

TAMARA C. DALEY
Department of Psychology
University of California, Los Angeles

THOMAS S. WEISNER
Departments of Psychiatry and Anthropology
University of California, Los Angeles

“I Speak a Different Dialect”: Teen Explanatory Models of Difference and Disability

What do teens with disabilities believe about their conditions, and what do they understand to be the causes, correlates, and consequences of disability? We elicited a cultural explanatory model (EM) of disability from a longitudinal sample of 23 European American adolescents with varied cognitive disabilities and delay. We asked teens how they were similar to or different from others, the name of this difference, its causes, severity, course, effects, associated problems and benefits, and need for treatment. IQ and type of disability strongly affected quality of responses only from the lowest functioning teens. A majority of teens had a reasonably rich and coherent EM, blending typical and disability themes of cultural knowledge and identity. The EM is a window into social context (schools, services, parents, and peers) as well as personal experience. Eliciting explanatory models from teens with disabilities is not only possible but also can enhance understanding of identity, family influence, and appropriate services. [disability; explanatory models; adolescence; culture]

After eras of “blaming” parents for their children’s disabilities and relying on biomedical labels as both correct and sufficient to explain and name various conditions, research and practice today recognize the significance of the meaning and understanding of disabilities held by family members and children themselves. What do teens with disabilities believe about their circumstances, and what do they understand to be the causes, correlates, and consequences of their conditions? That is, what are their cultural explanatory models (EMs) of their circumstances (Kleinman 1980; Weiss 1997)? An EM encompasses an individual’s beliefs in five domains of an illness or health condition: etiology, time and mode of symptom onset, pathophysiology, course of sickness, and treatment. Our report describes the explanatory models of adolescents with varying impairments in cognitive and social functioning and offers a basis for beginning a line of inquiry about

Medical Anthropology Quarterly 17(1):25–48. Copyright © 2003, American Anthropological Association.

disabled youths' EMs, a topic that has thus far received little study. We show that many teenagers with disabilities in fact have explanatory models of their conditions, and we suggest that exploring these models can assist in providing effective treatments and interventions.

The descriptive goal of this article, then, is straightforward but hardly easy to achieve. By definition, many adolescents with developmental delay have serious limitations with respect to communication, cognitive ability, and reasoning. Understandably, research on the nature of their EMs is inherently difficult. Only a few studies have provided systematic information, and none offer the holistic sense of an explanatory model. One approach, by Whitney-Thomas and Moloney (2001), focuses on self-perception. Working with a sample of nondisabled and learning-disabled high school students, they defined self-definition as high clarity about the future and the ability to describe oneself to others—but they did not elaborate on what young adults with disabilities actually thought of themselves with respect to their disability. Olney and Kim used focus group discussions among volunteer college students with disabilities to explore their experiences of disability and how disabled students “embrace their differences and integrate them into a cogent sense of self” (2001:566).

Other research with teens and young adults with disabilities has focused on how such individuals feel about themselves, using the construct of self-esteem. For example, Glenn and Cunningham (2001) found that teens with Down Syndrome rated themselves positively, but these researchers also acknowledged that the same results are found with four year olds, who confuse their desire to be a certain way with the reality of what they are. Cosden et al. (1999) found that among elementary and junior high students with learning disabilities (LD), increased knowledge about LD was *not* associated with higher self-esteem but was related to actual and perceived academic achievement.

Note that most studies have focused on self-worth or self-esteem and on specific disability groups. Grouping teens based on their diagnosis (for example, those with “Down Syndrome” or the “learning disabled”) confounds the diagnosis with the sample. Some adolescents may not perceive themselves as different at all, even though diagnosed with a specific disability. Others see difference but not in the areas that relate to their diagnosis. Still others may identify with the disability as defined by the researcher or the school they attend. Without assessing the teen's own perception and understanding of their disability, assessing a construct such as self-esteem does not get at the meaning behind these beliefs and disability categories. One cannot make the assumption that if a teen has low self-worth compared to his or her peers, this is necessarily *because* of the disability, yet this is often the implicit conclusion offered by some studies. In addition, this approach assumes that self-esteem is an important topic. In contrast, Skinner et al. (1999) show that Latina mothers of children with disabilities use spontaneous narratives that go far beyond self-esteem, emphasizing being good mothers and positive transformations in their lives.

What topics and beliefs would teens themselves bring up in addition to or instead of self-esteem? Many anthropological and qualitative studies of disability use aspects of the explanatory model framework, whether or not they use the term *explanatory model*. The rich qualitative literature in anthropology exploring the personal and cultural worlds of adults with disabilities shows disability as both a

fact in the world and a highly social construct (Ingstad and Whyte 1995; Murphy 1987; Stiker 1999). The same is true more specifically for cognitive disabilities, where the frank stigma associated with the label of mental retardation is especially powerful in a literate, high-technology society such as the United States (Dudley 1997; Edgerton 1970; Jenkins 1998). In other cultural communities, however, it is the inability to be a socially appropriate person rather than physical disabilities or even mental illness that matters most for community integration (Marshall 1996). And where accommodations to disability are pervasive and part of implicit culture, the impact of disability can be dramatically reduced. For example, when everyday competencies of typically developing individuals routinely include skills for communication with the disabled (such as a community all learning a local sign language to communicate with deaf individuals on Martha's Vineyard [Groce 1985]), social integration improves dramatically.

Gender, poverty, and those with power frame the lives of the disabled just as much as or more than the lives of typically developing teens (Charlton 1998; Frank 2000). The ways adolescents think about and experience their disabilities and differences—the EMs that are the focus of our report—provide a window into youths' "social suffering" (Kleinman et al. 1997), and these social conditions are likely to inform their EMs. Those with disabilities struggle to achieve what their cultural community defines as typical, that is, to wear a "cloak of competence." Yet, that cloak is worn by typically developing people in the community as well as those with disabilities, so everyone struggles with issues of acceptance, competence, and a true and "false" self (Edgerton 1993; Miller and Sammons 1999). The research literature, however, has not yet explored empirically what kind of explanatory models teenagers with disabilities might have.

Sample

A sample of 30 families was randomly selected from a longitudinal cohort of 102 European American families in the Los Angeles area to participate in a two-year ethnography. The original sample was recruited in 1985–86 through community agencies serving children with special needs. At that time, all of the participating families had a child who was judged by a professional or an agency to be "developmentally delayed." *Developmental delay* is a term of relatively recent vintage, and although it lacks definitional specificity, it characterizes the majority of children in special education today (Bernheimer and Keogh 1986). It is essentially a nonspecific "clinical" term with less ominous overtones for the future than *retarded*. Children with known genetic abnormalities were excluded from the sample, as were children whose delays were associated either with known prenatal alcohol or drug use by the mother or with postnatal neglect or abuse (Bernheimer and Keogh 1982, 1986). Further details concerning the original sample, recruitment, and attrition are available in Gallimore et al. 1996 and Keogh et al. 1998.

Cognitive and developmental assessments were obtained when the children were age three to four years, seven years, and 11 years. At modal age 11, each child was tested by independent developmental test specialists hired by our project team. The mean Binet IQ obtained was 66.68 (SD=20.29, with a range of 27 to 122). The cognitive/developmental scores at age 11 used in the present study were remarkably stable compared with earlier assessments, with a correlation from age three to

seven of .69 (Bernheimer and Keogh 1988; Bernheimer et al. 1993) and from age seven to 11 of .83 (Gallimore et al. 1996). In the current protocol, two nonverbal teens and one who declined to participate were excluded from the EM questions. The cognitive abilities scores of the 27 teens for whom questions were attempted ranged from 40 to 118 ($M=70.6$, $SD=18.6$). At the time of the interviews, teens ranged in age from 17.1 years to 19.0 years ($M=18.2$, $SD=.6$ years). Table 1 presents a summary of the current school placement, diagnoses as reported by parent, and IQ at age 11 for the 23 teens included in this sample. Pseudonyms are used to refer to teens throughout this article.

