Autism & Race: Engaging Racially & Ethnically Diverse Communities in Autism Research

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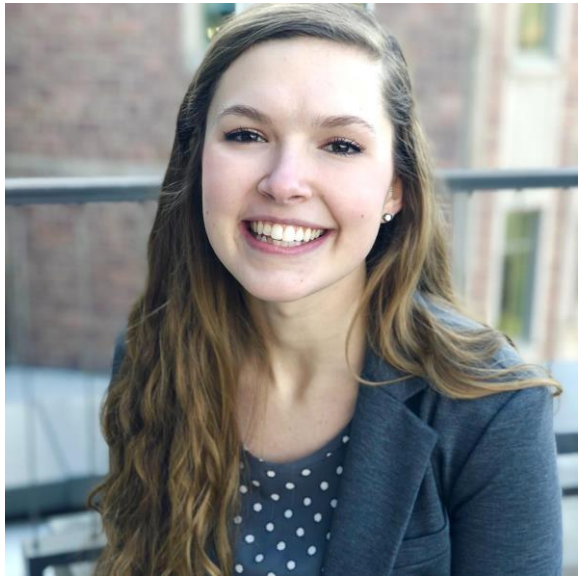
Working Group



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AUTISM & RACE: ENGAGING RACIALLY & ETHNICALLY DIVERSE COMMUNITIES IN AUTISM RESEARCH

SARAH DABABNAH ALLYSA WARE CHARINA REYES

AGENDA

- Introductions
- Overview of the Intersection Between Autism and Race
- Engaging Black and African Americans in Autism Research
- Engaging Asian Americans in Autism Research
- Discussion & Implications for Research

FAMILIES AND COMMUNITIES ARE THE CENTER OF CHILDREN'S LIVES…

- ….but are often left out of autism research.
- Parents as de facto "case managers"
- High levels of parenting stress & depression
- Family financial burden
- Strong relationship between parent and child outcomes

RACIAL & ETHNIC DISPARITIES IN AUTISM DIAGNOSES & TREATMENT

- Nationally, compared to White children, Black and Latinx children:
  - Receive a late or incorrect diagnosis;
  - Visit diagnosticians more often before being diagnosed;
  - Face more obstacles to receive healthcare services; and
  - Are underrepresented in autism research and early intervention services.

References: Mandell et al., 2007, 2009; Magaña et al., 2012; Dababnah & Parish, 2016; West et al., 2016; Zuckerman et al., 2013

DISENTANGLING POVERTY & RACE IN TIMELY AUTISM SERVICE ACCESS

- Poverty and limited education are clear contributors to autism-related diagnostic and service disparities (e.g., *Carr et al., 2016*).
- While parents with limited income and/or education are especially high risk of delayed diagnoses, racism and other service barriers persist for middle/high-income families of color (*Dababnah et al., 2018*):
  - *Example quote from college-educated Black mother of a child with autism:* "[Doctors] assume because I am Black…that I might not be as smart. So, I surprise you when I give you all the information….There are assumptions like…I'm just this person that has multiple kids. This is a Black woman. If you see my three kids, you assume I don't have a husband."

WHAT IS THE RESEARCH MISSING?

- Some research has explored predictors of late diagnoses and reduced service access for children of color with autism. Some examples (*Burkett et al., 2015; Dababnah et al., 2018; Lovelace et al., 2018; Pearson & Meadan, 2018*):
  - poor provider-parent relationships
  - community-based stigma of autism
- Family and community strengths, e.g. stronger relationship between family resilience and stress among Black parents (Kim, Dababnah, & Lee, 2020).

EXPANDING FOCUS TO OTHER U.S. RACIAL AND ETHNIC GROUPS

- Emerging information on the experiences of Latinx and Black families in the U.S.
- Limited literature focused on other ethnic and racial minority families
  - Studies of Korean-American and Arab-American caregivers underscore the complexity of stigma and persistent racism (Habayeb, Dababnah et al., 2020; Kim & Dababnah, 2019):
    - Isolation from family and from ethnic community
    - Service disconnect (e.g., independent living goals)
  - Disproportionately small representation in national datasets

BUILDING COMMUNITY AND CLINICAL PARTNERSHIPS TO BETTER SERVE CHILDREN OF COLOR

- We are missing opportunities to disrupt a service system with racist and classist roots and truly engage children, parents, other family members and community advocates in autism research and interventions.
- The burden of changing systems should **not** be on individuals, families and communities. Systems should examine:
  - Location and hours of clinics
  - Diversity (including neurodiversity) of service providers – which begins well before grad school!
  - Inclusivity of forms and procedures
  - Recognition that many standardized measures have been "normed" with primarily white, mid/upper-income samples
- Professionals are not the only "specialists," and self-advocates and caregivers are not just "service recipients." Parents and self-advocates are knowledgeable, powerful and capable of partnering with professionals!

