

Examining the Meaning Attached to Mental Illness and Mental Health Services Among Justice System-Involved Youth and Their Parents

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A large percentage of youth involved in the juvenile justice system experience mental health problems, yet many do not receive mental health care. In this study, we used a process-focused framework of mental health decision making to gain insight into the use of mental health services among these youth. In-depth interviews were conducted with nine youth and nine parents participating in a program servicing youth with mental health problems who have been in detention. Themes related to problem recognition, the decision to seek and participate in services, subjective norms, and juvenile justice system involvement emerged. Most families acknowledged their youth was having problems, but few defined those problems in mental health terms. This did not prevent them from seeking services, although some were not able to access adequate services until the justice system became involved. Participants were aware of negative attitudes about mental illness, and might have limited their social networks to shield themselves.

Keywords: *adolescent mental health; health care, decision making; illness and disease, experiences; mental health and illness; parenting*

Despite significant rates of mental illness and mental health needs among youth involved in the juvenile justice system (Costello et al., 1996; Teplin, Abram, McClelland, Dulcan, & Mericle, 2002; Wasserman, McReynolds, Lucas, Fisher, & Santos, 2002), rates of mental health service utilization prior to and during justice system involvement tend to be low, particularly among African American and Latino youth (Rawal, Romansky, Jenuwine, & Lyons, 2004). It is likely that multiple factors explain the low rate of service utilization among these youth, including limited access to services and inadequate insurance coverage (Hoberman, 1992). Attitudes about mental illness and mental health services might also be a significant barrier

to service access and participation, particularly among minority and low-income youth (Cauce et al., 2002).

Much of the research on attitudes and care seeking focuses on the decisions individuals make about entry into treatment, but from a process-focused perspective there are actually multiple decision points associated with care seeking and service utilization (Pescosolido & Boyer, 1999; Pescosolido, Brooks Gardner, & Lubell, 1998) that occur in the context of the influence of social networks (e.g., family, peers, community). This perspective guides our examination of how juvenile justice system-involved youth and their parents make sense of mental health problems and decide whether to access and participate in services. We also consider the role that juvenile justice system involvement plays in these meanings and decisions.

Meaning and Decision Making in the Context of Social Networks

A number of health help-seeking models have been adapted to help seeking for mental health problems (see Logan & King, 2001, for review). These models

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tend to describe help seeking as a linear process that begins with problem recognition, followed by the decision to seek help and the selection of a source of help, and ends with actual help seeking (Fischer, Weiner, & Abramowitz, 1983). Recent models of help seeking for children have elaborated on this sequential process (Logan & King, 2001), and included social, cultural, and systemic factors that might facilitate or impede help seeking (Sayal, Taylor, Beecham, & Byrne, 2002). However, there is evidence to suggest that help seeking is not always a linear process (Shanley, Reid, & Evans, 2008), and that there might be multiple influences affecting mental health service seeking and participation.

Rather than viewing service seeking as a linear process, decisions about treatment access and participation might be better understood from an illness career perspective that considers how decisions are made at multiple decision points in the process (Pescosolido & Boyer, 1999; Wright, Pescosolido, & Penslar, 1997). An illness career consists of five stages or critical decision points: (a) recognition of a problem, (b) the decision to seek care, (c) initial compliance or the decision to follow medical advice, (d) outcome (e.g., recovery, death, disability), and, in the case of a chronic illness, (e) secondary compliance or following a long-term treatment regimen. The illness career framework is intended to be dynamic. Individuals do not necessarily pass through the stages in order and might go back and forth between stages. In this article, we are particularly interested in how individuals recognize there is a problem and make the decision to seek and participate in mental health services.

How do individuals negotiate the critical decisions at different points of the illness career? In the early development of their Theory of Reasoned Action (TRA), Fishbein and Ajzen (1981) noted that rational decisions are influenced by significant others. In particular, they noted that behavioral intentions are influenced by subjective norms whereby subjective norms are produced by the interaction of normative beliefs (the expectations that personally important social groups endorse a specific decision) and motivation to comply (the relative importance of opinions offered by that social group).

Consistent with TRA, the Network Episode Model (NEM) emphasizes the central role of social interaction in the treatment decision-making process (Pescosolido, 1992, 2000; Pescosolido & Boyer, 1999). NEM grounds the individual decision process within a multilevel social network. According to NEM, social

interaction is not just a passive source of information but an active and dynamic component of decisions at all points of the illness career. Moreover, Pescosolido (1992) argued that these decisions are fundamentally embedded in the social world; the social behaviors that underlie a help-seeking decision typically require the action and/or reaction of key social agents. Originally developed to understand mental health care seeking among adults, the NEM has been adapted to examine how children obtain mental health services. The family network-based model (Costello, Pescosolido, Angold, & Burns, 1998), recognizing that youth rarely seek services on their own, elaborates the roles of parents and school personnel in dynamically affecting service seeking and participation.

