
Exploring Birth Defects Surveillance Programs and Opportunities to Align with MCH Title V Activities

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Oregon Birth Anomalies Surveillance System



MATERNAL AND CHILD HEALTH
Public Health Division

Overview

- BASS Program
- Oregon MCH Title V
- Program Alignment

*Although birth anomalies are sometimes referred to as birth defects, Oregon uses the term anomalies as a response to community input.



Oregon Birth Anomalies Surveillance System

Oregon BASS Program

Our Team

- Vivian Siu – Research Analyst (.5 FTE)
- Stephanie Glickman – Public Health Educator (.5 FTE)
- Yesenia Gonzalez – Administrative Specialist (less than .5 FTE)
- Suzanne Zane – CDC MCH Epidemiologist Assignee to Oregon (advisory role)



BASS Beginnings

1999

Oregon Legislative hearing regarding Fetal Alcohol Syndrome. Public Health Division, Office of Family Health is directed to address FAS.

2000 – 2002

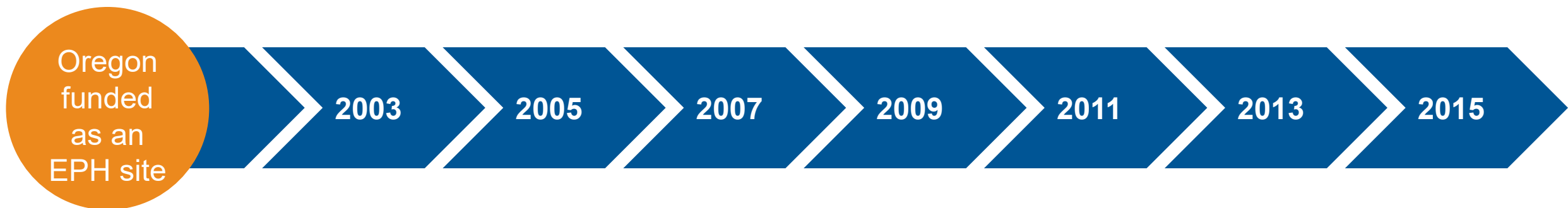
Early conversations begin about Oregon's need for conducting birth defects surveillance

