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## Perspectives of Dentists, Families, and Case Managers on Dental Care for Individuals With Developmental Disabilities in Kansas

Amanda Reichard, H. Rutherford Turnbull, and Ann P. Turnbull

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### Abstract

The status of dental care for individuals with developmental disabilities in Kansas was examined. Dentists, family members, and case managers reported general, but partial, satisfaction with the availability, accessibility, appropriateness, and affordability of such care. Reasons for the results and recommendations for further improvement are discussed.

For nearly 15 years, there has been a research-based consensus that people with developmental disabilities have experienced greater difficulty in securing health care than do people without disabilities. This difficulty has been especially problematic for several reasons (Palfrey, Samuels, Haynie, & Cammisa, 1994; Singer, Butler, & Palfrey, 1986). First, individuals with developmental disabilities, compared to peers in the typically developing population, have a greater variety and number of medical and dental care needs (Vittek et al., 1994; Ziring et al., 1988). Second, increased severity of a disability usually requires an increase in the amount of health care provider contacts (Boyle, Decoufle, & Yeargin-Allsopp, 1994; LaPlante, Rice, & Wenger, 1997). Third, early detection allows for prevention and potential improvements in health status and quality of life; barriers can impair health status and quality of life, yet can be cost effective (Levy & Hyman, 1993; Vittek et al., 1994). Finally, although antidiscrimination laws, especially the Americans With Disabilities Act and the Rehabilitation Act, prohibit discrimination, their implementation has been problematic (Matson, Holleman, Nosek, & Wilkinson, 1993).

As part of a statewide effort sponsored by Kansas Policy Council on Developmental Disabilities to determine the status of health and dental care for Kansans with developmental disabilities, the Beach Center on Families and Disability at The University of Kansas conducted three studies. One was focused on the training of physicians and dentists. Two others were focused on medical and dental care; one of these two also included a focus on obstetrical-gynecological care for women from populations other than European American and for lower socioeconomic populations. In this article we report the

results of the research on the status of dental care for persons with developmental disabilities in Kansas. We begin by describing the conceptual framework, then report the methods and results, and conclude with a discussion of the findings, which were surprising in light of comparable prior research, namely, dental care is generally available, accessible, affordable, and appropriate.

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### Conceptual Framework for the Study

Our conceptual framework for this research consisted of what we term the "Five A" inquiry: Is dental care (a) available, (b) accessible, (c) affordable, (d) appropriate, and (e) accountable? Our data yielded answers to the first four but not the last of these criteria.

#### *Availability*

*Availability* addresses the question of whether health care for the population under consideration is available; that is, does it exist? Subsumed under availability are questions related to transportation and distance to appointments, sufficient providers in relation to the numbers who need health care services, sufficient providers both who *can* and *will* give appropriate care, and whether health care providers are accessible by phone and for appointments when necessary.

Little is known about availability of such care in Kansas. There are no published data from surveillance strategies; only one recent study exists. Davis et al. (1999) concluded that only a small percentage of all child Medicaid recipients use that funding for dental care, primarily for two reasons: provider distribution and acceptance of Medicaid recipients by dentists. In Kansas, the distribution of providers does

not match the distribution of need, especially for Medicaid recipients. Similar to the national average of 58 dentists per 100,000 residents, there are 50 dentists in Kansas for every 100,000 residents. Moreover, "Currently, 3 percent ( $n = 35$ ) of all Kansas dental providers serve 49.6% of Medicaid enrollees, indicating that Medicaid dental patients are concentrated among a very small number of providers" (Davis et al., 1999, p. 10). In addition, only 27% of dentists in Kansas treated any Medicaid recipients in 1998. Similarly, more than 30% of caregivers of children who receive Medicaid have had difficulty locating a dentist who accepts Medicaid for payment (Davis et al., 1999).

Investigators have reported similar results in other states where dentists frequently refuse to treat Medicaid recipients. These investigators cited several reasons for dentists' refusal, most notably, poor reimbursement (Burtner & Dicks, 1994; Damiano, Brown, Johnson, & Scheetz, 1990; Lang & Weintraub, 1986; McKnight, Myers, & Dushku, 1992; Nainar & Tinanoff, 1997), especially in relation to the required time and efforts (Academy of Dentistry, 1996). Other reasons include frequent administrative encumbrances, including extensive paperwork (Damiano et al., 1990; Lang & Weintraub, 1986; Nainar & Tinanoff, 1997); stigma (Davis et al., 1999); dissatisfaction with frequent cancellations or broken appointments (Damiano et al., 1990; Lang & Weintraub, 1986); poor patient compliance with posttreatment regimens (Academy of Dentistry, 1996); and a self-imposed quota system that limits the practice of treating Medicaid patients to approximately 10% of a practice (Nainar, Edelstein, & Tinanoff, 1996). In addition, treatment of individuals with disabilities frequently requires additional skills, knowledge, and equipment that dentists may not have (Academy of Dentistry, 1996; Burtner & Dicks, 1994). Families also face barriers of availability other than provider willingness to treat, including multiple providers, multiple entry points, complex and lengthy applications, conflicting criteria across programs, redundant or otherwise burdensome administrative paperwork requirements, and limited patient-treatment time per patient despite greater time being made available (Hughes, Halfon, Brindis, & Newacheck, 1996; Palfrey et al., 1994; Reichard, Moberly, Morningstar, Turnbull, & Umbarger, 2001; Reichard, Turnbull, & Turnbull, 1999), and distance and travel logistics (especially in rural areas) (Davis et al., 1999; Palfrey et al., 1994; Reichard et al., 2001).

### *Accessibility*

*Accessibility* addresses the question of whether

health care is accessible to individuals with disabilities. The core inquiry is whether dental care complies with Section 504 of the Rehabilitation Act and the ADA, including provisions primarily related to language and structural accommodations. Unfortunately, no published studies exist to document the extent to which dentists comply with the ADA regarding structural or communication accommodations. Our data seem to be the first of their kind.

### *Affordability*

*Affordability* addresses the question of whether health care is affordable for families. Do families have some form of health insurance? If so, does the insurance provide sufficient coverage of necessary services? Finally, what are the families' out-of-pocket expenses?

