

My Profile Cards: The Importance of Providing Adequate Accommodations for Patients with Disabilities

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References

Introduction

Data collected in 2022 by the U.S. Centers for Disease Control and Prevention (CDC) estimated over 61 million individuals reported having a disability (CDC, 2024). Despite high prevalence rates, many physicians and health care workers report feeling unprepared or uncomfortable providing care to this population (Iezzoni et al., 2022).

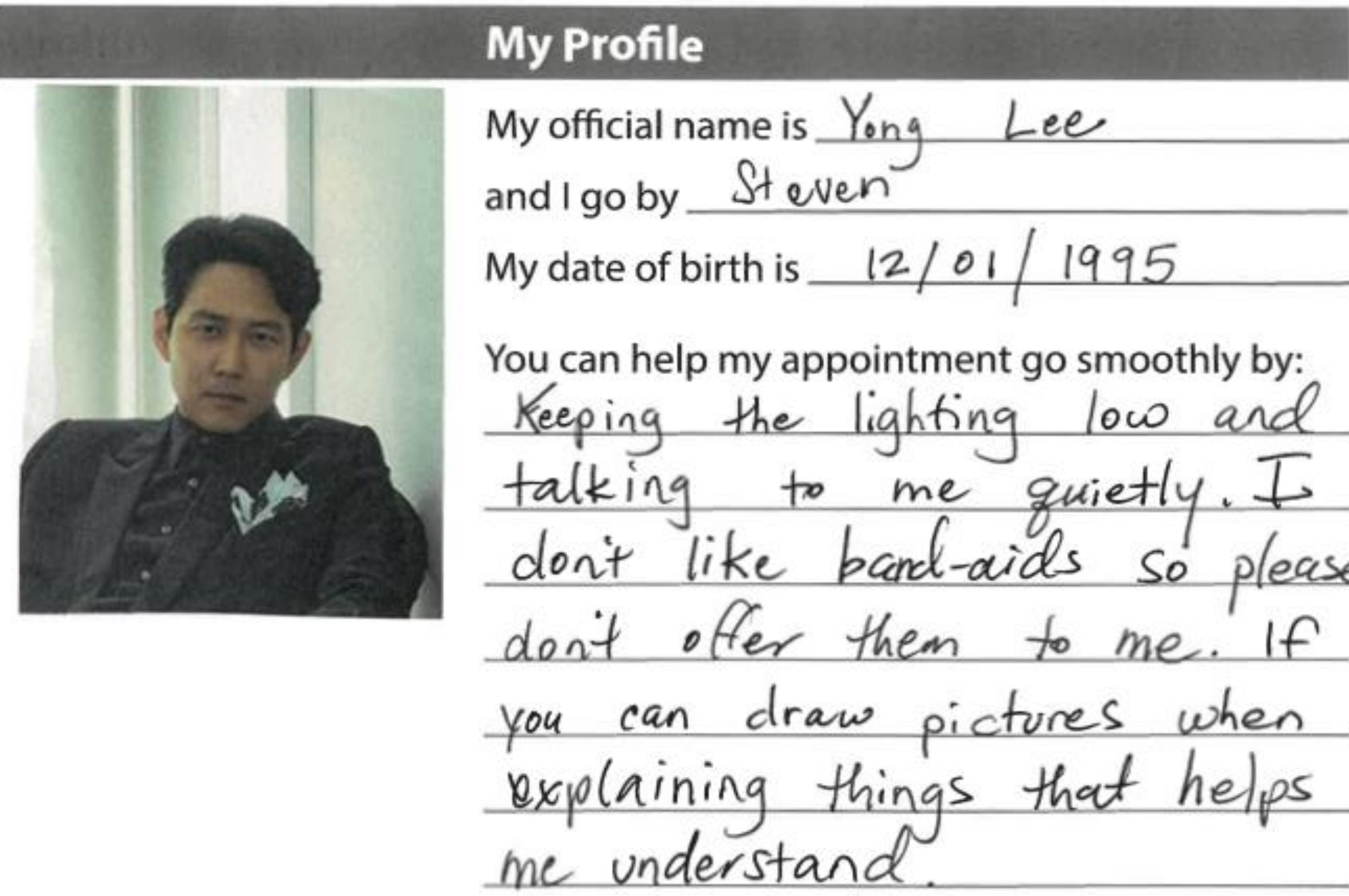
Patients with disabilities frequently encounter significant barriers in health care settings (Clemente et al., 2022):