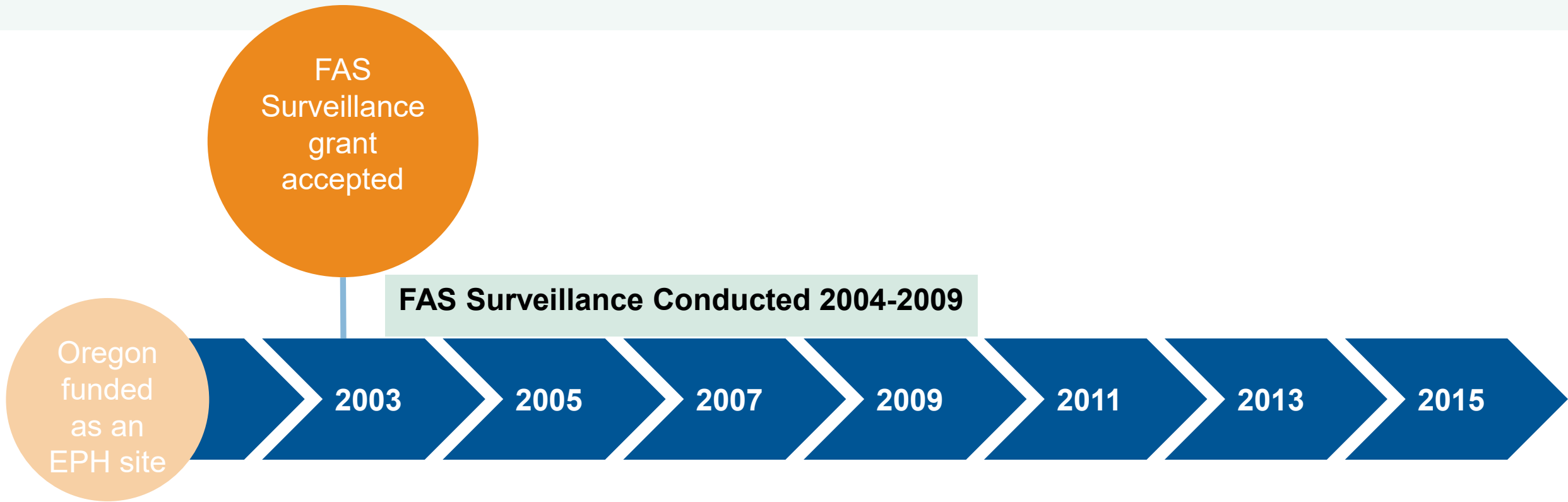
2001

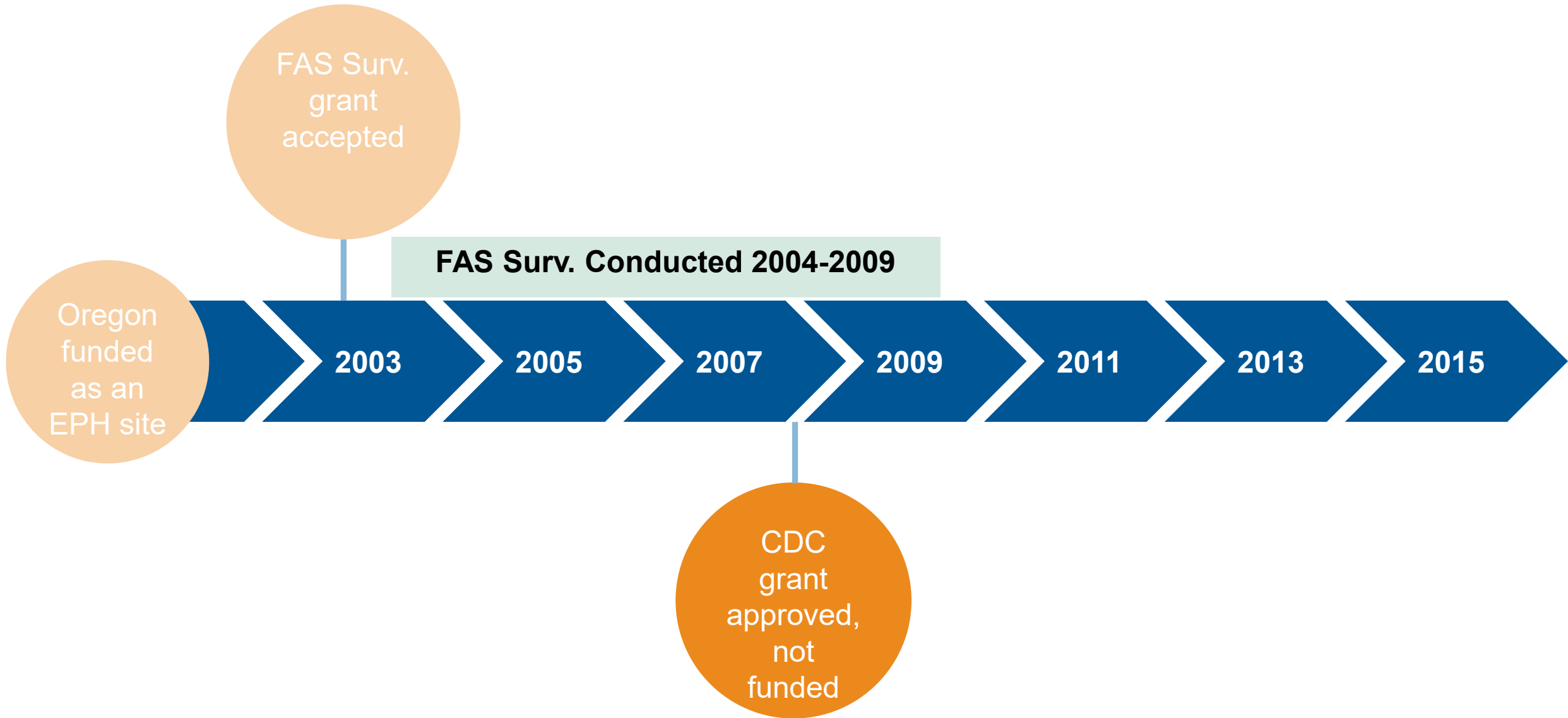
First Fetal Alcohol Syndrome prevention grant application submitted – accepted but not funded

