

Perspectives of Physicians, Families, and Case Managers Concerning Access to Health Care by Individuals With Developmental Disabilities

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Abstract

This study of the status of medical care for Kansans with developmental disabilities consists of reports from physicians, service providers, and family members. Overall, these three groups indicated satisfaction with medical care across the four criteria of availability, accessibility, appropriateness, and affordability. The bases for these results are outlined, and suggestions for improving satisfaction with health care are presented.

The recent (2001) Senate hearings and Surgeon General's Report (2002) on the health-care system and persons with mental retardation highlighted what the research literature already had established: There are "shortages of health-care professionals who are willing to accept" [patients with mental retardation] and "who know how to meet their specialized needs" (Report of the Surgeon General, 2000, citing U. S. Senate Appropriations Committee, Hearing Report No. 107-92). These patients "struggle with unwieldy payment structures that were designed decades ago." Further, "in most cases, neither the education and training of health professionals nor other elements of the nation's health system have been updated to reflect "the progress" that has been made in assuring that people with mental retardation can live with their families or in other community settings and determine what happens to them in the health-care system. "Especially as adolescents and adults, people with mental retardation and their families face ever-growing challenges in finding and financing primary and specialty health care that responds to both the characteristics of mental retardation and to the distinctive health-care needs of each life stage" (Surgeon General's Report, p. xi).

The literature supports these findings and so too, to an extent, does research on health care in Kansas for persons with developmental disabilities, including mental retardation (Reichard, Turnbull,

& Turnbull, 2001). We earlier reported our findings related to access to dental care (Reichard, Turnbull, & Turnbull, 2001). The present study contains findings concerning access to general health care. To set the background, we have reviewed, in condensed form, the research literature that undergirded the Senate hearings and Surgeon General's Report and our earlier research according to four criteria for health care: (a) its availability: Does it exist? (b) its accessibility: Is it accessible? (c) its appropriateness, from the perspective of the persons and their families or other direct caregivers: Do they believe that it satisfies their needs? and (d) its affordability: Is it within the financial reach of the patients?

In securing access to the health-care system, persons with developmental disabilities experience challenges that are different in kind and degree from those that other individuals face (Palfrey, Samuels, Haynie, & Cammisa, 1994; Singer, Butler, & Palfrey, 1986). This predicament is especially troublesome for a number of reasons. First, in comparison to typically developing peers, individuals with developmental disabilities have a larger number and range of health-care needs (Vittek et al., 1994; Ziring et al., 1988). Second, the greater severity of their disability most often necessitates a greater number of physician contacts (Boyle, Decoufle, & Yeargin-Allsopp, 1994; LaPlante, Rice, & Wenger, 1997). Third, potential improvements in

their health are more readily afforded by early detection (Levy & Hyman, 1993; Vittek et al., 1994). Finally, access to health care for persons with developmental disabilities is supported by legislation, but the implementation of these laws remains problematic (Matson, Holleman, Nosek, & Wilkinson, 1993). The literature identifies three general barriers to health care, and, not surprisingly, the Surgeon General's Report addresses each of them: (a) training, (b) funding, and (c) bureaucratic obstacles.

The Surgeon General's Report (2002) concluded that training is a barrier to health-care provision for persons with mental retardation and other related developmental disabilities. In that finding, the two strands of the research literature are reflected: physicians' perceptions of having received insufficient training for this population and difficulty with operational barriers.

One strand consists of recent studies that have documented physicians' own perceptions that they lack adequate preparation to treat individuals with developmental disabilities (Darling & Peter, 1994) and that they need more continuing education in these areas (Lennox, Diggins, & Ugoni, 1997; Levy & Hyman, 1993; Reichard, Turnbull, & Turnbull, 1999; Scott, 1990; Scott, Lingaraju, Kilgo, Kregel, & Lazzari, 1993). Another strand relates to the perspectives of families of individuals with developmental disabilities. They feel constrained in expressing their emotions and asking and receiving answers from physicians (Wilson, 1994), having their knowledge of the person heeded by physicians (Darling & Peter, 1994; Simons, 1987; Wilson, 1994), finding a physician willing and able to treat their child (Brooks & Dwyer, 1997), and satisfying all of their child's health-care needs (Sloper & Turner, 1992). Researchers also have documented physicians' lack of knowledge concerning the cultural values that families and patients with developmental disabilities bring to the health-treatment challenge (Brookins, 1993; Chestnut, 1994; Fishman, Bobo, Kosub, & Womeodu, 1993).

The Surgeon General's Report (2002) identified health-care financing as a goal to improving the health of people with mental retardation. The literature also reports the existence of funding-related barriers to health care. Third-party payment plans are insufficient to meet all of the needs of patients with disabilities (Bolden, Henry, & Alkian, 1993). Medicaid-eligibility requirements and lifetime spending limits constrict access (Palfrey et al., 1994) and predictably will continue to do so as

states, facing budget deficits in fiscal years 2003 and thereafter, impose ever-more stringent eligibility requirements and reduce the scope of consumers' benefits. The onset of adulthood causes some people to be dropped from their parents' private insurance, and in some cases the dropped adult will be ineligible for Medicaid or other third-party payer plans (Hughes, Halfon, Brindis, & Newacheck, 1996; Palfrey et al., 1994; Rosenfeld, 1994; Umbarger, Turnbull, Morningstar, Reichard, & Moberley, 2001). Finally, population-specific funding systems create gaps and prevent many individuals from qualifying for necessary funding (Hughes et al., 1996).