- Lack of accommodations for special healthcare needs (Morris et al., 2021).
- Incorrect assumptions or perceptions from health care providers regarding their disability status (Morris et al., 2021).
- Reduced healthcare access due to physical or organizational barriers (Clemente et al., 2022).

This literature review aims to explore these barriers and provide adequate accommodations beneficial for both provider and patient by using My Profile Cards.

My Profile Cards contain a photo of the patient, and a space for demographic information. Space is provided for patients to describe the best way for their healthcare providers to accommodate their special health care needs (Alencar et al., 2024).

My Profile cards are used in healthcare settings for patients to improve communication of special healthcare needs (Loo et al., 2020). There are not robust programs in place to enforce anti-discrimination legislation (Americans with Disabilities (ADA) Act Title II and Section 504 of the Rehabilitation Act)(Lagu et al., 2015). My Profile Cards encourage self-advocacy to uphold the rights provided by the ADA (Krahn et al., 2015).



Example of My Profile Card. Picture provided of patient, official name, preferred name, DOB, and space provided for patients to express healthcare needs.

Method

Researchers engaged in a literature search related to accommodations in healthcare and patient experience in a healthcare setting. The literature search was conducted through online databases using the following criteria:

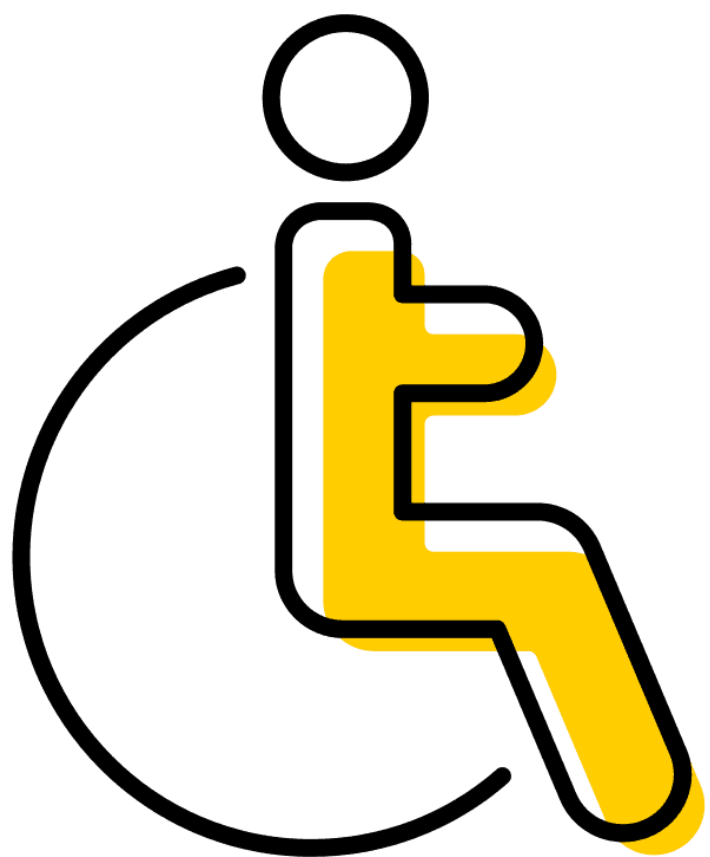
Inclusion Criteria

- Publication date: within the past 5-10 years
- Work /appointment setting: healthcare related appointments
- Population of participants: individuals with disabilities

Exclusion Criteria

- Non-peer reviewed journal articles
- Publication date: outside of the past 15 years

Databases utilized: Sprinter Nature, PubMed Central, Wiley Online Library, Google Scholar, and PLOS One

