In God We Trust, All Others Bring Data:

Getting the Information We Need to Improve the Care We Provide

Stephen Sulkes, MD
Strong Center for Developmental Disabilities
Division of Developmental-Behavioral Pediatrics
Golisano Children's Hospital
Rochester, NY

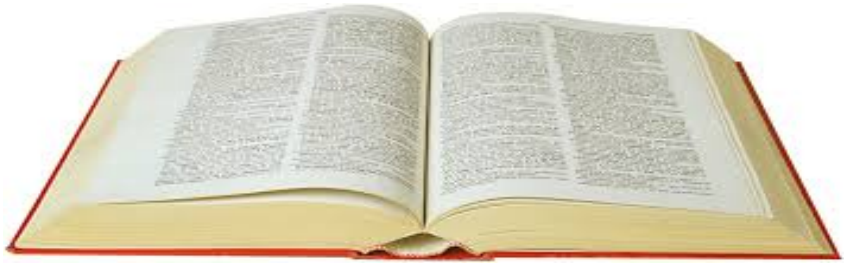
MEDICINE *of* THE HIGHEST ORDER

UNIVERSITY *of* ROCHESTER MEDICAL CENTER

Definition: Health Disparities (Healthy People 2020)

Differences in health due to racial, ethnic, religious, sexual orientation, socioeconomic, gender or **disability** status of a group of people

(previously termed "Inequities")



Definition: Intellectual Disability (AAIDD)

"A disability characterized by significant limitations both in **intellectual functioning** and in **adaptive behavior**, which covers many everyday social and practical skills. This disability originates before the age of 18."

Intellectual Function: Low IQ

Adaptive Behavior

Conceptual Skills: language, literacy, money, time, number, self-direction

Social Skills: interpersonal, gullibility, social problem solving, ability to follow rules

Practical Skills: ADL, Occupational, Healthcare, transportation, phone and money use

Definition: Developmental Disability (US DD Act)

A severe, chronic disability of an individual **5 years of age or older** that:

1. Is attributable to a mental or physical impairment or combination of mental and physical impairments;
2. Is manifested before the individual attains **age 22**;
3. Is likely to continue indefinitely;
4. Results in substantial functional limitations in **three or more** of the following areas of major life activity:
    A. Self-care;
    B. Receptive and expressive language;
    C. Learning;
    D. Mobility;
    E. Self-direction;
    F. Capacity for independent living; and
    G. Economic self-sufficiency.
5. Reflects an individual's **extended need** for…[coordinated services and supports].

Definition: Developmental Disability (NY State)

A severe, chronic disability of an individual **5 years of age or older** that:

1. is attributable to one of these:

a. Intellectual disability, cerebral palsy, epilepsy, neurological impairment, or autism;

b. Any other condition found to be closely related to mental retardation [sic] because such condition results in similar impairment of general intellectual functioning or adaptive behavior and a need for similar treatment and services

c. Dyslexia resulting from a disability as described above.

2. Originates before the age of 22
3. Has continued or can be expected to continue indefinitely
4. Constitutes a substantial handicap to such person's ability to function normally in society

(from Section 1.03 of the New York State Mental Hygiene Law)

History Lesson #1:
People with Intellectual Disabilities in Institutions

Norway, ~1935

- Ferric Chloride Testing of urine of 430 institutionalized people reveals 8 with PKU

Willowbrook, 1972:

- Crowding
- Inhumane Conditions
- Hepatitis Research
- Robert Kennedy and Geraldo Rivera
- Better Health Care Through Litigation

A Positive Ferric Chloride Test in Patients With Untreated PKU

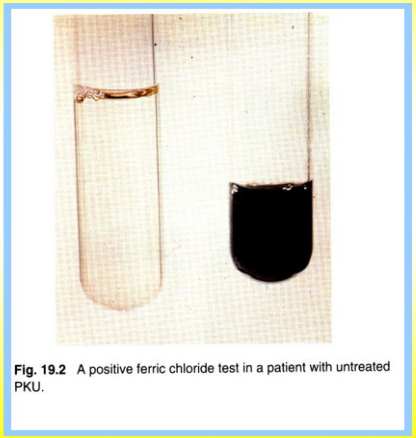


Fig. 19.2 A positive ferric chloride test in a patient with untreated PKU.

History Lesson #2: Down Syndrome Through the Ages

John Langdon Down, 1860

- Notes similar features in >10% of his patients at Royal Earlswood Asylum for Idiots
- Theorizes evolutionary "regression"
- Terms the condition "Mongolian idiocy"

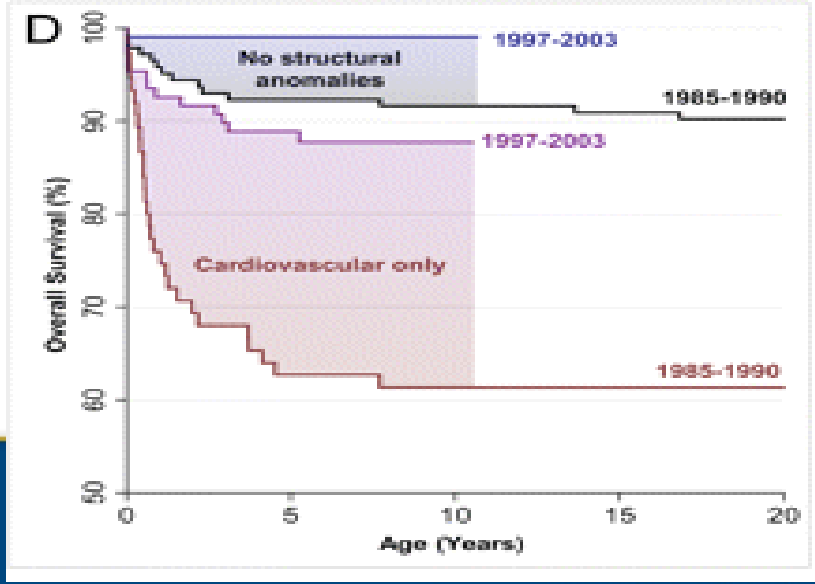
Gautier / LeJeune, 1958-9

- Demonstration of extra chromosome
- Demonstration that it's #21

Life Expectancy, 1983: ~25 years

Life Expectancy, 1993: ~55

Life Expectancy, 2017: ~60



Health After De-Institutionalization

2002: Janicki, Davidson, et al

- 1371 Adults over age 40 living in "Group Homes" of 4-15 adults in Western NY; **Reporting by residence nurses**
- Mean age: 53.5 +/- 11.1 years
  53% Male
  55.8% Obese
- Comparable to NHANES III data, except in
  Hypertension & hyperlipidemia
  Musculoskeletal disease
- **16% Hospitalized in past year**
  30% ED use in past year

Dental Survey: 2013

Special Olympics
Special Smiles®

Identified significant disparities in oral health for people with IDD in Finger Lakes region, based on surveys of dentists and of group home providers.

