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# "Sometimes I Feel Overwhelmed": Educational Needs of Family Physicians Caring for People with Intellectual Disability

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## **Abstract**

Primary care physicians who care for adults with intellectual disability often lack experience with the population, and patients with intellectual disability express dissatisfaction with their care. Establishing a secure primary care relationship is particularly important for adults with intellectual disability, who experience health disparities and may rely on their physician to direct/coordinate their care. The authors conducted semistructured interviews with 22 family physicians with the goal of identifying educational needs of family physicians who care for people with intellectual disability. Interviews were transcribed and coded using tools from grounded theory. Several themes related to educational needs were identified. Physician participants identified themes of "operating without a map," discomfort with patients with intellectual disability, and a need for more exposure to/experience with people with intellectual disability as important content areas. The authors also identified physician frustration and lack of confidence, compounded by anxiety related to difficult behaviors and a lack of context or frame of reference for patients with intellectual disability. Primary care physicians request some modification of their educational experience to better equip them to care for patients with intellectual disability. Their request for experiential, not theoretical, learning fits well under the umbrella of cultural competence (a required competency in U.S. medical education).

## Keywords

health; medical education; primary care; health disparities; communication

Adults with intellectual disability (ID) are living longer than ever before (Patja, Iivanainen, Vesala, Oksanen, & Ruoppila, 2000) and experiencing more age-related health problems after they leave the care of their pediatrician. In the United States, adults with ID typically access their primary health care through the community in which they live (Chew, Iacono, & Tracy, 2009) and, as such, may wind up placed with an adult primary care provider relatively inexperienced in the health care needs of people with ID. The type and quality of the care they receive have not been studied in depth, but people with ID have expressed dissatisfaction with aspects of their health care, particularly communication and the sense that their provider understands their needs (Brown & Gill, 2009). This dissatisfaction may lead over time to less frequent primary care visits and a less-than-solid alliance with their

primary care provider, which in turn can lead to increased hospitalizations and medical errors (Rosenthal, 2008).

It is unclear to what extent U.S. medical education focuses on the care of patients with disabilities, but studies suggest that this is an area of deficiency for many physician trainees (Minihan, Dean, & Lyons, 1993). Primary care physicians report a lack of education in providing care for adults with disabilities that leads to their discomfort with the population and may contribute to decreased availability of physicians for adults with ID (Reiss, Gibson, & Walker, 2005). For example, one survey of board-certified internal medicine physicians found that lack of education and training in the areas of childhood-onset conditions was associated with lower rates of caring for people with disabilities (Peter, Forke, Ginsburg, & Schwarz, 2009). In Australia, primary care physicians have noted a similar lack of training, particularly in communicating well with patients who have intellectual disability (Lennox, Diggens, & Ugoni, 1997). Primary care physician attitudes have been studied both in the United Kingdom (Bond, Kerr, Dunstan, & Thapar, 1997) and in Canada (Oullette-Kuntz, Burge, Henry, Bradley, & Leichner, 2003), and in both settings, physicians were found to have negative attitudes and inaccurate perceptions about patients with ID. There have been efforts to educate practicing physicians about the care of patients with ID (Eastgate & Lennox, 2003), though it is unclear whether these efforts have improved care.

In the United States, the literature suggests that physicians need early exposure to pediatric patients with disabilities, coupled with mentorship and debriefing about the experience (Sharma, Lalinde, & Brosco, 2006). Although many of the studies on physician attitudes and educational needs focused on the care of children, it is clear that there is a need for additional training and/or experience with adults who have intellectual disability during the medical education process. It is less clear what, exactly, that training should entail and how it should be carried out—and also, whether it should be different when focused on the care of adults. We sought to better understand the educational needs of family physicians who provide care for adults with intellectual disability. Through in-depth qualitative interviews, we aimed to explore and characterize areas of discomfort or need for practicing physicians, to better define elements that should be included in curricula during medical school or residency training.

## Method

We interviewed 22 family physicians over a period of about six months in 2010, making an effort to recruit both family physicians who see relatively few patients with ID in their primary care practices (referred to as *primary care* in this article) and family physicians who have chosen to focus their practice on the primary care of adults with ID (*ID-focused*).

