REVIEW OF DISABILITY STUDIES: AN INTERNATIONAL JOURNAL Vol. 20 Issue 1 (2024)

Research Articles and Essays

Health Profile, Primary Care and Preventive Care Utilization in Adults with Intellectual and Developmental Disabilities in Hawai‘i

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Abstract

Adults with intellectual and developmental disabilities (IDD) have poorer health outcomes compared to adults without intellectual and developmental disabilities. In describing the health profile, primary and preventive care utilization in adults with IDD, we found high primary care utilization and low preventive care utilization in a population with significant medical problems. We describe strategies to improve preventive care utilization for this population.

Keywords: intellectual and developmental disability, primary care, preventive care

Health Profile, Primary Care and Preventive Care Utilization in Adults with Intellectual and Developmental Disabilities in Hawai‘i

Adults with intellectual and developmental disabilities (IDD) are known to have poorer health outcomes than adults without IDD. As we work to improve the health and well-being of the IDD population, it is imperative that we study and understand the drivers of their health disparities.

Importantly, adults with IDD have greater medical complexity and a denser disease burden than adults without IDD. This population has a higher prevalence of a multitude of medical conditions, including asthma, arthritis, diabetes, cardiac disease, high cholesterol, high blood pressure, stroke (Reichard & Stolzle, 2011), hypothyroidism (Ptomey et al., 2020), and dementia (Ptomey et al., 2020; Takenoshita et al., 2020). A higher rate of polypharmacy (O'Dwyer et al., 2016) accompanies these conditions, adding to their overall complexity.

The dense burden of medical disease in this population is, not surprisingly, associated with disparities in health outcomes. In the United States, their life expectancy is 12 years shorter on average than their counterparts without IDD (Landes et al., 2021a). Like those without IDD, heart disease is the leading cause of death in people with IDD (Landes et al., 2021c), but that is where the similarities end. Diabetes mellitus causes disproportionately more deaths in those with mild to moderate IDD (Landes et al., 2021b) and those with IDD also have poorer cancer outcomes (McCarthy et al., 2007).

Health outcomes are influenced by many factors, including social and economic drivers, physical environments, and healthcare itself. People with IDD often have difficulty with and differences in communication, making symptom identification and investigation challenging for healthcare providers. Therefore, for this population, primary care, and preventive care can have an outsized influence on outcomes, and we must ensure both access to and quality of care.

Preventive care is important to maintain good health and for early detection of problems. From a dental standpoint, oral hygiene and health in the IDD population is significantly poorer than that of the general adult population, with higher rates of periodontal disease and untreated caries (Anders & Davis, 2010; Morgan et al., 2012). Poor dental health is known to lead to respiratory and cardiovascular disease (Stephens et al., 2018). Similarly, with vision care, many adults with IDD have untreated needs for distance, near vision, and cataracts (Warburg, 2001). It is easy to understand how poor vision can directly lead to poorer health outcomes—lowering medication compliance and limiting communication, mobility, and overall function. An additional critical aspect of preventive care is cancer screening, which is important for early detection and improved survival. People with IDD face multiple barriers to cancer screening (Steele et al., 2017) and women with IDD have lower rates of undergoing pap smears and mammograms (Horner-Johnson et al., 2014).

The importance of primary care and preventive care cannot be overstated in the IDD population. In this study, we sought to describe the medical complexity and primary and preventive care utilization of adults with IDD in the state of Hawaiʻi, investigating whether demographic or clinical factors were associated with utilization. In addition, because the state of Hawaiʻi requires an annual visit to a primary care provider (PCP) to access benefits for home and community-based services (HCBS) (State of Hawaiʻi, 2022), we hypothesized that there would be a high rate of primary care utilization and that preventive care utilization would be lower since it is not required to receive HCBS.

Method

Adults, 21 years and older, with IDD engaged in HCBS across six programs on four

Hawaiian Islands (Hawai‘i, Kaua‘i, Maui, and O‘ahu) were included in this study. A cross-sectional retrospective chart review of all Individualized Service Plans (ISPs) created during the 12-month period from August 2022 to July 2023 was performed.

