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# Primary Care for Adults With Physical Disabilities: Perceptions From Consumer and Provider Focus Groups

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**Background and Objectives:** *Family physicians lack data on how best to address the needs of adults with physical disabilities. We undertook this study to understand how consumers, educators, and other professionals perceive primary care for people with disabilities.* **Methods:** *We conducted six focus groups, three with 27 health professionals in primary care practices affiliated with an urban university medical center and three with 19 local adults, ages 21–64 years, with physical disabilities. From transcribed recordings, three investigators conducted separate content analyses. Independent author reviews and participant review confirmed saturation and agreement for major themes.* **Results:** *All groups perceived that generalist physicians and other health professionals need more education about disability issues. Multiple barriers limit care, including physical access and transportation, funding, limitations in professionals' knowledge and attitudes, communication gaps, and health systems failures. Both consumers and professionals recommended reducing barriers by educating professionals and trainees about disabilities and resources, improving provider-patient communication, enhancing physical access (eg, high-low examination tables, wide automatic doors, high-contrast signs and lighting, wheelchair scales), and increasing appointment times.* **Conclusions:** *Primary care must address the unmet needs of people with disabilities. Family medicine educators can begin by teaching learners how to coordinate care, access resources, and communicate about disability issues.*

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Health promotion for Americans with disabilities is a national priority.<sup>1,2</sup> Adults with disabilities, however, routinely experience problems with primary care services, including inadequate preventive care,<sup>3</sup> financial barriers,<sup>4</sup> and dissatisfaction with care.<sup>5,6</sup> The research literature offers clinicians and educators only limited insights into these problems.

Existing data identify gaps in primary care services for people with disabilities. Adults with major lower extremity disabilities, for instance, often miss needed preventive services.<sup>7</sup> Insurance and financial barriers<sup>4,8</sup> and scant disability training for generalist physicians<sup>9,10</sup> compound such problems. Not all studies, however, suggest that people with disabilities uniformly lack preventive care.<sup>11</sup>

Relatively few research efforts have approached the complex relationships between disability and quality of care, and fewer still have addressed medical education.

Our literature review revealed few relevant studies,<sup>12</sup> most of which used focus groups to target consumers with only one type of disabling condition.<sup>13-15</sup> Because most generalist clinicians care for patients with a variety of disabling conditions, we hoped to add to the literature what might be learned from a cross-disability perspective.

Our study's objectives were to learn, first, how consumers with a variety of physical disabilities perceive needs and recommendations regarding their primary care. Second, we sought to learn how perceptions of primary care professionals and educators compared with those of consumers.

## Methods

### Study Sites

We conducted three consumer focus groups at sites reflecting the urban communities surrounding the University of California, Irvine (UCI). The sites are described in Table 1. Three provider focus groups occurred at primary care practices. UCI's Human Subjects Committee approved the research protocol.

Table 1

## Participants and Sites for Focus Groups (n=46)

<i>Participants</i>	<i>Sites</i>	<i>Number</i>
<b>Three groups of consumers* with disabilities affecting:</b>	Dayle McIntosh Center (independent living center employees)	6
Mobility (13)	UCI Program in Geriatrics (primary care patients, most from UCI)	8
Vision (7)		
Voice/speech (3)		
Hearing (1)	UCI Family Health Center-Santa Ana (patients at federally-qualified health center)	5
Cognition (1)		
<b>Three groups of primary care professionals:*</b>	UCI Family Health Center-Santa Ana (clinicians and staff at health center)	10
Physician-teachers (11)	UCI SeniorHealth Center (serving numerous adults with disabilities)	9
Medical assistants (5)		
Nurse practitioners (2)		
Social workers (2)	UCI Department of Family Medicine (majority of UCI's primary care faculty clinicians)	8
Nurses (2)		
Other professionals (5)		

UCI—University of California, Irvine

\* We invited consumers ages 21–64 with a variety of physical disabilities to participate, purposefully selecting participants to maximize diversity of gender and ethnicity. Six consumers were Latino, and 13 were white; 15 were women, and four were men.

