

FASD Leadership Team



Christie Petrenko, PhD

*Research Associate Professor of Psychology
Associate Professor of Pediatrics
Mount Hope Family Center
Developmental & Behavioral Pediatrics*



Lynn Cole, DNP

*Associate Division Chief Director of Clinical Services
Associate Professor of Nursing
Developmental & Behavioral Pediatrics
Department of Nursing and Pediatrics*



Cristiano Tapparelo, PhD

*Research Associate Professor
Department of Electrical and Computer Engineering*



Reza Yousefi Nooraie, PhD

*Associate Professor
Department of Public Health Sciences (SMD)
Center for Community Health and Prevention*



Julianne Myers, PhD

*Postdoctoral Clinical Psychologist - FASD Fellow
Mount Hope Family Center
Developmental & Behavioral Pediatrics*

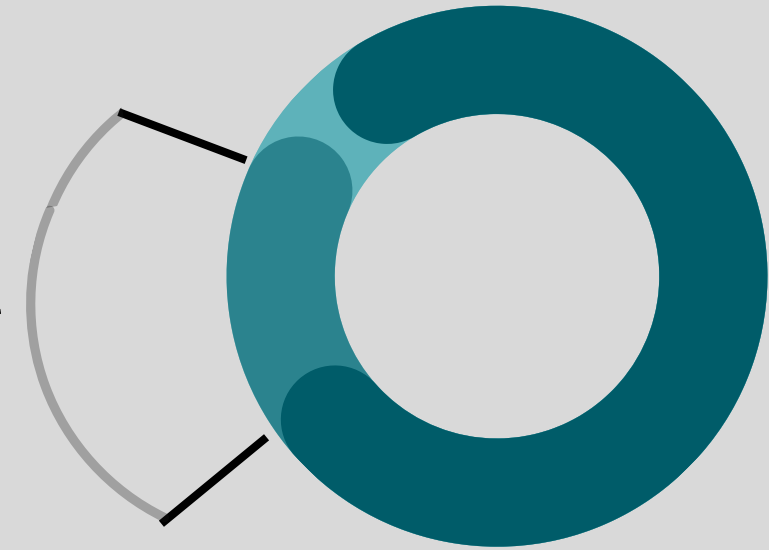
Background



1 in 20
youth have
an FASD

80 to 99%

of children with prenatal
alcohol exposure go
undiagnosed



A primary barrier to
diagnosis is

stigma

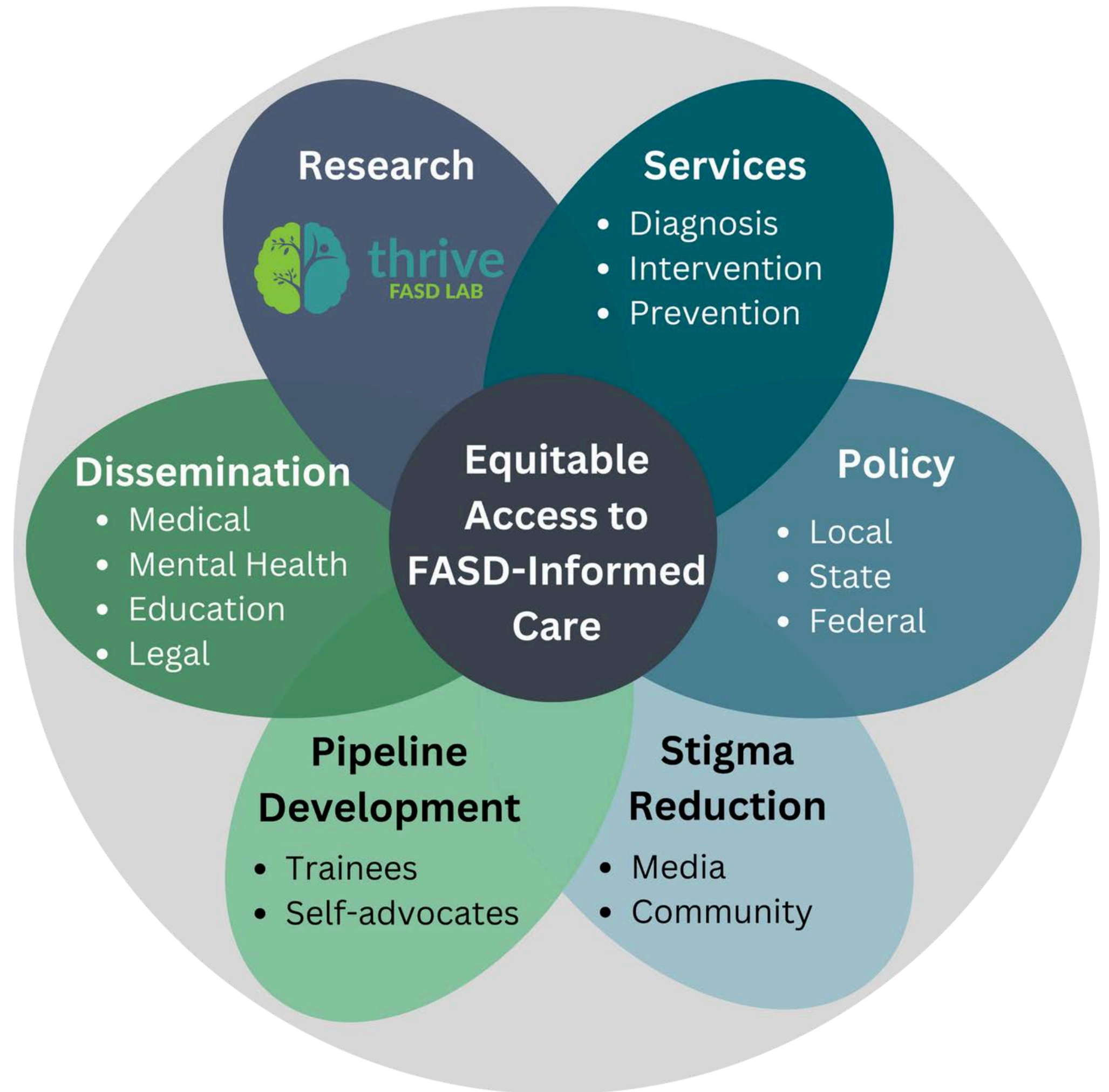


Lack of diagnosis impedes
opportunities to

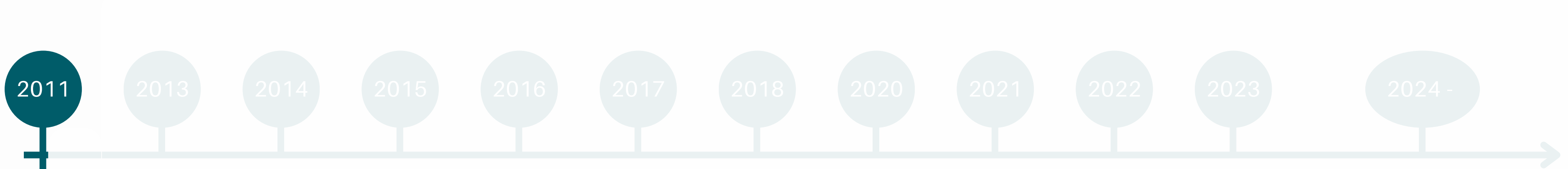
**prevent
life adversities**



Fetal Alcohol Spectrum Disorders Program



FASD Timeline at UR

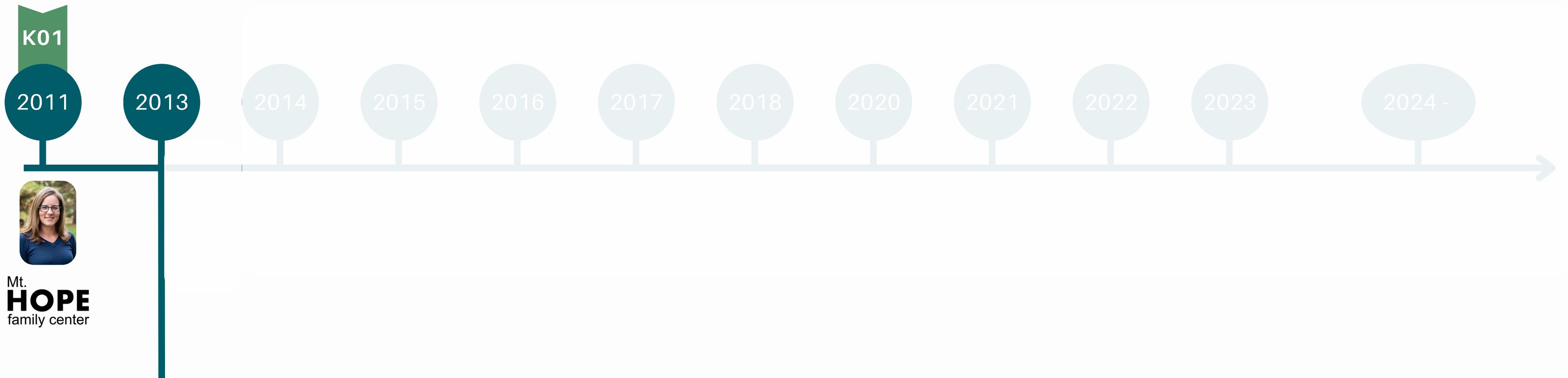


Mt.
HOPE
family center



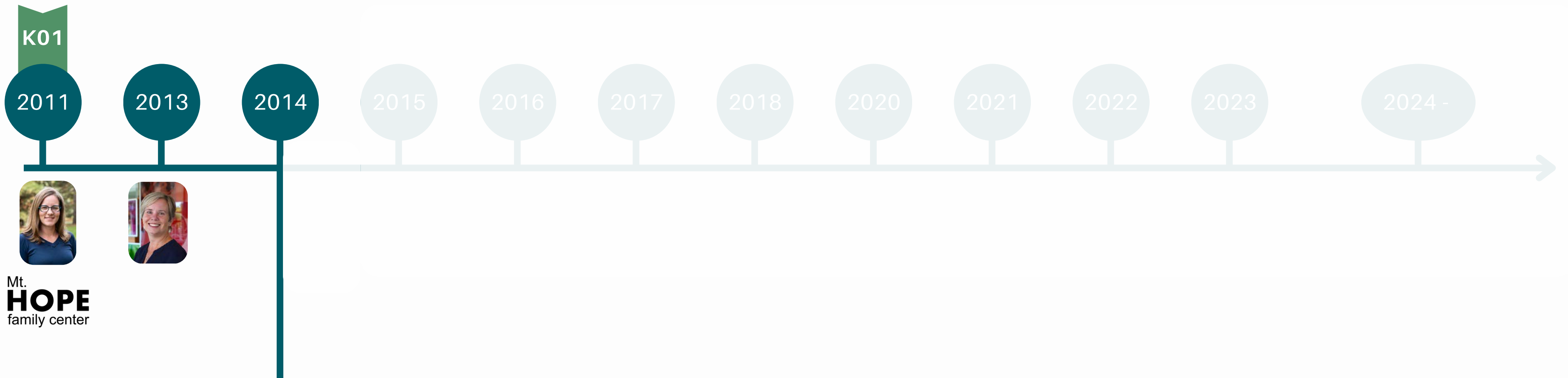
- Christie starts FASD program at Mount Hope Family Center
- K01 award - Families on Track Study
- Christie creates international collaboration through WHO and PAHO interdisciplinary diagnostic and research team

