Surgical Disparities in Cerebral Palsy or Equitable Surgical Outcomes in Cerebral Palsy

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The Great Paradox: That Exists In Our Current U.S. HealthCare System

- **The U.S. is one of the most technologically advanced in Healthcare in the World**

however,

- **When it comes to the Delivery of Healthcare, We are one of the worse amongst industrialized nations and the most expensive**

The Reality of Our Delivery System for Vulnerable Populations

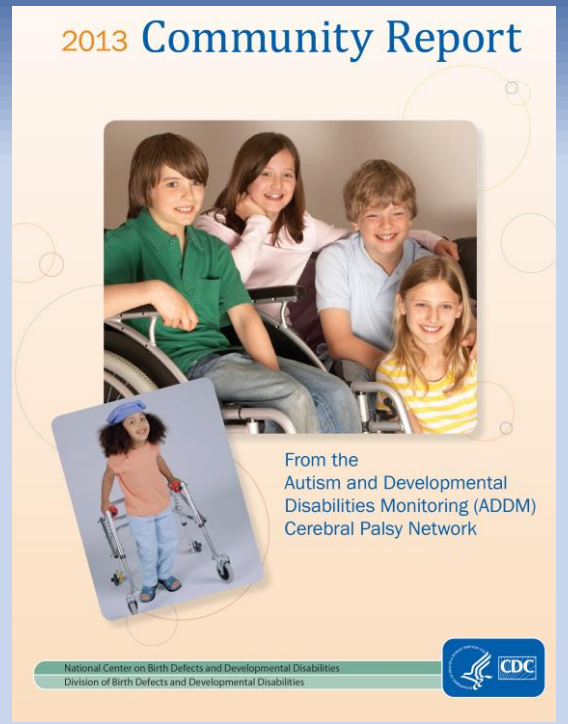
COUNTRY RANKINGS

Top 2*
Middle
Bottom 2*

	AUS	CAN	FRA	GER	NETH	NZ	NOR	SWE	SWIZ	UK	US
OVERALL RANKING (2013)	4	10	9	5	5	7	7	3	2	1	11
Quality Care	2	9	8	7	5	4	11	10	3	1	5
Effective Care	4	7	9	6	5	2	11	10	8	1	3
Safe Care	3	10	2	6	7	9	11	5	4	1	7
Coordinated Care	4	8	9	10	5	2	7	11	3	1	6
Patient-Centered Care	5	8	10	7	3	6	11	9	2	1	4
Access	8	9	11	2	4	7	6	4	2	1	9
Cost-Related Problem	9	5	10	4	8	6	3	1	7	1	11
Timeliness of Care	6	11	10	4	2	7	8	9	1	3	5
Efficiency	4	10	8	9	7	3	4	2	6	1	11
Equity	5	9	7	4	8	10	6	1	2	2	11
Healthy Lives	4	8	1	7	5	9	6	2	3	10	11
Health Expenditures/Capita, 2011**	$3,800	$4,522	$4,118	$4,495	$5,099	$3,182	$5,669	$3,925	$5,643	$3,405	$8,508

Notes: * Includes ties. ** Expenditures shown in $US PPP (purchasing power parity); Australian $ data are from 2010.
Source: Calculated by The Commonwealth Fund based on 2011 International Health Policy Survey of Sicker Adults; 2012 International Health Policy Survey of Primary Care Physicians; 2013 International Health Policy Survey; Commonwealth Fund *National Scorecard 2011;* World Health Organization; and Organization for Economic Cooperation and Development, *OECD Health Data, 2013* (Paris: OECD, Nov. 2013).