The Surgeon General's Report (2002) is on-point, especially with respect to its goal of increasing the sources of health care and ensuring that health care is accessible to people with mental retardation. The research literature documents conflicting criteria across programs, redundant administrations, multiple entry points, multiple providers, complex and lengthy applications, and paperwork requirements (Hughes et al., 1996; Umbarger et al., 2001). Living in a rural part of a state limits access (Umbarger et al., 2001). The shortage of physicians who will treat Medicaid beneficiaries is well-documented (Brooks & Dwyer, 1997; Nainar, Edelstein, & Tinanoff, 1996; Umbarger et al., 2001). Physicians themselves have reported barriers such as a limited time per patient, despite greater time requirements and issues of service coordination (Diamond & Zarafu, 1988; Palfrey et al., 1994; Umbarger et al., 2001). Further, disparities based on diversity and membership in minority communities is of concern not only in the Surgeon General's Report but also in the research literature (Singer et al., 1986).

Given the research literature, the Senate Committee Hearing Report, and the Surgeon General's Report, the topic we investigated is the degree to which the four criteria are met in Kansas.

Method

Survey

We surveyed three constituencies: parents of children and adults with developmental disabilities, case managers for adults with developmental disabilities, and physicians. To create equal representation across urban, suburban, and rural areas, we stratified the sample according to city/town (Fowler, 1993). At the outset, we acknowledge that there may be bias in the data resulting from the sampling.

The bias may arise from the fact that (a) the family members we accessed through the state parent training and information entity and the case managers we accessed through the local service-provider agencies most likely are those whose relatives or service recipients already receive services and (b) physician respondents may include only or largely those who provide services and, therefore, are willing to participate in the survey. Other than using the parent training and information entity, there was no other way to secure parent participation; the relevant state agencies were unavailable to us. Similarly, the most effective way to secure physician participation was to use the door-opening power of the physicians' own associations. The specific procedures for sample selection concerning access to dental care are described in Reichard et al. (2001).

Sample

There were 335 parent respondents for the original survey, a response rate of 26%. The majority of the parents (77%) had children with developmental disabilities who were 18 years old or younger. The majority (84%) was Caucasian. Thirty-one percent lived in urban areas, 39% in suburban, and 25% in rural areas. In Kansas, 86.1% of all residents are Caucasian, and 5.7% are African American (Kansas Demographics, 2000a); 72.5% of the state population is urban-based (Kansas Demographics, 2000b). Subsequent to the initial survey, an extension questionnaire was mailed to all parents who responded to the initial family survey ($N = 335$). (Because some questions remained unanswered following the initial survey, the need for the extension questionnaire was revealed in the process of the research.) We conducted follow-up by mailing reminder postcards to families who had responded to the initial survey. For the extension survey, we achieved a 36% response rate, and the demographics of this group were similar to those in the initial survey.

Thirty-eight case managers responded, achieving a 76% response rate. Each was employed by a Community Developmental Disability Organization, the only public entity authorized by the state legislature to provide services and supports for individuals with developmental disabilities. Forty percent of this respondent group served more than 120 individuals with developmental disabilities. Sixty-two percent of case managers reported working in rural areas, 16% in suburban, and 19% in urban areas.

The Community Developmental Disability Organization case managers, in turn, identified the physician participants by nominating the "most" and "least" effective physicians in their catchment area; the case managers did not reveal the names of the physicians to whom we distributed surveys. We mailed the questionnaires to a random sample of 149 physicians from mailing lists obtained from the state chapters of the American Academy of Pediatrics, the American Academy of Family Physicians, and the Kansas Association for Osteopathic Medicine for physician participants. From these lists, using the same cities/towns as the families, we chose every 6th physician from the larger catchment areas and every 4th physician from the smaller areas. There were a total of 40 physicians in this survey. Their response rate was 27%, with 45% of these practicing in urban areas, 28% in suburban, and 28% in rural areas. Most physician respondents (63%) had been in practice for over 10 years. Family practitioners (52.5%) and pediatricians (45.0%) composed the majority of the physician respondent groups.

Procedure and Analysis

We created our questionnaire by relying on our review of the literature and by securing advice from a participatory action research group consisting of individuals who had experience in acquiring medical care for individuals with developmental disabilities. All three questionnaires addressed the same topics; the physician survey, however, contained questions from a different perspective in an effort to eliminate the perception that the researchers were critical of the physicians' care (Fowler, 1993). The procedures for conducting and analyzing the survey data were the same ones used in Reichard et al. (2001).

Focus Groups

Following our survey, we conducted focus groups with each constituency, securing a total of seven focus groups. To select the participants, we used *purposive sampling*, or the selection of participants who are known to have characteristics matching researcher-selected criteria and expertise in the research topic (Brotherson, 1994). The criteria for selection are described below.

Sample

We held three focus groups each with families and case managers. These groups were composed of

members from the survey respondent groups. We telephoned respondents from the list to gain the participation of 3 to 5 members per group. There were 13 parent respondents and 11 case-manager respondents.

