



# Oregon 2020 Title V Needs Assessment Report



# Acknowledgments

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## Acknowledgements

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- » Spect-Actors Collective, Doulas Latinas International

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- » the Title V staff at the Oregon Public Health Division and the Oregon Center for Children and Youth with Special Health Needs; and
- » the Maternal and Child Health Bureau whose MCH Title V funding and technical assistance made this needs assessment possible.

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# Introduction

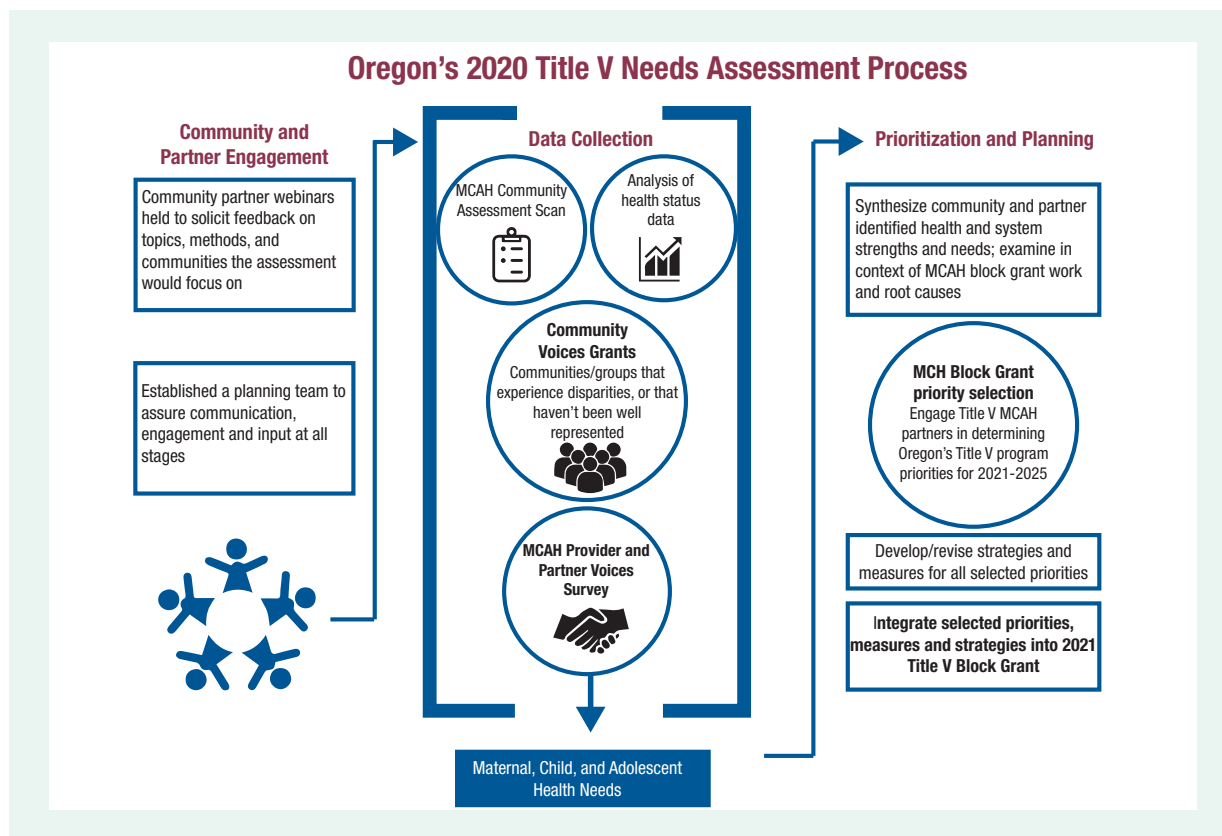
Oregon conducts a statewide assessment of the health needs of women, children and youth, including those with special health care needs, and families every five years. The needs assessment is conducted in partnership by Oregon’s two Title V entities: the Oregon Health Authority’s Public Health Division (PHD), and the Oregon Center for Children and Youth with Special Health Needs (OCCYSHN) housed at Oregon Health and Science University’s Institute on Development and Disability. The goals of the assessment are to:

- Better understand the health status and needs of Oregon’s women, infants, children and youth, including those with special health care needs, and their families;
- Engage stakeholders, partners, and communities in discussion of Oregon’s Title V MCAH work, its alignment with key MCAH system changes, and future opportunities to improve the health of the population;
- Inform the selection of priorities for the state’s Title V MCAH program for 2021-2025.

## Guiding Principles

Equity	Partnership	Frameworks
Focus on underrepresented voices	Respect and build upon prior community assessment work	Lifecourse perspective
Lead with race & identify disparities across marginalized identities	Seek opportunities for alignment in assessment and surveillance activities	Equity and social justice
Strive to meaningfully engage with communities most impacted by disparities	Look for opportunities to partner with local Title V grantees and community agencies to build capacity and align with their priorities	Social determinants of health
	Respect state and federal partner’s priorities e.g. ELD, SHIP, CCO	Root causes of disease including racism and trauma
		Public health modernization

# 2020 Needs Assessment Process



## Community and Partner Engagement

Engagement of the MCAH community and partners from across the state was critical at every stage of the 2020 MCAH Needs Assessment.

- During the planning phase, webinars were held to solicit partner input into the topics, methods, and communities that the assessment would focus on. A planning team structure was also established to assure communication, engagement and input at each stage of the process.
- Each component of the Needs Assessment, including the scan of community assessments, community voices grants, and partner/provider surveys, focused on a different method for engaging community and partners and assuring the broadest possible representation of MCAH voices were heard.
- The Title V priority selection process also focused on engaging partners, especially local Title V grantees, Tribal grantees, Community Voices grantees, and family representatives, to weigh the information gathered throughout the needs assessment and advise Title V Leadership on priorities to adopt for the 2021-2025 cycle.

# Data Collection

Keeping the guiding principles in mind, a mixed method approach was used to collect data for the Needs Assessment, which focused on community voices and partner input:



## Environmental scan of 41 community assessments conducted across Oregon:

- » This ensured that recent assessment efforts conducted by communities were honored and not duplicated.
- » Assessments from each county within the state were included, along with special population assessments conducted by community agencies.
- » This scan provided a ranking of national and state priority areas and allowed for community specific needs and emerging needs to be identified.



## Partner survey of 482 PHD and OCCYSHN partners

- » Respondents included but were not limited to stakeholders from coordinated care organizations, hospitals, health clinics, early learning hubs, school districts, schools, colleges, and community agencies.
- » Partners provided feedback on the importance of each priority area in terms of impact, equity, and impact of resource allocation,
- » Partners also reported on emerging needs they had identified in their communities and systems issues.



## Community voices:

- » A gathering of the voices of special populations of focus in partnership with community agencies, focusing on six special populations of focus: African American/ Black families, Hispanic/Latinx families, rural families, homeless families, immigrant and refugee families, and LGBTQ+ youth, with a special focus on transgender youth.

Public Health Division	Oregon Center for Children and Youth with Special Health Needs
<p>Mini grants were awarded to community agencies with connections to each special population. This facilitated the collection of perspectives which would otherwise have been inaccessible.</p> <p>Community agencies were supported in determining their own methods of culturally sensitive and responsive data collection.</p> <p>Data collection methods utilized included focus groups, listening sessions, Charlas (a dialogue), written surveys, and semi-structured in-person or phone interviews.</p>	<p>Through a Request for Proposal process, OCCYSHN contracted with the Sickle Cell Anemia Foundation of Oregon (SCAFO) and the Latino Community Association (LCA) in Central Oregon to conduct participatory needs assessments.</p> <p>OCCYSHN developed the questions guiding this research, and SCAFO and LCA participated in the development of the data collection methods, including the IRB protocol. They collected – and co-own – the data, participated in the analysis, and are participating in our dissemination efforts.</p> <ul style="list-style-type: none"> <li>» SCAFO conducted focus groups with families of Black children and youth with special health care needs (CYSHCN) throughout Oregon.</li> <li>» LCA conducted focus groups with immigrant families of Latino CYSHCN in Central Oregon.</li> </ul>



**Analysis of health status data from a range of sources including:**

- » Vital statistics
- » Census data
- » Survey data including: Pregnancy Risk Assessment Monitoring System & PRAMS 2; Oregon Behavioral Risk Factor Surveillance System; Oregon Healthy Teens, National Survey of Children’s Health, OCCYSHN Shared Care Planning Family Survey
- » Medicaid data
- » National Core Indicators data
- » Oregon Department of Education data
- » Review of public reports. As part of describing the aspects of Oregon’s systems of care for CYSHCN, OCCYSHN extracted results from its own reports and reports from state-level partners.

# Synthesis of Results

Results were synthesized and compiled into a set of 34 data tools, describing overall health and issues and concerns for each population group served by Title V, and addressing current, potential and emerging topics. These tools present the needs assessment results by MCAH population and topic, helping partners to understand the issues and providing guidance to the Title V program regarding priority selection. The tools contain both quantitative and qualitative results, including a comparison of Oregon and national data, trends over time, and an examination of racial and ethnic disparities when data were available. Results of the environmental scan, partner survey and community voices project are presented in the tools, as well as the context of each issue in Oregon, including current state and local efforts, and partner alignment.

