

# Description of Daily Living Skills and Independence: a Cohort from a Multidisciplinary Down Syndrome Clinic

Kavita Krell<sup>1</sup>, BA, Kelsey Haugen<sup>1</sup>, BA, Amy Torres<sup>1</sup>, BS, Stephanie L. Santoro<sup>1,2</sup>, MD

Affiliations: <sup>1</sup>Division of Medical Genetics, Department of Pediatrics, Massachusetts General Hospital, Boston, Massachusetts;

<sup>2</sup>Department of Pediatrics, Harvard Medical School, Boston, Massachusetts

## BACKGROUND

- The Mass General Hospital Down Syndrome Program is a multidisciplinary, DS specialty clinic that provides comprehensive care to 550 unique patients annually.
- This study was part of a series of ongoing projects within the program to improve the quality of our work over time.

## OBJECTIVES

Levels of independence vary in individuals with DS. We wanted to understand the current skills in our clinic population, and use this information to:

- gain understanding on the level of independence in our clinical cohort
- identify targets for future quality improvement work on independence

## METHODOLOGY

- Retrospective review of clinic electronic intake form.
- Descriptive statistics included mean, standard deviation, and frequencies.

TABLE 1

Demographics of 546 total patients	Total cohort (%)	Pediatric Intakes (%)	Adult Intakes (%)
Male	54	53	56
<b>Race (choose all that apply)</b>			
White	88	84.8	94.4
Black or African American	3.5	4	2.5
American Indian	0.36	0.57	0
Asian	9.5	13.7	2
Hawaiian	0.18	0.3	0
Other	3.3	4.8	1
<b>Ethnicity</b>			
Hispanic or Latino	16.7	24.9	2
Age (mean years)	22.3	10.2	35.4

## RESULTS

TABLE 2

Description of skills deemed most important and not yet attained.	Not important.	Not important to me now, but I want to try later.	This is important to me now.	Skill attained
I want to learn about the differences between healthy and unhealthy foods.	83	48	119	87
I want to learn how to provide my personal information (name, emergency contact person) when needed (for example, if I get lost and a police officer asks for my name).	66	42	119	110
I want to learn how to describe how I am feeling to my doctor (for example, "I feel pain", "I'm having a hard time breathing", or "I'm coughing")	89	65	118	65
I want to be able to prepare my own meals.	93	96	116	32
I want to exercise regularly.	65	41	112	119
I want to learn how to tell the difference between a stranger and a friend.	72	38	106	121
I want to be able to bathe/shower myself.	51	30	101	155
I want to understand sexual boundaries and privacy.	100	63	96	78
I want to have a plan for what I will do after finishing high school (e.g. more school, work, career goals).	113	47	93	84
I want to learn how to brush my teeth on my own.	48	26	90	173

TABLE 3

Description of skills related to medicine and medical encounters.	Not important.	Not important to me now, but I want to try later.	This is important to me now.	Skill attained.
I want to learn how to refill my prescriptions on my own.	233	73	17	14
I want to learn what each of my medicines is for (for example, "I take Synthroid for my thyroid").	205	55	33	44
I want to be able to find my medication list.	201	71	36	29
I want to learn about the risks of alcohol, drugs and tobacco use.	193	46	27	71
I want to learn where to find my doctor's phone number.	192	87	26	32
I want to learn how to find my insurance card.	178	98	19	42
I want to take my medications every day on my own.	169	59	23	86
I want to learn how to ask my doctor questions.	130	96	54	57
I want to learn how to swallow whole pills.	97	38	24	178
I want to learn how to call 911 if there is an emergency.	73	54	83	127
I want to sleep 7 to 8 hours per night.	65	13	65	194
I want to learn how to manage my period. (for females)	44	18	22	74

## CONCLUSIONS

- People with DS 13+ classified independence skills by level of importance or attainment.
- Sleeping 7 to 8 hours a night, using a public restroom on their own, dressing themselves, and swallowing whole pills were most often attained.
- Skills of highest importance were learning about healthy foods, preparing their own meals, communicating personal information, and describing symptoms to a doctor.
- Many skills related to medical encounters, medication, or physical wellbeing were most often classified as "Not important."
- Behavioral support and interventions would likely best be focused on some of the unattained, but important skills rather than those of lesser importance.
- Limitations: single site cohort, caregiver reported data, and exclusively used responses from electronic, English intake.
- Future study could expand to include other clinics or track skills over time.

## REFERENCES

- Matthews TJ et al. An assessment of health, social, communication, and daily living skills of adults with Down syndrome. *AJMG Part A*. 2018;176(6):1389-1397. doi:10.1002/ajmg.a.38721
- de Graaf G, et al. Parents' perceptions of functional abilities in people with Down syndrome. *AJMG Part A*. Published online December 24, 2018. doi:10.1002/ajmg.a.61004
- Bertoli M, Biasini G, Calignano MT, et al. Needs and challenges of daily life for people with Down syndrome residing in the city of Rome, Italy. *J Intellect Disabil Res*. 2011;55(8):801-820. doi:10.1111/j.1365-2788.2011.01432.x

## ACKNOWLEDGMENTS

Appreciation is given to the Laboratory for Computer Sciences for creating the electronic intake form, and to Dr. Brian Skotko, the Director of the MGH Down Syndrome Program, for his leadership and foresight to implement use of this intake form.

