



Caregivers Speak about the Cultural Appropriateness of Services for Children with Emotional and Behavioral Disabilities



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Caregivers speak. . .

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- ... more providers need to understand that we are capable parents of unique children.
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- ... providers need to work with caregivers more flexibly around issues of discipline.
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WHAT THE STUDY IS ABOUT AND WHY IT MATTERS

This study is about caregivers' views on the cultural appropriateness of services for their children with severe emotional and behavioral disabilities. This first section of the report describes why this topic is important.

What is culture?

Culture is a set of ideas, behaviors, beliefs and values that are shared by a group of people. Culture shapes our lives in many ways. In particular, culture is an important source of information about what is good and bad, what is right and wrong, and what is valuable and what is not.

Children learn cultural values and beliefs from the people around them as they grow up—family members, community members, people from the same region or the same country of origin, people with a similar heritage, people who speak the same language. A person can also share cultural values with formal groups and institutions like churches or schools, or with informal groups such as groups of friends, or groups of people who have shared similar experiences.

Cultural values play a role in the way we express ourselves, what we strive for in life, whom we will trust or listen to as an authority, and how we raise our children. If we do not understand the ways in which other people express themselves, we can't really "hear" what they are saying. If we don't understand another person's goals, we often can't make sense of their behavior. Being sensitive to cultural values is clearly very important in any situation in which we are working collaboratively with other people, since people working together need



to communicate well with each other in order to come to an agreement about which goals are worth pursuing.

Why do services need to be culturally appropriate?

Culture matters in the treatment of children and adolescents¹ with emotional or behavioral disabilities because culture can influence many aspects of assessment and treatment. If social workers, therapists, teachers, or other service providers are not sensitive to

or respectful of a child's culture, they may make wrong assumptions about what is causing a problem, how severe the problem is, the best way to help the child, and even what the goals of treatment should be. Many times, treatment will depend on a child's developing a trusting relationship with a service provider. Obviously, this sort of relationship will not develop if a child feels that a service provider is culturally insensitive, or feels that the provider's behavior is based on stereotypes and/or racist, sexist or other prejudicial attitudes.

In the case of children with emotional or behavioral disabilities, service providers' ability to understand and show respect for the caregiver's values is also essential. Caregivers play important roles

¹ In order to keep our sentences from becoming too confusing, we use "children" instead of "children and adolescents" from here on.

in planning and treatment. A caregiver is often the best source of information about a child's behavior, or the extent to which a particular aspect of treatment is helpful. Ideally, caregivers are partners with service providers in developing the treatment plan, and caregivers often have many roles and responsibilities within that plan. It is unlikely that a productive partnership can develop if a caregiver feels that the provider is insensitive to, or disrespectful of the caregiver's beliefs and values.

When caregivers and children feel that their cultural values and beliefs are being respected and supported by service providers, we can say that services are **culturally appropriate**.

How do we know that services are not culturally appropriate?

So far, much of the research in this area² has focused on the question of whether ethnic and racial minority children with emotional or behavioral disabilities tend to receive different diagnoses, to be referred to different types of programs or treatments, or to have different outcomes for treatment than do children from European American cultures. Overall, this line of research has provided evidence of a number of different ways in which European American children do tend to fare better in the mental health system than do children from ethnic or racial minorities—particularly African American and Native American children.

For example, compared to European American children with similar disabilities:

- African American students with serious emotional or behavioral disabilities are more likely to be placed in restrictive school settings;

²This research and the discussion here focuses on the situation in the United States.



- African American adolescents with emotional or behavioral disabilities are more likely to end up in the juvenile justice system rather than a treatment center; and
- Native American children with serious emotional or behavioral disabilities are more likely to be geographically and legally removed from home (and tribe).

There are, of course, other ways in which services can be culturally inappropriate. Children and caregivers can experience misunderstanding and prejudice, and consequently receive services that are inappropriate or ineffective, when providers fail to understand behavior and values derived from religious affiliation, being poor or disabled, or belonging to other types of social groups.

What was the goal of this study?

Existing research provides strong evidence of problems in the mental health services provided to chil-

dren from minority cultures. What this research does not tell us is exactly what goes wrong, or what goes right, when minority children and their caregivers interact with service providers. There is little research addressing other ways in which services can fail to be culturally appropriate.

The study presented here was an effort to begin filling in this gap in our knowledge. We asked caregivers to describe, in their own words, specific occasions when they were particularly satisfied or dissatisfied with the extent to which service providers respected their cultural beliefs and values. We used a broad definition of “culture” so that caregivers would feel free to talk not just about their ethnic or community values, but also about values which stem from belonging to a religion or other social group.