Method

Six fieldworkers contacted, secured permission from, and began visiting the 30 families. Each fieldworker worked with one to seven adolescents and families. During a regularly scheduled ethnographic visit with participants, fieldworkers explained to the adolescent that they would like to ask him or her some particular questions. Fieldworkers used open-ended, semistructured questions, based on Kleinman's (1980) original eight questions pertaining to the five domains of an illness EM.¹ These questions focused on how the teen perceives him or herself and how the parent perceives the teen in comparison with other adolescents. At the same time, we attempted to get as close as possible to the teen's thoughts and feelings about the developmental, cognitive, social, or physical difference that is most related to their disability (see Table 2 for questions). Interviews were tape-recorded for later transcription.

In this study, we posed additional questions to facilitate rapport around the topic of difference and guide the direction of the interview toward disability. For example, the initial questions were about how the teen was similar to and different from other teenagers he or she knew. Interviewers typically attempted to guide the responses toward identification of a difference or problem that would be appropriate to explore via the explanatory-model line of questioning. A common technique was to ask the teen what kind of class he or she attended at school and, based on that response, probe what it meant to the teen that the class was "special."

An important methodological and theoretical point about this process concerns how the fieldworkers approached the subject matter of disability. Fieldworkers were instructed to probe for a nonsuperficial difference perceived by the teen, using questions such as those listed in Table 2, but ultimately to complete the explanatory model with whatever the teen offered as his or her perception of what constituted the difference. Therefore, not all of the "differences" are diagnosable disabilities or the conditions for which the researchers initially included the teens in the study. Methodologically, this meant that subsequent questions may have focused on just one aspect of a teen's disability and neglected others. Theoretically, however, this outcome matched our intent because we aimed to allow the teens to represent their lives in their own words, whether or not they used phrases from the biomedical and educational systems.

Although their narratives were often extraordinarily rich, not all teens were able to complete the interview. We used the queries "How are you similar to other teens?" and "How are you different from other teens?" as "gatekeeper" questions, and teens unable to respond to them ($N = 7$) were not asked the remaining items. In

addition, several teens in the project are currently typically developing, that is, they currently have no cognitive, emotional, behavioral, or physical impairment identified by either a parent or professional, and they attend typical classes, despite their

Table 1
Summary of cognitive ability (IQ) as measured at age 11, diagnosis, current school placement, and average quality of response to explanatory model questions.

Name	IQ at Age 11	Professional and Educational Diagnoses as Reported by Parent ^a	School Placement ^b	Average Quality of Response
Bobby	118	PDD, ADD	General	1.00
Shannon	89	CP, LD, scleroderma	RSP	1.00
Regina	83	CP with spastic quadriplegia	RSP	1.00
Jared	72	CP, ADD, Leigh's syndrome	SDC	1.00
Josie	76	Seizure disorder, mild-moderate CP, visual impairment, sensory integration dysfunction, mild-moderate MR	SDC	1.09
Madison	93	Depression	RSP	1.25
Derek	76	Asperger's	SDC	1.36
Jay	69	Mildly MR, LD, behavior disability	SDC	1.36
Rudy	62	DD	SDC	1.36
Brett	74	Slipped vertebrae	SDC	1.38
Alex	89	CP, seizures, visual impairment	RSP	1.45
Maryanne	66	LD, mild-moderate MR	RSP	1.50
Daisy	56	CP, MR, LD	SDC	1.55
Jenna	72	ADD, LD, depression	SDC	1.55
Greg	100	Autistic tendencies, speech delay	General	1.67
Kaitlin	65	Aphasia, CP, MR, LD	Home Schooled	1.71
Cindy	78	DD	SDC	1.91
Rich	62	Aphasia/apraxia	SDC	2.00
Jake	54	DD	SDC	2.44
Jacob	49	ADHD, moderate MR	SDC	2.64
Don	40	Brain damage, LD, CP	SDC	3.00
Claire	46	Mild MR	SDC	3.00
Malcolm	48	Autistic tendencies, CP, brain damage	SDC	3.00

^aNote: All children initially received a diagnosis of developmental delay. These diagnoses, where they are no longer DD, have supplanted that original diagnosis. ADD = attention deficit disorder, ADHD = attention deficit hyperactivity disorder, CP = cerebral palsy, DD = developmental delay, LD = learning disabled, MR = mentally retarded, PDD = pervasive developmental disorder.

^bSDC = special day class, teen spends less than 50 percent of his/her time in regular classes, RSP = resource specialist program; teen spends 50 percent or more of his/her time in regular classes, General = teen spends 100 percent of time in regular classes and receives no special education services.

initial identification at age three to four as developmentally delayed. Because we were concerned with identifying explanatory models of adolescents with a current impairment, these teens ($N = 3$) were also excluded, as was one lower-functioning teen who did not want to participate.

We created a data table for each question listed in Table 2. Each question was considered independently and was coded once for quality and once for content. For quality of response, we used a three-point scale, where a rating of 1 indicated comprehension of the question and an intelligible response; a rating of 2 indicated some misunderstanding of the question, a response structured by the interviewer, or a somewhat limited response; and a rating of 3 indicated very limited comprehension of the response or a completely inappropriate or illogical response. Two raters independently coded 20 percent of the total number of responses to establish reliability for the quality measure. An alpha statistic of the interrater reliability for the three-point scale was .945, indicating strong concordance. The quality score for each teen was averaged across all responses to provide an overall indicator of how well the teens were able to respond to the questions. For coding of content, we devised separate coding systems using a bottom-up procedure developed by the first author, who was also a fieldworker, in consultation with other fieldworkers (Miles and Huberman 1994). The codes were kept as face valid, directly summarizing of the content, as possible.² Kappa statistics of interrater reliabilities for content coding ranged from .723 to .920.

Results

Quality of Response

Apart from the question of what teens thought about their disability, we were interested in how well they would be able to discuss this topic at all. The quality of response score provides an average of the quality of response across the questions, for all questions asked. These scores ranged from 1 to 3, where 1 was the highest quality. Three of the teens who were unable to respond to any questions at all received scores of 3. Three other teens were able to provide some type of response to the question "How are you similar to other teens," and their respective scores were 2.00, 2.44, and 2.64. For these six teens, who were so clearly limited in their ability to answer the questions, IQ at age 11 was highly correlated with the quality of their

Table 2
Teen interview questions.

-
1. What makes you similar and different from other kids you know?
 2. What do you call your difference/problem/teen's word? What name does it have?
 3. What do you think caused you to be different/have this problem/teen's word?
Why do you think it started when it did?
 4. How severe is it? Will it always be there?
 5. What does your difference/problem/teen's word do to you? How does it work?
 6. What are the main problems that being/having _____ have caused for you?
 7. What are the good parts/benefits of being having _____?
 8. What kind of help/treatment do you think you should receive.
-

response, $r(6) = .93, p < .01$. For the rest of the group ($N = 17$), however, there was no significant relationship between IQ and quality of response, suggesting that the ability of a teen to coherently respond to the questions cannot simply be predicted by the teen's tested IQ, except when responses are very poor, in which case IQ is similarly low. As we present our qualitative data on EMs, the interested reader can match teens' pseudonyms in the text to their IQs and diagnoses in Table 1.

Content of EM Responses

To determine the actual content of responses, we summarize the interviews according to each question we asked the teens, in the order we asked it. The order of the questions had an important affect on teens' patterns of responses and, consequently, our findings and interpretations of them.