Prior research justifies the conclusion that fiscal barriers abound. There are five elements of these barriers. First, significant numbers of individuals remain without sufficient other coverage reimbursed through private insurance or Medicaid to access the services they need (Bolden, Henry, & Allkian, 1993). Second, insurance caps limit the lifetime spending for health care and ineligibility for Medicaid or other funding results from strict eligibility requirements (Palfrey et al., 1994). Third, employers' benefit packages also tend to be insufficient, leaving the onus on parents to advocate against the insurance company or Health Management Organization (HMO) for needed services for their child (Rosenfeld, 1994). Fourth, when they become 21, individuals with developmental disabilities in some states age-out of Medicaid eligibility and other public-entitlement eligibility (Bolden, 1993; H. Waldman & Perlman, 1997; H. B. Waldman, 1997); they also age out of coverage by their parents' insurance (Hughes et al., 1996; Palfrey et al., 1994). Fifth, the current system of disability-categorical programs (where funding streams are separated into groups in which eligibility is determined for each group by disability) benefits certain population groups but often is too specific (and thus contributes to coverage gaps and ineligibility) for other individuals (Hughes et al., 1996).

Under Kansas' Medicaid plan, the state reimburses the services that the federal Medicaid program (Title XIX) requires it to reimburse. Title XIX considers dental services to be "optional services," not mandatory-reimbursement services. Similar to most other states, Kansas elects to provide some dental services. For children, Kansas reimburses "routine dental services like cleanings, x-rays, sealants, fillings, and extractions" (Kansas Department, 1999,

p. 34). Unlike in most other states (Davis et al., 1999), however, Kansas reimburses adult recipients for only "medically necessary extraction" (Kansas Department, 1999).

Rates of use among child Medicaid recipients in Kansas are similar to the low national rates of service (Celnick, Purvis, & Walker, 1996; Robison, Rozier, & Weintraub, 1998; H. B. Waldman, Perlman, & Swerdloff, 1999). In 1998, dental services were received by only 29% of children enrolled in Medicaid (Davis, 1999). Significantly, this rate for children is more than twice as high as the usage rate among the general Kansas population (14%) and the general national Medicaid population in 1998 (12%) (Health Care, 1998).

### *Appropriateness*

The question related to *appropriateness* is whether the dental care that is both available and accessible meets the needs of the population of persons with developmental disabilities. Criteria for appropriateness include whether health care providers (a) have the specialized knowledge necessary to treat any special needs and (b) treat the individuals and their families with respect concerning issues of disability (especially mental capacity), race, socio-economic status, and language barriers.

Recent studies have shown that dentists perceive that they are not well-prepared to treat individuals with developmental disabilities (Academy of Dentistry, 1996; Burtner & Dicks, 1994; Fenton, 1993; Stiefel, Turelove, Martin, & Mandel, 1997). In one survey, 60% of dentists indicated that they want more information about individuals with developmental disabilities (Reichard et al., 1999). Moreover, an Academy of Dentistry for Persons With Disabilities (1996) study, showed that "many dentists are reluctant to treat this population due to a lack of knowledge and understanding, feelings of inadequacy and an inability to obtain fees commensurate with the time and effort required" (p. 3). Fenton (1993) reported that dental schools lack clinical and didactic training concerning treatment for individuals with disabilities. Moreover, the American Association of Dental Schools' curriculum guidelines for predoctoral students require the application of these guidelines not to individuals with multiple or profound disabilities, but only to individuals with mild disabilities (Burtner & Dicks, 1994).

Other studies, however, show that dentists who have had significant exposure to and experiences with individuals with developmental disabilities in their training programs are willing to treat such individuals (Ferguson, Berentsen, & Richardson,

1991; Stiefel et al., 1997). Those same dentists say their general population practice benefits thereby (Ferguson et al., 1991).

Nevertheless, even dentists themselves admit that attitudinal barriers to care persist: "I don't think they [people with developmental disabilities] are treated with the same level of courtesy and respect as non-retarded dental customers" (Brooks & Dwyer, 1997, p. 2). Moreover, even if an individual receives treatment, it is highly unlikely that that individual will have a choice of providers (Brooks & Dwyer, 1997). The families also believe that poor care and mistreatment of their family member with disabilities demonstrate the lack of dentists' preparation and skills. Some parents report that dentists often dismiss the parents' knowledge and do not listen (Wilson, 1994). Others report unmet dental needs (Clevenger, Wigal, Salvati, Burchill, & Crinella, 1994; H. Waldman & Perlman, 1997).

Having reviewed the previous research related to the four criteria, we wanted to determine whether the Kansas profile is comparable or not to the national profile as noted in the research literature.

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## **Method**

### *Survey*

We first used mail surveys to collect data for this research. To select participants we solicited the help of agencies relevant to each constituency and used stratified sampling, stratifying by city/town, to ensure equal representation of rural, suburban, and urban areas (Fowler, 1993). Participants included three constituencies: parents of children with developmental disabilities, case managers at Community Development Disability Organizations, and dentists.

### *Sample*

Parent participants were parents of individuals with developmental disabilities who resided in Kansas. To secure their participation we contacted the state Parent Training and Information Center, Families Together. Then, to maintain confidentiality, we prepared self-stamped survey packets and delivered them to Families Together, where agency personnel attached mailing labels. Per our instructions, they created these labels from their roster by selecting 1,288 families; they selected everyone from 13 smaller cities/towns and every fourth person on the roster in three larger cities. We chose these 16 areas based on their geographic diversity and representativeness of the state, including equal representation of rural, suburban, and urban areas. We did not ascertain income/family

wealth data on our respondents. The response rate was 26% for this original parent survey. The majority of the children were European American (84%) and were under 18 years of age (77%). Twenty-five percent of parents who responded lived in rural areas, 39% in suburban, and 31% in urban areas. Following the original survey, we mailed an extension questionnaire to every parent who responded to our original family survey (335). (We discovered the need for the extension questionnaire in the process of the research. After examining the original survey data, we discovered that several questions were not answered.) We mailed postcards as a follow-up reminder to families to respond to the survey. Thirty-six percent of these families responded to the extension survey. Demographics of the extension questionnaire were nearly identical to those of the original survey.