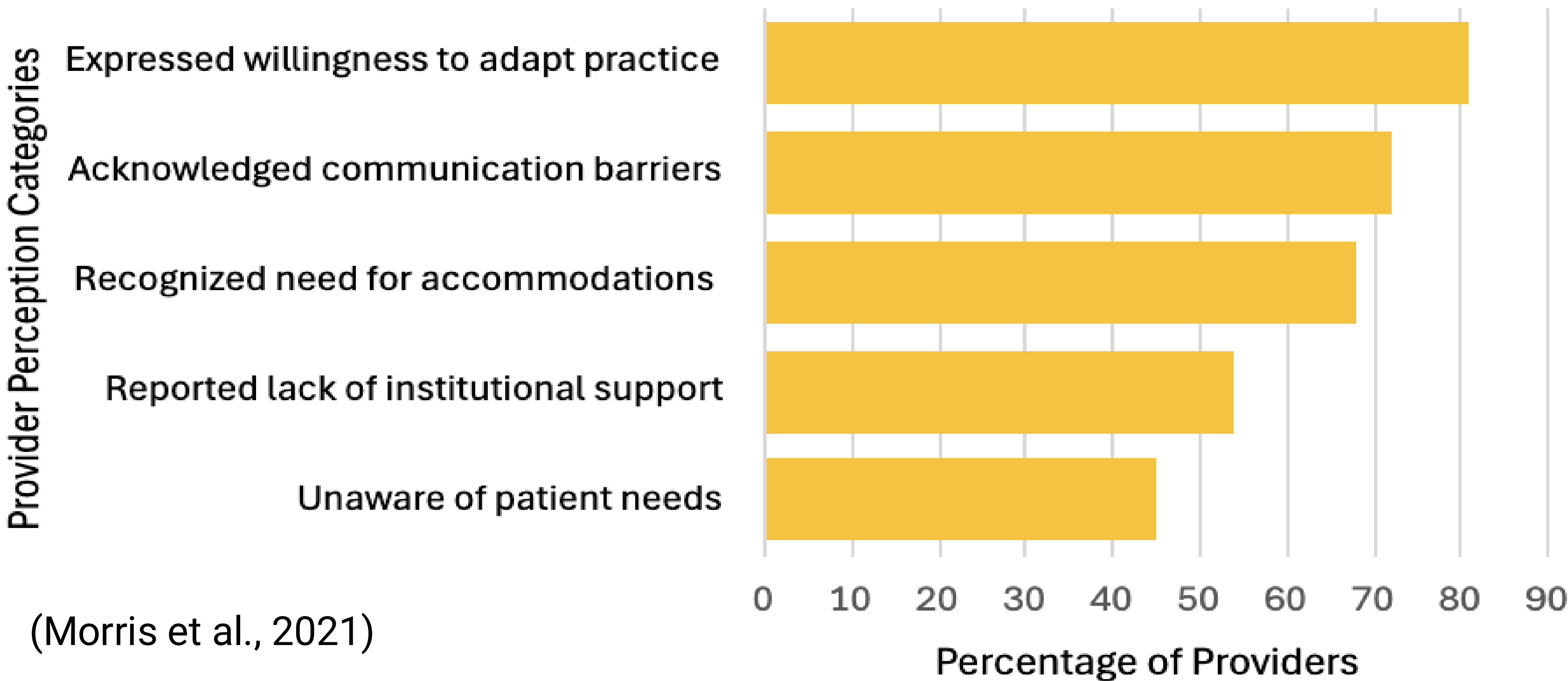


Findings

There is a large gap in research related to the use of My Profile Cards or similar accommodation tools in healthcare settings. Through analysis of peer-reviewed articles related to experiences in healthcare, accommodation cards are very beneficial in improving healthcare experiences and outcomes.

