

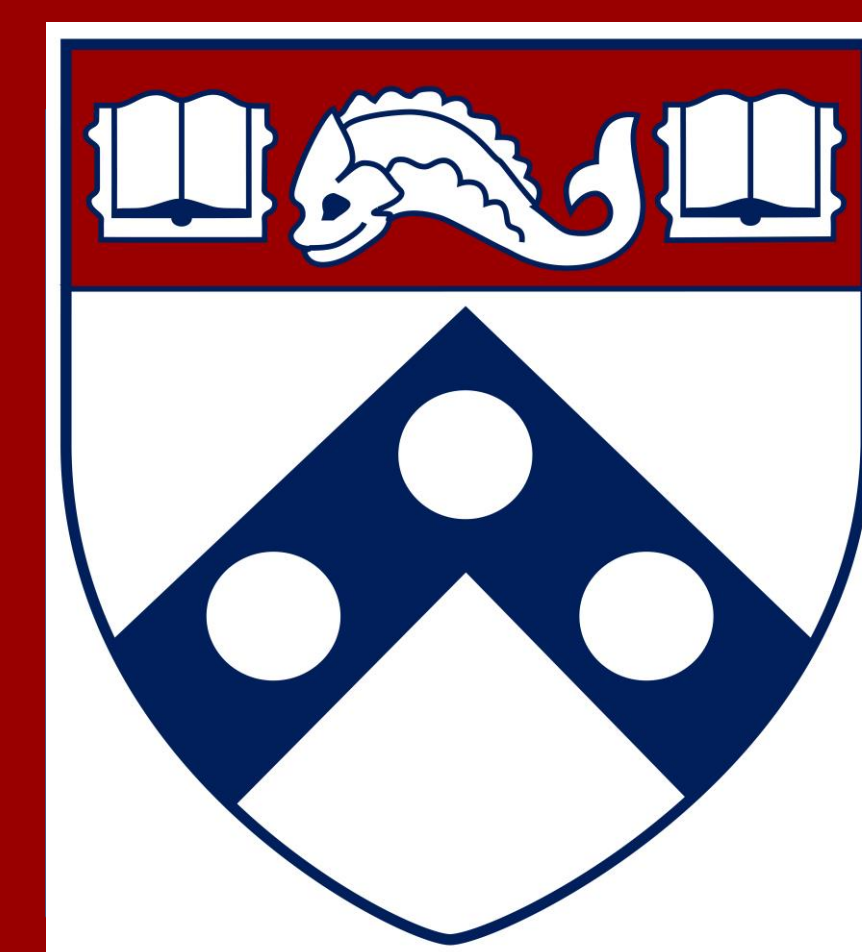
[the Penn crest]

Compassionate care for patients with Autism Spectrum Disorder

Margaret Lynn Beaudoin Kobb, M.Div., BA

Staff Chaplain, Diversity & Inclusion Core Council Co-Chair, Hospital of the University of Pennsylvania

MargaretLynn.Kobb@pennteam.upenn.edu



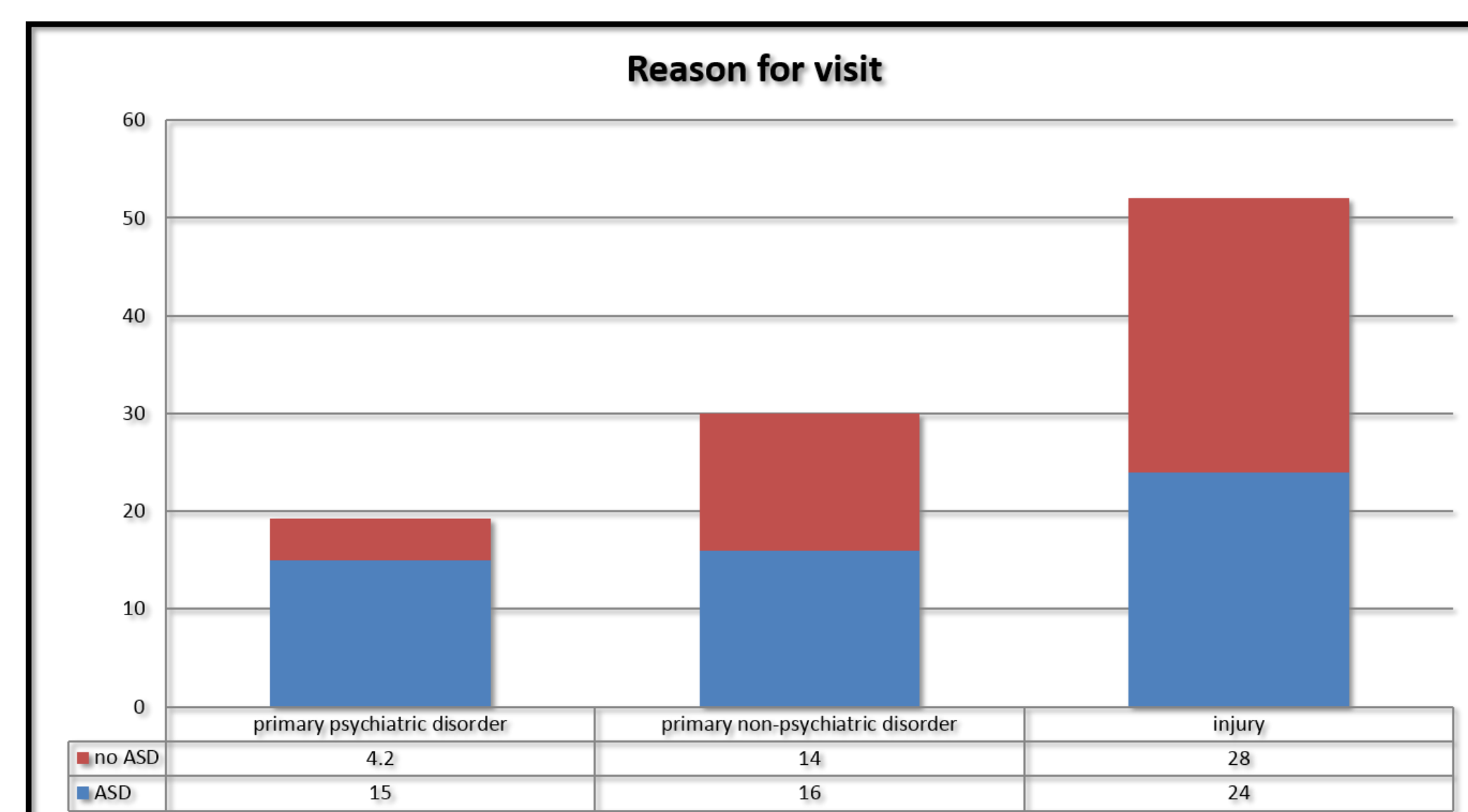
[the Penn crest]