Case manager participants worked in Community Developmental Disability Organizations, which coordinate supports and services for individuals with developmental disabilities from age 5 through adulthood in every area in the state. We contacted all 28 of these organizations to obtain case manager participants; 26 agency representatives agreed, resulting in participation of 26 of these (52 case managers). To gain their participation, we spoke with the Director of Case Management at each of the Community Developmental Disability Organizations, asking for their cooperation and endorsement for two case managers from their agency to each complete a questionnaire. We mailed two copies of the case manager questionnaire packets to each director who had agreed to participate and asked them to distribute the packets to two of the case managers who work with them. To follow up, we again contacted the director and asked them to please remind the case managers to whom they had given the questionnaires to return them. The case manager survey achieved a response rate of 76%. More than 40% of Community Developmental Disability Organizations included in the respondent group serve more than 120 individuals with developmental disabilities. Most case manager respondents (62%) described the area in which they work as rural, and 16% and 19% described their regions as suburban and urban, respectively.

Dentist participants maintained practices in Kansas and treated individuals with developmental disabilities. To gain their participation, we contacted the American Dental Association for a roster of their membership in Kansas. To achieve the same geographic representation as families, we selected dentists from the roster in each of the 16 areas where families had been selected and in a manner similar to the method by which families were

selected; every 4th dentist in the 13 smaller areas was selected and every 6th dentist in the three larger areas was selected. This selection resulted in a total of 162 potential dentist respondents. We received a survey response rate of 43% from dentists. The majority of these respondents (84%) had practiced for more than 10 years. Many practiced in suburban areas (44%), and 32% and 25% practiced in rural and urban areas, respectively.

### *Procedure*

There are at least three reasons to use surveys for data collection. First, the researcher can estimate the precision of the data by using probability sampling. Second, for some data needed, a survey may be the only available method for collecting it; no other sources, such as existing records, can provide the same information. Third, comparable information is ensured by collecting standardized measurements across respondents (Fowler, 1993). Moreover, it was appropriate to use mail surveys because we had a modest budget and our sample was spread out geographically (Mangione, 1995).

To develop the questionnaires for the survey, we conducted a thorough review of the literature to gain a command of existing relevant work. Then, to identify issues, we explored the topic through informal interviews and focus groups with a variety of people with knowledge or experiences in obtaining health care for individuals with developmental disabilities (Mangione, 1995), including members of the state Developmental Disability Council, parents, and case managers from a community living organization and a Community Developmental Disability Organizations. We pretested the draft in three ways: (a) through "critical reading" (Mangione, 1995, p. 24); (b) by having colleagues read it and provide feedback; and (c) for the parent questionnaire, by having a few parents completely fill it out (Mangione, 1995).

Parent and case manager questionnaires contained the same questions, but in slightly different formats. The dentist questionnaire addressed the topics from a different perspective to minimize the perception of researchers as critical of the work of dentists (Fowler, 1993). In an effort to ensure reliable, honest answers, we assured case manager and dentist respondents that their answers would be anonymous; it was made clear in the cover letter that in no way would anyone be able to identify who had filled out a particular questionnaire (Fowler, 1993). To indicate interest in further participation, case managers and dentists were encouraged to return a self-addressed, stamped postcard. Similarly, families had the option of remaining anonymous or indicating their interest in further participation in our research by listing their

contact information on their survey.

### *Analysis*

Once the surveys were returned, coders entered the data into a database using a clear set of coding rules (Fowler, 1993; Mangione, 1995). Responses to open-ended questions were typed in word for word. Following the data entry, the data were checked for "out-of-range" responses and for errors of "consistency" (Mangione, 1995 p. 103). The data from the closed-ended questions were transferred to SPSS, where procedures of that computer program were used for analysis. The data from the open-ended questions were analyzed using qualitative methods of organizing raw data, generating categories and themes, and interpreting themes and patterns (as described later for focus group analysis).

### *Focus Groups*

After the surveys, we conducted focus groups with each of these constituencies (i.e., families, case managers, and dentists), for a total of seven focus groups. We used purposive sampling to select participants. Purposive sampling involves selecting participants known to hold characteristics that match selection criteria established by researchers and to have expertise in the research topic of interest (Brotherson, 1994). The selection criteria used for this study are described next in the description of the sample.

### *Sample*

Three family and three case manager groups were composed from the list of survey respondents from each of the respective constituencies who had indicated their willingness to participate further. We contacted potential members by phone to request their participation until we had three to five members for each group.

Unfortunately, we were unable to gain the participation of practicing dentists from the survey respondent group. When we originally mailed the questionnaires, we enclosed a self-addressed, stamped postcard for dentists to indicate their interest in further participation. However, we received only a few of these postcards, and when we contacted those who had returned the cards, they were unable or unwilling to participate in the focus group. Instead, we used alternative methods for establishing this group. The three-member dental focus group was composed with the assistance of a dentist (the dentist providing care to a child of a colleague of the researcher) who volunteered to convene a group.

### *Procedure*

Focus groups are designed to elicit consumers'

feelings, manner of thinking, and perceptions about particular opportunities, products or services (Krueger, 1994). There were several advantages to using focus groups for this research. First, and most important, focus groups allow for probing. Second, costs to conduct them are typically low. Third, focus groups have high face validity. Finally, the environment of focus groups allows for a synergism among participants that encourages candid responses (Krueger, 1994).

We conducted the focus groups via teleconference. To the greatest extent possible for all groups, the members were chosen to ensure geographical representation of the state. Each group received a packet of information prior to the focus group, including informed consent forms and a general explanation of how the focus group would operate. Each focus group lasted between 45 minutes and an hour.

For each of the constituencies, we carefully selected questions to create an interview guide and one person served as the moderator for all of the focus groups to ensure consistency (Krueger, 1994). At the same time, the moderator remained alert for unexpected questions that could benefit the research (Krueger, 1994). We tape recorded all focus groups and transcribed the tapes for analysis.

### *Analysis*

This transcript-based analysis involved reviewing focus group transcripts and field notes. Two researchers read and analyzed the data separately and later met to reach consensus on any discrepancies in their interpretations. The analysis involved established techniques including (a) organization and reduction of raw data, (b) generation of categories and codes, and (c) interpretation of patterns and themes (Krueger, 1994; Stewart & Shamdasani, 1990; Taylor & Bogdan, 1998).

Upon first reading, two researchers indicated in the margins the important sentences and paragraphs. Then, they separately generated categories and codes by which to identify patterns and themes of the transcripts, and later reached consensus on this coding. After all transcripts were read and coded, the data were sorted by category and the lead researcher examined them to understand the thoughts of the focus group members. The second researcher read the written analyses of these interpretations. Wherever necessary, the researchers met to resolve discrepancies of interpretation.

