help maintain LGBT youth in their homes to prevent homelessness and the need for custodial care in the foster care and juvenile justice systems; 4) inform public policy and family policy; and 5) develop a new model of family-related care to promote well-being and to decrease the high levels of risk for LGBT young people that restrict life chances, positive youth development and full participation in society.

Our research is participatory so we partnered with key community organizations that focus on adolescents and included the "end users" of our work—pediatricians, nurses, social workers, teachers, families and youth—who provided guidance on all aspects of our research and resource development. We started with an in-depth qualitative study of white and Latino LGBT adolescents, ages 13-18, from diverse families that were accepting, ambivalent and rejecting of their child's LGBT identity. Our goal was to learn how families adjust and adapt after their youth come out or are "found out." We recruited adolescents and families from all over California and interviewed them in

English or Spanish. We interviewed the adolescent, at least one parent or guardian, and another key family member with knowledge of the child's experiences and family reactions—usually a grandparent, or older relative.

Our interviewers asked about child development and family life, sexual orientation and gender identity, religious beliefs and practices, ethnicity and culture, coming out, family response and adaptation over time, school-based experiences and victimization, resiliency, coping and sources of support. The youth and family interviews helped us identify more than 100 specific behaviors that families and caregivers use to express acceptance and rejection of their LGBT children. These include negative reactions such as excluding the youth from family events or activities because they look too "gay" and positive efforts such as finding LGBT adult role models to give the youth positive reinforcement and options for the future.

We realized that few families had an opportunity to talk about their child's LGBT identity, so our research interview provided a kind of narrative therapy. It became apparent that early intervention could have made a critical difference in helping maintain many adolescents in their homes. Instead, they ended up in foster care or on the streets because of family conflict related to their LGBT identity. Most poignant were families who did not understand that strategies they used to discourage or try to change their child's sexual identity or gender expression were experienced as rejection by their children. Parents perceived these behaviors (such as blocking access to LGBT resources and peers or expressing shame related to their child's LGBT identity) as ways of caring for their children—socializing them to live in an unaccepting or homophobic world.

These accepting and rejecting behaviors form the basis of our quantitative research, educational and skill building interventions and assessment tool (FAPrisk). We developed measures to assess the presence and frequency of each accepting and rejecting parental/caregiver reaction to the young person's sexual identity and gender expression during adolescence. We then measured each family reaction in a survey of LGBT young adults, ages 21-25, with the same characteristics as adolescents in our qualitative study. LGBT young adults were recruited from social, political, recreational and health-related venues that serve this population within 100 miles of our research office.

The results are highly intuitive and compelling, particularly in demonstrating the serious negative impact of family rejection. For example, in our first research paper, we found that LGB young adults who reported higher levels of family rejection dur-

ing adolescence were 8.4 times more likely to report having attempted suicide, 5.9 times more likely to report high levels of depression, 3.4 times more likely to use illegal drugs and 3.4 times more likely to report having engaged in unprotected sexual intercourse (which puts them at high risk for HIV and STDs), compared with peers from families that reported no or low levels of family rejection.[4]

Because families play such a critical role in child and adolescent development, it is not surprising that adverse, punitive, and traumatic reactions from parents and caregivers would have such a negative influence on risk behaviors and health status among LGBT young adults. Conversely, we also found in subsequent analyses that LGBT young people whose parents support them show much higher rates of self-esteem and greater well-being, with lower rates of health and mental health problems than young people from rejecting families.

We are using these behavioral out-comes, which predict risk and well-being, to help parents and caregivers of LGBT youth decrease rejecting and stigmatizing behaviors and increase supportive behaviors, thereby reducing their children's risk and promoting their well-being. In our work with ethnically diverse families with LGBT children, we have found that families are eager for information and guidance to help their LGBT children, and some families even change rejecting behavior overnight when they realize how negatively it affects their LGBT children.

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Addressing the Stigmatization of Mental Illness Experienced by Children

This paper examines stigmatization of children with mental health conditions by examining research on adults, and drawing parallels to the possible experiences of children. We also describe the limited findings on children and stigmatization.

