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CONCEPT PAPER

From inequity to access: Evidence-based institutional practices to enhance care for individuals with disabilities

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Abstract

People with disabilities experience barriers to care in all facets of health care, from engaging with the provider in a clinical setting (attitudinal and communication barriers) to navigating a large institution in a complex health care environment (organizational and environmental barriers), culminating in significant health care disparities. Institutional policy, culture, and physical layout may be inadvertently fostering ableism, which can perpetuate health care inaccessibility and health disparities in the disability community. Here, we present evidence-based interventions at the provider and institutional levels to accommodate patients with hearing, vision, and intellectual disabilities. Institutional barriers can be met with strategies of universal design (i.e., accessible exam rooms and emergency alerts), maximizing electronic medical record accessibility/visibility, and institutional policy development to recognize and reduce discrimination. Barriers at the provider level can be met with dedicated training on care of patients with disabilities and implicit bias training specific to the surrounding patient demographics. Such efforts are crucial to ensuring equitable access to quality care for these patients.

INTRODUCTION

People with disabilities experience significant health care disparities and the U.S. health care system is often insufficiently prepared to recognize and address their needs.[1–4] To maximize inclusion and legal protection, the Americans with Disabilities Act (ADA) defines a person with a disability as someone with a physical or mental impairment that limits one or more life activities.[5] While institutions and providers may acknowledge this legal definition and traditionally define disability using a medical model (which focuses on a person's impairments or differences and trying to “fix” them), the World Health Organization uses an international classification of function to define disability more accurately as a complex interaction between physical, intellectual, sensory, or emotional impairments within a person's surroundings. This definition opposes the more traditional medical model of disability and reflects the social model of disability, which emphasizes the removal of barriers (through accommodations) that restrict independence and freedom.[6–8]

Ableism is the belief that people with disabilities “need to be fixed or cannot function as full members of society” and that having a disability is a “defect” rather than a dimension of difference.[6,9] Ableism often results in objectification, invalidation, infantilization, or dehumanization of those with disabilities.[9] From a provider standpoint, this is problematic as it generates preconceived negative implicit and explicit perceptions about people with disabilities thus undermining the ability to connect with patients and negatively impacting health outcomes. On an institutional level, ableism undermines institutions' ability to engage with patients as it misaligns the ultimate priorities of medical care and promotes the notion of normalcy.[10]

People with disabilities experience barriers to care in all facets of health care, from engaging with the provider (attitudinal and communication barriers) to navigating a large institution in a complex health care environment (organizational and environmental barriers). At the provider level, the literature demonstrates provider use of archaic terms (such as variations on the word "handicap," using "wheelchair-bound," or describing persons with disability as "special" or "suffering") as well as physician discomfort and insufficient provider training when for caring for patients with disabilities.[11–15] Research also shows that uninsured adults with disabilities in the United States are more likely to rate their care as poor, to have unmet health care needs, and to have missed health care opportunities because of financial cost.[1,3] At the community level, there are data to show higher rates of nonaccidental trauma, smoking, obesity, heart disease, and stroke.[3,16] Regardless of disability severity, the disability community has less access to preventative care, which limits preventative services (such as breast exams, pap smears, and colorectal cancer screenings), and more gaps in insurance coverage.[3,17] At the institutional level, there are scheduling constraints, insurance coverage/payment lapses, poor perception of people with disabilities (often from insufficient or absent provider training), insufficient building and exam room designs, and lack of inclusion of the disability community in the medical field as health care providers.[11–13,17–19] Institutional construct, policy, and culture may not recognize the social model of disability and may be inadvertently reinforcing ableism, which can perpetuate health care inaccessibility and health disparities in the disability community.

METHODOLOGY

On behalf of the Academy for Diversity and Inclusion in Emergency Medicine (ADIEM) Accommodations Committee of the Society for Academic Emergency Medicine (SAEM), we developed a didactic session for the SAEM22 annual meeting. This article describes provider and institutional barriers experienced by three specific patient groups with disabilities or who require accommodations—(1) Deaf American Sign Language (ASL) user/deaf/hard of hearing; (2) blind/visually impaired; and (3) intellectual and developmental disability (IDD)—recommendations for evidence-based institutional and provider strategies that promote equity and access for patients with disabilities. A fourth group, patients with physical and mobility disabilities, also requires accommodations for accessible care. Since the provision of many of these accommodations are covered in building codes and departmental accreditation, we have not described them in detail in this article. The authorship team consists of faculty and residents with expertise, leadership, and advocacy experience surrounding individuals with disabilities at the departmental, institutional, and national levels. We performed a comprehensive literature search using PubMed, Google Scholar, and Congress.gov to inform a comprehensive appraisal of existing laws, barriers to inclusion for the three groups, and current best practices surrounding the approach for institutions in accommodating those with disabilities in the health care workplace and training environment. Search terms included general components (e.g., disab* health* law* right* legal, ADA, advocac*) and in combination with each of the disability groups covered (e.g., deaf*, hard of hearing, ASL, caption*, vis*, visual, blind*, intellectual disabil*, handicap*, mobility, policy) related to each general search term and each individual disability. Each of the authors researched a unique component of this work and presented it to the group for input, critique, and real-time group editing for the article, with all authors providing critical literature review. This work did not involve human subjects and, thus, was not presented to an institutional review board.