**Findings**

*Findings From Families' and Case Managers' Surveys*

Families and case managers reported problems through surveys with dental care in the following order of difficulty, from greatest to least: (a) affordability, (b) appropriateness, (c) availability, and (d) accessibility.

*Affordability.* According to case managers (93%), lack of funding was the biggest barrier to obtaining dental care. On the other hand, only 4.2% of families reported that their child lacks dental care due to little or no funding.

*Appropriateness.* Respondents discussed two types of appropriateness: (a) dentists' communication and (b) dentists' knowledge, skills and approach. Issues of communication engendered a wide range of responses. Although 29% of case managers reported that dentists did not communicate directly with individuals who had developmental disabilities, 40% rated dentists as "good" or "very good" communicators with these individuals (see Table 1). Among case managers, 34% said dentists did not allow extra time for communication barriers; 26% said dentists did not use such accommodations as sign language interpreters and padded time (extra time) slots. In these same three categories, only 17% of families ranked their children's dentist as "poor" or "very poor" in communication skills.

With respect to the category of dentists' knowledge, skills, and approach (e.g., attitude, ability to handle routine and extraordinary health maintenance, and ability to refer appropriately), case managers (46%) and parents (24%) indicated a weakness among dentists in their knowledge of individuals with developmental disabilities (see Table 2), with some parents noting that their child's dentist had no understanding of the disability and that they needed training concerning it.

All but 14% of case managers and 4% of families indicated that dentists' effectiveness in dealing with routine dental maintenance was average or above average. However, 34% of case managers rated the dentists' effectiveness in dealing with *extraordinary* dental needs (e.g., need for sedation, need for complex dental care) as "poor" or "very poor." On the other hand, many case managers (57%) and families (80%) indicated that dentists were friendly with individuals who had developmental disabilities, and only 14% of case managers and 7% of families considered the dentists to be "poor" or "very

poor" in this regard.

**Table 1** Ratings of Effectiveness of Dentists' Communication (in %)

Barrier	Poor	Neutral	Good
Communicate directly with clients whenever possible			
Case managers	29	31	40
Families	20	19	61
Allow extra time for communication barriers			
Case managers	34	46	20
Families	19	28	53
Make accommodations for communication facilitators when necessary			
Case managers	26	57	17
Families	17	53	31

**Table 2** Perceptions of Dentists' General Effectiveness (in %)

Barrier	Poor	Neutral	Good
Effectiveness in dealing with ordinary health maintenance			
Case manager	14	43	57
Families	4	13	83
Effectiveness in dealing with extraordinary health needs			
Case manager	34	29	43
Families	11	24	66
Knowledge about individuals with developmental disabilities			
Case manager	46	31	22
Families	24	31	45
Friendliness			
Case manager	14	29	57
Families	7	12	80
Flexibility in making unexpected but necessary special accommodations			
Case manager	24	39	36
Families	10	33	57

*Availability.* Availability of services involves the number of providers in the area in relation to the number needing services, the ease of locating care providers, and ease in making appointments. (There were no statistically significant differences according to the geographic area of the state - rural, suburban, or urban.) The majority of case managers (54%)

indicated that a dentist is available to more than 90% of the individuals with developmental disabilities whom they support. By contrast, 14% of the case managers indicated that a dentist is available to less than 10% of their clients. Nearly 82% of parents indicated that a dentist is available to their children. Nearly 41% of case managers and 28% of families noted that the number of dentists in their areas, in relation to the number of clients who needed dental care, was "poor" or "very poor; this finding did not vary significantly by geographic areas.

On two other measures of availability-appointments and quality - only 30% of case managers and 10% of families indicated difficulties in making appointments. Only 43% of case managers and 13% of families indicated their needs were *not* well met (see Table 3).

Finally, transportation was generally not an issue for many respondents. Most individuals with developmental disabilities had access to some mode of transportation for dentists' appointments, regardless of the distance they lived from their dentists (see Table 3). However, 27% of case managers and 13% of parents indicated that individuals with developmental disabilities have difficulty accessing transportation to these appointments. Most case managers (81%) and parents (68%) also noted that individuals with developmental disabilities travel less than 15 miles for dental care, whereas only 6% of case managers and 3% of parents indicated that they had to travel more than 45 miles.

**Table 3** Rating of Various Potential Barriers to Accessing Care (in %)

Barrier	Poor	Neutral	Good
How well consumers' needs are met			
Case manager	43	24	32
Families	13	18	69
Physical/structural accessibility of office buildings			
Case manager	19	19	61
Families	6	20	74
Clients' ease in accessing transportation to care			
Case manager	28	17	56
Families	10	31	59
Ease in making appointments			
Case manager	31	25	44
Families	15	17	68

*Accessibility.* Accessibility posed few problems for most respondents. Nineteen percent of case managers

indicated difficulties with accessibility. Only 6% of families noted difficulties in this area (see Table 3). Some experienced difficulty in opening the front doors. Others had problems with the dental work stations being too small or having too many cords and other equipment to step over.

*Findings from Families' and Case Managers' Focus Groups*

In addition to the surveys, focus groups consisting of families and case managers addressed the same issues as the surveys: (a) affordability, (b) appropriateness, (c) availability, and (d) accessibility.

*Affordability.* Some families noted that they had to pay out-of-pocket despite receiving Medicaid payments because of the difficulty of finding dentists who will accept Medicaid payments. Still others described having poor dental insurance coverage and having to pay more for their child with a disability because the dentist spent more time on and assigned more staff to their child or saw them after regular hours of business. Moreover, because of uncertainty about insurance policies' coverage, and the time and effort involved in advocating for coverage by insurance companies and completing paperwork required for reimbursement, parents experienced an extraordinary amount of stress: "(Y)ou get to a point where it is sometimes easier to pay than fight the insurance company. You have to choose your battles." Similarly, case managers reported that the Community Development Disability Organizations frequently had to absorb the costs for dental care that were uncovered by insurance or Medicaid, especially the cost of transportation. Several of these organizations had emergency funds set up for such expenses but used the funds sparingly, fearing they would exhaust and not be able to replenish them.

Case managers noted a number of available funding alternatives such as dental hygienist schools, dentists who allowed deferred payments, and free clinics; but even all of these options together were insufficient to meet dental care needs, especially if patients had no funding to begin with. Although Community Development Disability Organizations sought to meet the dental needs of individuals in their programs through emergency funds and other options, the dental needs of many of these individuals went unmet. As one case manager stated, "We've got probably 300 people in this area now that need dental care in [this] county, and we can't get it. Things that they were able to get at the state hospital they are unable to get."