Stigmatization's Impact

Research conducted primarily on adults suggest stigmatization has three effects: self-stigma, label avoidance, and public stigma.[5] Self-stigma decreases a person's sense of self-worth and self-efficacy. Children who internalize public stereotypes end up self-stigmatizing: "I must be a bad person because they say I have mental health problems!" Label avoidance is also harmful. To avoid being labeled as mentally ill (and the stigma that results), individuals may avoid meeting with psychiatrists or other mental health professionals so that they do not receive an official diagnosis. Consequently, they also fail to receive treatment.[4]

Public stigma, the focus of this paper, is the general population's endorsement of stereotypes that lead to discrimination—the behavioral result of stereotyping. Research on adults has found that the public tends to stereotype people with mental illness as dangerous, incompetent, and blameworthy. There is also evidence that the public's stigmatization of adults has actually worsened over the past 50 years.[20] Discriminatory behaviors that result from stigmatization include employers who do not hire people with mental illness, landlords who do not rent to them, or physicians who withhold some treatments. Specific findings on children's attitudes are not available, though it seems rea-sonable to think that younger persons hold similar negative perceptions of persons with mental health conditions. However, research on the stigmatization of children in adults has demonstrated that adults view children with mental health conditions as increasingly dangerous.[18]

Efforts to Decrease Stigmatization

There are three commonly researched approaches to addressing the public stigma of mental illness in adults: protest, education, and contact.[8] Protest occurs when individuals band together and demand that the media and general public change the portrayal of, or their attitudes toward, individuals with mental illness. Even though this approach can be successful in changing media such as advertising,[24] individuals often experience an increase in stigmatizing attitudes after the event.[9,15] Protest therefore may have limited value as an approach for reducing stigmatizing attitudes among adults, and similar limited effects for reducing stigmatization among children.

A second approach for combating mental illness stigma is education. Previous research among adults has shown that the more knowledge an individual has about a mental illness, the less likely that person will endorse stigmatizing views.[12,14] Education programs attempt to affect change by challenging the myths about mental illness with facts. These programs are mainly community-based and occur in many formats. They may include one session or multiple sessions and may be presented by a single or multiple speakers. One example of a myth of mental illness is that once an individual is mentally ill, he or she will never be better. However, research shows that 1/3 of individuals never need treatment after their first hospitalization and 1/3 of individuals fulfill life goals with treatment and support.[11,13] While research shows that educational approaches have resulted in some immediate reduction of mental illness stigma, additional findings suggest that individuals may return to baseline levels of stigmatizing attitudes at one-week follow-up.[8,9]

Although education-based research specific to mental illness stigma in children is limited, evidence suggests these approaches can increase general knowledge about mental illness at all ages.[22,25] These programs are popular due to their ability to reach a larger audience easily, through educational and mass media.[23] Other areas of research on the effectiveness of educational programs, such as multicultural educational programs for children, have shown results similar to those found in adult educational anti-stigma programs for mental illness. While there is an initial decrease in stigma, there appears to be a return to baseline endorsement.[1] As such, it is likely that mental illness anti-stigma programs for children will likely show a similar pattern of mixed, short-term outcomes.

The third stigma-reduction strat-

egy is contact. Direct interaction and building interpersonal relationships between individuals is the most effective strategy for reducing stigmatizing views and changing behaviors.[21] The stigma-reducing effect of contact

> *Direct interaction and building interpersonal relationships between individuals is the most effective strategy for reducing stigmatizing views and changing behaviors.*

is well-researched for various sub-populations who may be the focus of discrimination, including persons of color[16] and persons with physical and learning disabilities.[3] Research supports the short- and long-term effectiveness of contact in reducing stigmatizing attitudes and behavior.[2,10] There is evidence that using educational approaches in combination with contact results in the best shift in attitudes about mental illness.[21]

Coming Out

An important component of contact is disclosure of mental illness status, or "coming out"—letting people know about one's psychiatric history.[7] Many people choose not to disclose their mental illness because they fear the discrimination that may follow. For example, people who disclose may face mandatory treatment, or loss of housing and/or employment.[10] Unfortunately, when individuals choose to hide their illness, it reduces opportunity for contact and familiarity in the wider community—the very things which may result in reduced stigmatization.

While adults with mental illness may choose where, when, and to whom to disclose, children have less control of this choice. When adults disclose, they disclose to other adults that have the mental capacity to understand what is happening. For children, it is generally parents and teachers who ultimately control disclosure. The phenomenon of "forced disclosure" is not well-understood and there is a need for future research

in this area. In contrast, parents of a child with a mental health condition may choose to hide their child's situation so as not to risk stigmatization of the entire family. For example, when a person learns of a child's mental health condition, he or she may assume that bad parenting caused the child's mental illness.[6,19] To avoid these judgments, a child's mental health may remain hidden.