The complete set of data tools is available at: <https://www.oregon.gov/oha/PH/HEALTHYPEOPLEFAMILIES/DATAREPORTS/MCHTITLEV/Documents/2020%20Title%20V%20Data%20Tools%20Book%20Final.pdf>

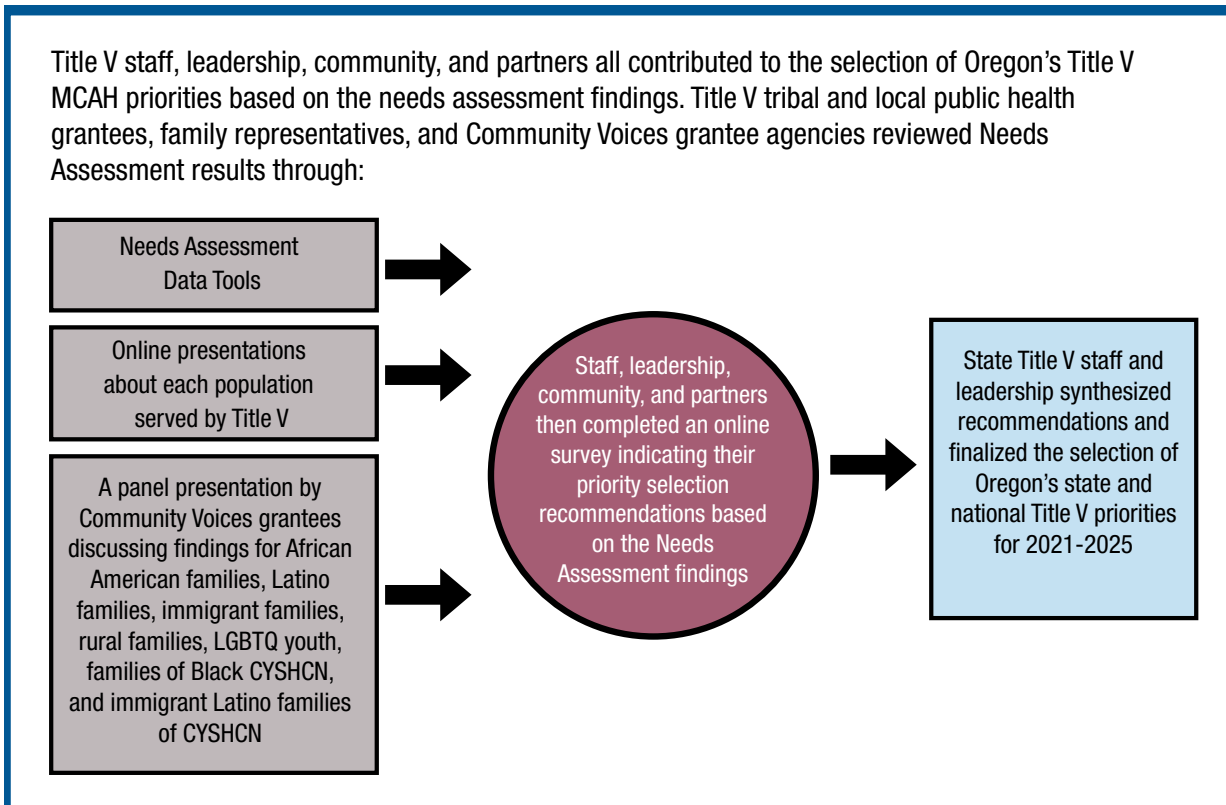
OCCYSHN's Needs Assessment report is available at: <https://www.ohsu.edu/sites/default/files/2020-10/OCCYSHN%202020%20Needs%20Assessment%20Report%20FINAL.pdf>.

## The report is organized into 6 chapters:

- » Chapter 1:  
How are Oregon Children & Youth with Special Health Care Needs Faring?  
Summary of Findings
- » Chapter 2:  
Compilation of Findings from Secondary Data Sources
- » Chapter 3:  
Health Care Needs, Access to Care, and Experiences of Racism for Black Children and Youth with Special Health Care Needs and Their Families
- » Chapter 4:  
Escúchenos! Immigrant Latino Parents of Children and Youth with Special Health Care Needs in Central Oregon Share their Experiences Accessing Health Care (English and Spanish versions are available)
- » Chapter 5:  
Oregon Systems of Care for Children and Youth with Special Health Care Needs
- » Chapter 6:  
Stakeholder Feedback on Title V Priorities for Children and Youth with Special Health Care Needs



# Priority Selection



## State MCAH Needs and Selected Title V Priorities and Performance Measures

The following Oregon MCAH needs were identified:

1. Assure safe and supportive environments
2. Assure stable and responsive relationships; resilient and connected families and communities
3. Improve lifelong nutrition
4. Increase health equity and reduce MCAH disparities
5. Address social determinants of health
6. Assure high quality, culturally responsive preconception, prenatal, inter-conceptions and post-partum services.
7. Assure high quality, family-centered, coordinated systems of care for children and youth with special health needs

To address the above state MCAH needs, the following state and national priorities and performance measures were selected for Title V work from 2021 - 2025. The selected cross-cutting state priority areas are key foundations of lifelong health. A focus on these in the 2021-2025 Title V cycle reflects the Title V program’s commitment to upstream approaches to mitigate the impact of racism, inequities, trauma, and social determinants of health on the MCAH population.

### State Priority Areas and Performance Measures

Priority Area	Performance Measures
Toxic Stress, Trauma, ACEs and Resilience	<ul style="list-style-type: none"> <li>A. Percentage of new mothers who experienced stressful life events before or during pregnancy</li> <li>B. Percentage of mothers of 2 year olds who have adequate social support</li> </ul>
Culturally and Linguistically Responsive Services	<ul style="list-style-type: none"> <li>A. Percent of children age 0 - 17 years who have a healthcare provider who is sensitive to their family’s values and customs</li> <li>B. Percent of new mothers who have ever experienced discrimination while getting any type of health or medical care</li> </ul>
Social Determinants of Health and Equity	<ul style="list-style-type: none"> <li>A. Percent of children in low-income households with a high housing cost burden</li> <li>B. Percent of children living in a household that received food or cash assistance</li> <li>C. Percent of households with children &lt; 18 years of age experiencing food insecurity</li> </ul>

### National Priority Areas and Performance Measures

Priority Area	Performance Measures
Well Woman Care	Percent of women, ages 18 through 44, with a preventive medical visit in the past year
Breastfeeding	<ul style="list-style-type: none"> <li>A. Percent of infants who are ever breastfed</li> <li>B. Percent of infants breastfed exclusively through 6 months</li> </ul>
Child Injury	Rate of hospitalization for non-fatal injury per 100,000 children, ages 0 through 9
Bullying	Percent of adolescents, ages 12 through 17, who are bullied or who bully others
Medical Home	Percent of children with special health care needs, ages 0 through 17, who have a medical home
Transition	Percent of adolescents with special health care needs, ages 12 through 17, who received services necessary to make transitions to adult health care

# Next Steps

Public Health Division	Oregon Center for Children and Youth with Special Health Needs
<p>The PHD is re-organizing its Title V program to better support an upstream cross-cutting prevention approach to the 2021-2025 priorities.</p> <p>Strategies, state and local level activities, and measures to address each priority area are being developed.</p> <p>Technical assistance and tools will be available to support local Title V grantees in developing Title V plans focused on the new priorities in Spring 2021.</p> <p>Local Grantees will begin implementation of strategies and activities related to the new priorities in July 2021.</p>	<p>Specific to needs assessment findings regarding the experiences of racism experienced by families of Black and Latino CYSHCN when seeking care for their child, OCCYSHN will:</p> <ul style="list-style-type: none"> <li>» Raise awareness of health care and other professionals who work with CYSHCN. OCCYSHN is collaborating with LCA and SCAFO to disseminate these findings.</li> <li>» Partner with culturally specific community-based organizations to ensure that its Title V Block Grant strategies are culturally responsive and seek to dismantle racism.</li> <li>» Collaborate with culturally specific community-based organizations to identify and promote culturally responsive health care practices.</li> <li>» Build and strengthen partnerships with culturally specific service organizations representing additional minoritized communities to advocate for Oregon CYSHCN and their families.</li> </ul>

# Appendix A: Data Tools

## Oregon's 2020 Title V Maternal, Child, and Adolescent Health Needs Assessment Data Tools

Prepared for Title V Stakeholder Meeting, January 14-15, 2020

# Appendix B: Detailed Methods and Results

## Environmental Scan

### Methods

The environmental scan was conducted to ensure that wherever possible, needs assessment efforts already conducted by communities were honored and not duplicated. The scan was a collaborative project between the OHA Maternal and Child Health Section, the OHA Adolescent and School Health Program, and the Oregon Center for Children and Youth with Special Health Needs. Assessment reports that had been completed in the last five years from across the state were compiled, including 30 from local health authorities, and 11 special population reports from community agencies. The local health authority reports provided a complete geographical representation of the state, and the community agency reports presented needs of specific marginalized communities. A comprehensive list of 72 maternal and child health needs was then developed, and each of the reports was scanned for mentions of need related to these topics. Mentions of the topics which did not explicitly indicate a need were not included, e.g. descriptive statistics were not included. This analysis provided not only a ranking of national and state priority areas but allowed for community specific needs and emerging needs to be identified. The qualitative analysis was conducted using NVIVO software.

