SEED Follow-Up Studies

Carolyn DiGuiseppi, MD, PhD

Study to
Explore
Early
Development

Study to Explore Early Development (SEED)

- Describe behavioral variation in pre-school children with ASD
- Describe developmental, medical and behavioral conditions associated with ASD in pre-school children
- Understand genetic and environmental factors that may contribute to ASD

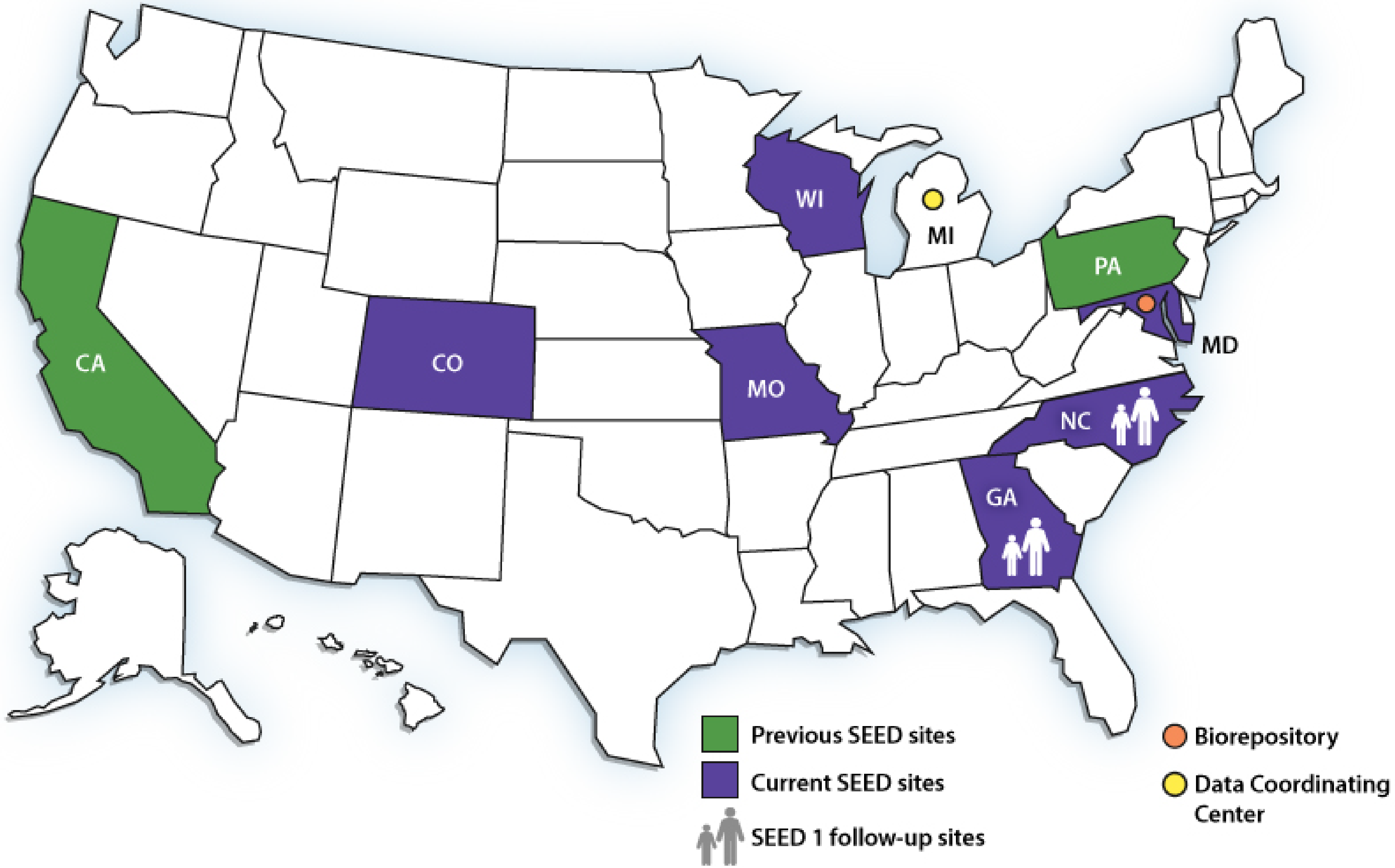
Study to Explore Early Development (SEED)

