

## Down Syndrome: Towards Optimal Trajectories and health Equity using Medicaid Analytic eXtract

**9 years** of Medicaid and Medicare claims and encounters data for all adults with Down syndrome, intellectual disability, and autism and a 1% random Medicaid sample



Ideal for a public health aim of large NIH-style grant or to document population health statistics for marginalized populations

### Demographics

		Down Syndrome	Autism	Intellectual Disability	Random Sample
		N=123,024	N=396,426	N=1,010,525	N=3,176,371
<b>Sex</b>	Male	51.6%	74.4%	53.8%	43.8%
	Female	48.4%	25.6%	46.2%	56.2%
<b>Race</b>	White	74.6%	74.4%	69.5%	61.3%
	Black	14.1%	16.8%	22.0%	23.7%
	Pacific Islander	1.1%	0.8%	0.8%	2.2%
	Asian	3.4%	3.3%	2.6%	6.1%
	Native American	0.9%	0.8%	0.8%	1.3%
	Multiple Races	1.1%	4.2%	4.4%	4.2%
	Unknown or missing (N)	3,829	15,041	46,232	120,877
<b>Ethnicity</b>	Non-Hispanic/Latino	88.3%	88.3%	87.9%	79.3%
	Hispanic/Latino	16.7%	11.7%	12.1%	20.7%
	Unknown or missing (N)	3,829	46,232	15,041	120,877
<b>Region</b>	Northeast	22.3%	25.0%	27.6%	20.1%
	Midwest	22.8%	25.2%	23.5%	19.7%
	South	31.6%	31.4%	26.7%	32.2%
	West	21.8%	18.0%	20.3%	25.3%
	Other / US territory	0.5%	0.5%	0.3%	1.4%

### Enrollment

		Down syndrome		Autism		Intellectual disability		Random sample	
		N=123,024		N=396,426		N=1,010,525		N=3,176,371	
		N	%	N	%	N	%	N	%
<b>Total Person Years (PY)</b>		820,273		2,277,565		6,879,001		12,384,921	
Median, Mean (SD)		7.2	6.5 (2.7)	5.4	5.5 (2.8)	7.8	6.6 (2.6)	2.7	3.3 (2.6)
<b>Continuously enrolled</b>		77,861	63.3	283,121	71.4	626,702	62.0	956,748	30.0
<b>Loss to follow-up</b>		13,214	10.7	35,380	8.9	146,314	14.5	1,384,630	43.6
<b>Deaths, deaths per 10,000 PY</b>		20,075	245.0	8,445	37.0	109,534	159.4	149,378	119.9

#### What we are studying:

**Outcomes:** Dementia, Sleep Apnea, Pregnancy, Mortality

**Health service uses:** Inpatient, Outpatient, Long term services, RX drug claims

**Policy:** Medicaid expansion, Home and community based service waivers, Policy changes, Enrollment types

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