This study uses information gained during interviews with 286 caregivers to address the following questions:

- How satisfied were caregivers with the cultural appropriateness of services?

- When caregivers speak about service providers’ respect—or lack of respect—for cultural beliefs and values, what sorts of satisfactions or dissatisfactions do they mention?
- Do caregivers from different ethnic backgrounds, or caregivers with different levels of education or income, tend to experience different sorts of satisfactions and dissatisfactions in this area?
- To what extent is satisfaction with the cultural appropriateness of services related to overall satisfaction with services?

The families who participated in this study were from diverse educational and economic backgrounds. Although most of the participants were European Americans, almost a quarter were African Americans and about a tenth were Native Americans. Each family in the study had a child between the ages of 5 and 18 with a severe emotional or behavioral disability. For details on the participants in the study, see the Background Information section at the end of this report.



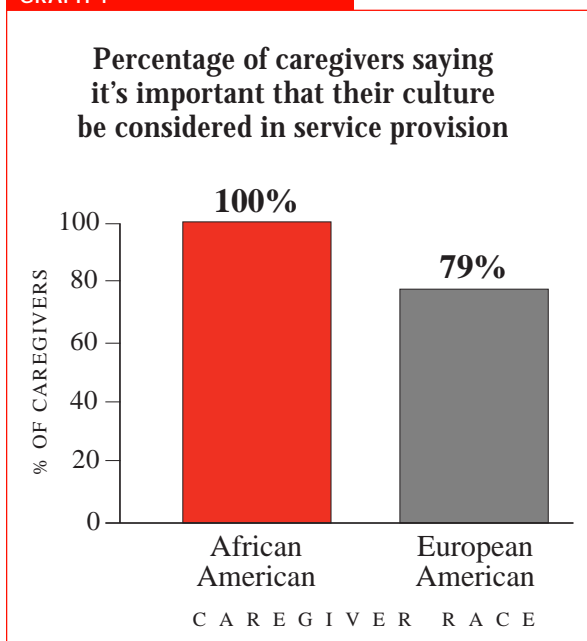
WHAT WE FOUND OUT

Do caregivers think it's important that services are culturally appropriate?

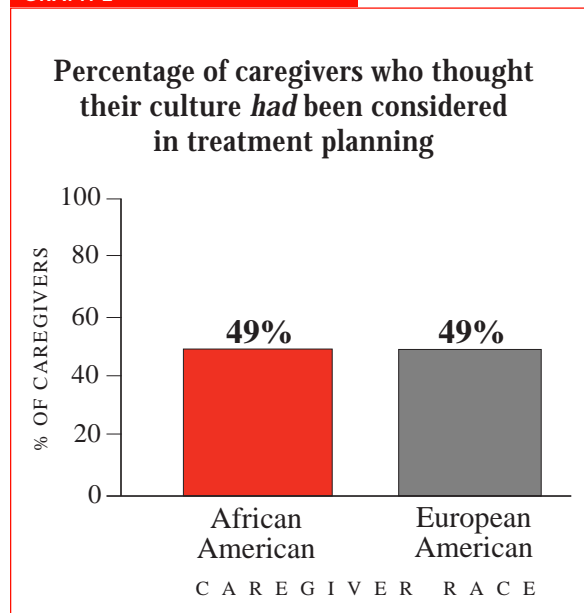
About eighty percent of family caregivers felt it was important that their culture be considered by their child's service providers. Not surprisingly, caregivers of African American children were more likely to say that culture was important, with 100% placing at least some importance on the consideration of culture. The rate among caregivers to European American children was still quite high at 79% (see graph 1). The numbers of Native Americans or other minorities in the study were not sufficient to make statistically valid statements about their responses as groups; however, in later sections of this report, in which caregivers' own words are quoted, examples from diverse groups of caregivers are offered.

There were no significant differences between caregivers from different economic or educational backgrounds on this question.

GRAPH 1



GRAPH 2



Do caregivers think that their culture was respected by service providers?

When asked whether or not their culture had been considered when the service plan was developed, European American and African American caregivers did not differ in the percentages saying “yes” — both rates were very close to 49% (see graph 2). There were also no differences between caregivers from different educational or economic backgrounds on this question.

The answers to this question seem to say that African American caregivers and European American caregivers are equally satisfied with the cultural appropriateness of services. But, what the answers to these types of “multiple choice” questions *cannot* tell us is exactly what caregivers are thinking about when they respond.