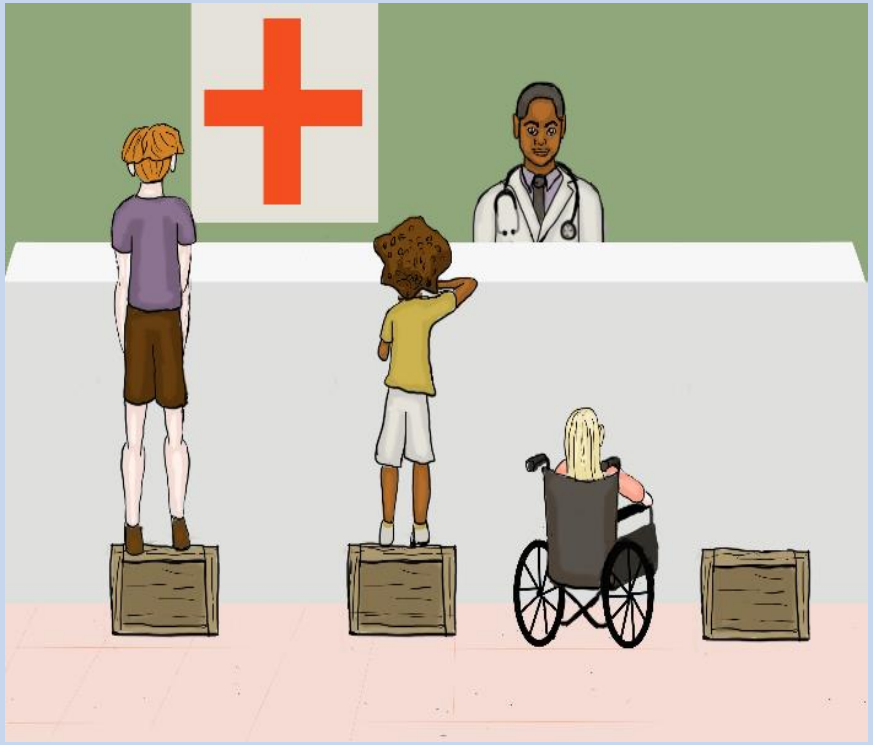
Cerebral Palsy: Background



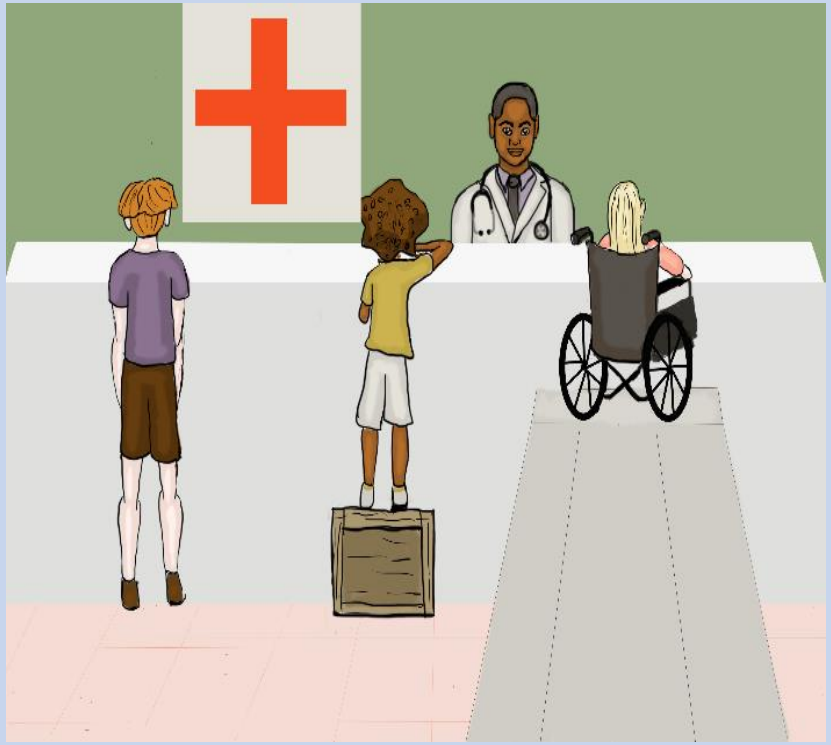
- CDC estimated that the combined lifetime costs for all people with CP who were born in 2000 will total $11.5 billion in direct and indirect costs

Conditions	Average medical costs (2005 dollars), per Medicaid-enrolled child, per year
Neither CP or Intellectual Disability	**$1,674**
CP Alone	**$15,047**
Both CP and Intellectual Disability	**$41,664**

Equality versus Equity



A) Equality is giving each individual equal resources regardless of need



B) Equity is giving individuals the necessary resources needed to achieve equal outcomes.