FASD Timeline at UR



- Lynn and Christie begin collaboration

FASD Timeline at UR

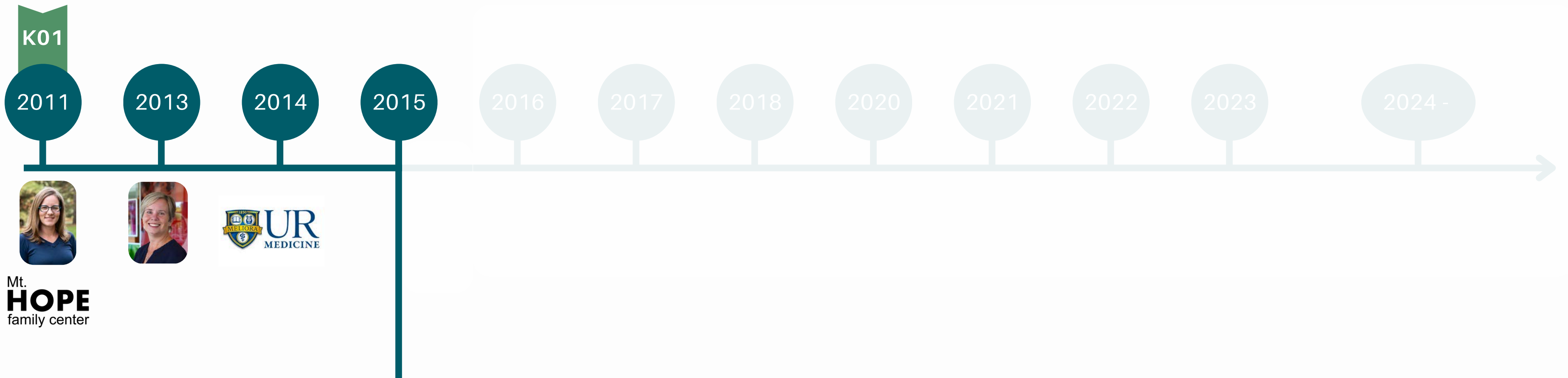


Mt.
HOPE
family center



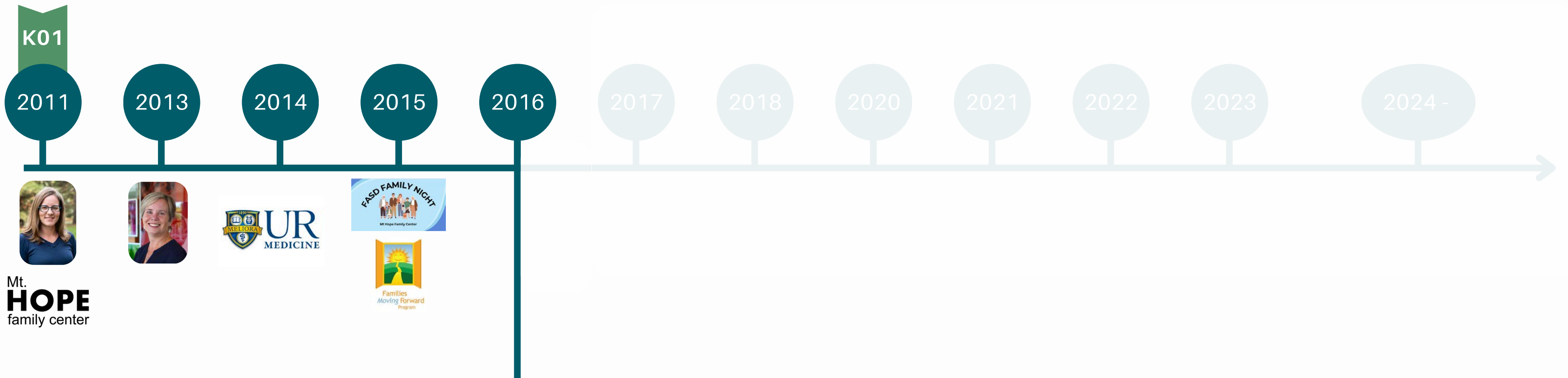
- First FASD Clinic
- Beginning of MHFC and DBP partnership
- Started with 1 evaluation a month

FASD Timeline at UR



- Family Night program starts
- Families Moving Forward transitions from research to sustainable service