ANALYSIS/DISCUSSION

Anyone who must seek care in the emergency department (ED) may feel stress surrounding their condition and well-being. In addition to these concerns experienced by all patients, those who have disabilities or require accommodations have the added stress of trying to navigate the complex emergency care system with additional challenges.[20] In this section, we highlight the unique challenges and barriers to care experienced by patients with disabilities.

D/deaf/hard of hearing

One of the most common barriers among the D/deaf/hard-of-hearing patient population is the lack of available access to comprehensible real-time health information from their providers, often due to lack of qualified ASL interpreters and/or Communication Access Real Time (CART) providers.[21,22] In many cases, people with hearing loss who can communicate orally may be dissuaded from asking for accommodations or provided the incorrect accommodations (i.e., provided an ASL interpreter when they do not know ASL). Their ability to speak may incorrectly be interpreted as being able to capture the entirety of the medical exchange. In such a stressful, high-stakes environment, capturing an entire conversation may be impossible, and some patients may feel pressured to proceed without the necessary accommodations. Sometimes, well-meaning family members or other ad hoc interpreters summarize, erroneously simplify, and transmit (sometimes incorrect) information through their own filters leading to miscommunication and medical error.[23] Similar to patients without disabilities, patients with disabilities may not wish their family members to be aware of their private medical conditions, thus precluding effective information exchange in these situations. Additionally, surrounding conversations (e.g., between bedside health care providers about options they are considering for the patient) and general public announcements are omitted when family or friends are used as ad hoc interpreters. Despite inconsistent enforcement, Title VI of the Civil Rights Act requires organizations receiving federal funds (i.e., Medicaid or Medicare) to provide meaningful access to language accommodations for all patients. Failure to provide language accommodations results in more medical errors and poorer health outcomes and may have negative financial implications for the noncompliant organization.[23–25]

Some patients with hearing loss belong to a community that uses ASL as their primary language, making English a second language. This group, often referred to as capital "D" Deaf, has shared life experiences deriving from a unique history and language.[26,27] Patients who rely primarily on ASL for communication may have a limited ability to communicate orally or through written English as ASL is its own distinct language with its own grammar, syntax, and structure separate from spoken English.[28,29] Other complexities to ASL include changes in cadence of signing and changes in facial expressions and body language, which can sometimes be misinterpreted by hearing providers (even as aggression) and cannot be fully conveyed via paper (or a small virtual tablet).[28–30] As previously mentioned, lack of certified ASL interpreters prevents accurate and efficient information exchange.[31] Also, relying heavily on written English during an encounter with a Deaf person with limited English proficiency may lead to misinformation and misunderstanding, a common occurrence in the Deaf community.[32] Deaf patients also encounter lower access to primary care (likely causing more emergency care), decreased inclusion in public health surveillance, and poor provider cultural sensitivity.[22]

Blind/visual impairment

Multiple provider and institutional barriers make navigating the health care environment challenging for blind or visually impaired community. Health care providers often lack training and awareness to appropriately support patients with visual impairment.[33] This limited awareness leads to incursions on a patient's personal space such as obtaining IVs or examining a patient without appropriate verbal communication beforehand. Providers can also underestimate or overestimate vision-impaired patients' ability to navigate their world. If abilities are underestimated, patients can be treated as incompetent. If abilities are overestimated, it may lead to insufficient communication.[34] Additionally, delivering meal trays or providing housekeeping services can feel intrusive when staff silently enters/exits a patient's room without knocking or providing appropriate introductions.

Institutional factors also significantly impact a blind patient's ability to autonomously seek and navigate health care. Patients with visual impairment are more likely to report lack of available transportation to medical appointments.[33,35] Often, patients' ability to see and read documents is overestimated and accommodations are not offered when provided written materials.[36] Hospital forms, medical records, and discharge instructions are rarely available in electronic modalities to allow patients to use adaptive voiceover software. Additionally, hospital signage is typically written in small font size and without proper contrast making it challenging to independently navigate spaces. This is exacerbated by commonly used fluorescent lighting in hospitals which decreases contrast of written material. Braille is an uncommon resource for most health care organizations. Finally, there is often a lack of privacy while attempting to read health information aloud due to inadequate treatment space.[37,38]

IDD

Individuals with IDD are at greater risk for health problems when compared with the general population leading to higher morbidity and earlier mortality.[39,40] Both acute and chronic illnesses in individuals with IDD may be exacerbated by a health care system that is fragmented, poorly resourced, and staffed by health care professionals without the necessary expertise to care for individuals with IDD. When compared to the general populations, patients with IDD may be frequent users of the ED due to their greater burden of chronic disease and lower access to some preventative services.[41]

Like other patients with disabilities, individuals with IDD experience barriers at the provider level (communication and attitudinal) and institutional level (organizational and environmental). At the provider level, patients with IDD demonstrate a wide range of communication skills and utilize a variety of strategies. Difficulty with typical verbal communication can be a significant barrier to emergency care for some patients with IDD, especially when combined with emergency personnel's lack of general comfort with IDD, lack of background with a particular patient, and a lack of training on alternate communication methods and strategies.[42] ED personnel may carry specific biases about patients with IDD. For example, staff and providers may assume a diagnosis of IDD means a patient cannot communicate or cannot participate in their own care, thereby excluding them altogether.