## Results

### National and State Priority Area Rankings

Ranking	Population Domain					
	Women's and Maternal Health	Perinatal and Infant Health	Child Health	Adolescent Health	CYSHCN	Cross-cutting (State Priority Areas)
1	Well woman care	Breastfeeding	Secondhand tobacco smoke exposure	Adolescent well visit	Medical home	Food insecurity
2	Oral health during pregnancy	Safe sleep	Oral health among children	Secondhand tobacco smoke exposure	Adequate insurance coverage	Culturally and linguistically responsive services
3	Smoking during pregnancy	Risk appropriate perinatal care	Adequate insurance coverage	Oral health among adolescents	Transition to adulthood	Toxic stress, trauma, & ACEs
4	Low risk cesarean delivery		Child physical activity	Adequate insurance coverage		
5			Child injury	Adolescent physical activity		
6			Developmental screening	Adolescent injury		
7				Bullying		

Ranking	MCAH Topic	Number of reports with mentions of need
1	Mental and behavioral health	27
2	Health care access	24
3	Housing	21
4	Poverty	20
	Substance use	
5	Employment	19
6	Alcohol use	18
7	Opioid abuse	17
8	Illicit drug use	15
9	Transportation	14
	Nutrition	
	Overweight and obesity	
10	Prenatal care	13
11	Education	12
	HIV & Other STDs	
	Homelessness	
12	Social connection	10
	Violence and crime	
13	Teen pregnancy and birth	9
14	Child abuse and neglect	8
	Racism	
	Injury	
15	Child care	7
	Environmental issue	
	Infant mortality	
16	Foster care	6
	Income inequality	
17	Incarceration	5
18	Asthma	4
	Immunization	
19	Birth outcomes	3
	Health literacy and awareness of services	
20	Contraceptive use	2
	Food deserts	
	Postpartum care	
	Recreational space and facilities	
	Sexual behavior	
	Suicide	
21	Intimate partner violence	1
	Chronic disease (diabetes, hypertension, etc)	

# MCAH Community Voices

## Methods

The MCAH community voices project allowed for the needs of six special populations of focus to be explored. Special populations of focus were selected based on two selection criteria:

1. Underrepresented or unrepresented in previous Title V Needs Assessment
2. Evident disparities in existing MCAH data

### **The special populations of focus selected were:**

1. African American/Black families
2. Native American families
3. Hispanic/Latinx families
4. Rural families
5. Homeless families
6. Immigrant and refugee families
7. Native American youth
8. LGBTQ+ youth, with a special focus on transgender youth
9. Spanish-speaking youth

### **A request for proposals was released, which asked applicants to provide:**

1. Brief description of their organization, including:
  - » Brief description of community served and impact of health disparities
  - » Geographic area served
  - » Why the organization was interested in the mini-grant opportunity
2. Project proposal including:
  - » The community the agency intended to engage and gather feedback from
  - » A description of the agency's prior experience soliciting feedback from community members, including youth if applicable
  - » description of how the agency would inform community members about the opportunity to provide feedback for the needs assessment (e.g. method of outreach, advertising)
  - » A description of how the agency would solicit feedback from community members (e.g. community meeting or listening session, surveys, community event, etc.), including the estimated number of people and geographical areas reached



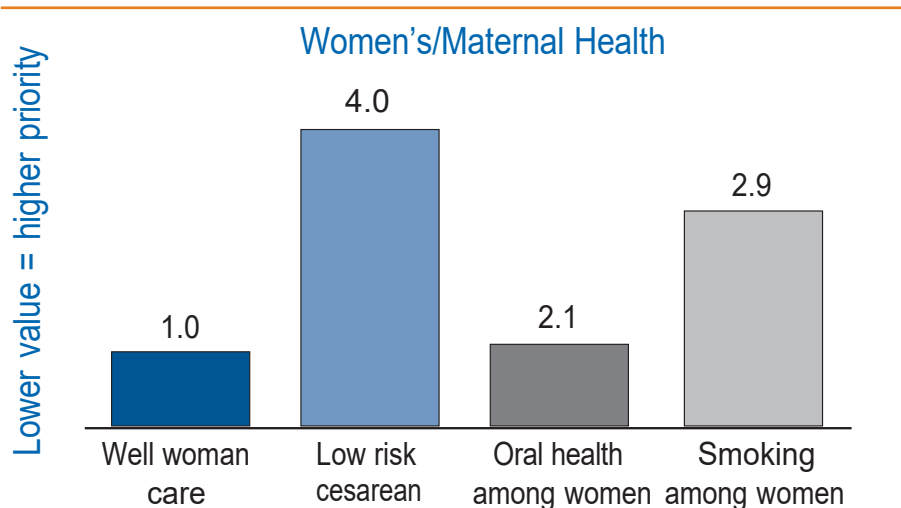
- » A description of the intended method used to synthesize community feedback and prioritize topics (voting, consensus building, strategy grid, etc.)
- » A description of how the agency planned to remove barriers/provide incentive for participants (e.g. timing/location of meeting, provision of child care, refreshments, transportation/parking, incentives)
- » A description of how the agency would ensure ensure voices/opinions of participants were heard and documented (e.g. interpretation/translation, recorder/note-taker, experience of facilitator, etc.).

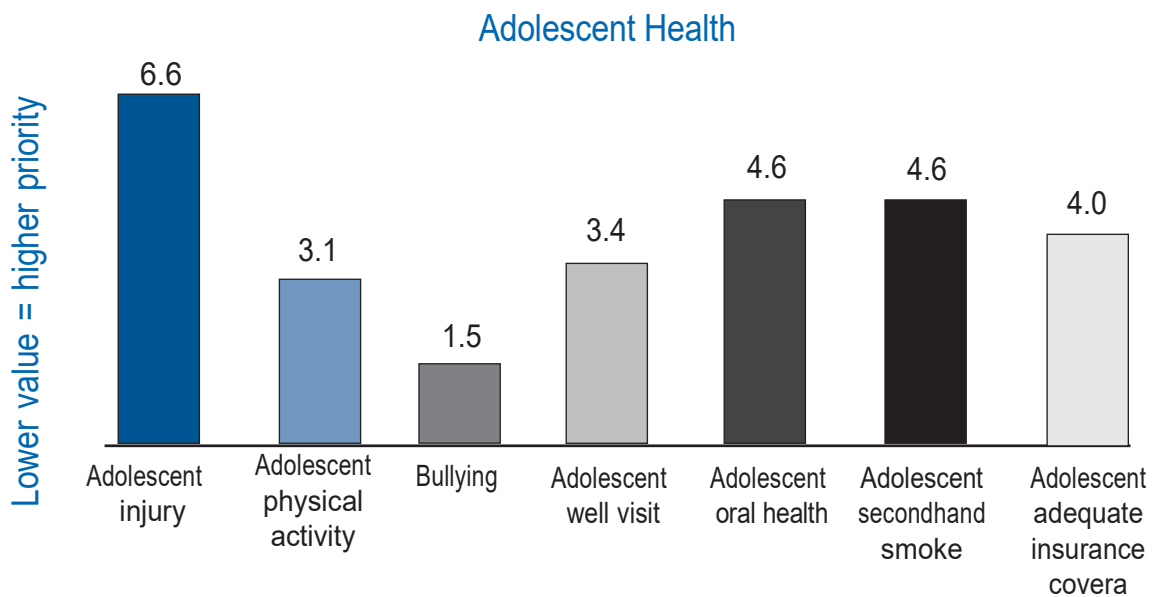
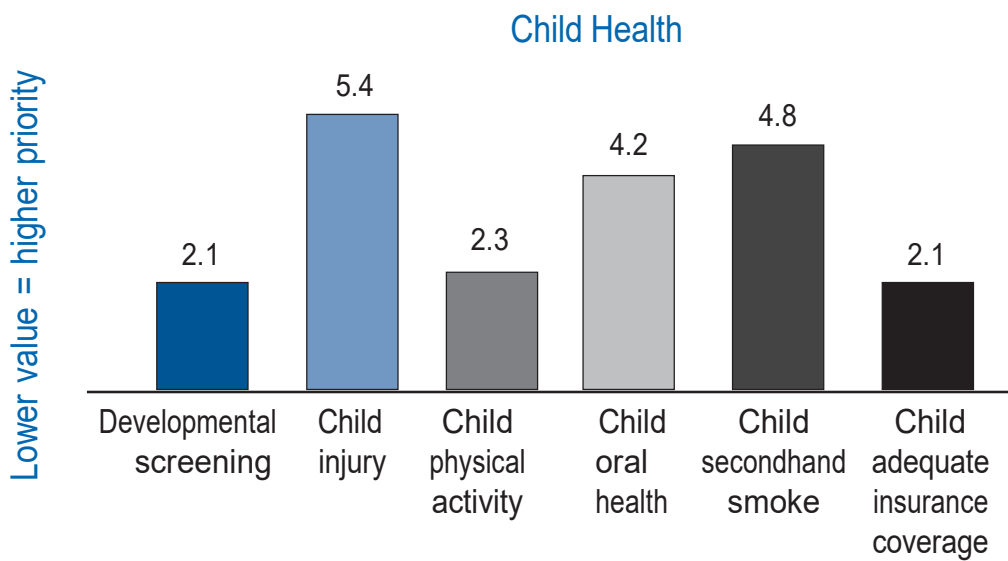
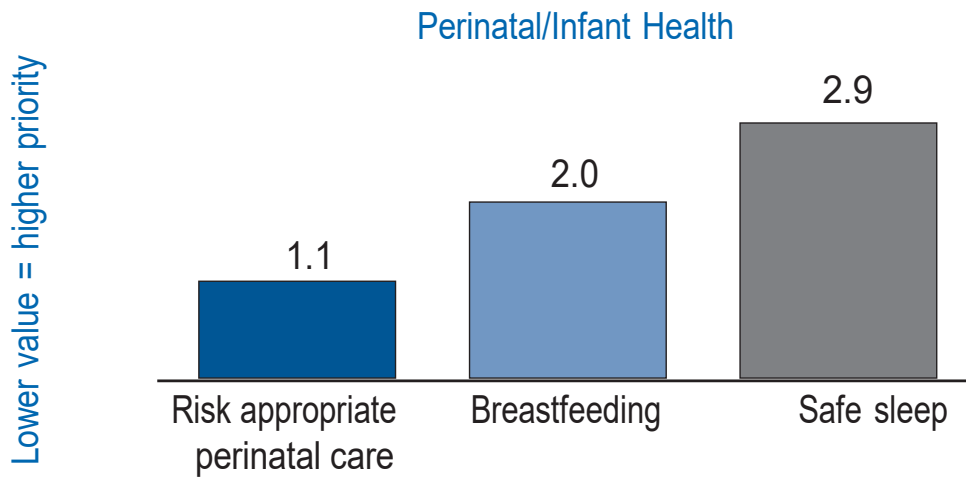
3. A budget proposal not to exceed \$7,000.