Based on these models, understanding mental health service utilization by youth with juvenile justice system involvement requires understanding how they and their parents decide if a problem exists, their decision to seek care, and their decisions to follow a recommended course of action. It also requires an understanding of the subjective norms youth and parents develop in their interactions with multiple networks (e.g., family, schools, peers) and the role of key members of these networks in this process. By better understanding this process and the definitions and decisions embedded in it, we can explore meanings as families make sense of and cope with mental illness and mental health services.

Methods

Juveniles (along with a parent or guardian) receiving linkage services as part of the Mental Health Juvenile Justice Initiative (MHJJ) were recruited for this study. Funded by the Illinois Department of Human Services, the MHJJ contracts with human service providers across the state to facilitate the identification, screening, referral, and case monitoring of juveniles in or at risk for detention who are identified as having a mental illness. Initiative criteria define mental illness as the presence of either a psychotic or an affective disorder. Juveniles with disruptive behavior disorders are excluded unless these are comorbid with a psychotic or affective disorder. Additionally, youth who are wards of the child welfare system are not eligible for services under this program.

A convenience sample of 9 youth with psychotic or affective disorders who had been in or were at risk for detention and their parents or guardians took part

in the study. As required by the research site, a community mental health agency in Chicago, MHJJ linkage liaisons (LL) made the initial contact and asked youth and their parents if they were interested in being contacted by members of the research team. Eleven families were referred to the study; nine families agreed to participate. Repeated attempts were made, but we were unable to contact the other two families. Assent was obtained from youth and permission and informed consent from their parents. Youth and parents were assured that the information they provided would not be shared with MHJJ program staff or the corresponding youth/parent participating in the study.

Given the exploratory nature of the investigation, we took a qualitative approach using in-depth and semistructured interviews (Miller & Crabtree, 1999). This technique was used to understand complex processes experienced by youth and their parents while making treatment decisions. Interviews were conducted separately with each youth and parent. Interviews were conducted by the first and second authors, and lasted from 40 to 90 minutes. Seven dyads were interviewed in their homes, and at the request of the parents, one dyad was interviewed at the mental health agency and one at the researcher's office. To allow themes to emerge and avoid premature closure, we began with a "grand tour" question (an opening question designed to get a broad description of the phenomena in the person's own words): Walk me through, in your own words, how this all started, what has happened to you (your child), and what you have done about it. Subsequent probes were derived from the Illness Career and Network Episode Model framework to explore the decisions, attitudes, beliefs, and subjective norms about mental illness, mental health treatment, and juvenile justice system involvement. Interviews were audiotaped and transcribed verbatim. All procedures were approved by the University of Illinois at Chicago Social and Behavioral Sciences Institutional Review Board.

Data Analyses

Our analytic approach was based on the dimensional analysis approach for analyzing data from grounded theory studies (Caron & Bowers, 2000; Schatzman, 1991). Conducting dimensional analysis involves a close scrutiny of the data to explain the phenomenon of interest by categorizing the perspective from which the phenomenon is presented by the subjects, the

context in which it is described, the dimensions of the phenomenon, the conditions under which it varies, and the consequences of the phenomenon. We made use of the computer software NVivo 7.0 (QSR International, 2006) to manage the transcript data. We chose NVivo because of its strengths in coding, matrix building, network display, and theory building. The first author and a graduate research assistant developed the initial coding framework and then both coded the transcripts independently. We then discussed coding of each transcript and resolved discrepancies by consensus. The second author, who conducted the majority of the interviews, reviewed the coding framework and coding decisions. When new dimensions of experience were encountered during the analytic process, the coding template was modified accordingly. After coding of the transcripts was completed, comparisons and connections were made between categories and cases to generate and assess rival hypotheses and to allow higher order themes to be identified.

Although we started with an open approach to the analysis so as to not overlook emergent themes, the Illness Career and Network Episode Models (Pescosolido, 1992, 2000; Pescosolido & Boyer, 1999; Wright et al., 1997) were used as sensitizing constructs. After scrutinizing the data to identify emergent themes and dimensions, we specifically examined responses to the illness career (IC) and NEM probes and scrutinized all of the data in terms of what participants said about how and by whom their "problem" was identified, and the factors (resources, beliefs, networks) that influenced the decisions that were made about what to do about the problem. We looked for themes that were and were not consistent with IC and NEM. We triangulated the data by examining the information from both members of the dyad (parent and youth), interviewer notes, and the literature.

Sample

Nine youth between the ages of 14 and 18 (mean 15.9, *SD* 1.4) participated. Seven were male, one was female, and 1 youth identified as both genders. In terms of race and ethnicity, 4 identified as non-Hispanic White, one as Hispanic White, and 4 as African American. The offenses for which they were currently involved in the juvenile justice system included domestic battery, criminal damage to property, residential burglary, vehicle theft, attempted murder, and drug charges. Six of the 9 had prior arrests.