FASD Timeline at UR

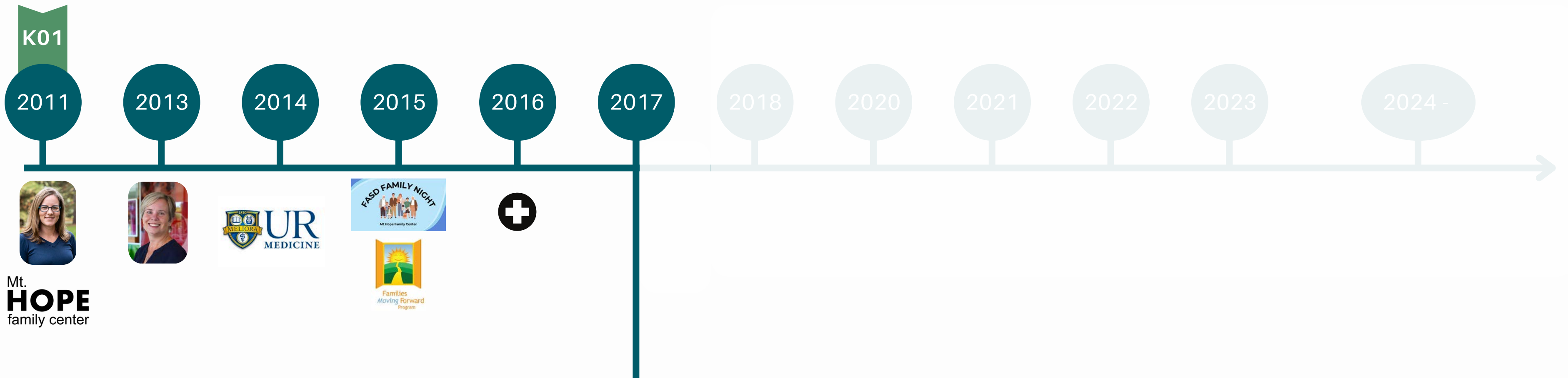


Mt.
HOPE
family center



- single discipline model began

FASD Timeline at UR

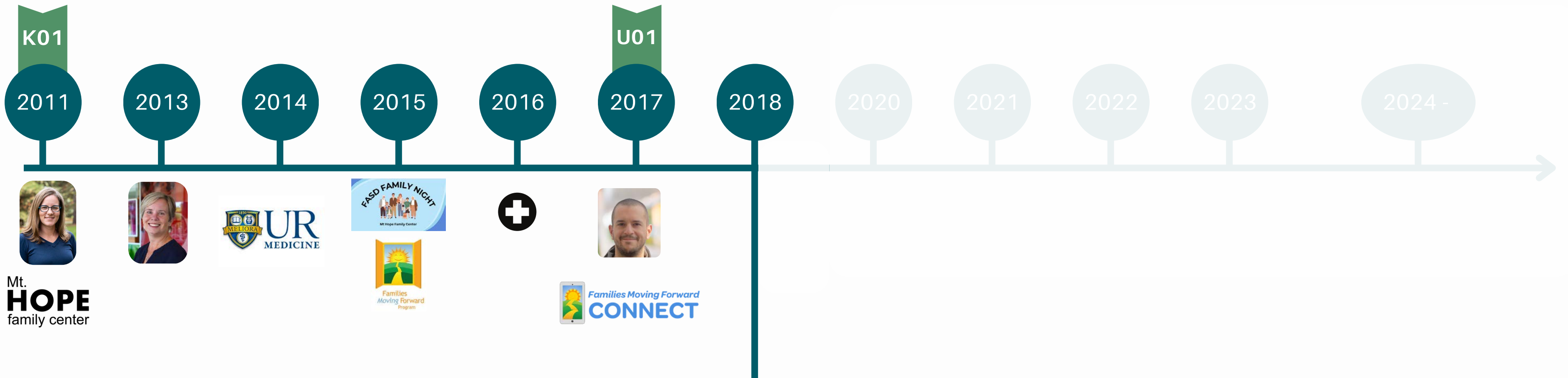


Mt.
HOPE
family center



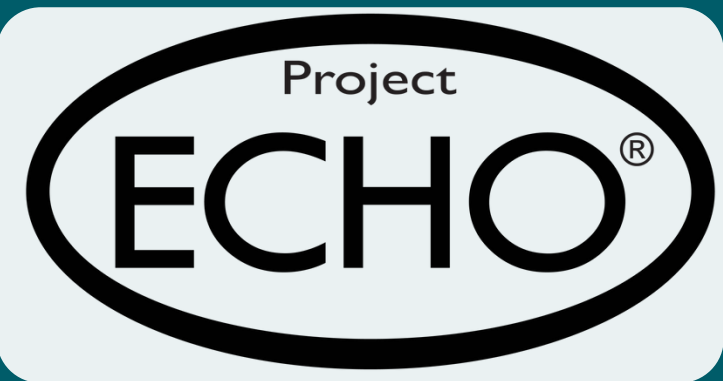
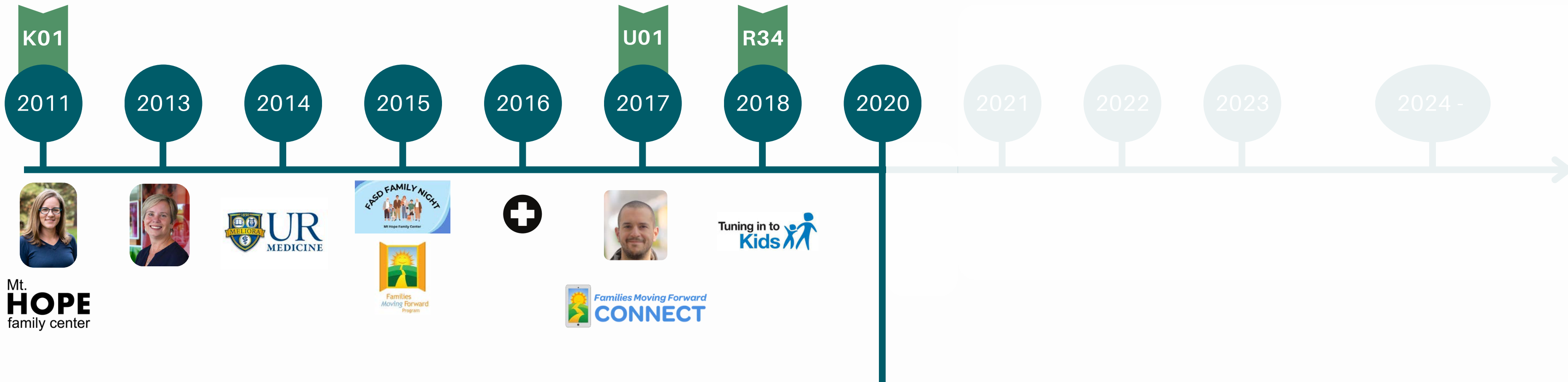
- 1st CIFASD U01 grant - FMF Connect
- Christie & Cristiano MPI

FASD Timeline at UR



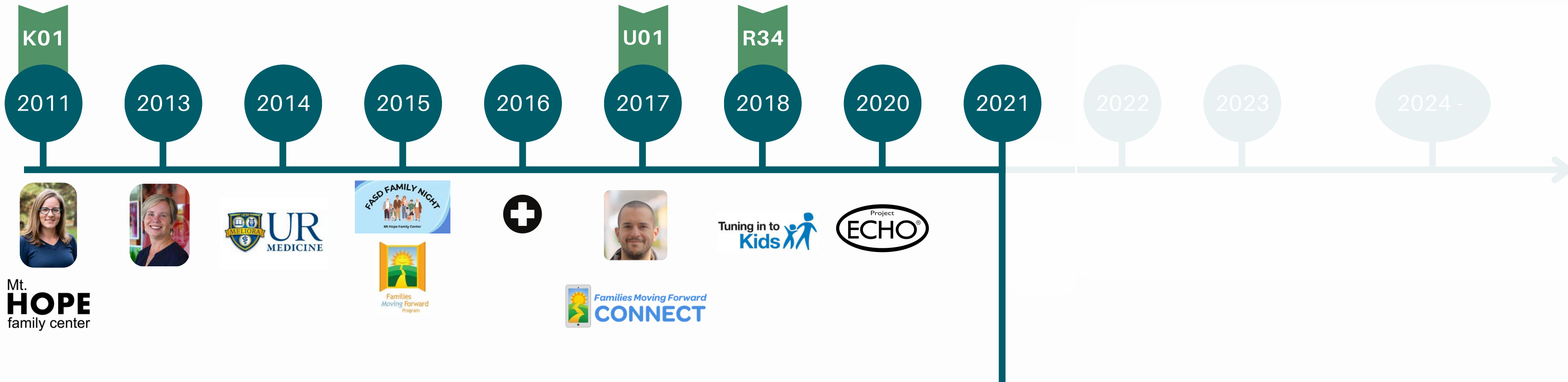
- R34 Tuning in to Kids grant

FASD Timeline at UR



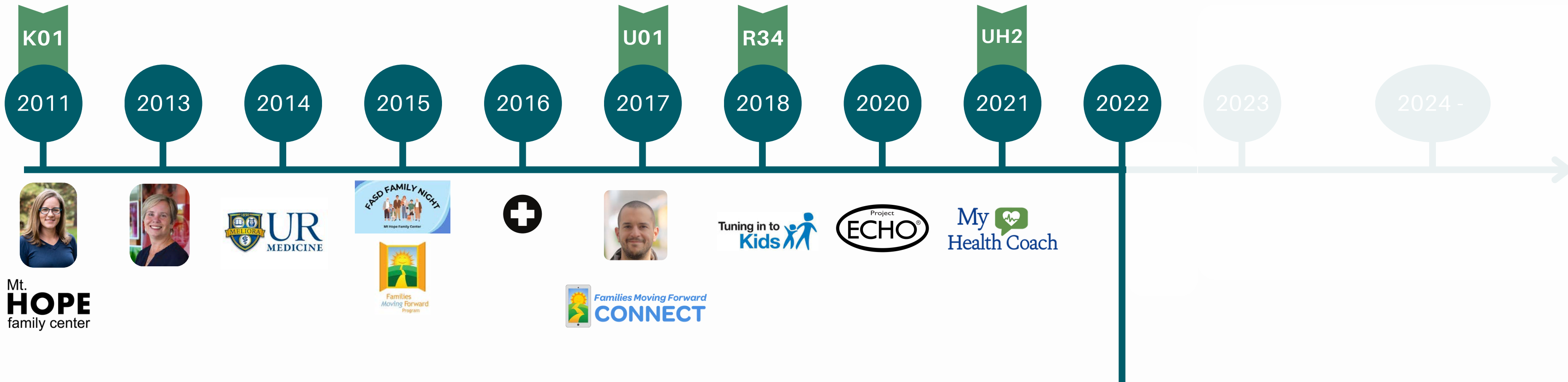
- expanding international diagnostic capacity through ECHO model

FASD Timeline at UR



- CIFASD UH2 grant - Christie & Cristiano MPI - My Health Coach
- created relationship with the Mazelsky family

FASD Timeline at UR







- CIFASD U01 renewed
 - Christie and Cristiano MPI
 - Lynn & Reza co-I
- Carson's F31 Teacher Website

FASD Timeline at UR



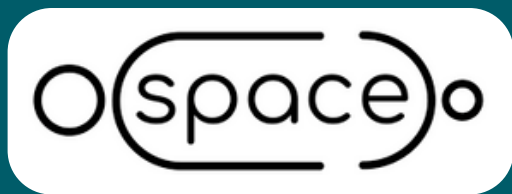
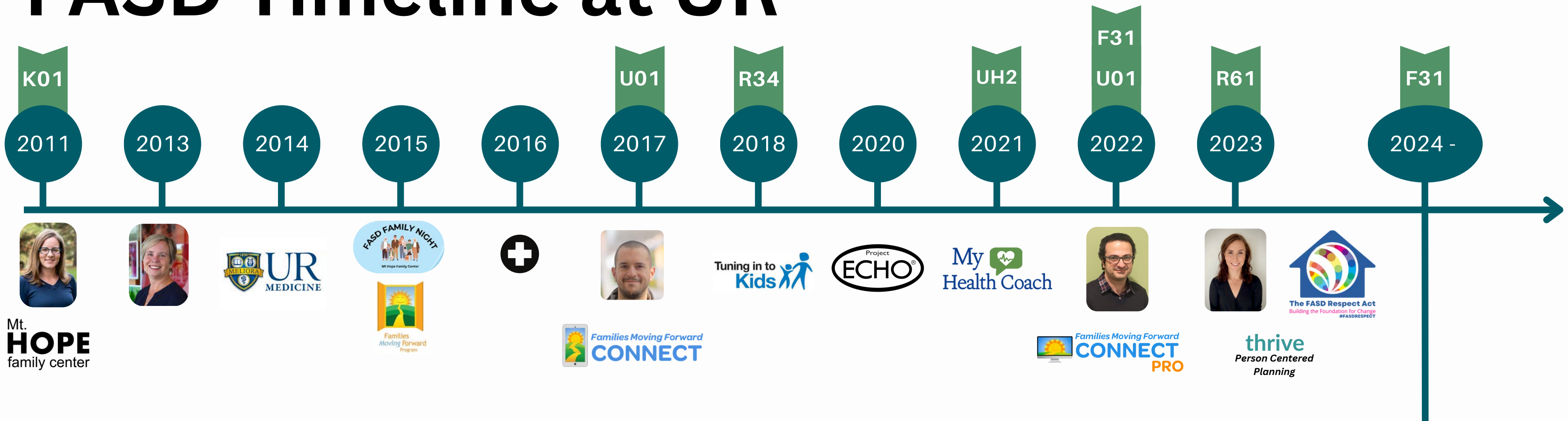