What did caregivers say when they used their own words to talk about the ways that services were or were not culturally appropriate?

When caregivers were allowed to use their own words to describe situations when they felt that their culture was or was not respected by service providers, their answers fell into several distinct categories.

Community/ethnic values. Caregivers talked about satisfactions and dissatisfactions with how well service providers understood or respected their community, racial, or ethnic culture. African American caregivers were much more likely than European American caregivers to give examples of both satisfactions and dissatisfactions in this area (see graph 3). While caregivers were more likely to describe dissatisfactions than satisfactions, a large percentage (particularly among African American caregivers) did describe ways in which they were pleased with how providers accommodated their ethnic or community values.

Within the more general category of community, racial, or ethnic values, caregivers were most concerned with the availability of programs with a fo-



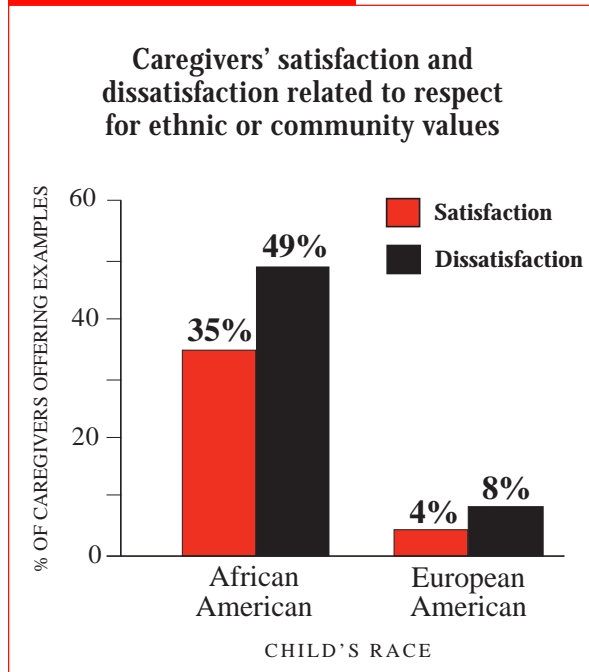
cus on ethnicity or service providers who shared the child's racial or ethnic background. **Almost a third** of African American caregivers described specific ways in which they were dissatisfied with the availability or provision of these kinds of services (see graph 4). This was also the most frequently cited dissatisfaction among Native American caregivers.

On the other hand, almost a quarter of caregivers to African American children described specific ways in which they were pleased with the provision of these kinds of services. Here are some examples of caregivers' comments regarding the availability of these kinds of programs.

In describing a dissatisfaction, one African-American mother said:

[Service providers] see all kids as the same, but I see it different. I see each race in its own mode. There should be more diverse psychologists and service providers to meet those races' needs. Personally, I see it as a matter of gut feelings-black psychologists can better help black children.

GRAPH 3



An Asian mother was satisfied with services, saying:

Her therapist was also of mixed Asian background, therefore they have similarities in backgrounds. This therapist knows how my daughter is feeling because she has been there.

And another African-American mother described a satisfaction:

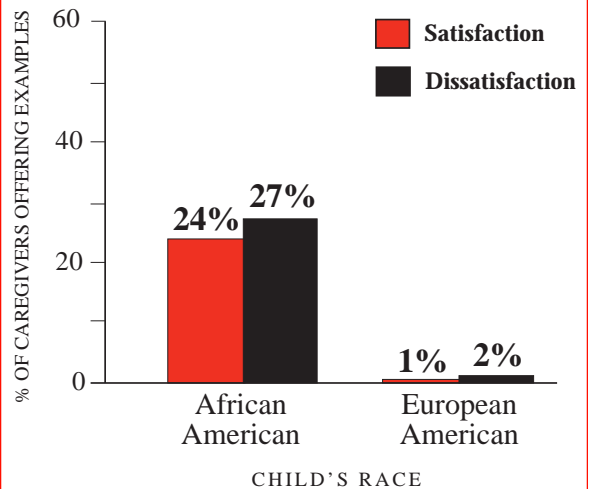
They were very sensitive to the fact that he was black. The XYZ was the only residential for blacks. They offered history for African Americans so kids could be more aware of their culture.