Data collected included demographics (sex, age, race, insurance, and living arrangement), presence and severity of intellectual and developmental disability (IDD), medical conditions (ICD-10 codes, the International Classification of Diseases, Tenth Revision, for classifying diseases and conditions), body mass index (BMI), number of scheduled medications, and times since last PCP visit, dentist visit, and vision screening. In accordance with current national screening guideline recommendations, time since last Pap smear was collected for women aged 21 to 65 (American College of Obstetricians and Gynecologists [ACOG], 2021), and time since last mammogram was collected for women aged 50 to 74 (Siu & Force, 2016). Descriptive statistics were used to describe the study population’s demographics, health status, and overall primary and preventive care utilization.

We used non-parametric statistics with a significance level set at $p > .05$ to compare primary and preventive care utilization by sex, race, presence/absence of Down Syndrome (DS), and autism spectrum disorder (ASD), severity of IDD, medical complexity, number of medications, and obesity class (Class 1 = BMI 30 to <35, Class 2 = BMI 35 to <40, Class 3 = BMI >=40).

Statistical analysis was performed using SPSS Version 28.0. Institutional Review Board approval was obtained for this study.

Results

Our study included the records of 158 adults with IDD. The characteristics of the study population are shown in Table 1.

Table 1

Study population characteristics

Characteristic	Overall, N=158 n (%)	DS, n=30 n (%)	ASD, n=39 n (%)
Sex			
Female	73 (46.2)	12 (40.0)	14 (35.9)
Male	85 (53.8)	18 (60.0)	25 (64.1)
Age (years)			
Median	36.5	35.5	32.0
Interquartile range	30.0 to 43.0	30.0 to 40.8	28.0 to 39.0
Race			
Asian	71 (44.9)	11 (36.7)	16 (41.)
Multiracial	36 (22.7)	7 (23.3)	6 (15.4)
White	27 (17.1)	9 (30.0)	8 (20.5)
Native Hawaiian/Pacific Islander	18 ((11.4)	2 (6.7)	4 (10.3)
All others	6 (3.8)	1 (3.3)	5 (12.8)
Medicaid insurance	156 (98.7)	30 (100.0)	39 (100.0)
IDD severity			
Mild	27 (17.1)	0 (0)	5 (12.8)
Moderate	80 (50.6)	21 (70.0)	15 (38.5)
Severe	14 (8.9)	4 (13.3)	3 (7.7)
Profound	10 (6.3)	1 (3.3)	2 (5.1)
Unspecified	27 (17.1)	4 (13.3)	14 (35.9)
Living arrangement			

Family home	136 (85.4)	29 (96.7)	37 (94.9)
Adult foster home	11 (7.0)	-	-
Independent	8 (5.1)	-	2 (5.1)
Group home	3 (1.9)	1 (3.3)	-

A slight majority of the study population was male (53.8%) and the median age was 36.5 years (IQR 30.0 to 43.0 years). Asian (44.9%), Multiracial (22.7%) and White (17.1%) were the three most common races. All but two individuals (98.7%) had Medicaid, which is a state and federally funded health insurance. In terms of IDD severity, half of the study population had moderate IDD, and the remainder were distributed approximately equally between less severe and more severe IDD. IDD severity was unspecified or missing in 17.1%. A high proportion of individuals lived at home with family (85.4%) and the rest lived in adult foster homes (7.0%), independently (5.1%), and in group homes (1.3%).

The study population included 30 individuals (19.0%) with DS and 39 individuals (24.7%) with ASD, all of whom had Medicaid insurance. Both groups were also majority male and had similar racial composition to the overall study population. The ASD group was significantly younger with median age 32.0 years (IQR [Interquartile Range] 28.0 to 39.0 years) ($p = .005$), which was expected given the more recent rise in ASD diagnoses. The vast majority of both the DS (96.7%) and ASD (94.9%) groups lived with family. In both groups, the majority had moderate IDD. However, in the ASD group 35.9% had unspecified or missing data on IDD severity. Due to the retrospective nature of this study, we were unable to discern whether the data was missing because the individual did not have IDD, which is common in ASD, or if IDD was present and the severity was not captured in the ISP.

Health Profile

The study population's health profile is detailed in Table 2.