thrive
Person Centered Planning



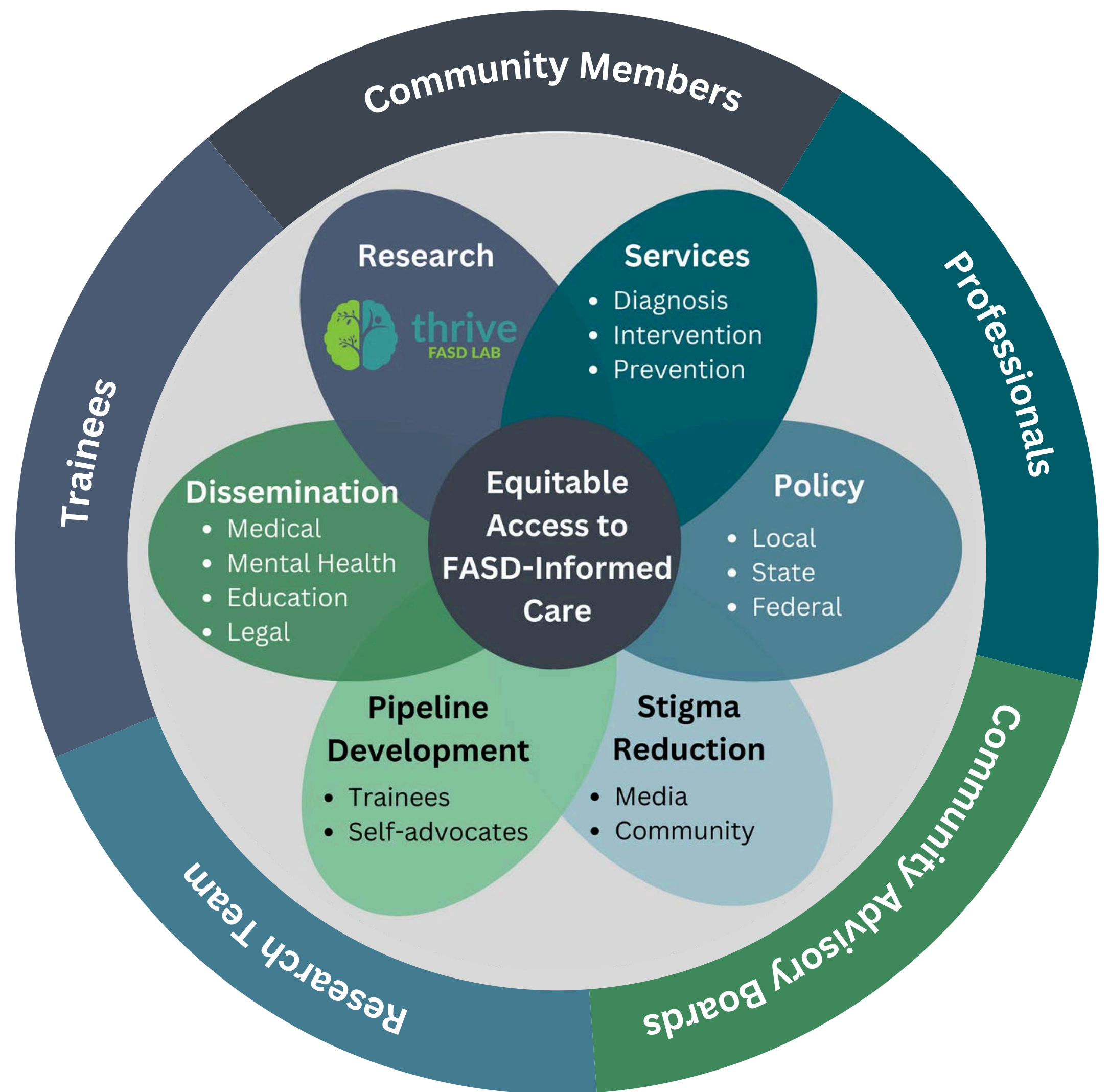
- R61/R33 Person Centered Planning grant
 - Christie PI, Reza and Cristiano co-I
- Julianne joins as FASD Postdoctoral Fellow
- UR sponsors FASD Respect Act

FASD Timeline at UR

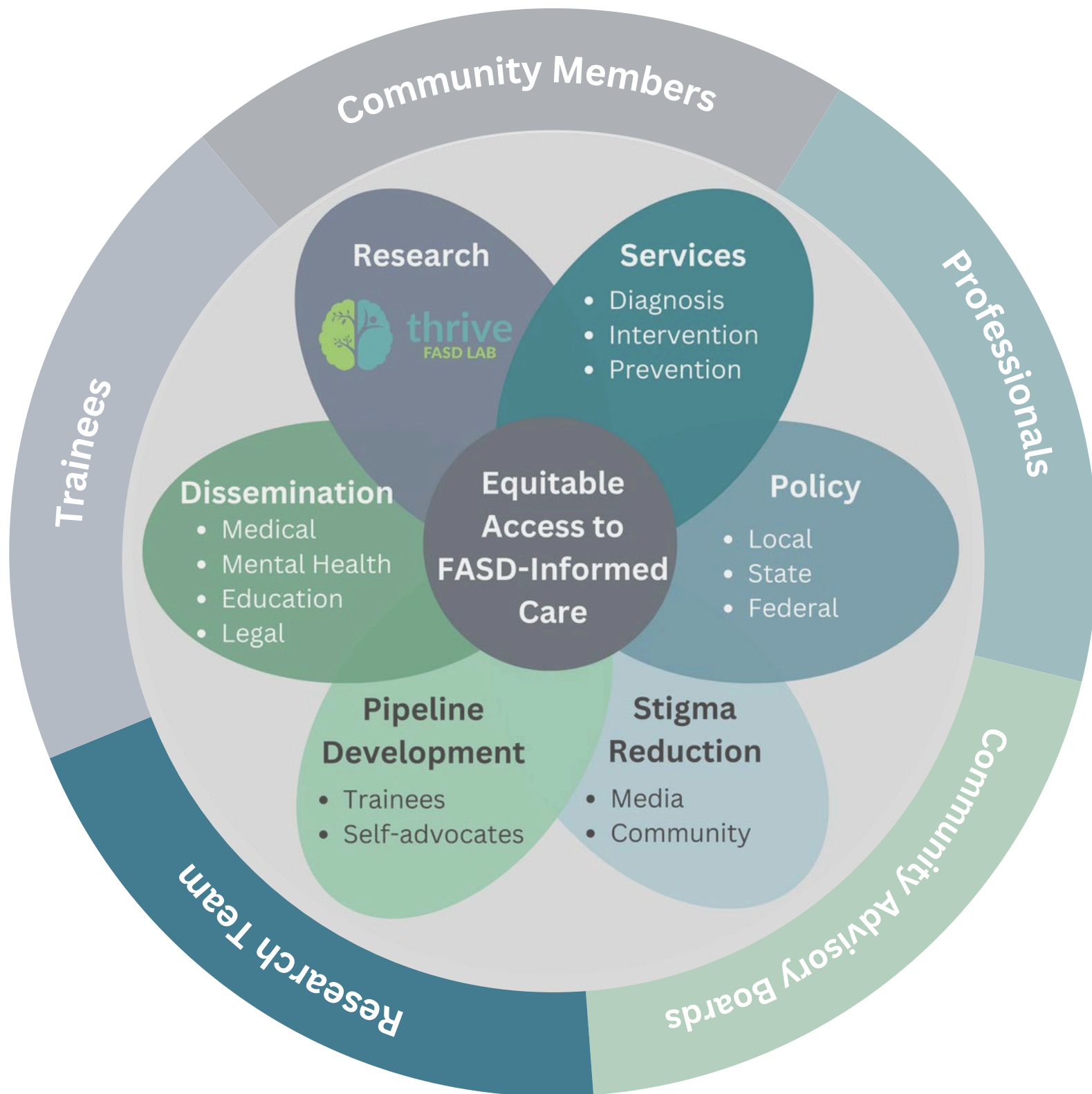


- Madeline Rockhold
 - F31 - Dialectical Behavioral Therapy for Adolescents in FASD
- Julianne Myers, PhD
 - SPACE Anxiety Intervention
- Emily Speybroeck
 - Court Appointed Special Advocate FASD Project
 - Community Based Participatory Research in FASD