All of the participating parents were female. Eight were participating youths' mothers, and 1 was a youth's grandmother. For simplicity, we will refer to all as parents or mothers. Parents ranged in age from 35 to 60 (mean 43.8, *SD* 7.9). Five were White and 4 were African American. Three were married at the time of the interview. They were caring for between two and seven children. Two had less than a high school education, 3 had completed high school, and 4 had some college or a degree. Six of the families had annual household incomes of less than \$20,000 a year.

Findings

Themes

The youth and their parents shared accounts of how they became involved in mental health services and the criminal justice system, their thoughts and experiences related to both, and the reactions of members of their social networks. A variety of themes emerged, many of which can be mapped to the IC and NEM frameworks. We organize the themes in terms of (a) definition of the problem, (b) problem recognition and decision to seek services, (c) treatment participation, (d) subjective norms about mental health problems and treatment, and (e) meanings for the future.

Problem Definition

Interviews with participants showed that recognizing that youth are experiencing problems and recognizing they have a mental illness or other mental health problem are not the same thing. All of the youth who were interviewed were diagnosed with either a psychotic or an affective disorder. However, participants rarely referred to these diagnoses when talking about the problems that led to the youth being involved in mental health services or the juvenile justice system. More often they spoke in behavioral or situational terms about the youths' problems. Thus, examining how families define the problem and attribute causes is important to understanding problem recognition as well as decisions about the appropriate response (e.g., seeking and participating in treatment).

A few youth and parents used diagnostic labels in describing the problems that led to involvement with the mental health and juvenile justice systems. The diagnostic label that parents and youth referred to most often was attention deficit-hyperactivity disorder (ADHD), but they did not necessarily regard ADHD as a mental health problem:

And I had found out just recently that he was diagnosed with ADHD and I didn't . . . I had no idea that he had this problem. I know that he had other problems but I didn't know that um that they said they thought he had ADHD. . . . Is ADHD like a mental thing? [parent (P)]

Only one mother made reference to a diagnostic label other than ADHD. In this instance, the mother, who was herself being treated for depression, described her daughter's problem as depression. She indicated, "In my family, I mean it, it runs in the family there's nothing I can do about it, you know, and I know she's, she's depressed—I know that for a fact" [P].

There were also instances in which participants recognized difficulties that might be considered mental health problems, but did not talk about them in terms of specific diagnoses. For example, although he did not use a specific diagnostic label, when asked if he thought he had a mental health problem, one youth said, "I can't say either because I don't know. Well, when I'm trying to kill myself, yeah" [youth (Y)]. His grandmother's answer to the same question also acknowledged a mental health problem:

Something's wrong with him because like I said, you don't see people that don't grieve or don't have no emotions on certain things and don't care because always he used to say, "I don't know. I don't care." Something has to be going on in his head for him not to mourn so I feel like something was wrong with him. [P]

Both parents and youth were more apt to describe problems in behavioral terms such as "acting out" and "anger management" rather than in terms of diagnostic labels used by clinicians. For example, one youth, whose mother indicated had been diagnosed with ADHD, and in her opinion, had some as-yet undiagnosed anxiety issues, stated, "I have anger management. They haven't been able to put anything on me" [Y]. This young man had been hospitalized twice and feared ending up locked in a psychiatric hospital forever. He acknowledged that he needed help for his problems "before it is too late," but did not define those problems in mental health terms.

According to the mother of a girl who had a prior psychiatric hospitalization and several violent offenses, her daughter was "just acting out," but did not have a mental health problem. The mother believed her daughter needed help and was committed to making sure her daughter got whatever counseling or other services she needed, but she did not define the problem

as a mental health problem. The daughter, who felt counseling was helpful, also rejected the idea that she had a mental illness: "They told me I was depressed, and I don't believe I'm depressed. I am happy as I can get. I'm not depressed. I'm just. . . . Sometimes I get emotional, and that's supposed to happen. I'm not depressed" [Y]. Similarly, a young man who accepted his ADHD diagnosis did not agree that he also had depression: "I think that's some bullshit!" [Y]. Two parent/youth pairs were in agreement that the issue was family problems, not a specific mental health problem. One youth expressed this clearly: "And it's not like, it's because I have a mental problem or anything like that, it's just 'cause like to help our family I guess" [Y].

Themes related to cause emerged spontaneously in several parent interviews. This seemed like an important component of how they defined the problem; thus, we asked the rest of the parents and the youth, "What do you think caused these problems?" All of the parents who indicated their child had ADHD acknowledged a biological or genetic causal component; none of the youth did. Rather than biological/genetic explanations, many youth and parents believed the youths' difficulties were a reaction to family problems. These families had experienced multiple stressors, including residential instability and parental substance use:

Well, but his father is locked up right now . . . we were drug addicts. . . . Like I am sure that had something to do with it. . . . Well, we've had like some traumatic incidences in our life. We moved a lot. They were always going to different schools. [P]

Like when I moved. . . . See, I'm not from Illinois. I'm from [another state], and I moved here like everything started going downhill. It seemed like everything was bad for me when I moved to the city. It's like we lost our apartment [when mom was using drugs]. Everything just was bad. [Y]