Results:

New training options

IDD Smilemobile

Special Olympics: US Data

Table 1. Comparative health indicators between Special Olympics athletes and the general population in the United States (2007-2014)

Indicator (Age)	Special Olympics athletes (%)	General population (%)
Mouth pain in Special Olympics athletes and general population (pain in face and jaw) (18+)	11.7	4.8[1]
Untreated Tooth Decay in Special Olympics athletes and general population (18-64)	25.6	23.7[1]
Missing teeth in Special Olympics athletes (missing teeth) and general population (broken or missing teeth) (18+)	32.7	16.9[2]
Hearing problems in Special Olympics athletes (Failed puretone hearing exam) and general population (any hearing problems) (12+)	29.6	16[3]
Exposure to second hand smoke in Special Olympics athletes (self-reported) and general population (serum cotinine levels 0.05-10 ng/ml) (12+)	36.2	25.3[4]
Obesity in Special Olympics athletes and general population – **(BMI≥30)** (20+)	42.3	35.5[3]
Overweight or Obese in Special Olympics athletes and general population – **(BMI≥25)** (20+)	73.7	69.1[3]
Sufficient Aerobic activity in Special Olympics athletes and general population. **(3 or more days per week)** (18+)	64.2	49.6[1]
Insufficient Aerobic activity in Special Olympics athletes and general population **(1-2 days per week)** (18+)	31.1	20.2[1]
Inactive - Aerobic activity in Special Olympics athletes and general population**(No days per week)** (18+)	4.7	30.2[1]

Strong Center for Developmental Disabilities: Western New York's UCEDD

- SCDD focus areas: Education / Employment / Health / Leisure / Recreation

- Health Disparities Focus
  - Identify and address health disparities for people with I/DD
  - Optimize community-based care to reduce disparities and health care costs
  - Part of Medical Center-wide effort to address health for people with IDD

University of Rochester IDD Leadership Council

Mission: Make URMC the best health care facility and Rochester the healthiest community for people with IDD across the lifespan

- Regional Health Care Delivery
  - Primary
  - Secondary / Tertiary
  - Oral Health
- Training
- Research
  - Basic / Clinical / Public Health

Challenges to Data Gathering

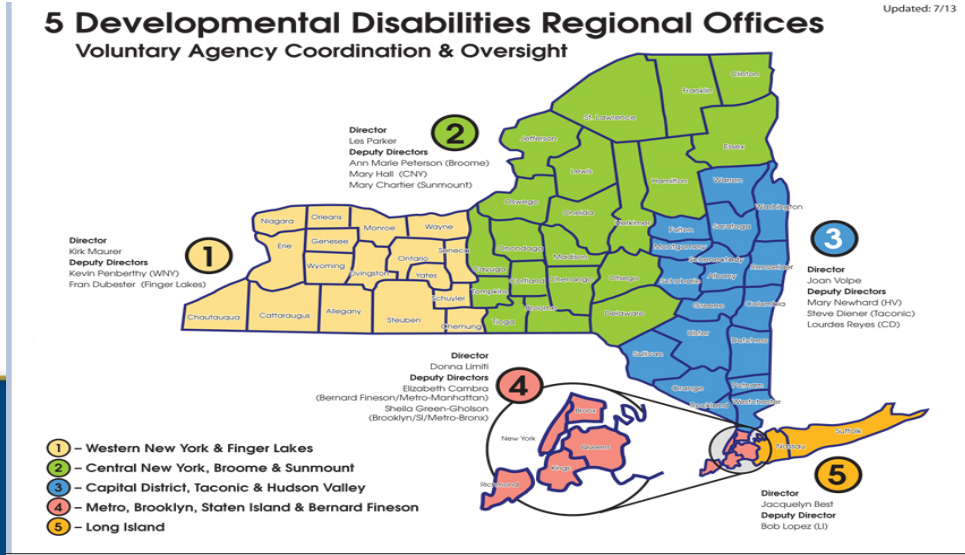
- Medicaid data inconsistently accessible → "-95" Medicaid Codes
- Health facilities don't code for IDD diagnoses → Accurate Problem Lists!
- DD system doesn't keep good accessible health data (paper records)
- Health data and functional data in separate places
- Bureaucratic impediments

→ DD Electronic records, RHIO

- Confidentiality issues → Own Your Problem List

Access to Health and Dental Care

- Establish baseline of access to health and dental care for people with IDD in Western NY
  - Who are the providers and dentists who see people with IDD?
  - How far do people travel for care?