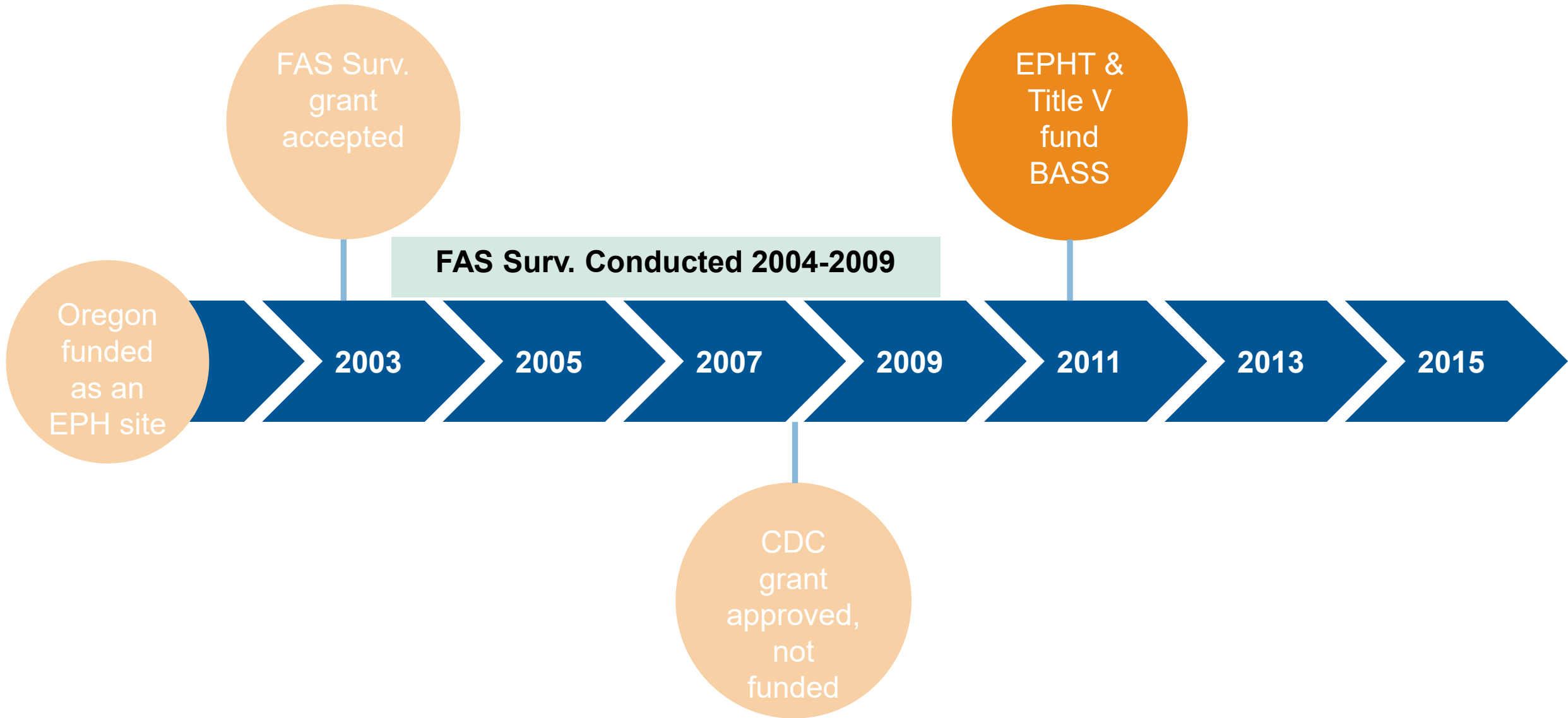
2002

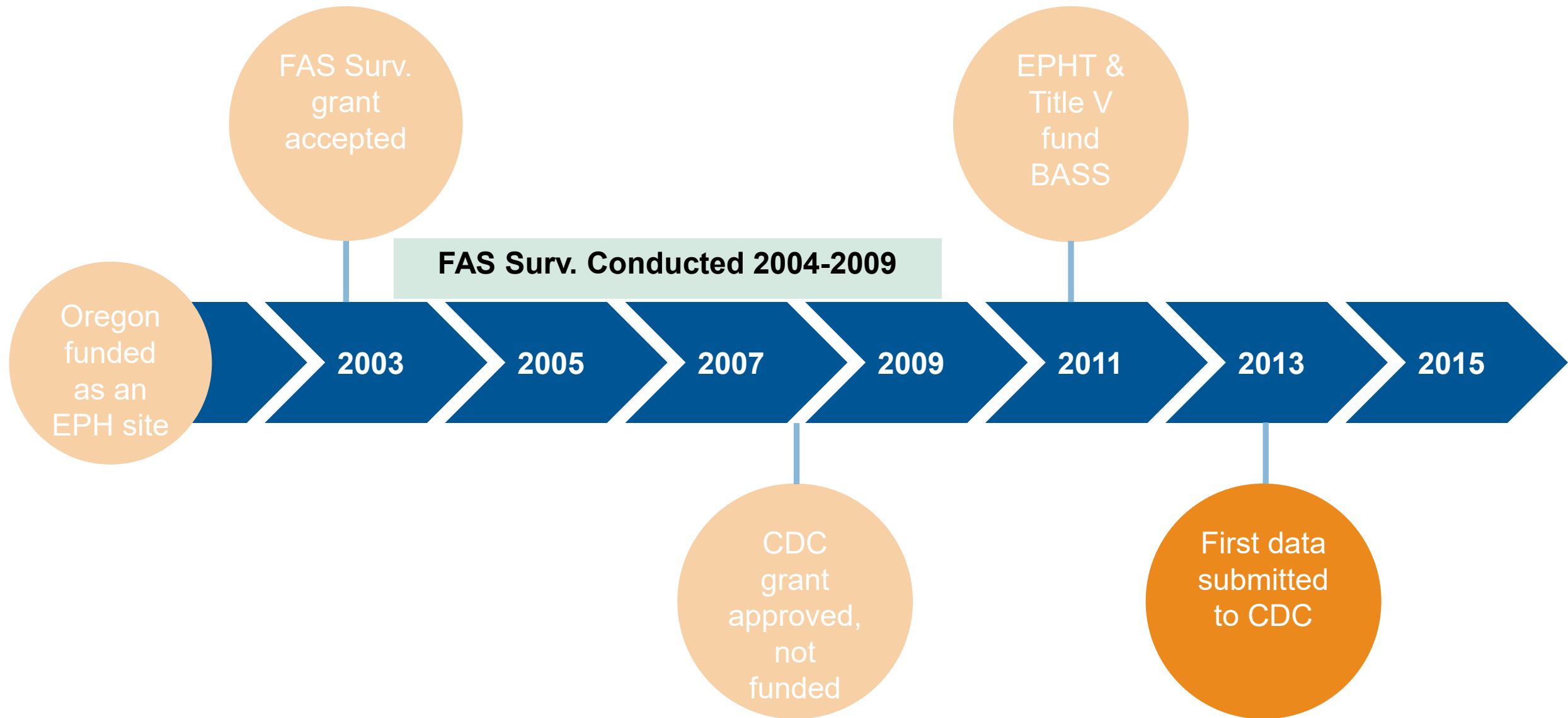
Oregon begins participating as a funded state Environmental Public Health site.

