Social Determinants of Health and Health Equity in Pediatric Neuropsychology

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1

Disclosures

- None

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2

Objectives

1. Describe the impact of social determinants of health (SDOH) on neuropsychological functioning in pediatric medical populations via Bronfenbrenner's ecological model.
2. Describe novel tools to measure SDOH in pediatric neuropsychology.
3. Identify potential interventions to address health equity in pediatric neuropsychology practice.

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3

Social Determinants of Health and Health Equity in Pediatric Neuropsychology

- **Social determinants of health (SDOH)**
  - **Introduction**
  - SDOH measurement
  - SDOH and importance in pediatrics
- SDOH in specific medical populations
  - Spina Bifida/Epilepsy
  - In utero exposure/Rare genetic conditions
  - Oncology
- Interventions and resources
  - Multidisciplinary clinics
  - Spina Bifida + within organization initiatives
  - Oncology and initiatives in the community
  - ECHO model
- Conclusions

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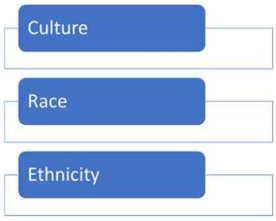
4

Terms



https://dictionary.apa.org/

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5

U.S. demographics

- Total Population: ~ 334.9 million (2023 estimate)
- Age Distribution:
  - Under 5 years: 5.5%
  - Under 18 years: 21.7%
- Race and Ethnicity:
  - White (non-Hispanic): 57.8%
  - Hispanic or Latino: 18.9%
  - Black or African American (non-Hispanic): 12.6%
  - Asian (non-Hispanic): 6.1%
  - Two or More Races (non-Hispanic): 2.8%
  - American Indian and Alaska Native (non-Hispanic): 0.9%
  - Native Hawaiian and Other Pacific Islander (non-Hispanic): 0.2%

USAFacts, 2024

U.S. Census Bureau. 2022-24

6

U.S. demographics

- Language Spoken at Home:
  - English only: 78%
  - Language other than English: 22% (67.8 million people).
  - Top 5 Languages: Spanish: 13%, Chinese: 1%, Tagalog: 0.5%, Vietnamese: 0.5%, Arabic: 0.4%.
- Health Insurance Coverage:
  - Private insurance: 65.4%
  - Public insurance: 36.3%.
- Educational Attainment
  - Less than high school diploma: 9%
  - High school diploma or equivalent: 28%
  - Some college, no degree: 15%
  - Associate degree: 10%
  - Bachelor's degree: 23%
  - Advanced degree (Master's, professional, or doctorate): 14%

USAFacts, 2024

U.S. Census Bureau, 2022-24

7

Variance in neuropsychological performance

- **Individual factors** (e.g., age, sex)
- **Medical factors** (e.g., age of onset, length and severity of illness or disease, and etiology)
- **Psychosocial factors** (e.g., insurance type, income, race/ethnicity, English as a second language)

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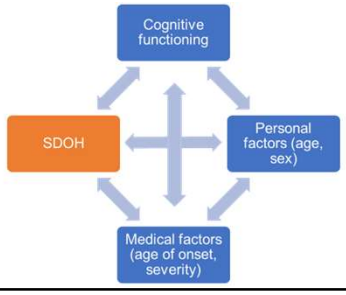
8

Neuropsychology and SDOH



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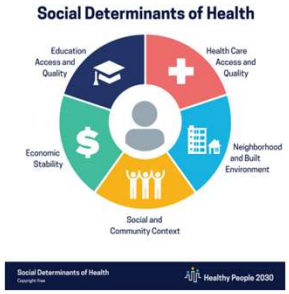
Variance in neuropsychological performance

- Variance accounted for by **socio-demographic variables** e.g., social determinants of health (SDOH)



Office of Disease Prevention and Health Promotion [ODPHP]
U.S. Department of Health and Human Services [HHS], 2025

10

Social Determinants of Health

- Definition:
  - "Conditions in the environments where people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks."
- Healthy People 2030 goal:
  - "Create social, physical, and economic environments that promote attaining the full potential for health and well-being for all."

Office of Disease Prevention and Health Promotion [ODPHP]
U.S. Department of Health and Human Services [HHS], 2025

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Social Determinants of Health

- Economic Stability
- Education Access and Quality
- Health Care Access and Quality
- Neighborhood and Built Environment
- Social and Community Context

Office of Disease Prevention and Health Promotion [ODPHP]
U.S. Department of Health and Human Services [HHS], 2025

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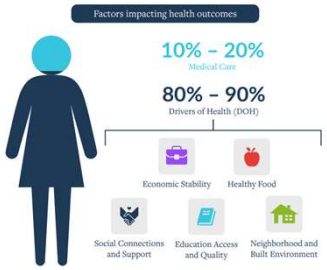
12

Social Determinants of Health



https://www.christenseninstitute.org/wp-content/uploads/2022/05/DriversofHealth.pdf

13

SDOH in Adult NP literature

Examples:

- Dementia: SES and education influence progression and management
- Mild Cognitive Impairment: Income and access to healthcare impact cognitive outcomes
- Adults with HIV: SES and race influence cognitive performance
- Traumatic Brain Injury: Supportive housing and social networks improve recovery and cognitive outcomes

14

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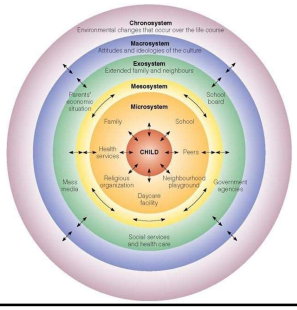
15

SDOH & Measurement

16

Bronfenbrenner's Ecological Systems Theory



17

Tools/variables to measure SDOH

- Common Individual Factors
  - Highest level of education
  - Employment
  - Housing
  - Food access
  - Utility needs
  - Language access
- Common Family Factors
  - Parental education
  - Parents employment
  - Housing
  - Food access
  - Utility needs
  - Caregivers' language access
  - Family structure
  - Income
  - Transportation access

18

Other tools/variables to measure SDOH

- Environment
  - Neighborhood characteristics (crime, safety, environmental toxins)
  - Home characteristics (exposure to chronic mold, lead, pests, etc.)
  - Access to transportation
  - School factors (technology, qualified staff, dedicated funding, early childhood educational services, transportation access)

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19

Other tools/variables to measure SDOH

- Clinical factors often considered as proxies for SDOH (e.g. SES)
  - Insurance
  - Wait times
  - Time to diagnosis/treatment
  - Cancellations/missed appts.
- Safety and trauma
  - Early childhood adversities (e.g., ACES)

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20

Abbreviated screening tools

TABLE 1. SUMMARY OF SCREENING TOOLS, WHERE THEY ARE ADMINISTERED, WHO/HOW ADMINISTERED

Screening tool title, authors	*Setting (type of application)*	*Who/how administered/number of questions*
Increm[16]	Pediatric emergency department; applied in research to test for practice (*research*)	Self-administered or face-to-face with research assistant; Computer-based; 23 questions (each with 2 follow-up questions)
WE CARE[17]	Community health centers well-child visits (*research*)	Self -administered (parent of patient); Paper-based; 6 questions
HealthBegins[22]	Various clinical settings (*clinical practice*)	Student, health care staff or provider; Paper; 15 main questions, 14 optional/additional questions
Health Leads[19]	Emergency departments and primary care (*clinical practice*)	Self/patient, student volunteers; Paper (available in Spanish); 9 questions plus available additional questions per domain
PRAPARE Protocol for Responding to and Assessing Patient Assets, Risks, and Experiences Version 1.0 © [a]	Various clinical settings (*clinical practice*)	Staff/health care provider[a]; Computer (available in multiple languages); 12 questions plus demographics
WeRIck[23]	Primary/family medicine clinics; (*research*)	Self (patient) or medical assistant; Paper; 11 questions
The Accountable Health Communities (AHC) Screening Tool[a] (Centers for Medicare & Medicaid Services, 2017; Billioux, Verlander, Anthony, & Alley, 2017)	Various clinical settings; (*clinical practice*)	Staff/health care provider/self; Paper- and computer-based; 16 HRSC questions, 26 total questions
HelpSteps[21]	Adolescent, young adult clinic; various settings (*research and clinical practice*)	Self; Computer/web-based; 12 main questions/domains with follow-up questions
AAFP Social Needs Screening Tool, The EveryONE Project[24]	Family or pediatric practice; (*clinical practice*)	Health care provider or patient; Paper (short or long form); 14 questions (long form)

[a]Health care provider = physician or nurse practitioner.
AAFP, American Academy of Family Physicians; HRSC, health-related social conditions.