- Brief web-based survey of Medicaid Service Coordinators in 21-county region in NY
- 6,958 records
  - 5,553 via survey; 1,405 direct from 1 agency
  - (1,774 records provided direct but incomplete)

Final N higher than initial estimate of regional population from OPWDD…

Study population by age group and gender

	Pediatric (0-20)	Adults	Total
Female	262 (4%)	2405 (36%)	2667 (40%)
Male	1173 (18%)	2846 (43%)	4019 (60%)
	1435 (21%)	5251 (79%)	**6948**

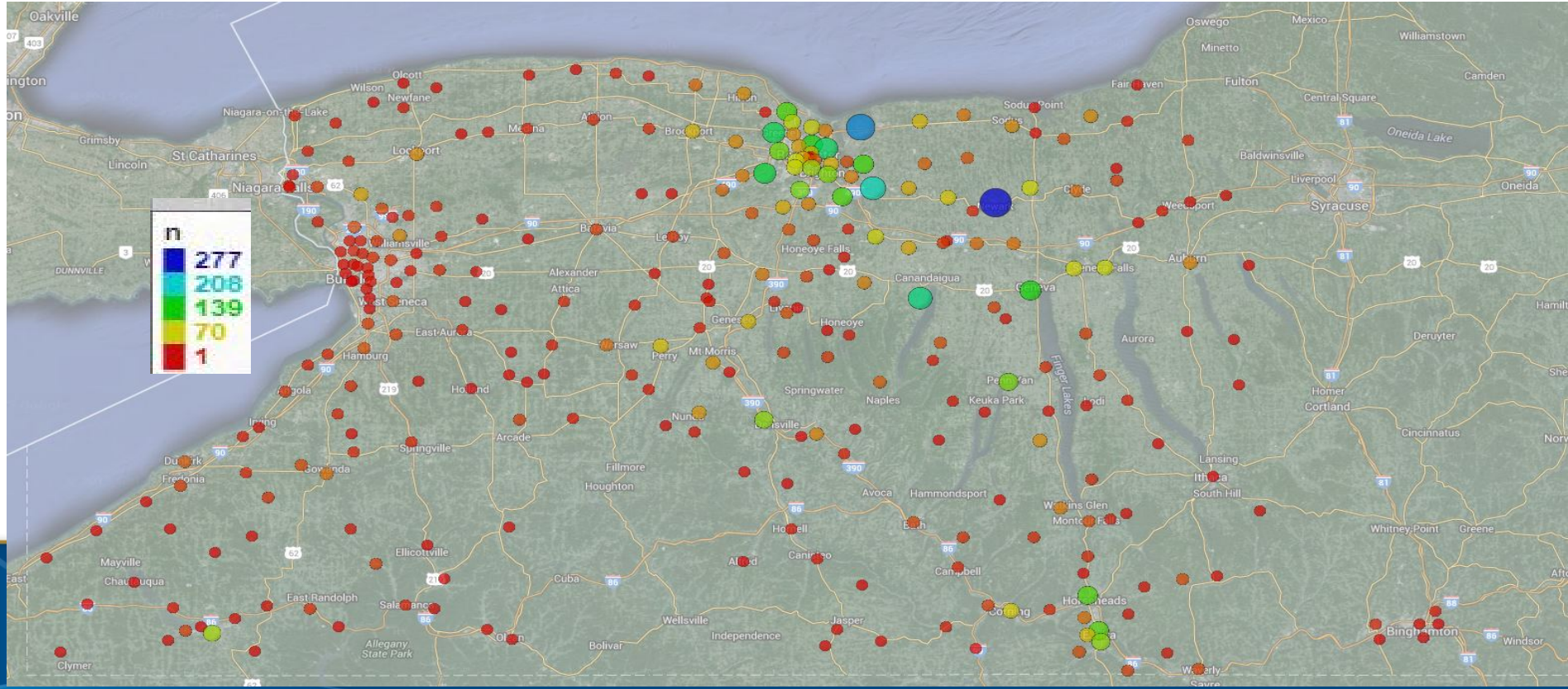
No PCP or No Dentist

	Pediatric (0 to 20)	Adult	Total
No PCP	10	41*	51 (<1%)
No Dentist	256	378*	634 (9%)

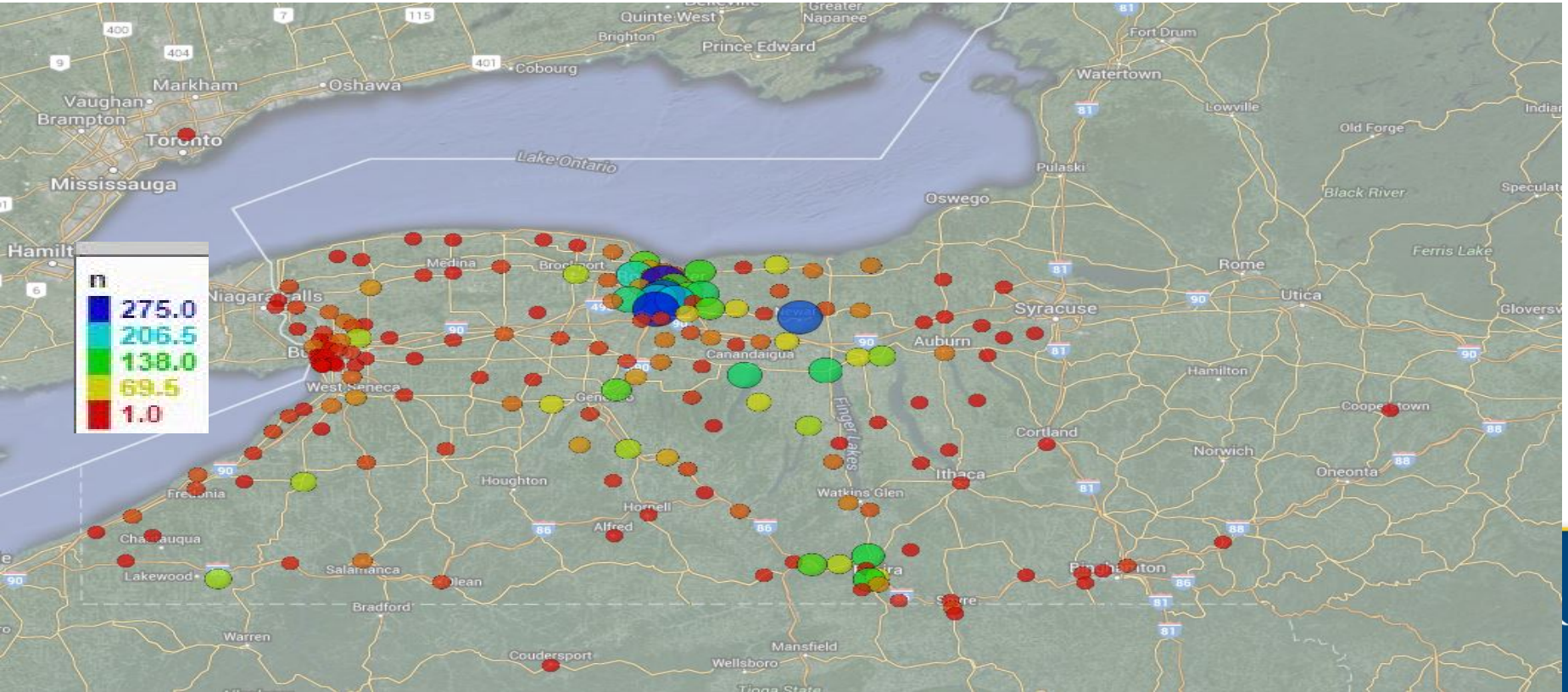
*Transition issue?