*Appropriateness.* Many parents had experiences with dentists that were sufficiently bad to warrant changing to a new one. Some even changed



multiple times. Several parents mentioned that their child's dentist had no understanding of his or her disability or was in need of training about it. Only one parent noted that the child's dentist understands the impact of her child's disability on her dental needs. Case managers found some dentists capable of treating patients with less severe disabilities but not those with more complex disabilities. As one case manager stated, "I noticed that with my consumers who can function and tell them exactly what's wrong and everything, they get better services than the ones who cannot."

Although many parents and case managers were generally pleased with their interactions with dentists, a few reported problematic aspects of some dentists' approaches, including (a) rushing through appointments, (b) not taking the time to explain the procedures to the patients, (c) barring parents from the examination room, and (d) generally being impatient. However, once families found a dentist with whom they were satisfied, they most often remained satisfied overall. Parents were especially pleased with the dentists' communication. Although some indicated the difficulty of finding a dentist who will listen, many others indicated that their dentists listen and do a good job of talking to their child. For example, one person described how her child's dentist takes his time, takes off his gloves, mask and white coat, holds her son's hand and gives him time to adjust while he explains to him everything that he is doing.

*Availability.* Some case managers reported that their areas simply do not have enough dentists trained to do the extra work required for patients with developmental disabilities, especially those who need sedation to receive care and those who have recently come from the state hospital, where they were accustomed to being sedated for treatment. In particular, case managers reported that some dentists (a) do not have enough patience with individuals who are afraid of the treatment, (b) give up too easily when trying to complete examinations, (c) refuse to treat patients who have not first received Valium, or (d) refuse to treat patients unless they are completely sedated.

Overall, transportation was not a problem for families unless it involved transportation to hospitals and, specialists. Most consumers have access to some mode of transportation for dental care visits regardless of the distance. Only case managers in rural areas mentioned transportation as a barrier; indeed, they have no acceptable regular solutions to this problem and therefore rely on staff, family members, and volunteers from churches or other community service agencies for help.

*Accessibility.* For many families, the accessibility did

not create a barrier. The most commonly mentioned barriers (where there were any) included doors at the entrance of the building, small examination rooms, and inconvenient parking.

*Findings From Dentists' Survey Responses*

The majority of dental practices (94%) were comprised of no more than 5% of individuals with developmental disabilities. The remaining dentists' practices (6%) consisted of between 6% and 20% of individuals with developmental disabilities. We discuss dentist survey findings in the categories of (a) treatment and (b) dentists' perceptions of barriers to dental care for individuals with developmental disabilities.

*Treatment barriers.* Thirty-three percent of the dentists acknowledged difficulties in providing treatment; an identical amount indicated none. The difficulties most frequently indicated by those who experience them included Medicaid reimbursement policies (37%), dentists' own lack of exposure to individuals with developmental disabilities (37%), insufficient training in developmental disabilities (32%), patient resistance to treatment (26%), and structural barriers (e.g., inaccessible parking and exam room equipment) (17%). A small number of dentists also noted a lack of insurance coverage for use of an operating room and the difficulty of maintaining hospital practice privileges.

The majority of dentist respondents (81%) said they had had some training on developmental disabilities, with only 20% of that group saying that it was available during their residency (versus preservice training). Generally, dentists were satisfied with the quality of the training they received (see Table 4). In addition, most dentists (73%) described themselves as either "generally comfortable or "completely at ease" in working with individuals with developmental disabilities. By contrast, 14% described themselves as "generally uncomfortable" or "completely ill at ease." The remaining respondents were neutral on this issue or chose to not answer this question.

**Table 4** Dentists' Ratings of Educational Training Regarding Developmental Disabilities (in %)

Education	Received training	Very adequate	Adequate	Inadequate
Dental school	81.3	7.7	61.5	30.8
Residency	12.5	50.0	50.0	--
Research/ experience	75.0	25.0	75.0	--
Continuing dental education	50.0	25.0	62.5	12.5

*Dentists' perceptions of barriers to dental care.* Most dentists (70%) indicated satisfaction with the number of patients with developmental disabilities in their practice. Some (17%) would have liked to have fewer patients with developmental disabilities than they had, and few (7%) would have liked to have more. This finding did not vary significantly according to geographical location (rural, suburban, or urban). In addition, most dentists (73%) believed there were sufficient numbers of dentists in their area to meet the needs of individuals with developmental disabilities. This report, however, varied according to geographical location; those within urban areas more often than those in either suburban,  $X^2 = 5.37, p = .02$ , or rural,  $X^2 = 4.50, p = .03$ , areas believed there were insufficient numbers of dentists in their area to meet the needs of individuals with developmental disabilities.

### *Findings From Dentist Focus Group*

In many but not all ways, the focus group confirmed or added to the survey data regarding treatment and dentists' perceptions of barriers to dental care access.

*Treatment.* Several themes emerged, with the interaction of treatment and disability being paramount. The focus group respondents agreed that they cannot predict the ease or difficulty of treating any individual with developmental disabilities because treatment varies according to the individual patient. They also believed that, regardless of the ease or difficulty, treating an individual with a disability takes more time; accordingly, they schedule fewer patients when seeing a patient with a disability, especially one with challenging behaviors. Many times patients required more accommodations, including equipment, training, and sedation. Related to this, one dentist remarked that pediatric dentists can more easily accommodate special needs: "They have accessible stations, quiet rooms, and equipment. In addition, they receive better training for a more accommodating approach with the children." One dentist stated that he now will only treat individuals with disabilities under anesthesia because "They are just too much of a problem, they are too disruptive, they make my stress level go up." Dentists noted occasional difficulty getting collaboration from physicians in making decisions about what medicine should be used in the dental office or in simply recognizing the presence of a developmental disability. Insufficient reimbursement clearly is a barrier: "Sometimes we go to a lot more trouble to treat these kids really without adequate reimbursement because we are getting reimbursed [the same as] when we treat an ordinary run of the

mill kid who comes through our practice." Finally, although the focus groups respondents had received little or no training regarding developmental disabilities in dental school, all believed that their experience and on-the-job training was the best teacher and had increased their comfort in treating patients with disabilities. One dentist, however, argued that a professional never gets enough experience to feel really comfortable. But, as he stated, "I don't beat myself up anymore like I used to when some kid would come in and I wouldn't be able to take care of them."

