HCARDD

Booking and Attending Annual Health Exams:

The Perspective of Adults with Intellectual and Developmental Disabilities

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Introduction

- Adults with intellectual and developmental disabilities (IDD) are more likely to have chronic health problems, experience high rates of morbidity, and have complex health issues.
- An annual health exam (AHE) is recommended for this population.
- Different aspects of physician-patient interactions can be improved for individuals with IDD, including communicating medical information, and respecting their privacy and autonomy.
- Tailoring primary care to the health-related needs of patients with IDD will likely improve patient satisfaction and increase AHE uptake.
- The CanMEDS framework is a Canadian tool to develop physicians' abilities to provide high-quality, patient-centered care. The roles of Communicator and Health Advocate, described in the CanMEDS framework are especially relevant to deliver optimal care to individuals with IDD.

Purpose

 To gain a deeper understanding of the support needs of adults with IDD with regards to AHEs.

Methods

Figure 1. Overview of methods.

Target Population: Individuals with IDD who were Ontario Disability Support Program recipients (N = 39,868).



An accessible information package (including details about the AHE, its importance, instructions on how to book an appointment, and a link to a video of the written information) was mailed.



85 adults with IDD completed a telephone survey

85 caregivers (for 127 adults with IDD) completed a telephone survey



13 adults with IDD completed an in-person interview

Results

<u>Participants</u>

- Age range: 24 to 61 years of age (M = 36.77, SD = 12.48)
- Males: 8 (62%); Females: 5(38%)
- Living Situation
 - Independently (alone, with friend, spouse, and/or children): 6
 - With family members (e.g., parents, siblings): 7