Table 2

Health Profile

	Overall, N=158 n (%)	DS, n=30 n (%)	ASD, n=39 n (%)
Number of ICD-10 diagnoses (including primary IDD diagnosis)			
5 or more	49 (31.0)	6 (20.0)	14 (35.9)
4	34 (21.5)	8 (26.7)	7 (17.9)
3	28 (17.7)	6 (20.0)	10 (25.6)
2	26 (16.5)	8 (26.7)	7 (17.9)
1	21 (13.3)	2 (6.7)	1 (2.6)
5 Most Prevalent Comorbidities			
Epilepsy	35 (22.2)	0	11 (28.2)
Hypertension	29 (18.4)	0	4 (10.3)
Lipidemias	29 (18.4)	7 (23.3)	4 (10/3)
Type 2 diabetes mellitus	16 (10.1)	0	7 (17.9)
Hypothyroidism	13 (8.2)	6 (20)	2 (5.1)
Obesity*			
Class 1 (BMI 30.0-34.9)	30 (21.1)	6 (20.0)	5 (12.8)
Class 2 (BMI 35.0-39.9)	11 (7.7)	1 (3.3)	5 (12.8)
Class 3 (BMI >40.0)	13 (9.2)	3 (10.0)	2 (5.1)
Number of medications			
5 or more	33 (20.9)	3 (10.0)	13 (33.3)

4	13 (8.2)	2 (6.7)	2 (5.1)
3	20 (12.7)	2 (6.7)	4 (10.3)
2	18 (11.4)	3 (10.0)	4 (10.3)
1	29 (18.4)	8 (26.7)	5 (12.8)
None	45 (28.5)	12 (40.0)	11 (28.2)

*BMI was missing for 16 participants

Medical Complexity

The number of medical conditions, including IDD, per individual ranged from 1 to 10. A majority, 86.7%, had at least one medical comorbidity in addition to their primary IDD diagnosis, with almost one-third (31.0%) having five or more total comorbidities. As a group, those with ASD tended to have more medical conditions than the DS group, but this difference was not statistically significant. Overall, the five most prevalent comorbidities were epilepsy (22.2%), hypertension (18.4%), lipidemias (18.4%), type 2 diabetes mellitus (10.1%) and hypothyroidism (8.2%). These were similar in the ASD group, but the DS group did not have any epilepsy, hypertension, or type 2 diabetes mellitus.

Obesity

The prevalence of obesity was 37.3% (Class 1, 21%; Class 2, 8%; Class 3, 9%). The prevalence of obesity was similar in the DS and ASD groups.

Medications

The number of scheduled medications ranged from 0 to 12. Polypharmacy, defined as being on 5 or more scheduled prescription medications, was present in 21%. Fifty-one percent were on 1 to 4 prescription medications and 29% were not on medication. The finding that polypharmacy was more common in the ASD group (33.3%) than the DS group (10.0%) trended toward statistical significance ($p = .059$).

Primary Care, Dental Care & Vision Screening

Primary care and preventive care utilization are shown in Table 3.

Table 3

Primary Care and Preventive Care Utilization

	Overall, N=158 n (%)	DS, n=30 n (%)	ASD, n=39 n (%)
Primary care	131 (82.9)	25 (83.3)	32 (82.1)
Dental care	101 (63.9)	20 (66.7)	23 (59.0)
Vision screening	48 (30.4)	8 (26.7)	14 (35.9)
Pap smears	11/69 (15.9)	0/12 (0)	1/14 (7.1)
Mammograms	5/14 (35.7)	0/2 (0)	None eligible

In the 12 months prior to ISP creation, 82.9% of individuals had seen their PCP, 63.9% had seen their dentist, and 30.4% had their vision screened. Rates of PCP visits, dental care, and vision screening in the DS and ASD groups were similar. Rates of primary care, dental care, and vision screening were not significantly different when compared by sex and by race.

One might suggest that those with more severe IDD and/or more medical complexity might receive more primary or preventive care than others given their higher risk for poor outcomes. However, the number of medical conditions (1 to 4 vs. 5 or more) and number of medications (none vs. 1 to 4 medications vs. 5 or more medications) were not associated with differences in utilization rate in primary care, dental care, or vision screening.

Rates of primary care and preventive care utilization were also compared across obesity classes. Those with Class 3 obesity had the highest rates of primary care utilization (100% vs. 81.8% in Class 2, 80% in Class 1, and 83.0% in those without obesity) and dental screening (76.9% vs. 45.5% in Class 2, 70.0% in Class 1, and 65.9% in those without obesity). Due to the small subgroup sizes, these differences did not reach statistical significance. Vision screening was around 30% across the groups.

