Improving access to regular, routine health care is a chief concern for patients, advocates, medical professionals, and policy makers within the United States. American consumers ranked health care as the leading concern for government to address according to a 2005 Henry J. Kaiser Family Foundation survey (Kaiser Family Foundation, 2005). Sixty-three percent of participants cited lower healthcare cost and access to care as chief concerns. Amidst increased healthcare reform, a growing portion of the population lacks health coverage, specialized care, care coordination, and prescription coverage. People with intellectual and developmental disabilities (IDD) such as intellectual disability (ID) and autism spectrum disorders (ASD), face disparities in health and health care and could benefit from care coordination and specialized care (Drainoni et al., 2006; U.S. Department of Health & Human Services, 2005). To better understand the challenges this population could face when receiving health coverage, we should also be aware of the special needs or supports they may need. Intellectual disability is characterized by significant limitations both in intellectual functioning and in adaptive behavior, which covers a range of everyday social and practical skills. This disability originates before the age of 18 (Schalock et al., 2010). ASD are defined as neurodevelopmental disorders with an onset in early childhood, characterized by deficits in social communication and social interaction, as well as by behavioral challenges (American Psychiatric Association, 2013). The Centers for Disease Control and Prevention (Baio, 2012) estimates that 1 child in 88 has an autism spectrum disorder.
Prevalence of disability and health disparity

An estimated 56.7 million Americans (20% of U.S. population) are living with a developmental, mental or physical disability, according to a 2012 published report from the U.S. Census Bureau (Brault, 2010). Today, over 97% of people with disabilities live in individual, family, or group homes as opposed to larger institutions (McNeil, 2001). In fact, the number of people with IDD living in state institutions declined from 194,650 in 1967 to 32,909 in 2009 (Lakin, Larson, Salmi, & Webster, 2010). Because most people with IDD live outside of centers with specialized care, they seek health care from providers in their community, as everyone else does. Physicians can expect to have patients with disabilities and should be prepared to provide quality care.

Barriers to quality health care for people with disabilities

Individuals with IDD experience increased barriers to routine care in comparison to their counterparts without disabilities. This population reports poorer health outcomes, increased secondary conditions, less access to preventive health services, and a lack of routine managed care (Drainoni et al., 2006; Duggan, Bradshaw, & Altman, 2010; Minihan et al., 2011; Pharr & Bungum, 2012; U.S. Public Health Service, 2002). Patients with IDD often encounter a healthcare network that is limited in scope, size, and preparation. This system often results in lower quality of care and gaps in service. Moreover, patients experience undiagnosed, delayed, or untreated medical needs (Campbell, 2009; Drainoni et al., 2006). A Henry J. Kaiser Family Foundation (2003) survey found 25% of nonelderly adults with IDD experience difficulty finding a medical professional who understands their disability. Drainoni et al. (2006) identified cultural and personal barriers such as misconception about individuals with disabilities,
insensitivity, lack of respect and reluctance to treat people with disabilities as contributors to access, care, and healthcare disparities for patients with disabilities. Assumptions about disability and limiting attitudes of medical professionals can also affect the quality of care and health outcomes for this population (Eastgate & Lennox, 2003; Drainoni et al., 2006; Campbell, 2009), becoming a major determinant of health (Symons, McGuigan, & Akl, 2009).

Improving access and quality of care is essential to eliminating the current health disparities among this population. Research suggests that quality health care can eliminate disparities, promote health, and improve health outcomes among this vulnerable population (U.S. Department of Health & Human Services, 2005; Drum, Krahn, Culley, & Hammond, 2005; Havercamp, Scandlin, & Roth, 2004; Campbell, 2009). With the passing of the Americans with Disabilities Act of 1990, the public’s perception of disability has gradually shifted with improved accommodations and decreasing obstacles in everyday living. Conversely, there is growing evidence that indicates healthcare barriers (e.g., medical cost, physical factors, lack of education, and negative attitudes of care providers) continue to impede the health of people with disabilities (Drainoni et al., 2006; U.S. Department of Health & Human Services, 2005; U.S. Public Health Service, 2002).

**ASD health disparities**

Within the disability group, children and adults with autism spectrum disorders present particular healthcare needs and higher rates of comorbidities that require specialist care (Kasari, Freeman, & Paparella, 2000; Kogan et al., 2008). As Krauss, Gulley, Sciegaj, and Wells (2003) pointed out, access to health care is not simply a question of having or even seeing a healthcare provider. Several factors including difficulties in diagnosing (Goin-Kochel, Mackintosh, & Myers, 2006), lack of care coordination (Krauss et al., 2003), unmet healthcare transition needs
(Scal & Ireland, 2005), or society’s lack of understanding (Woodgate, Ateah, & Secco, 2008), may limit the adequacy of the care received by people with autism spectrum disorders.