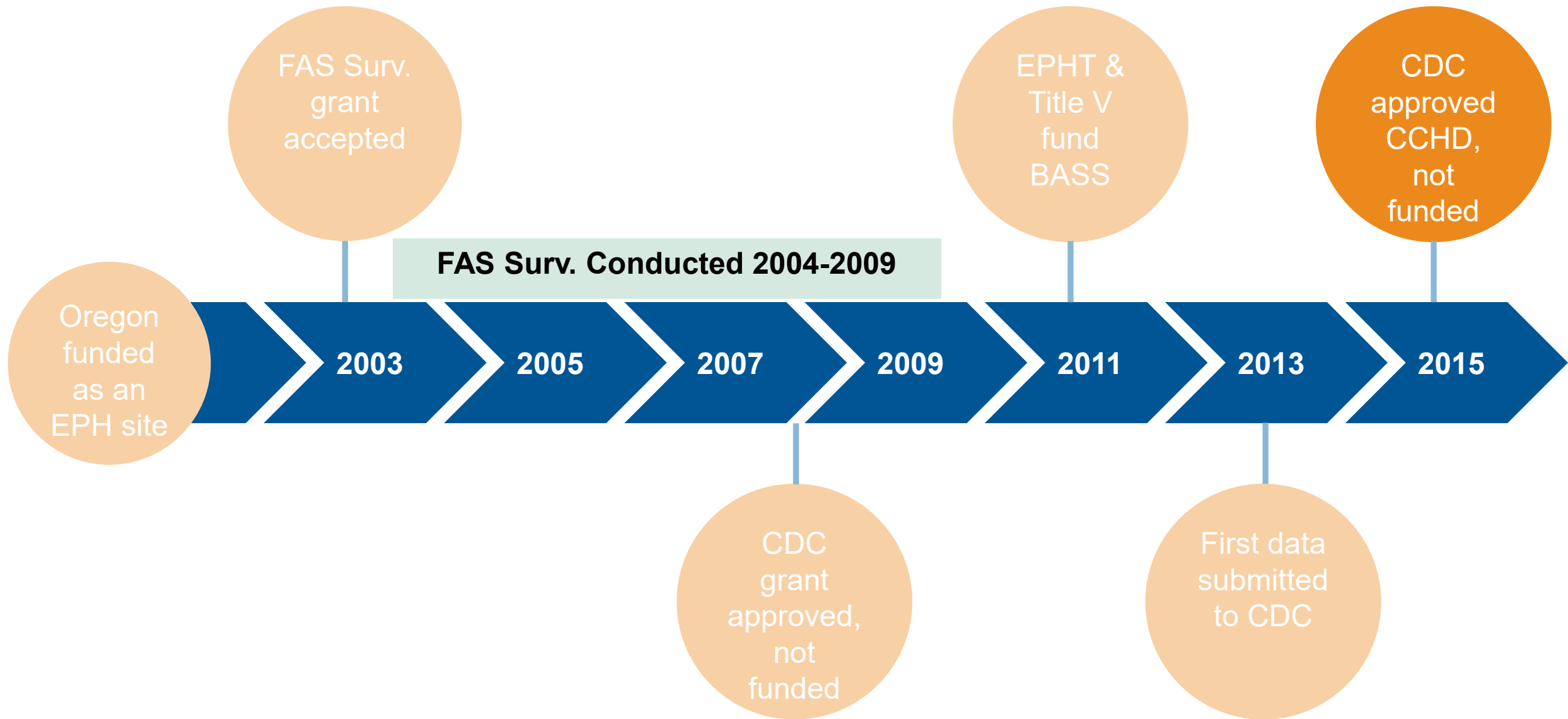












2016 – 2021: BASS funded by CDC!

Program focus areas:

- Surveillance
- Partnerships
- Family resources
- Data dissemination
- Program structure quality improvement



Surveillance

2016 – 2021 program funded

- Improve methodology
- Increase knowledge about BD prevention
- Expand conditions tracked
- Explore newborn screening of CCHDs
- Validity and reliability
- Active surveillance of CCHD

2021 planned activities

- Strengthen capacity
- Develop/improve data system
- Passive case finding with case verification

Current - program not CDC funded

- Maintain passive surveillance methodology
- Working towards migration to Filemaker database

Partnerships

2016 – 2021 program funded

- Expand collaboration
- Maintain advisory committee
- Collaborate with Oregon F2F HIC (Family to Family Health Information Center)

2021 planned activities

- Hospital systems to assess accessibility of medical records
- Work with CDC to improve surveillance methodology
- F2F HIC for outreach

Current - program not CDC funded

- Continued collaboration with Oregon F2F HIC
- Close collaboration with NBDPN Health Promotion Committee
- Innovations in Newborn Screening Interoperability
- Title V program to collaborate and reach external Title V partners

Family Resources

2016 – 2021 program funded

- Early identification
- Understand referrals systems
- Utilization of services for affected individuals and families
- Develop family resource bank including fact sheets
- Improve website

2021 planned activities

- Develop data driven primary and secondary prevention strategies
- Referral pathways to family resources through home visiting, WIC, 211info, geneticists, and specialists
- Social media

Current - program not CDC funded

- Social media
- Develop data driven primary and secondary prevention strategies (e.g. folic acid outreach)

Data Dissemination

2016 – 2021 program funded

- Accurate and timely information to organizations, agencies, and individuals
- Use data to inform policy and resource allocation
- Publications
- Presentations

2021 planned activities

- Contribute to multi-state data
- Develop dissemination plan
- Identify disparities

Current - program not CDC funded

- Data dashboard
- Continuous quality improvement of data visualization
- Identify disparities
- Presentations

Program Structure

2016 – 2021 program funded

- Program coordinator, research analyst, public health educator, CDC epidemiology assignee, administrative support
- Advisory Committee
- Funded by combination of MCH and CDC grant

