

# A Look at the Needs and Barriers to Care for Adults with Down Syndrome in Wisconsin

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## BACKGROUND

- Growing population of adults with Down syndrome (DS) due to longer life expectancy<sup>1,3</sup>
- Transition services prepare adolescents for adult healthcare, children with DS less likely than peers to receive them<sup>5,6</sup>
- 52% of DS adults seek care from pediatrics<sup>2</sup>
- Incomplete healthcare transition can lead to missing adult health care services<sup>4</sup>

## OBJECTIVES

1. To determine the needs and barriers related to accessing quality healthcare for adults with DS as perceived by stakeholders in the DS community.
2. To learn from caregivers and adults with DS about their experiences in healthcare.
3. To learn from healthcare providers regarding their experiences and attitudes related to providing healthcare for adults with

## DESIGN/METHODS

- Used qualitative and quantitative methods
- Interviewed 19 people including healthcare providers, community organization leaders, caregivers, and adults with DS
- Piloted a survey for caregivers of adults with DS and a survey for healthcare providers
- Analyzed interview data for central themes, compared with survey data

## RESULTS

Interviewee Role	# of interviews
Primary Care Provider	3
Specialty Provider	2
Other Healthcare professional	3
Community Organization Partner	3
Caregiver	9
Adult with Down Syndrome	3

Survey Responses	# of responses
Caregiver Survey	21
Healthcare Professional Survey	23

### Caregiver Survey

- All caregivers were satisfied or extremely satisfied with their healthcare provider, but many had negative healthcare experiences
- 0 caregivers reported transition services as easy to find, 12 never attempted to access them, 17 agreed that they would be useful.
- 9 caregivers reported mental health services as hard to find, 0 reported it easy to find
- 8 caregivers reported behavioral health services as hard to find, 2 as easy to find

*“The qualities that I look for in a good doctor is that they are experienced in what they do, that they are organized, and... is comfortable with both me and my mom answering questions” - self advocate*

*“We have been to doctors that... wouldn’t talk directly to [adult with DS], that would only speak to me and wouldn’t even look at her” – caregiver*

*“It is a challenge to find adult primary care and specialty care providers who are comfortable managing individuals with disabilities in general.” - primary care provider*

*“The minute we got 17 or 18 years old [the healthcare providers] don’t really know. They are just tracking her health, not the Down syndrome part... there is no expertise anymore” - caregiver*

Interview Themes	# of mentions
Need for Disability Training for Healthcare Professionals	31
Need for Educational Resources for Caregivers	19
Need for Evidence Based Guidelines	19
Comments on Healthcare Transition	39
Barriers to Healthcare Access	38
Social Determinants of Health	16

### Healthcare Professional Survey

- 15 were slightly uncomfortable or uncomfortable with adapting current screening guidelines for people with DS.
- 16 disagreed or strongly disagreed that they received training on how to care for adults with DS and/or IDD.
- 16 disagreed or strongly disagreed that they knew what is needed to transition a young adult with DS from pediatric to adult care.

## CONCLUSIONS

- Need for increased PCP training on healthcare transition
- All providers should be aware of new guidelines to increase comfort with DS population
- Caregivers and self advocates are interested in transition services but need help accessing them
- Findings consistent with previous work in healthcare transition
- Next steps include:
  1. Expand healthcare transition training activities through the LEND program
  2. Create opportunities to educate PCPs about new healthcare guidelines
  3. Establish a consultation clinic for adults with DS at the Waisman Center

## REFERENCES

1. Bittles AH et al. The four ages of Down syndrome. *Eur J Public Health*. 2007;17(2):221-225.
2. Jensen KM et al. Health care in adults with Down syndrome: a longitudinal cohort study. *J Intellect Disabil Res*. 2013;57(10):947-958.
3. Mai CT et al. National population-based estimates for major birth defects, 2010-2014. *Birth Defects Res*. 2019;111(18):1420-1435.
4. Mubanga N et al. Health Care Transitions for Adolescents and Young Adults With Special Health Care Needs: Where Are We Now? *J Patient Cent Res Rev*. 2017;4(2):90-95.
5. Nugent, J., et al. Disparities in Access to Healthcare Transition Services for Adolescents with Down Syndrome. *J Pediatr* 2018 197: 214-220
6. Prokup JA et al. Health Care Disparities of Ohioans With Developmental Disabilities Across the Lifespan. *Ann Fam Med*. 2017;15(5):471-474.

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