SKIN

IN-DEPTH REVIEW

Closing Gaps in Dermatologic Care for Patients with Intellectual and Developmental Disabilities: Practical Strategies for Training, Advocacy, and Person-Centered Practice

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ABSTRACT

Background Individuals with intellectual and developmental disabilities (IDD) represent one of the most underserved populations in healthcare and experience disproportionate burdens of dermatologic disease, delayed diagnosis, and barriers to specialty care. Despite the growing prevalence of IDD, dermatology training and clinical frameworks addressing the unique needs of patients with IDD remain limited.
Methods We conducted a targeted review of the literature to synthesize practical strategies to improve care delivery. A systematic search of Ovid MEDLINE was performed for U.S.-based, peer-reviewed articles published from 2014 to 2024 addressing healthcare access, stigma, quality of care, and outcomes among adults with IDD. Of 178 screened articles, 40 met inclusion criteria. Additional guidelines and policy reports were reviewed to contextualize gaps within dermatology education and practice.
Results Individuals with IDD experience substantial medical complexity and chronic care needs, which are known risk factors for dermatological complications, including chronic skin conditions, pressure injuries, infections, and wound complications. These risks are compounded by reduced access to dermatologic care and provider discomfort in managing IDD-specific needs. Key barriers include adequate training, communication challenges, implicit bias, fragmented care systems, and policy limitations. Three intervention domains emerged: (1) enhanced dermatology education and training; (2) advocacy for systemic and policy-level reforms; and (3) adoption of person-centered care models (Table 1).
Conclusion Improving dermatologic care for individuals with IDD requires coordinated educational, policy, and clinical interventions. Collectively, the literature indicates that these strategies are central to advancing equitable, high-quality dermatologic care for this underserved population.

INTRODUCTION

The prevalence of disabilities among adults in the United States has shown a significant increase in recent years. As of 2018, the estimated prevalence of U.S. adults with some form of disability was 30%.[1] Studies conducted over the past two decades show a consistent upward trend in disability prevalence across various age groups.[2-4] Individuals with intellectual and

developmental disabilities (IDD) are one of the most underserved groups in our healthcare system,[5] and dermatologists often serve as a primary point of contact for patients with IDD seeking treatment for various cutaneous conditions. These may include xerosis, seborrheic dermatitis, acne vulgaris, superficial fungal infections, rosacea, multiple nevi, and hidradenitis suppurativa.[6] Directly compared to individuals without disabilities, those with IDD have reduced life expectancies, reduced access to health care, increased discrimination by healthcare services, and overall worse health outcomes.[6] Current evidence suggests that creating an inclusive and safe environment where patients with IDD feel comfortable discussing their health concerns is crucial in addressing healthcare disparities and improving health equity.

In the U.S., 1 in 6 children have an intellectual and/or developmental disability,[7] and literature indicates that individuals with IDD experience stigmatization from an early age.[8] Youth with IDD are particularly vulnerable to stigma-based bullying, which can have profound negative impacts on their education, well-being, and overall health across their lifespan. Because dermatologic conditions are often visible and may further contribute to social marginalization, dermatologists frequently encounter patients with IDD at the intersection of medical care and stigma. However, challenges persist in providing optimal, inclusive care for individuals with IDD. Physicians across specialties report hesitancy in caring for patients with IDD due to factors such as perfectionism, lack of specialized education, and having to navigate fragmented treatment protocols.[9] In this context, a focused synthesis of existing evidence is needed to clarify how dermatology-specific education, advocacy, and care models can address both clinical and stigma-related barriers faced by individuals with IDD.

METHODS

To inform this review, we conducted a systematic literature search of the Ovid MEDLINE database to identify peer-reviewed articles published between 2014 and 2024 that examined healthcare access, quality, and outcomes for adults with intellectual and developmental disabilities (IDD) in the United States. The search included terms related to healthcare disparities, disability discrimination, health status disparities, social stigma, physician practice patterns, and refusal to treat. We included studies that discussed specific health disparities and described interventions to improve care for adults with IDD; we excluded articles that focused only on pediatric populations, were limited to a single condition, or were conducted outside the United States. After screening 178 results, 40 articles met inclusion criteria for full analysis. To ensure comprehensiveness, we also reviewed additional relevant clinical guidelines, government reports, and studies identified through targeted PubMed searches, which provided updated statistics and policy context not captured in the initial search.