Factors that affected support needs of individuals with IDD

Booking AHE

Level of autonomy

Getting to AHE

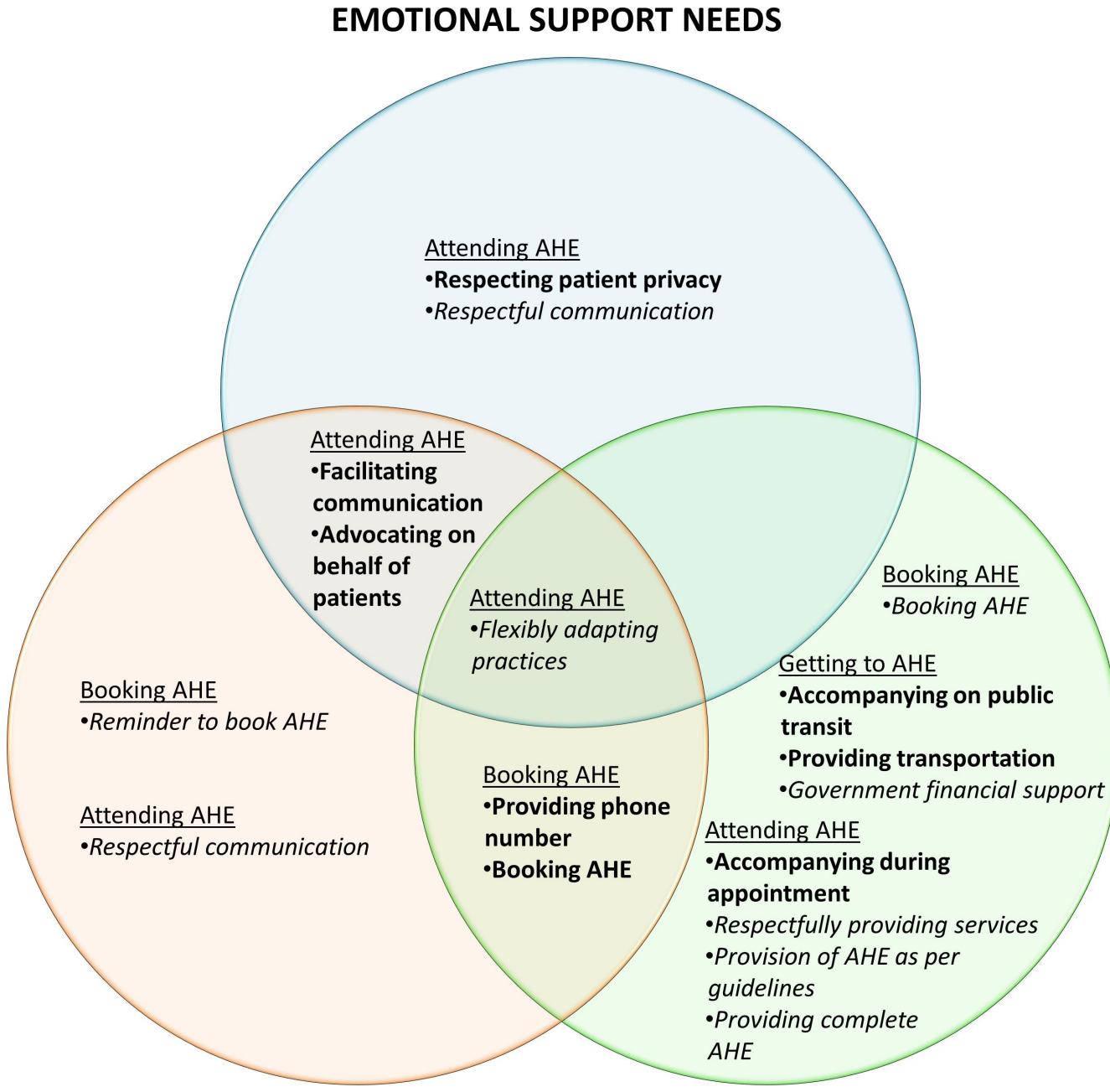
Socio-economic status

Attending AHE

- Self advocacy
- Continuity of care with the same physician

Results

Figure 2. Support needs of individuals with IDD when attending AHEs.



INFORMATIONAL SUPPORT NEEDS

INSTRUMENTAL SUPPORT NEEDS

<u>Legend</u> **Provided by informal caregiver = bold** *Provided by formal caregiver = italic*