Unfortunately, not a single physician from the survey respondent group agreed to participate in a focus group. It is unclear why physicians did not agree to participate in a focus group where their anonymity would be assured. To create a physician focus group, we contacted an established, statewide physician organization known to have a subcommittee especially interested in the health of individuals with developmental disabilities. The chair of this committee helped convene the focus group. Regrettably, the committee chair could enlist no more than 3 colleagues. Admittedly, a focus group consisting of only 3 individuals, each of whom already is a member of a disability-related subcommittee, will provide a limited broader perspective than the surveys.

Procedure and Analysis

The procedures for conducting and analyzing the focus group data were the same as those described by Reichard et al. (2001). Briefly, the procedures included teleconferences with focus groups, each lasting about 45 minutes. The analysis involved transcript-based qualitative methods of established techniques created by Krueger (1994), Stewart and Shamdasani (1990), and Taylor and Bogdan (1998).

Findings

We discuss the findings according to each constituency: (a) case managers and families and (b) physicians. We categorize the findings according to the framework that we followed in the research on dental care (Reichard et al., 2001), which was consistent with the Surgeon General's Report: availability, accessibility, appropriateness, and affordability.

Families and Case Managers' Perspectives

Families and case managers described access barriers in all four categories.

Availability. One measure of availability—a concern of the Surgeon General's Report because of physician shortages, waiting lists, primary and specialized care, and physicians' avoidance of patients with mental retardation (p. xi and xii)—relates to

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. Overall, physicians were not difficult to locate, but many families and case managers visited several physicians before finding one with whom they were satisfied.

Primary care physicians. The overwhelming majority of parents (99%) reported that their child had a primary care physician. Likewise, most case managers (87%) indicated that the majority of their clients had a primary care physician. Only one case manager indicated that less than 40% of her clients lacked a health provider. The majority of parents and Community Development Disability Organization consumers chose their physician through referral by an agency, a friend or family member, or other professionals. For those who had difficulties accessing a physician, the primary reasons were lack of funding and lack of transportation.

Many parents (74%) and case managers (72%) believed that there were enough physicians in their area in relation to the number of their individuals with developmental disabilities who needed primary care. Notably, among those 28% of case managers who did not believe that there were enough physicians, 60% were from rural areas.

The families in the focus groups reported that experiences varied with respect to how easy or difficult it had been to find a physician who satisfied them. Some families had no problems finding physicians and even interviewed physicians and/or their office staff to determine which one they preferred. Still other families indicated that they had no difficulty because their other children already visited a physician or their network of friends referred them there. Many of those who had not had a difficult time finding physicians lived in smaller, more rural areas. Most difficult was finding physicians who would accept new patients with Medicaid funding. Those who had to search often mentioned that they felt very fortunate to have found the doctor whom they found.

Almost all parents (97%) and case managers (95%) believed that their child's/ consumer's health needs were being met at a level that was *poor*, *neutral*, or *good* (see Table 1). Most parents (85%) and case managers (77%) also experienced ease in making appointments. According to case managers in the focus groups, the difficult part was finding the physician, not getting an appointment. Generally, the physician's staff worked with them to get con-

Table 1 Case Manager and Families' Ratings of Medical Care Services

| Medical services | Case manager | | | Family | | |
|---|--------------|---------|------|--------|---------|------|
| | Poor | Neutral | Good | Poor | Neutral | Good |
| How well consumers' needs are met | 5.4 | 43.2 | 51.3 | 3.4 | 31.6 | 65.0 |
| Physical/structural accessibility of office buildings | 13.9 | 5.6 | 80.5 | 6.8 | 13.7 | 79.5 |
| Distance to office | 5.6 | 27.8 | 62.2 | 12.8 | 17.1 | 70.1 |
| Clients' ease in accessing transportation to care | 31.4 | 22.9 | 45.7 | 12.7 | 33.6 | 53.6 |
| Ease in making appointments | 21.6 | 21.6 | 54.0 | 15.1 | 16.8 | 68.1 |

sumers in as soon as possible. One physician even collaborated with a nurse at a Community Developmental Disability Organization to conduct labs herself so that a visit to the physician was not necessary. A case manager stated that a clinic the consumers visited "almost makes [their] population a priority." Parents and case managers described waiting periods for getting to see physicians as similar to the average population.

Another measure of availability relates to transportation. If a family or case manager is unable to provide a person/patient with transportation to the health-care provider, then no matter how available the provider is to others, he or she is unavailable to the particular person. On the whole, the respondents did not find transportation to be a barrier to availability. For those for whom it was a problem, however, it was a serious one.

Primary care physicians. The distance to the primary care physician's medical office buildings was not prohibitive. Most families (87%) and case managers (70%) traveled less than 15 miles; no one had to travel more than 30 miles. Nonetheless, transportation (as distinguished from distance) was prohibitive for some consumers (31%). Focus group members explained that those individuals with disabilities who lived with elderly parents, those who did not like to ride in a car, and those who lived independently in places with poor public transit could have great difficulty finding a means to get to their appointments.

Specialist care. Those places that were more likely to pose barriers in terms of distance were hospitals and specialists. The distance to receiving specialist care was farther than to primary care for Community Developmental Disability Organization consumers and families. Thirty-five percent of families and 48% percent of case managers had to travel more than 45 miles to receive this care. On the

other hand, 25.7% of case managers and 43.3% of families had to travel less than 15 miles.