The physical environment in the ED is particularly challenging for patients with IDD, as the noise, light, and activity level can be quite disruptive for patients who may have difficulties with specific sensory stimuli. Additionally, a large ED team can be overwhelming or frightening for some patients with IDD. Moreover, small treatment spaces in many EDs may make transfers, mobility, and physical examinations challenging for patients who have a physical disability or utilize mobility devices. Hoyer lifts and teams may not be readily available to aid in patient transfers. The small treatment spaces may also make it difficult for a support person to remain with the patient throughout their care.

At the institutional level, one of the biggest barriers is ensuring that everyone caring for the patient understands the presence of a disability and needed accommodations. Utilization of the electronic health record (EHR) to identify disability and accommodations may assist in this, but many EHR systems do not clearly display this information.[43] Other institutional barriers impacting quality care for patients with IDD include institutional policies such as those limiting support person access and those governing transitions from pediatric to adult care.[44] Lack of care coordination services, such as social work or case management, may also impede effective care for patients with IDD.

IMPLICATIONS/RECOMMENDATIONS

All populations with disabilities

Combatting institutional (organizational and environmental) barriers with institutional change can have a significant impact across a variety of disability types. Applying the concept of universal design broadly across an institution streamlines departmental design, allowing for more usable communication tools, products, and health systems for all. Examples of universal design include power door sensors making entering/exiting accessible, automated teller machines with enhancements in sounds and appearance to allow for increased usability; audio and visual emergency alert systems; and appropriately sized halls, exam rooms, and common areas to accommodate anyone regardless of body size, posture, or mobility.[45] Partnering with your local disability community can assist with a needs assessment based on local patient demographics and match interventions with available institutional resources. When considering utilization of the EHR to optimize care, patients' required physical or language accommodations should be annotated (and easily visible) in their chart. Finally, it is paramount to implement institutional policies which aim to reduce (or eliminate) discrimination.[5,46] For example, institutions should create visitor policies that are flexible, allowing support persons for those with disabilities to accompany the patient at all times (when feasible). Also, policies assigning the financial and administrative burden to individual patients to seek and pay for accommodations should be revised to clearly redirect the burden to institutions and/or insurance organizations. If these policies are already in place for any individual for their routine health care, then they will be more easily utilized when the patient requires emergency care and may be the least able to perform self-advocacy.

To address barriers faced by patients with disabilities at the provider level (attitudinal and communication), clinicians and staff should participate in disability patient care and implicit bias training concordant with the resources and patient demographics of the institution. For example, if an institution has access to hoyer lifts, staff should receive training with this equipment. However, if operating in a lower resource environment where staff use other techniques to move patients, this should be included in the training (and hoyer lifts should not be included). Providers should standardize the idea that all patients, both those with and those without disabilities, should be asked their communication preferences (written, oral, language, etc.) at the start and end of any encounter. Additionally, while the perceived chaos of the ED offers challenges to all, patients with disabilities should (when possible) receive priority placement in rooms with doors over those with curtains or no privacy barrier to enhance care. Finally, all providers should recognize that bias toward those with disabilities exists and can create problems in providing appropriate health care to these patients.

There are no universal recommendations for training hours, topics, or formats as the number of hours and type of training will vary based on your institution's resources and patient demographics. As mentioned, the concept of universal allows for preemptive planning when caring for those with disabilities and avoids improvisational and inconsistent care plans (and their associated frustration and ineffectiveness). For suggested training resources or for those operating in a lower resource environment, consider choosing from a list of a recommended materials provided in Table 1.

D/deaf/hard of hearing

When thinking about people with hearing loss, there are specific institutional strategies that can improve access. Clear face masks should be considered when caring for this patient populations. To capture the entirety of a conversation, those with hearing loss who communicate orally may require a written transcript of the conversation. This is possible with CART translation. Similar to a court reporter, the CART provider creates a real-time written transcript of the speaker and all that is said, including incidental conversations and background ED announcements (which are available to patients without hearing loss). Additionally, patient information (pamphlets, discharge information, etc.), often written above a 10th grade reading level, should be written at a fourth to sixth grade reading level, making it more comprehensible for people who use English as a second language (like the Deaf ASL user) and for the large percentage of Americans with less than proficient reading skills (approximately 55% of US eighth graders and 67% of U.S. 12th graders are reading below a proficient level).[47–51]

At the provider level, all patients should be asked about their communication preferences upon arrival so that appropriate language, CART, or ASL services can be accessed. This type of patient-centered care is reinforced by improved provider cultural training and has been shown to lead to positive outcomes for the patient, lower health care costs, and lower medicolegal risk.[32,52,53] Additionally, oral communication can be facilitated with personal hearing aids or cochlear implants while some patients with hearing loss may rely on speech reading to improve understanding. Personal hearing aids can be utilized but require healthy batteries but are less effective in noisy environments (since all ambient sounds are amplified); thus, these patients may benefit from being placed in quieter treatment space. Also, providing contextual clues and visual communication (e.g., smile, concern), which can be obscured by an opaque mask, should be considered when communicating with a person with hearing loss.[54,55] To facilitate all forms of communication with deaf/hard-of-hearing patients, these patients should preferentially be placed in a well-lit private area. In addition, triage staff should note what patients who are deaf/hard of hearing are wearing to help identify them and ensure they do not miss their name being called.

