# 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 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.

> *"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."*

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

> *"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."*



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

> *"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."*

## 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.

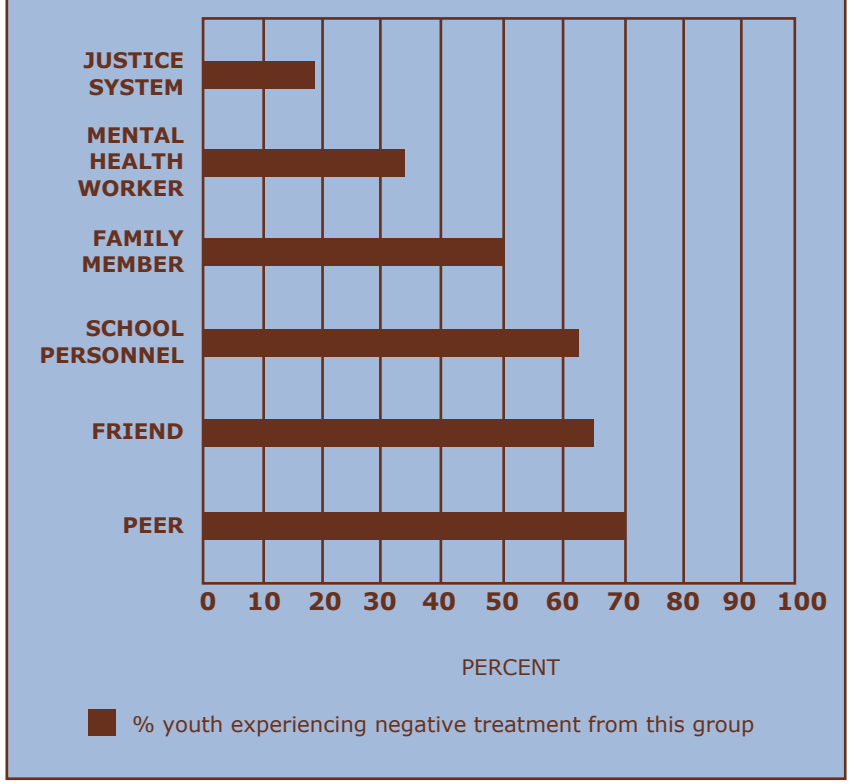
Next, youth were asked a series of questions to assess their self-stigmatization. Most of the young respondents stated that they felt bad about themselves "often" (39%) or "sometimes" (44%) because of their emotional or mental health condition. Top reasons endorsed as to why youth felt bad about themselves reflect 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 more affected by stigmatization from others also reported more negative effects from self-stigmatization ($r = .53$, $p < .01$).

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

*Positive "Stigmatization."* When

FIGURE 1. PERCENTAGE OF YOUTH EXPERIENCING NEGATIVE TREATMENT BY GROUP



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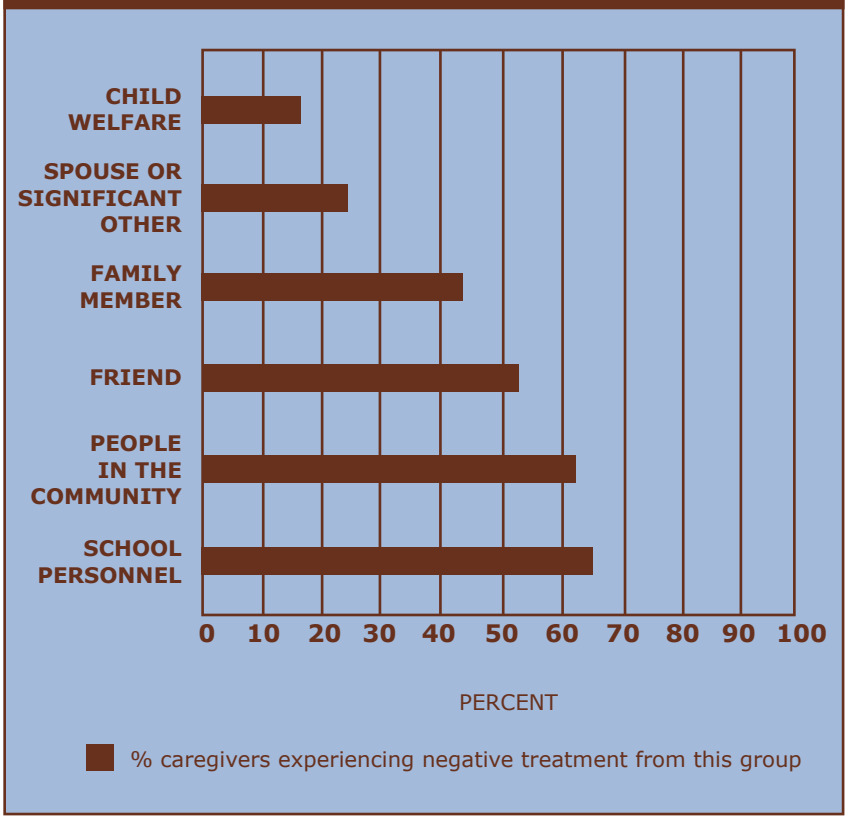
asked if other people treated them with extra care and understanding because of their mental health condition, 86% of the youth respondents said "yes." The people most likely to treat them positively were immediate family members and friends.