What Do We Know ?

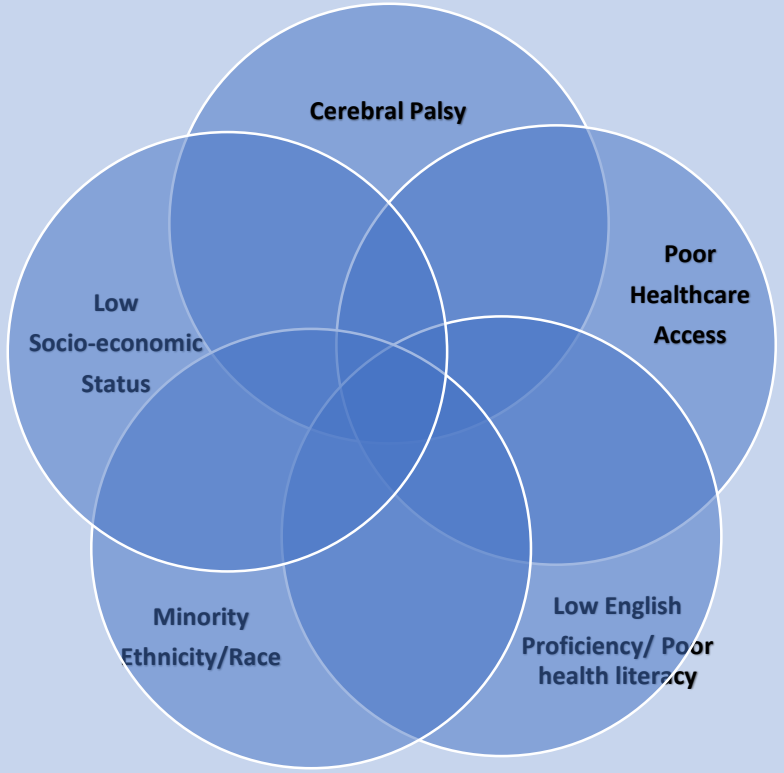
- Increase in cerebral palsy (CP) prevalence in non-Hispanic black infants (Van Naarden et al., 2016; Kirby et al. 2011; Wu et. al 2011; Yeargin-Allsopp 2008)
- Disparities found only in those with greater functional limitations (Maenner et. al. 2012)
- The distribution percentage for severe functional limitations (GMFSC, IV, and V) was found to be 70% higher in black children. (Maenner et. al. 2012)
- When both socioeconomic factors and prematurity were controlled for, there was a paradoxical reduced risk in black children, indicating the influence of these factors on CP prevalence (Durkin et. al. 2015)

What Do We Know?

- Low versus high socio-economic status was associated with 67% increased risk of developing overall CP and a 93% increased risk of spastic cerebral palsy (Durkin et. al. 2015)
- Both a decrease in maternal education and neighborhood socio-economic factors were associated with greater motor functional limitations in children with CP (Oskoui, 2016)
- Cerebral palsy children with mothers having lower than a high school education had a three times higher risk of being a GMFCS level 4 or 5

  (Oskoui, 2016)

Background: Overlapping Factors for Vulnerability to Poor Health in Children with CP



Risk Factors and the Cycle of Vulnerability in Children/Families with CP
(and other CSHCN with physical disability, and medical complexity)

The Child with Cerebral Palsy is often:

- medically complex, especially when there is greater motor involvement, therefore children with cerebral palsy are vulnerable to poorer health and heath-care outcomes, and higher medical costs.
- more prevalent in families with greater socioeconomic disadvantage making it more difficult for access to medical care, community resources, and access to durable medical equipment.
- also at risk for less educational opportunities, lower job opportunities with lower wages, decreased opportunities for social engagement,
- At greater risk for poor mental health

The Research Question and Null Hypothesis

- **Statement:** Little to No Data is Available on the presence of surgical disparities within the Cerebral Palsy Population

- **Research Question:** Do surgical disparities exist within the Cerebral Palsy population?