Moen et al. (2020)

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21

SDOH Community/Area-Level Factors

Area Deprivation Index (ADI)

- Neighborhood deprivation
- 17 variables from 5-year American Community Survey (ACS) estimates
- 1-100 ranking scale
- *Higher scores* suggest more deprivation
- Includes
  - Education
  - Income/employment
  - Housing
  - Household characteristics
- At the census block level

Kind et al., 2018

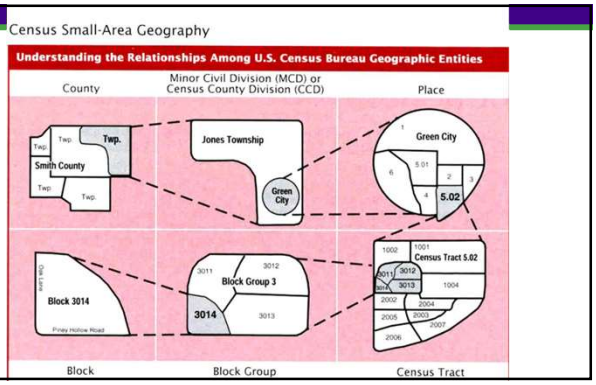
Child Opportunity Index (COI)

- Access to community resources
- Combined 29 indicators into single composite measure
- 1-100 ranking scale
- *Lower scores* indicate less access
- Includes
  - Education
  - Health and environment
  - Social and economic resources
- At the census tract level

Acevedo-Garcia et al., 2014

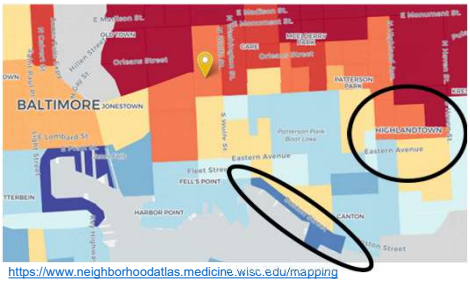
22

Census Small-Area Geography



23

Area Deprivation Index (ADI)



https://www.neighborhoodatlas.medicine.wisc.edu/mapping

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Child Opportunity Index (COI)

https://www.diversitydatakids.org/maps/

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25

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SDOH & Pediatrics

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Why SDOH is important in pediatrics

- Early life exposures inform long-term outcomes (Lu & Halfon, 2003)
  - Adverse Childhood Experiences
- Developing brain—less reserve
  - Environmental factors impact brain development (Tooley et al., 2021)
  - Increased burden in pediatric medical/neurodevelopmental populations?

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28

SDOH and Cognition: Pediatrics

- Neighborhood conditions influence neuropsychological outcomes:
  - COI and language, visual perception, and attention (Gornik et al., 2023)
  - ADI and FSIQ (Kalb et al., 2024)

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SDOH and Neuroanatomy: Pediatrics

- Community resources are associated with neuroanatomy:
  - SES and total and prefrontal cortical volume (Dennis et al., 2022)
  - ADI and prefrontal cortex, superior frontal gyrus, and hippocampus (Taylor et al., 2020)
  - Parental education and prefrontal cortical thickness (Lawson et al. 2013)
  - ADI and functional connectivity between brain ROIs (Rakesh et al., 2021)

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SDOH and Access to Healthcare: Pediatrics

- Family and community resources predict follow-through with neuropsychological evaluations (Gornik et al., 2024)
- Racial and ethnical disparities in access medical and dental services (Flores & Lin, 2013)
- Children in low income households less likely to access mental health services (Kataoka, Zhang, & Wells, 2002; Santiago, Kaltman, & Miranda, 201)
  - Related to health literacy (Winders Davis et al., 2013)

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31

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32

SDOH and pediatric neuropsychological functioning in specific medical populations

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SDOH in specific peds NP populations

- **Spina Bifida**
- Pediatric epilepsy

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Spina Bifida

- 4 Types:
  - occulta, closed neural tube defects (such as lipomyelomeningocele), meningocele, & myelomeningocele
- Etiologies:
  - Genetic, folic acid deficiency, environmental exposures, neighborhood disadvantage
- Treatments
  - Fetoscopic surgery
  - Post-birth surgery (within 24-48 hours of birth)
- Medical factors:
  - Hydrocephalus, Chiari II malformation, shunt failures/revisions, need for medical self-cares due to neurogenic bowel and bladder
- Neuropsychological deficits:
  - Motor
  - Attention & EF
  - Memory
  - Math
  - Reading comprehension
  - Social skills

35

SB guidelines & SDOH

- Regular Evaluation: Evaluate social determinants of health and immigration status regularly (Transition Guideline).
- Resource Provision: Offer resources and increased navigation support if needs are identified (Transition Guideline).
- Impact on Care: Addressing barriers can significantly impact long-term functional outcomes and access to care (Transition Guideline).
- Holistic Approach: Incorporate social, economic, and environmental factors into patient care plans (Transition Guideline).
- Family Functioning: Consider the impact of social determinants on family dynamics and support systems (Family Functioning Guideline).
- Mental Health: Recognize the role of socioeconomic factors in mental health and provide appropriate support (Mental Health Guideline).
- Quality of Life: Address social determinants to improve overall quality of life for individuals with spina bifida (Quality of Life Guideline).

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https://www.spinabifidaassociation.org/guidelines/

36

Spina Bifida & SDOH

- **Highest prevalence:** Hispanics/Latinos (Canfield, 2014, Abdelmageed et al., 2024)
  - Approximately 3.80-4.2 per 10,000 live births
    - Non-Hispanic white women (3.09)
    - Non-Hispanic Black women (2.73)
  - Higher rates in Hispanic/Latinos: genetic risk, folic acid fortification, demographic changes in the U.S. (Crider et al., 2011; Tinker et al., 2014)
- 1998: U.S. Food and Drug Administration (FDA) mandated all enriched cereal grain products be fortified with folic acid (Flores et al., 2018)
  - Corn masa flour (CMF) not included
  - Petition to add to CMF in 2016 was approved
- Overall prevalence has declined by 23%, severity decreased by 70% (most pronounced for non-Hispanic white mothers) (Mai et al., 2022)
  - Data prior to 2016

37

Spina Bifida & SDOH

- **Less likely to report bowel continence:** Hispanics/Latinos (Smith et al., 2019)
- **Higher urinary incontinence rates, bladder accidents, lower satisfaction bladder management:** Hispanics/Latinos (Chowanadisai et al., 2013)
- **Lower feelings of satisfaction and competence:** Hispanic parents (Devine et. 2012)
- **Less likely to undergo shunt revision**: Hispanic individuals (Punchak et al., 2024), children of minority race/ethnicity (Rocque et al., 2022)
- **Potentially preventable hospitalizations (PPH)**: Public insurance, Hispanic (Smith et al., 2023)
- **Medical adherence following a bowel management program**: Neighborhood disadvantage (defined by ADI) strong predictor (Simpson et al., 2024)

38

HRQOL

- Language and Latino immigrants living with spina bifida: Social determinants of health - the missing dimension in quality of life research (Castillo et al., 2019)
  - Systematic review, children 5-21yo w/SB and/or myelomeningocele
  - 18 studies met criteria
  - Only seven (39%) of studies stated that they included Hispanics/Latinos and only six (33%) reported including Spanish-speaking individuals.

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Individual and Family SDOH

- SES status associated with vocabulary scores on the KBIT (Bier at al., 1997)
- Disadvantaged children with SBM have lower Verbal IQ (Fletcher et al., 2004)
- Poverty associated with lower general ability in children with SBM, particularly language skills (Fletcher et al., 2005)
- Lower SES associated with poorer associative cognitive processes (Dennis et al., 2006)
- Annual household income explained variance in overall child cognitive functioning (Wohlfeiler, Macias, & Saylor, 2008)

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Individual and Family SDOH

- Associations of Ethnicity and SES with IQ and Achievement in Spina Bifida Meningomyelocele (Startwout et al., 2010)
  - Non-Hispanic White (n = 153) and Hispanic (n = 80) children with SBM
    - Stanford Binet Test of Intelligence-IV
    - Achievement subtests of the Woodcock–Johnson.
  - Parents completed questionnaires assessing the family environment [socioeconomic status (SES), resources, and educational opportunities]
    - Hollingshead 4-Factor Scale (Hollingshead, 1975)
    - Henderson Environmental Learning Process Scale (HELPS; Henderson, Bergan, & Hurt, 1972)
    - Family Resource Scale (FRS; Dunst & Leet, 1987)
  - **"Hispanic children with lower SES had lower verbal than nonverbal scores"**
    - "Hispanic children with higher SES and non-Hispanic White children demonstrated the reverse pattern"
    - "Verbal and nonverbal IQ interacted to predict reading and math performance"
  - Limitation?: SB was translated into Spanish
    - "Where necessary, tests and questionnaires were adapted for Spanish language participants (27% of Hispanic children were tested in Spanish)."
    - English norms used

41

Individual and Family SDOH

- Sociodemographic factors and health-related, neuropsychological, and psychosocial functioning in youth with spina bifida (Papadakis & Holmbeck, 2021)
  - 140 youth with Spina Bifida
    - 52.9% were Caucasian, 27.9% were Hispanic, 13.6% were African American, 1.4% were Asian, and 4.3% were multiracial
  - Non-Caucasian youth + youth with parents w/lower occupational status
    - Significantly fewer parent-reported attention and executive function problems compared to less at-risk youth
  - Youth without private health insurance
    - Significantly fewer parent-reported attention problems compared to youth with private insurance
  - Youth with non-college educated parents
    - Significantly fewer parent-reported attention and executive function problems, but also lower academic achievement than youth with college educated parents
  - Limitation?: Only parent reported measures of attention and EF

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42

Individual, Family, & Community SDOH

- Sociodemographic disparities in fetal surgery for myelomeningocele: a single-center retrospective review (Foy et al., 2021), Children's Wisconsin
  - 205 patients were identified with zip code and insurance data
    - 23 patients w/fetal surgery, 182 patients w/ postnatal surgery
    - Born 2000-2019
  - Patients treated with fetal surgery were significantly more likely to:
    - Have commercial insurance
    - Be from non-Hispanic White background
  - Tended to reside in zip codes w/higher median household income and come from less distressed communities as defined by the Distressed Communities Index (DCI) score (though non-significant for both)

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43

Community SDOH

- Health Disparities and Route of Repair of Fetal Myelomeningocele-Prenatal Versus Postnatal Repair (Ogunleye et al., 2024)
  - 51 fetuses
    - 86% (n = 44) underwent postnatal repair for SB
    - 14% (n = 7) received prenatal repair.
  - Patients who underwent prenatal repair exhibited lower COI scores across all domains (education, health, and environment, social and economic) on national, state, and metro levels compared to the postnatal group.
  - However, they did not reach statistical significance between prenatal and postnatal surgery groups
  - Limitation: sample size?