The coming out process for children is also impacted by the cognitive capacities of their peers. When children learn about mental illness in a peer, their ability to understand this information is limited by age and cognitive ability. This can lead to peers being fearful, avoiding, and less willing to help the affected child.[17]

Summary

Much of the work described in this paper evolves from the broad theory and research programs of social psychologists. Research suggests that contact is the best method of combating stigma of mental illness in adults and in children. It is important that research in this area continue in order to guide the development and evaluation of anti-stigma interventions. Challenging the barriers created by stigma will greatly open up the opportunities of children with mental health conditions. Anti-stigma programs such as the ones mentioned above will also help children with mental health conditions to participate in appropriate services. Together, mental health and well-being are promoted.

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STARS: Youth-Driven Mental Health Stigmatization Reduction Campaigns in Schools

The System Transformation of Area Resources and Services (STARS) project of central Minnesota is promoting a unique approach to addressing peer stigmatization of children and youth with mental health difficulties. STARS' Children's Mental Health Stigmatization Reduction Campaign is founded upon the belief that true stigmatization reduction will only happen through youth involvement, peer education, and awareness. Developed by social marketer Tara Freed, the STARS Campaign challenges youth in area schools to develop and implement original mental health awareness campaigns that are focused on reducing mental health stigmatization. This peer-education approach is open to any group of young persons aged K-12. STARS employs a variety of strategies to motivate youth and encourage them to be creative in designing and implementing their own anti-stigmatization programs.

How the Program Works

Schools find out about STARS mostly by word of mouth from STARS representatives. The project is also promoted by STARS' staff emailing and calling key personnel at local schools, such as principals, assistant principals, and school counselors. An anti-stigmatization campaign begins once a school contacts STARS to express interest. A group of students who wish to be involved are chosen by the school to work directly with STARS on developing an original campaign. There are three key pieces of the campaign development process that youth need to complete in order to produce their own campaign with STARS. These components are usually broken into three meetings with STARS staff.

During the first meeting, the policies and procedures for setting up a campaign are reviewed by STARS staff and the youth group. STARS staff explain that youth can create a budget of up to $1,000, but that all expenditures must be approved by STARS staff. Furthermore, in order for STARS to sponsor a campaign, the campaign's message must be positive, and not include "scare tactics," or messages that might reinforce negative perceptions of people with mental health difficulties. Additionally, STARS requires that all campaign materials be factual, culturally and linguistically competent, and supportive of all youth. Within the limitations of these guidelines, the youth are encouraged to develop any campaign that raises awareness about youth with mental health difficulties to fellow youth and the community.

Although all youth must go through the same process for getting their projects approved, the level of teacher and STARS staff participation in developing their project varies, depending on the age and grade of the students. At the elementary schools, teachers and STARS staff are more heavily involved in the planning processes, while in middle or high schools, students make almost all the decisions.

Once the youth have developed a campaign, they schedule the second meeting with STARS, during which the youth present a written campaign proposal that is broken into three parts. The first part of the proposal details their campaign. This part describes where and when the campaign will take place, and who the target audience will be. The youth also describe how the campaign will be implemented. The second part of the proposal lists the resources the youth need in order to complete their campaign, and the final part outlines the budget allocations.

After the youth deliver their campaign proposal during the second meeting, STARS reviews it and makes a decision on the proposal within a week. Given the interactive nature of the previous meetings, there are rarely any surprises, and most proposals are accepted. However, as the campaign evolves, STARS usually helps manage some of the logistical challenges that come up, and ensures that the campaign remains in line with the policy and procedural guidelines. Meeting three takes place in order to check up and finalize everything before the youth get started implementing the campaign.

Once the program is approved, the group of youth needs to choose a key adult advisor, and, if the group is based at a middle or high school, a key youth. These people will lead the campaign's development and implementation. They will also be the main contacts between their group and STARS. STARS' involvement and interaction with these key contacts varies throughout the campaign.

Campaign Examples

So far, STARS' youth-driven campaigns have been implemented in seven schools and have reached over 4,000 students and staff. Students at Clearview Elementary created the slogan, "Think green, don't be mean, so we can be seen and reach our dreams." Ivan Sand Community School's Youth Leadership class had

the idea of going "to the top" by educating their state representatives at Mental Health Day on the Hill at the state capitol. Additionally, the Sauk Rapids High School Improvisational Acting Group performed a silent skit depicting a young girl who managed to cope with the many negative influences that youth face today, such as drugs, stealing, and alcohol—without resorting to suicide. The skit was taped and is now shown at high schools around central Minnesota.

The Rocori High School Student Council organized a Suicide Prevention Day, where they handed out "You're Important" buttons and yellow ribbons to more than 850 students. They also sponsored a mother to come and talk to the entire school on how she was affected when her son committed suicide. On Wellness Day, The Monticello Middle School Peer Mentors performed a skit for their entire school. "Turnaround" focused on positive coping skills and making good choices. After the skit, the mentors broke the audience into five workshops and talked about what mental health means to them and where students can go for help.