Several youth had experienced significant traumas:

It started when his mother left him. She was on drugs and she left him and he was basically just out there for his self. . . . While his mother was in another city, she was killed. They found her along the Mississippi shore. He didn't cry nor did he show any signs of that he lost his mother. [P]

Well, I had a situation a couple years back with my step-mother's brother . . . like and that's a sexual abuse type of situation and my probation officer

thinks I have a lot of rage problems. Just like basically right after that . . . 'cause I couldn't say nothing about what was happening so for so long keeping it inside, keeping it inside I just got used to just leaving everything inside not letting anything come out in open and just ignoring the facts and just leaving it alone leaving it as a problem instead of a solution. Basically that's it. [Y]

Two of the youth, both African American young men from high-crime neighborhoods, indicated that the cause of the problem was just that they did not behave as they should. One indicated the cause of his problems was "probably because I don't respect my situation." The other attributed the problem to "being hyper, don't got nothing else to do . . . following my friends."

Problem Recognition and Decision to Seek Services

There was variation among the families interviewed in terms of the point that the youth's mental health/behavioral problem was recognized and the decision to seek mental health services was made. Most of the parents recognized that the youth was having some type of problem prior to the current juvenile justice system involvement; however, they did not necessarily consider the problem a mental health issue or turn readily to mental health services for help.

The youth with ADHD were most likely to have been identified either by the parent or the school prior to justice system involvement, and most likely to have received continuous services. The experiences of White and African American families in our sample differed. White parents reported resistance from the school system to recognize and address their child's needs, so they went outside of the school to seek treatment:

We suspected when he was in kindergarten, we suspected he had some problems. He would jump on people's backs. He was very hyper. He would not pay attention. He was bouncing off walls. We couldn't figure it out. We finally . . . you know we asked the teachers and of course they couldn't tell us anything because they would be liable so we basically diagnosed it ourselves. We figured out he had ADHD. We took him to a psychiatrist and they said, "Yes, he does have ADHD. Very hyper child." [P]

The African American youth were more often identified by other systems such as schools or child welfare.

One mother, whose son was placed in special education classes, indicated that school personnel had diagnosed her son with ADHD but did not tell her. She found out 3 years later at a staffing (a meeting of school personnel to discuss a particular student) by paging through his file:

I probably could have gotten him help earlier . . . while he was still young. Then he could have gotten used to taking medicines at 10 instead of trying to give them to him when he is a teenager and even more rebellious . . . I wish I would have known earlier. [P]

Several parents reported that they recognized their child was having difficulties and sought mental health services prior to the juvenile justice system involvement, but the youth and/or the parent chose to discontinue treatment because of dissatisfaction with the services. One mother had her daughter admitted to a psychiatric unit, but regretted the decision:

She went in there and tore her room up, so I called the police, and the police told me about [hospital]. [Hospital] ain't shit, the baby jail. If I'd a known that, I would've never called them. I would've never called them. [P]

This woman's daughter was released from the hospital with a prescription for antidepressant medication. After taking it for 2 days, she decided it did not help, so she stopped:

I had to take their medicine after I got out of the hospital, I took the medicine for two days, two days and I stopped taking it because it wasn't helping me. It wasn't doing nothing. It wasn't . . . I don't even know what it was supposed to do for me actually, so the medicine, they didn't have nothing to say about it. [Y]

Another mother described taking her daughter (who identified with both genders) to counseling after discovering she had been molested by a family member. The youth did not find counseling helpful or relevant, so she stopped going. "She said the lady wasn't, wasn't responding, wasn't talking to her, she was just sitting there listening. So [her daughter] thought it wasn't useful, it wasn't worth going" [P].

For 3 of the youth, the first contact with mental health services occurred during or as a result of their juvenile justice system involvement. For 2, it was initiated by the parent. One young man's grandmother shared her concerns about him with his probation officer:

I feel like something is wrong so I talked with his probation officer and they felt the same way after I told them why I felt like that and they took it from there. . . . That's how he became on medication because he was evaluated. [P]

Another youth's mother had wanted her son to go to counseling for some time, so she used the system for leverage and asked the judge to order it: "Well when we went to court, I had requested that, that my sons get family counseling because there's a lot of little, their, their dad's not really in their life" [P].

Only one parent indicated that the mental health/behavioral problem was initially recognized by a juvenile justice system actor. This mother was struggling with her own substance abuse and criminal justice system involvement:

And then [agency] got involved. I'm not sure how. We were just in court and the probation officer said, "Oh, I want to introduce you to someone who could be beneficial to your family," and that's how [agency] became involved and they were beneficial because my son attends [agency] and he goes every week and the things that I can't teach. [P]

Treatment Participation

The decision-making process is not over once the decision to seek and enter mental health treatment is made. To better understand decisions to follow treatment recommendations and participate, we asked youth and parents what they thought about getting mental health treatment, if the youth were participating as recommended (or required by the court), and who supported/encouraged the youth to participate.