CASE EXAMPLE: *MARYLAND PARENTS TAKING ACTION*

- Originally developed by Sandy Magaña and colleagues for Latinx parents of children with autism to increase autism knowledge, improve advocacy skills, and build social support
- Engaged community advisory board in Baltimore to adapt content for parents of young Black children with or at-risk for autism
- Peer mentors (i.e., parents of older Black children or adults with autism) delivered the program
  - *I think [PTA] was relevant because a lot of the times in African American communities, the disparities…I feel it get pushed under the rug in this country….[my Parent Leader] and I…actually spoke about that, not enough attention is put on African American families, and what we go through…*
- Two iterations: one community-based and one remote version for parents of children on autism or developmental evaluation waitlists
- Importance of cross-disciplinary collaborations and community partnerships, plus frequent and open communication with all stakeholders

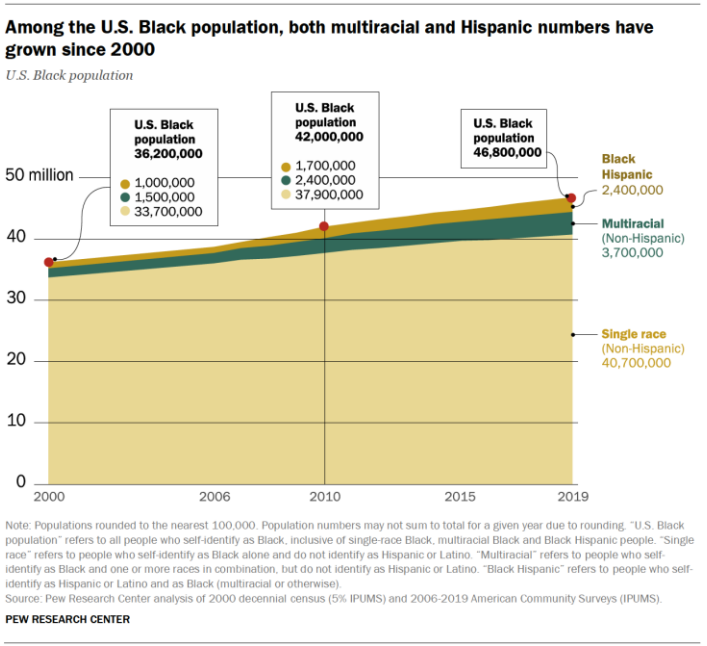
Dababnah, S., Shaia, W. E., Kim, I., & Magaña, S. (in press). *Parents Taking Action*: Adapting a peer-to-peer program for parents raising Black children with autism. (Special issue: Racial and Ethnic Equity for People with Intellectual and Developmental Disabilities.) *Inclusion.*

ENGAGING BLACK AND AFRICAN AMERICANS IN AUTISM RESEARCH

ALLYSA WARE

BLACK OR AFRICAN AMERICANS IN THE UNITED STATES

- The U.S. Black population is growing. 46.8 million identified as Black or African American alone or in combination in the United States in 2019. "That is up from 36.2 million in 2000."
- "At the same time, the Black population's racial self-identification is changing." Among those who self-identify as "Black or African American," the percentage who say it is their only racial or ethnic identification has declined over the past two decades.



PEW Research Center, https://www.pewresearch.org/social-trends/2021/03/25/the-growing-diversity-of-black-america/

BLACK OR AFRICAN AMERICANS AND AUTISM

- CDC estimates that 1 in 55 Black or African American children are diagnosed with autism (Maenner, et al, 2020).
  - For the first time, CDC found the same autism prevalence in black and white children
    - Black children identified received evaluations at older ages than white children
    - Black children who are not diagnosed with an Intellectual Disability might not be identified at the same rate as white children.

Centers for Disease Control and Prevention, https://www.cdc.gov/mmwr/volumes/69/ss/ss6904a1.htm?s_cid=ss6904a1_w

BLACK AND AFRICAN AMERICANS IN AUTISM RESEARCH

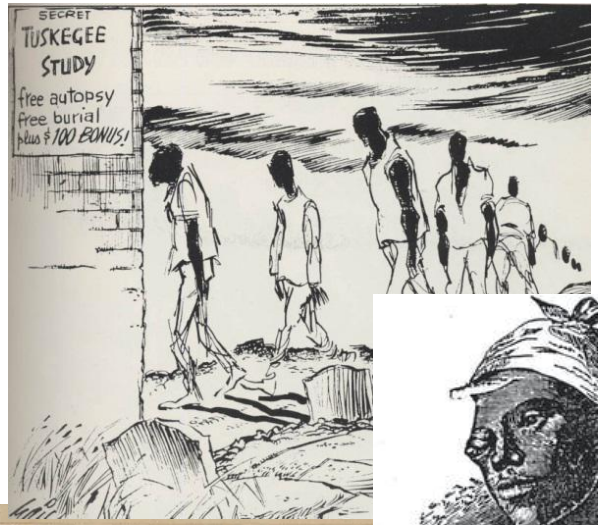
- Black children and families are underrepresented in autism research (Hilton, et al. 2010; West et al. 2016)
- Barriers to research involvement (Shaia et al., 2020):
  - Stigma around autism
  - Lack of trust in researchers and research methods
  - Research materials and processes that are not accessible to the community
- Facilitators to research involvement:
  - Highlighting importance of inclusive research
  - Offering information and support for child and family
  - Engaging with research team members from the local community

