



Baylor
College of
Medicine

Geographic and Socioeconomic Disparities in Access to Care for Adult Congenital Heart Disease Patients

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No disclosures

Background

- The adult congenital heart disease (ACHD) population is growing
 - Increased by 54% from 2000-2010
 - 2010 U.S. estimate: 1.4 million
- ACC/AHA recommend follow up at a regional ACHD center
 - At least every 12-24 months for moderate, complex disease
- ACHD center accreditation: 17 centers approved
 - Offered by Adult Congenital Heart Association (ACHA)



Marelli et al (2014). *Circulation*.
Gilboa et al (2016). *Circulation*.
Warnes et al (2008). *J Am Coll Cardiol*.
<https://www.achaheart.org/provider-support/accreditation-program/> Accessed 10 Feb 2018.

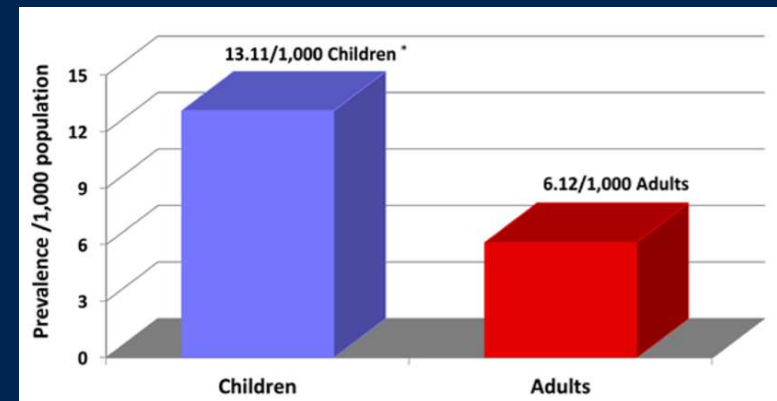
Study aims

1. Estimate ACHD population in the U.S.
2. Identify mid- to high-volume ACHD centers
3. Describe the distribution of patient driving times to ACHD centers
4. Evaluate specific socioeconomic factors that may compound challenges in accessing ACHD care

Methods

Estimating the ACHD population

- No U.S. prevalence estimates exist
- Key assumptions:
 - Geographic distribution of ACHD \approx general population
 - ACHD prevalence in U.S. \approx Canada
- Population data source: 2015 American Community Survey (ACS) 5-year estimate
 - Continuous data collection by U.S. Census Bureau
 - Socioeconomic factors: insurance status, household poverty, educational attainment



Marelli et al (2014). *Circulation*.
Langlois et al (2010). *J Rural Health*.
Langlois et al (2008). *Birth Defects Res A Clin Mol Teratol*.
<https://www.census.gov/programs-surveys/acs/> Accessed 10 Feb 2018.

Identifying ACHD centers

- No list of ACHD regional centers exists
- ACHD center data source: ACHA directory
 - Self-reported clinic, surgery, provider information
 - Publicly available
 - Used in 2010 study to describe ACHD workforce
- ACHD center database created using 2016-2017 clinic data
 - Clinic and affiliated hospital locations
 - Annual clinic visits, ACHD surgeries