Parents and youth were asked what they thought about getting mental health treatment. Just as many did not define the problem as a mental health problem, they did not consider the services they had received and were receiving to be mental health services. Several of the youth indicated they had never had mental health services, but had been to counseling, taken medication, and been hospitalized. Thus, we asked about the services they were getting through the MHJJ program, such as counseling and medication. Different themes emerged in the parents' and youths' responses. Common among the parents' responses was the sentiment that if one needs help, one should get it:

He needs it . . . if he needs it then he should have it. I don't think any more of the mental health than I do

anything for . . . what a medical, medical doctor for if you've got a physical problem. If you need help then you need help and you should seek the doctor. It is unfortunate that he just he . . . needs to see a mental [health] professional. [P]

Another parent indicated a similar perspective:

If you got it, you got it, you know and so what you try to do is try to get to the point and get you some help because mental health ain't nothing nice you know, and so get some help and try to get the right kind of medicine so you can come back. [P]

Several parents distanced getting counseling from having a mental illness, indicating that counseling was good, and it did not mean one "[was] mentally ill."

The youth were more concrete in their thoughts about getting mental health treatment. They generally were not happy that they had to get mental health services, but most saw some value or benefit. Several of the youth recognized that they needed treatment and felt it would help them have a better life:

Just too many people and too many questions; too many dates I got to show up here. . . . It's helping me even though I still got to go through it because that's what I think was best for me. [Y]

I don't want it, but then I want it because, I am like half and half. I need help, and then I just want to be free and go around with my friends, not free, but, just . . . enjoy my childhood. [Y]

Others indicated that getting mental health services was "okay," because it kept them out of trouble. For some, this meant services helped them avoid situations that would get them in trouble. For others, it was just what they had to do to remain in good standing with the court.

All but one of the youth indicated they were participating in counseling and related services at least some of the time. Those who participated more sporadically indicated that sometimes they didn't feel like going, or they had better things to do like hanging out with friends. These youth also seemed to find services less helpful and relevant than the youth who reported greater participation. Several of these youth also seemed to identify more with their juvenile justice system involvement and were not as concerned about it harming their reputation. In some cases it was quite the opposite: If getting in trouble with the law was normal, then it was not a problem for which one needed to get mental health services. Youth who

did not report identifying with delinquent peers were more likely to indicate that mental health services (or counseling, group, medication, and so forth) would help them stay out of trouble and get their life back on track. This was true of first-time offenders and those with more lengthy criminal histories.

For all of the youth, their mother was the primary person who supported and pushed them to participate in treatment. This might have been different if our sample included youth who were wards of the state:

She's doing the best she can. She making sure I take them on time. I do what I supposed to do, not get in trouble. She thinks it's okay. [Y]

My mom, she's . . . it's hard to explain her. She just don't want nothing to happen to me. She's emotional and sad. [Y]

Several youth indicated their siblings, fathers, and grandparents also encouraged them to participate. One youth referred to his sisters' encouragement:

They say, "Boy, you better go do this. You got to go to that place. You know you got to see that PO [probation officer]. You know you got to go to counseling." They be on my back. I'd be getting mad at that, too, but they care because they be on me. [Y]

One young man was the only one who indicated a family member discouraged him from adhering to part of his treatment. His father did not like him taking medication: "Well, he don't like me taking pills but I think it's a good thing because it's helping me out but he don't want me to take them anyway, but he okay" [Y].

Although most of the youth indicated that they did not share their mental health service involvement with their peers, 2 youth indicated that some of their friends encouraged them to participate in treatment:

But my friends push me more . . . they tell me, you know what I am saying, to continue my, you know, counseling and whatever they tell me to do because the faster I do as exactly what they tell me, the faster I get off probation . . . but most of my friends are like all that's BS, you ain't got to do all that. [Y]

This youth indicated that her ex-girlfriend encouraged her to participate because it could help her. Another youth also indicated "his girls" push him to participate.

An important source of encouragement and support for many of the youth and their mothers was the probation officer:

She has been his PO [probation officer] for a while . . . she was really concerned about his well-being and what he was getting his self in. She went out on a limb to try to help him so I think she deserve credit, too. [P]

Probation, I care what his probation officer thinks because she's been very good . . . a very good support for me as well as for him. [P]

Several youth also reported that their probation officer was helpful and supportive: "She helped me get in activities and stuff. Right now, she's trying to help me get into the Art Institute . . . and she helped me get back in this other school starting September, so she care a lot too" [Y].

Subjective Norms About Mental Illness and Treatment

Guided by the Network Episode of Model of treatment access and participation, we were particularly interested in the subjective norms about mental illness and mental health treatment among the social networks that the youth and their parents were involved in. It quickly became clear that many of the families' social networks were quite limited. Several families did not have extended family in the area, or if they did, they were estranged. A couple of the families had moved a lot, and thus had not developed networks within their communities. Only two families reported active involvement in faith communities. Two mothers indicated that because of everything they had been through with their child, they were not able to maintain friendships or dating relationships. These families were very isolated. One social network that was noticeably not mentioned as often as we expected was the school system. Several parents reported frustration about having to fight with schools to have their child's needs met. Only one parent and one youth indicated the school provided any useful support. It might be that many of the youth had moved around and changed schools too often to have developed a strong social network that included the school system. It is also likely that some schools are not doing a good job meeting the needs of youth with mental health problems.