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SDOH in specific peds NP populations

- Spina Bifida
- **Pediatric epilepsy**

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Pediatric epilepsy

- Types:
  - Generalized vs. Focal
- Etiologies:
  - Genetic, head injury (trauma), infection
- Medical factors:
  - Seizure type and frequency, early onset, medication side effects
- Neuropsychological deficits:
  - Intellectual disabilities
  - Attention & EF
  - Memory
  - Language
  - Behavior/emotion

46

Epilepsy

- **Lower surgery rates** for AA, Hispanic, Non-English speaking vs. whites (Nathan & Guiterrez, 2018)
- **Lower number of AEDs** for Spanish-speaking patients vs. US born (Myers et al., 2015)
- **Medication adherence barriers** disproportionately affect Black children w/epilepsy (Gutierrez-Colina et al., 2022)
- ↓ **likelihood of seizure control + remission** for Hispanic children (Gregerson et al., 2019)

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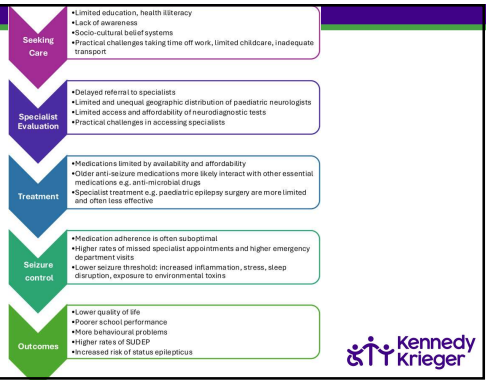
47



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48

Individual and Family SDOH

- Race/Ethnicity
  - Primarily White, non-Hispanic cohort suggestive of racial disparity among patients referred for epilepsy surgery evaluation (Berl et al., 2023)

TABLE 2 Patient demographics and seizure characteristics ($N = 534$).

		N (%)
Sex	Female	252 (47.2%)
	Male	281 (52.6%)
	Missing	1 (0.2%)
Race	White	405 (75.8%)
	Black	44 (8.2%)
	Asian	20 (3.7%)
	More than one race	13 (2.4%)
	American Indian/ Alaska Native	3 (0.6%)
	Unknown	49 (9.2%)
Ethnicity	Not Hispanic	446 (83.5%)
	Hispanic	74 (13.9%)
	Unknown	14 (2.6%)

49

Individual and Family SDOH

- Insurance
  - Children with private insurance undergoing epilepsy surgery evaluation were more likely to have neuropsychological evaluation (Berl et al., 2023)
    - Children who had neuropsychological testing: (**58% private**; 41.4% public; 0.6% self-pay)
    - Children who did not have testing: (**49.7% private**; 48.4% public; 1.9% self-pay) ($\chi 2 = 15.59$, $p < .001$)

50

Individual and Family SDOH

- Systematic review of 18 studies: social, cultural, and environmental factors that contributed to SDOH impacting epilepsy surgery (Winterhalter et al., 2024)
  - Children who underwent surgical evaluation: most commonly White, privately insured, college-educated caregivers
    - Five studies: differences in time to referral/surgery or rates of surgery by racial group, with most finding an increased time to referral/surgery or lower rates of surgery for those who were Hispanic and/or non-White.
    - Four studies: private insurance was associated with higher surgical utilization.
    - Three studies: higher household income was related to surgical utilization.

51

Individual and Family SDOH

- The impact of family factors on IQ in pediatric medically refractory epilepsy (Puka et al., 2017)
  - Higher IQ scores were associated with lower family demands (Family Inventory of Life Events and Changes [FILE])
  - Relationship between the extent of epileptogenic foci and IQ to be moderated by family demands
    - Patients with unilobar onset had similar IQ scores irrespective of family demands
    - Patients with multilobar foci had lower IQ scores with increasing family demands

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52

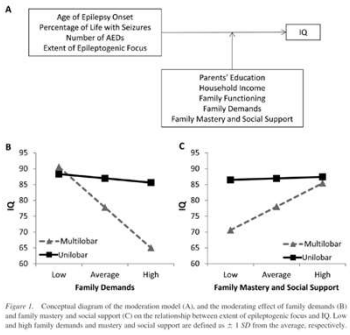

Figure 1. Conceptual diagram of the moderation model (A), and the moderating effect of family demands (B) and family mastery and social support (C) on the relationship between extent of epileptogenic focus and IQ. Low and high family demands and mastery and social support are defined as ± 1 *SD* from the average, respectively.

Puka et al., 2017

53

Individual and Family SDOH

- The Impact of Sociodemographic Disadvantage on Cognitive Outcomes in Children With Newly Diagnosed Seizures and Their Unaffected Siblings Over 36 Months (Oyegbile-Chidi et al., 2023)
  - 289 children (6-16 years) w/in 6 weeks of first seizure and 167 sibs had neuropsychological assessment
  - Sociodemographic disadvantage (SD) index was computed
    - 4 variables: caregiver's education level, race (self-identified), household income, and marital status
    - Collected via structured interview
  - Least disadvantaged group: exhibited the highest Full-Scale IQ, neuropsychological factor scores, and academic performances
  - Most disadvantaged group: worst performances across all tests
  - Findings stable over 36 months
  - Linear regression analyses: "**disadvantage was a more constant and stable predictor of cognitive and academic performance over time compared with clinical epilepsy characteristics and MRI/EEG abnormalities.**"

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54

Slide 52

LC0 71-item scale uses yes/no questions to assess the accumulation of simultaneous normal and non-normal life events and changes in life events experience by a family during the previous year;
Love, Christina E., 2025-03-31T03:54:59.622

LC0 0 The FILE asks questions with regard to intrafamily strains, marital strains, pregnancy and childbearing strains, finance and business strains, work–family transition strains, illness and family care strains, losses, transitions “in and out” of the family, and family legal violations
Love, Christina E., 2025-03-31T03:56:15.640

Community SDOH

- Area Deprivation Index (ADI)
  - Neighborhood disadvantage and health-related quality of life in pediatric epilepsy (Chiang et al., 2023)
  - Neighborhood disadvantage independently predicted HRQoL
    - Sole significant predictor of HRQoL when familial factors were incorporated
      - Parental psychiatric history
      - Medicaid insurance status
- Children with epilepsy living in disadvantaged areas were:
  - **4x** more likely to have diminished HRQoL
  - **5x** more likely to live with a parent with a significant psychiatric history
  - **4x** more likely to reside with a family receiving Medicaid insurance.
- Lesson: "Cumulative burden of social context, familial factors, and seizure-specific characteristics contribute to lower HRQoL in pediatric epilepsy"

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55

Community SDOH

- Area Deprivation Index (ADI)
  - Cognitive and brain health in juvenile myoclonic epilepsy: Role of social determinants of health (Struck et al., 2025)
    - JME participants resided in neighborhoods associated with significantly more socioeconomic disadvantage
      - Associated with significantly poorer performance across cognitive factor scores (general mental ability, speed/response inhibition, verbal learn/memory) and reading fluency.
    - Socioeconomic advantage in controls was associated with increased brain volumes and thickness (total subcortical GM and diverse subcortical structures as well as areas of increased cortical thickness and volume in frontal/prefrontal regions) that were largely attenuated or absent in JME

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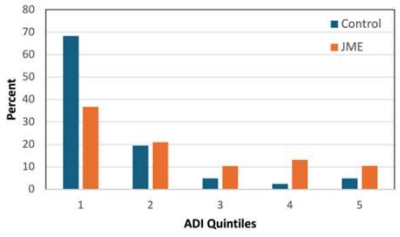
56

Community SDOH

- Area Deprivation Index (ADI)
  - Cognitive and brain health in juvenile myoclonic epilepsy: Role of social determinants of health (Struck et al., 2025)



57

Community SDOH

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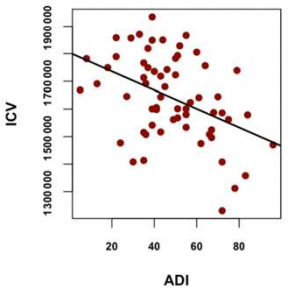