Evaluation Efforts Past and Future

Current evaluation of the STARS program is minimal. The youth involved in the project answer some basic questions about their perceptions of the campaign's success. Through

this basic evaluation process, STARS found that every campaign group felt that its project was a success, and that almost all of the campaigns affected more people than their original target audience.

STARS' goal is now to find out if these youth-driven campaigns are actually reducing stigmatization associated with youth mental illness. Therefore, STARS is currently working on revising its evaluation process in order to make it less subjective and more evidence-based. Campaign groups will still have to complete their own evaluations as before. However, people in the target audience will now be asked to complete a survey with questions relating to a vignette about a new classmate who is experiencing a mental health difficulty. Respondents will take the survey again at the end of the campaign. STARS' aim is to get at least 50% of the audience to complete the survey both times, with an ideal target of 80%. The results of these data will be used to measure the overall effectiveness of the youth–led projects. STARS also hopes to inspire and help other schools and service organizations nationwide develop and implement their own youth-driven campaigns.

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Stigma and the Cycle of Avoidance: Why Young People Fail to Seek Help for Their Mental Distress

Illness behavior is the set of purposeful actions taken by someone when faced with being unhealthy. According to Dingwall,[3] the three stages of illness behavior are: evaluating symptoms, deciding to act, and monitoring the effects of the chosen actions. Although presented in a linear fashion, these stages are in fact cyclical, as reassessment occurs when symptoms change or unsuccessful actions require new approaches.

However, it is common that people never act, or delay acting, on their symptoms; this is especially true for people experiencing mental distress. Young people in particular are unlikely to seek professional care for mental health concerns—it is estimated that as few as 17 percent of young adults with mental distress will seek professional care for their symptoms.[6] Even among those with a clinically defined disorder, only about a third will seek professional help to address their symptoms.[1,4]

There are many barriers that impact illness behavior in a person with a mental health condition. These include a lack of resources or insurance, a lack of awareness about mental health conditions, and poor access to and low awareness of possible treatments.[5] Stigmatization also can negatively impact all stages of illness behavior. Given the stigma associated with having a mental health "problem," people who might otherwise seek help may reframe their condition, reinterpreting their symptoms in order to define how they are feeling as unproblematic or "not that bad." People may not seek help due to embarrassment or shame. Stigma may also prevent people from seeking different treatment options if their mental health is not improving, since they may be fearful to admit that they are not getting any better.[2] As a result, people who experience mental distress may try to cope with their mental

health conditions by themselves even though social support and treatment are likely to improve symptoms.

Understanding Help-Seeking Behaviors

Although the process of help seeking has been explained theoretically using Dingwall's three stages of illness behavior, very little has been done empirically to document this process. One exception to this is the work conducted by Lucy Biddle and colleagues.[2] Biddle interviewed 23 distressed young adults, aged 16-24 years, about their help-seeking behaviors and their reasons for not seeking help. The indicators of their severe distress included suicidal thoughts, cutting, overdosing, and elevated scores on the Clinical Interview Schedule. The major interview topics explored were:

- young adults' concepts of mental distress and theories about cause, prognosis, and curability;

- interpretation of and responses to symptoms; perceptions of need for help;

- perceived outcomes of help-seeking;

- reasons for help-seeking or other actions, including possible "barriers" and "triggers";

- perceptions of help sources (both formal and informal); and

- involvement and responses of family, friends, and peers; and experiences of help-seeking.

The Cycle of Avoidance

Upon listening to the narratives of these young people, Biddle created a model to track the process of illness behavior in persons experiencing mental distress—the Cycle of Avoidance (COA, Figure 1). This model shows that young people will continuously push their threshold of tolerable distress to include extreme concepts of "normality," in order to avoid accepting their symptoms as "real" illness requiring help and support. Oftentimes, young people experiencing mental distress will go to great lengths to avoid attributing their feelings and behaviors to mental health problems, and therefore delay seeking help of any sort. Instead, they will continue to cope on their own and normalize their psychological difficulties. Eventually, many of these young people cross this threshold into help-seeking actions via either a crisis or external pressure, or due to self-realization that support is needed.

Young People Interpret Mental Distress

Using excerpts from the 23 interviews of young people, the COA comes to life through narrative. When conceptualizing distress, participants placed mental health difficulties into two distinct categories—"normal" distress and "real" distress—as opposed to seeing distress along a con-

tinuum from slight to serious. While the former was seen as a phase that would eventually pass, "real" distress was seen as extreme, rare, and often permanent. This was the type of distress that participants perceived to be "mental illness." According to them, people who experience "real" distress either:

"Generally can't control themselves that well, either the way they act or the way they behave… (they) are people who generally can't hack it almost. Their minds generally kind of break down and go through certain problems that drugs can overcome sometimes, or, I don't know what they do in those places, electric shocks" (16 year-old male, p. 990).