Shaia, W.E., Nichols, H.M., Dababnah, S. et al. Brief Report: Participation of Black and African-American Families in Autism Research. J Autism Dev Disord 50, 1841–1846 (2020). https://doi.org/10.1007/s10803-019-03926-0

"Since 1619 when the first enslaved people were brought to the British Colony of Virginia until June 19, 1865, when the last enslaved Black person was emancipated in the USA, Black people, and especially Black women, endured violent medical treatment and experimentation against their will. Enslaved Black people's bodies were exploited for the development of some aspects of US medical education in the 19th century. Medical schools relied on enslaved Black bodies as "anatomical material" and recruited students in southern states by advertising its abundance. This practice was widespread in the 19th and early 20th centuries. American medical education relied on the theft, dissection, and display of bodies, many of whom were Black."

-Ayah Nuriddin, Graham Mooney, Alexandre I R White

"Reckoning with histories of medical racism and violence in the USA"



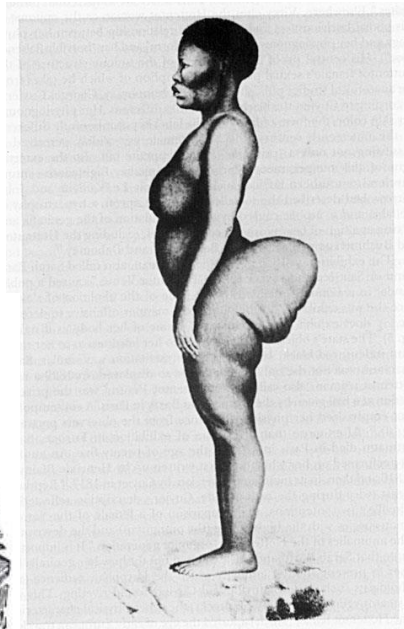
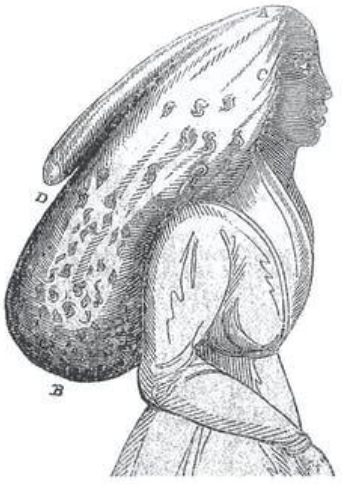
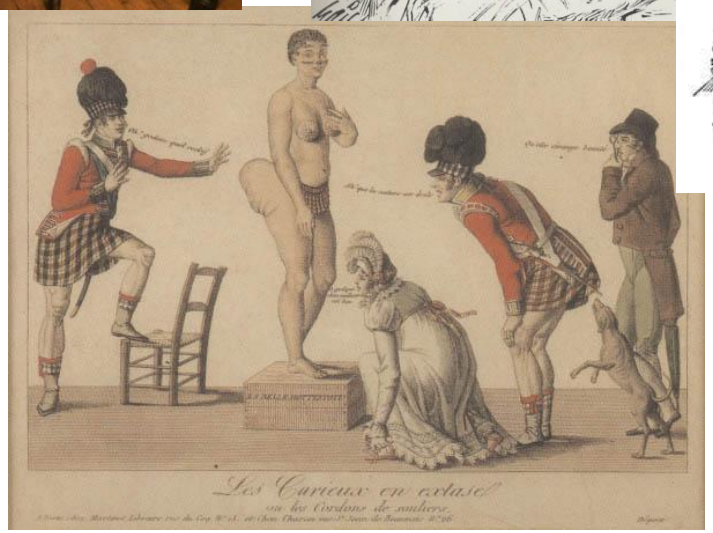


Fig. 5.—"The Hottentot Venus." Georges Cuvier, "Extraits d'observations faites sur le cadavre d'une femme connue à Paris et à Londres sous le nom de Vénus Hottentote," 1817.