58

Social Determinants of Health and Health Equity in Pediatric Neuropsychology

- Social determinants of health (SDOH)
  - Introduction
  - SDOH measurement
  - SDOH and importance in pediatrics
- SDOH in specific medical populations
  - Spina Bifida/Epilepsy
  - **In utero exposure/Rare genetic conditions**
  - Oncology
- Interventions and resources
  - Multidisciplinary clinics
  - Spina Bifida + within organization initiatives
  - Oncology and initiatives in the community
  - ECHO model
- Conclusions

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59

SDOH in specific peds NP populations

- Congenital/genetic disorders
  - **In utero exposure (e.g., FAS)**
  - Rare genetic conditions

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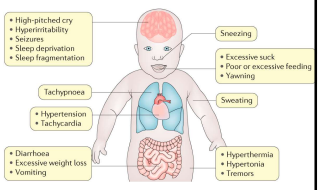
In utero exposures

- In utero exposure to opioids
  - Children with prenatal exposure to opioids ~2x more likely to have IDD than nonexposed youth (Bunikowsky et al., 1998), in addition to other developmental disorders (e.g., ADHD) and behavioral disorders (Ornoy, 2003)
- Neonatal abstinence syndrome
  - ~ 6 in 1000 newborns in the US every year (CDC, 2024)
  - Opioid use in pregnancy is associated with (Decker et al., 2023):
    - Greater maternal age
    - non-Hispanic white race/ethnicity
    - lower maternal education
    - Medicaid at delivery (proxy for SES)
    - poor or absent prenatal care
    - lower household income



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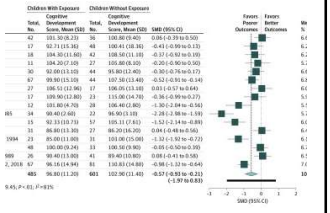
In utero exposures

- NAS diagnosis more common in:
  - Infants from areas with lower COI (Ogundiran & Gigl, 2025)
  - Counties with greater unemployment and shortages of mental health services (Patrick et al., 2019)
- Among children with NAS, there are discrepancies in clinical outcomes:
  - Hispanic infants likely to be from lower COI than non-Hispanic and urban infants, and more likely to require longer birth hospitalization suggestive of more severe NAS features (Ogundiran & Gigl, 2025)
  - Longer birth hospital stay is associated with ADI or degree of deprivation in mother's community (Vesoulis et al., 2020)
  - Non-Hispanic black newborns are less likely to receive pharmacological treatment despite similar severity of the syndrome (Akers et al., 2021)

62

In utero exposures

- Cognition
  - Study findings on the cognitive sequelae associated with prenatal exposure to opioids are mixed but trends of elevated risk for lower overall cognition and higher risk for IDD are well documented.



Nelson et al., 2020

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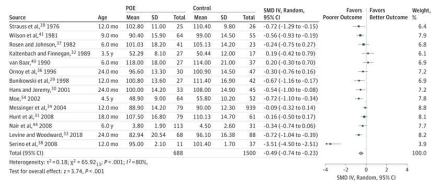
In utero exposures

- Additional risk for poorer motor and language outcomes



Source	POE Age	POE Mean	POE SD	POE Total	Control Mean	Control SD	Control Total	SMD IV, Random, 95% CI
Strauss et al.[29] 1976	12.0 mo	102.80	11.00	25	110.40	9.80	26	-0.72 (-1.29 to -0.15)
Wilson et al.[41] 1981	9.0 mo	90.40	15.90	64	99.00	14.50	55	-0.56 (-0.93 to -0.19)
Rosen and Johnson,[27] 1982	6.0 mo	101.03	18.20	41	105.13	14.20	23	-0.24 (-0.75 to 0.27)
Kaltenbach and Finnegan,[42] 1989	3.5 y	52.29	8.10	27	50.44	12.00	17	0.19 (-0.42 to 0.79)
van Baar,[43] 1990	6.0 mo	118.00	18.00	27	114.00	21.00	37	0.20 (-0.30 to 0.70)
Ornoy et al.,[28] 1996	24.0 mo	96.60	13.30	30	100.90	14.50	47	-0.30 (-0.76 to 0.16)
Bankowski et al.,[44] 1998	12.0 mo	100.80	13.60	27	111.40	16.90	42	-0.67 (-1.16 to -0.17)
Hans and Jeremy,[30] 2001	24.0 mo	100.00	14.20	33	108.00	14.90	45	-0.54 (-1.00 to -0.08)
Moe,[34] 2002	4.5 y	48.90	9.00	64	55.80	10.20	52	-0.72 (-1.10 to -0.34)
Messinger et al.,[24] 2004	12.0 mo	88.90	14.20	79	90.00	12.30	939	-0.09 (-0.32 to 0.14)
Hunt et al.,[31] 2008	18.0 mo	107.50	16.80	79	110.13	14.70	61	-0.16 (-0.50 to 0.17)
Nair et al.,[45] 2008	6.0 y	3.80	1.90	113	4.50	2.60	31	-0.34 (-0.74 to 0.06)
Levine and Woodward,[32] 2018	24.0 mo	82.94	20.54	68	96.10	16.38	88	-0.72 (-1.04 to -0.39)
Serino et al.,[38] 2008	12.0 mo	95.00	2.10	11	101.40	1.70	37	-3.51 (-4.50 to -2.51)
Total (95% CI)				688			1500	-0.49 (-0.74 to -0.23)

Heterogeneity: $\tau^2 = 0.18$; $\chi^2 = 65.92_{12}$, $P < .001$; $I^2 = 80\%$.
Test for overall effect: $z = 3.74$, $P < .001$

Favors Poorer Outcome | Favors Better Outcome | Weight, %

-4 -2 0 2 4
SMD IV, Random, 95% CI

Yeoh et al., 2019; Kim et al., 2021

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In utero exposures

- Prenatal exposure to opioids is related to later behavioral challenges in childhood and adulthood
  - ADHD features
  - executive dysfunction
  - internalizing and externalizing behavior
  - aggression
  - anxiety

Balalian et al., 2023; Jaekel et al., 2021

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In utero exposures

- **The literature on contributions of SDOH and postnatal factors on developmental outcomes remains limited. Largely existing research focuses on individual, parental and/or family factors.**
  - About half of differences in opioid exposed vs nonexposed children's cognitive/motor outcomes are explained by postnatal and family factors (parental stress, non-punitive parenting, parental involvement, parental state of anxiety)(Levine et al., 2021)
  - Greater number of caregiver changes or instability in living arrangements predict lower overall adaptive functioning (~↓2.65 points in communication and 2.19 in DLS scores with each caregiver change)(Bada et al., 2007)
  - Parenting and home environment mediates relationship between prenatal exposure and language outcomes (Kim et al., 2021)
  - After accounting for postnatal adversity, exposure explained ~6% of variance in IQ scores (Ravi et al., 2025)
  - ***Postnatal environments and experiences matter and may comprise of a larger risk factor to adaptive dysfunction than prenatal exposures.***

66

In utero exposures

- Fetal alcohol spectrum disorders
  - Leading preventable cause of intellectual disability
  - Estimated prevalence rate: ~1-5% (May et al., 2018)
  - Demographically, Native Americans have highest rate of FAS followed by African Americans and subsequently Caucasians (Russo et al., 2004)
    - Native American prevalence rate estimated 2-7 per 1000
    - Black infants nearly 7x increased risk for FAS, but also more likely misdiagnosed or diagnosed later given limited access to care and/or low SES

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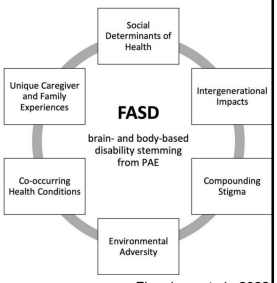
In utero exposures

- Fetal alcohol syndrome
  - Alcohol consumption during pregnancy is linked to SDOH and multiple individual and family factors.
    - Trauma (Bhengu et al., 2019)
    - Intimate partner violence (Deutsch, 2019)
    - Stressful life events (Edwards et al., 2019)
    - Mental health difficulties (Popova et al., 2021)
    - Lower level of maternal education (May et al., 2020)
    - Late prenatal health care (May et al., 2020, Popova et al, 2021)
    - Higher SES associated with greater alcohol consumption during pregnancy but lower SES is associated with more severe FASD diagnosis suggesting role of SES on developmental outcomes (McCormack et al., 2017, Pfinder, 2014)

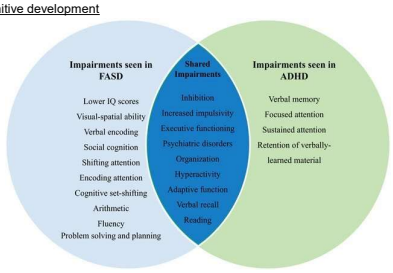


Flannigan et al., 2022

68

In utero exposures

Cognitive development



Burden et al., 2005

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In utero exposures

- Adolescents and adults with fetal alcohol exposure/FASD

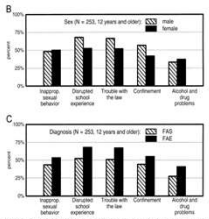

FIGURE 3. Lifespan Prevalence of Five Adverse Life Outcomes. (a) by Three Age Groups, (b) by Male vs Female, and (c) by Fetal Alcohol Syndrome (FAS) vs Fetal Alcohol Effects (FAE). Age group is defined by age at time of Life History Interview (LHI). n = 161 to 162 in the 6- to 11-year-old range, 160 to 163 in the 12- to 20-year-old range, and 87 to 90 in the 21 and older range. For adolescents/adults: n = 141 to 145 males and 106 to 108 females; n = 106 to 109 with FAS and 141 to 144 with FAE.