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

> *"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."*

FIGURE 2. PERCENTAGE OF CAREGIVERS EXPERIENCING NEGATIVE TREATMENT BY GROUP




## 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 common 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."*



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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 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.

*"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."*

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

*"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."*

## 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 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.

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

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



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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.

## 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*

## Reference

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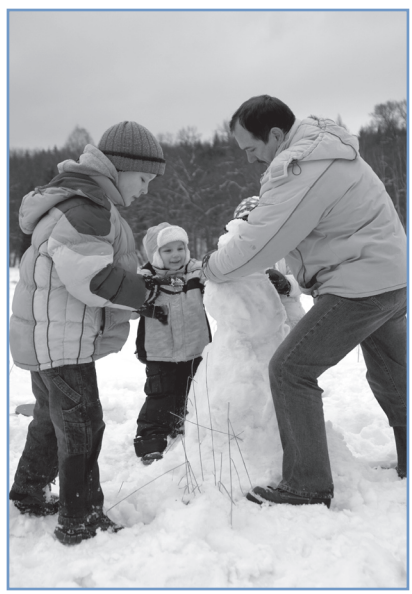
# What Do American Adults Think of Children's Mental Health Problems? Findings and Lessons From the First National Study

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 fielded 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.)



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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.

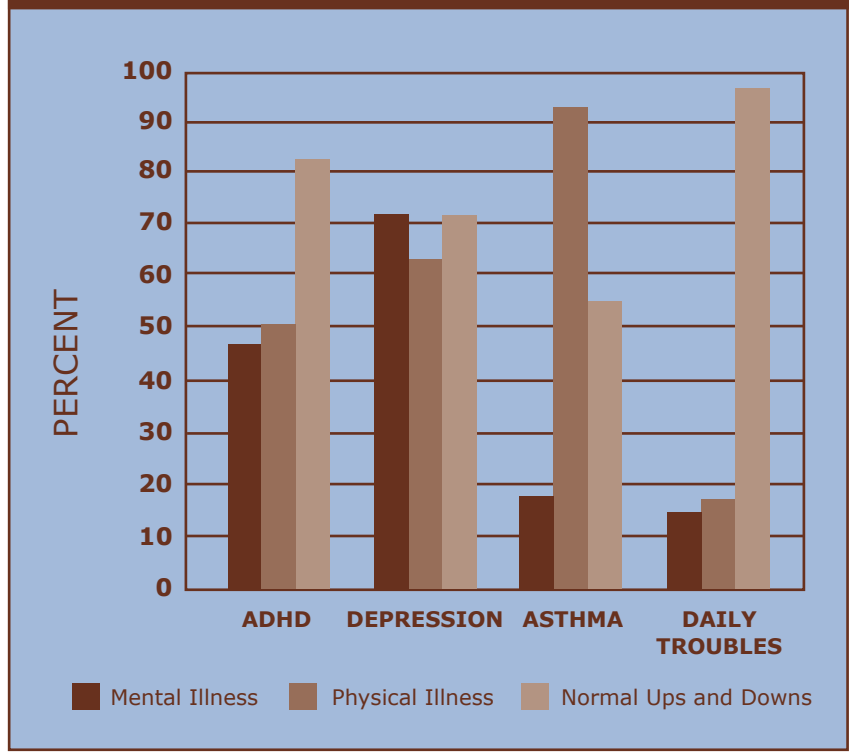
Our respondents suggest that a range of formal and informal "advisors," including family and friends, teachers, medical doctors, and mental health professionals, should be consulted when mental health problems emerge. The lowest levels of endorsement are found for psychiatrists and hospitals, and then 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



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