Case-manager focus groups indicated that several Community Developmental Disability Organizations and physicians have been creative in their approach to solutions to transportation barriers. In a couple of towns, physicians made house calls when necessary, especially in instances where mobility or medical issues prevented easy transportation. The organizations relied on staff and family members to transport consumers to the appointments; one of these organizations even enlisted churches and other community service agencies for transportation help.

Accessibility

One part of one of the goals of the Surgeon General's Report (2002) addressed accessibility to health-care services for people with mental retardation. It is not an inconsequential issue, particularly because the Americans With Disabilities Act and Section 504 of the Rehabilitation Act amendments of 1973 prohibit discrimination and assure access to health-care facilities and programs.

Physical access. As with transportation, accessibility of health-care facilities posed few problems for most. Structural accessibility of medical office buildings was generally not problematic. Only 7% of families and 14% of case managers indicated that the facilities their consumers/children visited were "poor" or "very poor" in physical accessibility. Among those for whom barriers to accessibility existed, doors at the entrance of the providers' buildings were the greatest barriers. Other commonly mentioned barriers were examination rooms that were too small to accommodate wheelchairs; lack of convenient parking places; and examination tables that were too high for a person to transfer onto from a wheelchair. One person noted that the ac-

cessibility seemed to get better and better every year, whereas another person indicated that there is a complete lack of accessibility at her health-care facility.

Communication. A different measure of accessibility relates to the competence of the provider and patient in communicating. Overall, families found communication issues less problematic than did case managers. Twenty-six percent of families noted that physicians did not allow extra time to compensate for communication barriers. Making accommodations for communications facilitators appeared not to be an issue for most families (52%). Many others who required communication facilitators (30%) were satisfied overall, but a substantial group (19%) was not. Although most families (66%) had above average experiences with physicians communicating directly with their child, a substantial number (20%) had below average experiences in this area. Parents in the focus groups raised the issue of communication often and emphasized the importance of effective listening.

By contrast, case managers were divided regarding their beliefs about communication. A large number of case managers described the physicians' communication with their consumers positively. Many praised physicians for communicating directly and effectively with consumers. Others mentioned the importance of good follow-up from physicians and their staff through phone calls, letter, and satisfaction surveys.

On the other hand, more than 40% of case managers indicated that physicians communicate "poorly" or "very poorly" with their consumers who have developmental disabilities. Moreover, as one case manager described in a focus group:

One thing that I encounter quite a bit is I'll accompany one person to the doctor and they'll have a discussion with me about someone else while the consumer is in the room. I get the impression that they don't think the other person understands what's going on.

Greater than 45% of physicians were described as "very poor" or "poor" at allowing for extra time for communication barriers. The majority of case managers (42%) were neutral when asked how well physicians made accommodations for communication facilitators when necessary. A notable 36%, however, indicated that physicians were "poor" or "very poor" at this task.

Appropriateness

Clearly, families and case managers are not in a position to evaluate physician practice; physician

peer-review procedures are far more reliable methods for evaluating appropriateness. On the other hand, relying on family and case-manager perspectives concerning appropriateness does amplify the Surgeon General's Report in two salient respects. First, the report itself is based on approximately 8,500 comments from lay and professional respondents (the report does not specify how many of the comments were from lay or professional respondents). Second, the report relied on the oral testimony given by lay and professional witnesses at five different sites throughout the country. It is arguable that lay perspectives (as distinguished from professional judgments) are not reliable bases for developing health policy and practice recommendations, but that argument should apply equally to the Surgeon General's Report and to this research. The use of those perspectives in the report warrants reporting them here.

Many families and case managers expressed concerns about physicians' attitudes, ability to handle ordinary and extraordinary health maintenance, and ability to refer appropriately. Some concerns related to the appropriateness of specialized and emergency services.

General concerns. Although a small number of families (17%) were dissatisfied with physicians' knowledge, most were very pleased. By contrast, 41% of case managers rated physicians as having "poor" or "very poor" knowledge of individuals with developmental disabilities, and 35% rated them as having "good" or "very good" knowledge of this topic.

According to families and case managers alike, physicians were generally effective at handling ordinary health maintenance. Only 2% of families and 3% of case managers rated physicians as "poor" in this area. Families (90%) and case managers (81%) rated physicians as average or above average on meeting extraordinary health challenges. Several parents and case managers noted their satisfaction with the willingness and ability of primary care physicians to refer to specialists. Improper referral, however, was an issue for several families, with one parent reporting that a physician would not refer her daughter because he was afraid of losing money but another reporting that her child's physician referred her too often for everything but the most basic care.

Nearly all case managers (95%) and families (95%) ranked their physicians as average or above average on friendliness with patients, but several noted that some physicians treat adults with developmental disabilities disrespectfully by treating

them like children. Similarly, nearly all families (85%) and case managers (95%) rated physicians as average or above average in making necessary but special accommodations. According to families and case managers, some physicians believed that their patients with developmental disabilities should be institutionalized and that some of their patients, especially those with more severe disabilities, did not need treatment at all.