Keeping in mind the constrained social networks of the families we spoke with, we explored their perceptions of the subjective norms about mental illness and mental health services among the social networks they were embedded in. We started out with their perceptions

of what the public in general thinks about mental illness and treatment before probing for their concerns about members of their personal social networks.

Several parents and youth volunteered their perceptions of mental illness stigma without prompting. We directly asked the others what they thought other people in general think about people with mental illness. All were acutely aware of negative perceptions of mental illness. Three themes emerged from the parents' responses: Mental illness is shameful, people with mental illness are "psycho," and mental illness is just an excuse for bad behavior. One parent said, "Some people think that it's embarrassing, the shame. . . . You know, they might label them as a person that went crazy or something like that" [P]. Other parents echoed that people think mental illness means being "crazy" or "psycho":

Oh, I think they think your kids are psycho. I think mental health has a very bad stigma, and I think that if you say you are going to family counseling, or if you say your kid is in counseling, well what's wrong with him? [P]

Three parents of youth diagnosed with ADHD stated that other people think mental illness is just an excuse for bad behavior and bad parenting. One of these parents said, "[People will say], 'Well that is just an excuse. You are just using that. No, he is just a bad kid.' . . . Those parents just don't care about their kid" [P]. The youth perceived that others think mental illness means that someone is mentally retarded or "psycho":

That they're crazy. . . . That they're retarded or something . . . there is something wrong with them . . . like they are dumb or something. [Y]

They think that they are crazy people and they don't deserve a chance at changing . . . um . . . they are not the people they want to hang around with. . . . They think they are like psycho, like they are going to do something like hurt them or cut ourselves or do something like that. [Y]

One youth noted that there is some benefit in people thinking one is crazy, but he would prefer people not think that about him: "I mean you know it's respect. Yeah, they wouldn't mess with you; they'd be scared of you. Nah, I wouldn't want anyone to think I'm crazy" [Y].

Another youth offered a rather sophisticated perspective, suggesting that some people are sympathetic

and would want to help a person with mental illness, whereas others would not like someone just because they had a mental illness. He also pointed to the media as a source of stigma about mental illness: “. . . and also how the media portrays people. A lot of times they kind of make them seem like not as good and stuff like that, so that’s where I’m kind of getting at” [Y].

Participants were probed about what they thought others in their social networks think about mental health problems and mental health services, and more specifically, if they were concerned about what others think. Concerns generally related to extended family and peer groups. Somewhat different themes emerged from the parents and youth. Several parents stated they did not care what other people thought:

Oh, please! Who gives a shit if they know. What they going to do for her? What is they going to do for her, okay? If they think they can, you know what I’m saying, help her, yes. I’d want them to know. We live it. This is it. [P]

I don’t care what people think. I really don’t care. I mean if it’s a point of asking for help and letting people know than keeping it to myself and having the same issues, I would rather tell. [P]

This did not appear to be a defensive or angry response, but rather a realistic acknowledgement that some people would judge them, but the only way to get the help and support they needed was to reach out for it. None of the youth shared this “I-don’t-care” attitude. Several indicated they did not tell other people about getting mental health services because it “ain’t no one’s business” [Y].

Both parents and youth expressed some concerns about what family members thought. Several mothers indicated that their relatives felt they were overreacting in getting their child into mental health services:

Well I know my parents thought I was making more of it than it was and that he’ll grow out of it or he’ll just be caught up in the system and he’ll just go to jail. . . . They think [youth] is just like his father. [P]

They were also concerned their families would think less of them as parents and less of their children:

Because he’ll [mother’s brother] put her down you know, make comments and tell everyone on his rich side of the family that, you know, what kind of

family, what kind of daughter I got. . . . He would say I was a bad parent. [P]

Several youth were also concerned that family members would think less of them. One young man said, “I don’t want them to know that I am like a screw-up” [Y].

Most of the youth did not tell their peers about their mental health service involvement, and expressed concerns about people not wanting to associate with them, starting rumors and disrespecting them:

There will always be that thing in you and then people will see you as an outcast. Looking like an outcast, be alone and a lot of other people laughing and you’re all sad and stuff. That is why I’ve never told anybody besides my family and people have found out. [Y]

Several youth were concerned that if people talked about them, they would have to respond. For example, one youth said, “And I feel like I am going to have to retaliate if they disrespect me on that” [Y].

One youth and his mother indicated they were not concerned about what other people thought, because getting counseling wasn’t that bad, and “it’s not because I have a mental problem or anything” [Y]. The youth, however, preferred not to discuss it with people, and to some extent, the stigma attached to counseling made him “not want to go to counseling a little more” [Y].