Pediatr Cardiol (2010) 31:511–514
DOI 10.1007/s00246-009-9629-5

ORIGINAL ARTICLE

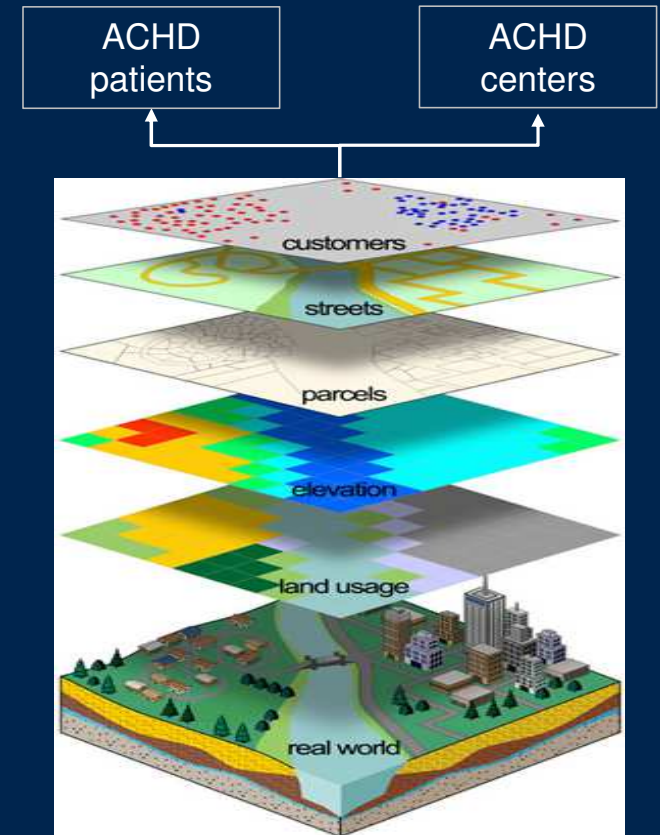
Care of the Adult Congenital Heart Disease Patient in the United States: A Summary of the Current System

Manisha S. Patel · Brian E. Kogon

Warnes et al (2008). *J Am Coll Cardiol*.
www.achaheart.org/your-heart/clinic-directory/ Accessed 10 Feb 2018.
Patel and Kogon (2010). *Pediatr Cardiol*.

Geographic Information System (GIS) mapping

- A GIS is designed to capture, analyze, and present data that have been spatially referenced to a location on earth
- County-level ACS data used
 - Ideal geographic level for national U.S. mapping
- Analysis limited to continental U.S.
 - No ACHD centers in AK, HI: cannot drive to center