Streissguth et al., 2004

70

In utero exposures

- Fetal alcohol syndrome
  - Neuropsychological outcomes
    - **Currently, research on postnatal predictors of cognition remains very limited and largely focuses on individual, parental and family factors.**
    - Lower SES, lower maternal education, rural residence linked to lower IQ and more problem behaviors (May et al., 2013)
    - Increased SES related to increased subcortical volumes in children without prenatal alcohol exposure, but no SES-brain associations among those with prenatal alcohol exposure (Uban et al., 2020; McLachlan et al., 2020)
    - High conflict family environment postnatally is associated with more problem behaviors, though adaptive functioning difficulties are comparable across family environment groups (Felicicchia et al., 2025)

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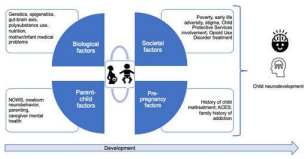
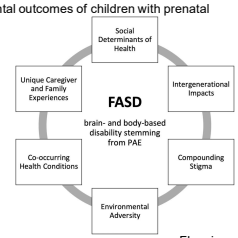
71

In utero exposures

Drawing from NAS and FASD, it is important to consider **dynamic risk factors pre/post-natally** and **intergenerational risks** when considering neurodevelopmental outcomes of children with prenatal opioid/alcohol exposure



Conradt et al., 2023



Flannigan et al., 2022

72

In utero exposures

Also important to consider transactional family dynamics, parent-child dyads and bidirectional effects on behavioral health.

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SDOH in specific peds NP populations

- Congenital/genetic disorders
  - In utero exposure (e.g., FAS)
  - **Rare genetic conditions**

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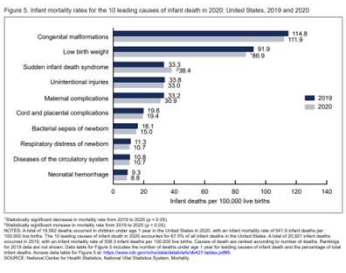
74

Genetic conditions



Xu et al., 2020

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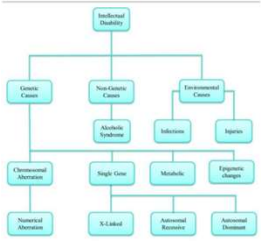
75

IDD and Genetic Etiology

- IDD occurs in ~1-3% of the general population (American Psychiatric Association, 2022)
- Among those with IDD, 40-60% have a genetic etiology and about half with undetermined causes (Ilyas et al., 2020)



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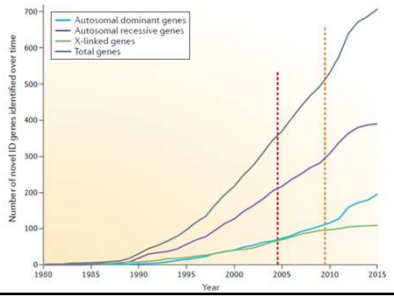
Genes Identified for IDD Over Time



Visser et al., 2016

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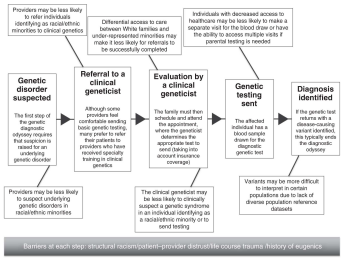
77

Genetic conditions: Rare disease diagnostic odyssey



- There are multiple junctures that can result in delayed diagnosis and appropriate care management

Fraiman & Wojcik, 2021

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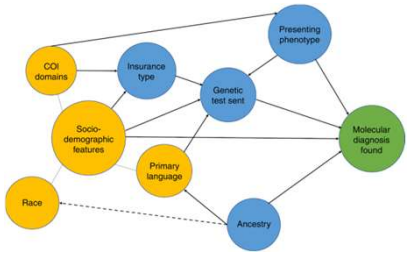
Genetic conditions: Rare disease diagnostic odyssey



- Likely different variables that impact each juncture of this journey

Wojcik et al. 2023

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Genetic conditions: Rare disease diagnostic odyssey

- Genetics consultation
  - Children belonging to minoritized racial groups or residing in low income neighborhoods are less likely to have access to subspecialty care like genetics (Bohnhoff et al., 2019)
  - Black children with neurological concerns are less than half as likely as White children to undergo a genetics evaluation (Baldwin et al., 2024)
  - Minority populations are also less likely to have a definitive genetic diagnosis (Landry et al., 2018, Florentine et al., 2022)

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Genetic conditions: Rare disease diagnostic odyssey

- What impacts referrals to genetic services?

Table 2 Summary of barriers identified in the systematic review

Barriers related to individuals	*Barriers related to healthcare professionals (HCP)*
1. Lack of awareness of personal risk	1. Non-genetic HCPs' lack of awareness of patient risk factors
2. Lack of knowledge and/or awareness of medical history of family members	2. Lack of obtaining adequate and/or accurate family history
3. Lack of knowledge of genetic services	3. Lack of knowledge on genetics and genetic conditions
	4. Lack of awareness of genetic services
	5. Inadequate coordination of referral
	6. Lack of genetics workforce

Delikurt et al., 2015

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Genetic conditions: Rare disease diagnostic odyssey

- Clinical genetic testing is underutilized in minority populations (Landry et al., 2018, Underhill et al., 2016)

- Genetic testing access (Cole et al. 2025)
  - White patients nearly 2x more likely to have at least 1 genetic test compared to Black patients
  - No difference in *referral rates* based on ethnoracial identity
  - Insurance denial rate for testing was lower for White patients than Black patients
  - Insurance type impact disparity in genetic testing based on the type of test

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Genetic conditions: Rare disease diagnostic odyssey

REVIEW | Genetics inMedicine

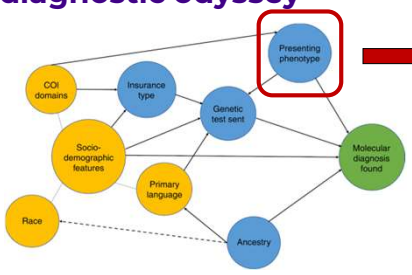
Towards a more representative morphology: clinical and ethical considerations for including diverse populations in diagnostic genetic atlases

Maya Koretzky,[1] Vence L. Bonham,[2] Benjamin E. Berkman,[1,3] Paul Kruszka,[4] Adebowale Adeyemo,[5] Maximilian Muenke[6] and Sara Chandros Hull[1,3]

Figure 1 Children with Down syndrome from Thailand, India, and Nigeria. Courtesy of Ekanem Ekure, S.J. Patil, Girdhar M. M., Antonio Richieri-Costa, and Voravuk Shotelersuk.

83

Genetic conditions: Rare disease diagnostic odyssey



Clinical phenotype (e.g., regression, risk for IDD vs no IDD, disorders with progressive vs stable features) **likely impacts timing of genetics testing, consultation, and follow-ups**

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Genetic conditions: Rare disease diagnostic odyssey

Age at 1st Clinic Appointment	
MEDICAL Predictors	Standardized Beta (p-value)
IDD/DD	β=0.02, ns
Growth Problems	β=-0.10, p=0.051
Dysmorphic/ Craniofacial Features	β=-0.11, p=0.035
Total Systems Affected	β=0.08, ns
r^2 total=0.02	
F total=2.55, p=0.038	
Abbreviations. IDD/DD = intellectual developmental disorder or developmental delay	

Age at 1st Clinic Appointment	
SOCIODEMOGRAPHIC Predictors	Standardized Beta (p-value)
Insurance	β=-0.14,p=0.009
English Proficiency	β=-0.05, ns
r^2 total=0.02	
F total=3.44, p=0.033	

Age at 1st Clinic Appointment	
NEIGHBORHOOD Predictors	Standardized Beta (p-value)
COI Education	β=-0.25,p=0.023
COI Health and Environment	β=-0.04, ns
COI Social and Economic	β=0.15, ns
r^2 total=0.02	
F total=2.16, p=0.09	
Abbreviations. Childhood Opportunity Index = COI	

Ng et al., 2024

Ng et al., 2024

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85

Genetic conditions: Rare disease diagnostic odyssey

Age at 1st Genetic Testing	
MEDICAL Predictors	Standardized Beta (p-value)
Step 1	
Age at 1st Appointment	β=0.91, p<0.001
Step 2	
Age at 1st Appointment	β=0.92, p<0.001
IDD/DD	β=-0.09, p<0.001
Growth Problems	β=0.01, ns
Dysmorphic/ Craniofacial Features	β=-0.05, p=0.030
Total Systems Affected	β=-0.03, ns
r^2 change=0.014	
F change=7.64,p<0.001	
r^2 total=0.84	
F total=368.38, p<0.001	