While many caregivers were pleased with programs targeted at specific racial or ethnic groups, a large number of African American caregivers expressed



GRAPH 4

Caregivers' satisfaction and dissatisfaction related to the availability of targeted programs



a nearly opposite opinion. These caregivers felt that it was important that services be “color blind”, and that minority culture children should receive exactly the same treatment as anyone else. They expressed satisfaction that services they received met this criterion (*see graph 5*). An African American mother said, as part of a description of a satisfaction with services:

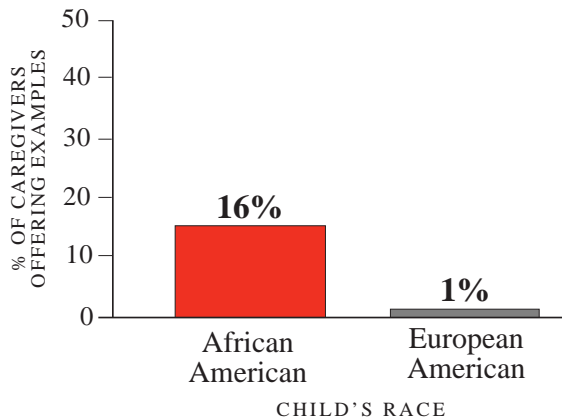
I'm not into culture. I believe everyone is the same. Our only difference is the skin. I don't believe anyone should be treated differently. I don't want Afrocentric [services] I just want good [services].

African American caregivers were frequently dissatisfied because service providers failed to understand that norms of behavior could differ between communities (*see graph 6*).

Some things which the school identified as behavior problems, I

GRAPH 5

Caregivers' satisfaction related to the provision of "color-blind" services



didn't. For example, [child] was braiding classmates' hair and the teacher said this was inappropriate. Blacks are more touchy and I thought it was OK. She is also loud and boisterous in the hall, and that is normal for black culture but not at her white school.

He was in a majority white school. Some of his behavior would not have caused as many problems in an urban black school as they did in his school. The child stands out more and gets picked out more due to his behavior and being black.

African American caregivers— and a small percentage of European American caregivers as well— also described examples of occasions when they had encountered racism, hostility, prejudice or bias from service providers (see graph 7).

Absolutely there was prejudice in many cases of their treatment of

me and my kids. White counselors don't have any interest in seeing a black child succeed.

By my being an Indian, a lot of the time they just did not take me seriously. What I had to say was not acknowledged.

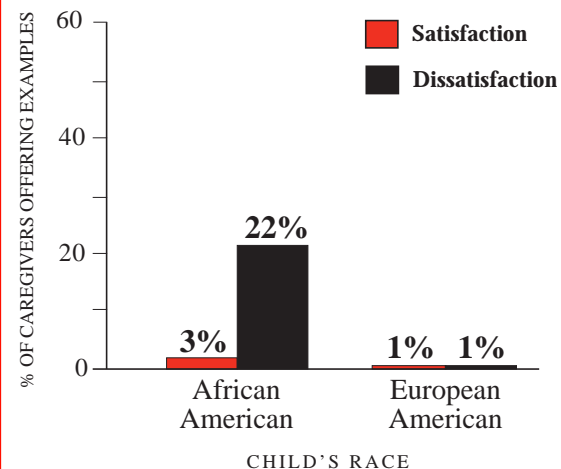
They were unfair on a racial problem. The school did not do a darned thing when my grandchild was attacked by black kids because she is white.

Some caregivers, like this father, talked about bias in the system as a whole:

The schools are set up to rear non-color middle class Americans. Everything-math questions, multiple choice questions-it's all geared toward white America. In particular, minority race kids are

GRAPH 6

Caregivers' satisfaction and dissatisfaction related to the understanding of community norms

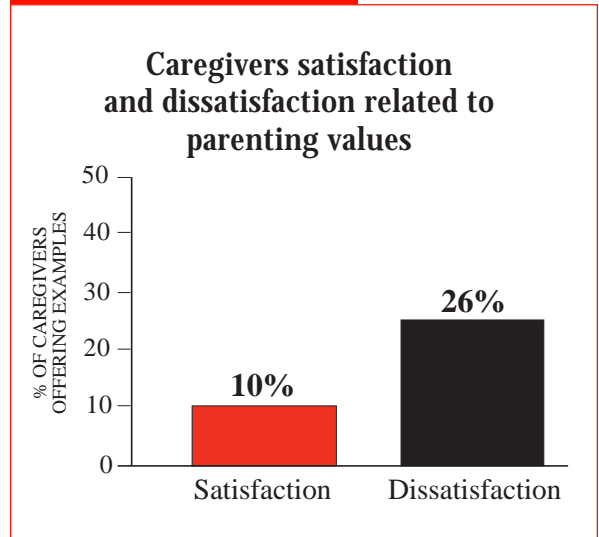


more likely to be classified as emotionally disturbed. Absolutely, the fact that [child] is bigger, physically developed, and black worked against her and got her into special ed. because she stood out. She felt different and it influenced her behavior.