Results

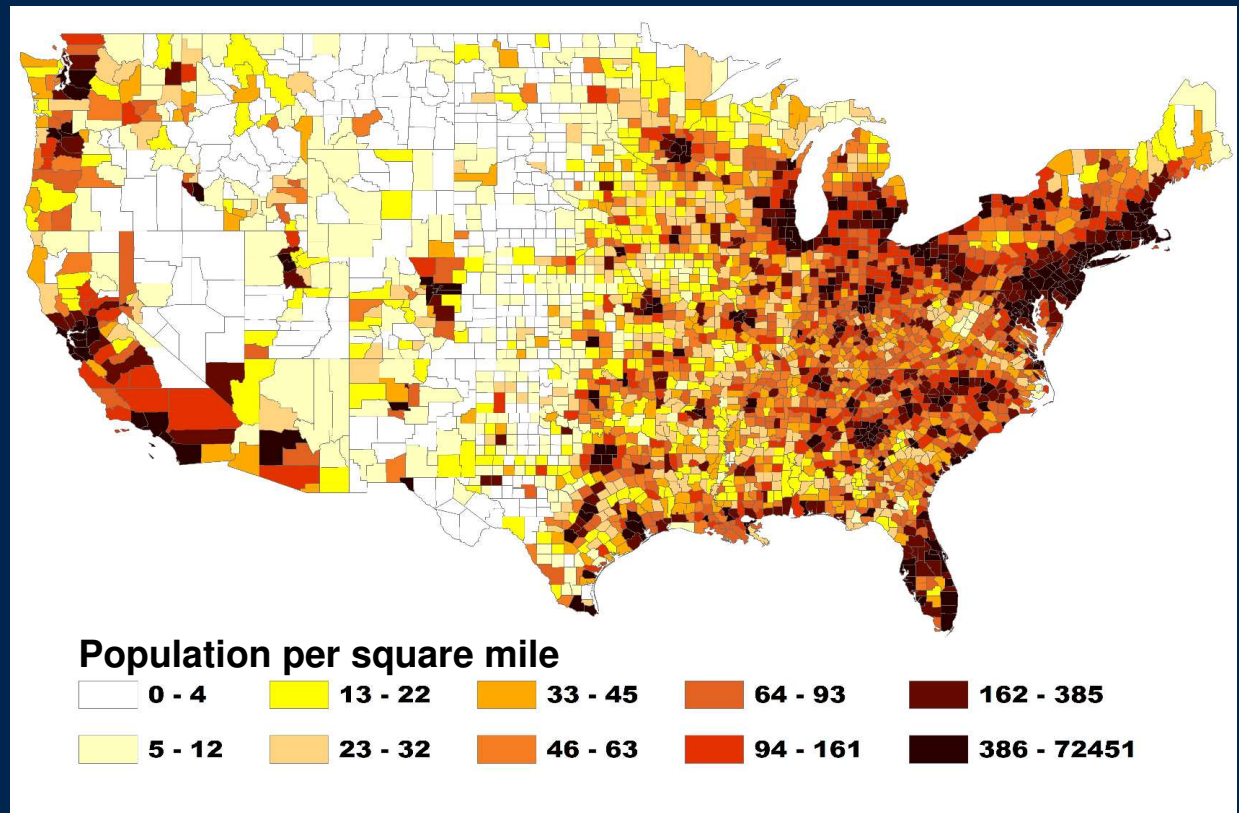
2015 U.S. ACHD population

Estimated ACHD
population:

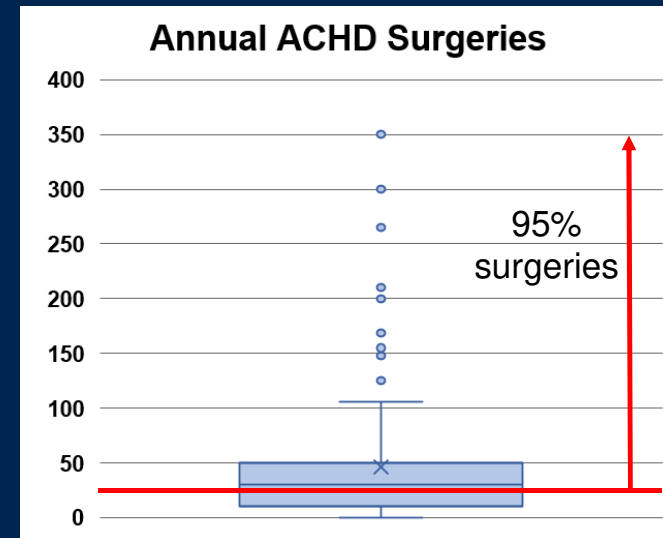
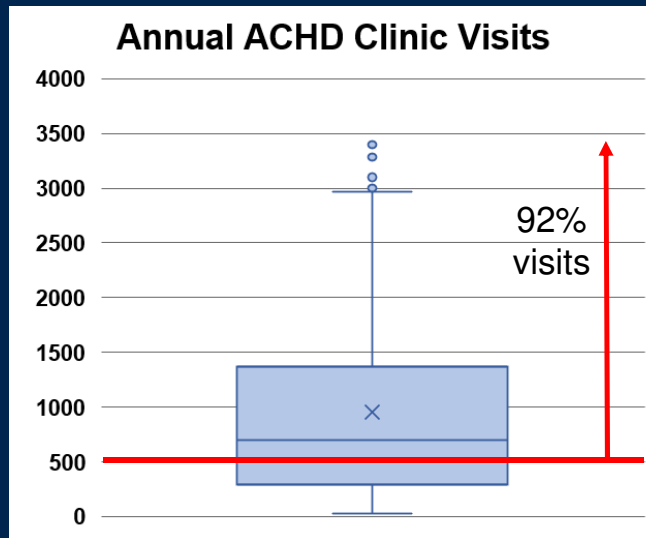
1,475,089

Estimated complex
ACHD population:

149,437

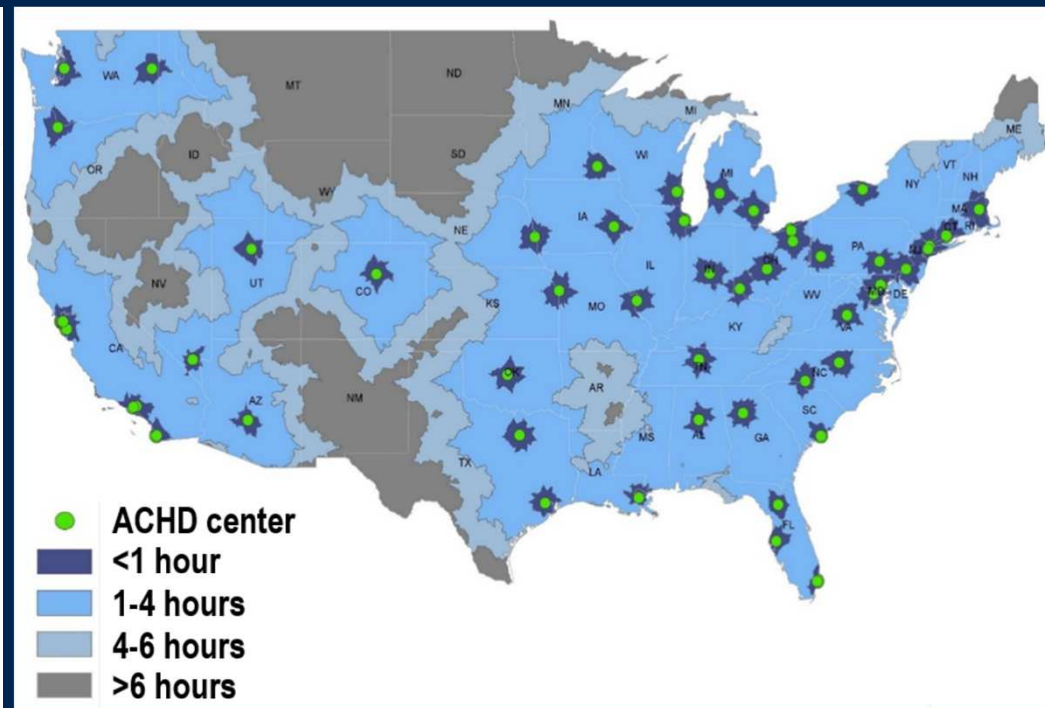
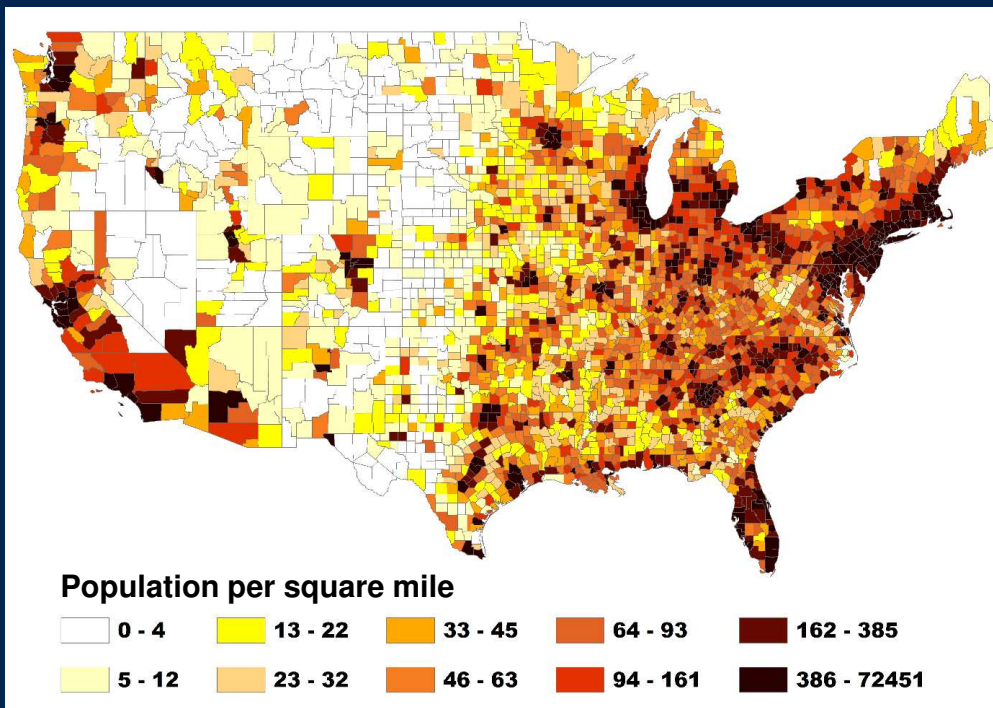