For patients who communicate in ASL, qualified in-person interpreters are the criterion standard and have been shown to improve clinical care.[31] An additional resource that may be available is the Certified Deaf Interpreter or CDI. These individuals generally are Deaf and are trained in information exchange between a hearing ASL interpreter and Deaf patients who may have limited language

TABLE 1 Recommended disability education training resources.

Disability type	Source	Brief description	Link
IDD	Health Care Access Research and Developmental Disabilities	This toolkit is an opportunity to share implementation tools with emergency providers who are interested in improving the care provided to patients with developmental disabilities.	https://centerforstartservices.org/resource/emergency-room-stabilization-protocols-individuals-idd
	Autistic Self Advocacy Network	Recommendations on the contents of best practice guidelines for health care providers treating children and adults with intellectual and developmental disabilities.	https://autisticadvocacy.org/2022/08/autistic-self-advocacy-network-comments-re-safe-initiative-call-for-testimony/
	Center for Disability Services	A Trauma-Informed Toolkit for Providers in the Field of Intellectual & Developmental Disabilities.	https://www.pacesconnection.com/fileSendAction/fcType/0/fcOid/468137553002812476/filePointer/468137553002812517/fodoid/468137553002812512/IDD%2520TOOLKIT%2520%2520CFDS%2520HEARTS%2520NETWORK%25205-28%2520FinalR2.pdf
	University of Hertfordshire Intellectual Disability and Health	Guidelines for Managing the Patient with Intellectual Disability in Accident and Emergency.	http://www.intellectualdisability.info/how-to-guides/articles/guidelines-for-managing-the-patient-with-intellectual-disability-in-accident-and-emergency
	Vanderbilt IDD health care E-toolkit	The IDD toolkit is devoted to information for the primary care of adults with intellectual and developmental disabilities offering health care providers best-practice tools regarding specific medical and behavioral concerns of adults with IDD, including resources for patients and families.	https://iddtoolkit.vkcsites.org/
	Developmental Disabilities Primary Care Program is a program of Surrey Place, Toronto	A toolkit with information and resources to improve the primary health care for adults with intellectual and developmental disabilities.	https://ddprimarycare.surreyplace.ca/
	The National Alliance to Advance Adolescent Health	Emergency Preparedness Toolkit for Young Adults with Intellectual and Developmental Disabilities and their Primary Care Team: A toolkit with two tip sheets to assist primary care teams.	https://www.thenationalalliance.org/publications/2022/3/29/emergency-preparedness-toolkit-for-young-adults-with-intellectual-and-developmental-disabilities-and-their-primary-care-team
Visual disability	American Foundation for the Blind (AFB)	The American Foundation for the Blind (AFB) has developed training materials to guide and support health care workers.	https://www.afb.org/blog/entry/resources-healthcare-workers
	Center for Medicare & Medicaid Services (CMS) Communication Access for individuals who are blind or have low vision	This resource describes how providers can assess their practices, develop such plans, and be prepared to implement accessible services and suggests ways to improve the provision of health care to people with disabilities.	https://www.cms.gov/files/document/omh-visual-sensory-disabilities-brochure-508c.pdf
Deaf/hard of hearing	Make Medicare Work Coalition	Toolkit for Working with the Deaf and Hard-of-Hearing.	https://www.rrf.org/wp-content/uploads/MMW-Deaf-Universal-Toolkit-05-24-12.pdf
	Hearing Loss Association of America	Guide for Effective Communication in Health Care.	https://www.hearingloss.org/hearing-help/communities/patients/
	L.A. Care Health Plan	Better Communication, Better Care: A Provider Toolkit for Serving Diverse Populations.	http://www.lacare.org/sites/default/files/la0784_provider_toolkit_201902.pdf
	Hearing, Speech & Deaf Center	Deaf 101: Communicating with Deaf and Hard of Hearing Individuals.	https://www.hsdc.org/services/deaf-101/

Abbreviation: IDD, Intellectual and Developmental Disability.

TABLE 2 Challenges and proposed institutional/provider solutions to optimize care for patients with disabilities.