Or, "Can kind of go over the edge of stress and it's like mental problems… you literally can't cope with getting up in the morning. You've got to that point then when you can't do anything… getting close to the edge and feeling life isn't worth living" (23-year-old female, p. 991).

Such extreme definitions of mental distress can understandably lead to a resistance to seek help and support.

The participants felt that "normal" distress should be dealt with by coping, whereas help and possible treatment should only be sought when experiencing extreme distress. This demonstrates a substantial gap between the beliefs of these young people and clinicians as to when is the best time to seek professional help for mental distress. Some of the young people regarded significant distress experiences as normal, and therefore not requiring professional support to alleviate:

"I wouldn't say I'm depressed, I would just say that I am really overstressed. But I suppose you could call it depression because the thoughts [of suicide] I get sometimes with it… I don't know because it is quite hard to decipher each one. I mean when do you say that stress is depression or depression is manic depression… and how do you say when somebody's upset or somebody's seriously depressed?" (18 year-old female, p. 993).

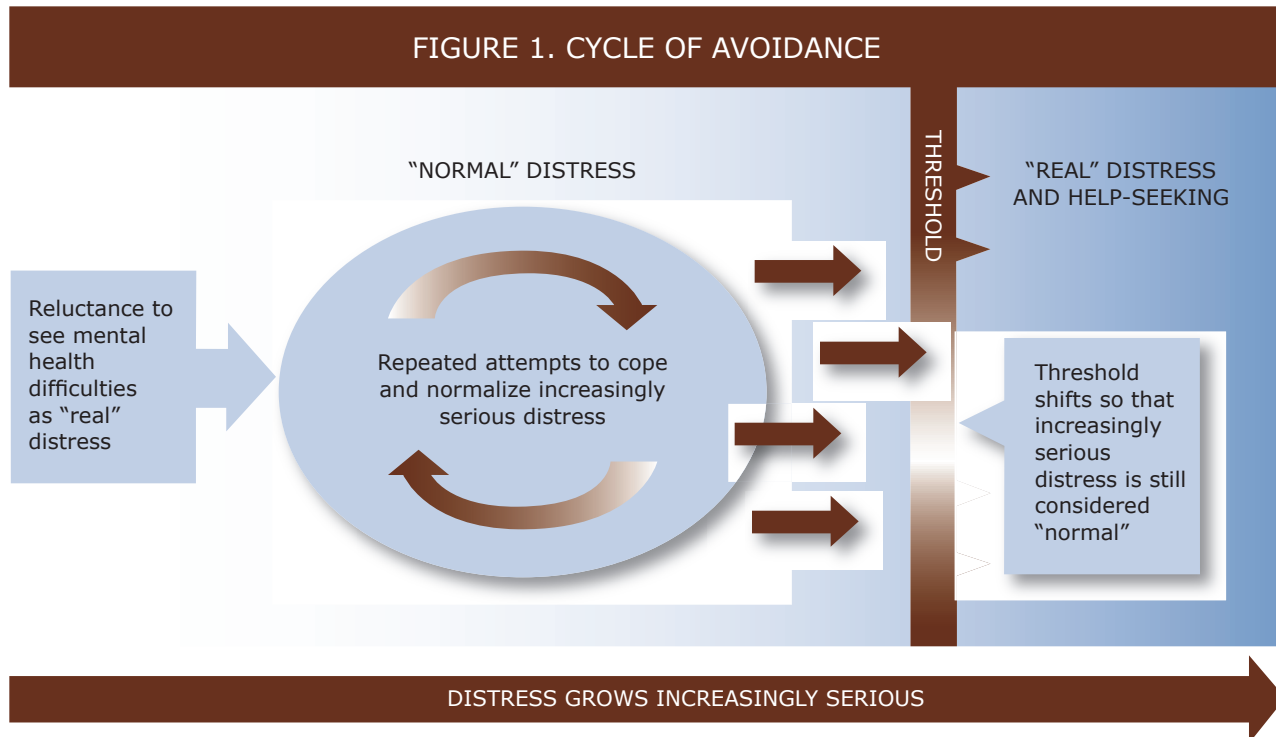Others resisted seeking help to the point where it was almost too late:

"I was really badly, like, depressed and I didn't go to the doctor's because I didn't think… I was ill. I didn't think I was ill so it ended up that I ended up in hospital [overdose]… I really needed to see for myself there was a problem…It took me to go into hospital to realize" (20-year-old female, p. 996).