About 40% of the adults with no PCP or no dentist were aged 21-30

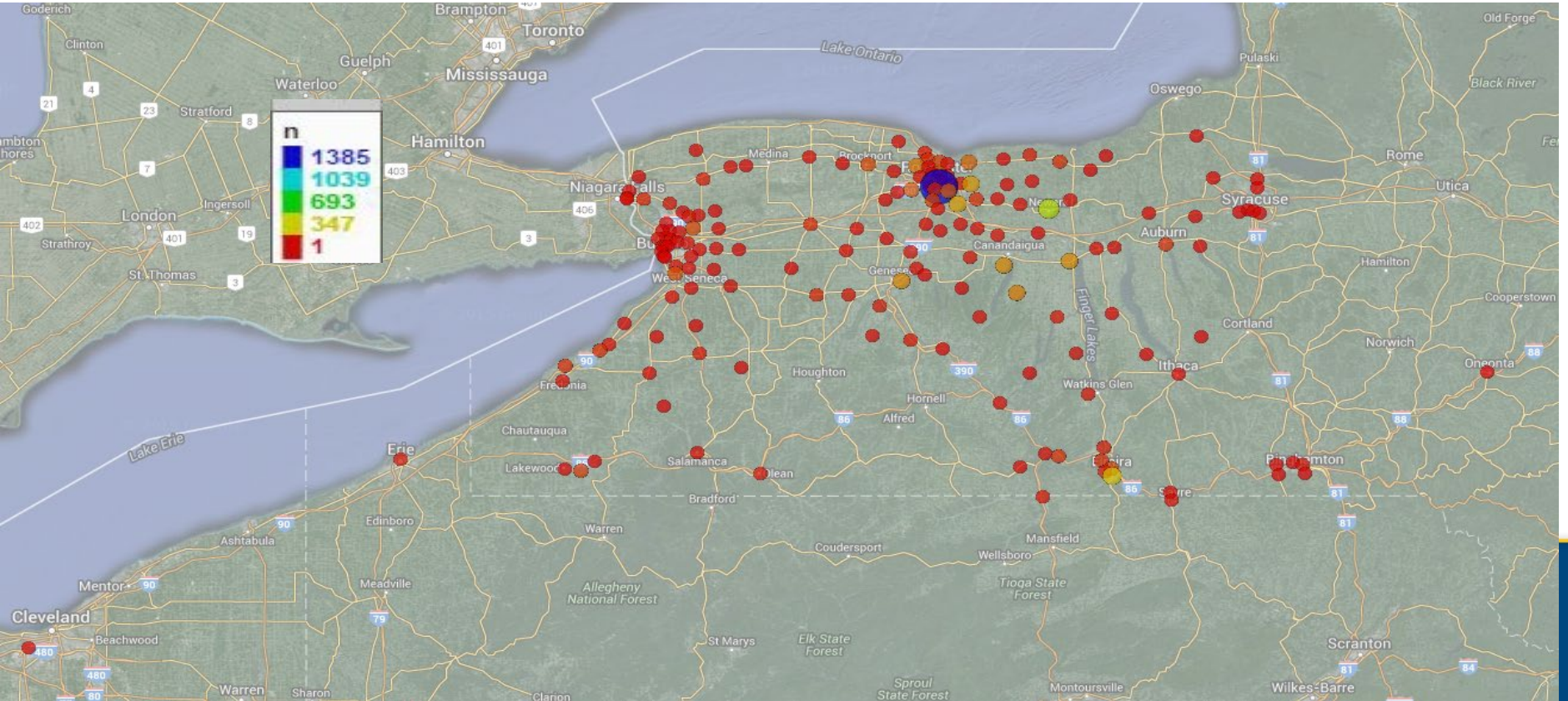
Where the people are



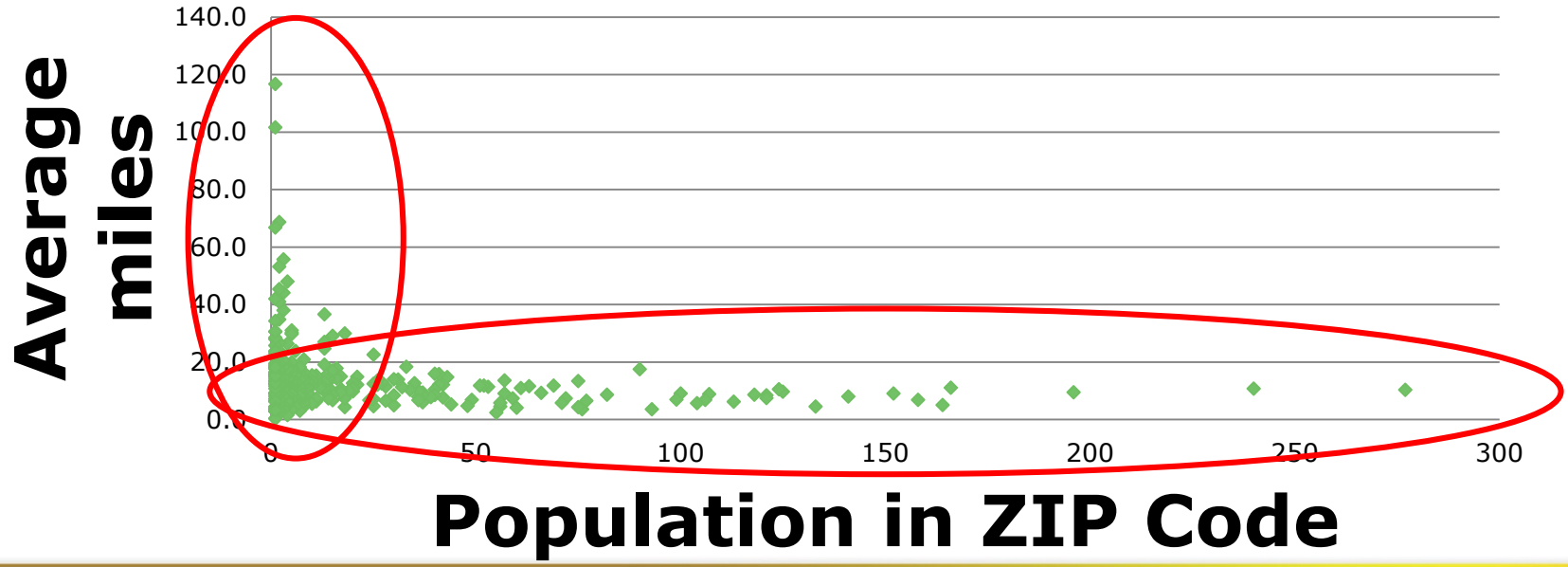
Where the primary care providers are



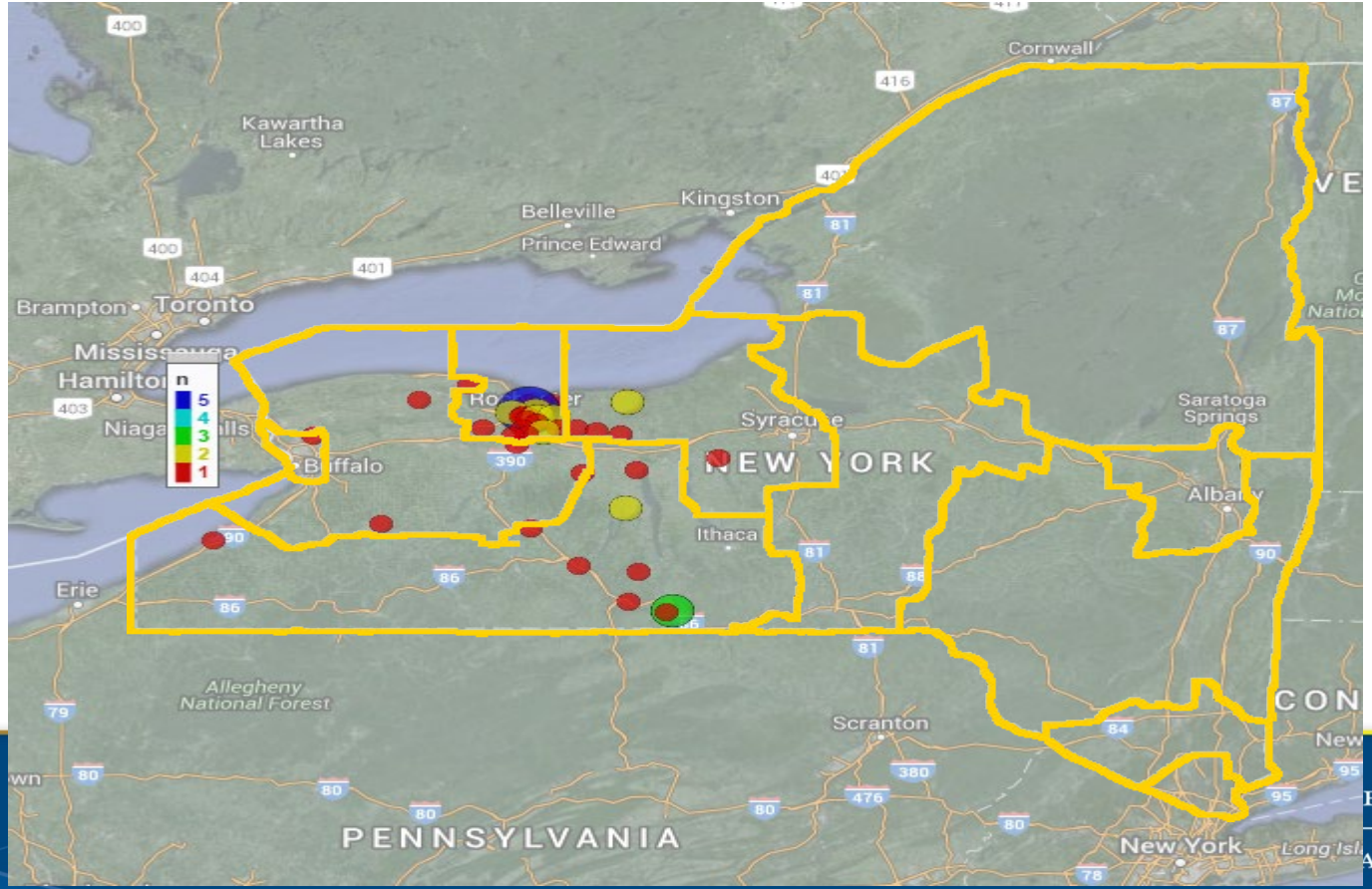
Where the dentists are



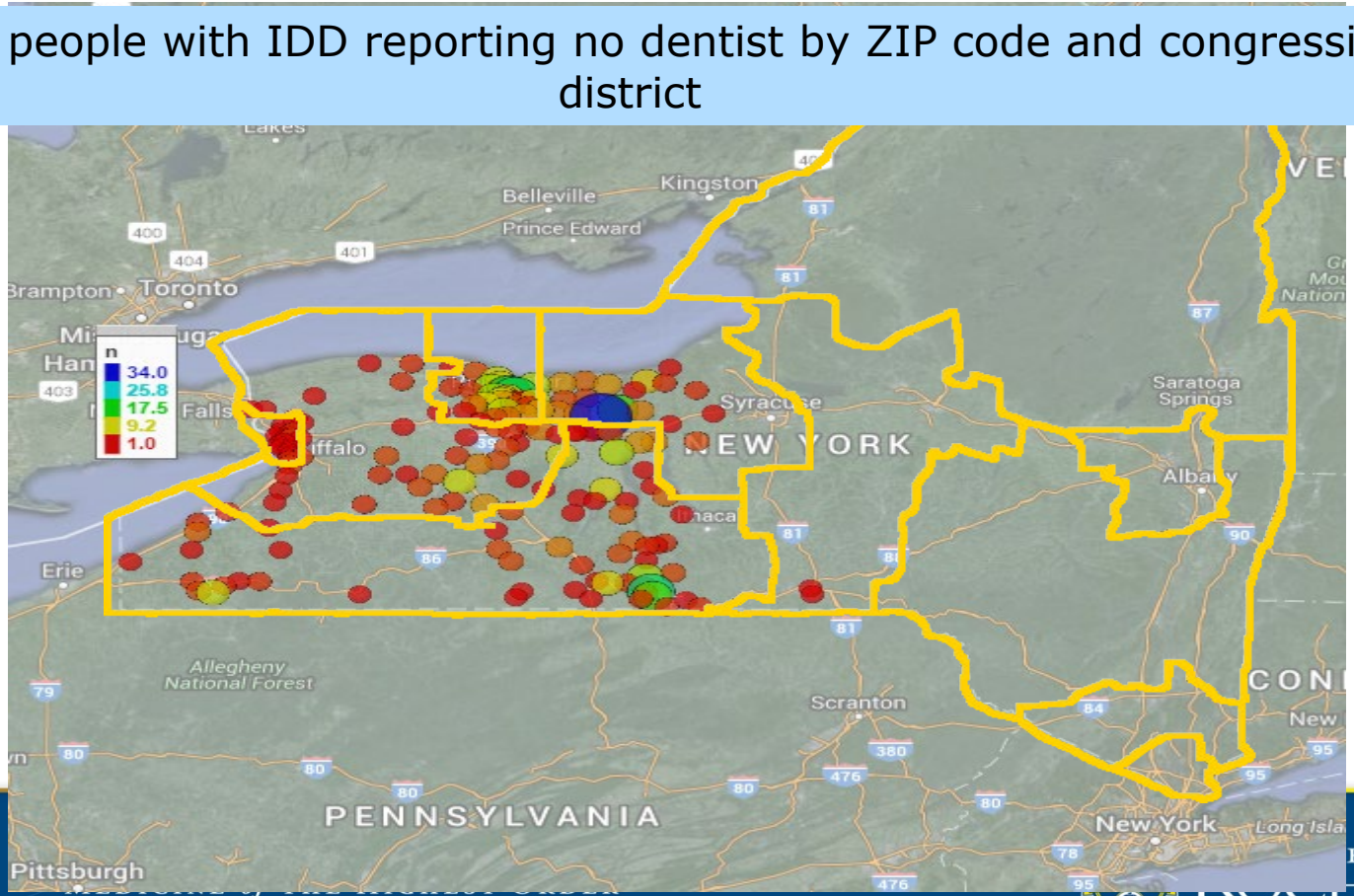
Average miles to PCP by population in ZIP Code