Age at 1st Genetic Testing	
SOCIODEMOGRAPHIC Predictors	Standardized Beta (p-value)
Step 1	
Age at 1st Appointment	β=0.91, p<0.001
Step 2	
Age at 1st Appointment	β=0.91, p<0.001
Insurance	β=-0.01, ns
English Proficiency	β=0.05, p=0.049
r^2 change=0.003	
F change=2.71,p=0.067	
r^2 total=0.83	
F total=563.92, p<0.001	

Age at 1st Genetic Testing	
NEIGHBORHOOD Predictors	Standardized Beta (p-value)
Step 1	
Age at 1st Appointment	β=0.91, p<0.001
Step 2	
Age at 1st Appointment	β=0.91, p<0.001
COI Education	β=-0.04, ns
COI Health and Environment	β=-0.04, ns
COI Social and Economic	β=0.06, ns
r^2 change=0.002	
F change=1.09,ns	
r^2 total=0.83	
F total=417.87, p<0.001	

Ng et al., 2024

Ng et al., 2024

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86

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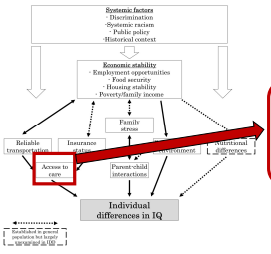

Access to care impacts:
- Preventive care
- Medical work-ups (imaging, labs, etc.)
- Intervention services

McKinney et al., 2024

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Genetic conditions: Rare disease diagnostic odyssey

- For example:
  - 22q11.2 deletion syndrome and attendance at specialized clinic, no-show rate was associated with:
    - Hispanic/Latino
    - Lower median household income
    - Lower parental education
    - Likelihood of required assisted income

Williamson et al., 2024

  - Caregivers with an affected member with Cornelia de Lange syndrome reported perceived benefits or barriers of service utilization:
    - Limited clinics with specialization in the syndrome
    - Travel distance and exposes
    - Insurance coverage
    - Poor communication on how to schedule clinics out of state
    - Poor advertisement of the clinics existence

January et al., 2016

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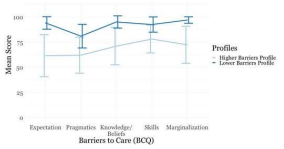
- Clinical outcomes
  - High barriers to care was associated with <u>less stable health course,</u> not being diagnosed in first 3 months of life, and <u>lower quality of life</u> compared to families with lower barriers (Wehrli et al., 2024)



Wehrli et al., 2024

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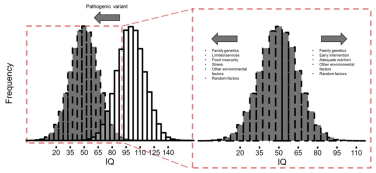
89

Genetic conditions: Rare disease diagnostic odyssey

- Cognitive outcomes--????
  - Many postulations, little evidence



McKinney et al., 2024

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90

Genetic conditions: Rare disease diagnostic odyssey

- Although studies are sparse, extant literature implicate importance of home environment and family systems in cognitive and adaptive outcomes.
  - Fragile X Syndrome: **Enrichment and learning opportunities** in home environment associated with **VIQ** in males and females (Dyer-Friedman et al., 2002)
  - Down syndrome: **Maternal education** is associated with later **expressive vocabulary** (Decker et al., 2019)
  - 22q11.2 deletion syndrome: **Higher SES** is related to better performance scores across **FIQ, Perceptual Organization, Working Memory, global adaptive functioning, and social skills**, combined with **less ODD features** (Shashi et al., 2010)

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91

Social Determinants of Health and Health Equity in Pediatric Neuropsychology

- Social determinants of health (SDOH)
  - Introduction
  - SDOH measurement
  - SDOH and importance in pediatrics
- SDOH in specific medical populations
  - Spina Bifida/Epilepsy
  - In utero exposure/Rare genetic conditions
  - **Oncology**
- Interventions and resources
  - Multidisciplinary clinics
  - Spina Bifida + within organization initiatives
  - Oncology and initiatives in the community
  - ECHO model
- Conclusions

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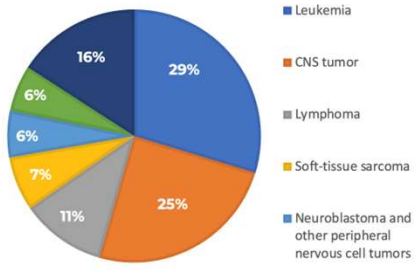
92

Childhood Cancer



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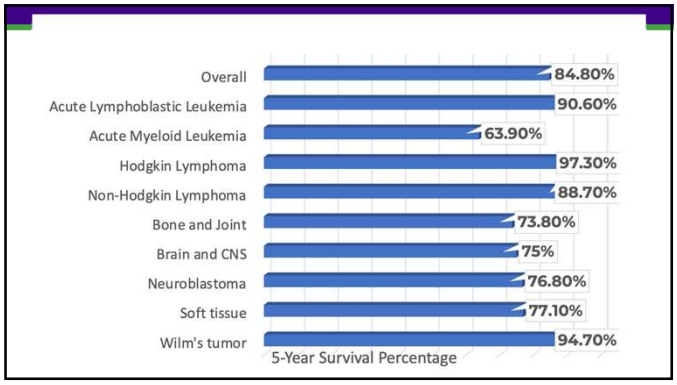
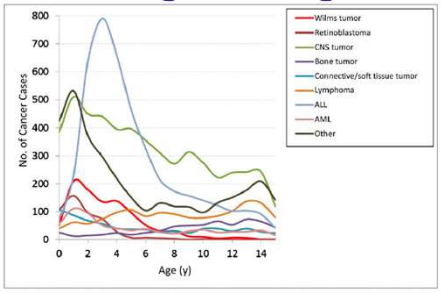
93



94

Incidence: Age at Diagnosis



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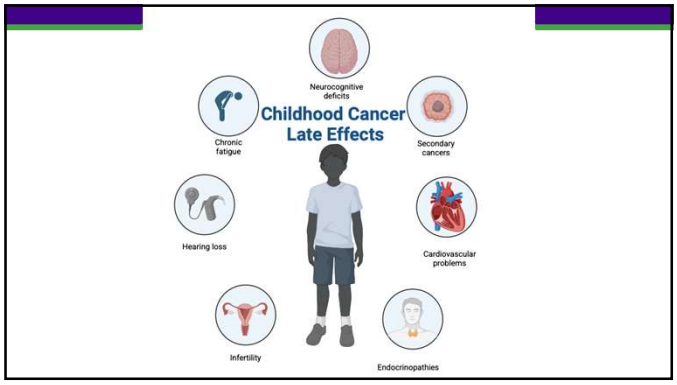
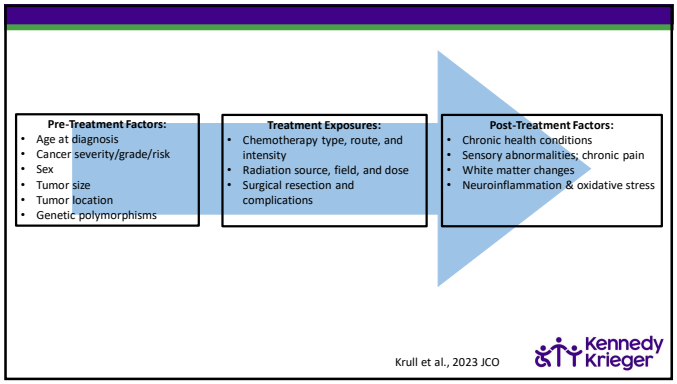
Cancer Treatments

- Individuals are placed on a treatment protocol based on specific medical factors, including age at diagnosis, tumor pathology/cancer type, and extent of disease progression.
- Treatment is often multi-modal, and may include a combination of surgery, radiation, chemotherapy, and/or bone marrow transplant.

96


Childhood Cancer
Late Effects
Neurocognitive deficits
Chronic fatigue
Secondary cancers
Hearing loss
Cardiovascular problems
Infertility
Endocrinopathies

97


Pre-Treatment Factors:
Age at diagnosis
Cancer severity/grade/risk
Sex
Tumor size
Tumor location
Genetic polymorphisms
Treatment Exposures:
Chemotherapy type, route, and intensity
Radiation source, field, and dose
Surgical resection and complications
Post-Treatment Factors:
Chronic health conditions
Sensory abnormalities; chronic pain
White matter changes
Neuroinflammation & oxidative stress
Krull et al., 2023 JCO
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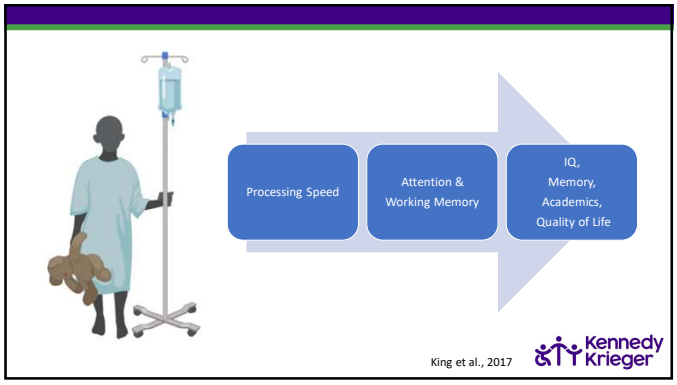
98