Stigma

Stigma is a key factor in determining how these young people come to define mental illness and when they seek help for it. They realized that there is a stigma against people with mental health conditions and felt that getting formal support for their distress would make them vulnerable to such judgments: "I just didn't think about speaking to the doctor because I didn't want to be sectioned [*in the UK, sectioning is the involuntary subjection of a person to mental health treatments or hospitalization*] or anything. You know there is a stigma about psychological health. There's like a black, black cloud and as soon as you sort of fall under it everyone else runs for cover"

FIGURE 1. CYCLE OF AVOIDANCE

"NORMAL" DISTRESS

THRESHOLD

"REAL" DISTRESS AND HELP-SEEKING

Reluctance to see mental health difficulties as "real" distress

Repeated attempts to cope and normalize increasingly serious distress

Threshold shifts so that increasingly serious distress is still considered "normal"

DISTRESS GROWS INCREASINGLY SERIOUS

Young people draw a sharp distinction between "normal" distress (which they see something temporary that can happen to anyone) and "real" distress (which they see as indicative of having a mental illness). As a result, they are extremely reluctant to see their symptoms as "real" distress, and they continually re-define "normal" to include increasingly serious distress. Often they are only willing to cross this psychological threshold—and admit that their distress is "real"—when they experience a mental health crisis.

(23-year-old male, p. 997). Concerns about being stigmatized were a prominent reason underlying not only the normalization of interviewees' mental status and avoidance of seeing their situation as "real" distress, but also their lack of help seeking.

Self-stigmatization was also apparent. Throughout Biddle's interviews, youth—who themselves had all demonstrated severe levels of distress—used many derogatory terms for mental illness including "screwy," "totally mental," "weird," "nutty," and "gone up there." Such interpretations of mental illness are bound to influence how young people perceive themselves and interpret their own symptoms, and whether or not they seek treatment. Because of these negative perceptions, it is understandable that young people would be motivated to dismiss their own distress as something that is "normal" and will eventually improve: "I wouldn't say I'm depressed. I'd say I've had a bad time of things for say longer than a couple of weeks or months or it's been a bad couple of months but I wouldn't say I'm actually depressed" (20-year-old male, p. 994).

Participants' corresponding resistance to seek help also makes sense as, according to their narratives, only people who are experiencing extreme symptoms should seek help. It is within this dichotomous framework of "normal" vs. "real" psychological distress that these young people make decisions as to whether or not they should seek professional support for their mental health. And if they do decide that their mental condition requires more formal help-seeking, they are placing themselves into the category of "screwy"—and vulnerable to self-stigmatization that may interfere with their treatment and chances for improvement.

Conclusion

This study is one of the few that addressed how both stigma and self-stigma affect young people's interpretations of their mental health and subsequent actions taken to address it. Using illness behavior as a starting framework, the COA model was created through listening to young adults' narratives of understanding and responding to their own mental distress. It was found that young adults go to great lengths to avoid defining their symptoms as "real" mental illness, which in turn prevents them from seeking help to alleviate their distress.

Stigmatization plays a significant role in driving the non-help seeking behavior which dominates the COA. Attempts to avoid interpreting symptoms as something about which to be concerned, and delays in help seeking until crisis were often driven by negative perceptions of persons with mental health conditions. Not wanting to be perceived as "weird" or a "nutcase in a padded cell," young people who experienced indicators of serious emotional distress such as suicidality and cutting went to great lengths to avoid labeling their feelings and behaviors as in need of professional mental health services.

The social meanings attached to the label "mental illness" caused the interviewees in this study to avoid what perhaps they knew were the "correct answers" and to resist medicalization of their distress. Stigma appeared to be a deeply entrenched belief system that permeated every aspect of illness behavior, and feelings of self-stigma likely exacerbated the low self-esteem that often accompanies distress. Defining oneself as having "real" distress and seeking help posed a serious threat to interviewees' self-identity and social identity and, in an attempt to avoid this, some of the young people in this study instead adopted negative coping behaviours, leading to spiraling distress and comorbidity. Where help was eventually sought, fear of stigma sometimes impeded full disclosure of symptoms or willingness to engage with treatment.

Practitioners need to be aware of such meanings and the perceived change in status that accompanies what might appear to be the straightforward act of seeking help or becoming a "patient." In particular, they should be aware that by diagnosing a mental health condition, they are potentially marking a young person as "not normal." Supporting young people in managing the psychological and social consequences of this should be paramount alongside any treatment actions.