What Does a Mental Health Problem Mean for the Future?

Parents acknowledged that their children would need extra help in the future, but most were optimistic that the youth would be okay:

I think it means he is going to have a harder life, yeah . . . I think he is going to need a lot of help in preparing him for the future. [P]

And the other thing, the mental health thing, well hey, big deal, okay. She got a few blocks in her brain. We’re going to set some traps and get rid of it or whatever. We going to work with her you know. I love my daughter. [P]

He probably turn out alright but he probably, he might not have to take them [medication] for the rest of his life, but he probably have to take them til he can control himself. [P]

Parents noted that juvenile justice system involvement improved their child's prospects for the future by providing access to services and giving the parent some leverage to get the child to behave and participate in services:

I think without the involvement of the court system he would not have as promising a future. It's amazing what someone on probation can, how many things you can get access to because your kid is on probation. [P]

So being in the system with her, I think in a way that the system saved my daughter because giving her these different outlets, programs to do, give her a chance to do other things instead of just . . . because the system do have a lot of things going on for kids, and it seems like you got to get in trouble in order to get it, okay, so here we go. [P]

Parents who had wanted their children to participate in counseling or other mental health services prior to their juvenile justice involvement were grateful for the leverage. One mother, who asked the court to order counseling, stated, "They [her two sons] got five years of probation, and now I have some leverage" [P].

Several of the youth were unable to respond to and asked to skip the question about what their mental health issues meant for their future. The few who were able to answer were less hopeful than their parents. One young man expressed fear:

I mean I have problems and I have to fix 'em before it gets too late, that's what I think. And like this when I am older, on probation forever, and I won't do anything stupid. . . . 'Cause I have seen like movies like where people that went into the hospital were crazy and, not crazy, had problems and couldn't be helped and I thought that was going to be me when I was older. I was scared. [Y]

Another youth's response appeared to be related to his mental health and criminal justice issues: "I don't think I'm going to get nowhere in life basically" [Y]. He indicated that his neighborhood had the highest incarceration rate in Chicago, and he expected he would end up in prison like everyone else he knew. In contrast, all of the youth were able to talk about what their criminal justice system involvement meant for their futures. Their main concern was that their record would interfere with them getting jobs, or for one youth, getting into college. However, many of these

youth (and their parents) seemed confident that their juvenile record would be sealed or expunged.

Discussion

Most of the participants in this study did acknowledge some type of problem that led the youth to become involved in mental health services. However, they generally did not define this problem in mental illness terms. The lack of acknowledgement of having been diagnosed with a mental illness, coupled with significant treatment histories for some of the youth, was not altogether surprising. An earlier study of how youth with disruptive behaviors entered treatment similarly found that problem labeling did not necessarily precede service entry (Arcia, Fernandez, Jaquez, Castillo, & Ruiz, 2004). This would be concerning if it prevented the youth from benefiting from mental health services, but this was not the case in either that study or the present study. Rather, defining the problem in some other way (e.g., as behavior issues, family problems) might have allowed the youth to participate while shielding them from at least some of the stigma associated with mental illness. Unfortunately, it did not hold true for the few youth who felt more comfortable with the delinquent label and found services in general less relevant.

On the surface, it might appear that because many of the participants did not identify the problem in mental illness terms or view the services they were involved in as mental health services, the negative subjective norms and meanings they associated with mental illness were not personally relevant. However, by listening to their accounts of how they "muddled through" the illness career and the role of others in this process, it became clear that mental illness was a frightening thing and could mean they were failures (youth or parents), not worthy of others' friendship, and not going anywhere with their lives. Parents were worried that their children's futures would be difficult. Fortunately, most found ways to distance themselves from these meanings so they could obtain services and work toward a better (or less frightening) future.

While managing to avoid the stigma of mental illness by defining the problem on their own terms, these families did not completely escape its impact. Our findings highlight a sense of isolation and lack of support. Some of these families might have distanced themselves from their natural social networks to avoid

disapproval and rejection, because they were acutely aware of negative subjective norms about mental illness and mental health services. Others hid their mental health issues, thus eliminating the possibility of support and encouragement. A few youth clung to their delinquent identity, thus gaining support from their peers, but relegating support for mental health issues to “irrelevant” status.

For all of the youth in the study, their then-current participation in mental health services was part of their probation requirements. However, many of the youth had prior treatment episodes that had been initiated by their parents or another social service entity. The dynamic nature of the IC model makes it extremely useful for considering how these youth and their parents recognized a problem, sought services, and made decisions about treatment participation, not necessarily in that order (Pescosolido & Boyer, 1999). Our findings are consistent with the idea of “muddling through” (Pescosolido et al., 1998). Furthermore, combining IC with NEM allowed us to elaborate on our consideration of the role of social norms beyond the TRA conceptualization (Fishbein & Azjen, 1981) to examine the relative influence of various social networks over time (Pescosolido & Boyer, 1999). In our study, components of participants’ social networks facilitated and/or created barriers to problem recognition, service entry, and service participation. Several parents, recognizing that their children needed help, had to distance themselves from family networks, fight school networks, and rely on criminal justice networks to get adequate services. Thus, other factors (e.g., symptom severity, parent burden) at times might have overridden the influence of many social networks in the decision to seek services. Youth reported some personal networks supportive of them seeking and participating in services, but also hid their service involvement from other social networks to shield themselves from negative responses.