- **Null Hypothesis:** No Racial or Ethnic, Geographic Surgical Outcome Disparities Exist in the Cerebral Palsy Population

Potential Specific Aims

- Determine whether surgical outcome disparities exist within specific surgical procedures: **spinal fusion, hip reconstruction**, SEMLS, **Intrathecal Baclofen Implantation**. (complications, intended functional outcomes) exist in the cerebral palsy population).
- Determine whether racial and/or socioeconomic disparities in access to surgical services exist in the Cerebral Palsy population
- Determine whether racial and/or socioeconomic disparities in postoperative support services (e.g. community services, therapy services) exist in the cerebral palsy population
- Determine whether racial and/or socioeconomic exist in obtaining needed equipment postoperatively
- If any of the above racial and/or socioeconomic disparities exist, determine which if any social determinants of health are the greatest risk factors for: disparities in access to surgical services, surgical outcomes, and postoperative support services.

Proposed Methods

- Retrospective Cohort study of a divers population of CP Surgical Patients (GMFCS 4,5) who have undergone: A) Hip Reconstruction and B) Posterior Spine Fusion
- Access: CPRN registry, HCUP Kids Inpatient Database, PHIS, ACS NSQUIP databases
- Stratify Cohorts by: 1)Race/Ethnicity, Language Proficiency, and 2) Socioeconomic Status
- Standardize a set of SDOH data to CP population relevant (e.g. Access to orthopedic/rehab services, community services, transportation, housing, food insecurity, etc.

Patient Engagement and Patient-Centered Outcomes

- Outcome Measures: Complication rate, Mortality rate, Length of ICU/Hospital stay, readmission rate, surgical site infection, cost of care

- By identifying whether surgical outcome disparities exist and their potential causes, we can better engage CP families from low socio-economic, and diverse racial/ethnic populations with potential solutions/interventions

Subject Population/Sample Size

- Data recruitment from multiple centers

Importance to CP Community/CPRN Fit/Target Funding

- Will promote equitable surgical outcomes for a large segment of the CP population
- Target Funding: NIH R21
- Current Participants: Kirk Dabney (Nemours AI duPont Hospital for Children), Mohan Belthur (Phoenix Children's Hospital), Paul Gross(CPRN, University of Utah), Jeffrey Leonard, Nationwide Children's Hospital, Maureen Durkin, Medical College of Wisconsin

References

- 1. Van Naarden Braun K, Doernberg N, Schieve L, Christensen D, Goodman A, Yeargin-Allsopp M. Birth Prevalence of Cerebral Palsy: A Population-Based Study. Pediatrics. 2016;137(1):e20152872.
- 2.Kirby RS, Wingate MS, Van Naarden Braun K, Doernberg NS, Arneson CL, Benedict RE, et al. Prevalence and functioning of children with cerebral palsy in four areas of the United States in 2006: A report from the Autism and Developmental Disabilities Monitoring Network. Res Dev Disabil. 2011;32(2):462–9.
- 3. Wu YW, Xing G, Fuentes-Afflick E, Danielson B, Smith LH, Gilbert WM. Racial, Ethnic, and Socioeconomic Disparities in the Prevalence of Cerebral Palsy. Pediatrics. 2011;127(3):e674–81.
- 4. Yeargin-Allsopp M, Van Naarden Braun K, Doernberg NS, Benedict RE, Kirby RS, Durkin MS. Prevalence of Cerebral Palsy in 8-Year-Old Children in Three Areas of the United States in 2002: A Multisite Collaboration. Pediatrics. 2008;121(3):547–54.
- 5. Durkin MS, Maenner MJ, Benedict RE, Van Naarden Braun K, Christensen D, Kirby RS, et al. The role of socio-economic status and perinatal factors in racial disparities in the risk of cerebral palsy. Dev Med Child Neurol. 2015;57(9):835–43.
- 6. Maenner MJ, Benedict RE, Arneson CL, Yeargin-Allsopp M, Wingate MS, Kirby RS, et al. Children with cerebral palsy: Racial disparities in functional limitations. Epidemiology. 2012;23(1):35–43.
- 7. Oskoui M, Messerlian C, Blair A, Gamache P, Shevell M. Variation in cerebral palsy profile by socio-economic status. Dev Med Child Neurol. 2016;58(2):160–6.

Thank You !
Questions. Comments, Feedback?