Count of people with IDD in the reporting NO primary care provider by ZIP code and congressional district



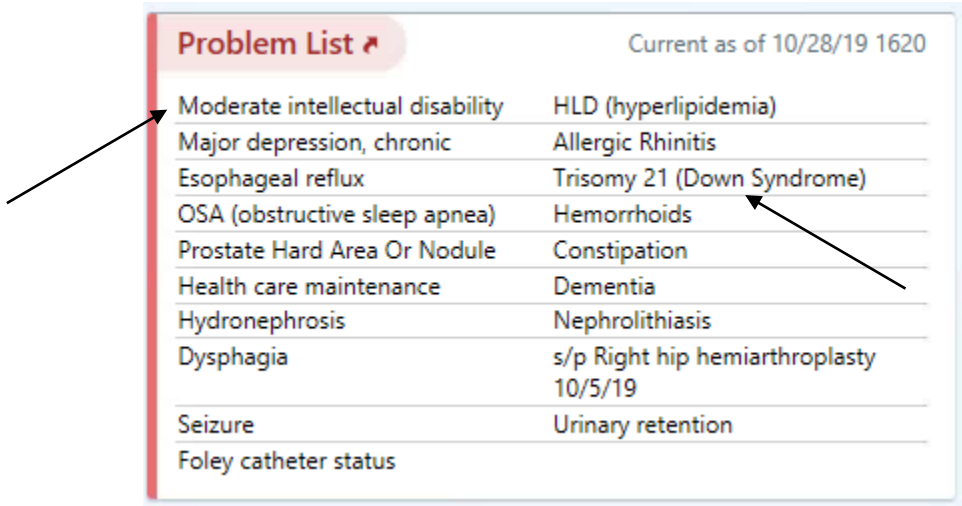
Count of people with IDD reporting no dentist by ZIP code and congressional district



Next Steps

- Does access to care differ by gender, age, residential setting, additional insurance?
- Identify community vs specialty settings
- Comparison group for distance and duration
- Outreach to identified PCPs and dentists for training opportunities; Provider needs assessment
- Share data with OPWDD and agency stakeholders
- Use data for other studies/grant applications
- Use location-specific data when meeting with government representatives (MUP)
- Expand data collection Statewide? Nationwide?

Helpful Problem Lists!