Parenting values. Caregivers from all races gave many examples of ways in which they felt that service providers did not respect caregivers’ choices about how best to parent their children. There were no differences between parents of different races, or different economic or educational backgrounds in the percentage expressing dissatisfaction or satisfaction with the overall issue of parenting. About a quarter of all parents described a specific dissatisfaction in this area, while only about one in ten gave an example of a satisfaction (*see graph 8*).

In some cases, caregivers were dissatisfied because they felt that providers did not listen to caregivers’

GRAPH 8

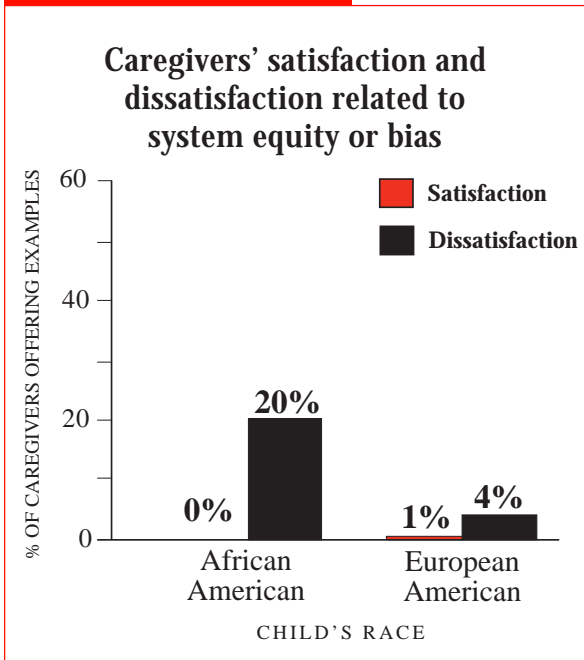


ideas about what was causing difficulties for the child, or what sorts of services or treatment the child should receive. For example:

We wanted the school to be more open to preparing him for college. They were not giving him that option.

We were told what he needed and he was told what he needed so there was no choice in the matter.

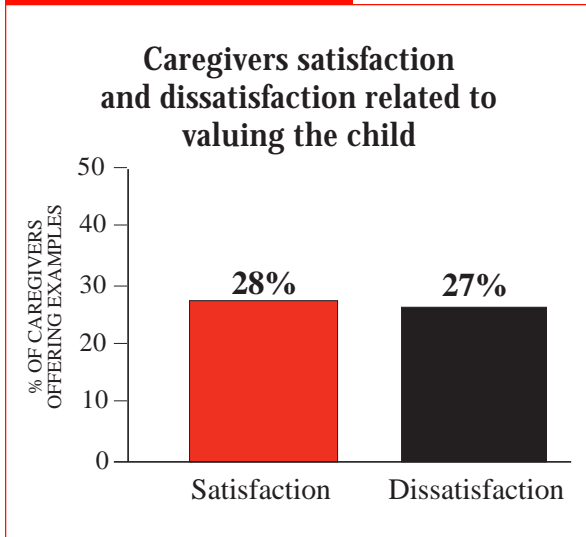
GRAPH 7



Caregivers were also often dissatisfied because service providers did not respect the choices caregivers made about how to deal with discipline issues. In particular, caregivers were dissatisfied because service providers criticized the use of physical discipline. Numerous caregivers from all backgrounds thought that physical discipline was an important part of good parenting.

ABC Center has their own methods of discipline which I don't agree with. They say no physical discipline but my culture values some spanking. . . The ABC Center parenting

GRAPH 9



classes didn't promote this. They said easy going. . . would get the job done.

I believe in spanking but the school and [state children's agency] don't believe in spanking.

This particular issue was raised somewhat more frequently by African American caregivers than by European American caregivers.

Respect for the child as a valuable individual.

Caregivers described many satisfactions and many dissatisfactions about whether their children were treated as individuals with promise and potential. Satisfactions often described providers' efforts to truly take into account the unique needs of the child, while dissatisfactions often described providers who could only see children as a "problems", "symptoms", or "labels". There were no significant differences between parents of different races, or different economic or educational backgrounds in the percentage expressing dissatisfaction or satisfaction with respect for the child. About a quarter of all parents described a specific dissatisfaction in this area, with a

slightly larger number— 28%— giving an example of a satisfaction (*see graph 9*).