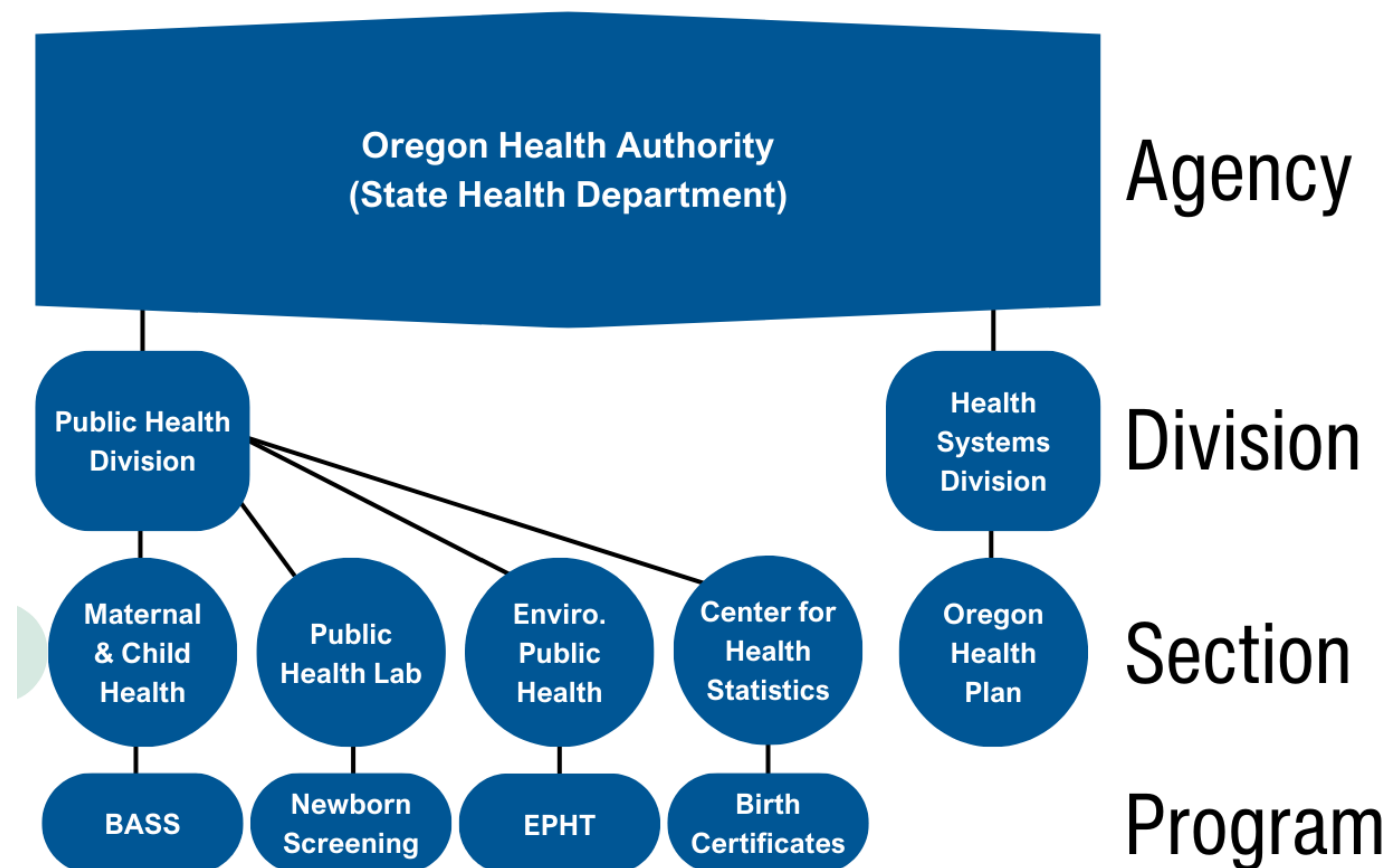
2021 planned activities

- Staff turnover
- MMRC abstractor to work with BASS
- BASS team excited to get started on new workplan

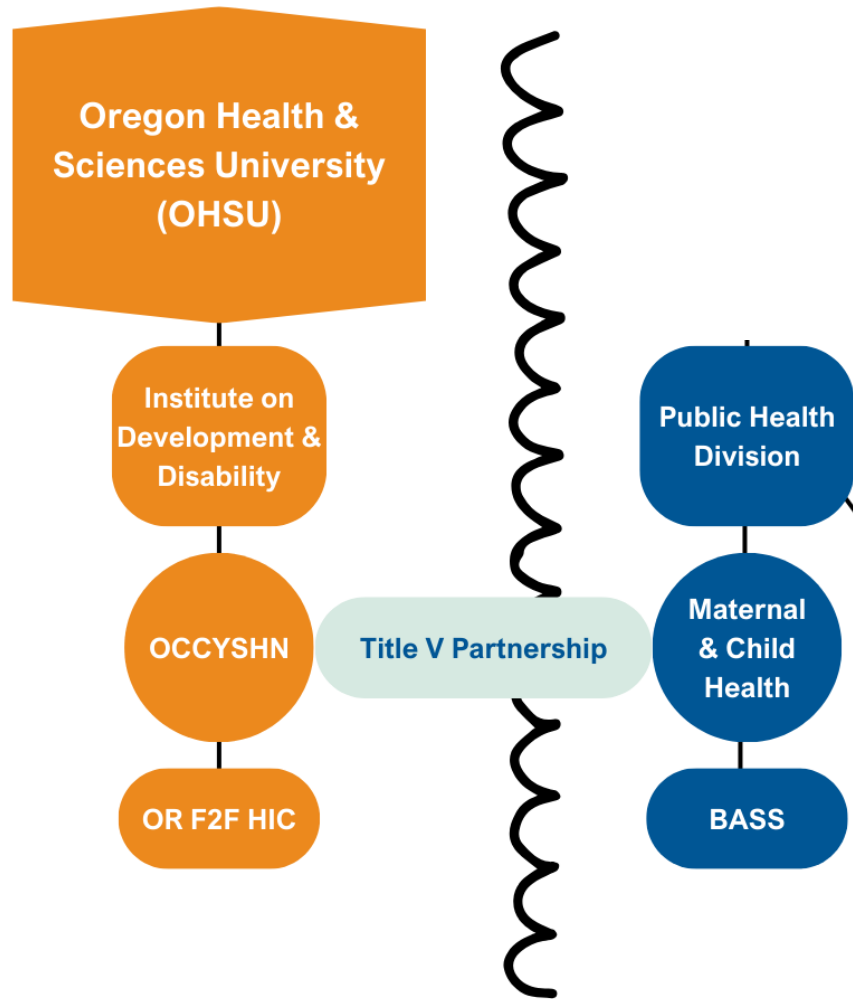
Current - program not CDC funded

- No program coordinator
- No abstraction
- Reprioritized workplan
- MCH leadership encouraged BASS team to continue program efforts
- Title V pays for BASS staff FTE