Fetal Alcohol Spectrum Disorders Program



Research Team



Primary Investigators

Christie Petrenko, Ph.D. MHFC / U. of Rochester

Cristiano Tapparello, Ph.D. U. of Rochester

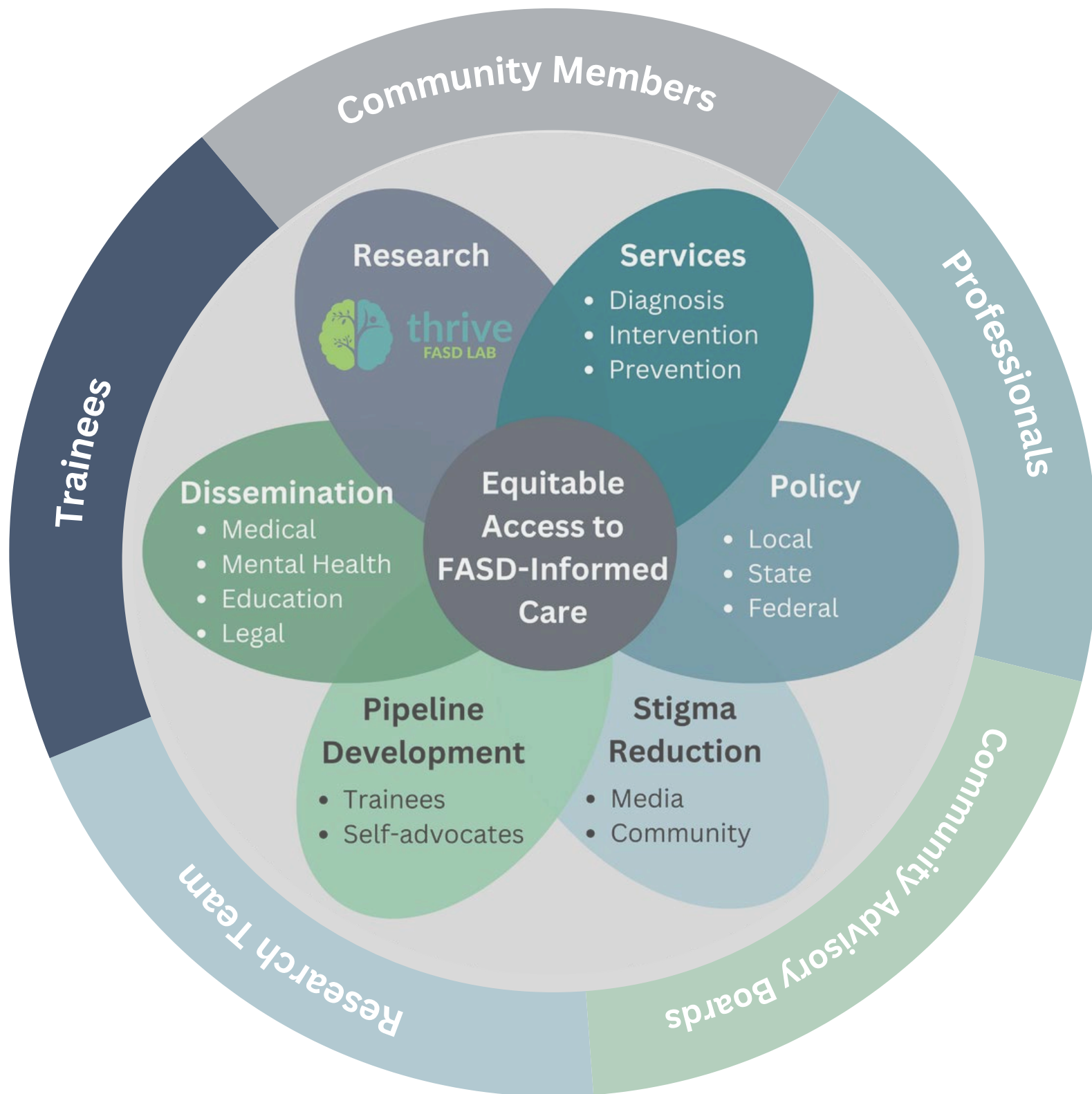
Co-PIs



Research Staff

Lab Manager
Project Coordinator
2 Research Assistants
Undergraduate Interns

Current Trainees



3 Graduate Students on Team

6 Trainees in Diagnostic Clinic

4 Trainees in FASD Mental Health

Community Members

Individuals with FASD

**International Adult
Leadership Collaborative of
FASD Changers**



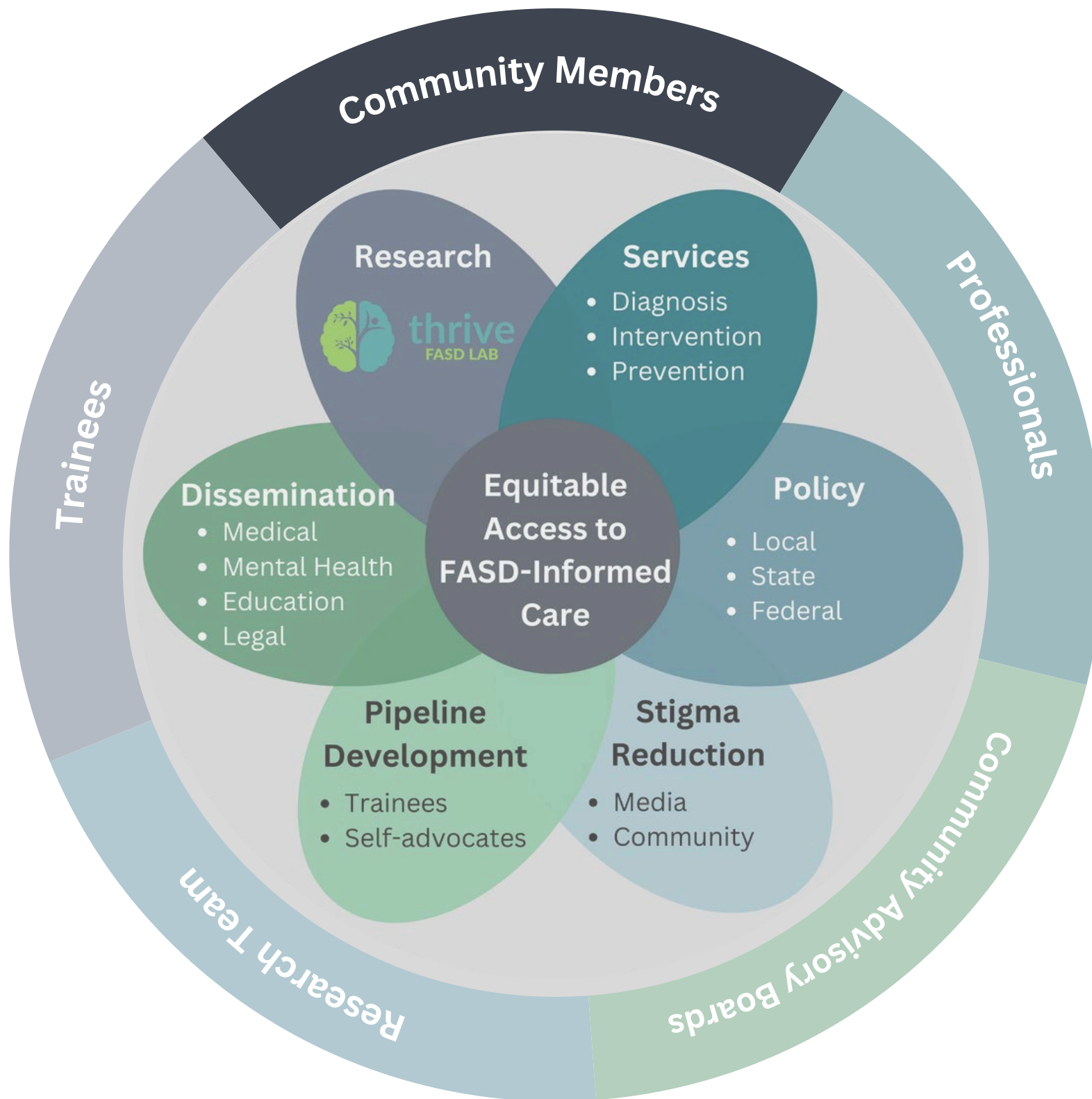
**2 working groups for
intervention research
projects**

Caregivers and Support Networks

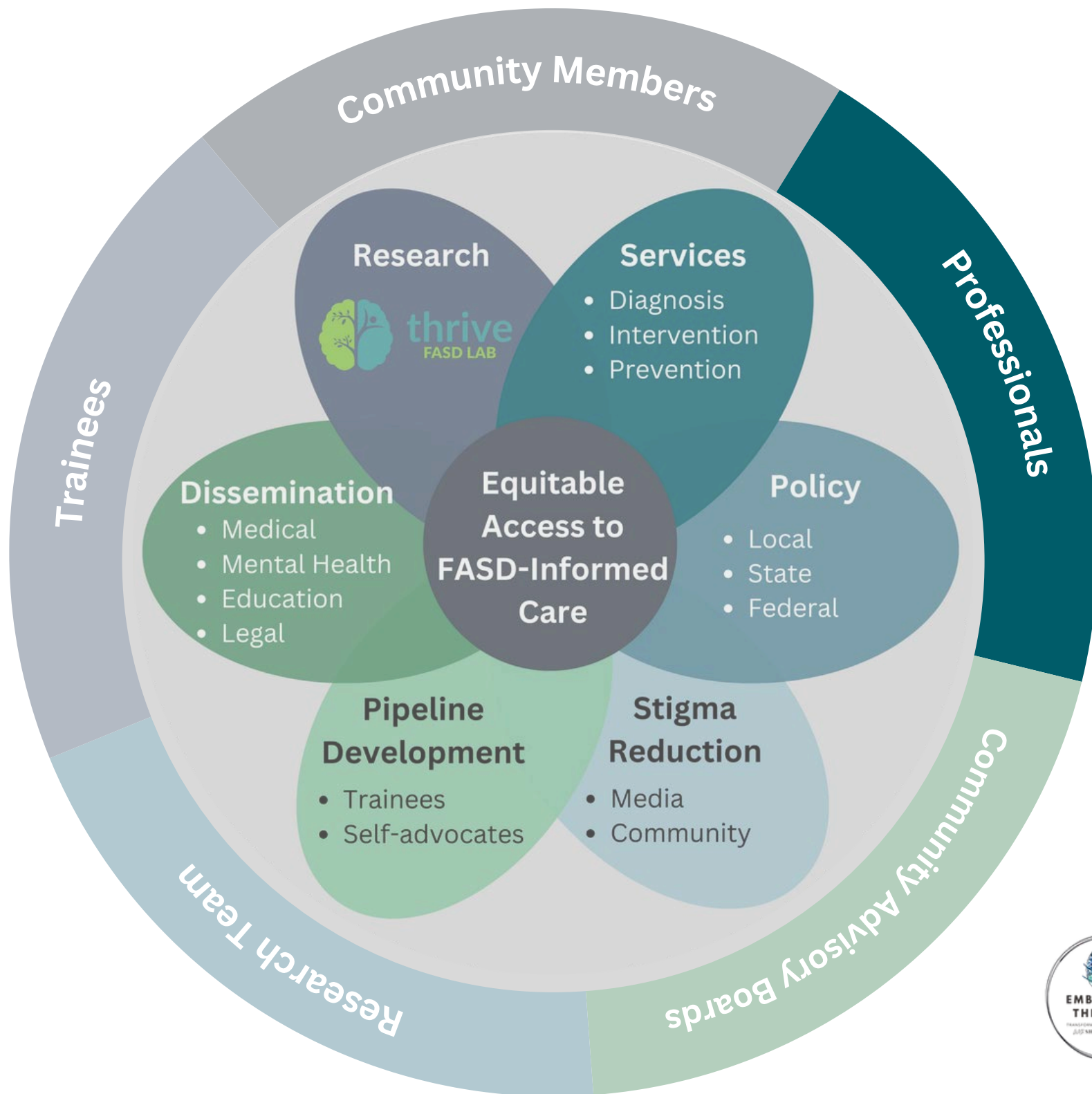
Working group for young adult intervention