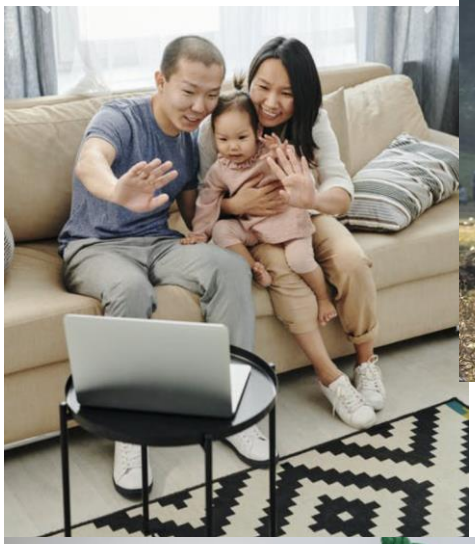


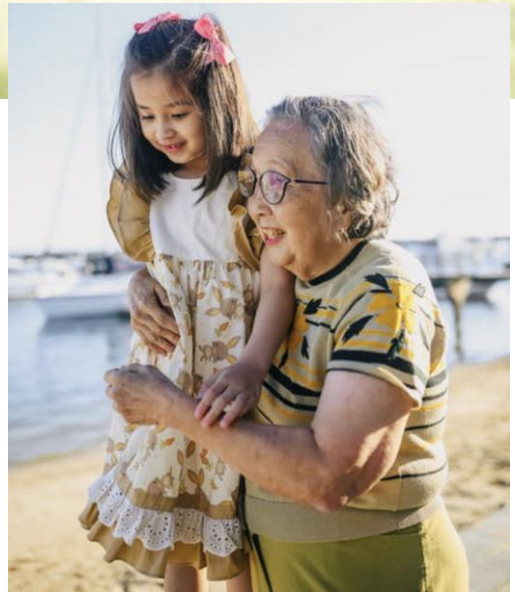
ENGAGING BLACK AND AFRICAN AMERICANS IN RESEARCH

- Develop relationships with the Black and African American Community
  - Include researchers with similar characteristics and experiences as the community you are trying to engage
  - Find out what issues are important to the community before starting your research projects
- Compensate families for their time by providing a stipend, as well as reimbursement for transportation, childcare, and food
- Make study materials accessible and easy to understand

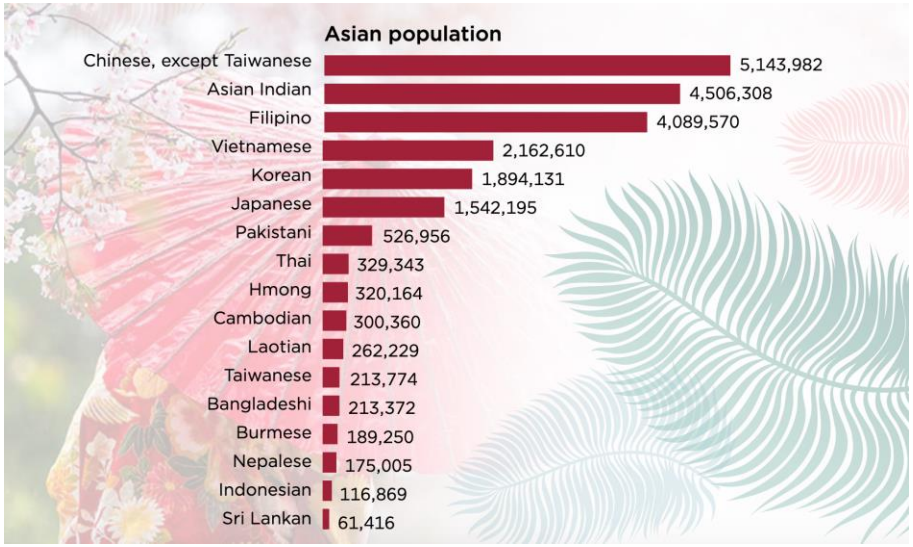
ENGAGING ASIAN AMERICANS IN AUTISM RESEARCH

CHARINA REYES





THE DIVERSITY OF ASIAN AMERICANS



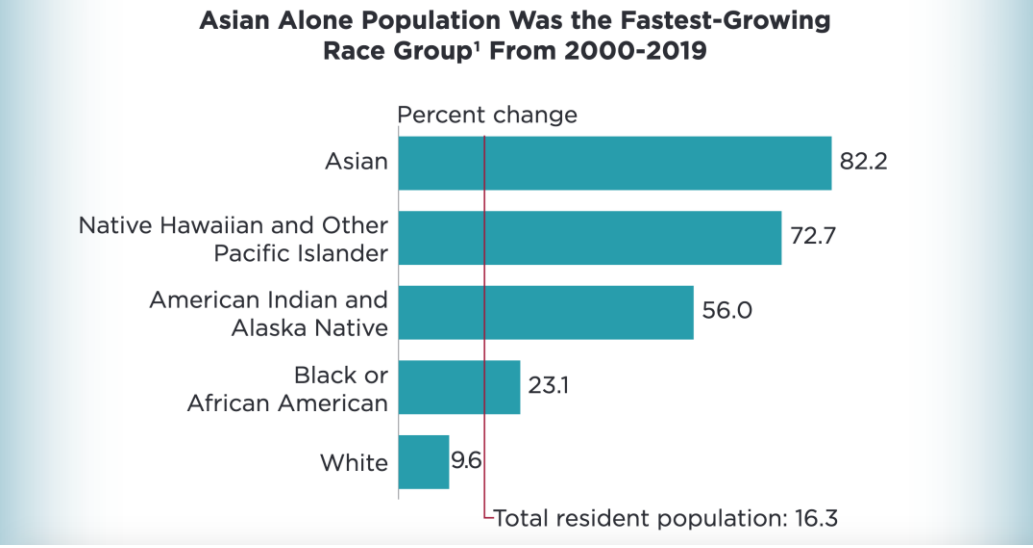
US Census Bureau. 2020. Asian and Pacific Islander Population in the United States. 2018 American Community Survey, 1-Year Estimates, Table B02018: Asian Alone or in Any Combination and Table B02019: Native Hawaiian and Other Pacific Islander Alone or in Any Combination .