Identifying ACHD centers



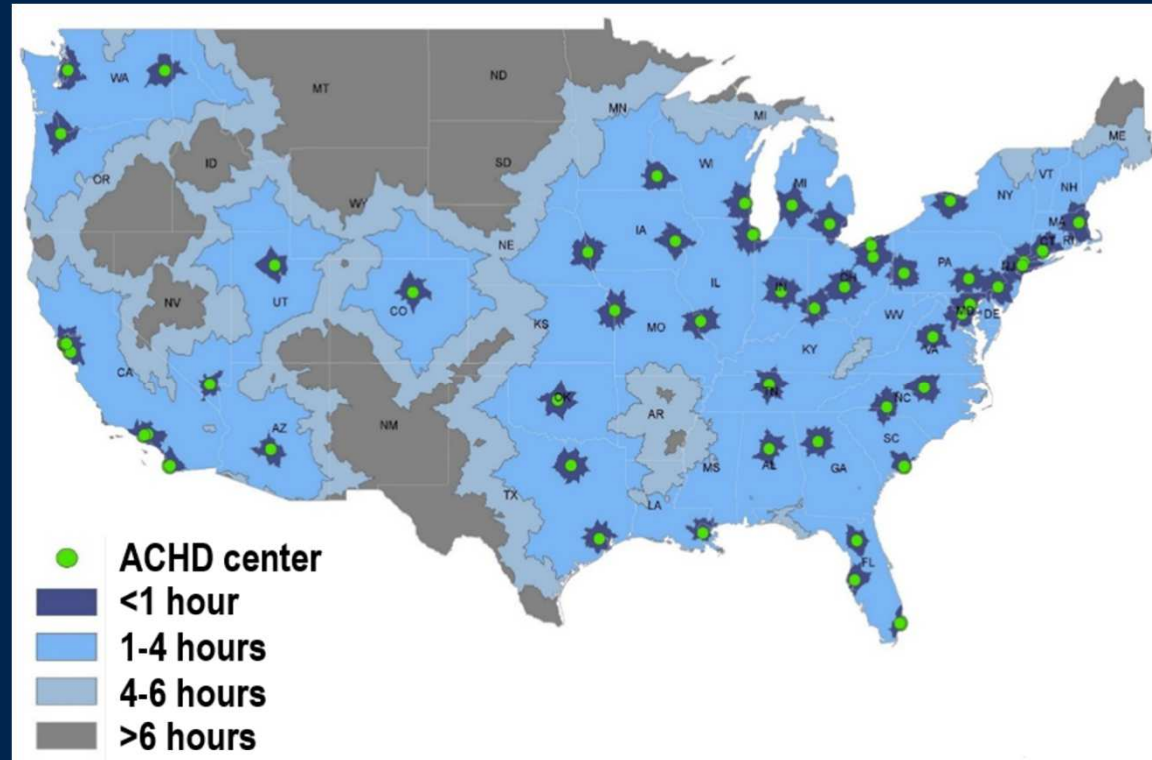
- Inclusion criteria: top 50% clinical and surgical volume annually
 - ≥ 500 ACHD clinic visits, ≥ 20 ACHD surgeries annually
- 56 mid- to high-volume centers identified