Category	Challenge	Institutional (I)/personnel (P) actions
All persons with disabilities	Communication needs	Ask the patient about their preferred method of communication (P) Establish policies that require both inquiry about and documentation of these needs to make standard across the organization (I)
	Noisy/high-stimulus environment	Prioritize the use of rooms with doors (vs. curtains) for those with disabilities to decrease stimuli and improve communication (I)
	Inability to respond to standard alerts	Implement multiple alert modalities (e.g., visual and audio) (I) Establish hospital policies that allow the presence of a support person(s) throughout the patient's encounter (I)
	Repeating requests for accommodation with multiple health care personnel Interactions with multiple people (reexplaining situation)	Documentation of needs in the electronic medical record (I/P) Establish a health passport that transfers between medical systems and offices (I) Visible signage outside patient rooms reminding personnel of patient's specific needs (I/P)
	Institutional and provider/staff bias	Include the topics of D/deafness, visual impairment, and IDD in standard cultural sensitivity training (I) Partner with community organizations to optimize policies and ensure persons with disabilities are included in decision making (I) Recognize that bias exists (P) Identify evidence-based institutional strategies and policies that promote equity and access for patients with disabilities/best practices to enact systems-based improvements to care (i.e., assignment of cost of interpreters services to the institution or insurance company) (I)
D/deaf and hard of hearing	Communication needs	Clarify, then use patient's preferred method of communication (e.g., spoken language, ASL, CART, writing, etc.) (I/P)
	Noisy/nonprivate environment	Use patient care areas that are quiet, bright, and private to optimize independent communication: (P) • Maximizes residual hearing and speech reading • Facilitates ASL comprehension • Prevents conversations conducted using ASL from being “overheard” by others
	Inability to respond to standard alerts	Create a pathway for personnel to alert patients that their name is being called (e.g., in waiting room) or for general safety alarms (e.g., fire, public general announcements) (I/P)
	Masks	Purchase and make available specialized masks made of clear material that preserve provider and patient safety (I/P) Conduct conversations while looking directly at the patient to enable full facial visualization and lipreading (P)
	Limited availability of communication resources	Contract with on-site or remote providers for ASL and CART (I) Partner with relevant community groups (I) Include ASL in interpreter programs (I) Hire and maintain a diverse workforce (I)
Visually impaired[58]	Difficulty/inability to read standard signage and other forms of written communication	Post signs with large font, in contrasting background colors, and in braille when feasible (I) Ensure that medical communication (i.e., discharge instructions) is available in an electronic format compatible with text-to-voice applications (I) Ensure discussion of discharge plan with patient prior to discharge (P) Offer to read any written materials and identify exactly where signatures are required (P)
	Unfamiliarity with service animals	Train staff on what is permissible to ask regarding service animals (I) Facilitate bathroom breaks for the animal at reasonable intervals (P)
	Communication needs	Signage on exam room door reminding personnel of patient's specific needs (I/P) Knock and announce yourself when entering and exiting rooms (do not just appear and disappear) (P) Introduce self and team members (P) Speak directly to the patient, not through a third party (P) Ask permission and explain your actions before physically touching the patient (P)
	Movement issues	Ensure removal of obstacles in hallways and within rooms (I/P) Learn about “sighted guide” techniques to properly guide patients (P)

TABLE 2 (Continued)

Category	Challenge	Institutional (I)/personnel (P) actions
IDD[61,62]	Variable communication abilities and unrecognized communication needs	Take time to establish the patient's style of communication and baseline (P) • Listen to the patient • Speak slowly, pause • Understand that all behavior is a form of communication
	Provider/staff lack of understanding of IDD, presence of biases/assumptions	Implement required training (I) Engage the disability community in provider education (I) Presume the patient can participate in their care and treat them as fully participating patients (P) • Speak directly to the patient • Ask for consent before doing anything
	Loud, bright ED environment with a multitude of personnel	Use rooms with doors and lights that can be turned down/off (P) Consciously minimize personnel in the room (P) Utilize only essential equipment to minimize noise (beeping monitors) and unnecessary tactile stimulation (P) Obtain, train, and use sensory machines (such as sensory-regulation item) that may be helpful for some patients (I/P)
	Lifelong medical issues unfamiliar to adult health care practitioners	Establish policies allowing patients with specific diagnoses and/or being followed by pediatric specialists to continue being seen in the pediatric ED past 18 years of age (I) Implement comprehensive transition plans for patients moving from pediatric to adult care (I)
	Need for continuity of care for chronic issues	Creation of a health care passport with baseline, accommodation needs, medical issues (I) Improve access to social work/case management (I)
	Policies that do not take IDD into account	Engage the disability community in education and policy writing (I)

Abbreviations: ASL, American Sign Language; IDD, Intellectual and Developmental Disability.

comprehension, neurologic or mental health issues, or temporary deficits in language due to a severe medical condition at the time of evaluation.[56] Facial expression is an important part of ASL and clear face masks should also be utilized with this group. If the institution cannot arrange in-house ASL interpreters/CART (for budgetary or other constraints), explicit instructions for obtaining these services should be readily available to guide providers. Options include an outside contract with qualified professionals for in-person or video remote interpreter services or utilizing "certified" (through a formal interpreting department or organization) volunteer hospital employees who are fluent in ASL. Video remote interpreting (VRI) is often used in clinical practice, either through a tablet or through screen. While there are many limitations to VRI such as limited internet connection and visual constraints, using a screen larger than 19.5 inches and placing the screen no farther than 2 feet away can optimize effective communication. Also, prepping the video interpreter with the location, individuals involved, and brief context can aid in accurate interpretation.[57]

Blind/visual Impairment

To improve care and augment information exchange for patients with vision loss and blindness, institutions should conduct provider training around guided sight, how to appropriately interact with service animals and how to address service animal needs, and how to properly assist visually impaired persons. Physical modifications (i.e., high-contrast tape/signage, good lighting, minimizing background noise, options for larger print or braille medical information) can improve accessibility for this population.[58,59] Finally, improvement in audio, telephone, or electronic access to information in patient charts and discharge instructions can facilitate comprehension. If this is not possible, staff should be instructed to privately read medical information to patients with visual impairments to avoid incomplete information exchange.[58] A needs assessment with the local target community may help guide recommendations.