- Originate from over 20 countries with over 100 different dialects
- 57% of Asian Americans were born in another country.
  - This includes 71% of Asian American adults.

Budiman, A. and Ruiz, N. 2021. Key facts about Asian Americans, a diverse and growing population. Pew Research Center.

ASIAN AMERICANS: IN NUMBERS

- Asians are the fastest growing racial or ethnic group in the US
  - Population grew 82% from 2000-2019
- 23 million identified as Asian alone or in combination in the United States in 2019.



US Census Bureau. 2021. A Diverse Nation. 2000 to 2010 Intercensal Estimates (2000-2009) and Vintage 2019 Estimates (2010-2019).

ASIAN AMERICANS AND AUTISM

- Autism prevalence among Asian/Pacific Islander children was 17.9 per 1000 children (Maenner, et al, 2020)
  - Similar to that among White and Black children

Maenner MJ, Shaw KA, Baio J, et al. Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2016. MMWR Surveill Summ 2020;69(No. SS-4):1–12. DOI: http://dx.doi.org/10.15585/mmwr.ss6904a1external icon.

Supplementary Table 7: Numerator and denominator counts by race/ethnicity — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2016

	Non-Hispanic White		Non-Hispanic Black		Asian/Pacific Islander		Hispanic	
SITE	Numerator	Denominator	Numerator	Denominator	Numerator	Denominator	Numerator	Denominator
Arizona	148	7883	16	1302	8	719	89	7167
Arkansas	430	25923	96	7926	18	970	49	5079
Colorado	287	22065	43	2793	17	2044	142	13767
Georgia	123	6510	195	9895	46	1998	64	5664
Maryland	81	4831	69	3522	13	725	12	885
Minnesota	141	5736	95	3676	34	2090	36	2043
Missouri	119	7804	73	6291	3	706	3	790
New Jersey	443	13245	188	7159	54	2004	315	10562
North Carolina	245	10522	112	4020	40	1418	63	3272
Tennessee	253	16203	90	5181	13	875	39	3523
Wisconsin	343	20193	93	6744	25	1615	97	6313
All Sites Combined	2613	140915	1070	58509	271	15164	909	59065

ASIAN AMERICANS AND AUTISM RESEARCH

- Among Medicaid-enrolled children, Asian children received more school-based services than white children (Bilaver et al., 2020).
  - However, Asian children were less likely to receive outpatient services (-2.6%)
  - Received significantly lower case management services (-8.3%) compared to other racial groups

Bilaver, L.A., Sobotka, S.A. & Mandell, D.S. (2020) Understanding Racial and Ethnic Disparities in Autism-Related Service Use Among Medicaid-Enrolled Children. J Autism Dev Disord / https://doi.org/10.1007/s10803-020-04797-6

Shorey S, Ng ED, Haugan G, Law E. The parenting experiences and needs of Asian primary caregivers of children with autism: A meta-synthesis. Autism. 2020 Apr;24(3):591-604. doi: 10.1177/1362361319886513. Epub 2019 Nov 13. PMID: 31718238.

ASIAN AMERICAN AND AUTISM RESEARCH

- In a qualitative study of Chinese immigrant families of children with autism, parents endorsed challenges navigating the US health care system and obtaining a diagnosis for their child (Sakai et al., 2019).
  - Similar findings were revealed in a survey–based study of Asian American parents of children with autism in Maryland (Dababnah et al., 2020)

Dababnah, S., Kim, I., & Wang, Y. (2020, November). Needs assessment of Maryland Asian American caregivers of children with developmental disabilities. Baltimore, MD: University of Maryland. https://www.ssw.umaryland.edu/academics/faculty/sarah-dababnah/

Sakai, C., Mulé, C., LeClair, A., Chang, F., Sliwinski, S. K., Yau, Y., & Freund, K. M. (2019). Parent and Provider Perspectives on the Diagnosis and Management of Autism in a Chinese Immigrant Population. Journal of developmental and behavioral pediatrics : JDBP, 40(4), 257–265. https://doi.org/10.1097/DBP.0000000000000660

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ASIAN AMERICAN AND AUTISM RESEARCH

- Parents reported benefit of having available interpreters, however physicians endorsed difficulties in finding interpreters trained in explaining developmental disorders and mental health conditions (Sakai et al., 2019).
  - In the Maryland Needs Assessment (Dababnah et al 2020), of those who required interpreters, 48% reported that language interpreters were not available when they needed them, over 40% said interpreters did not help them understand what healthcare professionals said
- Stigma in the community was also reported as diagnostic barrier (Dababnah et al., 2020; Shorey et al 2020).