Driving time to ACHD centers



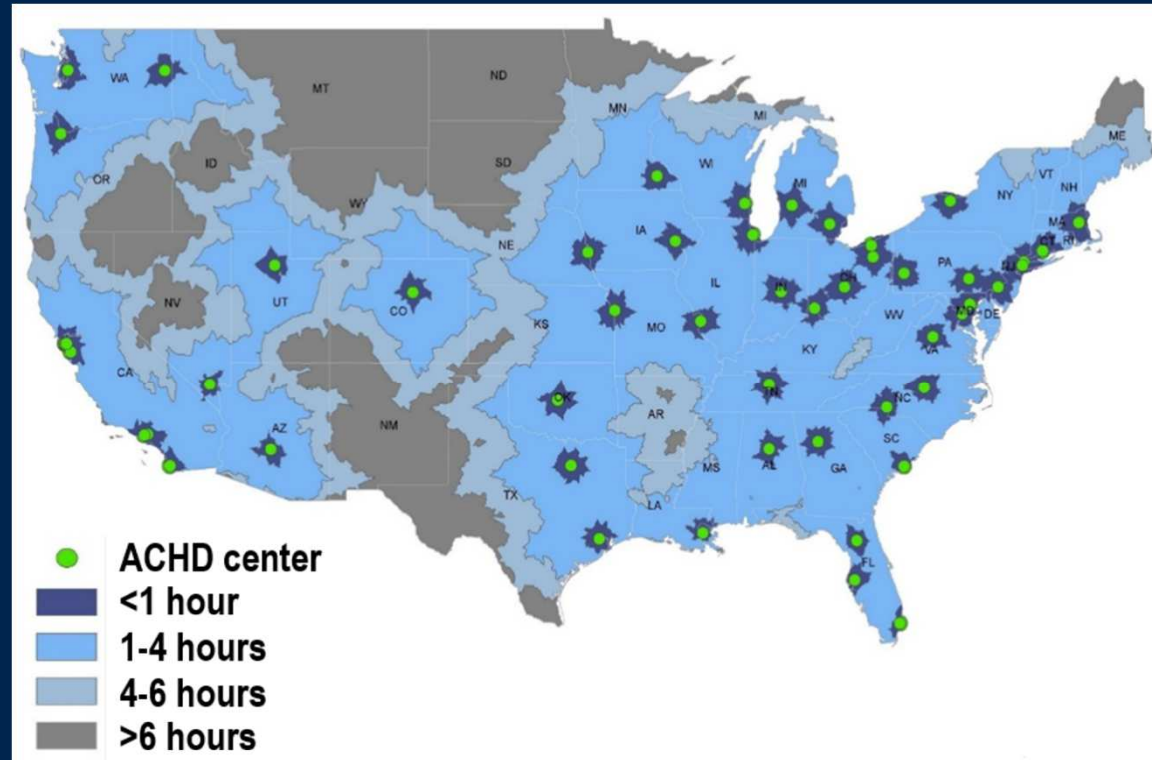
Driving time to ACHD centers

		% of total pop.	All ACHD N	Complex ACHD N
Driving time	<1 hour	54.9	809,215	81,979
	1-4 hours	39.7	586,305	59,396
	4-6 hours	3.4	49,956	5,061
	>6 hours	2.0	29,613	3,000



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Insurance status

Driving time to ACHD center								p-value
<1 hour		1-4 hours		4-6 hours		>6 hours		
N	%	N	%	N	%	N	%	
584,253	72.2	412,758	70.4	31,472	63.0	14,243	48.1	<0.001
224,961	27.8	173,547	29.6	18,483	37.0	15,369	51.9	
809,215		586,305		49,956		29,613		

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Household income

Driving time to ACHD center								p-value
<1 hour		1-4 hours		4-6 hours		>6 hours		
N	%	N	%	N	%	N	%	
704,017	86.8	492,496	84.5	41,462	82.8	23,987	81.1	<0.001
105,198	13.2	93,809	15.5	8,493	17.2	5,626	18.9	
809,215		586,305		49,956		29,613		

Household income

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Educational attainment

Driving time to ACHD center								p-value
<1 hour		1-4 hours		4-6 hours		>6 hours		
N	%	N	%	N	%	N	%	
291,317	35.7	149,684	25.5	11,490	22.9	7,107	24.3	<0.001
299,410	64.3	256,567	74.5	22,480	77.1	13,652	75.7	
809,215		586,305		49,956		29,613		

Educational attainment

Driving time to ACHD center								p-value
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809,215		586,305		49,956		29,613		

Summary

Conclusions

- ~1.5 million ACHD patients live in the U.S.
- 56 ACHD centers account for 92% of clinic visits, 95% of surgeries
- 45% of ACHD patients live >1 hour drive from an ACHD center
 - 5% live >4 hour drive
- Longer drive time to access ACHD care is associated with lower socioeconomic status

Limitations

- No national population-based registry for ACHD patients
- No external validation of ACHA center data
- Factors other than clinical and surgical volumes not evaluated in identifying ACHD centers

Future directions

- Validation of ACHD patient distribution estimates
- GIS analysis using:
 - Individual-based demographic data
 - Accredited ACHD centers
 - Board certified ACHD physicians
- Analysis of ethnic and racial disparities

Acknowledgments

CHD Disparities

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