Organizational Structure

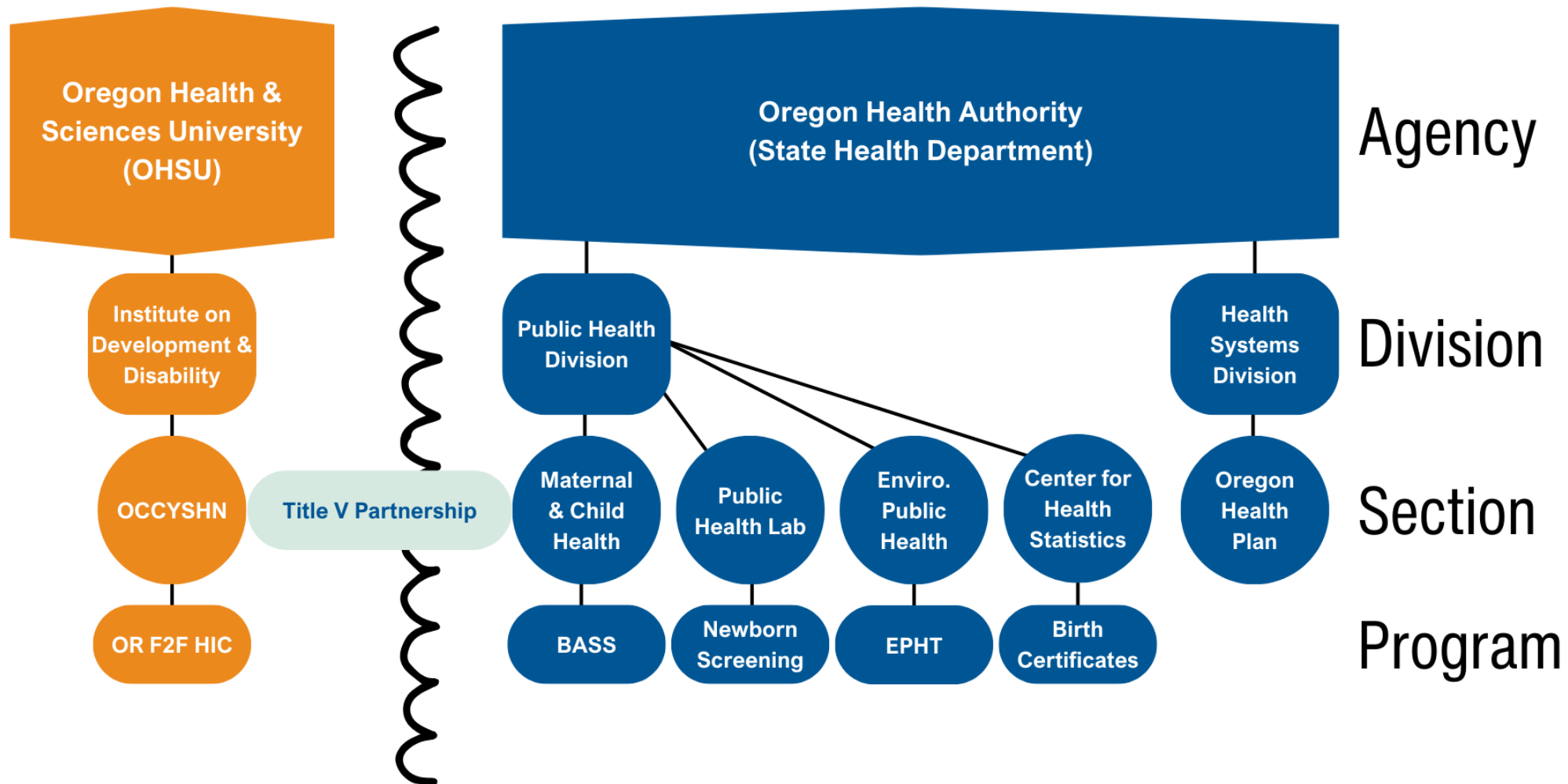


BASS - Oregon Birth Anomalies Surveillance System
EPHT - Oregon Environmental Public Health Tracking



OCCYSHN - Oregon Center for Children & Youth with Special Health Needs
OR F2F HIC - Oregon Family to Family Health Information Center

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Title V Block Grant

Federal Title V Structure

Federal funding to state MCH programs to support activities that improve the health of pregnant women, children, adolescents, and children and youth with special health needs.