*Dentists' perceptions of barriers to dental care.* Under affordability, dentists reported funding as a barrier. Some families do not have the insurance necessary to cover the care; others find that their insurance will not cover the more costly but necessary care. Furthermore, some dentists charge a behavior management fee for the extra time required, yet insurance usually does not reimburse that expense.

With respect to appropriateness, dentists reported that careproviders often wait until there is a problem before bringing their clients to a dentist, rather than making regular preventive visits. Indeed, one dentist emphasized that Community Developmental Disability Organizations staff often do not conduct good follow-up care due to, he believes, insufficient staffing of group homes.

With respect to availability, focus group respondents noted the reticence of some general-practice dentists to see patients with developmental disabilities and their lack of awareness of how and where to refer these patients. Contrary to the survey data, one dentist identified transportation for rural residents as a major barrier because they are forced to travel out of town to obtain care, given that local dentists have insufficient proper training or willingness to treat them.

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## Discussion

The overall results of this research seem to be contrary to the results of other research related to dental care for persons with developmental disabilities. Taken as a whole, our data reveal more positive than negative findings concerning dental care, whereas the data from other research posit significantly more problems. When, however, further analysis was undertaken of the data in this research, some discrepancies among the three respondent groups (families, case managers, and dentists) appeared. With them also emerged some areas of dental care in which there is consensus

among the three respondent groups that substantial problems exist.

### *Affordability*

Family focus group members, case managers in the surveys and focus groups, and dentists in the survey and focus groups all indicated some problems with the reimbursement of dental care services. Financial barriers included Kansas' restrictions for adult Medicaid-beneficiary patients, and for all age groups, the lack of patients' own funds, insufficient insurance coverage, and the quota system that dentists use to limit the number of Medicaid-beneficiary patients they will treat. By contrast, family survey respondents were the only group that indicated no problems with the affordability criterion.

What explanation might exist for the Kansas finding in the family survey that there are not problems with affordability, especially because all the other results contradict this one? One explanation may be that the majority of family survey respondents were parents/family members of minor children who were covered by third-party reimbursement under either a family dental insurance policy or under the state's Medicaid program. A family dental insurance policy may cover and the state's Medicaid program does cover children under 21, a broader range of procedures than it does for adults.

These findings suggest that advocacy for a more generous Medicaid coverage of dental care for adults is warranted. The present coverage is limited to medically necessary extractions. In this respect, it is reactive policy, covering only surgical-type procedures that are deemed necessary to remove threat of life and omitting any coverage of health-maintenance and prevention treatment. As Richmond (1998) noted, efforts to change dental care should "[involve] our moving beyond diagnosis and treatment (as important as they are) and beyond our well-developed efforts at disease prevention to an emphasis on health promotion or improvement in quality of life" (p. 2). These findings also suggest the need for advocacy for more efficient reimbursement procedures, especially as an incentive for more dentists to treat more individuals with developmental disabilities, particularly those who benefit from the Medicaid program.

Not surprisingly, inadequate funding remains the primary reason that individuals with developmental disabilities (especially adults) do not have access to sufficient dental care. As discussed by Kastner, Walsh, and Criscione (1997), although various managed care approaches have been proposed as solutions to the barriers of cost and care

coordination for individuals with developmental disabilities accessing health care (Kastner, 1997), their overall impact on dental-care access is uncertain. Clearly, some problems exist in managed care regardless of the type of care under consideration. There is reluctance on the part of states to enroll in fully capitated managed care plans child Medicaid recipients who receive their benefits as a result of SSI rather than Aid for Dependent Children (AFDC) status (H. B. Waldman et al., 1999). In addition, all of the demonstration projects discussed by Kastner et al. serve only specific categorical populations, excluding some sectors of the disability population (in some cases very large sectors). Moreover, some states exclude dental care services from their managed care plans, believing that dental coverage would make the plans fiscally unsound (H. B. Waldman et al., 1999).

Nevertheless, there are several potential advantages of managed care that, if they were to apply to dental care, could result in better health outcomes for individuals with developmental disabilities. First, families would experience less paperwork and fewer out-of-pocket expenses (Kastner, 1997). Second, preventive care could become more available and more frequently used. Finally, there is the potential to "avoid unnecessary and duplicative procedures" (H. B. Waldman et al., 1999, p. 63).

Managed care will likely remain a large mechanism of the health care system. Therefore, advocacy is warranted for the inclusion of characteristics of managed care that are necessary for ensuring good quality dental outcomes for individuals with developmental disabilities, similar to those presented by Kastner et al. (1997) for good health outcomes.

In Kansas, dentists find the reimbursement rates to be unacceptably low (Davis et al., 1999); this study confirms that finding. Even if reimbursement rates are raised to a level nearly commensurate with 100% of usual and customary and reasonable rates, as arguably is necessary (Nainar & Tinanoff, 1997), that may not be sufficient, at least in Kansas, in the absence of other policy changes to increase the number of dentists who will accept Medicaid. For example, after the rates were raised in 1997, the number of participating dentists declined over the next year (Davis et al., 1999).

Accordingly, Davis et al. (1999) proposed five policy changes for Kansas: (a) delivery structure change to create public health clinics and extended hours for private dentists; (b) changes in reimbursement involving a three-tier plan of reimbursement, capitation, and an increase in fees; (c) increasing the supply of dentists and dentist

"extenders" (hygienists); (d) "privatizing" services for a new Medicaid dental program; and (e) expansion of prevention and education endeavors. They are careful to point out, however, that these are not prescriptions, but merely "touch points" for stakeholders to consider and take up (Davis et al., 1999). Based on our findings, we endorse these touch points as mechanisms for addressing the problem of insufficient numbers of dentists participating in Medicaid.

In addition, as Lam, Riedy, and Milgrom (1999) discussed, we need to gain an understanding of how the concerns of front office staff in dentist offices affect the numbers of Medicaid recipients that dentists treat. Once we understand these concerns, we must find ways to address them. One approach is to conduct training workshops on topics such as the importance of attitudes, parent education, and early intervention (Lam, 1999). This option may benefit Kansas as well.