\*\* Participating professionals cared for patients and taught family medicine learners at the UCI primary care practices that provide the most care for adults with disabilities. We purposefully selected the 20 female and seven male participants to reflect the population of those professionals most involved in clinical work and teaching related to disabilities.

### Participants and Sampling Methods

We conducted focus groups with consumers. In separate sessions, we conducted focus groups with primary care health professionals from different disciplines.

From a total population of approximately 287,900 adults with disabilities ages 21–64 years in our county,<sup>16</sup> we purposefully invited a sample of 26 adult consumers from this age group, attempting to balance different physical disabilities. For the provider groups, we invited 33 UCI primary care professionals, of whom 13 were clinician-educators.

Nineteen consumers and 27 professionals agreed to participate (Table 1). Stated reasons for declining included busy schedules (five) and illness (two). Of the 11 participating physicians, one was a chief resident and 10 were attending physicians in family or internal medicine, two with geriatrics fellowships. Altogether, the providers' practices included more than 1,000 adults with disabilities. Provider-patient relationships linked a small minority of participating professionals and consumers.

### Instruments and Data Collection

We used focus groups<sup>17</sup> because of their advantages for exploring new topics.<sup>18</sup> For each type of group, one investigator drafted a separate structured question set (Figure 1) that the other investigators edited. To enhance discussion, we developed and included in each question set a list of model practice characteristics derived from a literature review. Two investigators jointly conducted six focus groups of 60–90 minutes' duration, making field notes and audiotaping the sessions, which were transcribed afterward.

### Data Analysis

All three authors (two family physicians and a physician assistant, all experienced in working with people with disabilities) independently reviewed the written transcripts and field notes from each session. Using structured summary forms,<sup>19</sup> we conducted content analyses of each record according to well-described qualitative research techniques.<sup>19</sup> We coded major and minor themes during multiple readings, examining interconnections and relationships to larger categories.<sup>19(pp245-62)</sup> Each written summary underwent two independent, secondary reviews, after which all investigators resolved minor discrepancies during research group meetings.<sup>19(pp76-7)</sup> We gave all study participants the final results to critique.<sup>19(pp275-7)</sup>

### Results

Content analysis revealed clear recurrent themes, with marked thematic agreement across the independent summaries and secondary reviews (Table 2). In the participant review, 13 participants offered comments; two added minor points, and none disagreed with our findings. Both focus group types reached theoretical saturation in that the final sessions introduced no new themes. We grouped the findings according to three main areas the focus groups revealed.

#### *Creating the Ideal Primary Care Practice for Adults With Disabilities*

**Clinicians.** A recurrent major theme involved the need to educate providers, staff members, and trainees about disabilities. Several consumer participants requested cultural sensitivity and disability awareness training:

Figure 1

## Summary of Focus Group Question Sets

Introductory question	1. What <b>kind of disability</b> do you have and how does it affect your life?
Transition question	2. Here is a list of different types of primary care practitioners. They all provide general medical care, including preventive care and coordination of sub-specialty services. <b>What has your own primary care been like?</b> <ol style="list-style-type: none"> <li>1. Family physicians</li> <li>2. General internists (internal medicine physicians)</li> <li>3. General pediatricians</li> <li>4. Nurse practitioners</li> <li>5. Physician assistants</li> </ol>
Key questions	3. Tell us about any <b>unmet needs</b> you have for primary health care. [For provider focus groups: <b>What do you need</b> so that you can provide the best care for people with disabilities?] 4. Have any barriers prevented you from getting the primary care that you need? If so, <b>what are the barriers?</b> [For provider focus groups: Tell us about the <b>barriers you face</b> in providing primary care to people with disabilities.] 5. Here is a list of different things we could emphasize in a model practice for people with disabilities. <b>Which do you think are most important, and why?</b> <ol style="list-style-type: none"> <li>1. Make the primary care office attractive.</li> <li>2. Affiliate the practice with the medical school.</li> <li>3. Ensure the practitioners' overall skill and competence.</li> <li>4. Provide plenty of conveniently-located disability parking.</li> <li>5. Make sure the practitioners are comfortable with disabilities, that they spend time with patients and answer their questions.</li> <li>6. Ensure physical access (e.g., accessible bathrooms and exam tables, level pavement outside, wide automatic doors).</li> <li>7. Strategize with consumers about how to make health care affordable.</li> <li>8. Be sure it's easy for people to contact the office by phone or email.</li> <li>9. Have interpreters available (e.g., spoken language, sign language).</li> <li>10. Hire staff who seem comfortable with disabilities and treat everyone with respect.</li> <li>11. Provide free or low-cost transportation to and from the visits.</li> <li>12. Offer on-site services (e.g., social work, physical therapy).</li> <li>13. Minimize wait times before patients can see the practitioner.</li> <li>14. Make it easy to get a follow-up appointment with the practitioner.</li> <li>15. Ensure that patients can see a sub-specialist when they need to.</li> <li>16. Provide positive images of people with disabilities (e.g., hire office staff who have disabilities themselves).</li> <li>17. Stock reading materials (e.g., health care brochures) in Braille and large print.</li> <li>18. OTHER – including anything else that is important to <b>YOU!</b></li> </ol>
Ending questions	6. Of everything we talked about, what <b>one piece of advice</b> would you give to us as we develop a model practice for consumers with disabilities? 7. Are there any important <b>topics we missed</b> that you would like to comment on now?

Table 2

## Summary of Recommendations from Focus Groups\*

Practical changes can enhance disability care within primary care practices:

- “Everyone who works with us needs more training!”
  - Knowledge about disabling conditions, community resources, cultural sensitivity, mental health, sexuality, assistive technology, disability forms, student and resident training
- Ensure adequate physical access for patients with disabilities.
  - Mobility disabilities: disability parking, wide automatic doors, lifts, wheelchair scales, high-low tables, large rooms, split-level check-in with a counter at wheelchair height
  - Visual disabilities: signs with large print and high visual contrast, good lighting and high contrast in office décor, “auditory landmarks,” escorts to and from curb
- Develop systems to ensure quality of care: on-site services, streamlined referrals to subspecialists and community resources, interpreters (eg, American Sign Language), case management, easy ways to contact office, inpatient discharge planning.
- Focus on the chief complaint during the visit, not just on the disability.
- Take time to listen to consumers’ needs and follow up on addressing them.
- Promote positive images of disability, eg, hire staff members with disabilities.
- Lengthen appointment times, including longer intake visits for people with disabilities.

\* Includes all major recommendations themes that the focus groups identified.

“Clinicians and their staff do not need to know about every disability, as long as they do not make assumptions about a person’s disability and capacity.”

Providers themselves described specific educational needs: how to access disability resources, coordinate care and adapt health maintenance visits, address sexuality and contraception, order durable medical equipment, complete forms for disability status and home care, and plan for hospital discharge. A clinician-educator commented, “In our residency training... the adults who have multiple disabilities are typically taken care of...by many specialists, so when we see them as primary care in residency, we feel a little lost. Like, we’ll just let the neurologist take care of that or we’ll let the...GI doc take care of that. And we don’t know how to fit into the role since there are so many specialists. [We need to learn] how to coordinate care, be part of the team.”

Other educators explained the lack of training: “I think knowledge and education is one big barrier for some of us who do not have a lot of exposure to...taking care of people with different kinds of disabilities. I think that we learned just by doing a lot of times.... So, for example, I’ve never been taught a thing about, you know, prostheses, how to put them on, take them off, what the patient experiences.... I mean, all those things are complete unknowns.”

Physician participants expressed mixed sentiments that “the biggest teachers have been the patients.” A lay-teacher role may empower consumers but emphasizes that few medical students or residents receive much training about disability issues. Most consumers and

professionals agreed with “cross-training” for all health professionals, from front office staff to clinicians. A minority of professionals, however, perceived disability as exceeding the usual scope of primary care, instead recommending disability fellowships for interested clinicians. Although nearly all participating clinicians characterized themselves as lacking knowledge about disabilities, not all expressed interest in learning more: “I feel very apprehensive about being asked to do something that I am not interested in. I don’t want to provide [the] care.... I don’t feel equipped to do that.”