Consultants on project development

Focus Groups



Professionals



Researchers

Mental Health Providers

Psychologists

Working group for young adult intervention

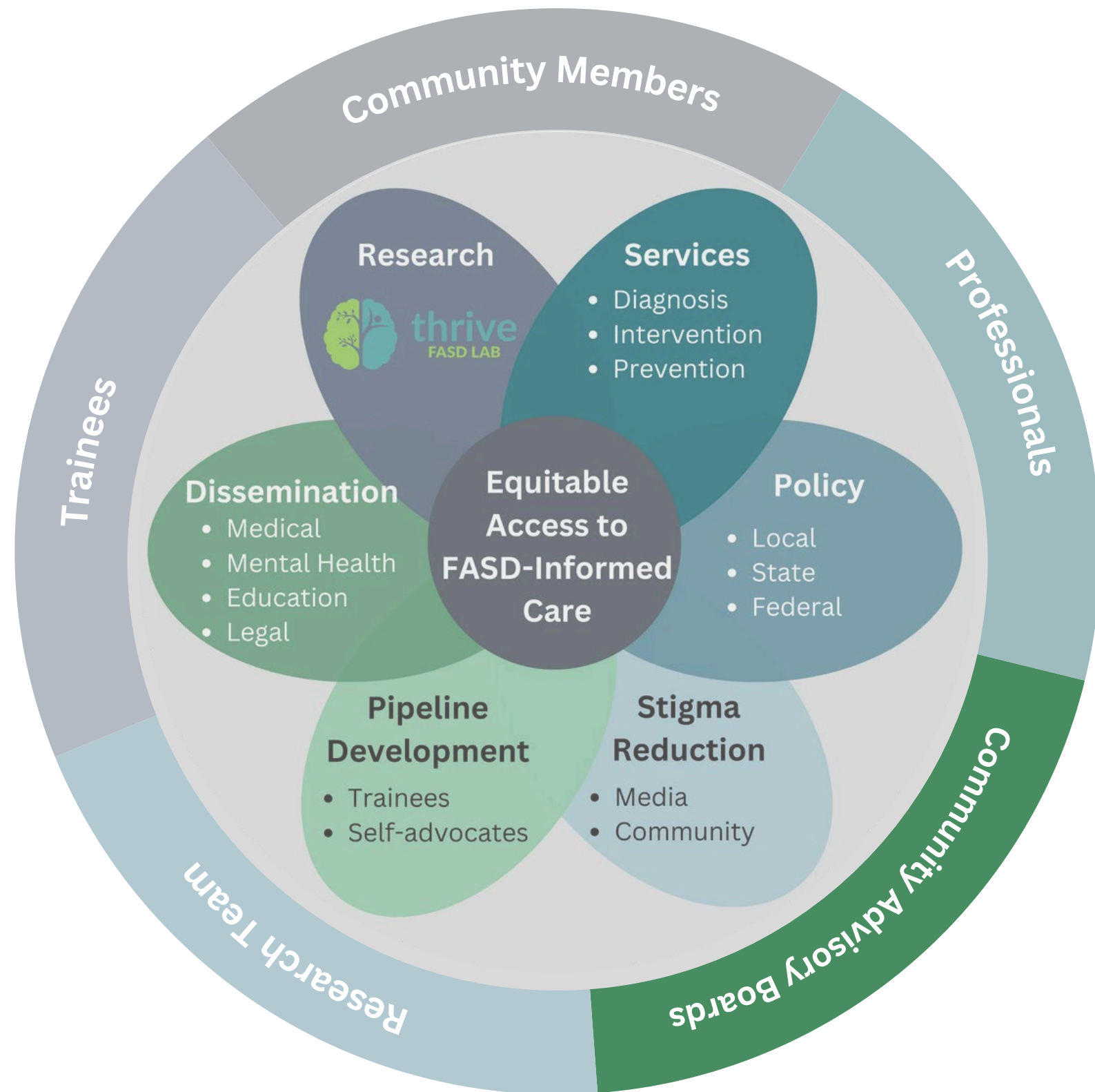
Teachers and Education Specialists

Social Workers and Systems Advocacy Groups

Focus Groups



Community Advisory Boards



Professionals

**Community
Members**

Research Team

**Regular meeting of community and researchers
to inform projects**



Core Values



Community Partnerships



Strengths-based



Implementation Science



Co-creation



Trauma-Responsive

Core Values



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Implementation Science

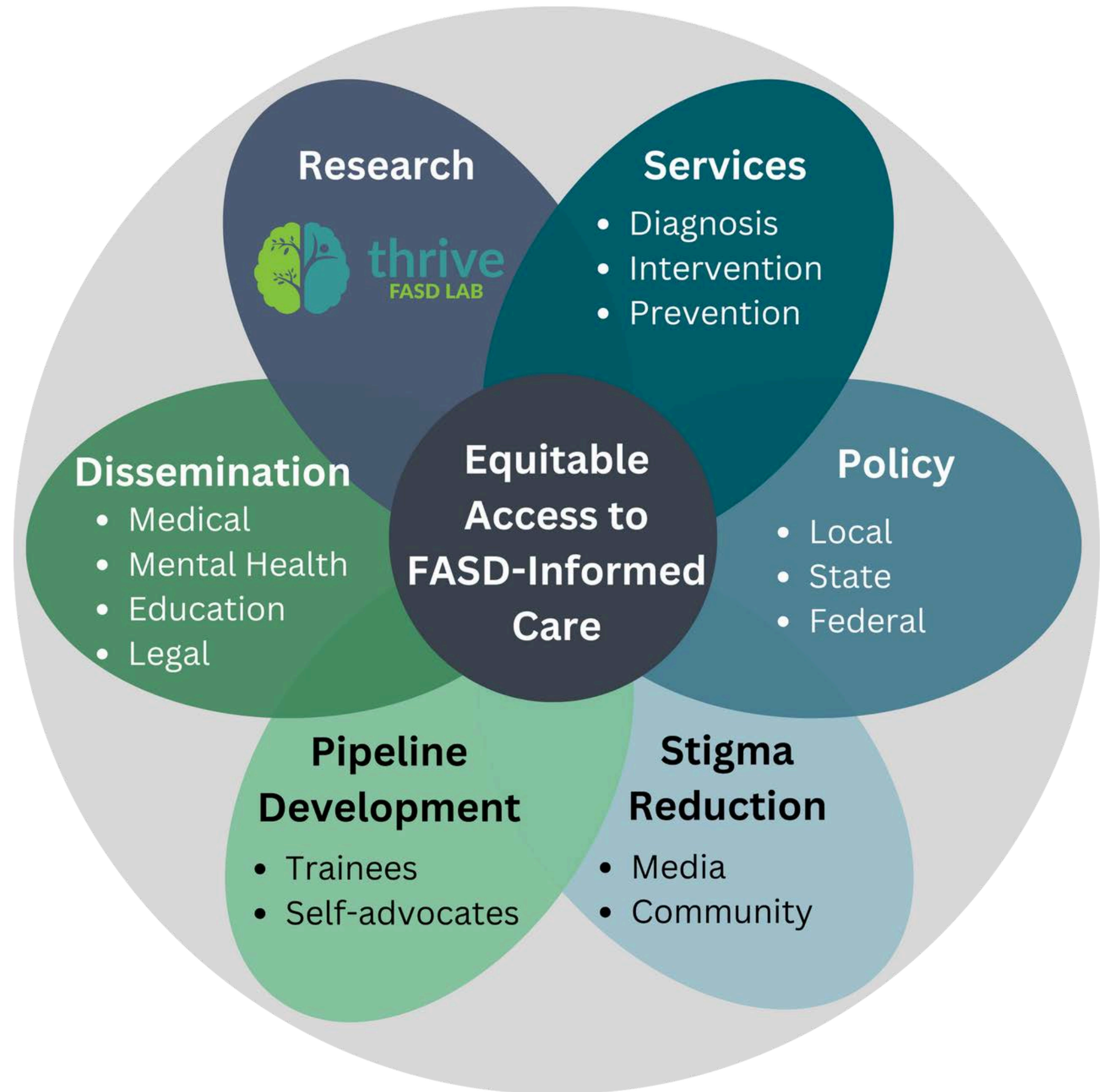


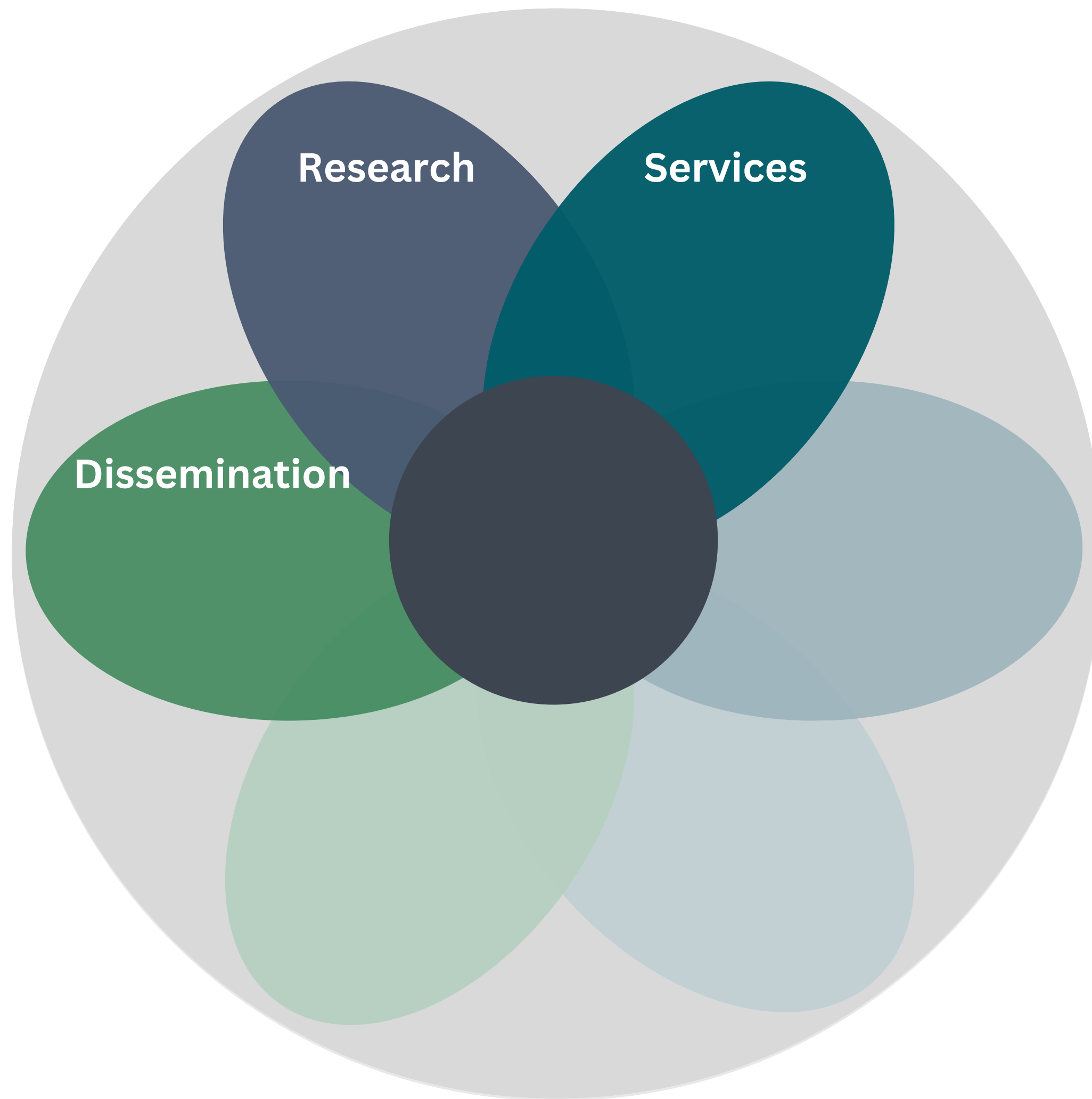
Co-creation



Trauma-Responsive

Fetal Alcohol Spectrum Disorders Program





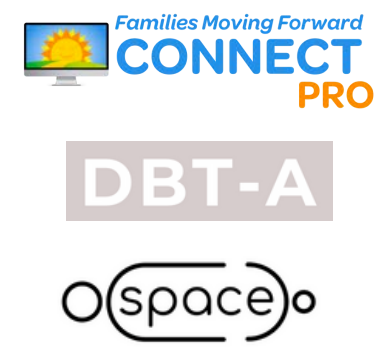
Current FASD Research Projects

12 current projects

Increasing
community
supports and
services

Bridging gaps in
systems of care

Current FASD Research Projects