Women's Preventive Care

Only 11 of 69 (15.9%) women aged 21 to 65 years had undergone cervical cancer screening in compliance with national guidelines (i.e., within the last 36 months), and only 5 of 14 women aged 50 to 74 years had undergone breast cancer screening in compliance with national guidelines (i.e., within last 24 months). In the DS group, none of the 12 women eligible for cervical cancer screening had received a Pap smear in compliance with national guidelines, and neither of the 2 women eligible for breast cancer screening had received a mammogram in compliance with national guidelines. In the ASD group, only 1 of the 14 eligible for cervical cancer screening had undergone a Pap smear. None in the ASD group qualified for breast cancer screening.

While the cervical and breast cancer screening in women in the DS and ASD group was almost non-existent, due to the low overall screening rates and small size of the DS and ASD groups, the difference in screening rates was not statistically significantly different. Owing to small obesity subgroup sizes, we were not able to compare cervical and breast cancer screening rates across obesity classes.

Discussion

Adults with IDD in HCBS have a complex medical disease burden at a young age with significant rates of polypharmacy. While this is reflective of the literature, our study has additional important findings regarding primary and preventive care utilization in adults with

IDD.

Primary care and preventive care are medical cornerstones of health outcomes. The IDD population often has difficulty in symptom identification and communication, elevating the importance that primary and preventive care play in their overall health and outcomes. In Hawaiʻi, an annual visit to a primary care provider is mandatory to access HCBS (State of Hawaiʻi, 2022). Our results show that adults with IDD are largely compliant with this requirement, putting our study population close to par with non-IDD (MedQuest, 2023) adults in the general population (CommonwealthFund, 2022).

Not surprisingly, but importantly, engagement with preventive care, which is not required for HCBS, was lower than primary care engagement. In our study, we found that dental, vision, and female preventive care had lower participation than primary care. It is important to note that while vision screening and female preventive care were covered benefits under Medicaid, preventive dental care did not become a Medicaid benefit in Hawaiʻi until January 1, 2023 (MedQuest, 2023), which was during the study period. Our study is not able to discern the reasons for lower preventive care utilization, but postulate that there may have been issues of geographic access, provider inexperience or unwillingness to provide care to adults with IDD, and provider and/or caregiver beliefs about the necessity of preventive care.

Prioritizing preventive care in this population would be expected to not only improve well-being and health outcomes, but also to reduce overall healthcare costs. A means to improving health outcomes in the IDD population could include requiring preventive care to access benefits such as HCBS. To improve the IDD population’s use of preventive care, we need a multi-pronged approach that addresses:

1. Policy and benefit design

2. Healthcare provider readiness
3. Caregiver awareness and perception.

Policy and Benefit Design

Our results demonstrate the effectiveness of mandated primary care participation, which prompts consideration of tools to increase utilization of additional preventive services. While policymakers must contemplate barriers to access, including geographic constraints and patient anxiety, they can harness interest in HCBS to urge increased preventive care participation. For example, HCBS intake procedures can include mandatory discussions about preventive care and service providers can facilitate medical linkages. While HCBS providers hold power as a centralized point of contact with the IDD population, it is vital that they maintain a person-centered approach and guide clients to medical care while respecting individual preferences and needs.

Benefit design is perhaps the most important tool to direct patients to care. Providing comprehensive coverage for all preventive care, including dental and vision care, reduces the likelihood of patients skipping screenings to avoid costs. The inclusion of preventive services in a health plan also signals the importance of these services to patients and families. In Hawaiʻi, preventive dental care was not a covered benefit under Medicaid until January 1, 2023. This could have been a driver of lower dental care utilization in our study population.

Policymakers must also address the unique barriers that impact their communities. Medical student training incentives and interstate licensing compacts can bring additional providers to areas with shortages. Robust telehealth options can alleviate geographic distance strain in rural areas. Transportation coverage mitigates inequities for those who cannot drive or safely navigate public transit. Identifying pain points impacting the local population enables policymakers to craft effective solutions tailored to community need.

