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INTRODUCTION

- Patients with Down Syndrome (DS) have unique primary care needs in addition to routine care
- However, previous research has shown that adherence to these guidelines is inconsistent and lacking
- Caregivers perceive these barriers to arise from a lack of provider understanding of the support needed for patients with DS
- **We administered a survey to Connecticut healthcare providers to assess perspectives on preventative care for adults with DS**

METHODS

Provider Inclusion Criteria

- 18+ years old
- Hartford Healthcare Providers
- Employed in CT and/or nearby states

Survey Information

- 24 questions included
- Assessed perspectives on resources that could improve care, extent of training, provider knowledge on the specific care for adults with DS

Outcomes

- Primary: Resource Perspective Score
- Secondary: DS Knowledge Score

Statistical Analysis

- SPSS v.26 analysis software
- REDCap software for data collection

SURVEY RESPONSES & RESULTS

Outcomes	Median	IQR
<i>Resource Perspective Score (N=68)</i>	7	6-9
<i>Maximum Score of 23</i>		
<i>Down Syndrome Knowledge Score (N=70)</i>	11	9-14
<i>Maximum Score of 20</i>		
Survey Questions	Frequency	Percentage
<i>Involved in providing care to adult with DS</i>		
Yes	66	81.5%
No	6	7.4%
Unsure	4	4.9%
Did not answer	5	6.2%
<i>Feel received adequate training to include those with DS</i>		
Yes	22	27.2%
No	53	65.4%
Did not answer	6	7.4%
<i>Know who to contact for information to include those with DS</i>		
No, I do not know who to contact	56	69.2%
Yes, I work within a division that has knowledgeable staff who can include those with Down syndrome	7	8.6%
Yes, I know who to contact but they are in a different division	12	14.8%
Did not answer	6	7.4%
<i>Received Disability Awareness Training</i>		
Yes	40	49.4%
No	36	44.4%
Did not answer	5	6.1%
<i>If yes to training, did it include DS specific information?</i>		
Yes	9	11.1%
No	35	43.2%
Did not answer or N/A	37	45.7%
<i>Aware of AAFP yearly thyroid function test recommendation</i>		
Yes	26	32.1%
No	43	53.1%
Maybe	2	2.5%
Did not answer	10	12.3%

PROVIDER DEMOGRAPHICS

Variable	Frequency
<i>Gender, n (%)</i>	
Male	29 (35.8%)
Female	47 (58.0%)
Other/Prefer not to answer	5 (6.2%)
<i>Race/Ethnicity, n (%)</i>	
White	59 (72.8%)
Asian	7 (8.6%)
Black or African American	3 (3.7%)
Hispanic or Latino	3 (3.7%)
Two or more races	2 (2.6%)
Prefer not to answer	7 (8.6%)
<i>Education Level, n (%)</i>	
Professional School degree	49 (60.5%)
Advanced Nursing degree	16 (19.8%)
Doctoral degree	5 (6.2%)
Physician Assistant degree	7 (8.6%)
Bachelor's degree	2 (2.5%)
Master's degree	1 (1.2%)
Other/Prefer not to answer	1 (1.2%)
<i>Age, median (IQR)</i>	43.5 (36-54)
<i>Years in Role, median (IQR)</i>	10 (3.5-17)

CONCLUSIONS

- Many PCPs, APPs, and other interprofessional clinicians care for adults with DS, yet a majority report having inadequate training, resources, and knowledge to care for these patients
- These factors create barriers to care that likely contribute to the adverse health outcomes of adults with DS
- A multifactorial approach by the healthcare systems to incorporate DS-specific care into provider training could reduce the healthcare cap for adults with DS

FUTURE DIRECTIONS

- Incorporate disability awareness training into hospital settings, outpatient systems, and medical education programs
- Connect healthcare providers with caregivers directly to discuss improvements in care
- Distribute survey to other healthcare organizations to identify system-specific areas of improvement

SURVEY



REFERENCES



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