How are you similar to other teens? This category was coded into five domains: similar because of (1) the daily routine and activities; (2) likes, preferences, and hobbies; (3) personality; (4) basic aspects of personhood, such as age, needing to eat, having organs; and (5) not similar to others. A sixth code was assigned in cases where teens were not able to answer or did not provide a response. Twenty-two teens were asked the question and provided 43 responses. Of these, the single category with the most responses ($N = 17$) focused on teens' activities and their daily routine. Specific responses included "going to college, getting good grades," and "go to parties, and date women." Jacob, despite his low level of functioning, was able to respond, "I do jobs . . . I do work. Yeah, and I go on field trips." Josie sounds very much like a typical teen when she notes, "We talk about music, we talk about boys, we talk about the past, when we were in middle school. So, you know, we like to talk about things that happened to us."

Eight responses focused on teens' interests (e.g., music), preferences (e.g., trends and clothes), and hobbies. Josie, for example, related that "everyone in [the class] likes the same kind of music as I do." Madison's response was eloquent and noted both similarities and differences:

I think that when it comes down to shallow things, not really important, deep things, like music and TV shows and you know, things that aren't really that important, I'm like them a lot. Like clothes and fashion and you know daily teenage things. But when it comes down to how my mind works, and my maturity, I think that I'm not like them.

Eight responses pointed to basic similarities, such as age and needing to eat. Jay poignantly declared, "I am normal. I *do* bleed red blood. I *do* know how to read. I know how to do everything the kids do." Bobby wittily replied that he is similar to others because "I have a brain, two eyes, a heart, all the little organs."

Four responses, such as Regina's, focused on the teen's personality:

My personality; I'm happy, and I do pretty much everything I can; I try adapting stuff if I have to so I can do them. I pretty much kind of ignore that my disability is there when I'm out in public, don't focus on it. And I'm pretty much trying to live the life of a normal teenager.

In six cases, the response indicated that the teen perceived him- or herself as unique, unlike others at all. Rudy, for example, said, “I really don’t be similar to many kids. I don’t copy what they do.” Greg initially began to describe similarities but then explained, “You know, I don’t really feel related to all the kids, at all. I mean, I still have a lot of friends. I don’t feel close, similar, you know. Just because, I don’t know, it’s just that kids are—I don’t know.”

Overall, the teens’ responses reflected everyday aspects of being an adolescent: things they do, things they like, who they are. Some responses even incorporated the “personal fable” (Elkind 1967) characteristic of U.S. adolescent development—the notion that one’s self and experiences are unique and cannot to be readily understood by others. Thus, in general, *most of the teens we interviewed perceived similarities between themselves and other teens that one could easily imagine might be expressed by typically developing adolescents*. Our conversations started with a general query that often received a very general answer—one framed in terms of the “cloak of competence” (Edgerton 1993), of typicality. Some adolescents, however, either blended the “typical” and unusual or focused on their disability, comparing themselves to a disabled peer group. Jared explained, “Well, there are two kinds of other kids: normal and disabled. I think I’m like normal kids because I can dance, I can sing.” There is also an interesting mix of the typical and the unusual reflected best in the eight responses of teens who likened themselves to others in very basic human aspects. Although several of these teens gave dry answers in an attempt to be witty (e.g., “I have a brain, a heart, all the little organs”), for some this type of concreteness of response reflects a cognitive limitation (e.g., “I’m like other teens my age because we’re the same age”).

How are you different? Responses were coded into five broad domains: (1) disability; (2) personality/maturity; (3) likes, preferences, and hobbies; (4) treatment by others; and (5) beliefs/religion. The overall goal of this question was to focus on a problem the teenager was experiencing, particularly if it related to the disability. Interviewers probed to varying degrees, resulting in an array of responses. Sixteen teens were able to provide reasonable answers to the question and produced 25 responses (although we posed the question to 22 teens, six responses were not codeable according to the above five categories).

Of the 25 responses, eight related directly to the disability. Alex, for instance, conceded that “Some people have, um, better knowledge on things. I’m just slow, slow learner,” and Rudy noted that he is different because he is “probably slower learn, more different stuff and probably do more as I go through.” Derek candidly explained, “I had a disability and they [the other kids at school] didn’t.” Regina, a teen in a wheelchair, immediately explained her difference as “having the disability, having to have the wheelchair, having to maybe go a little slower than other kids. Having to do things like sports and other stuff differently.” Other teens were able to point specifically to less visible limitations, as in this exchange:

Jay: They [other kids at school] don’t have problems.

Interviewer: What do you mean by that?

J: They don’t have anger management problems. I do.

I: Okay, so you feel like you’ve got some anger management problems. Is that the thing that makes you the most different from other kids?

J: Yes.

Two responses related to how the teen perceived he or she was treated by peers, a topic that indirectly relates to the teen's disability:

Like there are some kids that are being mean. Oh, I don't know like, there are some kids that are being mean to me or something like that I choose to ignore them and not cause sometimes they'll like maybe they'll talk about me, and I had that happen when I was playing sports and stuff. And they'll, like, sometimes they'll talk about me and it's like, sometimes they hurt my feelings. [Kaitlyn]

I mean [the other teens] really liked me and helped me, but they treated me as if I was helpless. And they treated me as if I didn't know how to do anything. Like, greeeeaaat. So, at times it was kind of fun but at other times it was kind of boring, because, you know, I can do things, I'm not dumb. I can figure it out. And the only way I'm going to get independent is by trying. [Josie]

Six responses indicated that the things the teen liked were different from the likes of typical teens. Jenna, for example, said, "My music's like the goth music," and Josie cautioned the fieldworker, "Don't laugh—but I talk to myself. . . . And I sing in the shower!"

Five responses described a personality difference, again reflecting traces of the adolescent personal fable.

I try to be more like myself, and copy no one else. Cause a lot of people, they hang out with the same people, dress like they do, and act like they do. I try to act like myself, it's hard, but . . . especially with all your friends, because sometimes they seem to have control over you. That you don't even realize sometimes. But I try to just be myself. [Shannon]

Well, here's the thing. There are rational people without having any emotion. Adults are rational without having any emotions. Kids are emotional without having any ration. Now, I'm being extreme, but in a sense it's also true. But, a lot of kids will do things because they're . . . I still find it immature that they'll still do things out of total emotion, it feels good to do it. Sometimes I have to think about the consequences. So, in a sense when I think like that. Some people I'm more mature in a sense, but in other ways I'm not. Like I'm more shy than most kids, in an immature way. Well, I don't know how that can be immature but it's younger. You know? [Greg]

The responses of three teens referred either to religion or other beliefs. One of them, Daisy, explained, "My parents are really strong Christians, so, like some of my friends, they don't have parents that are Christians."

Describing how they are different from others, these teens refer to activities, preferences, and personality (15 of 25 responses), as they did when questioned about similarity. It is only in their sparseness and, sometimes, lack of clarity that many of their answers differed from those of typically developing youth. When probed, however, over a third of respondents referred either directly or indirectly to a difference related to a disability. That many teens skirted mention of disability at this point in the conversation was notable. Here again, during the early phases of our conversations, many adolescents' continued to wrap their replies in a cloak of competence. At times their answers seemed to suggest that the teens did not fully grasp the question frame. As with many other questions, however, it seems to us

that this was perhaps partly *because* they were attempting to depict their similarities and differences in as typical a way as possible—and for some this is hard to do. As the conversation proceeded, however, the teens used more specific disability-related frames perhaps in response to questions focused more specifically on their EMs.

Name/identification of difference. Because of the array of physical, mental, emotional, and behavioral impairments characterizing our sample, coding how a teen identified his or her problem was based on whether the response included a specific name, label, or diagnosis, or was descriptive.

Seventeen teens responded to this question; seven used a specific label, some in addition to describing their difference in broader terms.

Regina: When people ask me, “What is your disability,” I just say CP.