<https://amchp.org/title-v/>

“Title V today gives states **flexibility** with **accountability** for systemic approaches to improve health access and outcomes for ALL women, children, youth and families. Title V has been dubbed the framework, the **infrastructure** and even the “glue” for states’ and territories’ overall strategies, policies and programs. Over the years, many strengths have evolved from Title V: flexibility, adaptability, broad mission focused on national health objectives, responsiveness to states’ and territories’ needs, and accountability for performance. While the dollars for Title V may be a relatively small proportion of a state’s total budget for family health programs, used effectively they can have a big impact.” - **AMCHP**

Title V Framework - Domains

Women/Maternal Health

Perinatal/Infant Health

Child Health

Adolescent Health

**Children and Youth with
Special Health Care Needs
(CYSHN)**

**Cross-Cutting/
Systems Building**

Oregon MCH Title V Structure

In Oregon, Title V funds are shared between:

- State public health
- Oregon Center for Children and Youth with Special Health Needs (OCCYSHN at OHSU)
- Local public health
- Tribes



Oregon's Title V Framework

State-level Priorities:

Foundations of MCAH

- Social determinants of health and equity
- Trauma, ACEs, and resilience
- Culturally and linguistically responsive services

National Priorities:

- Well woman care
- Breastfeeding
- Child injury prevention
- Bullying prevention

Work focused on:

- Policies and systems
- Workforce capacity and effectiveness
- Assessment and evaluation
- Community, individual and family capacity

To support/enhance:

- Thriving and equitable communities
- Resilient and connected families and communities
- Safe and responsive environments
- Nutrition and healthy development
- Healthy individuals and families

Women/Maternal Health Domain

National Performance Measure

- **Percent of women with a past year preventative visit**

Evidence-informed Strategy Measures (summary of relevant highlights)

- Focus on women's behavioral health needs
- Cultural responsiveness
- Community based perinatal, women's and infant health advisory groups to share best practices, strategize and impact policy change. Engage affected communities including people of color in leadership.

Perinatal/Infant Health Domain

National Performance Measure

- **Percent of infants who are ever breastfed**
- **Percent of infants breastfed exclusively through 6 months**

Evidence-informed Strategy Measures (summary of relevant highlights)

- Workplace laws around chest/breastfeeding with a focus on populations with additional barriers.
- Workforce training, especially around cultural responsiveness
- Community based perinatal, women's and infant health advisory groups to share best practices, strategize and impact policy change. Engage affected communities including people of color in leadership.

Children and Youth with Special Health Care Needs (CYSHN) Domain

National Performance Measure

- **Percent of children with and without special health care needs, ages 0 through 17, who have a medical home**
- **Percent of adolescents with and without special health care needs, ages 12 through 17, who received services to prepare for the transition to adult health care**

Evidence-informed Strategy Measures (summary of relevant highlights)

- Primary care involvement in shared care planning
- Young adult with medical complexity/family participation in transition preparation appointments

Cross-Cutting/Systems Building Domain

Title V's priorities and strategies in this domain are focused on improving the foundations of maternal, child and adolescent health. OCCYSHN (Oregon Center for Children and Youth with Special Health Care Needs) and MCAH (Maternal Child and Adolescent Health) have included strategies that are centered in:

- Trauma-informed care
- Equity and anti-racism
- Workforce diversity
- Addressing systems-level disparities
- Access to care
- Partnerships
- Community capacity
- Economic supports and housing
- Food sovereignty/security
- Emergency preparedness

Title V – Other Programmatic Efforts

Title V funding also supports work beyond the identified priority areas including the BASS program. Additional Title V funded work includes the following:

- Oregon Mothers Care
- Home Visiting
- PRAMS
- Safe Sleep
- Assessment and Evaluation and Informatics

These efforts include partnerships that BASS can tap into to help with our outreach efforts and deeper understanding of data trends.

What are your state Title V priorities/strategies?



<https://mchb.tvisdata.hrsa.gov/Home/StateApplicationOrAnnualReport>

Program Alignment

Aha! Moment

Surveillance and health education components of BASS have substantial areas of overlap with Oregon's Title V Women's and Infant Health.

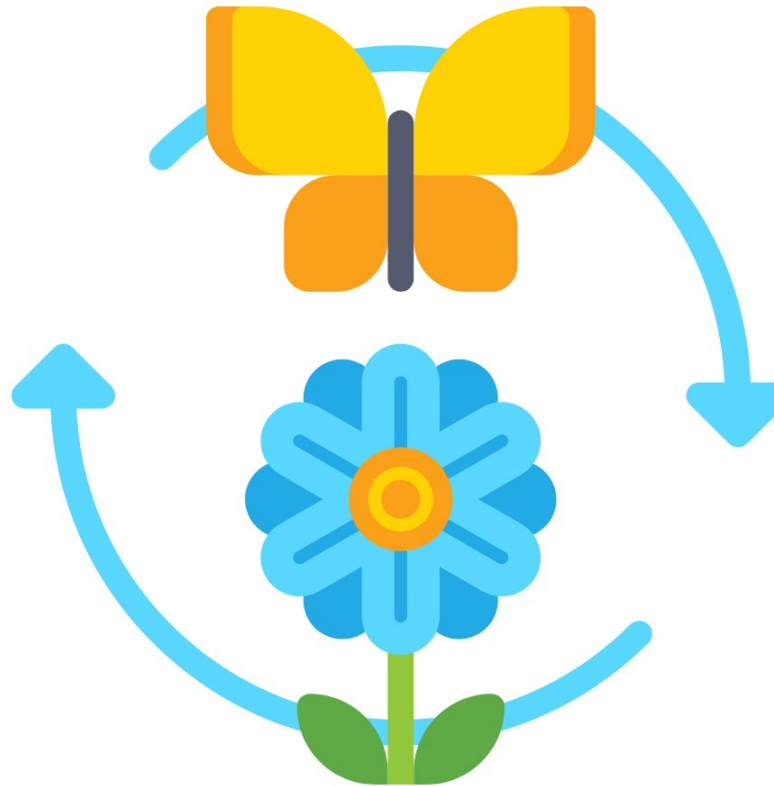


Why align with Title V?