Dababnah, S., Kim, I., & Wang, Y. (2020, November). Needs assessment of Maryland Asian American caregivers of children with developmental disabilities. Baltimore, MD: University of Maryland. https://www.ssw.umaryland.edu/academics/faculty/sarah-dababnah/

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CURRENT CHALLENGES

- Limited studies exist focused on Asian American families of children with autism
  - A scoping review identified only a small number of mostly qualitative studies (Kim et al., 2020)

- Data on Asian Americans and Native Hawaiian Pacific Islanders are often aggregated into a single group
  - While they may share similarities, treating Asian Americans and Native Hawaiian Pacific Islanders as a homogenous group creates an assumption that these groups share similar cultures and beliefs (Doan et al., 2019).

Đoàn LN, Takata Y, Sakuma KK, Irvin VL. Trends in Clinical Research Including Asian American, Native Hawaiian, and Pacific Islander Participants Funded by the US National Institutes of Health, 1992 to 2018. JAMA Netw Open. 2019;2(7):e197432. doi:10.1001/jamanetworkopen.2019.7432

Kim, I., Wang, Y., Dababnah, S. et al. (2020). East Asian American Parents of Children with Autism: a Scoping Review. Rev J Autism Dev Disord. https://doi.org/10.1007/s40489-020-00221-y

CURRENT CHALLENGES

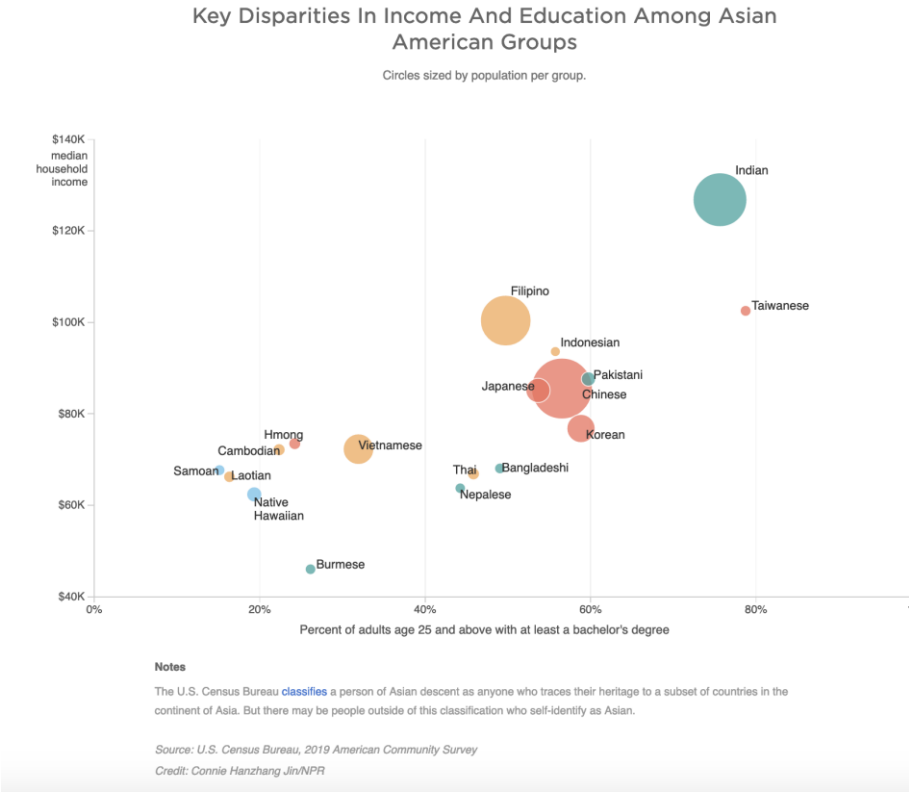
Model Minority: Overcoming the Myth

While it may highlight the strengths of Asian Americans, the model minority stereotype may also tend to overstate the financial, educational, and social support of Asian subgroups when presenting aggregated data

Yi and colleagues (2016) commented that "*Both the stereotype and this persistent lack of disaggregated data perpetuate a cycle wherein Asian American populations are excluded from consideration for public service programming and funding.*"

Yi, S. S., Kwon, S. C., Sacks, R., & Trinh-Shevrin, C. (2016). Commentary: Persistence and Health-Related Consequences of the Model Minority Stereotype for Asian Americans. *Ethnicity & disease*, *26*(1), 133–138. https://doi.org/10.18865/ed.26.1.133

Jin, C. 6 Charts That Dismantle The Trope Of Asian Americans As A Model Minority. NPR. May 2021. https://www.npr.org/2021/05/25/999874296/6-charts-that-dismantle-the-trope-of-asian-americans-as-a-model-minority



CURRENT CHALLENGES

- Challenges in **recruiting** Asian immigrants (Katigbak et al., 2016)
  - Limited access to research

"I'm glad to see this research. We are an undeserved community - no one believes that Asian children could be anything less than "smart". My husband and I are the children of immigrants, we're highly educated. So an autism diagnosis hit us like a ton of bricks." (Dababnah et al., 2020).