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Breaking the Silence: Parents' Experiences of Courtesy Stigmatization in the Workplace

Felicity, a single mother of three, no longer talked to her co-workers about her oldest son. She shared stories about her other two children, their successes in school, participation in after-school activities. She discussed typical parenting concerns, but had learned that stories about her oldest son made others uncomfortable. These were not happy stories. At work, she had learned to compartmentalize—the pain, the struggles, the lack of sleep, and the fears. She carefully separated, like egg yolks from their whites, stories about her other two children, which more closely resembled her co-workers' stories about their "typical" children, from stories about her "different" child. Perhaps this was a strategy for self-protection as well as protection of her son.

The more out-of-sync with developmental norms her son became, the more out-of-sync Felicity felt with her co-workers. At first, Felicity had felt comfortable telling co-workers that her first born was especially emotionally sensitive. She was even okay about letting a couple of them know that he was seeing a therapist. But while her co-workers would regale her with stories of their children's achievements, there was never the right moment to share that her son had just been placed in a classroom for children with severe emotional disturbance, or had threatened suicide. She silenced herself, knowing that others would not understand. She felt ashamed. She wondered what kind of parent they thought her to be. They must see her as incompetent, a bad mother. It was

stressful enough that she frequently left work to pick up her son who often could not tolerate the classroom environment, or took daily phone calls from her sons who fought endlessly with each other at home after school. She knew her supervisor doubted her work ethic and that co-workers complained about her state of distractedness. Felicity worried that they saw her as an unreliable employee, a flaky coworker.

Courtesy Stigmatization

Many family members of individuals with mental health disorders have experiences like Felicity's, which are referred to as *courtesy stigmatization*. Courtesy stigmatization reflects the prejudices, negative judgments, and discrimination extended to others—particularly partners, family members, and close friends—who are caring for, or significantly connected to, an individual with a mental health disorder.[1] Courtesy stigmatization can occur both directly, through overt acts of discrimination or rejection,

and indirectly, through feelings of shame, being blamed, self-blame, embarrassment, and fear of direct acts of discrimination or others' negative judgments.[2]

Parents and other caregivers of children with mental health disorders experience courtesy stigmatization throughout their lives. For example, family members may experience blame for their child's disorder through comments from extended family members, mental health professionals, school personnel, or employment supervisors. These interactions lead to feelings of guilt and loss, heightened fears of discrimination, and concern about negative judgments. Family members may become increasingly socially isolated both because they lack supportive resources, and in order to protect themselves from exposure to more stigmatization.

Parents, especially mothers, are particularly vulnerable to courtesy stigmatization, as they often are held accountable for the well-being and socialization of their children. Faced with public perceptions of mental illness, including attributions of causation, parents respond by attempting to minimize family exposure to stigmatization. Strategies used by parents to manage stigmatization focus largely on controlling the dissemination of information regarding their child's mental health. Parents may also selectively participate in public outings and only socialize with others who would understand.[2] Over time, parents learn when to conceal and when to reveal information, not only about

their child's mental health status, but also regarding the fuller story of the family's experience.

In the Workplace

A parent is not free from the experiences of courtesy stigmatization in the workplace. With or without directly disclosing or discussing a child's mental health status, the effects of courtesy stigmatization are felt. Employed parents of children with disabilities, especially mental health disorders, are often hesitant to let anyone within the workplace know about their children's disorders. Shellenbarger[5] refers to this reluctance as a "code of silence" in the workplace that keeps these parents quiet. In the workplace parents are cautious about disclosing the particulars of their family situation, fearing stigmatization and possibly career penalties.[3] However, even without openly disclosing, family concerns spill into the workplace through interruptions by telephone calls from the child's school, unexpected departures in response to a child crisis, and stress that affects performance and health. These "spillover" effects can shape supervisors' and coworkers' perceptions. They come to believe that the parent is not adequately meeting job responsibilities.

Parents of children with mental health disorders are subject to double jeopardy regarding courtesy stigmatization in the workplace. Because of the public's misperceptions about the etiology of children's mental illness, parents are held responsible for their children's mental health problems and can be labeled as *bad parents*. At the same time, disruptions and absences from work resulting from exceptional care responsibilities may lead co-workers and supervisors to form the perception of the parents as *bad employees* as well. Stigmatizing comments and responses can become internalized by the parent, shaping self-narratives and decisions, and creating shame and self-blame. Parents of children with mental health disorders experiencing courtesy stigmatization

may feel isolated and misunderstood by their supervisors and coworkers.