Six community agencies were ultimately selected and awarded with mini grants to collect data. The three special populations of focus for which no contract was finalized were Native American families, Native American youth, and Spanish-speaking youth. These populations, along with others such as Asian and Pacific Islander families, will be the focus of data collection in future years of the Title V Block Grant.

The six awarded agencies were provided with the topics to discuss with participants, and the questions that needed to be answered to meet the deliverables of the contract. Each agency was supported in determining the method of data collection that was the most suitable and culturally responsive for the community they served. Methods utilized by the grantees included focus groups, listening sessions, Charlas (a dialogue), written surveys, and semi-structured in-person or phone interviews. The use of mini grants to agencies with connections to specific communities allowed perspectives to be collected that would not otherwise have been accessible.

## Results



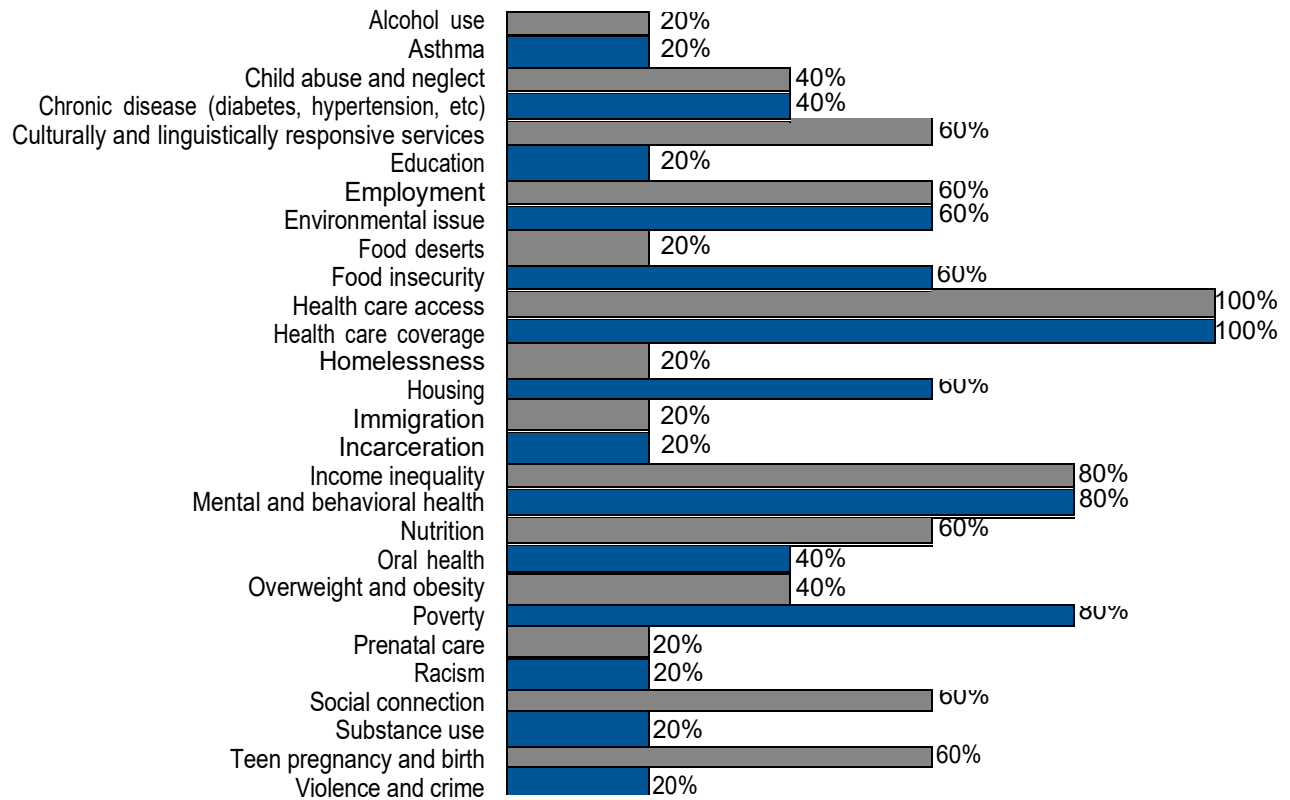


Rank	Women's/ Maternal Health	Perinatal/ Infant Health	Child Health	Adolescent Health	State Priority Areas
1st	Well woman care	Risk appropriate perinatal care	Developmental screening/ adequate insurance coverage	Bullying	Toxic stress and trauma
2nd	Oral health	Breastfeeding	Physical activity	Physical activity	Culturally and linguistically appropriate services
3rd	Smoking	Safe sleep	Oral health	Adolescent well visit	Food insecurity
4th	Low risk cesarean		Secondhand smoke	Adequate insurance coverage	
5th			Injury	Oral health/ secondhand smoke	
6th					
7th				Injury	

#### List of emerging needs identified:

- » Alcohol use
- » Asthma
- » Child abuse and neglect
- » Chronic disease (diabetes, hypertension, etc)
- » Culturally and linguistically responsive services
- » Education
- » Employment
- » Environmental issue
- » Food deserts
- » Food insecurity
- » Health care access
- » Health care coverage
- » Homelessness
- » Housing
- » Immigration
- » Incarceration
- » Income inequality
- » Mental and behavioral health
- » Nutrition
- » Oral health
- » Overweight and obesity
- » Poverty
- » Prenatal care
- » Racism
- » Social connection
- » Substance use
- » Teen pregnancy and birth
- » Violence and crime