At the provider level, using the following common techniques for guided sight can augment the patient–provider relationship and patient safety: (1) ask if a patient would like to be guided; (2) offer an arm for the person to grip just above the elbow (they may prefer to grip the shoulder); (3) walk slightly in front, making sure that the pace is not too fast or too slow; (4) state if stairs are present and whether they go up or down making sure to give warning of approaching ground level; (5) explain changes in ground surface, such as moving from a tiled floor to carpet; and (6) always guide someone into a chair facing forward.[58] The American Foundation for the Blind publishes several resources to train health care providers to care for patients who are visually impaired.[60]

IDD

There are specific strategies that can be implemented by institutions to improve care for patients with IDD. At the institutional level, it is critical to establish specific policies that allow for patients with IDD to continue being cared for in the pediatric ED, when appropriate, past the age of 18.[61,62] Health care passports are another intervention that can be implemented at an institutional level to promote accurate communication and exchange of information.[63] In addition, implementing policies within the ED that reduce noise and stimulation for patients with sensory sensitivity is critical. This includes allowing for a limited care team to reduce the number of personnel interacting with the patient, placing patients in quiet rooms with doors that close, and utilizing sensory machines when appropriate.[61,62] Additionally, utilizing the EHR to improve the continuity of care and communication between both primary and specialty care may reduce ED utilization for patients with IDD.[64]

At the provider level, staff and providers should receive training regarding how to effectively communicate with patients with IDD, especially given the wide range of communication skills and styles in this population.[65] This training should include an approach that establishes how the patient communicates, who the patient wants in the room, inquiry of the patient's baseline and triggers, what accommodations the patient needs, and whether a care plan exists. Once these questions have been answered, it is the responsibility of the providers and staff to listen to the answers and use the provided information to appropriately care for the patient. Providers and staff must also receive training that leads them to start the encounter believing the patient with IDD can and will participate in their care. Training on supported decision making as well as implicit bias are crucial to ensuring the patient with IDD is allowed to maximally participate in their own care.

Providing compassionate emergency care to patients with disabilities requires overcoming several challenges by utilizing some the aforementioned strategies. For a list of these barriers and matched strategies, please see Table 2. Institutions and medical education training programs bear responsibility in addressing these challenges. Institutions need to partner with local organizations comprised of persons with disabilities to ensure that their concerns and accommodations are considered. Residency training programs have the responsibility to make sure their learners understand implicit biases and how they impact care for persons with disabilities.

CONCLUSIONS

Equitable emergency care for patients with a variety of disabilities requires buy-in at all levels of health care from the single provider to the policies written within an institution. Creating an institution that trains for and expects unbiased care while providing an environment that can be modified to suit the needs of individual patients with disabilities is essential. This can only be achieved by implementing evidence-based practices that remove barriers and improve access for individuals with disabilities to reduce health care disparities for this vulnerable population.

CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.

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REFERENCES

1. Gulley SP, Altman BM. Disability in two health care systems: access, quality, satisfaction, and physician contacts among working-age Canadians and Americans with disabilities. *Disabil Health J*. 2008;1:196-208.
2. Office of the Surgeon General (US); Office on Disability (US). *The Surgeon General's Call to Action to Improve the Health and Wellness of Persons with Disabilities*. Office of the Surgeon General (US); 2015.
3. Krahn GL, Walker DK, Correa-De-Araujo R. Persons with disabilities as an unrecognized health disparity population. *Am J Public Health*. 2015;105:S198-S206.
4. Mahmoudi E, Meade MA. Disparities in access to health care among adults with physical disabilities: analysis of a representative national sample for a ten-year period. *Disabil Health J*. 2015;8:182-190.
5. Department of Justice, Civil Rights Division. *Americans with Disabilities Act Title III Regulations: Nondiscrimination on the Basis of Disability by Public Accommodations and in Commercial Facilities*. Department of Justice; 2010.
6. Goering S. Rethinking disability: the social model of disability and chronic disease. *Curr Rev Musculoskelet Med*. 2015;8:134-138.
7. Poffenberger CM, Coates WC, Backster A, Rotoli J. Making emergency medicine accessible for all: the what, why, and how of providing accommodations for learners and physicians with disabilities. *AEM Educ Train*. 2022;6:S71-S76.
8. WHO. *International Classification of Functioning, Disability, and Health: Children & Youth Version: ICF-CY*. World Health Organization; 2007.
9. Bogart KR, Dunn DS. Ableism special issue introduction. *J Soc Issues*. 2019;75:650-664.
10. Reynolds JM. Three things clinicians should know about disability. *AMA J Ethics*. 2018;20:E1182-E1188.
11. Iezzoni LI, Rao SR, Ressalam J, et al. Physicians' perceptions of people with disability and their health care: study reports the results of a survey of physicians' perceptions of people with disability. *Health Aff*. 2021;40:297-306.
12. Rotoli J, Backster A, Sapp RW, et al. Emergency medicine resident education on caring for patients with disabilities: a call to action. *AEM Educ Train*. 2020;4:450-462.
13. Sapp RW, Sebok-Syer SS, Gisondi MA, Rotoli JM, Backster A, McClure PC. The prevalence of disability health training and residents with disabilities in emergency medicine residency programs. *AEM Educ Train*. 2021;5:e10511.
14. Todd C. Curriculum inventory in context. AAMC. 2016.
15. Agaronnik N, Campbell EG, Ressalam J, Iezzoni LI. Exploring issues relating to disability cultural competence among practicing physicians. *Disabil Health J*. 2019;12:403-410.
16. Disability and Health Program, Division o f Human Development and Disability, National Center on Birth Defects and Developmental Disabilities, Centers forDisease Control and Prevention. *Disability and Health State Chartbook: Profiles of Health for Adults with Disabilities*. Centers for Disease Control and Prevention; 2006.
17. Diab ME, Johnston MV. Relationships between level of disability and receipt of preventive health services. *Arch Phys Med Rehabil*. 2004;85:749-757.

