A: Primary Care Services and Quality
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The Autism Intervention Research Network (AIR-P) is funded by the Maternal and Child Health Bureau at HRSA.

This project is supported by the health resources and services administration (HRSA) of the U.S. Department of health and human services (HHS) under the autism intervention research network on physical health (AIR-P) grant, UT2MC39440. The information, content and/or conclusions are those of the authors and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.
PROBLEM
• Autistic adults have a higher prevalence of co-occurring medical conditions with limited access to healthcare
• Lack of physician training for working with autistic individuals

MISSION
• To improve primary care for autistic adults
• Incorporate guideline-driven practices for general population + personalized accommodations

RESEARCH AGENDA
• Promote autistic individuals’ self-determination in health care
• Enhance primary care provider training
• Improve mental health and psychiatric care
Needle Anxiety Study

NEEDLE ANXIETY PROGRAM

• Tiered approach for patients with trypanophobia (fear of needles)
• Currently implemented in one UCLA Clinic – working on expanding across all clinics
• 2 papers written sharing lessons learned and implementation process, to be published with AIR-P Supplement 2
  • Three-tiered needle anxiety program: Improving the medical experience for individuals with IDD and needle phobia
  • Implementation and Outcomes of a Minimal Sedation Protocol to improve healthcare for individuals with IDD and needle phobia
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QUESTIONS
B: Community-based Lifestyle Interventions
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Community-Based Lifestyle Intervention Node Leader, AIR-P
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Node Overview: Community-based Lifestyle Interventions

We aim to prioritize the support, development, and evaluation of interventions that:

1. Create social connectedness
2. Build self-advocacy capacity
3. Engage families and communities
4. Improve the 6 pillars of lifestyle wellness
Lifestyle medicine is an evidence-based approach to preventing, treating and even reversing diseases by replacing unhealthy behaviors with positive ones—such as eating healthfully, being physically active, managing stress, avoiding risky substance abuse, adequate sleep and having a strong support system.
• Collaborating with Drexel University and the Community College of Philadelphia on their Project Career Launch, a school-to-work transition program that prepares autistic young adults for employment.

• As part of this collaboration, we hope to provide a virtual version of our adulting class:
  • 8-10 weeks
  • Community sample of approximately 25 students 18 and older
  • Focuses on mental and physical health informed by a needs assessment from the class prior to course start
COVID FAMILY STUDY

COVID-19

- Difficulty accessing well-child care
- Delays in routine childhood vaccinations
- School shutdowns
- Loss of school-based services
- Inability to access assessments
- Inability to access services
- Lost opportunities for socialization and play
- Family losses
### Variable Quotes

| Recs for service improvement | "train the teachers"
|------------------------------|------------------|
|                              | "resume evaluations"

"My kids are having a very difficult time with the online learning and several of them have adhd. They can't sit still, can't juggle the assignments and the access to the platforms. I'm not tech savvy either and have 8 kids. I can't help them. The schools haven't put forth effort for the most part to help their special needs and it is excuse after excuse."

| Success with obtaining services | "private services"
|--------------------------------|---------------------|
|                                | "advocacy"
|                                | "virtual methods"
|                                | "great teachers"

"I have become a bulldog to advocate for my kids. I'm infuriated. I am demoralized by how the districts don't care and do what's necessary to get the child under enough control or managed enough so the parents go away. That's been my experience. They don't care. They can't even figure out what they're doing next week so we are low on the priority. Lend at UCLA has helped us with some advocating. Overall, it's been the worst academic experience of my 22 years of parenting."

| Physical health solutions | Exercise "yoga", "trampoline", "zoom play with friend"
|---------------------------|--------------------------------------------------|
| Coping tools              | "zooming with family"
|                           | "meditation"
|                           | "talking about things together"
|                           | "antidepressants"

"Laughter, Gratitude, Mindfulness, Perspective. Going to the beach. And we all love to read and have a great home library and use that to help our minds travel when we are stuck in place."
COVID FAMILY STUDY

Income Plays a Large Role

Need Best Practices for Remote Learning

Medical Services Impacted Less

Investment Needed for Mental and Physical Health Support
LEND Clinic: Redesigning Primary Care for Autistic Individuals

AIR-P RESEARCH SCHOLARS STUDY

SHEIDA RALEY (Kansas University Center of Developmental Disabilities)
Community-Based Self-Determination Intervention to Enhance Goal Setting and Attainment: Targeting Employment, Postsecondary Education, Community Participation, and Physical Health Outcomes

KENDRA LILJENQUIST (University of Washington)
Informing the Design of Culturally Relevant Transition Programming for Racial/Ethnic Minority and Linguistically Diverse Young People and Their Families
QUESTIONS
C: Gender, Sexuality and Reproductive Health
Gender, Sexuality and Reproductive Health Node

Node leaders: Lisa Croen, PhD; Maria Massolo, PhD
Division of Research, Kaiser Permanente Northern California

Guiding principle: Sexuality and relationships contribute to life satisfaction, health, and well-being for all individuals

Goal: To improve sexual and reproductive healthcare and outcomes for autistic people across the lifespan, with a focus on autistic women and sexual and gender minorities (SGM; e.g., lesbian, gay, bisexual, transgender, queer, intersex and asexual)
Gender, Sexuality and Reproductive Health Node