## Percent of special populations of focus that identified each emerging need



# Partner Survey

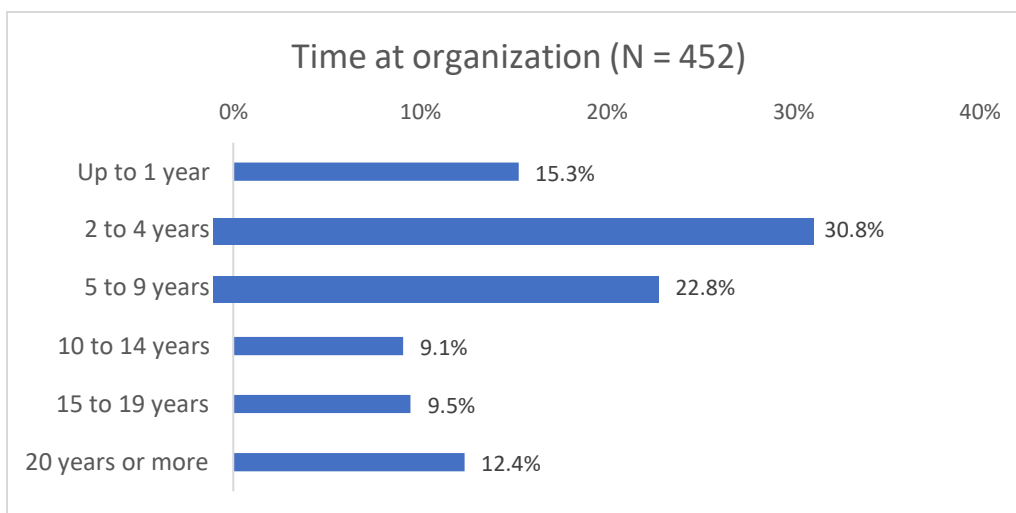
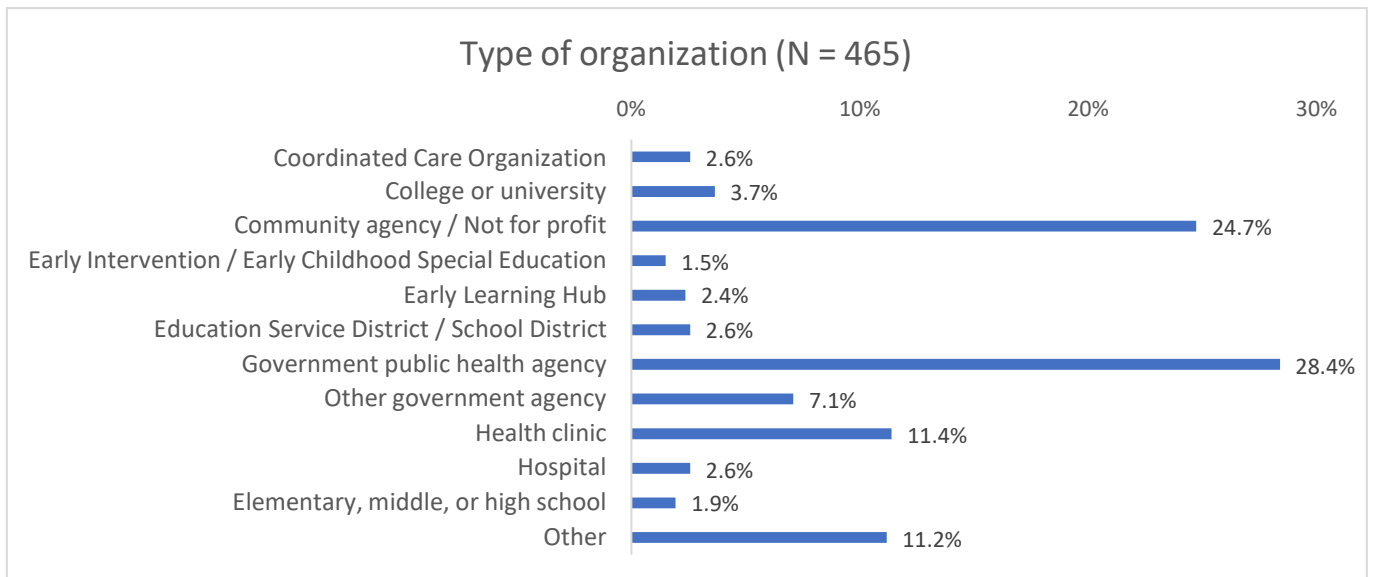
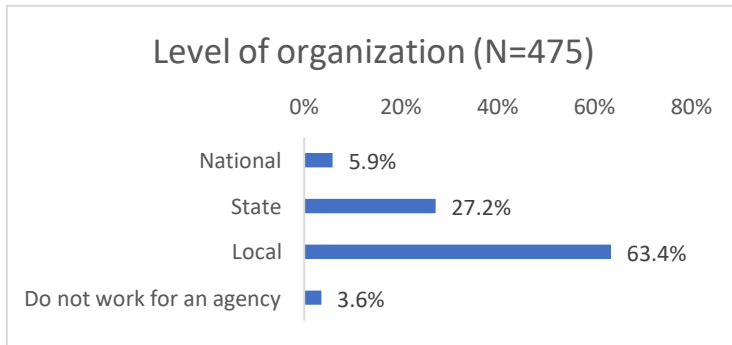
## Methods

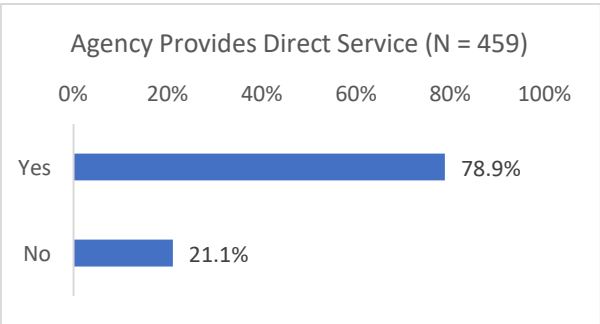
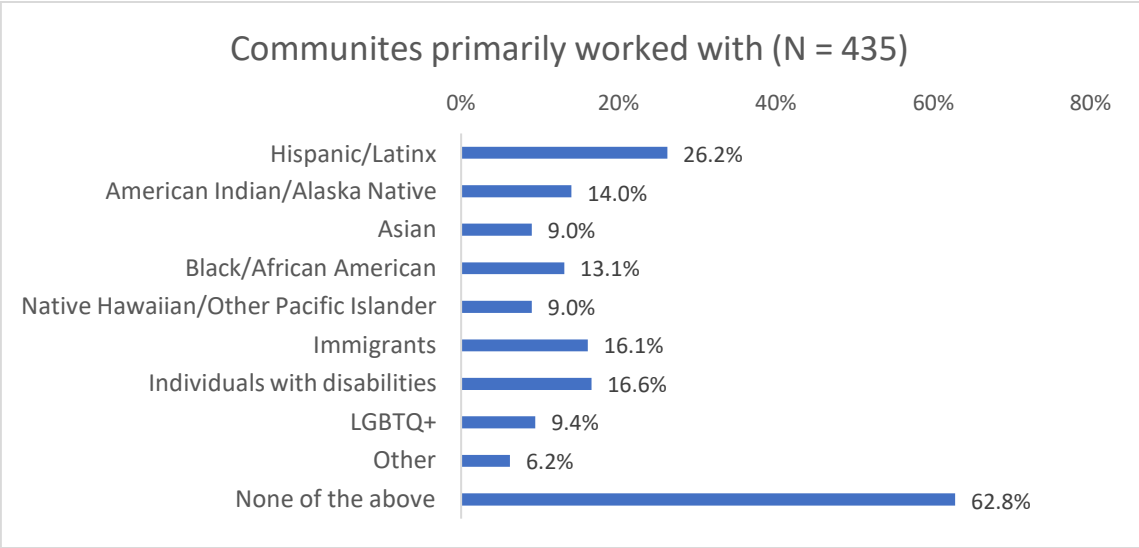
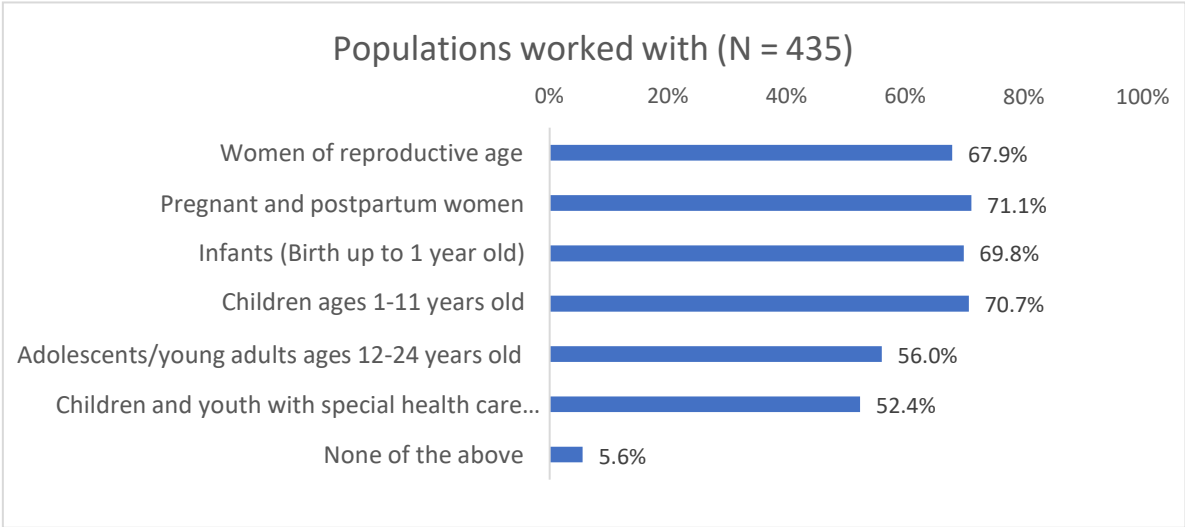
An online survey was administered to MCAH and OCCYSHN partners through Survey Monkey. Recipients of the survey were encouraged to forward it to other relevant stakeholders of maternal and child health in the state, to create a snowball effect and widen distribution of the survey. The survey questions included:

1. Information regarding the agency and position of the respondent, including whether the agency served any of a list of special population groups
2. Topic specific questions: a set of questions for each of the national and state priority areas, and a predetermined list of emerging needs, on the importance of:
  - » impact of the topic
  - » impact on health equity
  - » impact of applied resources to the topic
3. A ranking of each of the national and state priority areas within each population domain
4. A question about other emerging needs identified in the community served by the agency
5. Questions regarding systems issues in Oregon
6. Demographics of the respondents