Increasing
community
supports and
services



Connecting
Communities



Mental
Health



App-based
supports

Bridging gaps in
systems of care

Current FASD Research Projects

Increasing
community
supports and
services

Bridging gaps in
systems of care



Courts



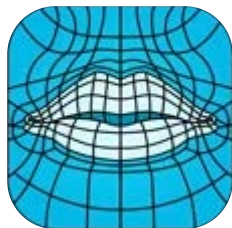
Schools



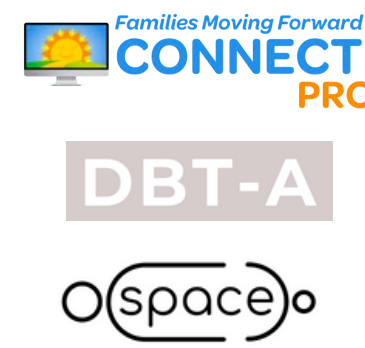
Medicine



**Nurse Practitioner
Training**



Current FASD Research Projects

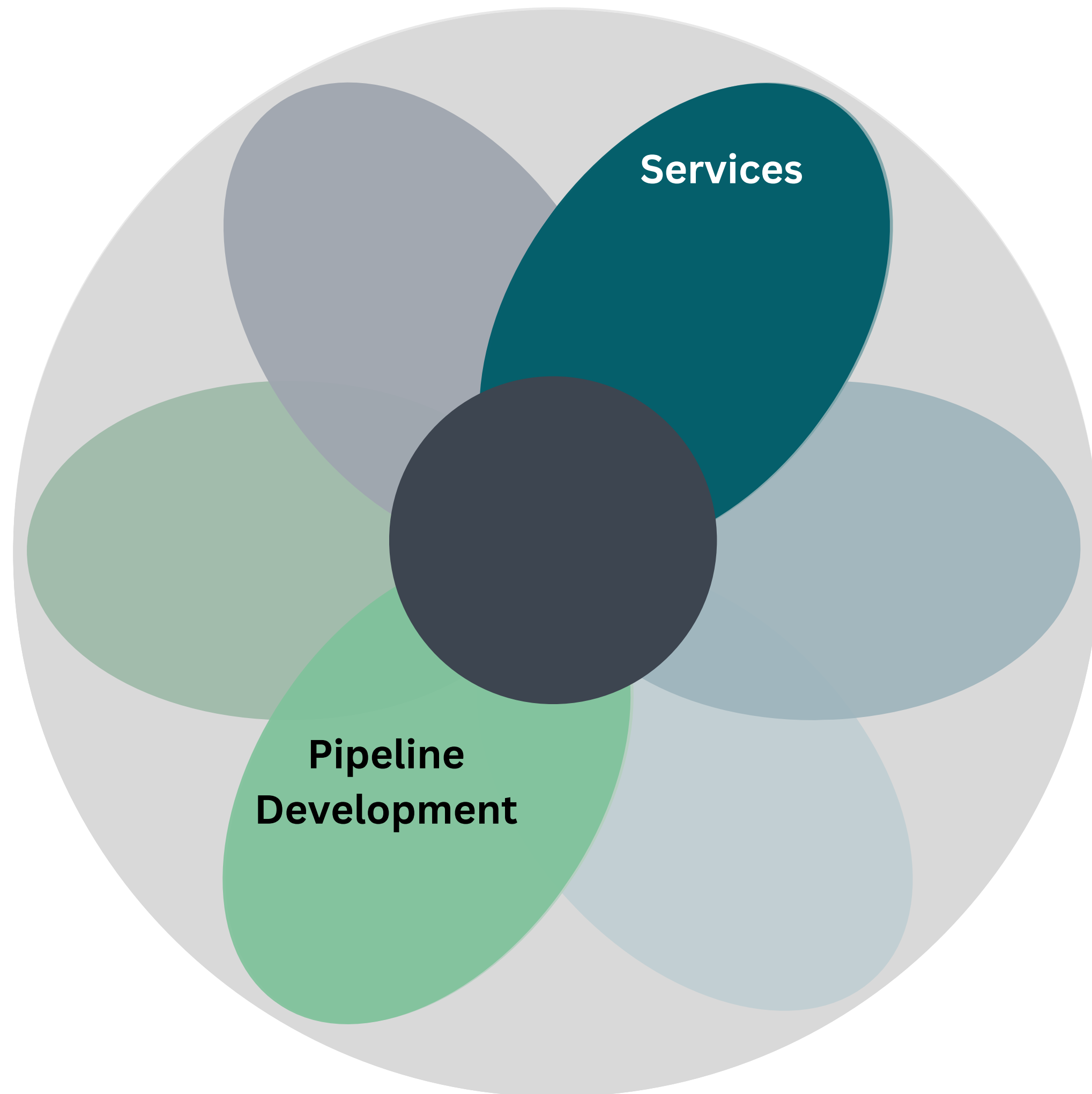


Increasing community supports and services



Bridging gaps in systems of care





Services

**Pipeline
Development**

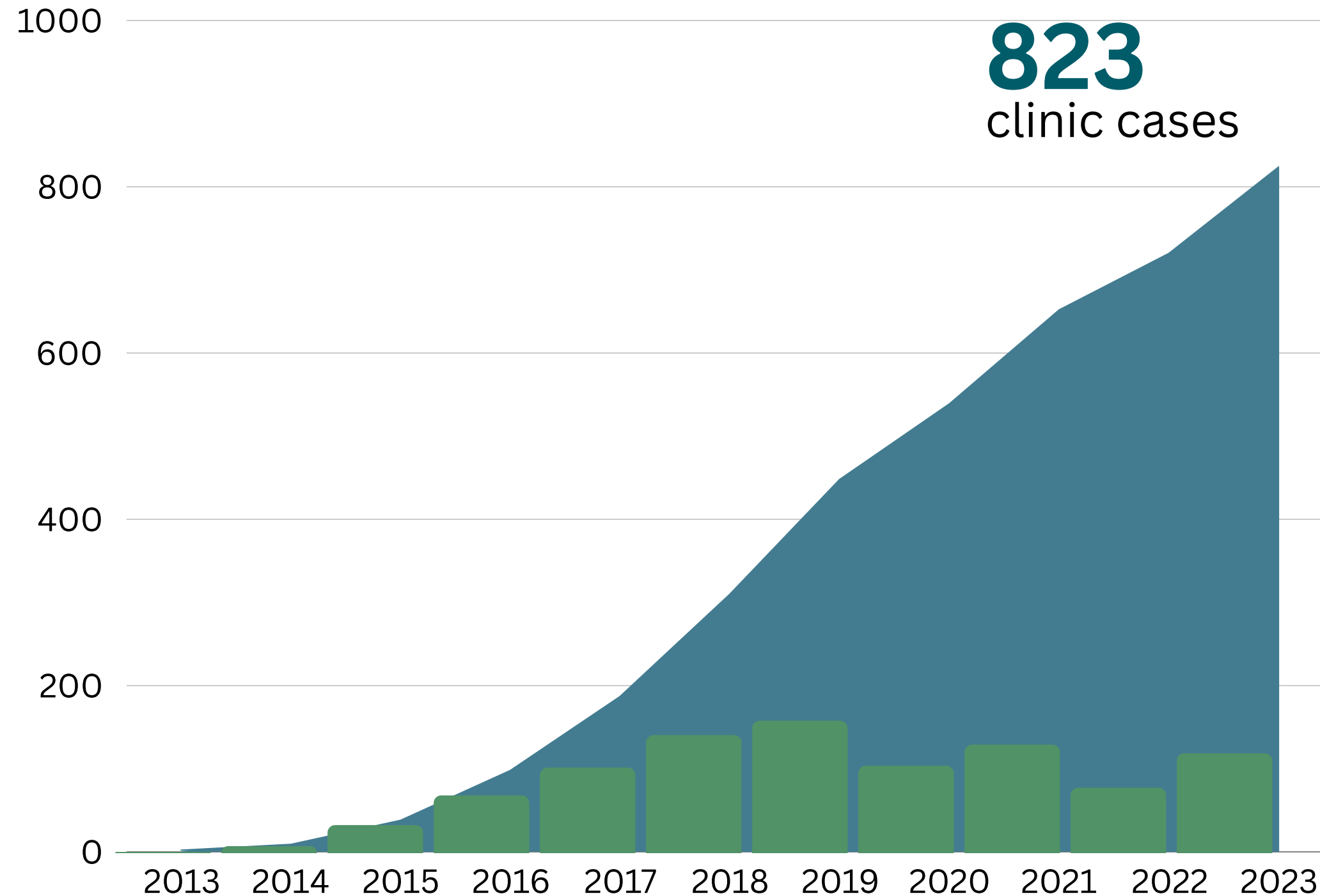
Pipeline Development

- Undergraduate students (60+ per year)
- Graduate students
- Medical residents and advanced practice trainees
- Medical, mental health, and educational professionals
- Community members

Services

- FASD Diagnostic Services
- FMF Parent Consultation Program
- Community Consultation Program
- Family Night Support Program
- FASD Lending Library