Dababnah, S., Kim, I., & Wang, Y. (2020, November). Needs assessment of Maryland Asian American caregivers of children with developmental disabilities. Baltimore, MD: University of Maryland. https://www.ssw.umaryland.edu/academics/faculty/sarah-dababnah/

Katigbak C, Foley M, Robert L, Hutchinson MK. Experiences and Lessons Learned in Using Community-Based Participatory Research to Recruit Asian American Immigrant Research Participants. J Nurs Scholarsh. 2016 Mar;48(2):210-8. doi: 10.1111/jnu.12194. Epub 2016 Feb 2. PMID: 26836035; PMCID: PMC5296612.

CURRENT CHALLENGES

- Challenges in **recruiting** Asian immigrants (Katigbak et al., 2016)
  - Limited English proficiency and linguistic mismatches
  - Shared ethnicity may not be sufficient at times to engage participants
  - Competing commitments of the participant (family, child care, work responsibilities)

Katigbak C, Foley M, Robert L, Hutchinson MK. Experiences and Lessons Learned in Using Community-Based Participatory Research to Recruit Asian American Immigrant Research Participants. J Nurs Scholarsh. 2016 Mar;48(2):210-8. doi: 10.1111/jnu.12194. Epub 2016 Feb 2. PMID: 26836035; PMCID: PMC5296612.

CURRENT CHALLENGES

- Cheah and colleagues (2020) found that almost half of Chinese American parents and youth in their study reported being targeted by COVID-19 racial discrimination online and/or in person (Cheah et al., 2020).
  - Findings also revealed higher levels of perceived racism was associated with poorer mental health in parents and youth
- Dababnah et al (2021) found that some Asian American parents of children with developmental disabilities endorsed concern about discrimination several months into the pandemic
  - Furthermore, almost half of the parents in their study reported their child had not been able to receive alternative services for those cancelled as a result to the pandemic

Cheah CSL, Wang C, Ren H, Zong X, Cho HS, Xue X. COVID-19 racism and mental health in Chinese American families. Pediatrics. 2020; doi: 10.1542/peds.2020-021816

Dababnah, S., Kim, I., Wang, Y., & Reyes, C. (under review.) Brief report: Impact of the COVID-19 pandemic on Asian American families with children with developmental disabilities.

ENGAGING ASIAN AMERICANS IN RESEARCH

- Use of tools/ tests with cultural and linguistic validity if available (Chen et al., 2005)
- Use of culturally tailored recruitment materials
  - Javier et al (2019) found that use of scenes of Filipino family members, testimonials of previous Filipino participants including one speaking in Tagalog, and highlighting Filipino values, in a recruitment video for a parenting program resulted in a 2.7x odds of enrolling, compared to the control

Chen H, Kramer EJ, Chen T, Chung H. Engaging Asian Americans for mental health research: challenges and solutions. J Immigr Health. 2005 Apr;7(2):109-16. doi: 10.1007/s10903-005-2644-6. PMID: 15789163.

Javier JR, Coffey DM, Palinkas LA, Kipke MD, Miranda J, Schrager SM. Promoting Enrollment in Parenting Programs Among a Filipino Population: A Randomized Trial. Pediatrics. 2019 Feb;143(2):e20180553. doi: 10.1542/peds.2018-0553. PMID: 30679379; PMCID: PMC6361353.

ENGAGING ASIAN AMERICANS IN RESEARCH

Community-Based Participatory Research (Katigbak et al., 2016, Chen et al., 2005; Javier et al., 2019)

- Establishing collaborative networks within the community and organizations
- Developing equal partnerships among researchers and community members
  - Shared decision making in identifying the research problem, analysis of data and interpretation of results
- Opportunity for "co-learning"

Chen H, Kramer EJ, Chen T, Chung H. Engaging Asian Americans for mental health research: challenges and solutions. J Immigr Health. 2005 Apr;7(2):109-16. doi: 10.1007/s10903-005-2644-6. PMID: 15789163.

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FUTURE AREAS

- Identifying unique strengths and challenges among origin sub-groups of Asian American families and individuals with autism
- Engaging 'hidden populations' in research (Katigbak et al., 2016, Chen et al., 2005)

Chen H, Kramer EJ, Chen T, Chung H. Engaging Asian Americans for mental health research: challenges and solutions. J Immigr Health. 2005 Apr;7(2):109-16. doi: 10.1007/s10903-005-2644-6. PMID: 15789163.