Interviewer: Okay. And then, if you say CP, somebody’s going to say, “What’s CP?”

R: And that would be a hard question because there are so many cases of CP that I wouldn’t know exactly how to define it. I could answer questions *about* my disability like why I can’t walk without a walker and why I’m in a wheelchair.

I: OK, why can’t you walk without a walker?

R: Because . . . if I try to walk I’ll fall. The walker is my legs.

Interviewer: So why are the other kids in that class?

Jay: They’re slow.

I: What does that mean?

J: They’re . . . just got it wrong. I wouldn’t say it, cause that’s offensive, because *I am mentally* [emphasis added], but really, they’re not all there. They’re slow in the head, they have a hard time functioning than I do.

I: Okay. So what do you mean by you’re “mentally?”

J: Retarded.

I: So you think you’re mentally retarded?

J: I know I am.

Josie: They’re just problems, they’re problems I have. Seizure disorder is a problem I have. You can’t control it. You can’t control my vision, I mean we tried to, with a patch.

Derek: I have Asperger’s.

Interviewer: And what’s Asperger’s?

D: It’s a form of autism.

I: Do you know anything else about it?

D: Yes. . . . Most people with Asperger’s are very gifted. They learn things quick. They got good memories. . . . They’re beyond extremely high functioning. . . . And they’re mostly normal.

I: But they’re mostly normal, okay. What else do you know about it?

D: Um, that most of them are good looking.

I: Anything else?

D: I don’t think there’s anything else.

Jenna: Umm, ADD.

Shannon: I don’t know why I’m in there [the resource room]. I think . . . the only thing I know is that I have a little bit of dyslexia, I know that.

Ten teens identified their difference in vague terms, one saying, for example, that “a lot of it is my memory.” Cindy named her difference as “shy.”

Interviewer: If you had to put one word. You’d say, “I’m different from you because _____.

Greg: Oh, I see. Because I’m aware. I’m aware.

I: You’re more aware?

G: I’m more aware. That’s the only reason. Or you know what? I’m different from you because I’ve worked on it. I guess that’s not one word.

The teens that could and did respond clearly have a grasp of and can describe their disabilities for the most part. But they did not always do so immediately or use a standard diagnostic label.

Cause. Cause was coded into one of four categories: (1) medical explanations; (2) environmental explanations; (3) attributions to inborn traits or heredity; or (4) other attributions or “I don’t know.” Teens’ responses were relatively evenly split among these categories. Regina was one of five respondents who provided a medical explanation of her disability: “The pneumonia I got when I was born and the amount of oxygen. . . . All I know is it had something to do with the pneumonia and not enough oxygen to the brain,” and Josie suggested that her seizures “could have been something the doctor wanted me to take and then caused it, I don’t know.”

Five responses pointed to environmental causes, that is, things that happened in the family or at school, or something related to the way the teen was raised. For instance, Cindy believed that other teens’ problems (although not her own) might have been caused by the fact that “their parents have gotten a divorce . . . their parents might not pay attention.” Greg’s response was more specific:

Because, I guess I wasn’t exactly valued by society. I wasn’t exactly valued in a sense by society, you know. Or valued by people there. I wasn’t fast, I wasn’t into sports, you know. They didn’t value what I was into. I was into being creative, art, and people still don’t value that stuff, you know.

Six responses attributed cause to inborn characteristics. Derek, for example, said he was “just born that way,” and Jared explained that “it’s genetic.” When asked what that meant, he tried to clarify by saying, “I don’t know what that means . . . I do know. But it’s complicated, even too complicated for me to explain.” Finally, five teens responded that they were not sure what had caused their difference. Daisy, for instance, said, “I don’t know. I have no idea. The doctors didn’t even know. . . . I just know that it started and I’ve had it ever since.”

Contrary to the fieldworkers’ expectations, based on the high levels of religiosity expressed by many of the teens’ parents during the study, there was limited mention of God and religion in teens’ own causal explanations. One teen (Jay) directly mentioned God as involved in causing his disability, and God was discussed by teens in other contexts during conversations with the fieldworkers. For example, prior to attributing her disability to pneumonia, Regina discussed it in the following terms:

My disability is not an accident; He [God] let it happen for a reason. I don’t know what that reason is because in my human eyes I can only see what’s here on earth. God sees the big picture: the past, the future, and the present. It was best; I don’t

know why, but I'm gonna find out some day in heaven. [God wanted me to have a disability] so I'd be more open minded to listening to my mother about God; so I wouldn't be so rebellious. He sent Jesus to die on the cross so I could see more clearly what it's like to suffer . . . I have to follow the Lord's lead in all that.

It is clear that these teens are aware of a range of causes of disability—including biomedical, environmental, and genetic explanations—that are culturally recognized by professionals and others. Leaving aside the questions of the validity of their causal accounts and where the ideas came from, it is clear that many teens had given thought to the question of causation before our conversations. From interviews with the parents and ethnographic data, we know that some of these explanations relate directly to core narratives, central stories defining the teen's life.

Severity. The teen's perceived severity of the problem was coded according to one of three categories on a three-point scale: (1) not bad or a little bad; (2) a medium or middle-sized problem; or (3) severe. The majority of teens responding to this question perceived their problem as small ($N = 5$) or medium ($N = 5$). Derek said simply, "It's not that big of an issue," and Josie noted that it is "not severe right now. Sometimes they [seizures] can get severe." Teens often talked about the extent of their problems in relation to other teens, both disabled and nondisabled.

I would say, I got to be one of the lucky ones, because I look at when I was born and how tight my muscles were and how down my head was, and I look at the surgery doctors gave me when I was six, and I look at what the difference, and then I look at other people with CP that maybe weren't able to be so lucky. And I realize, you know what, I might not be able to walk very fast or very well, but I have use of my legs, my hands, my voice, my eyes. I can see, I can taste, I can feel. I've got have all five senses, and I've got my brain. [Regina]

Cause you know a lot of the kids that I've seen around, they can't walk very well. They can't swim as good as I can. I mean, I have a friend, she can swim pretty good, but I have a friend who really can't swim. She's blind. She can swim but she's blind, so it really makes it hard. And I look at her and I look at me, and I go, well, I'm actually doing really good! [Daisy]

Respondents' relative lack of emphasis on severity or seriousness, like the deferral of the topic of disability earlier, is important to note. Only three of the teens provided responses indicating that they thought their problems were very or extremely severe. Those who did were more articulate and had more pervasive problems (e.g., autism spectrum disorders) that affected many areas of life. Two had a diagnosis of autism, a disorder that, by definition, is one that "touches upon everything," as Bobby described it. The third, Jay, had extreme behavior problems, with his parents reporting the most behavior problems of any teen in the ethnographic sample of 30. The pervasiveness of his problem was very clear in his day-to-day life, and his behavior was a daily issue at home and school.

Course. We coded responses to the question, "Will it always be there?" (1) yes; (2) no; or (3) another response. Ten of 16 teens who responded to the question saw their difference as permanent. One of them, Derek, explained that "once you're born with a disability, it's always going to be there," and Regina lamented, "Yeah.

I wish it wasn't, but I have to learn to live with it." Jared's perspective was similar: "I don't expect it to increase or decrease. But I go through life expecting the worst."

Three teens thought their difference would change, and three gave other responses. Among the latter group, Josie responded, "Let's hope not. I hope my seizures go away someday. That's been my dream for a long time." Referring to her vision problem, however, this same teen added, "I never want [it] to go away, because then I can't go to special camps! After I'm disqualified to go to the camps because of the age limit, THEN I want the vision to get better, BUT, until that happens, the vision [problem] stays!"