Symptomology & Barriers to Care

- What we see:
 - Lack of eye contact
 - Not answering questions, or not answering right away
 - Recoiling from touch
 - Repetitive movements
 - Vocalizations that are not words
 - Extreme reactions to sensory input
- How that impacts medical care:
 - Difficulty/inability to communicate verbally
 - Medical history? Allergies?
 - Pain level?
 - Needing help with self care tasks?
 - Touch is necessary in medical treatment
 - Blood draws
 - Vital checks
 - Wound inspection
 - The noise, smell, brightness of the hospital could send a patient into sensory overload

National Trends of Care Disparity

- Patients with autism are more likely than their neuro-typical peers to be admitted to the hospital through the emergency department, and to have their stay extended for non-medical needs, and to be readmitted soon after¹
- Staff report feeling unprepared to meet the needs of this population, but formal training seldom exists
- To the untrained eye, behaviors typical to autism can look threatening, leading to higher incidence of both chemical and physical restraint



[a bar graph showing that patients with autism get admitted to the hospital more often than their neurotypical peers]

¹Vohra, Rini et al. (2016). Emergency Department Use Among Adults with Autism Spectrum Disorders (ASD). Journal of Autism and Developmental Disorders, Vol. 46: 1441-1454.

Prevalence & Reclassification

- ASD affects more than 6.5 million people in the U.S., roughly 2% of the population²
- The Diagnostic Statistical Manual of Mental Disorders, 5th ed. reconfigured the parameters, with hopes of increasing the availability of treatment



[a green umbrella with DSM-5 printed on it with all of the conditions that make up autism spectrum disorder beneath it]

²Baio J, Wiggins L, Christensen DL, et al. Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2014. MMWR Surveill Summ 2018;67(No. SS-6):1-23.

Patient, Family, Community

- Caregiver issues:
 - 84% of adults with ASD live with their parents³
 - 48% of individuals attempt to elope from safe environments⁴
 - Dual themes of hyper-vigilance and resilience
 - High levels of caregiver burnout
- Continuum of care needed throughout the lifespan:
 - Lack of transitional care when patients become adults

³Autism Speaks. What is autism? Retrieved from <https://www.autismspeaks.org>

⁴Interactive Autism Network Research Report ASD Elopement, 2011 http://www.iancommunity.org/cs/ian_research_reports/ian_research_report_elopement

Care for the Individual Patient

- Language:
 - Calm, concrete language
 - Prompting
 - Ask the patient directly!
 - "Simple, not childish"
- Environment:
 - Minimize needle sticks
 - Low lights in room, mindful of noise level
 - Need for a single-occupant room
- Behavioral Approach:
 - "First-Then" language
 - Make a list (words or pictures)
 - Give warning of changes in staff, routines, medications with as much notice as possible
 - Remember that behavior **is** communication!
- Interdisciplinary perspective:
 - Need for multi-disciplinary approach more than other patients
 - Utilize family/caregivers
 - You are the expert in your field
 - The caregiver is an expert in the patient

Changes System-Wide

We are capable of making adjustments to our clinical practices that will provide outstanding, compassionate care for patients with autism by instituting:

- Autism Response Teams in every facility
 - 24-hour coverage by interdisciplinary team
 - Similar model to every other referral service
- Disability Liaison
 - Like a nurse navigator, this is a person who would help to connect medical team to social work, outside agencies, various specialists
- System-wide training
 - We prioritize diversity training
 - Frequently does not include disabilities
 - Put it front & center during new employee orientation
 - Refresher courses on-line