Nurse Practitioner Driven Home Based Primary Care Access and Immunization Initiative for Adults with Autism and/or Intellectual Disability

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Depending on the severity of the impairment, individuals with autism spectrum disorder (ASD) and/or intellectual disability (ID) can have difficulty with traditional primary care office visits. The clinic environment is unfamiliar and overstimulating, and even if a clinic room can be adapted to provide less stimulation, individuals and their caregivers must still navigate overstimulating environments and waiting rooms. Regular primary care helps to ensure health maintenance, prevent illness, gain access to preventative services such as immunizations, and reduce the cost of healthcare overall. Telehealth is one option to eliminate the need to navigate the overstimulation of the clinic environment. However, these individuals can have difficulty understanding how to interact with a provider via telehealth, and there is a loss of needed hands-on assessment. Similarly,

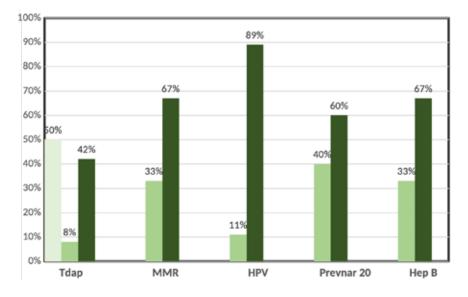
this platform cannot provide immunizations and other preventative care.

The disparity in this population has been extensively documented. Research has shown that adults with ASD and/or ID experience barriers to primary care due to overstimulation of the clinical environment, especially those with the most severe impairment (Stein Duker & Goodman, 2022). Sensory overload, long wait times, and a decrease in providers trained to care for individuals with ASD and/or ID contribute to the low rates of preventative care like immunizations (Doherty et al., 2020). In a descriptive study conducted by Maltais et al. (2020), adults with a diagnosis of ID with more severe impairment had an increase in disparities in access to primary care and preventative services, and similarly, Ali et al. (2023) found that individuals with lower cognitive functioning cannot meaningfully participate in telehealth visits.

Healthy People 2030 includes four goals, one of which is to attain healthy, thriving lives and well-being free of preventable disease (Health and Human Services, 2020). Immunizations help to meet this goal. Immunizations are the best protection from preventable diseases and have saved lives for over 100 years (Centers for Disease Control, 2024). Castro et al. (2023) found that the prevalence of immunizations was lower in adults with disabilities from 2016 – 2021 and Doherty et al. (2020) found that reasonable adjustments such as providing home visits could help ensure individuals with ASD and/or ID are not excluded from primary health care.

To reduce this disparity and build upon successful research, a home-based primary care (HSPC) pilot study was implemented at the Center for Special Health Care Needs, which is a medical home for adults with pediatric-onset chronic disease at ChristianaCare. Caring for over 1,200 adults in both primary and specialty care, primary care providers helped to identify those individuals who could most benefit from a primary care visit at home. These individuals would meet the criteria of being diagnosed with ASD and/or ID and struggle with increased anxiety and possibly aggressive behavior when in the clinical setting. These would also be individuals who were not up to date with immunizations according to the Center for Disease Control (CDC) Adult Immunization Schedule

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Reasons and Percentages for Each Vaccine Not Given

(AIS) for 2024. Guardians were contacted and offered a home primary care visit as well as immunizations that were needed. The immunizations offered were based on the time of year; this pilot was outside of the timeframe for COVID-19 and Influenza immunizations, and the immunizations stocked in the clinic could be transported safely in a cooler. Visits were scheduled for those who expressed interest even if they declined the recommended immunization(s). Data on age, race, ethnicity, insurance, group home residency, and last in-person visit was collected. Reasons for immunization not being administered were also collected and ranged from declined, behavior preventing administration, and insurance denial.

Prior to the initiation of the six-week pilot, 41 individuals were recommended for a HBPC visit. Attempts were made to contact all of the individual's guardians to explain the program and schedule a visit during the time of the pilot. In the end, there were 32 individuals seen for a HBPC visit. The most frequently observed age was 19-30 years (n = 20, 62.50%). The most frequently observed category of gender was Male (n = 20, 62.50%). The most frequently observed category of race was Caucasian (n = 22, 68.75%). The most frequently observed category of ethnicity was non-Hispanic/Latino (n = 30, 93.75%). The most frequently observed category of insurance was public Medicare/Medicaid (n = 27, 84.38%). The most frequently observed category regarding having HBPC visits in a group home was No (n = 20, 62.50%).

To evaluate the question to be answered by this pilot, namely does HBPC compared to in-clinic visits impact immunization rates over six weeks in this population, a two-tailed paired samples t-test was conducted to examine whether the mean difference between total immunizations recommended and total vaccines given was significantly different from zero. The result of the two-tailed paired samples t-test was significant based on an alpha value of .05, t(31) = 6.02, p <.001, indicating the null hypothesis can be rejected. This finding suggested the difference in the mean of total immunizations recommended and the mean of total immunizations given was significantly different from zero. The mean of the total immunizations recommended was significantly higher than the mean of the total number of immunizations given.

In evaluating the reasons and per-

centages for immunizations not given 63% were declined, 20% were not given due to individual behavior, and 17% were denied by insurance, specifically tetanus, diphtheria, and pertussis (TdaP) vaccine is not covered as part of routine primary care by some insurance carriers. An interesting finding showing that more education is needed is related to the human papillomavirus (HPV) vaccine. This vaccine showed the highest rate of declination at 89%, with many guardians believing the vaccine is not needed for those who are not sexually active.

In conclusion, this HBPC pilot brought primary care into the homes of individuals with ASD and/or ID who struggle to get primary care due to the overstimulation of the clinic environment. Immunization rates for this small population in this short pilot study did show a statistically significant increase in compliance with the CDC, 2024 AIS. The project also identified a need for further education specifically related to the importance of the HPV vaccine for those who are not sexually active. *

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