As our EM questions moved closer to focusing on specific aspects of disability such as severity, fewer teens were "missing the point" of the questions or "denying" that their disability might be permanent. These teens accurately perceived their difference as a lifelong condition and, to varying degrees, appear to have accepted this. Similarly, the two teens who thought their condition would go away had named their difference "shyness," difficulty learning about money, and slower learning—which very well could diminish or disappear altogether.

What does it do? Effect of the difference. We grouped the difference or disability as having (1) a negative effect, (2) a positive effect, or (3) no effect. Fifteen teens responded to this question, providing 20 codeable ideas of what their difference "does" to them or how it works. Ten of these responses suggested that the difference had a negative effect in a variety of domains. Alex noted that "It just, um, makes my homework, like, kind of a lot harder to do . . . longer to do my homework. Jenna explained, "I can't concentrate that long." Shannon gave more detail of the effect on her, first noting

I would always, like, mix up letters and I'll write my R's, like they're supposed to go this way and I'd write them this way, and P's I do that, I switch letters, and so if I say RAH, I put the H in front of the A. I'll do that sometimes. Just stupid stuff like that, like I should know . . . so I'm not the best speller.

She then described both a negative and positive effect:

I think it affects me in school and stuff, like trying to get it, and stuff. But I think it's going to end up making me a stronger person because when we get older—because I was in speech until ninth grade—and I was in it ever since I could talk, and my mom was in speech too. And I can't even tell. So when I get older, it's not going to make as big a difference like it is now.

A smaller number ($N = 4$) of responses suggested that the teen perceived the difference as having a positive effect, such as Madison, who explained,

I mean, when it comes down to daily things, it doesn't [work]. I mean, going to school, and just hanging out with my friends, it's not like it really affects me. But when it comes down to the way I think about certain things, like say me and [name] have a fight, I'm not going to be all like, "boo hoo," you know, I'm going to be like, "okay." I'll just wait around and see what happens. . . . When I have a fight with a friend, or when something happens, like I'm just having a bad day, the way I see certain things.

Seven respondents suggested little or no effect, such as Regina, who explained, "It just means I have to do things a little differently, but I can still do them. I can still

have a normal life, I can still get out. Just cause I have a disability doesn't mean I have to stay confined in the house," and Rudy, who noted that "it really doesn't affect [*sic*] me at how slow I am, just as long as I know what some of the words are, it's no big deal."

Here teens mentioned a wide range of effects including positive or neutral impacts. Our interpretations of these responses, in the context of others, is that in most cases teens were well aware of the negative effects. Some, however, mentioned effects that were sometimes surprisingly constructive, given the stigma they face on a daily basis. As suggested by responses to the next two questions, teens perceived both problems and benefits associated with having a difference or disability.

Problems associated with the difference or disability. Problems teens associated with their difference or disability were coded as falling into four categories: (1) affected the way the teen was treated by others; (2) affected the teen's abilities or behavior; (3) caused no problem at all; or (4) some other response. Seventeen teens each provided one response. Teens clearly pointed toward the effect that their difference had on their abilities and behavior, with half the responses describing a negative impact of some sort, such as Cindy's complaint that "I don't get to know a lot of people. . . . People think that I don't want to talk to them," and Jenna's acknowledgment of problems with concentration. Jake, a teen with limited verbal skills, noted problems "counting money," which means that in his daily life he can't work. Alex described the problems as "just [needing] help in certain areas" such as English and history, whereas Derek identified "social skills and anger problems." Shannon elaborated on the problems her difference has caused her:

It only matters to me because I know I have to be in special ed class and I don't like that part. But I can't go in the regular classes because I wouldn't make it. I was in a regular math class, and I hated that. All my friends were like, "Oh, I'm in Algebra, what did you get?" "Oh, a low math." I didn't even tell them I got out of it eventually. I didn't like being in the resource math. . . . I feel different. I feel left out from everyone else. But I know I could be in an all-day class, so I'd be with really bad people, so I guess I'm lucky I'm not like that.

Three teens highlighted the way they are treated by others as a problem caused by their difference. The most dramatic description came from Bobby, who suffered merciless bullying in middle school, or as he explains, "Persecution! Being beaten up, assaulted. You don't get much worse than that. Assault is pretty, pretty bad." Brett bitterly noted,

I don't like being in a class, I don't like being classified. Like I'm not classified as regular. I'm classified as outcast. Me and my friend Chris are outcasts. I only hang out with outcasts. That's who I'm associated with. And outcasts don't have a life, outcasts are dogs in other people's eyes. They don't deserve to have things that middle or upper class people have. Because they think that we're lower than them and that we can't take care of ourselves. And in reality, we can, if people would just give us a chance. And people aren't willing to do that.

Three teens felt that their difference caused them no problems at all, and three provided other responses, for example, that their differences made other people worry or that they had to depend on others. Such problems are expressed by typically developing as well as disabled teens and are often framed in a way that indicates re-

gret. In their experience, unavoidable patterns of behavior or limited ability lead to unavoidable troubling.

Good parts and benefits. The benefits teens associated with their perceived difference were coded into four categories: (1) getting accommodations or help; (2) it allows perspective; (3) it results in special skills, abilities, or labels; or (4) no perceived benefit. Fifteen teens gave responses to this question, producing 23 codeable answers—six more than the number of problems they listed. Consistent with the proportion of responses that described the problem as affecting an ability or behavior, nine of the responses describing the good parts or benefits of having a disability focused on getting accommodations or help. Regina and Jared, teens in wheelchairs, both mentioned being able to go places such as amusement parks and not having to wait in line. Although Jared saw that benefit as “the biggest one,” he added, “I have a lot of friends, with and without disabilities. All over . . . like at the coffee shops. And I had friends in the group home.” Jenna, more focused on school, noted as an advantage

I guess getting into DSS [Department of Social Services]. . . . Getting note taker help. Yeah, and I can get books on tape . . . I can get like tutors, um, I can get like lots of other stuff, like for tests I can get extra time on tests.

Three of the responses explained how the difference gave the teen either a skill or a label. Josie, for example, describes how her difference “makes me special, well yeah, I’m special anyway, but having special needs makes you extra special.” Derek noted special skills, such as “being able to learn things quick and being gifted, and knowing things and having a photographic memory, being multilingual.” Shannon, a teen who has many insights about her disability, explained:

I guess it makes me unique, in a way, because not everyone is born like that, but at the same time, it’s frustrating. So, I guess that’s a good thing. And the good thing is that I know I’m going to learn all of it, just in time. That inside I know I’m just as smart as everybody else, it just takes me longer. I’ll call myself stupid all the time, but even inside I know I’m not. I just say that out of anger.

Five responses described having a particular kind of “skill”—in the sense of gaining perspective or having something to offer others.

And just, just being able to show people that being different is not bad. I think maybe one of the good things about having a disability is I’ve *had* to rely on other people whether I like it or not, and so I think that’s kept me from getting out of—getting into a lot of the trouble that a lot of teens my age get into. . . . Like drugs, and guns. Cause I see that—yes, I’m disabled, but I don’t need that stuff to make me happy. [Regina]

I like to think that I try to see every perception of something. You know. Just be open by I could make a better diplomat than anyone here because, that’s over-generalizing. But I could make a good diplomat because I’m not going to be like, “that’s not good, like it says right here in the good book of Job that you have to do it this way and not that way.” It’s like I’m not going to have to force my opinion on someone, it’s your opinion, I might not even agree with you but I’m open to it. [Greg]

It makes me think that I am . . . in a way . . . not better but just like, wiser than other teenagers. I mean, I think it's like because, I was always used to being around younger people, that I never like tried to become friends with older people. Maybe if I start, like having 19, 18-year-old friends, then that would be better, because maybe we'll have more in common. [Madison]

Three responses incorporated the idea that there were no benefits associated with having a disability, although the teens may not have expressed this consistently. Daisy, for example, began by saying that she could get help from her mother because of her CP, But she later seemed to have trouble thinking of any other benefits, despite the interviewer's prompting.