Children aged 2-5 with ASD

Children aged 2-5 with non-ASD developmental disabilities (DD)

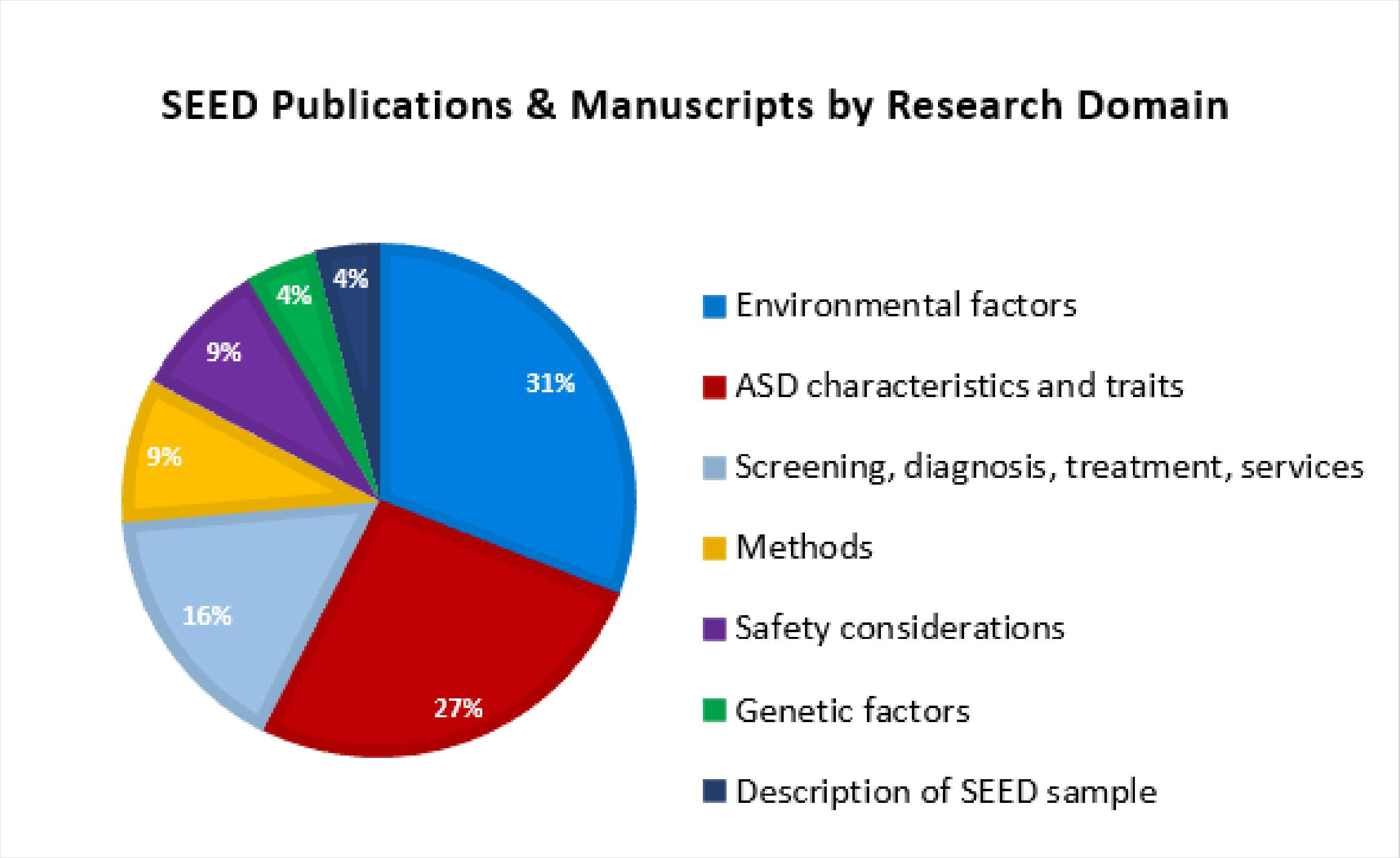
Children aged 2-5 from general population

Study to Explore Early Development (SEED): Phases 1, 2, and 3



Study to Explore Early Development (SEED)

- **63 peer-reviewed papers** in leading scientific journals
- 85 ongoing analyses for additional papers