The services they received as a result of the youth’s criminal justice involvement were important supports for the parents and most of the youth. Caring, nonjudgmental, and supportive probation officers and clinicians seemed to make an important difference. Many of the families had accessed services prior to the current juvenile justice involvement, but the services were either not adequate or were unresponsive or unsatisfactory. An adaptation of NEM, the Gateway Provider Model (Stiffman, Pescosolido, & Cabassa, 2004), takes into account the importance of key members of youths’ social networks that might identify problems and

direct the youth to services. These “gateway providers” influence the initiation and trajectory of treatment, and their knowledge of available resources is a strong predictor of service provision. The MHJJ program clinicians served as critical gateway providers (Stiffman et al., 2004), giving families access to a broader range of more responsive services. The fact that the youth had to get in trouble to access these services is a sad reality of underfunded child mental health and educational systems.

Limitations

The data we obtained from the in-depth interviews were very rich and helped us further our understanding of how juvenile justice system-involved youth with mental health problems and their families make sense of and decisions about mental health service participation. There was variation among participants in the study. However, our sample might not represent the broader range of experience of this population. Given our recruitment procedures, our sample was biased toward youth who were participating in MHJJ linkage services, were willing to be interviewed, and had a parent who was willing to participate. Youth who regularly missed appointments with MHJJ staff were less likely to be approached for the study. Additionally, parents and youth who were less engaged in services might also have been less willing to be contacted by the researchers. Finally, the population we recruited from excluded youth who were wards of the state, and likely had different social networks than youth who were living in more permanent arrangements.

Another limitation is that we met with each participant only once rather than developing a relationship with them over a period of time in which they could feel more comfortable sharing their perspectives and experiences with us and that allowed us to examine important themes over time. We did not have the resources to do so in this study. However, what we have learned from the current study will inform our future research on factors influencing youths’ treatment participation over time and their subsequent psychosocial and criminal justice outcomes.

Conclusion

Negative subjective norms about mental illness and mental health services abound in the general public and in the social networks of youth/families that

are dealing with mental health issues and juvenile justice system involvement. The families in this study had very constrained social networks and often defined the youths' problems in non-mental health terms, perhaps in an attempt to shield themselves from stigma. For many, juvenile justice system involvement opened up access to a broader array of resources and support than had been previously available to them.

In terms of future research, our findings suggest the need to examine the influence of problem definition, subjective norms, and social networks on treatment participation and outcomes over time in a more representative sample of juvenile justice system-involved youth with mental health problems. A larger, more representative sample would allow us to test specific hypotheses and examine differences across a number of variables.

In terms of implications for practice, our findings suggest several points of intervention that might improve service access and utilization for youth with mental health problems, prior to or during juvenile justice system involvement. First, existing efforts to understand and reduce mental illness stigma, particularly those aimed at youth, need to be redoubled. Several studies have found that adults who have or are at risk for mental illness who have stigmatizing attitudes about mental illness (Leaf, Bruce, Tischler, & Holzer, 1987), or perceive that others do (Link, Cullen, Struening, Shrout, & Dohrenwend, 1989), are less likely to seek or fully participate in mental health treatment. A recent study of the impact of stigma on care seeking among a national probability sample of adolescents had similar findings (Penn et al., 2005). Adolescents who endorsed more negative attitudes about mental illness were less likely to seek treatment when needed. Of interest, negative attitudes were less relevant when adolescents believed treatment would be effective. Thus, efforts to reduce stigma and increase knowledge about treatment effectiveness might be helpful. It is also critical that when youth do seek services, they are provided in a way that is experienced as responsive and effective.

Second, providers working with youth and families affected by mental illness should focus efforts on supporting families in developing or reconnecting with healthy social networks (U.S. Public Health Service, 2000). The protective benefits of social support on mental health are well established (see Thoits, 1995; Turner, 1999). Unfortunately, the benefits of social support might be attenuated for youth in disadvantaged areas (Wight, Botticello, &

Aneshensel, 2006). Thus, along with long-term efforts to improve social conditions in disadvantaged areas, in the short term, providers could "aim to foster, in essence, a protective internal environment for adolescents faced with a threatening external environment" (Wight et al., 2006, p. 124).

Third, from a systems perspective, we cannot afford to limit access to a comprehensive array of quality services to youth who are lucky enough to get into programs such as the MHJJ Initiative as a result of their juvenile justice system involvement. Rather, the child mental health system must provide a broad range of services to families before youth enter the juvenile justice system. This, of course, would require significant shifts in resources.

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