## Sample

Family physicians were recruited through a series of e-mails or phone calls to local academic departments, private practices, a national e-mail list for physicians interested in care for people with ID, and a large e-mail distribution list for a regional annual meeting. We used purposive sampling targeting several different groups of physicians, first trying to recruit several physicians in academic practice, then private practice, then "ID-focused" physicians through a national e-mail list, and finally a nonspecific e-mail to conference attendees. Our sampling did not attempt to represent targeted geographic regions. About half of the physicians interviewed lived and practiced in the northeastern United States, but we also interviewed physicians from the Midwest, the South, and the West Coast.

Table 1 provides descriptive information on the participants interviewed for the study. A total of 16 participants were primary care–focused, and six were ID-focused. We also

collected demographic information on the gender of the physician (9 male and 13 female) and the practice setting (nine academic and 13 community-based, with community-based including community health centers and private practices). We did this because physicians in primarily academic settings generally see fewer patients per week than physicians in community practices, and we thought that patient volume might affect their answers. We also looked at the number of years in practice, describing it as less than 10 (six physicians) and 10 or more (16 physicians). We did this for two reasons: first, with increasing years of experience, the likelihood increases that physicians will have seen more patients with ID and might have accrued more knowledge or experience. Second, we thought that residency education might have changed over time, and comparing physicians who completed their residency fairly recently with those who experienced residency training less recently might allow us to see if differences existed in their responses. Table 1 gives additional information about the demographic breakdown within the primary care and the ID-focused groups.

It was impossible for us to tell how many physicians might have read our recruitment emails and decided not to respond to them. The three e-mail lists we used included approximately 50, 40, and 200 physicians. Of the physicians who responded, 100% consented to be interviewed, and we were eventually able to find mutually convenient times to interview them all. While we initially thought that we would need more participants to reach thematic saturation, based on ongoing coding and analysis we reached saturation and were able to stop recruiting at 22 participants.

#### **Procedure**

When physicians responded to a recruitment e-mail, they were contacted by a member of the study staff (by e-mail or phone), and a mutually convenient time was arranged for their interview. Most of the interviews took place at the physician's practice site, and several were done by phone. A few subjects were also interviewed on-site at the regional conference. All of the participants expressed good understanding about the nature of the research and readily gave their consent. The consent forms were either signed before the interview (when the interview was done in person) or signed and faxed before or after the telephone interview. Physician participants were not compensated for participating in the study. The study was approved by the Boston University Institutional Review Board (IRB).

Several of the physicians were known to one or more of the interviewers because of their involvement regionally and nationally with research and curricular initiatives related to the care of people with ID. However, in most cases, the physician participants were not interviewed by a person they knew. The interviews were conducted by three research assistants and two of the coauthors, depending on who was available at the time the participant could meet.

Physician participants were interviewed using a semistructured interview guide (see the Appendix) that covered (a) the extent of their experience caring for people with ID, (b) their experiences providing care to people with ID and the resources they felt they needed to provide better care, (c) their previous life experience and medical training in providing health care to people with ID, and (d) their recommendations for a family medicine curriculum for the care of patients with ID. This interview guide was generated through several conversations and drafts among the coauthors. We also showed it to colleagues involved with a national initiative to develop curricula in this area to allow them to give feedback on the content. The interviews were audiotaped and transcribed verbatim afterward. The transcriptions were done by the research staff, and in almost every case, the transcription was done by the staff member who had done the interview, to increase the likelihood of accuracy.

## **Analyses**

We conducted 22 interviews, which generated approximately 76 pages of single-spaced text. We conducted our analyses using tools from grounded theory methodology (Charmaz, 2006). The interviews were transcribed verbatim and initially coded line by line by at least two members of the research team, who provided one- or two-word summaries of the line content. Next, the coders met to review the summaries jointly and categorize them into second-level codes that defined each content area more broadly. Third, the coders met and jointly reviewed the second-level codes to begin to develop themes from the data. We used an iterative process, periodically going back to the data to confirm the meaning of the themes that were emerging. At least two members of the research team reviewed each step of this process, and one coauthor was present for all the coding sessions.