# Results

## Organizational Details





## Specified immigrant countries/regions of origin:

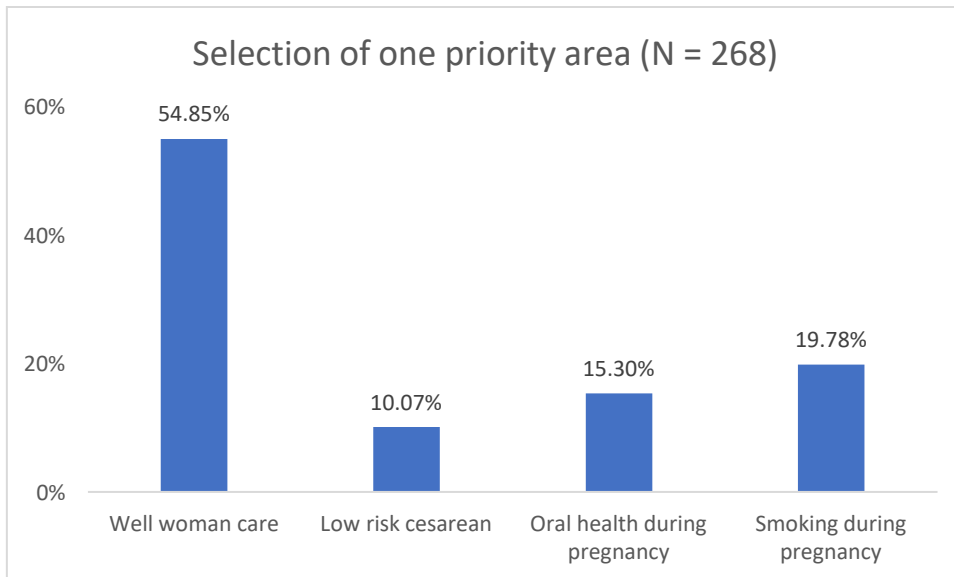
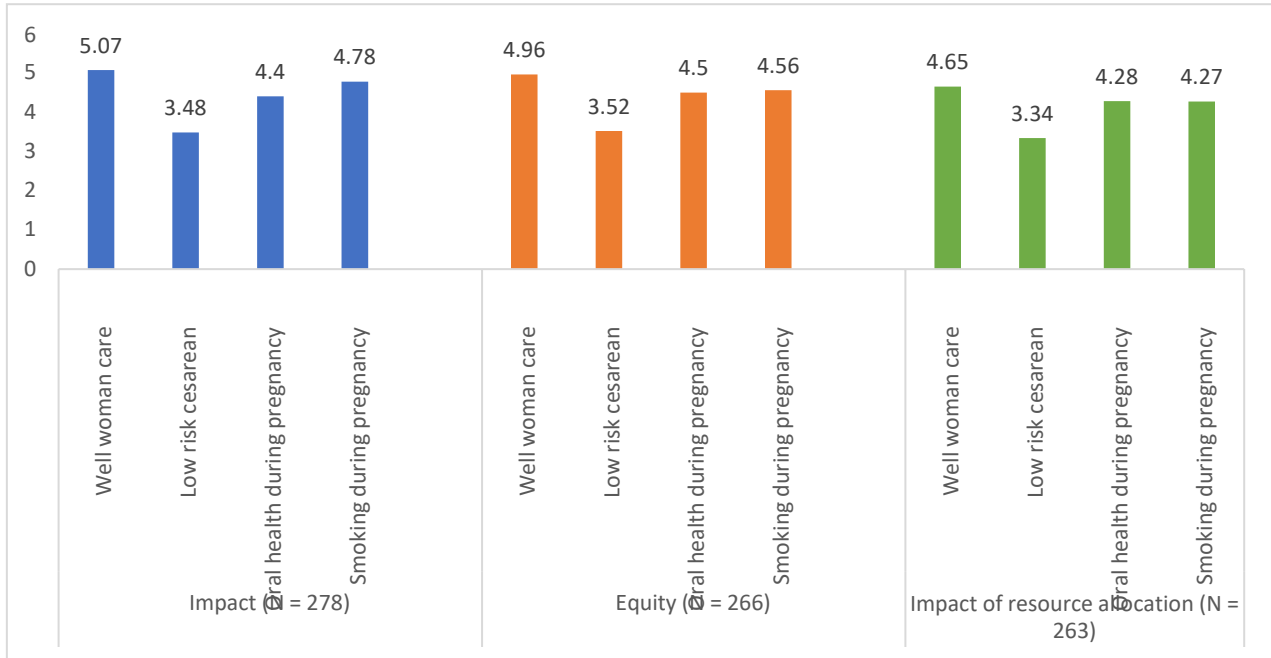
- Afghanistan
- Bhutan
- Burma
- China
- Chuuk
- Colombia
- Congo
- Cuba
- Egypt
- El Salvador
- Eritria
- Ethiopia
- Guam
- Guatemala
- Hawaii
- Honduras
- India
- Iran
- Iraq
- Kenya
- Korea
- Laos
- Mexico
- Nicaragua
- Peru
- Rohingya
- Russia
- Rwanda
- Saudi Arabia
- Somalia
- Spain
- Syria
- Thailand
- Ukraine
- Vietnam
- Yemen
- Venezuela

## Specified other communities:

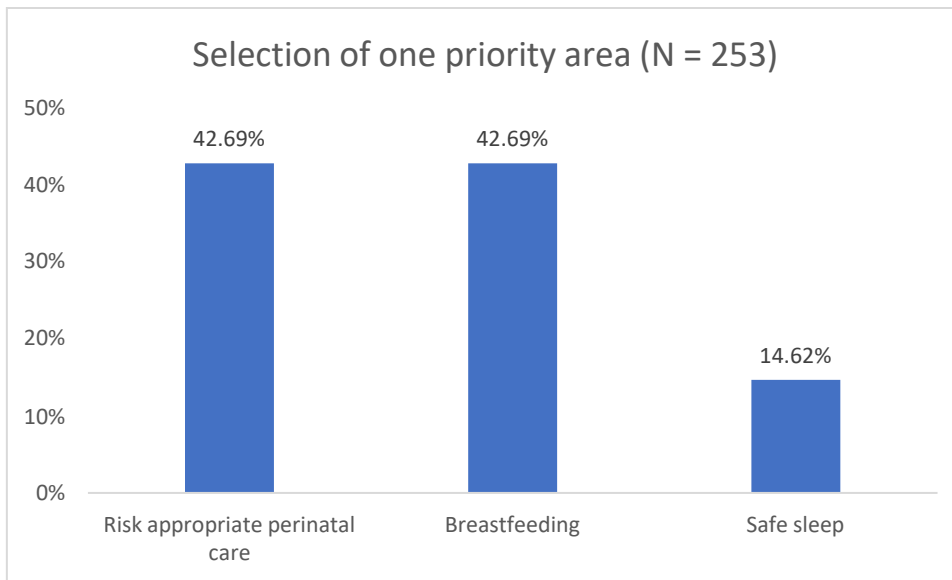
- Low-Income/working poor/employed but cannot afford health insurance
- Immigrants
- Families affected by incarceration
- Individuals with disabilities
- BIPOC
- People who have experienced violence, abuse and other forms of trauma/ Families with 5+ identified risk factors for abuse and neglect
- Young parents
- Families experiencing high levels of stress
- Tribal Nations/Native Americans/Tribal members/Indigenous
- Families with DHS involvement
- Rural communities
- Medicaid, underinsured and uninsured
- Individuals experiencing homelessness/homeless youth/runaway
- Mental Health
- LGBTQ
- Refugees
- Food Insecure people of all types
- Marginalized traditionally underserved youth in school or housing settings
- Migrant farm workers/migrant and seasonal workers
- The Deaf Community
- School districts
- Health care delivery sector
- Youth
- anyone who works in agriculture
- Parents of school aged youth, policy makers in the community/ Families with young children
- Adult students, working families
- Foster youth