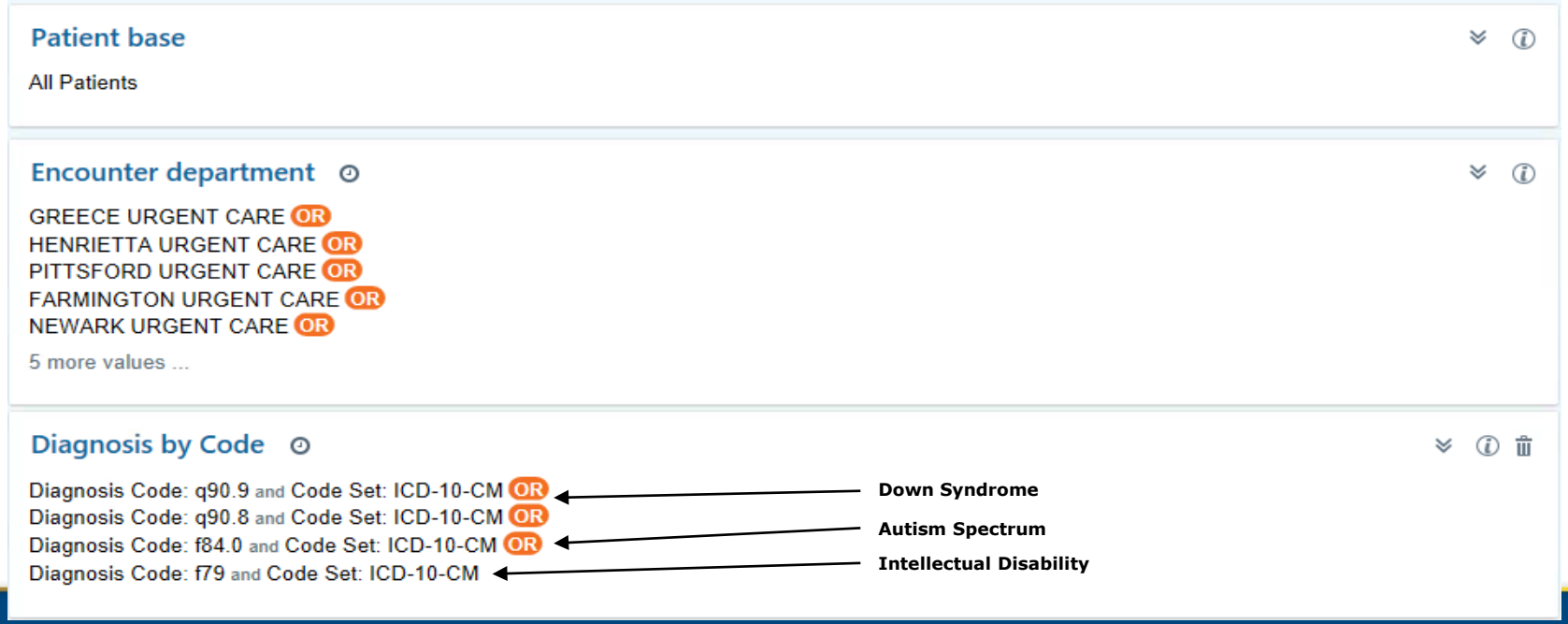
Problem List Current as of 10/28/19 1620

Moderate intellectual disability	HLD (hyperlipidemia)
Major depression, chronic	Allergic Rhinitis
Esophageal reflux	Trisomy 21 (Down Syndrome)
OSA (obstructive sleep apnea)	Hemorrhoids
Prostate Hard Area Or Nodule	Constipation
Health care maintenance	Dementia
Hydronephrosis	Nephrolithiasis
Dysphagia	s/p Right hip hemiarthroplasty 10/5/19
Seizure	Urinary retention
Foley catheter status	

Medical History

Diagnosis	Date	Comment	Source
Allergy history unknown			Provider
Alzheimer disease			Provider
Anxiety disorder			Provider
Atypical chest pain			Provider
Cataract			Provider
Constipation			Provider
Depression			Provider
Down syndrome			Provider
Esotropia			Provider
GERD (gastroesophageal reflux disease)			Provider
Hemorrhoids			Provider
Hyperlipemia			Provider
Obstructive sleep apnea			Provider
Osteoarthritis			Provider
PNA (pneumonia)			Provider
UTI (urinary tract infection)			Provider

Sample Search



SUCCESSFUL TRANSITION FOR PEDIATRIC TO ADULT SERVICES

- Many adults with special health care needs have difficulty making the transition from pediatric to adult health services.
- Clinically, it has been observed that individuals with behavioral challenges may have even greater difficulty than others in connecting with adult health services.

Purpose

- Explore factors associated with successful transition and transfer to adult health services for individuals with IDD and other special health needs

Hypotheses: Individuals with IDD and significant behavior problems…

- Will be less likely to have successfully transitioned health care to adult providers
- Will be more likely to have dental work under general anesthesia