### *Appropriateness*

The data on appropriateness are more complex than the data on affordability. Fortunately, the data from the surveys and focus groups of families and case managers reveal only one area in which a majority find problems: case managers in the area of communication (60% of case managers believe that communication between the dentist and the client/manager is poor). This means that for most areas of appropriateness (i.e., quality of ordinary treatment, dentists' friendliness, communication with patients and care providers, and dentists' knowledge of disabilities), little or no improvement is indicated by the findings. A cut-off point of a simple majority, however, disguises some problems in appropriateness.

For example, slightly more than a quarter of the family survey respondents (27%) believed that communication was ineffectual. In addition, nearly half (46%) of the case manager survey respondents and nearly a quarter (24%) of the family survey respondents believed that providers' knowledge of disability is problematic. Also, 44% of the case managers believed that there is insufficient extraordinary treatment effectiveness.

Likewise, dentists also indicated general satisfaction with aspects of the appropriateness of care they provide. The greatest problems they noted with respect to appropriateness were external to themselves (i.e., patient resistance and problems with respect to preventive and follow-up treatment that should be provided by caregivers). The only area in which a noteworthy number of dentists (33%) in the survey conceded to having had problems was in providing treatment to individuals with developmental disabilities. Among this group, many

named a lack of exposure to individuals with developmental disabilities and insufficient training as the primary reasons why they experienced such problems.

Based on these results, Kansas' dentists are, in many ways, working effectively at meeting the dental care needs of individuals with developmental disabilities. At the same time, communication with patients, knowledge of and preservice training in disability-related care, and provision of extraordinary treatment are areas warranting some improvements.

Therefore, based on our findings, as well as other research data (Fenton, 1993; Romer, Dougherty, & Amore-Lafleur, 1999; H. B. Waldman et al., 1998), we recommend that preservice and inservice training of dentists and their staff focus on (a) understanding specific developmental disabilities, their dental management, and the effect of specific disabilities on the general health of dentists' patients; (b) understanding how to work with individuals with developmental disabilities; and (c) applying principles of family-centered care (Reichard, Turnbull, & Turnbull, 1999). Training also seems warranted in (d) how to conduct appropriate and thorough examinations, (e) how to assure efficacious follow-up, (f) standards and procedures for referrals to specialists, and (g) treatment of individuals with challenging behaviors (Reichard et al., 1999).

In addition, we recommend that dental schools and continuing education programs include in their curricula more material regarding individuals with developmental disabilities and their special needs. Moreover, dental schools should find means for increasing exposure of dentists-in-training to this population. To do this, they could begin by employing two approaches. First, similar to what has been suggested for training physicians (Birenbaum & Cohen, 1998), dental schools could establish partnerships with University Affiliated Programs (UAPs) to create and strengthen training for dental students. Second, dental schools could use the models employed by various medical schools (and some dental schools already) where families are involved in training dentists by either having (a) families address the class or (b) individual students matched to "shadow" a family for a period of time so that they achieve a more holistic understanding of the child, gain ideas for behavior management, and learn better communication skills (Center for Children, 1994; Children and Family Consortium, 1998; Marrone, Helm, & Van Gelder, 1998).

### *Availability*

The data on availability warrant the conclusion that, generally, dental care is available to individuals

with developmental disabilities. Case manager survey and focus group respondents found nearly all availability criterion (i.e., dentists to patient ratio, ease of obtaining appointments, wait times, and transportation) to be less satisfactory than family members. (We address this discrepancy in perspectives of case manager and families in a later section on tentative explanations.)

Dentists generally were satisfied with the extent to which their practices involve persons with developmental disabilities and with availability in their areas. The only problem in availability they noted seemed to be one of distribution: according to dentists, fewer dentists are available in urban areas than in other areas of the state.

That rather singular finding suggests that in those areas with too few dentists, improved efforts are needed to supplement existing means for encouraging them to practice there. Suggestions offered elsewhere could be helpful in Kansas. For example, as Jones (1998) suggested, collaborative efforts of the public and private sector can expand and enhance current support of dental student loan repayment programs for the establishment of practices in underserved areas. Jones also advocated expanding educational opportunities for students and oral health professionals "to learn of the need, responsibility, and special care treatment of vulnerable populations as discussed and recommended in the Institute of Medicine's Future of Dental Education Report, "Dental Education at the Crossroads: Challenges and Change" (Jones, 1998, p. 5).

Where transportation poses a barrier, it is most often due to either logistics or insufficient funding, not distance. As a start, community organizations could help alleviate this obstacle. For example, one case manager recommended securing the assistance of local civic or religious organizations for either funding, or, more simply, volunteers to transport. Moreover, advocacy efforts are needed to ensure that Medicaid covers transportation needs.

### *Accessibility*

*Accessibility* of health care facilities has posed relatively few problems, with only 19% of case managers and 6% of family respondents in the survey identifying problems. Where accessibility problems exist, as identified by families and case managers in focus groups, they relate to parking lots, building entrances, and examination room equipment. Dentists, however, frequently reported their belief that they had appropriately accommodated their patients. Thus, for a small group of dentists, further compliance with the accessibility standards required by the Americans

With Disabilities Act may be necessary, and increased efforts to foster sensitivity and accessibility training in preservice and inservice training programs are warranted.

Having identified (within each of the four dimensions) some of the advocacy and training implications of these findings, we are left with the following question: What explains these Kansas data? Note that the question is not why the Kansas data differ from data obtained in comparable research in other parts of the country. We cannot make that comparison because the two sets of data do not allow it. The single narrow question, then, is why the Kansas data reveal what they do.

One explanation may lie in the nature of the respondents and of the persons with developmental disabilities for whom they are responsible. That is to say, the data may be explained by differences in respondents' perceptions. On the one hand, dentists may be disinclined to report data that reflect negatively on themselves and their practice, but, self-interest aside, they may also believe that they generally meet the criteria of appropriate, available, and accessible treatment. Clearly, they find fault with the affordability criterion. For them, it is economics of practice, not the nature of practice itself, that is problematic. True, they admit to needing more training, and true, too, these data were collected before the State Child Health Insurance Program (SCHIP, T. XXII, Social Security Act) was implemented to benefit low-income and un/underinsured children, but the fact of the matter remains that it is the economics of practice that are most problematic.