In the focus groups, case managers indicated that other aspects of some physician's approaches were problematic. For example, some individuals have gone in for a routine physical examination and were never touched; physicians sometimes signed off on physicals that they had not completed. In addition, some parents and case managers indicated problems with long waits in waiting or exam rooms and rushed appointments with little time to ask questions.

Parents and case managers also discussed the importance of physicians' trust-building collaborations with them. Some physicians were very cooperative in this regard. For example, one mother reported that her physician trusted her judgments and shared information with her. Another mother reported how meaningful it was for her that her physician gave her his pager number. Other physicians were less willing to collaborate. For instance, one parent described her struggle with her child's primary care physician to get her child's seizures under control. Another told how a physician declined to order tests that the parent believed were necessary and that, as a result, her daughter suffered brain and other physical damage. Numerous parents also indicated their displeasure with physicians who were arrogant and who displayed "know-it-all" attitudes.

Specialist and emergency care. Most parents (84%) and case managers (89%) indicated that the person with a disability had been referred to specialist(s) and that these referrals were almost always appropriate, although they were also infrequent. Overall, parents rated emergency care as satisfactory or better (94%); however, 22% of case managers believed emergency care was "poor" or "very poor." Case managers were also dissatisfied with nonemergency, hospital-based care. Families were more highly satisfied than case managers with nonemergency hospital based-care (90%).

Affordability

The Surgeon General's Report noted the "ever-growing challenges in finding and financing primary

and specialty health care that responds to the characteristics of mental retardation and to the distinctive health-care needs of each stage of life" (p. ix) and devoted one of its six recommendations to financing issues. Our data clearly justify these findings and attention.

Primary-care physicians. Many parents and case managers reported that their children/consumers received Medicaid. Some of these children had their parents' private insurance as well and a smaller group also received HCBS Waiver services. As one mother explained, however, she hesitated to use HCBS with anyone other than primary care physicians because she was afraid that her son would receive less effective or less adequate care simply because he was a Medicaid beneficiary.

Medicaid funding presented problems in a number of ways. First, because of the poor reimbursement level and rate, physicians were loath to accept patients with Medicaid. They typically limited the number of Medicaid recipients in their practice to a low percentage. Second, the reimbursable coverage was limited. For example, although most primary care services were usually covered, labs sometimes were not. Third, parents and case managers had to expend a large quantity of energy, time, and money to ensure that their children's/consumers' health care was covered.

General funding issues. Many parents noted that between policies, paperwork, and taking care of problems with insurance companies, they experienced an extraordinary amount of stress in paying for health care. As one mother stated, "You get to a point where it is sometimes easier to pay than fight the insurance company. You have to choose your battles." Case managers reported that the Community Development Disability Organization frequently had to absorb the costs for health care that were not covered by insurance or Medicaid, especially the cost of transportation. Several of these organizations had an emergency fund set up for such contingencies. Case managers hesitated to use these funds for fear of exhausting them and then not being able to meet the health needs of their service recipients.

Physicians' Perspectives

We describe the perspectives of physicians in terms of (a) treatment barriers and (b) barriers to medical care for individuals with developmental disabilities. These two categories subsume all the

criteria of availability, accessibility, appropriateness, and affordability.

Treatment barriers. Thirty-eight percent of the 40 physicians who responded to our survey indicated that they experienced barriers to providing care to individuals with developmental disabilities (e.g., 36.8% noted lack of training on developmental disabilities; 32%, a lack of exposure to individuals with developmental disabilities; and 63% found Medicaid reimbursement policies to be a barrier. The three focus group members concurred that a lack of training on developmental disabilities sometimes created a barrier for physicians. One of them indicated how physician responsibility for this information was necessary as a result of all the advances in technology. Another physician mentioned that pediatricians have become a huge referral source for family practitioners and other primary care physicians and that training on developmental disabilities needs to be a significant part of medical school and pediatric residency.

Survey data showed that the training of most physicians (82%) included information about developmental disabilities. As seen in Table 2, physicians were most likely to receive some training on developmental disabilities in medical school. This training, however, was more likely than other forms of training to be considered inadequate. Residency provided the most adequate experiences, but a relatively high percentage of physicians found the experience inadequate. Similarly, continuing medical education provided many with "adequate" or "very adequate" training but was also found to provide a substantial amount with "inadequate" experiences.

Physicians' comfort level. Physicians' level of comfort in treating individuals with developmental disabilities appeared not to create a barrier overall. Most physicians rated themselves as either "generally comfortable" or "completely at ease" in working with individuals who had developmental disabilities. Even so, 13% reported themselves as "generally uncomfortable."

Physicians' perceptions of barriers. More than half of the physician survey respondents described themselves as content with the number of consumers with developmental disabilities in their practice. Nearly as many would have preferred to have more patients with developmental disabilities in their practices as would have liked to have fewer. At the same time, the majority of physicians (83%) believed that there were enough primary care physicians in this state to meet the needs of individuals with developmental disabilities. Physicians who reported having too many patients with developmental disabilities were significantly more likely than those who either were not affected or would like to have more patients to report that there were not enough primary care physicians in the state, $\chi^2 = 7.51, p = .02$. None of these results varied significantly by geographic region type (rural, suburban, and urban).