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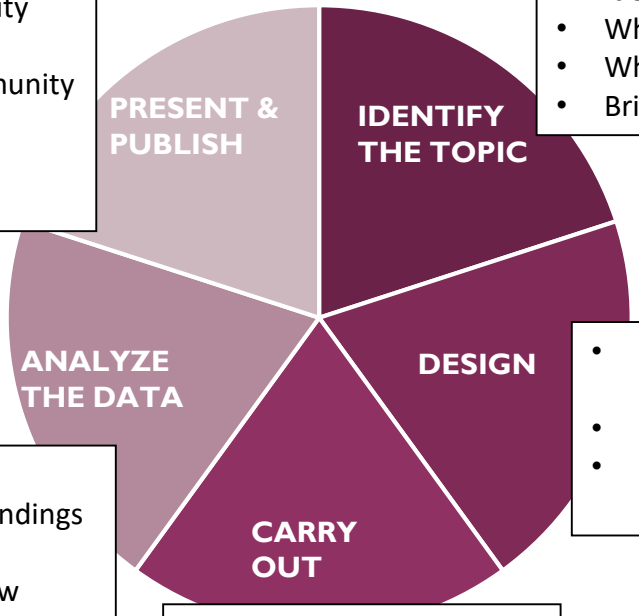
DISCUSSION & IMPLICATIONS FOR RESEARCH

THE RESEARCH CYCLE



- Identify a community first
- What a researcher is interested in
- What families are interested in
- Bring those two together

- Family partners help design surveys, interview guides, fliers, other materials
- Families help test instruments
- Representative of the communities being studied

- Recruit participants
- Lead focus groups
- Administer surveys
- Conduct interviews

- Code interviews
- Discuss the meaning of findings
- Think about what the community needs to know about the study

- Where can findings be distributed?
- Communicate to family/community networks
- Present at conferences and community events
- Leave something behind for the community

CYSHCNET

WE CAN DO BETTER! WE *HAVE* TO DO BETTER!

- Listen to self-advocates, parents, and other advocates!
- Train primary healthcare providers on implicit bias and values affirmation in communicating with patients and family members
- Collaborate with researchers to document and address racial and ethnic disparities, including provider-level factors
- Include paraprofessionals and community health workers to facilitate communication and follow-up between parents and providers
- Partner with other child- and family-serving organizations (e.g., childcare providers, schools)
- Recognize the increased barriers facing communities of color and advocate for policies that directly address institutionalized racism and classism

COMMUNITY-ENGAGED RESEARCH MATTERS!

- We cannot address racial and ethnic disparities without more intervention research that is:
  - Inclusive of families;
  - Culturally relevant;
  - Multilevel (e.g., involve schools/teachers, childcare providers, policymakers); and
  - Multidisciplinary.
- Community partners should not be an afterthought in research studies. They are essential to reaching the most underserved populations, and should be core part of the research team.
- Community-engaged intervention research takes time, particularly to build trust with an array of community partners; hire and train new staff; and reach those not already connected to services.
- Autism researchers need measures that are:
  - focused on child/family strengths and appropriate for diverse cultural groups;
  - include open-ended questions and other forms of data to provide fuller picture of outcomes of interest (e.g., Parenting Stress Index + open-ended questions).
- More support for local (city/county/state/region) autism research consortiums could pool resources, reduce redundant services, share knowledge, and increase collaboration.

RESOURCES

- CYSHCNet Guide to Family Engagement will be available in Fall of 2022, free of charge on the CYSHCNet website: www.CYSHCNet.org
- Engaging Parents and Stakeholders in Patient-Center Pediatric Research and Research Agenda Setting: https://medschool.cuanschutz.edu/docs/librariesprovider94/default-document-library/coconet-link-1_4-18-18.pdf?sfvrsn=98c40ab9_2
- Family Engagement in Systems Assessment Tools (FESAT): https://familyvoices.org/familyengagementtoolkit/
- The Standard of Compensation for Youth & Family Partners: https://cyshcnet.org/compensation-guide-for-youth-family-partners/

Autism & Race: Engaging Racially & Ethnically Diverse Communities in Autism Research

Questions and Answers

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To Join INSAR Visit: http://autism-insar.org/membership
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INSAR INSTITUTE 2021
AUTISM & INTERSECTIONALITY
JUNE 17 - JULY 21, 2021

Central Elements between Intersectionality, Autism & Gender: The Research in 2021

Wenn Lawson & Jac Den Houting

Monday, July 19th, 6:00 PM EDT

Autism & Neurodiversity: Intersectionality and Social Justice

Steven Kapp & TC Waisman with Christina Nicolaidis

Thursday, July 22nd, 2:00 PM EDT

Coming Soon: INSAR STC Anti-racism Resources Repository

Email StudentCommittee@autism-insar.org for more information