On the other hand, families and case managers seemingly have perceptions different than dentists. They are not apt to practice the same kind of professional protectionism as do dentists. Moreover, they have differences from each other that may explain why, on the whole, families were more satisfied than were case managers with dental care for individuals with developmental disabilities in their care. Among the family respondents, 77.5% were providing care to minors; we do not have data showing the percentage of minors and adults served by the case managers, although, in Kansas, the Community Development Disability Organizations generally serve far more adults (76%) than children (24%) (Kansas Department, 1998).

Does age make a difference? Arguably, it does. Children may be more amenable to treatment and less resistant to it simply because of their age. Also, children may have fewer dental-care needs than do adults; their teeth are less apt to have acquired diseases requiring uncomfortable treatment. Finally, given that the case managers

are responsible for adults, many of whom have recently been deinstitutionalized (Kansas has closed two of its four state developmental disabilities treatment centers/institutions in the last decade and is reducing the population of its other two institutions (Braddock, Hemp, Parish, & Westrich, 1998), it may be that their perceptions are based on their experiences with individuals who needed more dental care (this assumes they did not have sufficient care in the institutions) or were more often sedated during treatment when in the institutions than in community-based care (recall that the dentist focus group respondents noted the sedation proclivity of dentists other than themselves).

Another explanation may also be based on respondent perception. Family respondents reflected experiences with one person, whereas case manager respondents reflected experiences with more than one. There may be an "accumulation" effect in play, with the experiences having to do with one person (the family's child) being more positive than the experiences having to do with many (the case managers' several clients).

A third explanation may also relate to respondent perception. Family respondents may have received dental care from the same provider who serves other family members. If that is so, and it is likely because the family respondents had minor children receiving care, it may be that the family respondents were reporting on care based on a relationship between the dentist and the family as a whole. If so, the relationship may influence the type of care the minor with a disability receives. It is likely that, if a dentist provides care for an entire family and the entire family thus is satisfied with that dentist (because they remain in his or her care), the dentist also provides care for the family member (child) with a disability that is satisfactory to the family. The perception of care, then, may be influenced by the relationship between the dentist and the family as a whole.

Of course, the data could be explained by two other factors, namely (a) the existence for 8 years of the Americans With Disabilities Act and Kansas dentists' general compliance with its requirements of accessibility and accommodations and (b) the fact that dental treatment for persons with developmental disabilities may not always be so different than dental treatment for persons without disabilities and, thus, may not be so problematic for dentists, families, and case managers.

Finally, the Kansas data may be explained simply by the fact that they are unique to this state. The state is geographically large (82,282 square miles) (Weber, 2000) but thinly populated (total population, when data were last collected, was

2,638,667, or 32.1 persons per square mile) (Policy Research Institute, 1998). It is a state of many small towns, with 529 towns with populations under 2,500 people (Population Estimates Program, 1999a), and with only four cities having more than 100,000 people (Population Estimates Program, 1999b). Further, it is a state with a tradition of caring for its own; it has its own culture of caring, derived in part from the relationships that form in smaller towns, from the scarcity of population and its rural geography, and from a residual frontier/neighborly mentality.

It is not the fact that everyone knows everyone else in every town in Kansas and that dentists look out for their fellow citizens; that is an ideal, not a reality. It is a fact, however, that in a state where "family dental practice" means just that, where the Community Developmental Disability Organizations are the principal (and in some places, the only) service provider systems, and where dentists (and other professionals) serve in community leadership roles (including on the boards of directors or community advisory boards of Community Developmental Disability Organizations), the nature of care, and certainly the perception of the nature of care, may have their own qualitative peculiarities and, thus, may create different data than obtain in research in other places.

Indeed, that sense of community and reciprocity—a sense of responsibility, equal to the importance of caring for ourselves, to assure that dental care will be available for those who need assistance caring for themselves—may well explain why the Kansas data seem so different (at least for the population we reached) than other data. More than this, the absence of that same sense may lie at the root of most of the barriers we know exist for individuals with developmental disabilities in accessing dental care. Generating values and practices that support individual responsibility within the community will allow the logistical changes necessary (e.g., managed care policies, structural accessibility, and communication) to occur far more naturally and with greater ease.

### *Further Research*

The dentist respondents arguably were those with an interest in the topic of dental care for individuals with disabilities (Fowler, 1993); thus, they may have given different answers than would practitioners who lack this interest. Further, the range of family demographics was limited because we located the families for this research through the state Parent Training and Information Center, which, like other such groups, has more white and middle-income family members than families with

lower incomes and other ethnicities. Finally, the case manager data reflected perspectives about individuals in the Community Developmental Disability Organizations service system but not those who are unconnected with that system. Based on these sample characteristics, we recommend further research on families from ethnically, linguistically, and culturally diverse populations; on families with lower incomes; and on families who are not connected with the PTI or Community Developmental Disability Organizations networks. This conclusion is particularly justified because other research shows that all of these cultural diversity characteristics are potentially exacerbated by the effect of socioeconomic and ethnic status in the United States. Not only are people with low income and people of some ethnic groups at greater risk for dental and medical problems, but ethnic groups are also overrepresented in lower socioeconomic groups (Brookins, 1993; Cornelius, 1993; Fujiura & Wamaki, 1997, 2000; U. S. Department of Health and Human Services, 1990). As a result, culturally diverse families who live in poverty remain especially vulnerable and in need of changes within the current health care system (U. S. Department of Health and Human Services, 1990).

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## Summary

In surprisingly numerous ways, many individuals with developmental disabilities in Kansas have been able to obtain the type and quality of dental care they prefer and need. In some areas, however, sufficiently larger numbers of them have experienced problems in obtaining satisfactory dental care to warrant some change. The most substantial areas for change include improvements in Medicaid coverage of dental care for adults, changes in Medicaid policies to encourage more dentists to accept Medicaid, and dentists' increased exposure to and training regarding individuals with developmental disabilities.

A closing observation seems apt. The fact that some problems exist among those with the greatest access to funding and insurance is perhaps the most troubling finding, for it may mean that those individuals with less financial resources are experiencing far greater barriers. Indeed, poorer access among populations with lower incomes has been documented in other research (Bursting, Lipsitz, & Brennan, 1992; Cornelius, 1993b; McCarthy, 1998; Newacheck, Hughes, & Stoddard, 1996; Pappas, 1994). Health care marginalization - one

is tempted to say "discrimination" - is intolerable in and of itself. When compounded with economic marginalization - yes, discrimination - it is doubly intolerable. The good news is that the news could be worse. The bad news is that it could be better.

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