Study selection followed a PRISMA-informed approach, including database searching, title and abstract screening, full-text review, and application of predefined inclusion and exclusion criteria. Due to heterogeneity in study design and outcomes, a formal quality appraisal tool was not applied; instead, studies were synthesized descriptively to identify recurring themes and gaps in the literature.

DISCUSSION

Disease Burden and Barriers to Dermatologic Care in Individuals with IDD

Individuals with IDD experience substantial medical complexity and chronic care needs, which are known risk factors for dermatological complications such as skin breakdown, pressure injuries, chronic wounds, and secondary infections.[10,11] Studies suggest that inequities in access to healthcare further exacerbate these problems due to fewer referrals to specialist services and subsequent delayed diagnoses.[12]

We have identified three key interventions for dermatologists aimed at addressing healthcare disparities for individuals with IDD, informed by findings from the existing literature, established disability and health equity frameworks, and the authors' synthesis of gaps specific to dermatologic practice. These interventions focus on improving the quality and accessibility of healthcare services for this vulnerable population. The first intervention focuses on enhanced dermatology education and training, addressing current gaps in medical school and residency program curricula regarding IDD-specific care. The second intervention highlights the importance of advocacy efforts, policy reforms, and systemic change to create an equitable healthcare system for this vulnerable population. Lastly, the third intervention underscores the importance of person-centered care, tailoring healthcare approaches to the unique needs of each individual with IDD to promote autonomy and improve health outcomes. Key practical strategies are outlined in **Table 1** to guide dermatologists in implementing these recommendations.

Table 1. Practical Strategies to Reduce Dermatologic Care Disparities for Patients with IDD

Barrier	Impact on Dermatologic Care	Recommended Strategies for Dermatologists
Limited provider training in IDD care	Missed diagnoses, discomfort treating complex cases	Integrate IDD-specific curricula in dermatology residency (capacity assessment, obtaining consent, health literacy, adaptive communication)
Lack of awareness of device-related complications	Untreated dermatitis around trach collars, ostomy sites, gastrostomy tubes	Include formal education on pressure ulcer staging, chronic wound care, tracheostomy/ostomy site management, and skin complications of medical devices
Provider bias and stigma	Patients perceived as "too complex" → lower referral rates	Implement experiential learning opportunities to increase comfort and reduce implicit bias; adopt "person-first" language training

Anxiety and sensory sensitivities during physical examinations	Procedural distress, avoidance of needed care	Use sensory-friendly environments; employ desensitization strategies
Fragmented care coordination	Discontinuity during transitions (pediatric to adult care), missed follow-ups	Develop individualized transition plans; coordinate with caregivers; use multidisciplinary approaches
Physical access and transportation barriers	Missed appointments, untreated skin conditions	Expand teledermatology services with clear protocols; advocate for coverage and digital access support
Caregiver knowledge gaps	Poor wound care, preventable complications	Provide structured caregiver education on basic dermatologic hygiene, skin monitoring, and early
Inconsistent policy standards	Systemic disparities persist	Advocate for national guidelines through AAD; adopt frameworks like NICHE-MED to fund curriculum improvements

Intervention 1: Dermatology Education and Training Gaps Identified in the Literature

Healthcare providers often report inadequate training on managing IDD-specific needs, exacerbating healthcare disparities. Recent literature has shown significant gaps in the education of future medical providers in medical school and residency programs regarding patients with IDD and reports physicians feeling uncomfortable accepting these patients into their clinical practice.[13] Physicians frequently experience implicit bias towards this population in practice, as a recent review found that individuals with disabilities were often implicitly labeled as "incompetent, cold, or child-like."[13]

Dermatologists have a rare opportunity to address these disparities early on, potentially mitigating downstream stressors within medical environments. Children and adolescents with IDD may experience implicit stigma in healthcare settings, which has been associated with adverse mental health outcomes across the life course.[7] Although dermatologists do not formally assess developmental functioning, dermatologic documentation can include observations such as exam tolerance, sensory sensitivities, and care-related challenges. When framed using deficit-based language (e.g., "red flags," "deficits," or "co-morbidities"), such descriptions may inadvertently reinforce implicit stigma; in contrast, strengths-based terminology (e.g., "clinical signs," "areas of challenge," or "co-occurring conditions") represents a practical, actionable strategy for more inclusive dermatologic care.[7]