## Results

The physician participants in our study provided background information about the current volume of patients with ID they were seeing in their practices and how those patients were assigned to them. They also reflected on any other nonmedical experiences with people with ID (volunteer work, etc.). In discussing their educational needs, they identified several areas of need regarding knowledge, communication, and unfamiliarity with the population, which are elaborated below.

All of the physician participants felt that they had been inadequately prepared to engage in the clinical care of adult patients with ID, even those who chose to focus their practice on the care of adults with ID. Most of the primary care–focused physician participants saw few patients with ID as part of their primary care practice and did not know how those patients had come to be assigned to them. A few more had developed relationships over time with area group homes or community agencies that had come to know them as physicians willing to take new patients with ID, and so they had a slightly larger panel and more of a working relationship with community residential providers. Interestingly, the vast majority of physician participants, even the "experienced" ones who had chosen to focus on patients with ID as the bulk of their practice, had little or no life experience with anyone who had ID. For the few who did, they were unable to tie that life experience to a desire to provide medical care specifically to that population (or may have been unaware of its influence):

So, uh, way back in college I did work with some kids with autism. Um, it was a program where they get them to ride horses.... It was very rewarding, and that I think has been the extent of my experience prior to residency. (Dr. N, primary care)

Oh yeah, [name], she has intellectual disability; she was my aunt; she was my father's sister. Um I grew up with her, She was just a part of my life; I didn't really think of her as being influential in my way of thinking about people with disabilities or health care issues or anything like that. (Dr. T, ID-focused)

While our primary aim was to identify themes associated with the idea of educational needs for family physicians, we also found related themes within each area that more fully illustrate the emotional and psychological experiences of the physician participants in this study as they provide care for people with ID. Both the ID-focused and primary care participants identified several themes germane to the topic of educational needs: (a) the idea of "operating without a map" or not knowing enough, (b) the idea of discomfort or lack of confidence interacting with patients with ID, and (c) unfamiliarity with the broad community spectrum of patients with ID. The physician participants also described complex emotional and psychological responses to working with individuals with ID: (a) feeling adrift and not being able to identify potential resources that could help, (b) feeling overwhelmed and out of control about interactions with patients with ID, and (c) anxiety

about challenging behaviors exhibited by patients with ID. These are presented below with exemplary quotes from providers.

## Operating "Without a Map"

Physicians related several different frustrations with their current clinical situation providing care to people with ID. They received little or no formal training; they had a relative paucity of clinical experience working with the population; they felt undersupported by their practice in terms of care management; and they lacked information about where to access valuable educational and community resources that might help them. Most physician participants, both ID-focused and primary care—focused, described their educational experience and preparation as inadequate:

I don't remember any specific curriculum directed towards caring for people with intellectual disabilities. So, I feel like most of my training has been on the fly. (Dr. E, primary care)

Well, I definitely do not have the knowledge I need to take care of people, and I've had patients in my practice die because of it. (Dr. D, ID-focused)

They also described numerous frustrations in caring for people with ID in their current practice settings, ranging from insufficient physical space in the office to a lack of staff support with care coordination and follow-up:

Oh I can say without a doubt, 'cause I was in a private practice for 20 years, that our practice was not set up to take care of this population. (Dr. L, ID-focused)

It took two and a half people to get them [patients with intellectual disability] in the office, and it really wasn't safe to get them on the exam table because of space issues. (Dr. D, ID-focused)

Participants described a lack of knowledge about resources available to them in practice—both educational resources such as evidence-based recommendations for care or consultants and how to access community resources that could be used to support their patients. However, it was unclear whether participants were frustrated by a true lack of resources or a lack of knowledge about how to access resources that exist:

I don't know. I guess if there was some... data, some... kind of guidelines around consent and around screening in developmentally disabled individuals, it might have helped me. I guess that having a consultant to go to might have helped me. (Dr. H, primary care)

[I thought]... there [was] very little known about care for this population, but, um, after spending several years looking into it, there is a fair amount known, it's just not coalesced into ways that are easy for clinicians to access and to absorb and to integrate into their practice (Dr. D, ID-focused)

This lack of integration adds to the frustration we noticed in the physician participants: they not only are "operating without a map" but also lack basic information about where to get help or even whether help is available. This lack of information makes it very difficult for physicians to improve their knowledge even if they had the time or energy to do so.