Clinical Impact

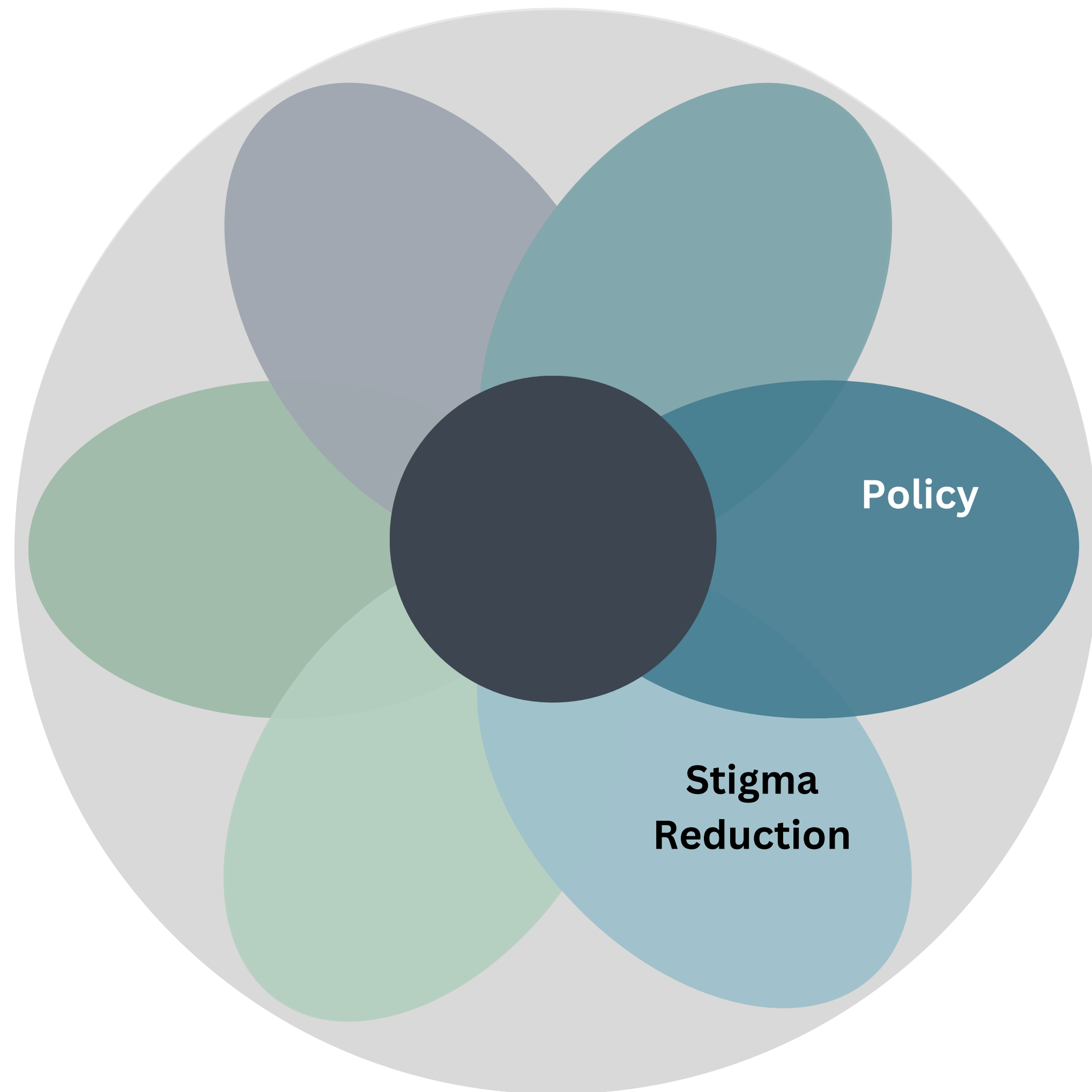


823
clinic cases

200+
providers trained in NY state this past year

600+
families receiving FASD-informed
medical care each year

15-18
families receiving FASD-informed mental
health care each year



Stigma Reduction



Policy and Action

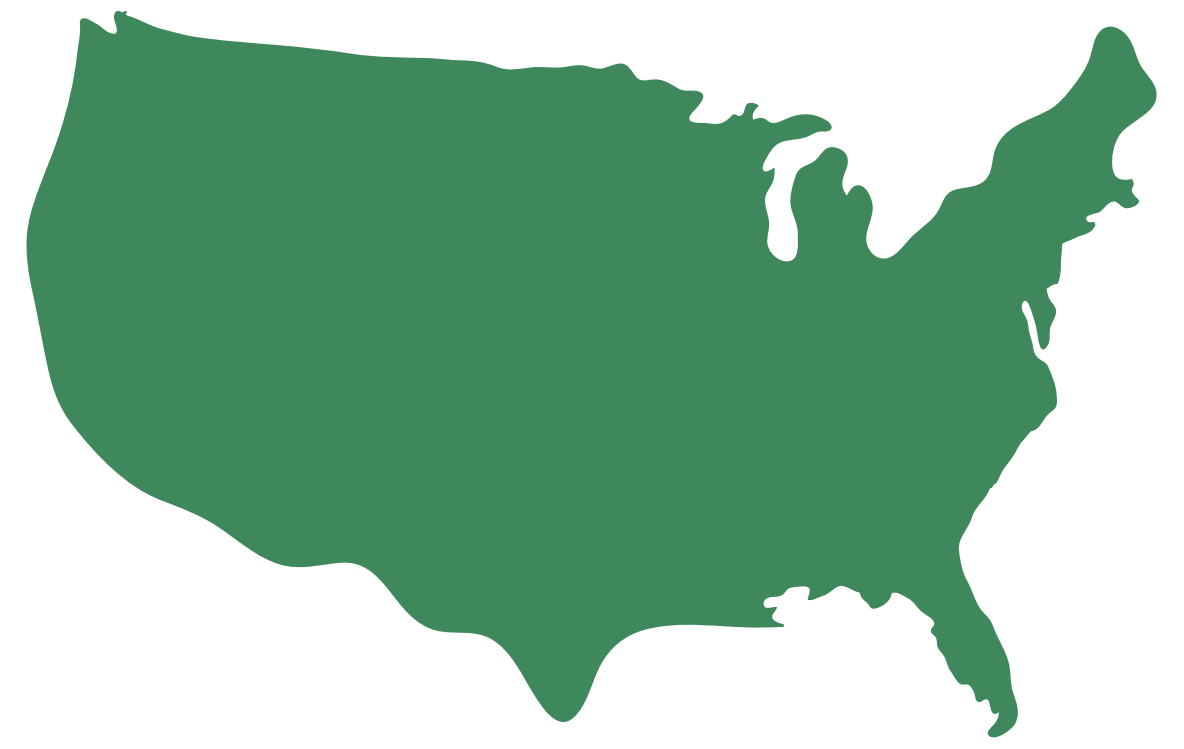
Give **FASD** a seat at the table.



Local



State



National

Policy and Action

Give **FASD** a seat at the table.

Local



Policy and Action

Give **FASD** a seat at the table.

State

Recognition of FASD as a disability
for OPWDD service eligibility



Elma Borčilo



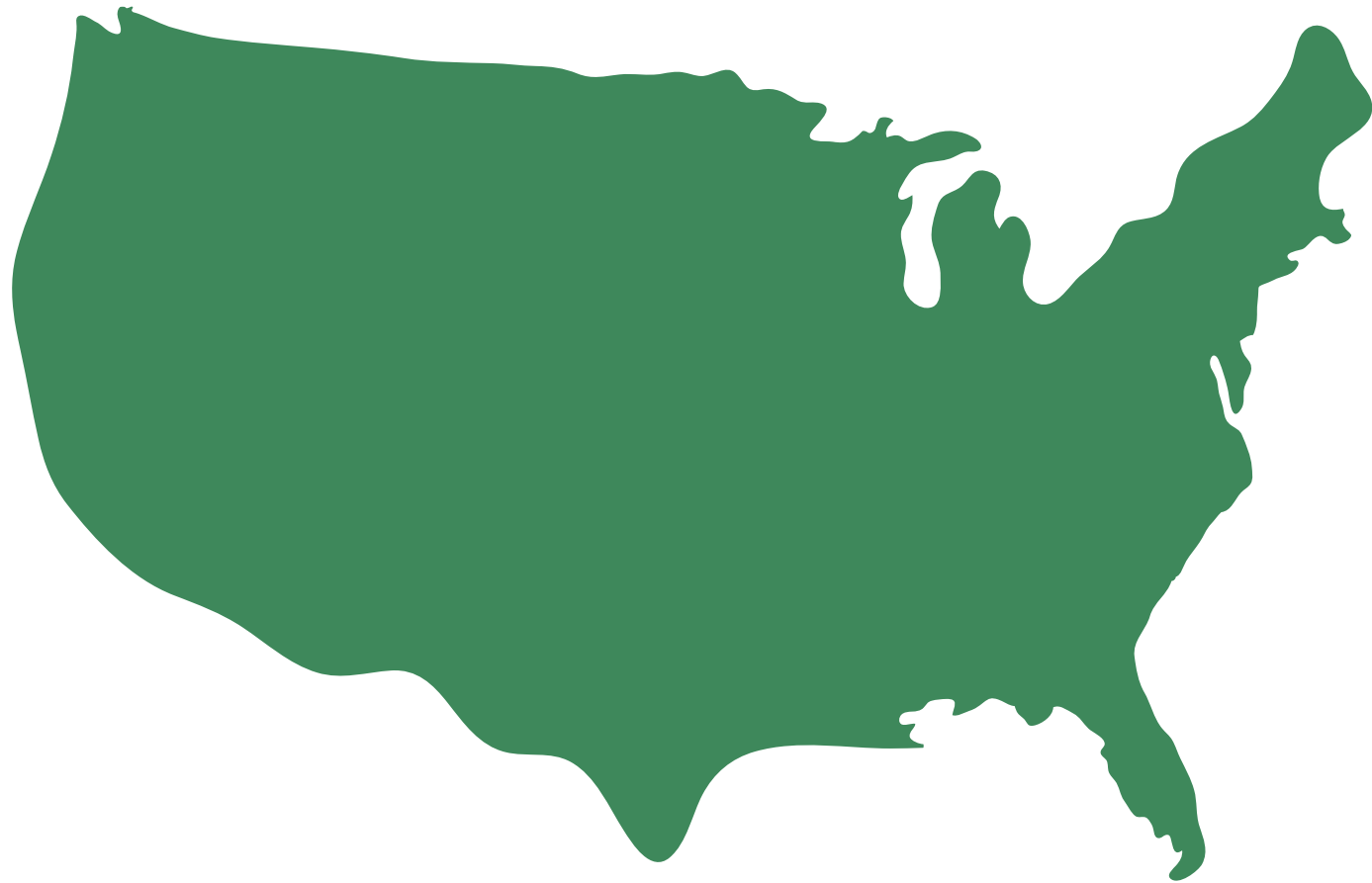
Samra Brouk



Sarah Clark

Policy and Action

Give **FASD** a seat at the table.



National

FASD Respect Act is now fully
supported by university



Formed working relationship with
Representative Morelle

Planning upcoming visit to MHFC

Listening to the Community



Listening to the Community

Wanting answers to questions like...

- How does the brain age over time?
- What are the effects of long term exposure to chronic stress, higher neurological work load, and chronic health?
- Are there difference in neurological pain response systems of individuals with FASD?