Perceived need for treatment. The teens' ideas about what help or treatment they need now were coded as (1) material; (2) emotional; (3) training, teaching, instruction; (4) the amount and type received are okay; or (5) none wanted. Thirteen teens responded to our question about treatment and provided 18 different examples of the kind of help they felt they needed. Responses were spread across the categories, although a third indicated a need for training or educational help. Derek, for instance, wanted help related to "social skills . . . learning how to relate to others." Other teens voiced different needs:

Well, I don't want people to actually do it for me. I don't want people, like Jeff is going to teach me how to tie shoes. I don't want him to do it for me, I want him to guide me through it. Shows me the first step, like little baby steps at a time. That's how I want people to help me. [Josie]

I would like to have help with money. . . . Making money and managing money. And I would like to get help moving out of my house. Because that's going to be very stressful on me, and I know it's going to be stressful on my parents, because they have my nephew now that they have to take care of, and my brother and sister that are still going through school. And I know they don't need- they say they don't need me, but they need me. [Brett]

Four responses highlighted material help. Josie mentioned needing medication for her seizures if they are "really bad," and Regina explained that she wanted "just help with getting equipment for technology for when I get to college. . . . When I get there, I would need like a notetaker to take notes for me, and maybe we'd have to make sure voice technology is up to par by then. That to me is the biggest thing."

Three responses focused on emotional help, and two responses indicated satisfaction with the amount and type received. After explaining that medication was good for large seizures, Josie described the kind of help she would like for smaller seizures.

Josie: If they're little tiny seizures, I like them to be aware, and I want them to look out. I want them to know where I am, I want them to actually have me in sight. This way, you know, I can still be having a good day, but if I'm having a small seizure so they know to come over to me and help me through it.

Interviewer: And how do people help you though it?

J: Well, they just tell me everything's okay, and they kind of stay near me so I don't fall. Whatever. Or sit me down.

I: Kind of be there?

J: Yeah, to guide me. That's the kind of treatment.

In three cases, teens indicated that they did not need any help because of their difference. As Shannon explained, “I think they’re doing everything right. I don’t think it could be any different.” Five of the responses either reflected an uncertainty about what had been helpful (“I don’t know”) or pointed to something was not helpful. Brett, for example, had very clear ideas about how the main “help” he had received, special education, was actually a hindrance:

I should never have been in special education. That’s my thing. If I was in special education for a couple of years, yes, great fine. But to have been through, have been in special education all throughout high school, and learning the same things over and over again, I believe it was wrong. See, the school board tells, gives the schools an agenda of what to teach the special ed students. And they have to do that, and they can’t give a good student more, a higher level of work, they have to mainstream him. All the way, if he wants to do what should be done. It should be gone up step by step, not mainstreamed all the way, like they were trying to do to me. And it didn’t work, because they did it too fast.

Two Integrated Cases

To provide the reader with a sense of the coherence and depth of individual explanatory models across the different domains, we present a summary of two teens’ models, along with complementary ethnographic data. The teens represent two different levels of functioning and awareness about disability issues: one teen has mental retardation, and one teen is of average IQ but has an autistic disorder.

Case 1: Jay. Jay was born with a life-threatening heart condition and underwent several surgeries during his infancy and early years to correct the condition. He experienced a loss of oxygen at birth and is currently diagnosed as mentally retarded. At age 11, Jay was tested and found to have an IQ of 69. He is currently mainstreamed only for physical education. He is highly verbal and articulate but clearly impacted by both his cognitive limitations and, more significantly, his behavior problems. Jay’s parents have openly discussed his limitations with him since he was young. His mother expressed surprise that other parents might not take this route, asking, “How can you compensate for your weakness if you don’t know what it is?”

Jay identified two primary differences between himself and other teens: an *anger management problem*, a term he said he has heard used by teachers at his Individualized Education Plan (IEP) meeting and also read in his own school folder, and “mentally retarded.”³ He views the anger management problem as having an environmental origin (“I’ve been bossed around all my life by teachers, it’s about time I stand up for it . . . I’ve packed it in for too long”), although he also noted that anger was one of the problems caused by mental retardation. His mental retardation, he says, was caused by a “cut off [of] the blood flow and the oxygen to my head.” Jay perceives his anger problems as much more severe than the mental retardation, explaining that he may have to take medication soon to control his anger because his parents and teachers have “tried everything else in the book.” He compares himself to other mentally retarded kids, noting, “I’m not *that* severe. I don’t have to wear Depends . . . I don’t have to sit in a wheelchair, I don’t have to do none of that. I thank my lucky stars every day that I don’t have to do that.”

Although Jay dislikes attending church, in everyday conversations he talks about obeying God, and he was one of the few teens to incorporate God into his explanatory model. He explained that attention deficit disorder, another problem he identified in himself, will occur “if God wants you to have it. . . . If he don’t want you to have it, you can’t have it.” Jay’s explanatory model also implies that God plays a role in determining how permanent his differences are. Although Jay hopes to get rid of them someday, he doesn’t have any idea how. When we asked him if he had thought about it, he explained, “No, cause I’m going to leave it all up to God. If he wants to get rid of it, he gets rid of it, if he doesn’t, he doesn’t. Hopefully to God, I hope to God he takes it away.”

Jay faces a daily struggle, both wanting to overcome his anger and yet strongly identifying such behavior as part of him. Jay insisted that being angry only hurts others and oneself and noted that it causes only one problem: “doing stuff you’re going to regret. And then you get mad, you don’t think, you do stuff—I’m not saying *you* [the fieldworker] are, but some other people, they get angry, and they do stuff they don’t mean to do, and that’s probably where I fit in. Cause I’ve done stuff I don’t mean to do.” Yet Jay proudly used the phrase *hell-raiser* in reference to himself during the interview, and his explanatory model was consistent with his ethnographically observed behavior. For example, months before the EM interview, at an IEP meeting attended by the fieldworker, Jay had also referred to hell-raising. From Jay’s perspective, there was a lot riding on that meeting: he desperately wanted to return to his old high school, from which he was expelled for aggression toward other students. As the school psychologist spoke of Jay’s “aggression,” Jay raised his hand, interrupted, and said with a big grin, “Excuse me, but I prefer to use the term *hell-raising!*”

Despite his cognitive limitations, Jay has an extremely rich and coherent explanatory model for his difference, one that includes sophisticated relationships among the problems he identifies and several possible causes, his understanding of his limitations (“you get things confused sometimes, you get some things mixed up”), his assessment of the seriousness and permanence of his problems, and his recognition of the difficulty inherent in wanting to overcome his problems yet not relinquish the part of his identity linked to them.

Case 2: Bobby. Around kindergarten age, Bobby was diagnosed as autistic. Throughout his elementary school years he continued to make great improvements and currently displays wide scatter in his abilities: he is able to read and comprehend at a college level, voraciously devours current events and history, and attends regular classes, receiving no special assistance. He does very poorly in most school subjects, however, and has only recently begun to make genuine friendships. Bobby’s parents have never discussed the nature of his disability with him, telling him only that he has a learning disability.

Bobby has intensively analyzed his social and communication differences and provided evidence through his explanatory model that he has an accurate perception of his impairment. Bobby describes his difference in terms of “isolation” and speaking a different dialect than others (“their linguistic ability is more slangy”). In the absence of being told about his impairment, Bobby has constructed

a logical and coherent story. When asked simply to tell the fieldworker how he got to be the person he is, Bobby had an immediate answer:

Well, I grew up in a neighborhood with nothing but people who have moved on in life. You know, old married couples whose families have moved out, the elderly, the middle aged. That's why I tend to speak in an elevated tone. I really didn't have much exposure to fellow children, so I kind of, well that's why I'm kind of strange and bizarre. And when I did go into school, it was pretty horrendous. I learned very quickly that I was not really appreciated.