Study to Explore Early Development (SEED)

SEED 3 ended June 2021

Complete data available for >6000 families in SEED 1-3, including >2000 children with ASD

Previously enrolled children now aged 5-19 years

What’s next? SEED Follow-Up Studies

Gain insights into life course experiences of children with ASD and DD by re-contacting and collecting data on SEED 1-3 participants

Part 1: Follow-up Surveys of Existing SEED Participants

Aim: better understand how adolescents and young adults with ASD differ from those with other DDs or from the general population

Administer surveys to caregivers of existing SEED 1-3 participants

Part 1: Follow-up Surveys of Existing SEED 1-3 Participants

Core Survey – caregivers of all participants

Age-specific Survey – varies with current age of child

Second Follow-Up Survey - adult SEED participants & caregivers

First Follow-Up Survey: SEED 1-3 Caregivers

- Co-occurring symptoms & conditions
- Level of supports needed
- Health & mental Service use & need
- Educational, community, and social supports
- Bully & discrimination
- Child safety
- Family & financial impacts
- Independence & adaptive behavior

Age-Specific Surveys

Domains assessed	Respondents	Current age of enrolled child
Executive function and sensory challenges	SEED 3 caregivers	Aged 5-8
ASD symptoms, transition planning, parent expectations	SEED 2 caregivers	Aged 10-14
Employment, vocational training	SEED 1 caregivers	Aged 16-19

Second Follow-Up Survey: SEED 1 Participants

Caregiver Survey (10 min)

- Changes in health care access or needs
- Vocational/occupational training & support
- Changes in daily activities and social participation
- Post-secondary education

Adult Child Survey (40 min)

- Anxiety & Depressive symptoms
- Substance abuse
- Suicidality
- Quality of life
- Social camouflaging
- Sexuality, gender identity, and relationships
- Resiliency

Follow-up Surveys of Existing SEED Participants: Life course experiences of children with ASD & DD

- Health service needs and utilization
- Community and social supports
- Bullying and discrimination
- Safety and suicide
- Family and financial impacts
- Independence and adaptive behavior
- Planning for exit from high school and vocational training
- Self-reported relationships, quality of life

Part 2: In-Person Assessment of Intellectual Abilities of SEED Participants

- How intellectual functioning relates to adolescent and young adult outcomes
- The relationship between intellectual functioning and daily activities
- How these abilities change as participants age
- Factors that affect the trajectory of their abilities

In-Person Assessment of Intellectual Abilities of SEED Participants

- SEED 1 and 2 participants with ASD or other DD whose caregiver completed the first follow-up survey invited to clinic
- Two standardized Instruments
  - Stanford-Binet Intelligence Scales, Fifth Edition (SB-5) – assess cognitive abilities
  - NIH Toolbox Pattern Comparison Processing Speed Test – assess how well a person can make sense of new information compared to other people the same age

Part 3: Maximize the impact of existing SEED data

- Analyze the data to understand characteristics and needs of children with ASD
- Use the data to identify subgroups susceptible to contributing factors
- Share findings with scientific, professional, and public audiences

In Closing…

Longitudinal follow-up of children with ASD may inform strategies for predicting needs and improving the quality of life of children and families affected by ASD

Improved understanding of the health and functioning of individuals with ASD as they mature can reduce the adverse public health and economic impacts of ASD

Study Team

- Carolyn DiGuiseppi, MD (PI)
- Cordelia Robinson-Rosenberg, PhD, RN (PI)
- Kristina Hightshoe, MSPH
- Kaylynn Aiona, MPH
- Brian Barger, PhD
- Brian Be, LEND alumnus, autistic
- John Brinton, PhD
- Christine H. Cook, BA
- Tessa Crume, PhD
- Ethan Dahl, PhD
- Sandra Friedman, MD, MPH
- Brady Holst, MPH
- Susan Johnson, PhD
- Eric Moody, PhD
- Nuri Reyes, PhD
- Ann Reynolds, MD
- Steven Rosenberg, PhD
- Jessica Sanders, MD
- Sarah Schmiege, PhD
- Lori Silveira, PhD
- Haley Sturges, MS
- Julia VanDyke, MS
- Nicole Withrow, PhD, RDN

Thank you!