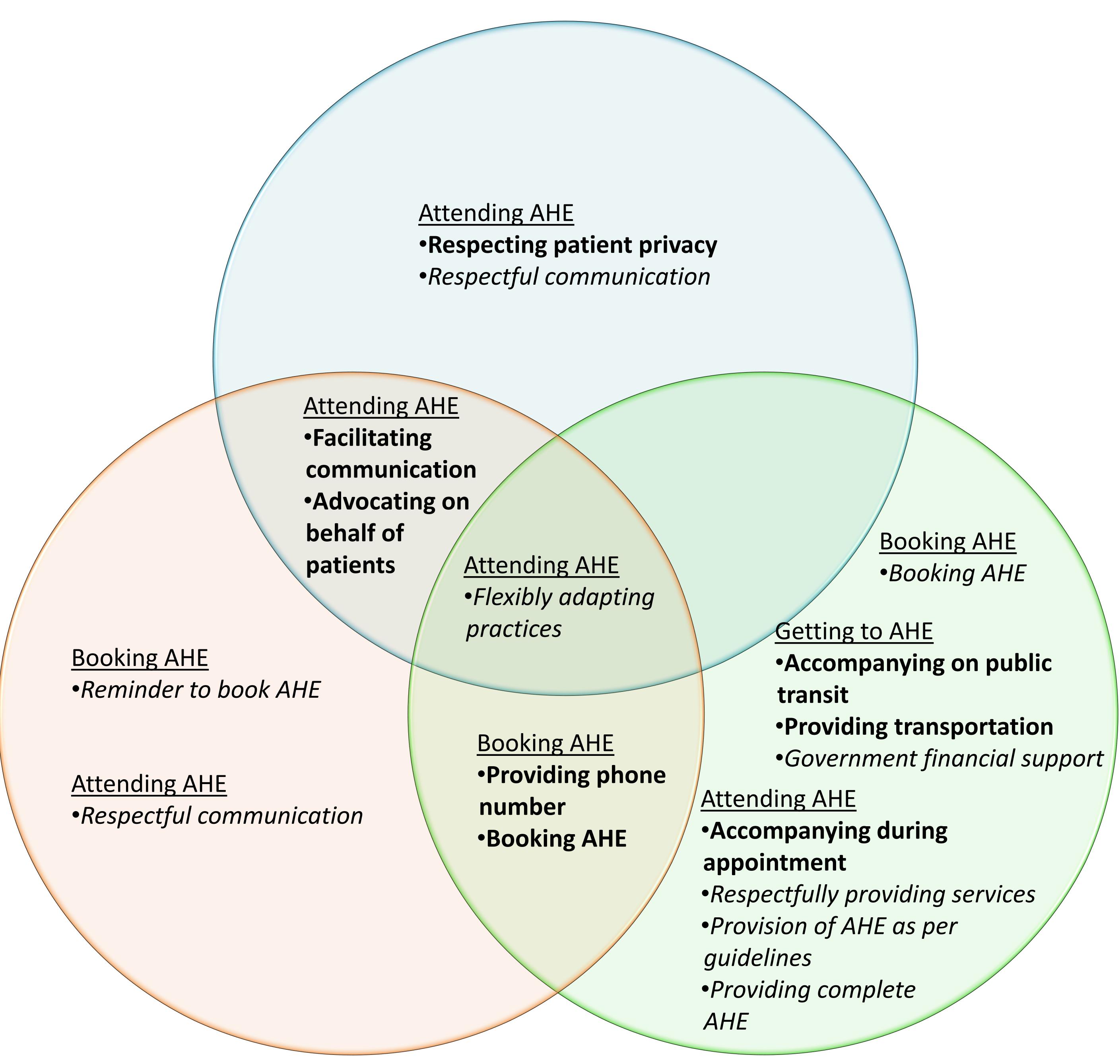
Implications and Conclusions

- When booking and traveling to AHEs, support needs were primarily instrumental, and typically met by family caregivers. When attending AHEs support needs were predominantly emotional, and were expected to be met by physicians.
- Individuals with IDD have different needs and require varying levels of support. **Patient-centered care**, in which caregivers and physicians adapt to individuals' needs and preferences, **is crucial to support adults with IDD in accessing the AHE**.
- This population would especially benefit from interactions with physicians who are able to communicate effectively and advocate for their health needs. The CanMEDS Communicator and Health Advocate roles are, therefore, highly relevant to physicians caring for patients with IDD.
 - Physicians can foster physician-patient rapport and trust by providing accessible health-related information, and engaging patients in decision-making.
 - Given that individuals with IDD often have difficulties self-advocating, and that health advocacy can reduce health inequalities, patients with IDD may require additional health advocacy to help diminish existing health disparities.





EMOTIONAL SUPPORT NEEDS



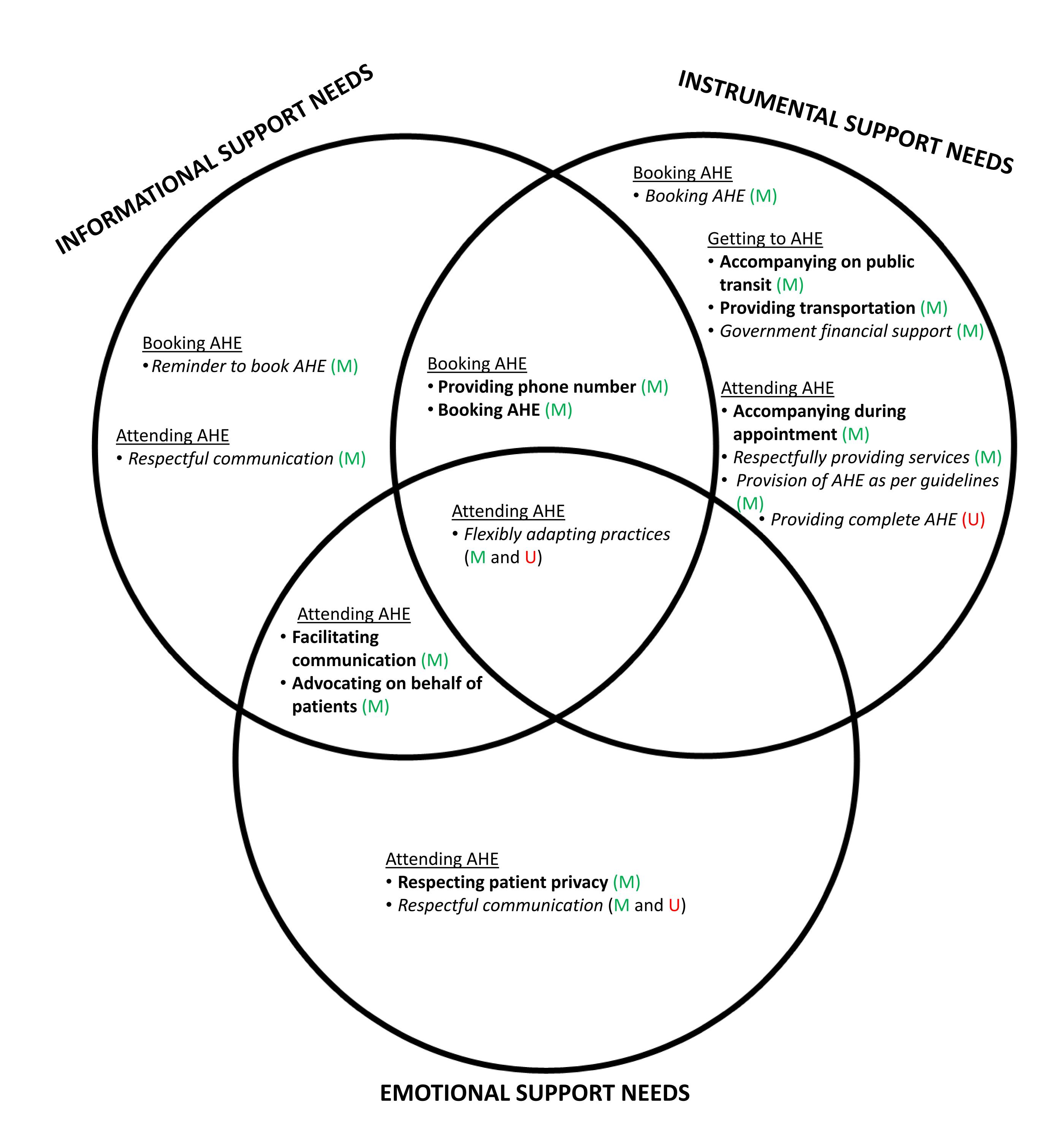
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