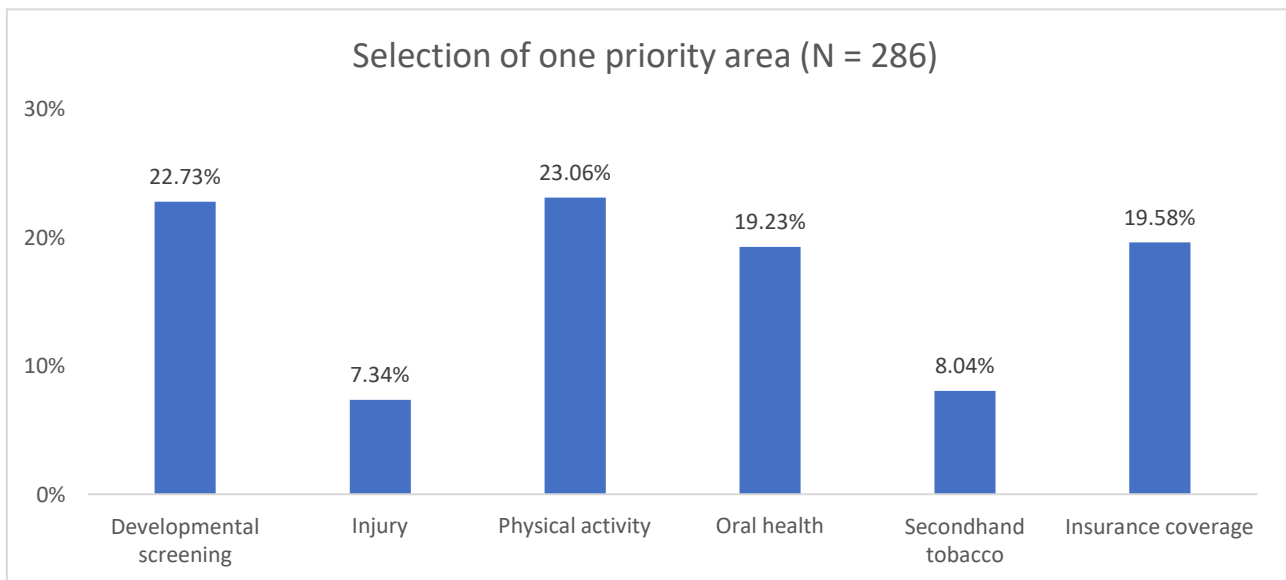
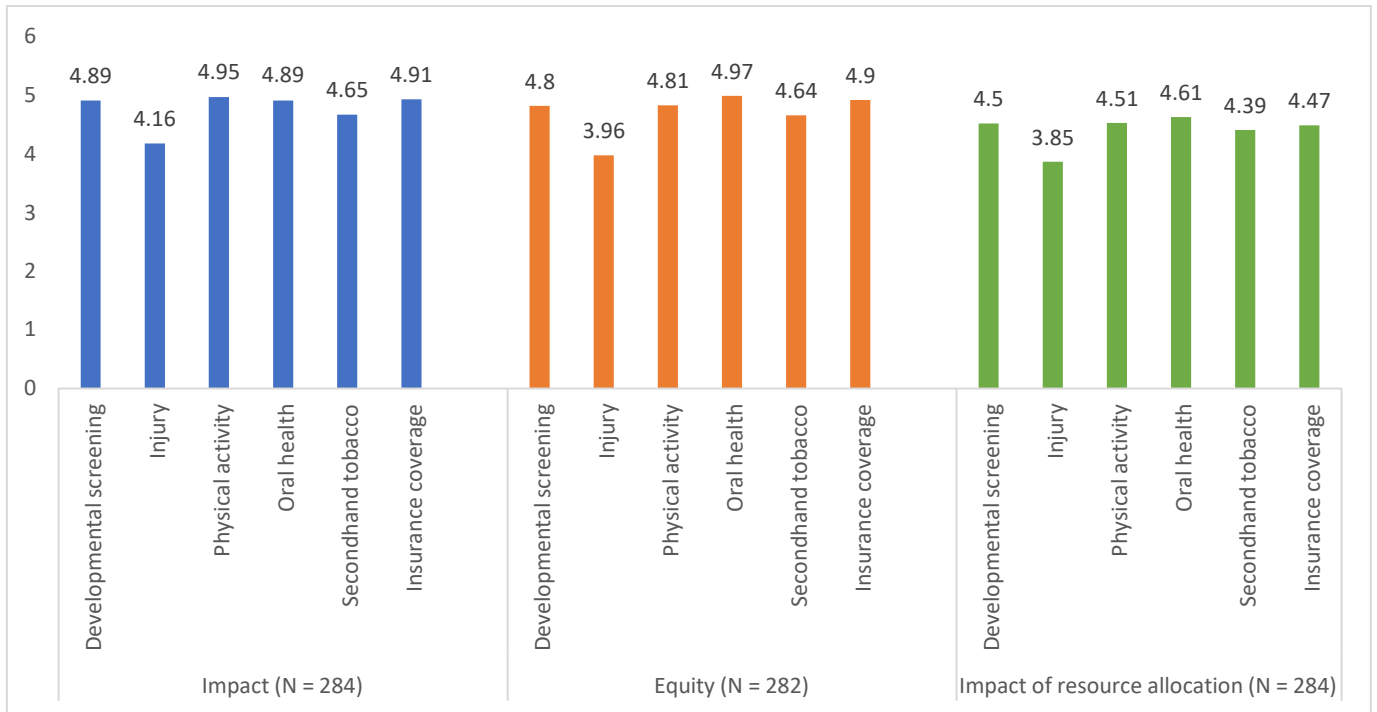
## Women's/Maternal Health (N = 323)



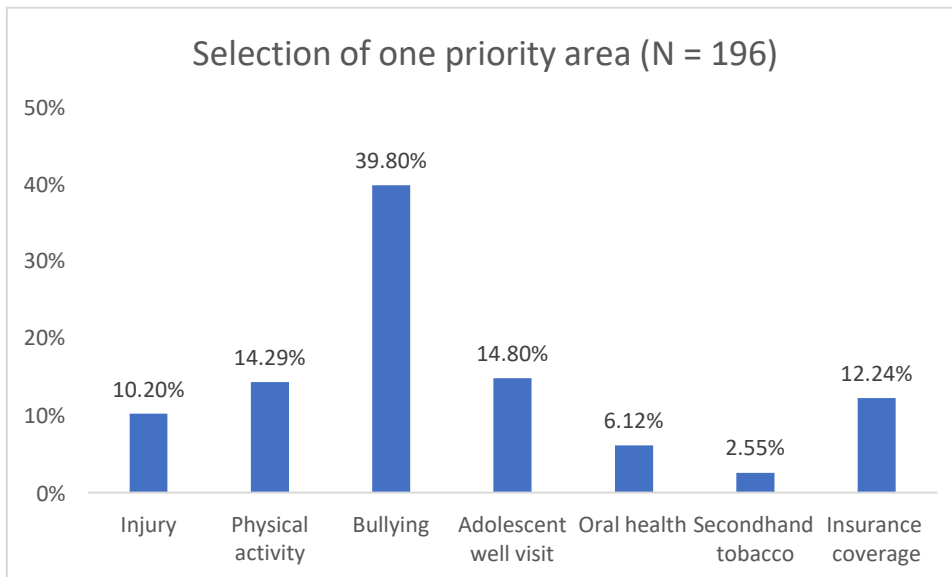
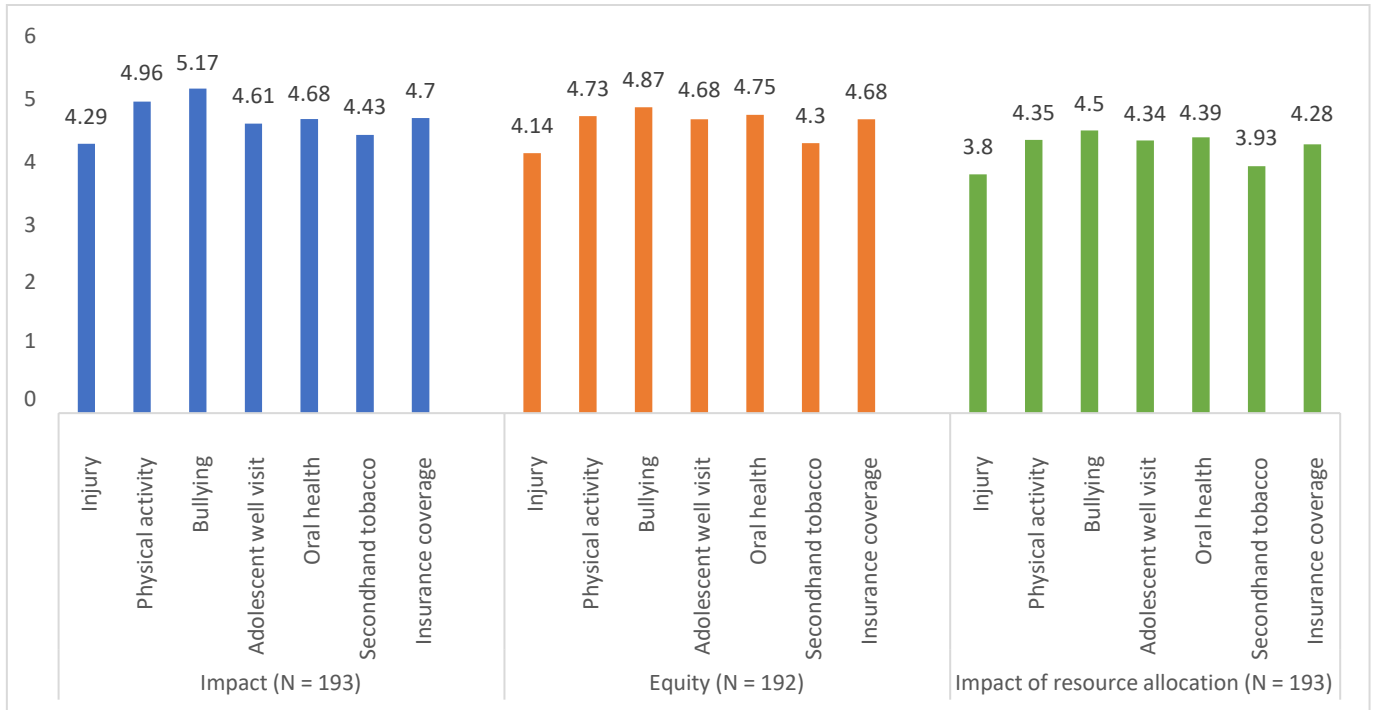
## Perinatal / Infant Health (N = 264)