When we first encountered caregivers' comments about respect for the child as a valuable individual, we were puzzled that caregivers would consider this an issue related to "culture". But as we saw how frequently this type of issue came up, we began to understand that these caregivers shared values that they had developed from caring for, and loving, children whose behaviors were often difficult, challenging, or hard to understand. Caregivers were pleased when they encountered service providers who also shared these values:

They recognized, acknowledged his Tourette's, but they cared for him for who he is.

Some of his teachers could see that he was funny, witty, intelligent, and had valid things to say.



By the same token, caregivers often expressed dissatisfaction because providers did not value their children as individuals:

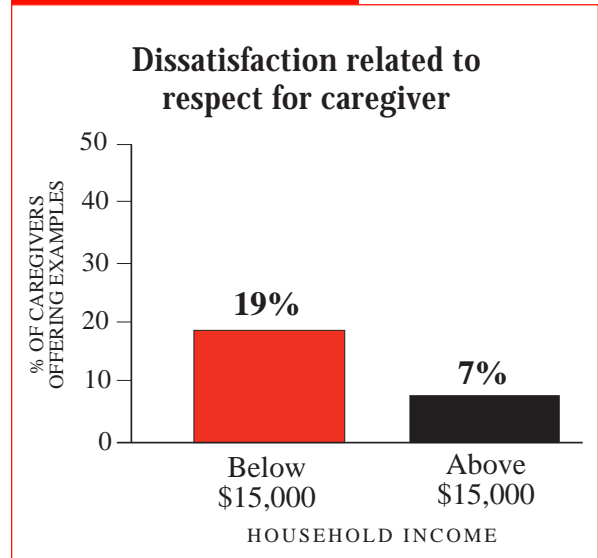
They see him as a syndrome and treated him like that, not taking into account that he's a person with his own individual needs.

Respect for the caregiver. Caregivers also expressed dissatisfaction when they felt they were not respected by providers. In some cases, caregivers said this was because providers looked down on people who were poor or had little formal schooling. In other cases, the causes seemed more personal.

[Service worker] was inappropriate and cruel to me. She called me a liar in front of my kids and let me know she didn't like me because I'm fat.



GRAPH 10



In contrast, this mother was satisfied with the respect shown her by service providers:

Services at ABC Center were respectful, especially of someone using a medical card.

Our analyses showed that caregivers from low-income households were almost three times more likely than other caregivers to talk about an experience in which they felt they were not respected by service providers (see graph 10).

Religious values. Finally, caregivers also commented on the extent to which the family's religious or spiritual values were respected by service providers. As was the pattern in each of the previous categories, caregivers were more likely to express dissatisfaction with services, with 8 percent doing so:

[Child] got into church here, but service providers did not approve. They did not believe [child] could be saved by God. XYZ Day Treatment was not Christian oriented.

I'm Pentecostal and everything I believe in as far as parenting is based on biblical principles. But they treat things like religious beliefs like they are not important or applicable.

However, about 5 percent of caregivers expressed satisfaction with providers' respect for their religious beliefs or values:

I liked that prayer, church, the importance of schoolwork and proper behavior are all affirmed at her school.

Were caregivers who were dissatisfied with the cultural appropriateness of services also less satisfied overall with services?

Results from other analyses indicated that caregivers who provided examples of dissatisfac-

tions in any of the areas related to the cultural appropriateness of services also had lower scores on a measure of overall satisfaction with services. (Interestingly, caregivers who described satisfactions with the cultural appropriateness of services did not score higher on the measure of overall satisfaction.)

Compared to European Americans, African American caregivers did not have lower levels of overall satisfaction; however, overall satisfaction with services was lower among the subset of African American caregivers who described ways in which providers had failed to respect community or ethnic values.



SUMMARY

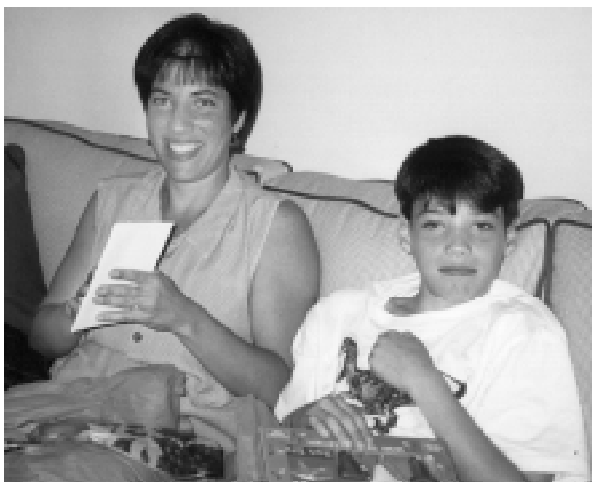
Caregivers say that. . .