Parents of children with ASD are less likely to be satisfied with care (Kogan et al., 2008) and report having difficulties in receiving an ASD diagnosis (Shattuck et al., 2009), requiring an average of 4-5 appointments before ASD is recognized (Goin-Kochel et al., 2006). Children with mild or atypical ASD symptoms or who have less cognitive impairment are especially likely to face a protracted diagnostic process (Shattuck et al., 2009). During this time, parents’ concerns about the child’s development and ASD ‘red flags’ (e.g., deficits in social communication, impaired communication skills, unusual behaviors, etc.) are often dismissed by healthcare providers who are unfamiliar with autism spectrum disorders. Children and adults with ASD and their families are likely to face healthcare access problems after receiving the ASD diagnosis. The most common access problems are getting referrals for services unless referral is directly related to the patient’s disability (Krahn, 2003); being denied services such as behavioral health services on the basis that such services are the responsibility of the educational system (Krauss et al., 2003; Ruble, Heflinger, Renfrew, & Saunders, 2005); lack of referral sources or problems finding skilled and experienced specialty doctors (Krauss et al., 2003; Liptak et al., 2008; Ruble et al., 2005); or difficulties related to the coordination of care between specialty doctors and other providers (Golnik, Ireland, & Borowsky, 2009; Krauss et al., 2003). Compared with children with other special healthcare needs, children with ASD are less likely to receive care within a medical home (Golnik et al., 2009; Kogan et al., 2009).
Healthcare transition

While families have difficulty securing adequate health care for their children with ASD, transition to adult healthcare providers is especially difficult for youth with ASD (Stewart, 2009). Although the need of an appropriate healthcare transition plan and training in adult medicine has been addressed by both the American Academy of Pediatrics (2002) and the Society for Adolescent Medicine (2003), in a study conducted by Scal and Ireland (2005) only 30.08% of people with special healthcare needs 14 to 17 years old had developed a plan for addressing transition needs, and only 29.93% had discussed seeing a doctor who treats adults. Resources or guidelines to facilitate this transition are not always available, and preventive practices, screenings, and dental services are often not adequately provided (Bruder, Kerins, Mazzarella, Sims, & Stein, 2012). Families also report a lack of coordinated, family-centered and comprehensive care (Brachlow, Ness, McPheeters, & Gurney, 2007) that contributes to their difficulty during this period, along with other variables such as society’s lack of understanding and feelings of isolation (Woodgate et al., 2008).

Identifying those factors associated with best practices to increasing access to health care for both children and adults with ASD will improve well-being across the lifespan of people with autism. However, IDD knowledge in general, and autism competency in particular, among primary care providers remain outdated according to current research and practice (Heidgerken, Geffken, Modi, & Frakey, 2005; Volkmar, Wiesner, & Westphal, 2006). A broader knowledge about autism should be provided when training medical students throughout their careers (Shah, 2001). This training should also include an exposure to the medical home model of care (Carbone, Behl, Azor, & Murphy, 2010), which emphasizes care coordination and patient-centered care (Cooley, 2004) across the lifespan.
Although people with IDD (including autism) heavily depend on providers to manage routine care (Wilkinson, Dreyfus, Cerreto, & Bokhour, 2012), physicians describe themselves as lacking the needed skills to work with individuals with IDD (Bruder et al., 2012; Dosreis, Weiner, Johnson, & Newschaffer, 2006; Golnik et al., 2009; U.S. Department of Health and Human Services, 2005) and feeling uncomfortable caring for patients with developmental disabilities (Wilkinson et al., 2012). This lack of training is exacerbated by little exposure to this population and may lead some healthcare providers to view the health concerns of patients with IDD as an unavoidable part of their disability, or to refuse to serve people with IDD under the Medicaid program (Havercamp et al., 2004).

Primary care providers function as gatekeepers to specialty care, so this lack of disability competence could interfere with patients with IDD, who in fact report that they don’t receive enough health information from providers to play an active role in their healthcare decisions (Masuda, 1999; Reiss, Gibson, & Walker, 2005).

To avoid such situations, changes in medical curricula are necessary to provide the health care and services needed.

The solution: medical education

Training medical students to care for patients with disabilities could prevent the aforementioned problems. Introducing concepts from the World Health Organization’s *International Classification of Functioning* (2001) would help medical students appreciate the social and societal aspects of disability in addition to the medical model of care. This perspective will enhance the physician’s ability to engage patients in open communication and partnership without discomfort (Duggan, Bradshaw, & Altman, 2010; Minihan et al., 2011; Wilkinson et al.,
Disability training increases knowledge and skills and decreases negative attitudes, behaviors and assumptions (Woodard, Havercamp, Zwygart, & Perkins, 2012; Symons et al., 2009). Furthermore, first-hand experience with people who have disabilities greatly reduces their discomfort treating patients with IDD (Wilkinson et al., 2012).

Training culturally competent physicians is a major goal of the Accreditation Council for Graduate Medical Education (2007) and is now a required component of medical training. Physicians are trained to appreciate the beliefs, values, and traditions of their patients. Eddey and Robey (2005) describe the “culture of disability” as a pan-ethnic culture that requires core competencies to be met by medical professionals to ensure suitable care for individuals with disabilities. As Symons et al. (2009) stated, “getting the opportunity to talk to a disabled patient and hear her voice her concerns regarding how doctors treat her made me realize how important it is to treat them the same as you would treat any other patient.”

By implementing a medical curriculum that increases sensitivity to people with disabilities and also provides core concepts and key aspects about people with IDD and healthcare issues, medical schools can improve trainees’ confidence and comfort, while replacing negative assumptions and stereotypes with an open frame of mind that asks questions and listens to the needs and preferences of their patients.

We hope the resources provided on this site will be used to incorporate an understanding of disability in healthcare education.
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