Responses to open-ended questions on the survey and to focus group questions revealed other barriers. First, insufficient time was a tremendous barrier in treating individuals with developmental disabilities. This was especially true because the insurance companies were intolerant of the need to spend more time with individuals in their appointments; yet, most survey respondents believed that they had successfully accommodated this need. They also stated that insufficient follow-up through community coordinators posed a barrier.

The physician focus group also suggested potential barriers for families in accessing health care for people with disabilities. First, a lack of training was a barrier for a number of reasons. Most importantly, physicians with limited training or experience in developmental medicine were sometimes not proactive soon enough to get interventions started as early as they should have been. In addition, such physicians made it more difficult for families to start getting services because they did not refer families and may have misunderstood important services. This was especially adverse because intervention before age 3 is free of cost. Similarly,

Table 2 Physicians' Ratings of Educational Training Regarding Developmental Disabilities (in %)

| Educational training | % who received | Very adequate | Adequate | Inadequate |
|----------------------|----------------|---------------|----------|------------|
| Medical school | 94 | 10 | 35 | 55 |
| Residency | 92 | 36 | 43 | 21 |
| Research/experience | 87 | 19 | 70 | 11 |
| CME ^a | 84 | 19 | 54 | 27 |

^aContinuing Medical Education.

these physicians prioritized incorrectly, being mainly concerned with physical problems but not dealing with the developmental issues.

Second, physicians discussed the problem of too few developmental specialists, noting insufficient funding as a potential reason, due to the large number of and thus expense of people who receive Medicaid.

A third physician-identified barrier experienced by families was waiting lists. As one physician stated, "I hate them having to wait five months. I mean I preach early intervention and then make them wait five months to get into my office." Fourth, primarily due to poor reimbursements through Medicaid, families encountered difficulty locating doctors who will treat their *adult* children with disabilities.

Finally, funding for families was inadequate, impeding access to preventive care. Sixty-five percent of the physician survey respondents noted their membership in at least one managed care organization. These physicians reported that they did not know about the policies of these managed care organizations and how these policies affect individuals with developmental disabilities. There was great variance among physicians regarding the quantity of their patients with developmental disabilities who used Medicaid; more than 50%, however, indicated that more than half of these clients used Medicaid.

Discussion and Recommendations

The perspectives of family caregivers, case managers, and physicians yield a mixed picture. The criteria of availability, accessibility, appropriateness, and affordability are met for some but not all respondents and in some but not all ways for those for whom the criteria are met. Many parents and case managers indicated that they have experienced *no* barriers to medical care. Some parents described how helpful it is for physicians to take their time, have patience, refer appropriately, and trust parents' input. In addition, they expressed their appreciation of physicians who listened to them and their child and who communicated well with their child. Case managers most appreciated physicians with flexible scheduling, those who collaborated with Community Developmental Disability Organizations, nurses and other staff members, and accessible facilities. They also acknowledged their gratitude for those physicians who made house calls to their agency.

Families and case managers differed in ways that can explain why, on the whole, case managers were less satisfied than were families with medical care for those in their care. Seventy-seven percent of family respondents provided care to minors; although our data do include the percentage of adults versus minors served by the case managers, the Community Developmental Disability Organizations in Kansas generally serve far fewer children than adults (24% and 76%, respectively). Arguably, age makes a difference. Children may receive treatment more amenable with less resistance simply due to their age. Also, children may have fewer medical needs than do adults; their bodies are younger and less apt to have acquired diseases requiring uncomfortable treatment.

Respondent perception may also provide another explanation for differences in views of families versus case managers. Whereas family responses reflected only one individual's experiences, case managers' responses reflected many people's encounters. An accumulation effect may result from experiences with one person (the family's child) being more positive than the experiences having to do with many (the case managers' many clients).

A third respondent perception explanation may be that family respondents may have received medical care from the same provider who serves other family members. Given this, the family respondents' responses were likely based on a relationship between the physician and the family as a whole, and this relationship may have influenced the type of care the minor with a disability received as well as the level of the family respondent's satisfaction.

Availability as Affected by Geography and Attitudes

The majority of families reported having no problems with the availability of physicians. For those who experienced problems, difficulty locating a physician stemmed from either too few careproviders practicing in their area in relation to those with a need or from a lack of providers who are able and willing to care for them.

Generally, our results demonstrated no clear pattern as to where the areas of greatest need lie. From the Surgeon General's Report related to increasing the source of health-care services, one would have expected that rural patients would have faced the greatest availability barriers. That was not so, and the comments of one case manager may explain why:

Maybe because it's out here in rural America where they're not as specialized. I mean, as far as you don't have a specialty, you have to deal with everything. I think maybe that's a lot of it because they keep going back for more training and they're more in tune to what they have to know about our people here in rural America.

Kansas offers a school-loan repayment plan for physicians in exchange for providing services in rural areas. This plan has contributed some, but apparently not enough, to resolve the availability barrier. In light of the recent (2003) cutbacks in Medicaid benefits and eligibility in Kansas and the Surgeon General's Report, it may be timely to create a joint task force of medical school faculty and administrators, officers and staff of medical organizations, state and local government officials, family-advocacy organizations, and local service providers to address this barrier.