#### **Discomfort with Patients**

Participants described their overall discomfort and lack of confidence working with people with ID. This discomfort, more than any other specific curricular area, seemed to be the main issue leading to their frustration. In some cases, the discomfort was expressed as stereotyping patients with ID based on the few the physicians had known:

With the intellectual disability there's no hidden agenda or... sort of like, "what you see is what you get," you know. And it was sort of really pure. Beautiful, you know, people. (Dr. U, primary care)

I think that that should be part of our training because we are going to see people who aren't being locked up and people are being taken care of at home. (Dr. M, primary care)

It also led to their feeling overwhelmed or out of control during interactions with patients with ID:

I think definitely including how to interact well with the patient who has intellectual disability. I think that's the hardest part.

'Cause I feel like if you are not interacting well, then you are not in control of the visit, so I think that is a big part of it. (Dr. V, primary care)

Thus, physician discomfort was related to a sense that they did not know what to expect from patients with ID when they came to the office. In some cases, these feelings were accompanied by anxiety about challenging behaviors exhibited by patients with ID, especially when physicians did not know what to do to diagnose or treat the behavioral issue:

Sometimes I feel overwhelmed by the visits, like when my patient hit my computer and knocked it off the desk and broke the screen 'cause that's just how she lashes out and I didn't realize that. (Dr. V, primary care)

I think that people who are most difficult to serve in a mainstream practice are the individuals who have challenging behaviors. (Dr. D, ID-focused)

These uncomfortable experiences, in some cases culminating in fear and anxiety for participants, led to their feeling adrift and insufficiently prepared to take on the primary care of patients with ID.

## Unfamiliarity with the Community of People with Intellectual Disability

Participants spoke at length about their unfamiliarity with the daily lives of people with ID. Most of these comments came up in the context of describing what they would like to have included in medical school or residency curricula about the care of people with ID. The overwhelming sense among participants was that rather than focusing on specific facts or details that could be looked up, the curriculum should focus on early, community-based exposure to a range of people with ID, primary care approaches to the care of people with behavioral and communication issues, learning about and accessing community and educational resources, and the importance of an available mentor:

I think as in so much of medicine, experience is really the best teacher, so more exposure, perhaps, with training and with people who are... experienced to deal with these patients. (Dr. I, primary care)

Having a mentor who does take care of people with special needs on a regular basis and has a lot more comfort in that area... that would have been nice to have. (Dr. N, primary care)

I think it would have been good to go by a group home to see what happens in everyday living.... As a physician I see these types of patients once every three to four months, and between then I really don't know what goes on in their lives. (Dr. M, primary care)

It is interesting to note that both the primary care and ID-focused physician participants felt that a clinically based curriculum emphasizing the *approach* to the patient with ID would be more helpful than learning details about various syndromes or types of disabilities. This ties in with the themes of anxiety and lack of control that emerged above; more immersion in the community and exposure to a broader spectrum of people with ID might make physicians feel more familiar and less anxious with different types of behavior that can be expressed in the office setting.

## **Discussion**

Physicians in our study described important challenges related to experiences that heightened feelings of anxiety and fear when providing primary care to patients with ID. They described educational needs to increase their knowledge of the daily lives of their patients with ID, and subsequently a sense of competence, and to decrease their discomfort interacting with this unique population. From the physician's perspective, they are trying to provide care for patients (a) about whom they do not feel knowledgeable, (b) whom they perceive as different and somewhat intimidating, and (c) for whom they lack appropriate resources and support.

In the past, similar phenomena were noted among physicians caring for patients early in the AIDS epidemic (Cooke, 1992)—anxiety, fear, and ultimately, avoidance. While some physicians undoubtedly feared accidentally contracting HIV from patients, it is also likely that many physicians' avoidance of HIV-positive patients had to do with their own lack of knowledge, anxiety, and sense of those patients as "different." With time, of course, nearly every primary care physician had met and cared for someone with HIV or AIDS, and medical training began to focus on and normalize aspects of the treatment of these patients. Currently, most physicians and allied health professionals perceive patients with HIV/AIDS positively (Talley, Ritzdorf, & Muma, 2010).