Another provider agreed: “If I were taking care of that population, it could be a burn-out.” A third recalled hearing a resident physician refer to a gang-affiliated teenager as having “gotten what he deserved” with his spinal cord injury.

### Consumers

Consumers offered educationally relevant suggestions for improving patient-provider communication, including treating consumers as equals (“I want them to focus on me, direct the questions directly at me, not at my kids.”), avoiding making them feel rushed (“It would help for them to slow down. How effective are they if they don’t listen?”), and providing appropriate cues to blind patients (“We can’t see who is talking to us so it’s like, ‘Are they talking to us?’ You know, all they have to do is say, ‘Mrs [name]’, or whoever....”). Consumers tended to agree that “a lack of education” for primary care physicians is a major cause of these miscommunications.

Somewhat unexpectedly to us, several consumer participants reacted negatively when clinicians asked what they themselves thought was wrong with them: “I don’t mind doing a cooperative effort in a lot of communication... But I don’t want to inform my own doctor... or teach someone. Like, why don’t I just go to medical school myself?” Other consumers volunteered a creative solution: hiring professionals who have disabilities themselves.

#### *Clinicians and Consumers*

In addition to improved education and communication, all focus groups recommended practical changes to improve primary care for people with disabilities. Both consumers and providers agreed with virtually every item on the “wish list” we presented to them (Figure 1) and added little to it. When asked their priorities, they confirmed physical access as the top priority: disability parking, wide automatic doors, large rooms, high-low tables, wheelchair scales, and lifts. Suggestions included escorts from curb to office and a wheelchair-level check-in counter. Several blind participants recommended large-print, high-contrast signs (white or yellow lettering on a dark background) and high-contrast colors on walls and flooring to enhance safe navigation, along with “auditory landmarks,” ie, “Turn right at the fountain.”

Another set of themes surrounded enhancing systems to improve quality of care for people with disabilities. Consumers and providers urged longer appointment times, especially new-patient slots. Providers also advocated case management, experts in billing/coding and insurance, specialized hospital discharge planning, on-site ancillary services, and easier ways to contact the primary care office.

#### *People With Disabilities Experience Major Unmet Needs for Primary Care*

All three consumer focus groups repeatedly emphasized that people with disabilities lack adequate primary care, although a few consumers reported no difficulties (eg, “I have a family practice physician and, um, she’s great.”). Most consumers perceived that their primary care professionals lacked time, training, equipment, and resources to complete appropriate medical histories, physical examinations, health screening, diagnostic assessments, and follow-up for patients with disabilities. Virtually all perceived office appointments to be too short to handle their often-complex medical issues. Consumers lacked access to needed sub-specialty services, experiencing delays or “busywork” burdens (needing to track paperwork themselves) to obtain referrals.

The provider groups reinforced the consumers’ perceptions. As one professional commented, “I feel I’m not giving the best care”. Others lamented “not really

being able to link up... patients with disabilities... with resources” and not “being able to do a complete physical exam on them.” Several providers underlined delays in obtaining subspecialty referrals.

#### *Multiple Barriers Limit Primary Care for People With Disabilities*

Consumer and provider participants agreed on a variety of barriers. Physical access barriers topped the list and included problems with transportation to and from visits. Further difficulties included entering primary care offices—“That awful ramp in front... you either have to go backwards up that ramp or you grab onto the rail and pull yourself up”—and then accessing needed services once inside: “Unfortunately, I’m having gynecological problems, and they just look down there and say, ‘Okay,’ and they don’t want to take the time to get me up on the table... How come they don’t have tables that can lower... so that they can have a good look and diagnose you properly and accurately?” (consumer)

Professionals’ cognitive and attitudinal barriers caused further difficulties. Most consumers reported encountering misinformation, lack of knowledge, or prejudice: “Attitudes aren’t great,” “[professionals] seem to be afraid of us.” Several told stories of clinicians deferring the chief complaint because of the disability: “I’ve gone to visit the doctors not related to my vision, and right away they want to look at my eyes. Like... why are you looking at my eyes?... I just felt like just a specimen that they were curious about.”