Availability as Affected by Transportation

When transportation posed a barrier in getting to medical offices, most often the problem was not due to distance but to either insufficient funding for the transportation or logistics. A potential solution to this impediment lies with the assistance of community organizations. For example, one case manager recommended gaining local help from religious or civic groups for either volunteers to transport or for financial support. In addition, advocacy efforts are needed to ensure that Medicaid continues to cover transportation for health-care visits.

Accessibility and Appropriateness as Affected by Patient Competence and Third-Party Back-Up

Barriers to accessibility and appropriateness sometimes are inherent in a disability. As several of the parents and case managers stated, many individuals with developmental disabilities are unable to independently make appointments and follow through with them. For them, there must be an assurance of some type of advocate or care facilitator to assist or conduct those tasks. Parents and case managers also noted how, more than any other factor, the patients' challenging behaviors sometimes impede their treatment.

This finding suggests that pre- and in-service training of physicians should include (if it does not already) (a) learning how to accommodate challenging behaviors and (b) greater exposure to individuals with developmental disabilities. Also, because behavior challenges may mean that the prac-

itioner has to take more time or may have to make other accommodations, such as breaking one appointment into several, improvements in reimbursement from Medicaid and other insurers seem warranted.

Accessibility and Physical Barriers

By and large, health-care facilities do not present physical obstacles. For some, however, the parking lot is inaccessible; for others, it is the entrance to the building; and for a few, it is inaccessible exam room equipment. For those who have not complied, enforcement of the structural standards of the Americans With Disabilities Act is necessary.

Appropriateness as Affected by Affective, Attitudinal, and Knowledge Barriers

The only criteria in which the majority of family and case manager respondents indicated barriers related to providers' knowledge and skills, attitudes, and communication practices. They commonly listed physicians who do not listen to their patients, physicians who do not take enough time, and those who do not take their patients' concerns seriously. Some parents and case managers also noted that the physicians frequently are not well-trained and/or are not knowledgeable about their patients and their disabilities.

On the other hand, few physicians perceived their practice to have barriers to providing care for individuals with developmental disabilities. Most did not view communication as a barrier. Among those who indicated barriers, those mentioned most frequently were insufficient time and inadequate training.

These barriers indicate a need for changes in two areas: (a) pre- and inservice training for physicians and (b) reimbursement policies. Training should include a focus on a better understanding of the various developmental disabilities, how these disabilities affect patients' health, and how they should be medically managed (including evaluation/examination, follow-up, and referral).

Family and case manager responses also point to a need for training to focus on greater application of family-centered principles. Physicians' own reports that they have insufficient time to treat individuals with developmental disabilities implicate a need for changes in third-party policies, especially Medicaid.

At the same time, it is important to note that

physician's age may affect the training and behavior. Training in developmental disabilities and chronic illnesses has, over the years, become required by the American Board of Pediatrics. The more recently a physician was trained, the more likely he or she is to have had more training in these areas. Even so, greater knowledge alone does not ensure an outcome of particular desired behaviors.

Affordability

Although the families who responded to the survey pointed out little difficulty in the area of affordability, case manager and physician respondents reported financial barriers. The discrepancy is likely due to the variation in age group; that is, family survey respondents were more likely than case manager respondents to be relaying the experiences of minors, who are more likely to receive coverage from the parents' insurance. In addition, Kansas Medicaid covers more medical services for children than adults.

Some of the individuals with developmental disabilities who experienced financial barriers to medical care lacked funds of their own or sufficient insurance to cover their needs. Others received Medicaid and could not access care because physicians limit the amount of Medicaid recipients they will treat. The care that Medicaid recipients received may have been restricted by Medicaid's greater limitations of coverage of some health-care services than other insurance. In addition, choice of careprovider is severely limited for Medicaid recipients so that, even if they find a provider, they have little ability to change if they are dissatisfied. Changes in Medicaid and managed-care policies and rates unquestionably are necessary to enable all individuals with developmental disabilities to access funding for the health care they need and to create a funding stream that makes the ADA access more than a paper-based promise.

Limitations of Research

The primary limitation of this research involves response bias. It is highly likely that the responses received from physicians were from those with an interest in the topic of health care for individuals with disabilities. Their answers are potentially very different from practitioners who do not have such an interest. In particular, the level of comfort of these respondents, the amount of training they received, and the amount of individuals with developmental disabilities comprising their

practices probably rated higher scores for the respondents in this research than would be true of a non-self-selected group.

Similarly, the research is limited by the restricted scope of family demographics because we enlisted the assistance of the state Parent Training and Information Center to locate the families. It is not certain that this organization reaches traditionally un- and underserved families, despite its best efforts. Our family respondents did not, then, necessarily reflect the perspectives of the un- and underserved families nor did it exclude them. We did not ask the family respondents about their cultural, ethnic, or linguistic characteristics and have no way to know whether un- or underserved families are sufficiently included in these data. We do know that the Caucasian population of Kansas is 86% and that in itself is a limiting factor.

Had our survey included broader demographics, we may have had different results. Specifically, a larger sample of families, including those with lower income, might well have shown less positive ratings in all categories of barriers. Moreover, all of the problems discussed above are potentially exacerbated by the effect of socioeconomic and minority status in the United States. Individuals from some ethnic minority groups and those who have low incomes have a higher risk for developing health problems, and lower socioeconomic groups have an overly high representation of ethnic minorities (Brookins, 1993; Cornelius, 1993a; Healthy People, 1990, 2000).