. . .there is success and failure in the provision of culturally appropriate services.

Results from this study show that about half of caregivers—regardless of race, education, or other personal variables—felt that service providers had done at least a fairly good job in respecting their cultural values during treatment planning and service delivery. This seems like both a success and also a failure, since the remaining half of caregivers felt that service providers were not particularly respectful of culture.

. . .more providers need to understand that we are capable parents of unique children.

Caregivers from all backgrounds were highly concerned that providers often failed to see each child as a unique individual, *not* just a syndrome, a label, or a problem. Relatively large numbers of caregivers from all backgrounds also said that service providers failed to appreciate caregivers' knowledge of their child, and caregivers' ability to parent effectively. On the other hand, there were many caregivers who were pleased that service providers did appreciate the children as individuals and the caregivers as capable parents.



. . .there are many ways in which services are not respectful of the beliefs and values of children and caregivers from minority communities.

Close to half of minority family caregivers described specific ways that their community or ethnic values were disrespected by service providers. Caregivers who gave examples of these types of dissatisfactions also tended to be less satisfied overall with services. These results reinforce the words of minority caregivers who emphasized:

We're not ready to say we're there, as far as solving the race problem with [services].

[Providers] in general could be more sensitive and conscious of the struggles or racism in this culture.

Don't say, "Just put it behind you."

That does not validate the reality of what people of color experience with racial prejudice.

. . .there are also many examples of ways in which service providers have been respectful of the beliefs and values of minority families.

Over one third of minority caregivers talked with satisfaction about the way that their community or ethnic values were respected by service providers. In sum, while there is evidence of significant failure to provide culturally competent services to minority families, there is also evidence of significant success.

. . .providing culturally appropriate services is more difficult than just following a recipe.

Caregivers' voices emphasize that not all minority families want or need the same kinds of services.

For example, some caregivers said that children from minority cultures needed therapists from the same background, or that they needed targeted programs to support their culture. At the same time, other minority caregivers insisted that the best services were those that were “color-blind” and treated all children the same.

This study indicates that service providers need to develop their understanding of the values, norms, and ways of life in different communities and cultures. At the same time, providers also need to be able to see people as individuals who reflect culture and community in unique ways. Promising research in cultural competence suggests that an important first step is for families and providers to work together to define their goals for treatment, how the goals can best be achieved, and how they can resolve disagreements when they arise. What is needed from future research is a deeper understanding of how providers can gain, as this grandmother astutely points out, “knowledge, skill and attitude”:

Mostly it didn't matter what culture the therapist was, it depended more that the individual therapist had knowledge, skill and attitude, not just his being black.

... providers need to work with caregivers more flexibly around issues of discipline.

Caregivers were also dissatisfied with providers' ideas about discipline. In particular, caregivers felt that providers were too rigid in their belief that physical punishment was never appropriate. Caregivers in this study pointed out that there is a difference between spanking (or other physical punishment) and abuse, and that there were times when physical punishment was necessary.

In making these claims, caregivers are supported by a growing body of research which supports the

idea that non-abusive spanking, *carefully used*, can be a very effective means of discipline, and that physical discipline is not necessarily inconsistent with the kind of warm, authoritative parenting that has previously been linked to good outcomes for children. There is clearly a need for providers to be more flexible in engaging caregivers around issues of discipline.

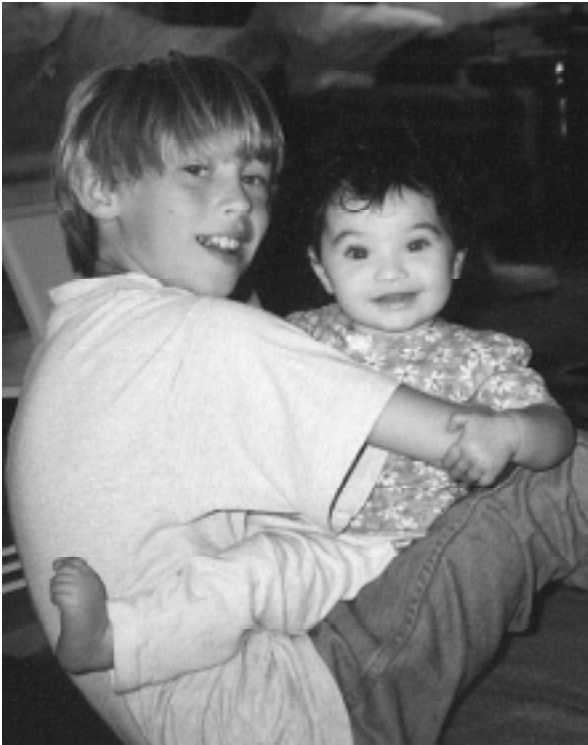
... providers need to understand that norms of discipline can differ between communities.