Processing Speed
Attention & Working Memory
IQ, Memory, Academics, Quality of Life
King et al., 2017
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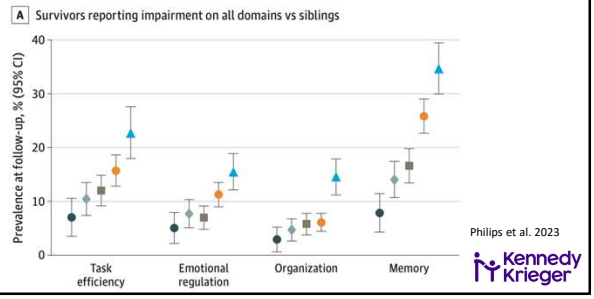
99

Rates of Neurocognitive Impairment



Philips et al. 2023

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100

Individual and Family SDOH			
Parental Mental Health	*Parental Education*	*Sex*	*Family Function/Environment*
• Executive dysfunction in CNS tumors (Peterson et al., 2019) • Verbal and performance IQ in leukemia, lymphoma, & solid tumors (Barrera et al., 2008) • School competence per teacher report in leukemia, lymphoma, & solid tumors (Barrera et al., 2009)	• Social outcomes in CNS tumors and leukemia (Barrera et al., 2005) • Processing speed and verbal memory in CNS tumors (Laliberte et al., 2021) • Academic performance in CNS tumors (Ach et al., 2013) • Adaptive functioning in CNS tumors (Raghubar et al., 2019)	• Females treated with CRT report greater cognitive impairments than males (Peterson et al., In Progress) • Female ALL survivors report greater memory impairments and emotional dysregulation (van der Plaas et al., 2021)	• Family function and child's depressive symptoms in CNS tumors (Laliberte et al., 2021) • Family expression and cohesion reduced child's distress in leukemia, lymphoma, & solid tumors (Jobe et al., 2010; Peterson et al., 2019) • Family cohesion and processing speed in leukemia, lymphoma, & solid tumors (Barrera et al., 2008) • Family support and academic achievement in CNS tumors (Ach et al., 2013)

101

Community SDOH		
Area Deprivation Index	*Child Opportunity Index*	*Economic Hardship Index*
• Adaptive functioning in CNS tumors (Nolan et al., 2023)	• IQ and academic achievement in CNS tumors (Peterson et al., 2024) • Processing speed, working memory, parent reported executive functioning, and parent reported internalizing and externalizing problems in CNS tumors (Nielsen et al., 2023)	• Predicted intellectual and academic outcomes at diagnosis and change in IQ and math skills across time in CNS tumors (Mule et al., 2023)

102

Socio-Economic Status		
Insurance Type	*Financial Resources*	*Hollingshead*
• Public insurance and IQ in CNS tumors (Chang et al., 2023)	• Grade retention in CNS tumors, leukemia, & lymphoma (Barrera et al., 2019) • Parent reported executive functioning in CNS tumors (Laffond et al., 2012)	• Parent reported attention difficulties in CNS tumors and leukemia (Butler et al., 2013) • Parent-reported working memory in CNS tumors (Howarth et al., 2013)

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103

SDOH and Mortality in Pediatric Oncology

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Race & Ethnicity

- Acute Lymphoblastic Leukemia (ALL)
  - Overall survival rates: Hispanic < non-Hispanic White
- Acute Myeloid Leukemia (AML)
  - Overall survival rates: Black < non-Hispanic White
- Hodgkin lymphoma
  - Overall survival rates: Black < non-Hispanic White
- Brain tumors
  - Hazard of death: Hispanic and Black > non-Hispanic White.
- High-grade gliomas
  - Overall survival rates: Hispanic < non-Hispanic White

Aristizabal et al., 2022; Kahn et al., 2016; Johnson et al., 2011; Haizel-Cobbina et al., 2021

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Insurance

- <50% of **Medicaid-insured** children and AYAs with blood cancer have continuous insurance coverage 1-year prior to and through diagnosis (Zhang et al., 2023).
- ALL patients with **no or public insurance** had lower overall survival compared to ALL patients with private insurance (Abrahão et al., 2015).
- **Public or no insurance** was significantly associated with death for adolescent patients (ages 15–19 years) with lymphoid leukemia, acute myeloid leukemia, Hodgkin Lymphoma, and unspecified carcinomas (Tran et al., 2021).

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Socio-Economic Status

- **Median household income**
  - Population: brain tumors (Dressler et al., 2017)
  - Population: Hodgkin Lymphoma (Khullar et al., 2020).
- **Percentage of families living below the poverty line**
  - Population: ALL (Acharya et al., 2016)
- **Area Deprivation Index**
  - Population: ALL (Shraw et al.; 2020)
  - Population: Heterogenous sample of Childhood Cancer Survivors (Ehrhardt et al., 2023)

107

Parental Education

- Higher **parental education** is associated with improved survival in CNS tumors and leukemia (Mogenson et al., 2016; Simony et al., 2016).

108

SDOH and Access to Oncology Services

109

Access to Oncology Services

- Access to radiology services (Gallo-Bernal et al., 2024)
- Access to neuro-oncology appointments (Aguirre et al., 2024; Gruszczynski et al., 2022)
- Access to quality palliative care (McKee et al., 2023)
- Medical interventions (Sharma et al, 2022)
- Access to neuropsychological services (Peterson et al., 2025)

110

SDOH and Access to Oncology Research

111

Disparities in Research by Race

- Only 2% of approximately 10,000 NCI clinical trials have representative minority participants (Nazha et al., 2019)
- Black and Hispanic patients less likely to be treated at NCI designed (Wolfson et al., 2015)
- People of color represent only 14% of clinical trial participants (Chen et al., 2014)

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Disparities in Research by Language

- Limited use of Non-English questionnaires (Grant et al., 2020)
- English as a primary language used an inclusion criteria (Hughson et al., 2016)

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Disparities in Research by Age

- Survival disparities persist among AYAs (age 15 to 21).
- AYAs have lower clinical trial participation rates compared with younger age cohorts (Janardin & Miller, 2023)
  - Insurance status
  - Psychosocial challenges
  - Treatment centers
- Poor enrollment in cancer clinical trials may contribute to inferior survival gains compared with children.

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Disparities in Research by SES

- Medicaid patients were half as likely to enroll in clinical trials than people with private insurance (Baquet et al., 2006)
- Patients enrolled onto clinical trials were significantly less likely to be uninsured (Saterent et al., 2002)
- Geographic areas with higher socioeconomic levels had higher levels of clinical trial accruals (Saterent et al., 2002)

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115

Social Determinants of Health and Health Equity in Pediatric Neuropsychology

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- **Interventions and resources**
  - **Multidisciplinary clinics**
  - Spina Bifida + within organization initiatives
  - Oncology and initiatives in the community
  - ECHO model
- Conclusions

116

Multi-disciplinary clinics

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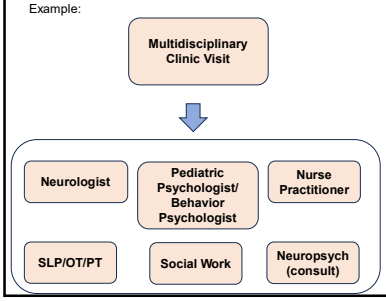
117

Multidisciplinary Clinic Models

Example:



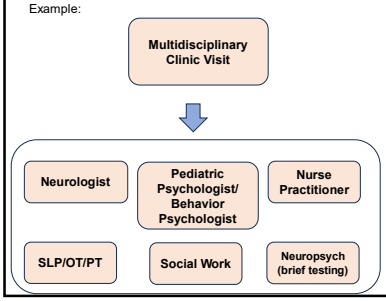
Advantages:
- Specialized care with providers having expertise in the specific condition
- NP can offer recs that may not always require full testing
- NP can provide consultation services and monitor need for full evaluation

Disadvantages
- Requires bought out time for NP
- Requires a referral system where patients determined to need NP can be seen for a full assessment within reasonable time
- Long day of appointments for the patient
- Requires reliable patient caseload to financially sustain the model and scheduling

118

Multidisciplinary Clinic Models

Example:



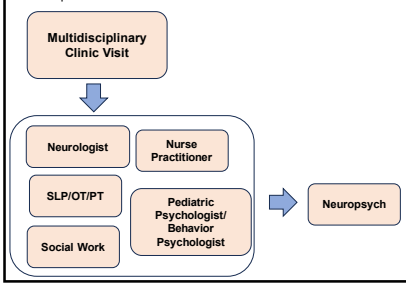
Advantages:
- Specialized care with providers having expertise in the specific condition
- NP can offer recs that may not always require full testing
- NP can provide abbreviated testing on areas at risk (e.g., concussion)

Disadvantages
- Requires bought out time for NP
- Requires a referral system where patients determined to need NP can be seen for a full assessment within reasonable time
- Long day of appointments for the patient
- Requires reliable patient caseload to financially sustain the model and scheduling

119

Multidisciplinary Clinic Models

Example:



Advantages:
- Specialized care with providers having expertise in the specific condition
- NP do not require bought out time to spend a day in clinic
- Patients can receive a full NP evaluation soon after multidisciplinary clinic visit

Disadvantages
- Requires multidisciplinary clinic members to screen the need for NP
- Requires NP to work out decision-making criteria to determine those who need NP
- Requires NP to save assessment slots for the clinic, but some patients may no-show or decline NP testing post-multiD visit
- Requires coordination for patients out of state (e.g., teleNP vs in-person testing)
- Requires reliable patient caseload to financially sustain the model and scheduling

120

Multidisciplinary Clinic Models

Example:

Pediatric Post-COVID Rehabilitation Clinic at KKI

Pre-visit: Clinic coordinator screens intake questionnaires and medical records, gathers insurance information, and coordinates with NP team in the event abbreviated testing needs to be completed in person at multi-D visit or days before/after

- **Neurologist**
- **Nurse Practitioner**
- **Rehab Physician**
- **Behavior Psychologist**
- **Educational Specialist**
- **Social Worker**

→ **Neuropsych (abbreviated testing)**

At visit: Multi-D team screens for cognitive, academic and adaptive changes.