Research Findings on Workplace Stigmatization

We explored courtesy stigmatization specific to the workplace through focus groups with employed mothers caring for children with mental health disorders.[4] Four different types of stigmatization were identified through a review of focus group transcripts: (a) direct, (b) indirect, (c) perceived, and (d) internalized. Parents' reports of *direct stigmatization* included being blamed for their child's disorder, coworker resentment of work interruptions, lack of understanding about the child's illness or caregiving needs, and discrediting of professional competence. The *indirect stigmatization* described by the participants included experiences such as witnessing other parents of children with mental health difficulties receive disapproval and judgment by supervisors and coworkers:

"My supervisor has not indicated to me—but I've observed her interactions with other employees who have had situations—immediate family, children, or parent, or spouse, those kinds of situations—and her expectation is that that does not impact on your work. You don't bring that—work and family are two different things."

Perceived stigmatization is the act of construing or anticipating stigmatization without observable evidence. Parents may exhibit perceived stigmatization when feeling blamed for their children's mental health problems and resented by coworkers:

"I think that I am judged… 'Why do you have a son that acts this way? Can't you handle your child? Why are you getting these phone calls at work?'…

I just can hear people thinking it and saying it. 'What is wrong with you as the parent?' And then, 'If you can't handle your child, can you do your job?'"

Lastly, *internalized stigmatization*, the direction of stigmatizing attitudes towards oneself, was expressed in parents' reports of feeling professionally inadequate and blaming themselves for their children's problems.

Focus group participants spoke of a core strategy to manage courtesy stigmatization by controlling the dissemination of information about their child's condition.[2] Employed parents may choose to disclose their

> *Because of the public's misperceptions about the etiology of children's mental illness, parents are held responsible for their children's mental health problems and can be labeled as "bad parents."*

children's mental health status within the workplace as a strategy to enhance work-life integration, particularly the fit between their work and care responsibilities.[4] Disclosure may enhance organizational and interpersonal support; conversely, it may heighten stigmatization and job insecurity. The decision whether or not to disclose is complex, and is influenced by a number of personal and workplace variables. Workplace variables include the type of job held by the parent, workplace culture, availability and accessibility of formal support, and perceptions of informal support. Some parents may feel that disclosure is not a choice they want to make, but that it is necessary in order to request flexibility or avoid job termination. The level of family-friendliness of the workplace culture may significantly influence the disclosure decision. Issues of privacy, confidentiality, and work-family boundary management are important personal considerations.

Participants in the focus groups discussed what they consider when making a disclosure decision, including the type and amount of information to share. Different telling strategies included: (a) full disclosure, (b)

limited disclosure, (c) "bending the truth," and (d) self-censoring. These disclosure patterns iterate sensitive information to the workplace in different amounts, based in large part on the stigmatization patterns found among co-workers. For example, full disclosure reveals the child's mental health condition and the challenges the worker faces due to the child's interaction with a variety of systems:

"I just let them know right up front that I was on a one-to-one basis with the police, one-to-one basis with the emergency room, one-to-one basis with almost anybody who would be emergency personnel… I was just really up front with this job that I have now. I said my child does get in to trouble."

In contrast, other participants talked about self-censoring, not disclosing, and the challenges faced by the family due to the child's mental health difficulties:

"I just got to the point that I wouldn't even tell them. 'I'm going home for the day.'—That is how I would leave it, because if I tried to be honest and tell my situation, they weren't very understanding."

Conclusion

Our conversations with parents have revealed that their experiences in the workplace are greatly affected by patterns of stigmatization found in American society. When human resource professionals or supervisors are approached by parents who are requesting flexible work arrangements, the reasons given by employees affect the employer's willingness to grant them. If the organization has a culture that supports stigmatization, making genuine and full disclosure difficult, workers may struggle to speak up for the work arrangements they need.

In May 2008, a U. S./Canada Forum on Mental Health and Productivity, entitled "The Mental Health of Working Parents and Their Children" was held at Harvard University Medical School. This forum brought together 70 business, government, and mental health leaders who listened to working parents and their children describe their struggles to find the help that they needed. The clear message from this forum was that the workplace has much to gain from combating stigmatization and permitting parents to talk about their

family's real challenges and needs.

With more organizations supporting diversity training for human resource professionals, supervisors, and staff, it is important for the 5-10% of U.S. workers having children with mental health disorders to be recognized as bringing diversity into the workplace. With greater knowledge about the reality of children's mental health disorders and the struggles of parents who seek supports for their children and family in the community, employers can combat stigmatization in the workplace. Increasing attention to the challenging experiences families of children with mental health disorders bring to the workplace will reduce courtesy stigmatization, allow parents to ask for the workplace supports they need, and enable employers to retain valued workers.

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