Proposed Node Priorities
- Sexuality Education
- Sexual and Reproductive Health Services
- Sexual Victimization and Abuse
- Sexual and Gender Minority Health

Work guided by:
- Stakeholder advisory group
- Identification of urgent knowledge gaps
- Workforce development (clinicians, researchers)
Gender, Sexuality and Reproductive Health Node

Current Projects
• Landscape review and identification of research priorities
• Research studies
  1. Addressing Reproductive Health and Obstetrics/Gynecology Health Care in Autistic Adults (Ames)
  2. Health equity promotion for sexual and gender minorities on the autism spectrum (Holmes)

Contact:
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D: Health Systems and Services
Health Systems and Services Node

Lindsay Shea, MS, DrPH
Paul Shattuck, PhD

LJL42@Drexel.edu
Health Systems and Services Node

Mission: Create new ways to measure how research and policy improve care coordination and service delivery

We focus on population-level life course outcomes across diverse groups and a wide range of outcomes that impact physical health, from employment to communities.
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Co-occurring neurologic conditions such as seizures and insomnia are prevalent in autistic individuals and can present across the lifespan.

- Autistic individuals are at up to 30% higher risk for seizures compared to the general population (Achkar & Spence, 2015).
- Sleep disturbances are reported in up to 80% of autistic individuals (Accardo, 2015; Malow, 2012).
- Motor dysfunction/differences/impairments are also prevalent in autistic individuals and can manifest in a heterogenous manner across a lifespan (Fournier et al, 2010; Bhat et al, 2011).
Co-occurring Neurologic Conditions

• Seizures/epilepsy
  • Can impact adaptive function, cognition, and overall development.

• Sleep disturbances
  • Impact cognition, affective regulation, exacerbate co-occurring behavioral conditions, worsen quality of life.

• Motor dysfunction
  • Increase sedentary behavior, impact physical health, reduce opportunities to engage with peers, potentially impact development of cognition, communication, and more complex motor abilities.
Gaps in care

- Recognition of these co-occurring conditions by health care providers.
- Appropriate screening, first line treatment/referral, recognition of side effects.
- Etiology of these conditions and cascading effects and interventions: initial focus on motor dysfunction.
- Studies that include evaluation of individuals with co-occurring neurologic conditions.
Expressive Movement Initiative

Mission

• Provide an expressive outlet for individuals with developmental disabilities
• Foster mentorship and a sense of community among students and volunteers
• Eliminate the stigma and reduce the challenges associated with disability on the UCLA campus and beyond
• Served over 150 children in person and over 60 children virtually (nationally)
• Launched the first pilot program virtually in 2021

https://www.emiucla.org
Genetic evaluation in Autistic Individuals

- Autism has a heritability of 80%, a monozygotic concordance rate of 70–90%, dizygotic concordance of around 10%, and more than a 20-fold increase in risk for first-degree relatives (Bai et al., 2019).
- While a proportion of autism risk is attributable to common variants, rare copy-number variants (CNVs) and protein-disrupting single-nucleotide variants (SNVs) have been shown to significantly contribute to autism etiology (Bacchelli et al., 2020)
- Exome sequencing has identified de novo genetic changes in 15% of autism cases
- Microarray testing identifies a genetic etiology in 20% of autism cases
- Fragile X testing identifies a diagnosis in 1% of autism cases
Gaps in Knowledge

• What is the diagnostic utility of genetic testing?
• What is the clinical utility of genetic testing?
• Is the genetic testing approach cost–effective?
Genetics Utility

- Opportunities for interventions (available or through natural history registries, research)
- To better understand the clinical course of genetic conditions
- Reach out to community physician practices and families
- Provide genetic counseling to address the uncertainty of what caused it and will it happen again (diagnostic journey)
- Many times more than one affected child is born before a diagnosis is made (family planning, recurrence risks)
- Anticipate complications (like cancer, seizures)
- Develop a personalized medical plan to each individual
- Provide community/professional resources
Genetics Node Priorities

• Reduce the diagnostic journey for autistic individuals
  • Provider and patient health literacy
  • Promote least invasive sample collection (saliva versus blood, etc) and reduce impact of stressors whenever possible
• Educational advocacy
• identifying individuals with a rare genetic diagnosis, particularly among underserved populations
Genetics
Node Priorities

• Network to identify study cohorts and deploy natural history studies for defined genetic causes of autism
• Gaps in knowledge on the benefits of genetic testing on medical care for patients with autism: clinical utility
  • Anticipate healthcare needs, preventative care, co-occurring physical conditions
  • Participate in developing personalized medical plans
• Medical provider training: physical exam findings suggestive of a genetic etiology, genetic counseling, and testing algorithms
Genetics Node Priorities

• Enhance our understanding of the impact of genetic diagnoses in patients with autism/DD from underrepresented groups

• Couple early DD/autism detection with early genetics evaluation

• Mentor trainees in autism intervention research with an emphasis on impact of genetics:
  • Prioritize involvement of junior investigators in pilot project grants

• Leverage genetics into each intervention study to understand:
  • the phenotypic spectrum of neurodiverse genetic causes of autism
  • Potential causes why the intervention is successful or not