Post-visit NP testing: Post-COVID-Clinic-affiliated neuropsychologists reserve slots for this clinic and thus can schedule the patient to be seen within 2 weeks in-person or via telehealth.

- No significant effect of test modality on screening battery (Luedke et al., 2024)

121

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122

Multidisciplinary Clinic Models

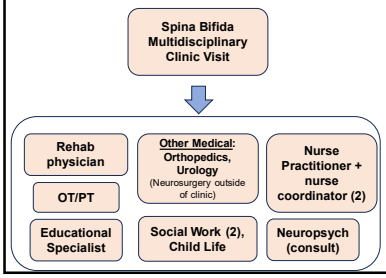
Spina Bifida Multidisciplinary Clinic Visit

- **Rehab physician**
- **OT/PT**
- **Educational Specialist**
- **Other Medical: Orthopedics, Urology** (Neurosurgery outside of clinic)
- **Social Work (2), Child Life**
- **Nurse Practitioner + nurse coordinator (2)**
- **Neuropsych (consult)**

- Monitor based on medical/neurological status, school transitions
- Following clinic, refer to outpatient neuropsychology evals at intervals prior to kindergarten, 3rd grade, 6th grade, 9th grade, transition, etc.).
- Sub-clinics: lifespan
  - Babies <12 months (Dr. Lauren Bradstreet)
  - Transition youth/adults (Dr. Catherine Stephan)
- Consultation with Arabic speaking neuropsychologist (Dr. Christina Salama)

123

Multidisciplinary Clinic Models



- Monitor based on medical/neurological status, school transitions
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- Sub-clinics: lifespan
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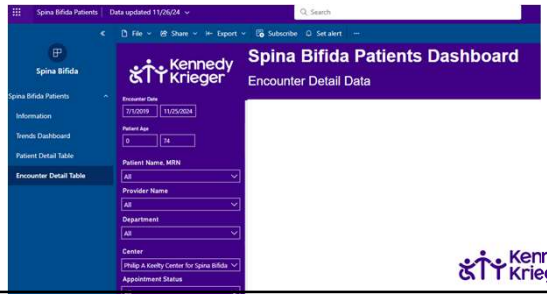
124

SB clinic data



125

SB clinic data

- 318 patients
- Age: <1 year to 75yo, mean=20.80, median=17.00
- Race: 48.7% white, 21.4% Black, 5.3% Hispanic, 3.1% Asian, 1.9% multiracial, 10.1% other, 9.5% unknown
- Ethnicity: 45.0% unknown, 41.2% non-Hispanic, 12.9% Hispanic, .6% Arabic, .3% decline to answer
- Preferred Language: English 89.6%, Spanish 8.8%, Arabic 1.3%, French .3%
- Needs interpreter: Yes 9.7%
- Public insurance 61.7%, private 38.4%
- MD 86.2%
  - AL, DC, DE, LA, MS, MT, NC, NJ, PA, TX, VA WV
- ADI mean state 5.51, national 37.35

126

Within Organization Initiatives

- Food pantry program
  - Food insecurity screening using the Hunger Vital Sign
- Universal suicide screening ages 8+
- TeleTapp program (hotspots, devices during COVID)
- Transportation
- Patient navigation, case management via insurance
- Future Directions: Language Access, translation

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127

SB clinic data: Hispanic/Latinos

- 41 patients (12.9%)
- Age: <1 year to 67yo, mean=14.73, median=12.00
- Preferred Language: Spanish 63.4%, English 36.6%,
- Needs interpreter: Yes 58.5%
- Public insurance 92.7%, private 7.3%
- MD 97.6%
  - DE
- ADI mean state 7.27, national 51.80

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128

Within Organization Initiatives

- Future directions: Spanish sub-clinic


Jessica De Curtis Fernandez, MD


Christina Eguizabal Love, PsyD


Talia Kellner, LMSW

129

Future Directions

- Addressing social determinants of health through customization: Quality improvement, telemedicine, and care coordination to serve immigrant families (Castillo et al., 2023)
  - Customization of electronic medical records (EMR) to identify SDOH
  - SB clinic was the first clinic within the enterprise to rollout the use of an adverse SDOH mitigation activity.
  - Social prescriptions to address SDOH
    - Food insecurity: provided phone number to local food pantry
    - Transportation: referral, education re: medical transport via public insurance
    - Immigration & asylum related issues: clinic SW counseled families on appropriate steps and directions for assistance

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130

Future Directions

- Addressing social determinants of health through customization: Quality improvement, telemedicine, and care coordination to serve immigrant families (Castillo et al., 2023)

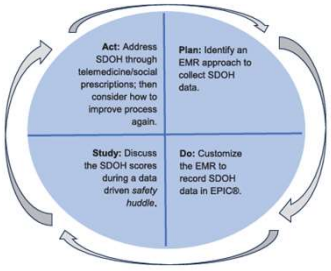
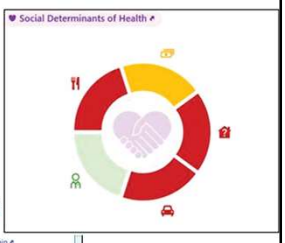


Fig. 2. Plan-Do-Study-Act for a social determinants of health (SDOH) related project. EMR: Electronic medical record.

131

Future Directions

- Addressing social determinants of health through customization: Quality improvement, telemedicine, and care coordination to serve immigrant families (Castillo et al., 2023)



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132

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  - ECHO model
- Conclusions

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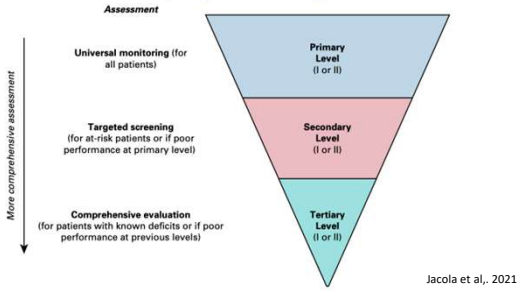
133

Tiered Neuropsychological Services



Jacola et al,. 2021

134

Building Community Partnerships

- Bridging gaps between the hospital and school:
  - Educational liaisons
- Increasing access to medical services:
  - Ronald McDonald House
- Be aware of local resources:
  - Food banks
  - Housing programs
  - Events for children with complex or chronic medical conditions

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Neuropsychologists as Advocates

- Collaborate with community organizations
- Advocate for public policy and programs that address SDOH
- Be aware of resources at the local, state, and federal level for patients with at-risk SDOH
- Participate in advocacy efforts

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136

Research

- Evaluate inclusion/exclusion criteria
- Consider incentives for research participation
- Consider SDOH at various levels
- Disseminate your research findings

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137

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138

Community health care

- Communicating practice approaches to other medical professionals to improve assessment and care management to underserved communities

About This Program

The Pediatric Long COVID ECHO will provide training, mentorship, and support to pediatric primary care providers and allied health professionals on emerging best practices and evidence-based care for pediatric patients with Long COVID.

The Pediatric Long COVID ECHO will address capacity, access, and equity of care for vulnerable and underrepresented populations of children, children with intellectual and developmental disabilities, children in rural communities, and children who are uninsured or underinsured. This ECHO will also enable earlier interventions and empower primary care and community providers to diagnose, treat, and manage long COVID.

How ECHO Works

Moving Knowledge, Not Patients

Through technology-enabled collaborative learning, ECHO creates access to high-quality specialty care in local communities.

Hub and spoke knowledge-sharing networks create a learning loop:

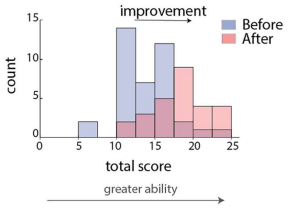
Community providers learn from specialists.

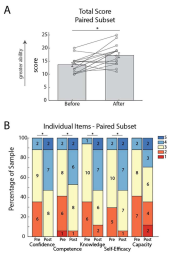
Community providers learn from each other.

Specialists learn from community providers as best practices emerge.

139

Community health care





Villatoro et al., 2025

140

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141

Conclusion

"Do what you can,
with what you have,
where you are."

- Theodore Roosevelt

142

Thank you for watching!

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Rachel Peterson, PhD, ABPP-CN: petersonr@kennedykrieger.org

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143