Methods

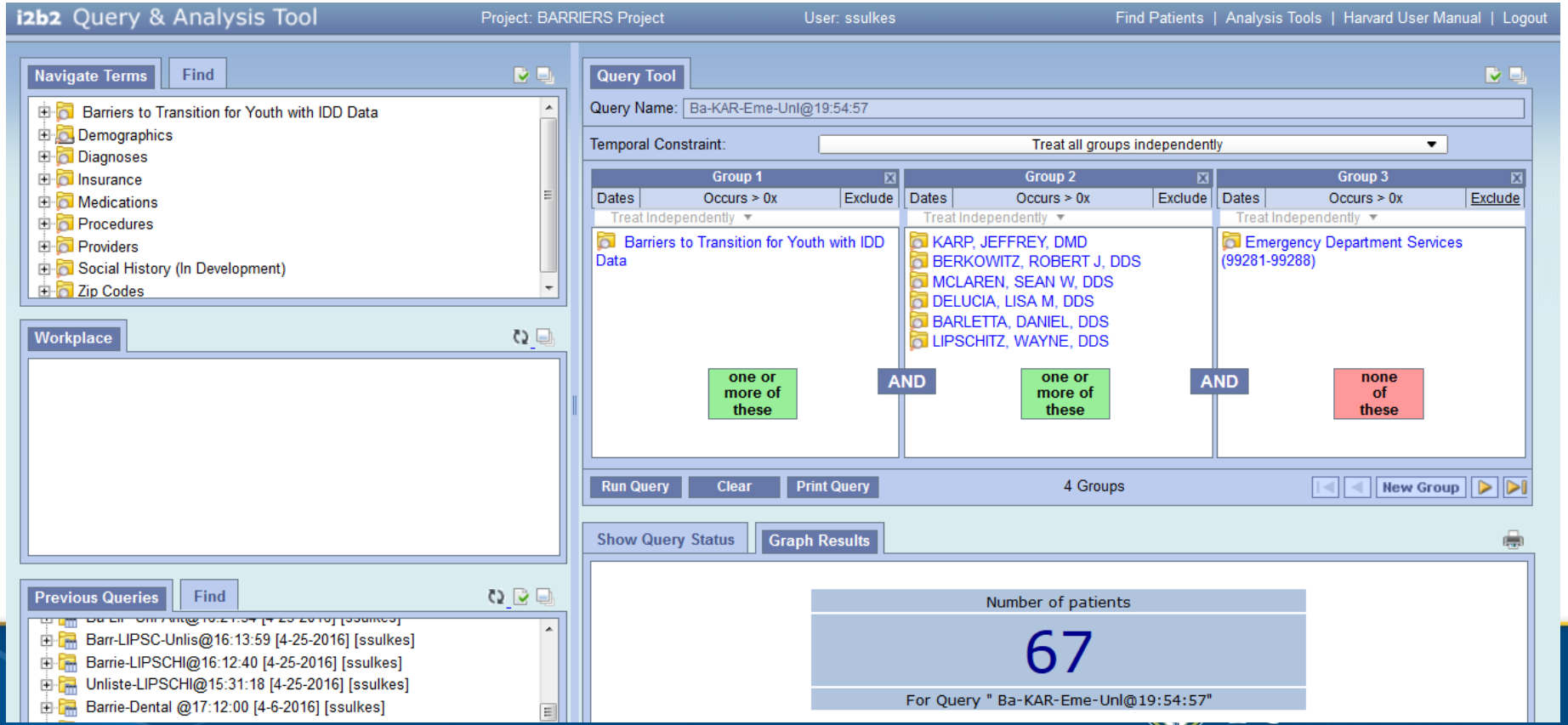
- The Epic i2b2 data tool was used to extract de-identified data from patients served at URMC between the implementation of Epic and 9/30/15, when ICD-10 coding was instituted
- Subjects were patients age 12-30 years with an IDD diagnosis identified
- Demographic data were noted
- Independent variable: use of behavioral medication
- Dependent variable 1: current primary physician
- Dependent variable 2: dental care under general anesthesia

IDD Diagnoses

ICD-9	
277.5	Mucopolysaccharidosis
277.8x	Carnitine and metabolic myopathies
299.x	ASDs
315.x	Learning disability
317.x	Mild ID
318.x	ID, moderate or greater
319.x	ID, unspecified
330.x	Degenerative CNS disease
331.4	Hydrocephalus
333.7	Cerebral Palsy
335.21	Dystrophies
343.x	Cerebral Palsy
345.x	Epilepsy
359.0, 359.1, 359.21	Muscular dystrophies

ICD-9	
740.x	Brain malformations
741.x	Spina Bifida
742.x	Brain malformations
756.17	Spina bifida occulta
758.x	Trisomies and other chromosome anomalies
759.5	Tuberous sclerosis
759.81	Prader-Willi
759.83	Fragile X
759.89	Other genetic syndromes
760.71	Fetal alcohol
V79.2	"Mental retardation"
V79.3	Developmental handicap in childhood
V79.9	Mental handicap

Sample Search



Results

- The variable of being on psychotropic mediation as a proxy for behavioral problems does not correlate with delayed transition to adult primary health services
- % of participants on/off medications comparable and not stats significant
- Average age of the groups are the same from the group where they came … not staying older with pediatricians
- Use of psychotropic meds did significantly correlate with use of GA for dental work

Doubling Down: Health Disparities in People with IDD from Minority Populations

Mangaña et al, 2016: MEPS / NHIS dataset analysis

- 1131 Adults with IDD, nationwide
- IDD identified based on **self-reported** functional and diagnostic reporting (MR/ID, CP or other developmental problem)
- Compared people with IDD +/- minority status and people with minority status +/- IDD

People with/without IDD	Non-Latino White	Non-Latino Black	Latino
Fair/Poor Health	23.2 / 3.4%	40.6 / 7.0%	44.9 / 6.6%
Fair/Poor Mental Health	24.4 / 3.9%	37.8 / 4.5%	42.3 / 3.8%
BMI>30	32.7 / 24.5%	39.2 / 36.3%	40.3 / 28.1%
Diabetes	5.3 / 4.3%	8.6 / 6.7%	10.9 / 5.3%

Policy Advocacy Opportunity: People with IDD as a Medically Underserved Population (MUP)

HRSA identifies MUPs based on a score based on:

- ratio of primary care physicians to population;
- infant mortality rate (IMR);
- percentage of the population which is age 65 and over; and
- percentage of the population with incomes below the poverty level
- Geographic delimiter:
  - Local
  - State
  - National?

- Need: Data comparing population with IDD to comparable group within geographic area.

Proposal: HEADs UP bill (H.R. 2417)

RE-Introduced by Rep. Seth Moulton (D-MA), co-sponsor Brian Fitzpatrick (r-PA)

- Other co-sponsors to date: Sean Maloney, Jose Serrano, Joe Morelle, Sheila Jackson Lee, Josh Harder, Paul Tonko, Peter Visclosky, John Katko (5 from NYS!!)
- House Energy and Commerce Committee

Bill to designate people with idd as a "Medically Underserved Population"

- Loan forgiveness for providers focusing on IDD population
- Federally Qualified Health Clinic (FQHC) status for centers serving people with IDD, and encouragement for current FQHC's to serve this population better
- Enhanced visa status for foreign-trained providers serving population
- Encourages research benefiting population with IDD at NIH

National advocacy for re-introduction needed!

→ If you're going to the Hill, talk about it, or refer people to Steve Sulkes

Summary

- Common sources of health care delivery data are often not useful for study of people with IDD
- Data from the DD system, Electronic Health Records, and from national datasets can provide valuable insights to health and health delivery for this population