A recent nationwide survey of forty-seven internal medicine primary care residency program directors revealed they felt that their residents were inadequately educated to

care for the IDD population, with only approximately 29% of those programs offering any IDD-specific curricula.[14] While the Accreditation Council for Graduate Medical Education mandates competency in professionalism, including "respect and responsiveness to diverse patient populations, including but not limited to diversity in gender, age, culture, race, religion, disabilities, national origin, socioeconomic status, and sexual orientation,"[15] recent surveys have demonstrated that disability-specific components of these requirements are inconsistently implemented across U.S. residency programs.[14] The directors listed barriers such as lack of advocacy for the work, lack of space in the curricula, lack of expertise in the care of people with disabilities, and lack of expectation by the educational governing boards.[14]

Evidence consistently indicates that specialized training related to the care of individuals with IDD remains limited across U.S. medical education, including within dermatology residency programs. Studies have identified this lack of structured IDD-focused education as a contributing factor to provider discomfort and variability in care delivery.[7,14] One potential explanation proposed by the existing literature is that these educational gaps may reflect a broader underrecognition of the dermatologic needs of individuals with IDD within the specialty. In support of this interpretation, there is currently no formal position statement from the American Academy of Dermatology addressing dermatologic care considerations for this population, underscoring an absence of specialty-specific guidance.

Interventions incorporating disability-focused curricula into medical education have been associated with improvements in provider attitudes and selected clinical outcomes. Alongside competency curricula, the literature suggests that experiential learning may offer additional benefit. Facilitating structured interactions between trainees and individuals with IDD has been described as a mechanism for improving clinical comfort, consistent with contact theory.[15] Several training programs outside of dermatology have reported implementing structured learning objectives aligned with core competencies, including patient care, medical knowledge, practice-based learning and improvement, interpersonal and communication skills, professionalism, and systems-based practice. For example, the University of California, San Francisco (UCSF) Family Medicine Residency has adopted this approach. In contrast, few dermatology residency programs have published comparable, structured frameworks addressing care for individuals with IDD, highlighting a gap in specialty-specific training efforts.

In addition to broader training improvements, the literature highlights the importance of dermatology-specific curricula that address health literacy and effective communication strategies for patients with IDD. Structured educational modules focusing on adaptive communication techniques have been associated with improved trust and reduced distress during clinical encounters.[16] Several authors have also emphasized the importance of training clinicians to assess decision-making capacity and to obtain informed consent in a respectful and legally sound manner, which is particularly relevant for dermatologic biopsies and other procedures that may need to be conducted in-office.[17]

Another area identified in the literature involves education on the prevention and management of dermatologic complications related to medical devices. Many patients

with IDD rely on tracheostomies, gastrostomy tubes, or ostomies, all of which can cause significant skin problems if not properly managed. Peristomal skin complications affect up to 80% of people with an ostomy and commonly include irritant contact dermatitis from leakage, friction injuries from frequent appliance changes, and fungal infections in warm, moist areas.[18] Similarly, skin breakdown under tracheostomy collars can lead to pressure injuries, maceration, and localized infections if moisture and friction are not carefully addressed.[19] Prior studies suggest that clinician education on risk recognition and preventive strategies, including barrier protection and moisture control, may help mitigate these complications.[20]

Collectively, the literature supports the inclusion of IDD-specific content within dermatology residency education as a strategy to improve clinician preparedness for managing common yet frequently underrecognized skin conditions within this patient population. Embedding these competencies within training programs has been described as a means of supporting safer, more inclusive dermatologic care and may contribute to reducing disparities in dermatologic outcomes among individuals with IDD.

Intervention 2: Policy-Level Systemic Barriers Affecting Dermatologic Care

While medical education reform represents an important component of efforts to improve dermatologic care for individuals with IDD, broader policy-level and systemic factors are also relevant to understanding structural barriers to care. In addition to residency curricula, legislative initiatives, community-based programs, and professional guidance represent potential mechanisms through which access to specialty care may be influenced. In this review, these system-level considerations are discussed as part of a broader synthesis of factors that may shape access, patient-clinician interactions, and stigma-related barriers in dermatologic care for individuals with IDD.

Despite recommendations from the U.S. Surgeon General and the Association of American Medical Colleges to incorporate disability training into medical education, surveys indicate that only half of U.S. medical school deans report offering such training.[7,21] Limited exposure during training may persist into practice, where dermatology remains among the subspecialties with relatively few formal IDD-specific educational frameworks. This gap has been associated with reported challenges related to informed consent, guardianship, and medical complexity.[22-23] These considerations underscore the potential role of national standards for disability competency training within residency programs, with professional organizations such as the American Academy of Dermatology as a key stakeholder in guideline development in this field.