- A. Increased self-advocacy and independence.
 - Users report better communication with providers (Morris et. al., 2021).
 - 92% of patients with 22q11.2 deletion syndrome reported My Profile Cards as helpful (14%) or very helpful (86%) (Loo et al. 2020) in advocating for themselves at appointments.
- B. Improved provider perceptions of patients with disabilities.
 - 86% of healthcare professionals report improved perception of patients with disabilities (Alencar et al. 2024).
 - Drivers of discrimination (lack of knowledge, apathy, and assumptions) are all addressed through My Profile Card use (Ames et al. 2023).
 - Using My Profile Cards provides sufficient knowledge of personal condition and removes assumptions by providers (Morris et. al., 2021)

Provider Perceptions on Accommodations



This table illustrates provider perceptions on of patients with disabilities. This demonstrates the gap in education of medical professionals on disability related care.

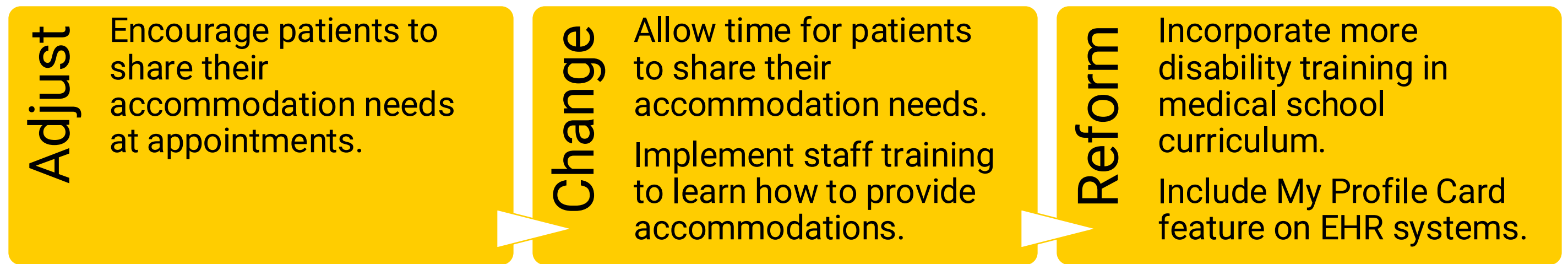
Discussion

The findings of this literature review indicate a low level of implementation for the use of My Profile Cards or accommodation cards in practice but support the potential benefits of implementing accommodation cards.

- **Infrequent implementation:** Cards are underutilized by clinicians. A lack of regular updates to cards and inconvenience of format discouraged use (Mudrick et al., 2020).
- **Improving perceptions of people with disabilities:** Providers recognizing abilities of patients with disabilities is a huge benefit of the use of accommodation cards (Morris et al., 2021).
- **Positive experiences for patients and providers:** Patients who use accommodation cards (Loo et al. 2020) report the cards to be very helpful. The use of these cards is able to speed up appointment times which reduces the burden on the healthcare system and provides the necessary information without requiring extensive storytelling.
- **Limitations:** This study utilized information from a wide variety of subjects and sample populations which may cause variability in results and limit generalizability

Future Directions

Healthcare outcomes improve upon implementation of accommodation cards. To make benefits of accommodation cards more widespread, the ACR (Adjust Change Reform) Framework outlines potential future action steps (Mindy, 2024).



- **Policy:** Policy changes have the power to reduce the strain and responsibility of upholding rights illustrated by the ADA and Section 504 on individuals and providers. The US Department of Health and Human Services (HHS) proposed updates to Section 504 to further protect equitable access to healthcare for people with disabilities ("New Proposed Rules," 2024).
- **Further research is required:** Involving minority groups in research is critical to providing equitable care.
- **Disability stigma:** Stigma poses a large problem in receiving and providing equitable care. Perceptions by providers of people with disabilities are largely negative. Many healthcare professionals report that they do not feel equipped to provide care to these populations (Morris et al., 2021).
- **Objectives to increase implementation:** Standardization of the format of accommodation cards is a critical next step to increasing use of cards. Challenges of maintaining relevant information and difficulty in accessing cards for providers are noted problems (Mudrick et al., 2020). Including an accommodation card feature on electronic health records (EHR) systems would increase likelihood of use (Mudrick et al., 2020).

Acknowledgments

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