Healthcare Provider Readiness

Healthcare providers need to be prepared to care for people with IDD (Smith et al., 2021). Communication with and performing procedures on people with IDD is different and requires skills that are not yet taught in today's mainstream healthcare professional education (Edwards & Hekel, 2021; Lee et al., 2023). As a result, people with IDD have a worse experience with healthcare, reporting poorer quality and quantity of provider interactions compared to the general population (Stone et al., 2023). Education during medical, nursing, and allied health school that includes a curriculum on the nuances of caring for patients with IDD would begin to close this gap, as would continuing education for those already in practice.

Primary care is highly utilized by adults with IDD, and providers must be knowledgeable about the importance of preventive care in this population. Beyond that, providers must be prepared to discuss preventive services with their IDD patients and their caregivers. Since there is often a high-trust relationship with a PCP, patients may be most comfortable with them. Therefore, PCPs must be facile at performing preventive care procedures within their professional scope, such as Pap smears for cervical cancer screening. Specialty care providers, including dentists, require similar skills to take care of this population.

Geographic availability is also imperative in the effort to improve preventive care utilization. While rural areas quickly come to mind, other geographic constraints are also important to consider. For example, archipelagoes may have overall adequate numbers of primary and specialty physicians and healthcare facilities. However, we often see them geographically concentrated on one island, often the financial and governmental center, making these resources difficult for those living on the other islands to access.

Lastly, it needs to be formally recognized that taking care of patients with IDD is different and necessarily more time-consuming than taking care of patients without IDD. Provider reimbursement should reflect the additional effort that it takes to provide good care to this population.

Caregiver Awareness and Perception

Adults with IDD typically rely on their caregivers to identify their primary and preventative care needs, arrange these visits, serve as their advocate for effective communications with providers, support in decisions regarding care, and ensure that the recommendations made by their providers are followed. These caregivers are often family members of the person with IDD who are balancing the support needs of the person with IDD alongside the needs of other family members, the family unit as a whole, and their own self-care needs. Because of this, caregiver awareness of the importance of the preventative and primary care needs of these persons with IDD is critical to ensuring their ability to appropriately prioritize these needs. For caregivers who are experiencing excessive caregiver burden or stress, additional supports may be necessary to ensure that the caregiver has the necessary resources and capacity to both ensure the necessary preventative and primary care visits occur and to serve as an advocate for the person with IDD.

Addressing existing misconceptions around the need for or effectiveness of primary and preventative care for adults with IDD may also contribute to increased engagement. It is common for an adult with IDD to be actively engaged with providers representing a range of disciplines simultaneously (e.g., neurology, behavioral health, and gastroenterology), which could lead to an assumption by caregivers that their healthcare needs are being adequately addressed. However, preventative and primary care are critical to ensuring that emerging health concerns are identified and that treatment for existing health concerns continues to be effective and positively impacting overall health outcomes.

Another commonly held misconception is that women's health screenings are only necessary for women who are sexually active. Caregivers of adult women with IDD who hold this belief are likely to determine that these screenings are unnecessary, resulting in missed cervical and breast cancer screenings. A similar misconception related to vision could also impact a caregiver's understanding of this preventative care need in that caregivers of adults with IDD could believe that vision screenings are only necessary for those who have known or suspected vision challenges.

Including the IDD Community

Inclusion of the IDD community in each of these three areas (policy and benefit design, healthcare provider readiness, and caregiver awareness and perception) will ensure the development of the most effective and impactful programs. Where appropriate and when possible, adults with IDD should be brought directly into the conversation in a setting and format where their contributions can be impactful. Caregivers of adults with IDD also represent an important stakeholder group to include as they are intimately aware of barriers to care and are also often a crucial gateway to access for healthcare services.

Study Limitations

This chart review of administrative data in ISPs was not without limitations. A significant constraint lies in the potential for inaccuracies within the administrative records themselves as these documents serve administrative purposes rather than research objectives. Inaccurate codes, misclassifications, and incomplete documentation may introduce biases and compromise the overall accuracy of the extracted data and our analyses. We saw this specifically in the missing data on IDD severity in the ASD group.

Additionally, the inherent selection bias in relying on data from individuals in HCBS may affect the generalizability of our findings to broader populations with IDD, particularly those with less severe IDD who are not engaged in HCBS.

Conclusion

Primary care and preventive care are critical to the health outcomes of people with IDD. Health behaviors are promoted when tied to HCBS access. Engagement in preventive care is suboptimal in the adult IDD population. To improve the health and well-being of this population, consideration should be given to strategies that tie preventive care to HCBS access.

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