National organizations, including the United States Public Health Service (USPHS) and the National Academies of Medicine, have called for action to improve healthcare access for individuals with IDD. Systemic inequities have been associated with delayed access to specialty care and higher reliance on low-volume care settings, which may contribute to delayed diagnosis and undertreatment of common dermatologic conditions such as pressure injuries, atopic dermatitis, and chronic wounds.[24] These challenges may be compounded by communication barriers, atypical symptom presentation, and disparities related to race, ethnicity, and socioeconomic status. Policy interventions addressing transportation

access, financial barriers, and structural bias have been proposed as mechanisms to improve equitable care.

Community-based and preventive care models have also been examined as strategies to address dermatologic disparities in IDD populations. Studies of nurse practitioner-led in-home programs suggest potential benefits for health promotion and early intervention.[25] Within dermatology, a potential approach is nursing-led approaches focused on skin assessment, hygiene education, and prevention of pressure injuries, although workforce limitations, including shortages of nurses trained in IDD, remain a barrier.[25]

Telehealth has been evaluated as a means of improving access to patient care for individuals with IDD, particularly following its expansion during the COVID-19 pandemic. While teledermatology may reduce geographic and mobility-related barriers, studies also highlight persistent inequities related to technology access, cost, and digital literacy.[25] Addressing these challenges through policy-level support and insurance coverage has been emphasized to ensure teledermatology serves as a facilitator rather than a barrier to care.[25]

Although not dermatology-specific, referral-based programs such as the Developmental Evaluation, Training, and Consultative Team (DETECT) have been described as a model for how referral networks and community-based infrastructures can be adapted for dermatological care.[26] Similar referral networks within dermatology may support timely access to specialty services and improved care coordination. Overall, the literature supports a multifaceted approach integrating education, community-based care models, telehealth, and policy initiatives to address systemic barriers to dermatologic care for individuals with IDD.

Intervention 3: Person-Centered Models and Access-Focused Interventions

Person-centered care is described as an approach that emphasizes patient-physician relationships, autonomy, and tailored interventions that reduce healthcare inequities for individuals with IDD. Programs such as the Systemic, Therapeutic, Assessment, Resources, and Treatment (START) Network and the Needle Anxiety Program illustrate patient-centered approaches to reduce procedural distress and support individualized care delivery.[27] Telehealth has also been examined as a complementary tool for follow-up care and mental health support, particularly for patients facing geographic or mobility-related barriers.[25] Together, these approaches have been associated with improved continuity of care.

Individuals with IDD experience documented disparities in access to care and procedural outcomes, including delays in cancer screening, higher postoperative complication rates, and challenges related to symptom recognition for non-dermatologic conditions.[28-30] The literature describes strategies such as individual risk assessments, adaptive communication tools, and supportive services (e.g., transportation assistance) as mechanisms to facilitate timely diagnosis and treatment. Additional approaches, including inclusive language practices, procedural desensitization, and appropriate use of sedation, have been discussed as components of supportive and dignified care.[31]

A persistent challenge in caring for individuals with IDD is the transition from pediatric to adult healthcare systems, a period associated with increased

fragmentation and loss of continuity of care. Studies suggest that individualized transition plans can reduce care disruptions and support patients and families in navigating adult medical environments.[32-33] Multidisciplinary approaches underscore the importance of communication and shared decision-making in improving long-term health outcomes for individuals with complex care needs.[9] Across the lifespan, individuals with IDD report lower satisfaction with provider communication, particularly in adulthood, emphasizing the need for dermatology-specific communication strategies that promote continuity, trust, and patient engagement.[32]

CONCLUSION

This review synthesizes current literature highlighting persistent disparities in dermatologic care for individuals with intellectual and developmental disabilities (IDD) and identifies key domains in which gaps in access, training, and care delivery remain. Evidence suggests that educational initiatives focused on disability competency, system-level policy and advocacy efforts, and person-centered care models may help address barriers contributing to delayed diagnosis, suboptimal treatment, and reduced patient engagement in dermatologic settings.

Despite increasing recognition of health inequities affecting individuals with IDD, the available literature remains limited with respect to dermatology-specific outcomes and formal evaluations of training or care delivery interventions within dermatologic practice. Few studies directly assess dermatologic disease burden, specialty access, or the impact of targeted educational frameworks for dermatologists caring for this population. Future research focused on these gaps may help inform evidence-based strategies to improve dermatologic care delivery and outcomes for individuals with IDD.

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