Results of the current study also agree with previous research findings in saying that caregivers from different communities tend to value different forms of discipline. A number of studies have shown that spanking is more widely approved of in African American communities. Within these communities, the non-abusive use of physical discipline does not seem to be associated with negative effects in children. When providers cannot understand that norms of discipline differ between communities, it reaffirms black caregivers' perceptions that the system is biased in its evaluation of their ability to parent.

... providers need to be more sensitive to the additional burdens that come with having limited income.

Almost one in five low-income caregivers described ways in which service providers had disre-





spected them, viewing them, for example, as “lazy” or “losers” or “trash”. Caregivers’ words tell us that many service providers are not sensitive to the ways that having limited income places additional burdens on caregivers as they interact with the mental health system. Caregivers’ words, as reported here, indicate a serious need for further attention to this issue.

. . .there’s a lot left to learn and to do.

Caregivers’ words make it clear that much needs to be done to further educate and train service providers in cultural competence. We also need to know more about which sorts of education and training work, and which do not. In evaluating these efforts, we need to focus on the perceptions of children and families as we work toward the goal of building systems of care that are flexible and responsive to diverse value systems.



BACKGROUND INFORMATION

This study uses data collected from families who participated in an evaluation of the Robert Wood Johnson Foundation's Mental Health Services Program for Youth in Multnomah County, Oregon. Multnomah County includes the city of Portland, and is the major metropolitan county in the state.

Data were collected through structured interviews with parents or other caregivers and through written questionnaires completed at the time of the interview. The interviews were conducted by graduate-level social work students. The entire interview process took from two to two and a half hours and was generally conducted in the parent's or caregiver's home. At the completion of each interview, the respondent was paid \$25.

The families that participated in the study had a child was between 5 and 18 years old. This child had a DSM-III diagnosis, had received more than one service in the previous 6 months, and had experienced substantial limitation in at least two major life areas (e.g. school performance, relationship development, family life, and self-care). Most of the caregivers who participated in interviews were women (90%), and most (69%) were biological or adoptive parents, although 21% were foster parents and 6% were other relatives. Just over half of the caregivers were employed (56%), and 51% had at least some college or trade school education. Household income for 44% of the families was below \$15,000, and for 22% of the families was above \$25,000. The majority of the children in the study were boys (69%).

Sixty-seven percent of the children were white, 22% African American, and 9% Native American, while representation from other races was less than 3%. When caregivers were asked to pick from a list of diagnoses or names for their children's dis-



abilities, the most common responses were attention-deficit/hyperactivity disorder (41%), emotional disorder/seriously emotionally disturbed (30%), and learning disability (25%).

Caregivers were asked how important they thought it was for their culture to be considered in the creation of the child's service plan, and the extent to which the child's culture had been taken into account in the activities and services provided under the plan. Their responses were grouped into two categories: "not at all or a little" or "some or a lot".

Caregivers were then asked to provide specific examples of the ways in which their cultural values either had or had not been considered in the assessment of their child's behavior, in the development of the service plan, and during the course of the activities and services that were provided to the child. Responses to these open-ended questions consisted of caregiver descriptions of occasions during which they had felt that their cultural values either had or had not been respected. Caregivers' answers to the open-ended questions were transcribed for analysis.

Since one of the goals of the study was to learn more about what caregivers included in the broad

definition of “culture”, a coding system was developed to reflect the types of values that were at stake on the occasions described in the interview responses. The coding system also reflected whether or not the particular cultural value or belief had been respected or disrespected on that occasion, i.e. whether the caregiver was offering a compliment or a complaint about the provided services.

Interrater reliability was quite high, with agreement ranging from 82% to 94% for the type of belief and from 86% to 98% for whether the response included a satisfaction, dissatisfaction, or other sort of comment.

**For further information or details about
this study, visit our web site at:
www.rtc.pdx.edu**