18. DeLisa JA, Thomas P. Physicians with disabilities and the physician workforce: a need to reassess our policies. *Am J Phys Med Rehabil*. 2005;84:5-11.
19. Drainoni ML, Lee-Hood E, Tobias C, Bachman SS, Andrew J, Maisels L. Cross-disability experiences of barriers to health-care access: consumer perspectives. *J Disability Policy Stud*. 2006;17:101-115.
20. Steinberg AG, Barnett S, Meador HE, Wiggins EA, Zazove P. Health care system accessibility. Experiences and perceptions of deaf people. *J Gen Intern Med*. 2006;21:260-266.
21. Abou-Abdallah M, Lamyman A. Exploring communication difficulties with deaf patients. *Clin Med*. 2021;21:e380-e383.
22. Barnett S, McKee M, Smith SR, Pearson TA. Deaf sign language users, health inequities, and public health: opportunity for social justice. *Prev Chronic Dis*. 2011;8(2):A45.
23. VanderWielen LM, Enurah AS, Rho HY, et al. Medical interpreters: improvements to address access, equity, and quality of care for limited-English-proficient patients. *Acad Med*. 2014;89:1324-1327.
24. Youdelman MK. The medical tongue: US laws and policies on language access. *Health Aff*. 2008;27:424-433.
25. Act CR. Civil Rights Act of 1964. Title VII, Equal Employment Opportunities. 1964.
26. Leigh IW, Andrews JF, Harris R. *Deaf Culture: Exploring Deaf Communities in the United States*. Plural Publishing; 2016.
27. Richardson KJ. Deaf culture: competencies and best practices. *Nurse Pract*. 2014;39:20-28.
28. Aarons D. *Aspects of the Syntax of American Sign Language*. Citeseer; 1994.
29. Liddell SK. *Grammar, Gesture, and Meaning in American Sign Language*. Cambridge University Press; 2003.
30. Sandler W, Lillo-Martin D. *Sign Language and Linguistic Universals*. Cambridge University Press; 2006.
31. Karliner LS, Jacobs EA, Chen AH, Mutha S. Do professional interpreters improve clinical care for patients with limited English proficiency? A systematic review of the literature. *Health Serv Res*. 2007;42:727-754.
32. Laur A. Healthcare access for deaf patients–the legal and ethical perspectives. *Medico-Legal J*. 2018;86:36-41.
33. Withers J, Speight C. Health care for individuals with hearing loss or vision loss: a minefield of barriers to accessibility. *N C Med J*. 2017;78:107-112.
34. Heydarian NM, Hughes AS, Morera OF, Bangert AS, Frederick AH. Perspectives of interactions with healthcare providers among patients who are blind. *J Blindness Innov Res*. 2021;11.
35. O'Day BL, Killeen M, Iezzoni LI. Improving health care experiences of persons who are blind or have low vision: suggestions from focus groups. *Am J Med Qual*. 2004;19:193-200.
36. Agaronnik N, Campbell EG, Ressalam J, Iezzoni LI. Communicating with patients with disability: perspectives of practicing physicians. *J Gen Intern Med*. 2019;34:1139-1145.
37. Richards JR, Ozery G, Notash M, Sokolove PE, Derlet RW, Panacek EA. Patients prefer boarding in inpatient hallways: correlation with the national emergency department overcrowding score. *Emerg Med Int*. 2011;2011:1-4.
38. Moskop JC, Sklar DP, Geiderman JM, Schears RM, Bookman KJ. Emergency department crowding, part 1—concept, causes, and moral consequences. *Ann Emerg Med*. 2009;53:605-611.
39. Closing the Gap: A National Blueprint to Improve the Health of Persons with Mental Retardation. *Report of the Surgeon General's Conference on Health Disparities and Mental Retardation*. U.S. Department of Health and Human Services, Public Health Service, Office of the Surgeon General; 2002.
40. Lantman-De Valk H, Metsemakers J, Haveman M, Crebolder H. Health problems in people with intellectual disability in general practice: a comparative study. *Fam Pract*. 2000;17:405-407.
41. Reichard A, Stolzle H, Fox MH. Health disparities among adults with physical disabilities or cognitive limitations compared to individuals with no disabilities in the United States. *Disabil Health J*. 2011;4:59-67.
42. Reichard A, Turnbull HR III. Perspectives of physicians, families, and case managers concerning access to health care by individuals with developmental disabilities. *Ment Retard*. 2004;42:181-194.