Bobby sees his communication and social difficulties as a direct result of his upbringing. He, did, in fact, live in a somewhat secluded neighborhood as a child and spent much of his time with retirees, who welcomed his company. There were other children in the neighborhood, but Bobby's mother recalls that in typical autistic fashion, he was largely oblivious to his peers.

Bobby's social and communicative differences clearly cause him stress at times: he has been known to curl up in a ball in a closet to avoid large social gatherings at his home, and he endured severe bullying during middle school. He now has come to view his differences as an integral part of who he is. In everyday conversation, Bobby continually refers to the "geeky" subculture to which he belongs because of his difficulty understanding others. With his few friends, he creates elaborate role-playing games that allow him to change who he is for a short time. As he insightfully explained to the fieldworker, "I always choose characters that are the exact opposite of me: this one is really attractive, good with the ladies, a drinker and smoker!" In his room, Bobby displays a small sign that reads, "You laugh at me because I'm different. I laugh at you because you're all the same."

Bobby recognizes both the genuine pervasiveness of his disorder ("Affected my entire life. Touched upon everything. How I think, *everything*. Even the tiniest difference, if you're a young person, it affects everything . . . because people notice it and they use it against you") as well as the permanence. When asked whether these differences would always remain, Bobby replied instantly, "Of course. There's not really anything I can do to change it. And I don't really want to change it. I mean, I've survived this long, fought this hard to be my own self, been beat up for it and persecuted for it, and withstood it all. I don't think I really want to change now."

Discussion

We have demonstrated that teens with developmental, cognitive, emotional, and behavioral problems have ideas on a wide range of topics relating to their difference or disability, as illustrated by the fact that about half the teens in this sample were able to provide meaningful EM responses. Teens used a range of disability-specific explanations, referencing peers who are disabled, comparing themselves to disabled peers, noting that their difference impairs certain cognitive, physical, or emotional aspects of their lives, and recognizing the roles played by others in either assisting them or contributing to their difficulties. Teens also gave a variety of responses to questions, however, that are reflective of typically developing teens as well, for example, highlighting aspects of their personality, hobbies, activities, and beliefs that are either similar or different from those of other teens. A number of

teens blended these two models and produced thoughtful and coherent descriptions of who they are and how they view themselves.

It is clear from our conversations with them that their sense of identity and self-conception go well beyond the simple constructs of self-esteem and self-worth that have generally been examined in the psychological literature to date. These teens discuss how they feel about themselves, and it is clear that their disability plays a role in their self-evaluation. It is also clear, however, that asking teens simple questions about their perceived worth misses the rich and varied beliefs they have about *why* they are good, *how* they are different, and what this *means* in their daily lives. Teens often described themselves by referencing rich and varied social and interpersonal experiences and specific, concrete contexts and activities. Exclusively individualistic, decontextualized accounts were rare.

Our findings suggest that explanatory models are important adaptive tools by which individuals make sense of their worlds. In that sense, grasping the EMs of youths with disabilities can only assist policy makers' and service providers' goals and broaden how we think about family adaptation (Gallimore et al. 1999) and about the age at which appropriate interventions are useful, whether early in life (Weisner et al. 1996) or during adolescence. The teens in our sample who responded to our EM questions have clearly grappled with difficult questions facing all adolescents—Who am I? Why am I like this?—and are emerging as young adults with answers to these questions. Some in our sample who did not or could not respond surely have formulated at least some notions regarding those issues as well, even if they could not express them.

An important distinction between the explanatory model framework as it has been commonly used by anthropologists and others and its application in this population relates to the issue of identity. Whether the teens in our sample articulate it or not, the reality is that their disabilities are not conditions curable through treatment. Furthermore, they cannot fully comprehend the effect their disabilities have had on their lives, because, in addition to the influence of cognitive deficits, they have known no other way of being. In this latter regard, our teens are analogous to the members of any other cultural community who have a worldview and set of beliefs that are implicit and largely unquestioned. Even though they know *of* other ways of being, or thinking, or behaving, those other ways are not *their* schema and do not match their experience. Our teens, of course, know of typical development—but from a position of lifelong disability that comes from sociocultural positioning as well as their own cognitive and physical competencies (Skinner et al. 1999). Our data suggest that the teens in our sample have a kind of blended, layered sense of self and identity—drawing from and using typical identities and experiences, yet framed within a life of disability.

By knowing more about a teen's own sense of self and perceived needs, interventions can be more effectively tailored to the individual. Our sample of adolescents with disabilities is similar to the majority of youth in special-education programs today; although heterogeneous, they are in fact representative of this large group. Our study suggests that *about half* the teens we interviewed were able to provide meaningful and useful answers to our questions, and others were able to meaningfully respond to at least some of them. Hence, these data are relevant to formulating interventions for many teens currently in special-education programs.

Listening to teens' explanatory models for their situations also can help open up avenues of communication among them, their parents, and professionals. Yet there are contemporary culture-historical circumstances that make examining disabled teens' experiences difficult. Perhaps more significant than the cognitive limitations of the teens, the strong cultural models of the person and moral assumptions about labeling that prevail at this juncture in history, ironically, might preclude asking people about the very thing that makes them "other." Whether in the schools or the media, an understandable and important goal is to minimize the stigma associated with disability or to normalize certain aspects. Some in society at large will avoid the topic altogether. Even members of our fieldwork team sometimes felt uncomfortable talking directly about the topic of disability, especially when they were the ones to broach it. Some teens, however, clearly found our interviews a forum for speaking about their lives that they otherwise did not have. If we had avoided open discussions of the very real and salient differences that distinguish teens with disabilities, then we, like others, would have missed the opportunity to better understand the diverse and interesting views that teens hold. By taking their explanatory models more explicitly into account, teens and their families might well facilitate the teens' development and thereby further their well-being.

The explanatory model method, however, demands that respondents possess both cognitive and language skills, and disabled teens are frequently impaired in one or both of these areas. Like the teens struggling to communicate with us, we struggled to make the questions clear to them on their terms and at times to understand the teens' responses. As indicated by the quality of response scores, cognitive abilities clearly play a role in the degree to which these teens were able to discuss the various topics. Still, cognitive ability alone does not serve as an indicator of competence to respond to our questions, because meaningful responses were often uncovered across the range of ability scores. Revisiting Table 1 shows that, leaving aside the very lowest IQ and functioning teens, there is little relationship between quality of response and IQ.

Although several teens in our sample simply did not understand our questions, it is still highly likely that they have some sense of their disability. An interesting question is whether these lower functioning and nonverbal teenagers are able to express an understanding of their disability, and of the explanatory model domains, through nonverbal means. We have ethnographic evidence that they often do, and such nonverbal signs perhaps can be incorporated into future EM analyses. If professionals are willing to invest the time to actually engage with lower functioning teens, they may elicit meaningful answers even from those they may not suspect of having explanatory models of disability. We discovered, for example, that several teens whose parents believed them to be "oblivious" to their difference, in fact were acutely aware of it. Another important area for further research using explanatory models is to develop ways to discriminate between teens with different kinds of abilities and disabilities that affect the way they express their understanding to others.

Now that we have established the range of explanations and descriptions the adolescents in our sample have, we can turn to studies of how they are patterned within each teen's answers (our two case reports suggest such patterns) and across all the teens' answers. We now will be able to compare teens' responses to those of their parents, because we also asked parents the same questions. Because we have

longitudinal data on each teen's childhood at home and at school, we can search for antecedents and correlates of the development and impact of EMs on teens' lives. We can also attempt comparative studies of cultural or ethnic variations in EMs. One result of our conversations with adolescents about their explanatory models is to open up a variety of new research questions about explanatory models.