In two of the three provider focus groups (but in none of the consumer groups) some participants interpreted any “disability” as implying cognitive impairment, despite the moderators’ instruction to focus on physical disability. One provider group dwelled on a past event in the office: “She’s autistic and she was mostly retarded... And she started taking her clothes off and running around. It was really, really hard to contain her.”

Other providers who had evidently witnessed this incident returned to it throughout the discussion. We also perceived a “not in my backyard” sentiment: “I would look for funding to find land and/or a building and have a building identified as a disabled clinic and advertise it [as] exclusive for disabled.” “Make sure you hire people that really want to work with this part of the population.”

Overlying health systems barriers created additional obstacles, some of which stemmed from failure to plan ahead for disability-related needs: “Our systems are not set up to anticipate the needs of patients with disabilities. Even getting an interpreter for sign language... just doesn’t happen correctly.” (provider)

Hospital discharges frequently lacked follow-up systems. Two consumers volunteered separate stories about calling to make appointments and being assured

that a personal care attendant would not need to come along. Upon arrival, both were told the attendant was needed after all. Another consumer commented: "They gave me a form and they said it was a checklist... And I'm like, 'I can't see this form to fill it out.' And they're like, 'Well, then, did you bring someone with you?'... I'm a young adult and, you know, I usually go everywhere by myself... But... I don't always have someone to just come and be my reader... for a checklist."

The focus groups also mentioned linguistic, cultural, and economic barriers. Others noted problems in obtaining equipment and services for consumers lacking legal US residency.

Finally, while all focus groups willingly imagined a model practice for people with disabilities, they often dismissed the image as feasible only "in a dream world." This mixed sentiment incorporated both enthusiasm ("Send us invitations when you open!"—consumer) and pessimism ("I think this is medicine in a perfect world but realize it's not going to happen."—consumer).

## Discussion

Despite some differing perceptions, both the consumer and provider focus groups agreed that people with disabilities need substantial improvements in their primary care services, some of which could be addressed through provider education. Subtler lessons learned included that professionals should avoid an exaggerated focus on the disability rather than on the chief complaint. In other situations, clinicians must strike a balance between empowering patients and burdening them with the perceived responsibility for being their own disability experts.

Our results dovetail with those of the published literature and add to it a broader cross-disability perspective. Focus groups of people with visual impairments<sup>15</sup> reported, as we did, barriers to communication and physical access. In group interviews, deaf and hard-of-hearing participants<sup>20</sup> added additional points such as potentially dangerous miscommunications when clinicians bypass interpreters. Our results further support those of cross-disability surveys detailing financial barriers to care.<sup>4</sup>

Limitations in our study deserve mention. Despite our best attempts, we only enrolled in our focus groups one participant with a hearing impairment, possibly because others may not have considered hearing impairment to be a disability.<sup>14</sup> Targeted recruitment likewise failed to enroll any non-English speakers. While combining health professional supervisors and support staff in the same groups may have curtailed freedom of expression, the inter-participant interaction may also have elicited richer data.

Nonetheless, we believe this study's results provide valuable insights into the views of consumers with disabilities and their primary care professionals. As our

participants highlighted and as experts have agreed,<sup>21</sup> health care systems and policies need a paradigm shift to address the unmet primary care needs of Americans with physical disabilities. The greatest lessons from our focus groups may be the participants' practical suggestions, some of which help to clarify how physicians' offices can comply with the Americans With Disabilities Act,<sup>22,23</sup> such as removing architectural barriers and providing alternate means of communication. Recommendations especially relevant to education include teaching family medicine learners how to coordinate disability care, access resources, address sexuality and other neglected health maintenance issues, and communicate more effectively with their patients with disabilities. We hope that present and future family physicians will help turn these recommendations into realities.

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