43. Mudrick NR, Breslin ML, Nielsen KA, Swager LC. Can disability accommodation needs stored in electronic health records help providers prepare for patient visits? A qualitative study. *BMC Health Serv Res*. 2020;20:1-18.
44. Ally S, Boyd K, Abells D, et al. Improving transition to adulthood for adolescents with intellectual and developmental disabilities: proactive developmental and systems perspective. *Can Fam Physician*. 2018;64:S37-S43.
45. Disability and Health Inclusion Strategies. Center for Disease Control and Prevention. 2020. Accessed September 10, 2022. https://www.cdc.gov/ncbddd/disabilityandhealth/disability-strategies.html
46. Rehabilitation Act. 2020. Accessed September 10, 2022. https://acl.gov/about-acl/rehabilitation-act#:~:text=Title%20VII%20of%20the%20Rehabilitation,the%20U.S.%20Department%20of%20Education
47. Davis TC, Wolf MS. Health literacy: implications for family medicine. *Fam Med*. 2004;36:595-598.
48. Greenberg D. Adult literacy: the state of the field. *Perspectives on Language and Literacy*. Vol 39. The International Dyslexia Association; 2013:9-11.
49. Hutchinson N, Baird GL, Garg M. Examining the reading level of internet medical information for common internal medicine diagnoses. *Am J Med*. 2016;129:637-639.
50. Stossel LM, Segar N, Gliatto P, Fallar R, Karani R. Readability of patient education materials available at the point of care. *J Gen Intern Med*. 2012;27:1165-1170.
51. Reardon SF, Valentino RA, Shores KA. Patterns of literacy among US students. *Future Child*. 2012;22:17-37.
52. Baker A. *Crossing the Quality Chasm: a New Health System for the 21st Century*. British Medical Journal Publishing Group; 2001.
53. Oates J, Weston WW, Jordan J. The impact of patient-centered care on outcomes. *Fam Pract*. 2000;49:796-804.
54. Gutierrez-Sigut E, Lamarche VM, Rowley K, et al. How do face masks impact communication amongst deaf/HoH people? *Cognitive Research: Principles and Implications*. Vol 7. National Association of the Deaf; 2022:1-23.
55. McKee M, Moran C, Zazove P. Overcoming additional barriers to care for deaf and hard of hearing patients during COVID-19. *JAMA Otolaryngol Head & Neck Surg*. 2020;146:781-782.
56. Shuler GK, Mistler LA, Torrey K, Depukat R. More than signing: communicating with the deaf. *Nurs Manage*. 2014;45:20-27.
57. Minimum Standards for Video Remote Interpreting Services in Medical Settings. National Association of the Deaf. 2016. Accessed December 30, 2022. https://www.nad.org/about-us/position-statements/minimum-standards-for-video-remote-interpreting-services-in-medical-settings/
58. Cupples M, Hart P, Johnston A, Jackson A. Improving healthcare access for people with visual impairment and blindness. *BMJ*. 2012;344:e542.
59. Schneider K. Caring better for patients who are blind or visually impaired. *Am Fam Physician*. 2013;88:774.
60. Resources for Healthcare Workers to Better Support People Who Are Blind, Low Vision, or Deafblind. American Foundation for the Blind. 2021. Accessed December 30, 2022. https://www.afb.org/blog/entry/resources-healthcare-workers
61. Guidelines for managing the patient with intellectual disability in accident and emergency. 2002 Accessed September 17, 2022. http://www.intellectualdisability.info/how-to-guides/articles/guidelines-for-managing-the-patient-with-intellectual-disability-in-accident-and-emergency

62. Emergency Room Stabilization Protocol for Individuals with IDD. Accessed September 17, 2022. https://iddtoolkit.vkcsites.org/er-idd-stabilization-protocol/
63. Heifetz M, Lunsky Y. Implementation and evaluation of health passport communication tools in emergency departments. *Res Dev Disabil*. 2018;72:23-32.
64. Wood D, Hall A, Hou T, Wludyka P, Zhang J. Continuity of care to prevent emergency room use among persons with intellectual and developmental disabilities. *J Policy Pract Intellect Disabilities*. 2007;4:219-228.
65. Caretta-Weyer HA, Hess JM. Bridging the gap: development of an experiential learning–based health disparities curriculum. *AEM Educ Train*. 2022;6:e10820.

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