NOTES

Acknowledgments. This work is supported by grants # HD19124 and HD11944 from the National Institute of Child Health and Human Development. The authors gratefully acknowledge the support of Robert B. Edgerton, Ronald Gallimore, Barbara Keogh, Lucinda Bernheimer, Kazuo Nihira, and their other colleagues in UCLA's Center for Culture and Health and the Mental Retardation Research Center. The Fieldwork and Qualitative Data Laboratory (Grant # P30 HD04612) at the Center for Culture and Health provided support for the EthnoNotes field note system. Most of all, we thank the families and youth participating in this study for their dedication to having their stories heard.

Correspondence may be addressed to Tamara Daley, University of California, Los Angeles, Box 951563, Los Angeles, CA 90095-1563, tcdaley@ucla.edu.

1. The original Kleinman questions are (1) What do you think has caused your problem? (2) Why do you think it started when it did? (3) What do you think is happening to your body when you have the pain? How does this work? (4) How severe is your illness? Will it have a long or a short course? (5) What kind of treatment do you think you should receive? (6) What are the most important results you hope to receive from this treatment? (7) What are the chief problems your illness has caused for you? (8) What do you fear most about your illness?

2. Our codes are, of course, not the only codes that could have been derived. We have quoted extensively from the adolescents' conversations with us throughout our presentation of the results, to ensure a focus on the content and to allow the reader to consider for him or herself the relevance of the code categories. The codes help to open up for description and analysis the EM data themselves.

3. By law, every student in special education must have an IEP, which is reviewed annually, typically by the teacher, parent, a school administrator, any psychologists involved with the case, and the child or teen, if he or she wishes.

REFERENCES CITED

- Bernheimer, Lucinda P., and Barbara K. Keogh
 1982 Project REACH Final Report. Preschool Longitudinal Study. Los Angeles: University of California.
 1986 Developmental Delays and Developmental Disabilities in Preschool Children. *In* Advances in Special Education Vol. 5. Developmental Problems in Infancy and the Preschool Years. Barbara K. Keogh, ed. Pp. 61-93. Greenwich, CT: JAI Press.
 1988 The Stability of Cognitive Performance of Developmentally Delayed Children. *American Journal of Mental Retardation* 92:539-542.
- Bernheimer, Lucinda P., Barbara K. Keogh, and Jennifer J. Coots
 1993 From Research to Practice: Support for Developmental Delay as a Preschool Category of Exceptionality. *Journal of Early Intervention* 17(2):97-106.
- Charlton, James I.
 1998 *Nothing about Us without Us: Disability Oppression and Empowerment*. Berkeley: University of California Press.

- Cosden, Merith, Katherine Elliott, Sharon Noble, and Eve Kelemen
 1999 Self-Understanding and Self-Esteem in Children with Learning Disabilities. *Learning Disability Quarterly* 22:279–290.
- Dudley, James R.
 1997 *Confronting the Stigma in Their Lives: Helping People with a Mental Retardation Label*. Springfield, IL: Charles C. Thomas.
- Edgerton, Robert B.
 1970 Mental Retardation in Non-Western Societies: Towards a Cross-Cultural Perspective on Incompetence. *In Socio-Cultural Aspects of Mental Retardation*. H. Carl Hayward, ed. Pp. 523–559. New York: Appleton-Century-Crofts.
- Edgerton, Robert B., ed.
 1993 *The Cloak of Competence*, 2nd edition. Berkeley: University of California Press.
- Elkind, David
 1967 Egocentrism in Adolescence. *Child Development* 38:1025–1034.
- Frank, Gelya
 2000 *Venus on Wheels. Two Decades of Dialogue on Disability, Biography, and Being Female in America*. Berkeley: University of California Press.
- Gallimore, Ronald, Lucinda P. Bernheimer, and Thomas S. Weisner
 1999 Family Life is More than Managing Crisis: Broadening the Agenda of Research on Families Adapting to Childhood Disability. *In Developmental Perspectives on Children with High-Incidence Disabilities*. Ronald Gallimore, Lucinda P. Bernheimer, Donald L. MacMillan, Deborah L. Speece, and Sharon Vaughn, eds. Pp. 55–80. Mahwah, NJ: Erlbaum.
- Gallimore, Ronald, Jennifer J. Coots, Thomas S. Weisner, Helen E. Garnier, and Donald Guthrie
 1996 Family Responses to Children with Early Developmental Delays II: Accommodation Intensity and Activity in Early and Middle Childhood. *American Journal on Mental Retardation* 101:215–232.
- Glenn, Sheila, and Cliff Cunningham
 2001 Evaluation of Self by Young People with Down Syndrome. *International Journal of Disability, Development and Education* 48(2):163–177.
- Groce, Nora Ellen
 1985 *Everyone Here Spoke Sign Language. Hereditary Deafness on Martha's Vineyard*. Cambridge, MA: Harvard University Press.
- Ingstad, Benedicte, and Susan Reynolds Whyte
 1995 *Disability and Culture*. Berkeley: University of California Press.
- Jenkins, Richard, ed.
 1998 *Questions of Competence. Culture, Classification and Intellectual Disability*. New York: Cambridge University Press.
- Keogh, Barbara K., Lucinda P. Bernheimer, Ronald Gallimore, and Thomas S. Weisner
 1998 Child and Family Outcomes over Time: A Longitudinal Perspective on Developmental Delays. *In Families, Risks, and Competence*. Michael Lewis and Candice Feiring, eds. Pp. 269–287. Mahwah, NJ: Erlbaum.
- Kleinman, Arthur
 1980 *Patients and Healers in the Context of Culture*. Berkeley: University of California Press.
- Kleinman, Arthur, Veena Das, and Margaret Lock, eds.
 1997 *Social Suffering*. Berkeley: University of California Press.
- Marshall, Mac
 1996 Problematizing Impairment: Cultural Competence in the Carolines. *Ethnology* 35(4):249–263.

- Miles, Matthew B., and A. Michael Huberman
1994 *Qualitative Data Analysis*. Thousand Oaks, CA: Sage.
- Miller, Nancy B., and Catherine C. Sammons
1999 *Everybody's Different. Understanding and Changing Our Reactions to Disabilities*. Baltimore: Paul Brookes.
- Murphy, Robert Francis
1987 *The Body Silent: A Journey into Paralysis*. New York: Henry Holt.
- Olney, Marjorie F., and Amanda Kim
2001 *Beyond Adjustment: Integration of Cognitive Disability into Identity*. *Disability and Society* 16(4):563–583.
- Skinner, Debra, Donald B. Bailey Jr., Vivian Correa, and Patricia Rodriguez
1999 *Narrating Self and Disability: Latino Mothers' Construction of Identities vis-à-vis Their Child with Special Needs*. *Exceptional Children* 65(4):481–495.
- Stiker, Henri-Jacques
1999 *A History of Disability*. Ann Arbor: University of Michigan Press.
- Weisner, Thomas S., Catherine Matheson, and Lucinda Bernheimer
1996 *American Cultural Models of Early Influence and Parent Recognition of Developmental Delays: Is Earlier Always Better Than Later? In Parents' Cultural Belief Systems*. Sara Harkness, and Charles M. Super, eds. Pp. 496–531. New York: Guilford Press.
- Weiss, Mitchell
1997 *Explanatory Model Interview Catalogue (EMIC): Framework for Comparative Study of Illness*. *Transcultural Psychiatry* 34:235–263.
- Whitney-Thomas, Jean, and Mairead Moloney
2001 *"Who I Am and What I Want": Adolescents' Self-Definition and Struggles*. *Exceptional Children* 67(3):375–389.

Accepted for publication June 24, 2002.