While other researchers have commented on the lack of formal training in ID topics in primary care residency settings (Peter et al., 2009), the specific educational needs of primary care physicians who care for patients with ID have not been fully described to date. Our findings unveil the emotional and psychological barriers that contribute to physicians' difficulties treating this population. Our findings are most similar to publications regarding attitudes in nursing and allied health students (Boyle et al., 2010; Jones, Binger, McKenzie, Ramcharan, & Nankervis, 2010; Oermann & Lindgren, 1995). Most notably, our findings concur with the conclusions of these studies that early and frequent exposure to patients with behaviors outside the realm of one's own experience is important in helping the trainees gain comfort and confidence interacting with those patients.

Misconceptions of adults with ID may diminish physicians' ability to form significant bonds and provide quality health care to people with ID, despite good intentions and genuine efforts. Throughout, those who identified themselves as "primary care—focused" physicians made remarks that highlighted their inexperience. Comments that they are all "beautiful people," "they act out and become violent," or "they are not locked up anymore" point to stereotypes that would likely be disproved through more experience. These misunderstandings may be more or less prevalent in different countries depending on the social position of people with ID and/or the funding sources for medical education and formative experiences of future physicians. In this U.S. sample, however, almost all primary care physicians were unfamiliar with and harbored significant misconceptions about people with ID.

## Limitations

This study focused on a convenience/purposive sample of family physicians who responded to e-mail solicitations and may not represent the entire spectrum of family physicians in the United States. However, based on our experience and expertise, we had little reason to expect significant geographic variation in training, nor did participants report this. We also interviewed only participants who self-identified as being interested in this topic. If anything, this might tend to bias participants' responses toward their appearing more comfortable or experienced caring for people with ID. Given the discomfort and anxiety expressed by the study's participants, we think that physicians not interviewed for the study are likely to be even less comfortable or informed taking care of patients with ID.

## **Implications**

The culture of disability has been described in medical, psychological, and educational literature (Eddey & Robey, 2005). Researchers note the need to improve education in communicating with individuals who have nonstandard speech, understanding the values and needs of people with disabilities, and encouraging self-advocacy and interdependence. There is also precedent for using standardized patients with disabilities as part of medical student training in family medicine (Eddey, Robey, & McConnell, 1998). In recent years, medical education has focused on cultural competency as a goal of training, and the Accreditation Council for Graduate Medical Education (2007) has identified it as a required competency of residency training. Curricula dedicated to increasing exposure to the population and disproving some of the stereotypes physician trainees may have would increase physician comfort and confidence in taking care of people with ID and could also fulfill Accreditation Council for Graduate Medical Education requirements in cultural competency training.

Regional and national efforts are under way to define the elements of a curriculum on ID for primary care trainees. As medical educators make decisions about topic areas to include in this curriculum, efforts should also be made to foster early exposures and experience for trainees and appropriate debriefing to help broaden their perspective and increase their confidence in caring for people with ID.

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# Appendix. Interview Guide for Physician Participants

Tell me about your practice. Do you take care of any people with intellectual and developmental disabilities (IDD)?

- **a.** How did those patients wind up coming to you?
- **b.** How do you feel about the number of people with IDD that you see—would you like there to be fewer or more, or is it the right amount?
- **c.** Do you think your practice is set up to take care of people with IDD?

Tell me about some of the good and bad experiences you've had taking care of people with IDD.

**a.** Was there ever a time when you felt like you didn't know enough to provide excellent care? Why? What did you do about it? What would have helped you during that time?

**b.** Are there certain types of disabilities that you feel less comfortable taking care of? Tell me more about that.

Did you have any prior experience with people with IDD before becoming a doctor—life experience or volunteer work? Tell me about that. What was it like?

What was your training like in terms of taking care of people with IDD? Do you remember any specific education or training on that topic?

If you were helping to design a curriculum on this topic, what would you include?

**Table 1**Demographic Characteristics of Physician Participants

Characteristic	Inexperienced (general practice not focused on ID)	Experienced (ID-focused practice)	Total
Gender			
Male	6	3	9
Female	10	3	13
Number of years in practice			
<10	4	2	6
10+	12	4	16
Type of practice			
Academic	8	1	9
Community (including community health centers)	8	5	13
Total	16	6	22

Note. ID = intellectual disability.