- MCH leadership sees importance of BASS and decided to support with Title V funds
- National effort to strengthen partnership between Title V and birth defects prevention efforts
- Shared goals and outcomes
- Existing Title V Women and Infants Team includes priority specific work and other related work (e.g. Oregon Mothers Care) – opportunities to collaborate
- Strengthen collaboration between programs to ensure communications and opportunities for partnerships are optimized
- Leverage existing efforts and reduce duplication of work
- Outcomes and interventions/goals are mostly the same on BASS and Title V Women's and Infants teams

Program Symbiosis

BASS benefits from Title V policy-level expertise, local-level partnerships, flexible workplan, and equity approach.



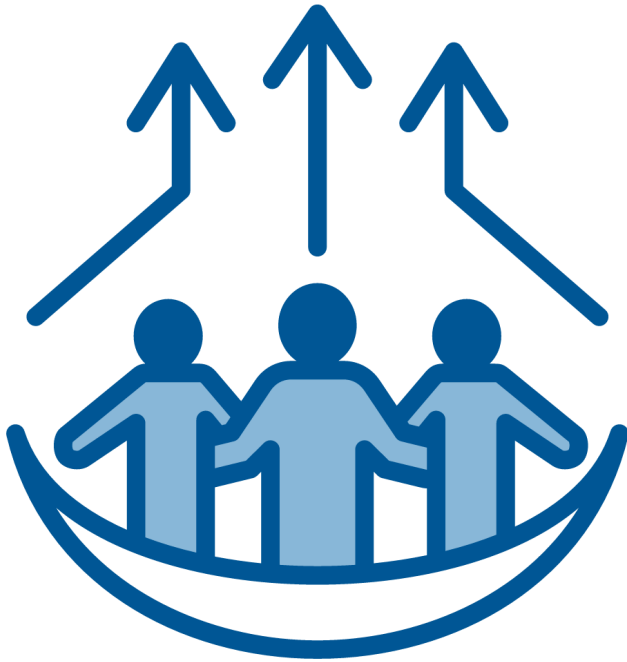
Title V benefits from BASS surveillance data, health education efforts for outreach, in-house expertise of impacts of birth anomalies, and partnerships.

Shared Program Outcomes

- Healthy pregnancies
- Healthy childbirth
- Healthy infants
- Families impacted by birth anomalies to have the resources they need to thrive
- Individuals with birth anomalies to live happy, healthy lives



Aligned Strategies



- Oregon MothersCare is increasing access to health insurance, prenatal care, and other resources for pregnant individuals.
- Well-woman care increases access to preconception and inter-conception care.
- Breastfeeding promotion and connection with WIC.
- OCCYSHN provides support and resources for families.
- Surveillance of birth anomalies and neonatal abstinence syndrome.
- Education and outreach promoting healthy habits
- Partnership with Family to Family Health Information Center – family informed program decisions, data informed resources for families

BASS – Title V Proposal to MCH Leadership

- BASS team to join monthly meetings with Title V Women and Infants team
- Add state-level strategy to the Title V Well Woman Care Plan in 2023
 - Strategy to strengthen partnership, identify opportunities for collaboration, revised BASS workplan to reflect those activities
- Anchor the existing BASS work plan to reflect the Title V funded BASS scope of work



Benefits of Collaboration

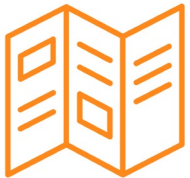
- Broad view of work
- Reduces duplication
- Bridges information gaps
- Leverages connections and existing efforts
- Reduces MCH siloes



Current BASS – Title V Activities



- Data to action
 - Analysis of folic acid consumption rates from PRAMS data and planning improvements for outreach to include engagement with Title V partners



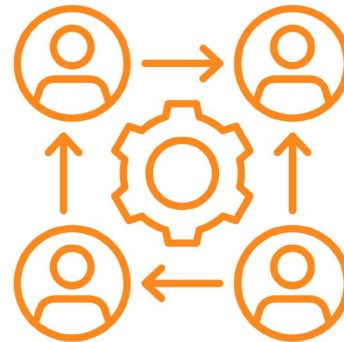
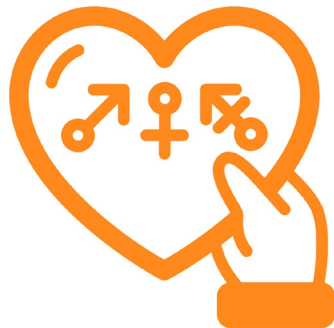
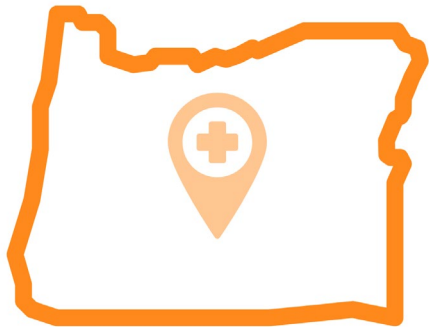
- Health promotion
 - Updating pregnancy outreach for Title V funded sites to include birth anomaly prevention tips



- Cross program collaborations and shared work plans
 - Joint BASS/Title V team

Future BASS – Title V Activities

- Map out existing and potential partnerships
- Incorporate gender inclusive language
- Improve understanding of internal/external workflows
- Facilitate data exchange with partners



Challenges

- Limited capacity without CDC funding
- BASS is still relatively young - lack of infrastructure
- BASS staff are stretched between competing priorities
- No state mandate or funding
- CYSHN is part of a different organization

Contact our team!

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