Yet another bias is represented in the results. As several parents indicated, many have had a long search to find the physician whom their child currently visits. In filling out the questionnaire, however, they most likely responded only about their child's current practitioner(s). Thus, the full range of experiences of these families is not represented in the results; instead, only the most recent and likely most positive ones are covered.

Furthermore, although the restrictions of the research limited us to primary care physicians, many families and case managers emphasized the importance of examining barriers present in specialist care as well. Specialists, most notably neurologists, ophthalmologists, and psychiatrists, faced an entirely different set of barriers. Some families also discussed their fears about transitioning their children from pediatricians to doctors who care for adults. As evidenced by the responses of the case managers cur-

rently serving adults, many of these fears may be based in reality.

Summary

Other research on the health status of individuals with mental retardation and the Surgeon General's Report properly call for a multifaceted approach to address problems that we have categorized as (a) availability (the report noted a shortage of those willing to accept patients who have mental retardation, a shortage of professionals who know how to meet their specialized needs, and the existence of waiting lists); (b) accessibility (the report recommended providing adaptive equipment and assistive technology); (c) appropriateness (the report noted issues around the quality of health care and training of health-care providers); and (d) affordability (the Report noted limitations in third-party payer plans).

As the data reported here indicate, it has not been difficult for many individuals with developmental disabilities in Kansas to access the health-care system. This general rule has its exceptions. Perhaps most troubling is the finding that such impediments exist for those who have the best access to insurance and funding, which implies that families who have less financial access encounter far larger impediments. In point of fact, other researchers have found that populations with lower incomes have inferior access to care (Burstin, Lipsitz, & Brennan, 1992; Cornelius, 1993b; McCarthy, 1998; Newacheck, Hughes, & Stoddard, 1996; Pappas, 1994), including research conducted in our lab (Reichard, Sacco, & Turnbull, 2002).

For those in Kansas (and perhaps other states) who want to adopt the six goals set out in the Surgeon General's report, it is useful to place those recommendations alongside our data. Goal 1 relates to health promotion and involves three action steps, none of which is justified under our data but may be under other criteria. The steps related to self-care and wellness, reducing care burdens, protecting from environmental/workplace hazards, and assessing wellness against outcomes cannot be supported by our data, but neither are they diminished by anything we uncovered about our respondents' satisfaction with the Kansas health-care system.

Goal 2 addresses how to increase the knowledge and understanding of health and mental retardation and to ensure that knowledge is made practical and easy to use. Action steps that our data

do not justify include (a) involving families in planning health services and research, (b) developing a research agenda, (c) implementing protection for human research subjects, and (d) enhancing the visibility of health and mental retardation research. Two action steps that our data justify are (a) collecting data on health utilization, organization, and financing and (b) providing assistance for individuals with disabilities, their families, other caregivers, and providers in funding, evaluating, and using health research to enhance health-care service delivery and outcomes.

Goal 3 calls on the nation to improve the quality of health care for persons with mental retardation, thereby directly addressing the criterion of appropriateness and, to a lesser degree, the criterion of availability. Our data are subsumed in and support each of the action steps set out under Goal 3: identifying priorities for health-care quality improvement, developing standards of care for monitoring the quality of care, ensuring that practice promotes improvement in health care, and establishing state and regional awards for excellence in health care.

Goal 4 also addresses our criteria of appropriateness and availability by calling for training of health-care providers in the care of adults and children with mental retardation, and its action step of integrating didactic and clinical training on that topic has already been initiated at the University of Kansas Medical School as a result of earlier research conducted by Reichard and colleagues (Reichard, Turnbull, & Turnbull, 1999) and as a result of other factors. Likewise, its action steps of providing interdisciplinary training and continuing education already are underway in Kansas.

Goal 5 seeks a financing system that improves outcomes. That goal is totally consistent with our criterion of affordability and subsumes our findings. Each of its action steps—related to outcomes and financing, definitions of *effective* and other terms, identifying packages of services that produce good outcomes, leveraging funding, and creating cost offsets—is supportable through our data.

Goal 6 calls on the health-care system and policy leaders to increase the sources of health-care services and ensure that health care is accessible to people with mental retardation. That goal is on point with our criterion of accessibility and, to a lesser degree, with our criteria of appropriateness and affordability. Here, too, our data support that goal and its action steps related to increasing the

number of providers who can serve diverse populations (Reichard et al., 2001) and investigate provision of data on the huge problems of access by minority and poor citizens, creating easier access, developing more community-based care, expanding the types of health professionals available to patients with disabilities, supporting providers to provide care, furnishing specialized equipment, and ensuring continuity of health.

Undoubtedly, the Kansas health-care system, in the perspectives of the families, case managers, and physicians who participated in this research, is acceptable; no great changes are required. However, it is equally clear that some changes are required, and a good benchmark for the who, what, when, where, why, and how of the changes exist in the Surgeon General's Report. To the end of implementing that report in Kansas, we believe that additional research may be warranted to broaden the number and type of participants (creating a data pool larger than ours) and to examine in detail the differences among individuals with developmental disabilities according to race/ethnicity and level of income. Much more information is needed regarding geographic residence (urban vs. rural, region of the state) and type of care (primary vs. specialist).

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