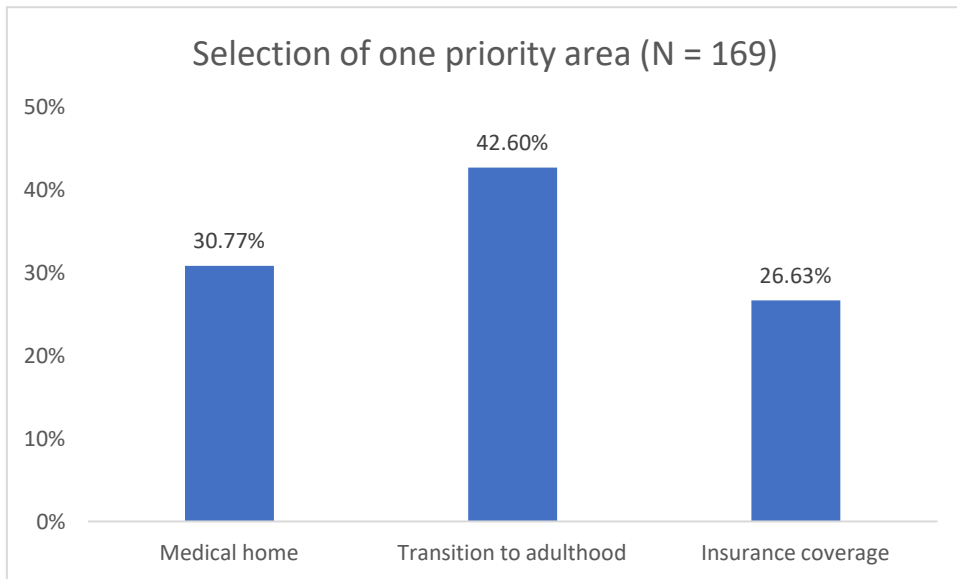
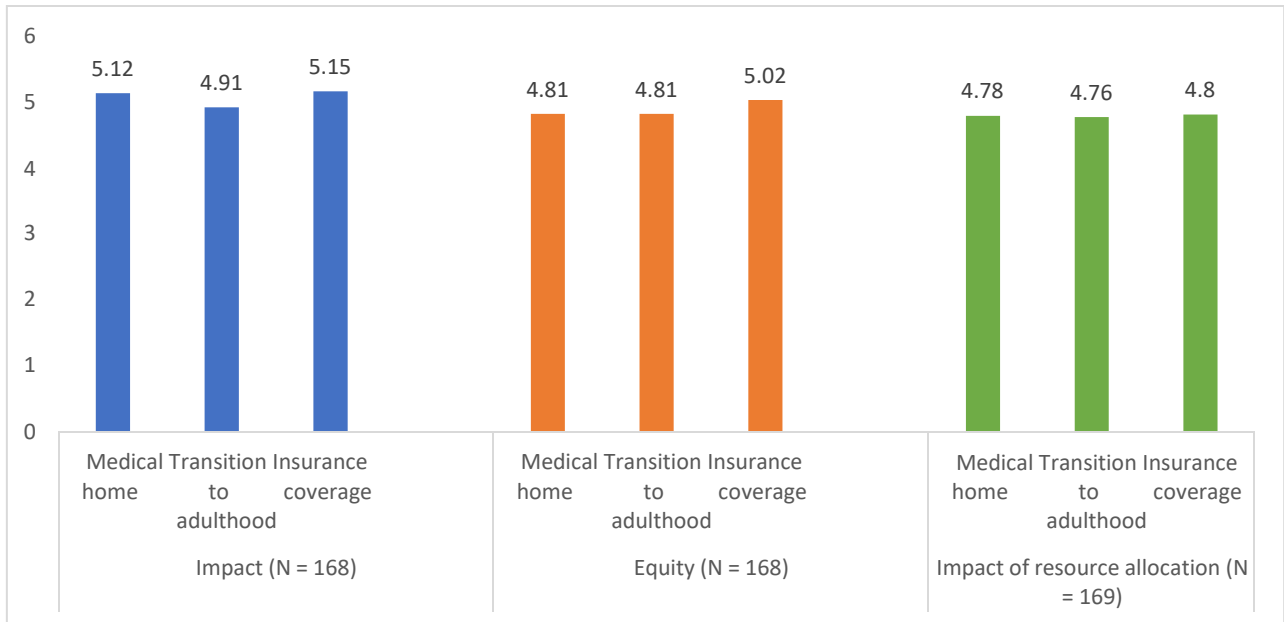
## Child Health (N = 309)



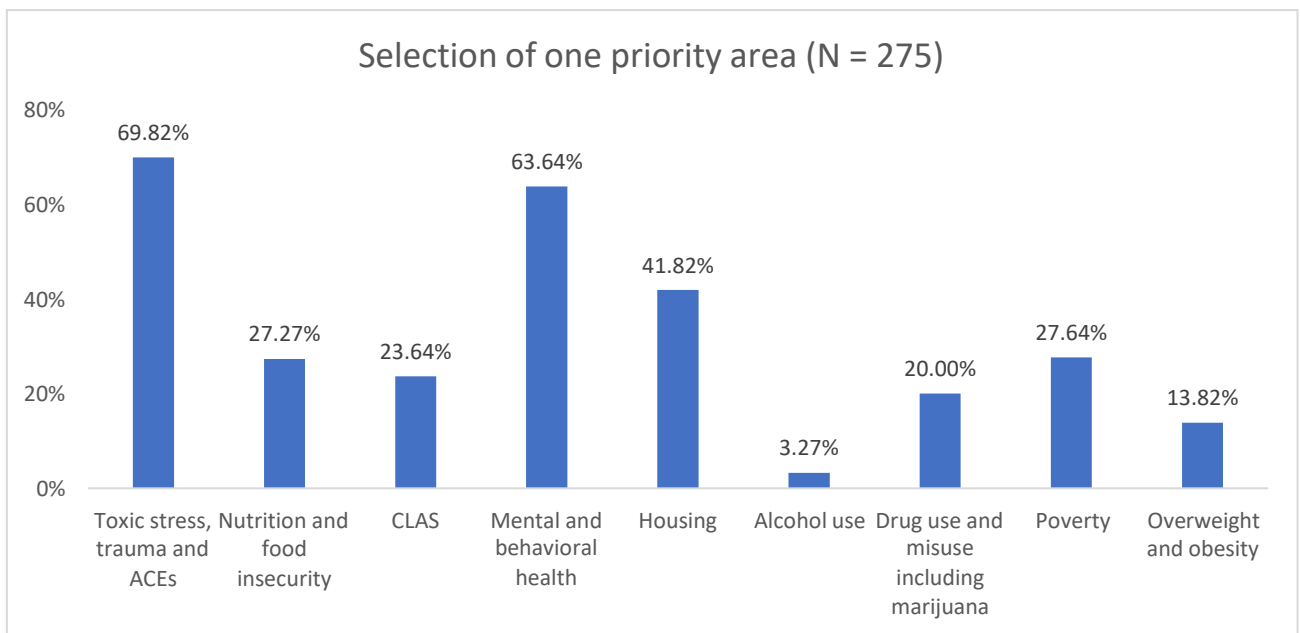
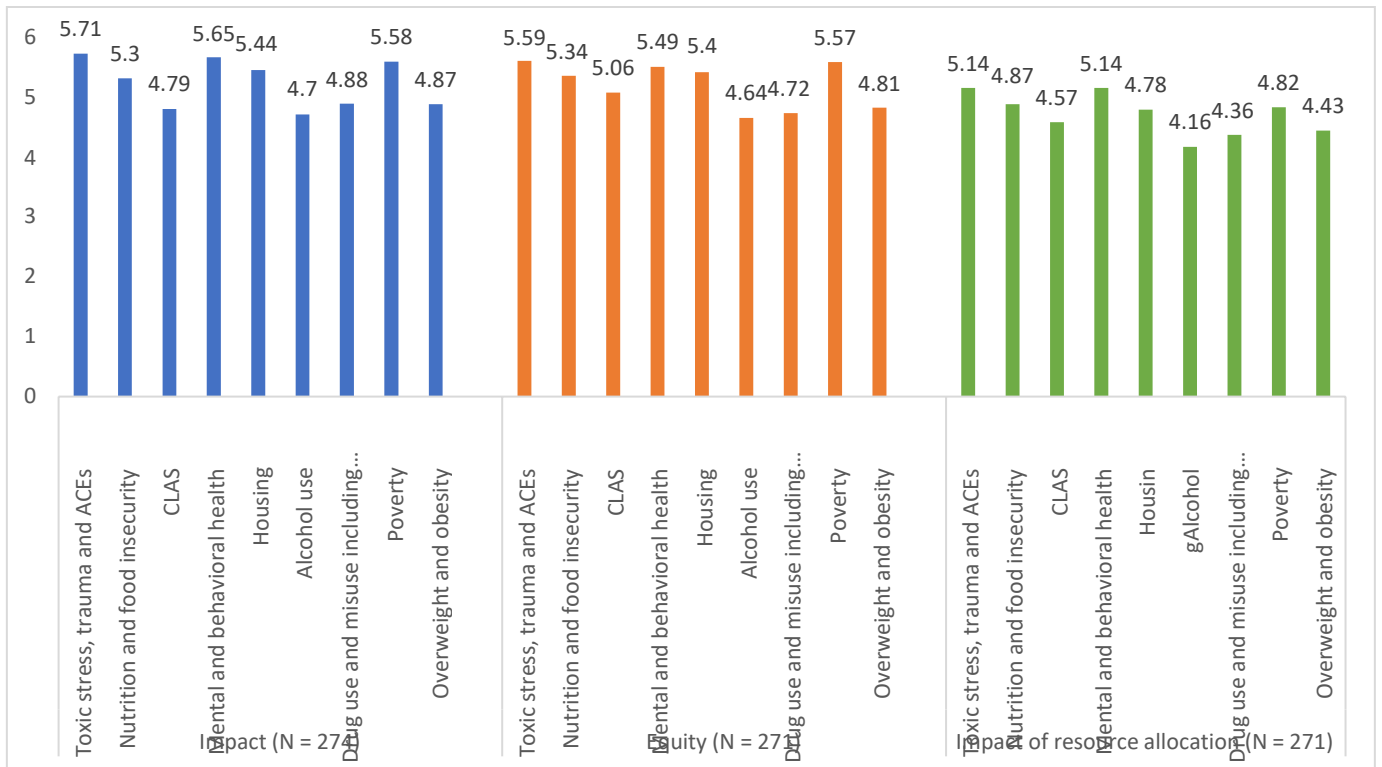
## Adolescent Health (N = 206)



## CYSHCN (N = 174)



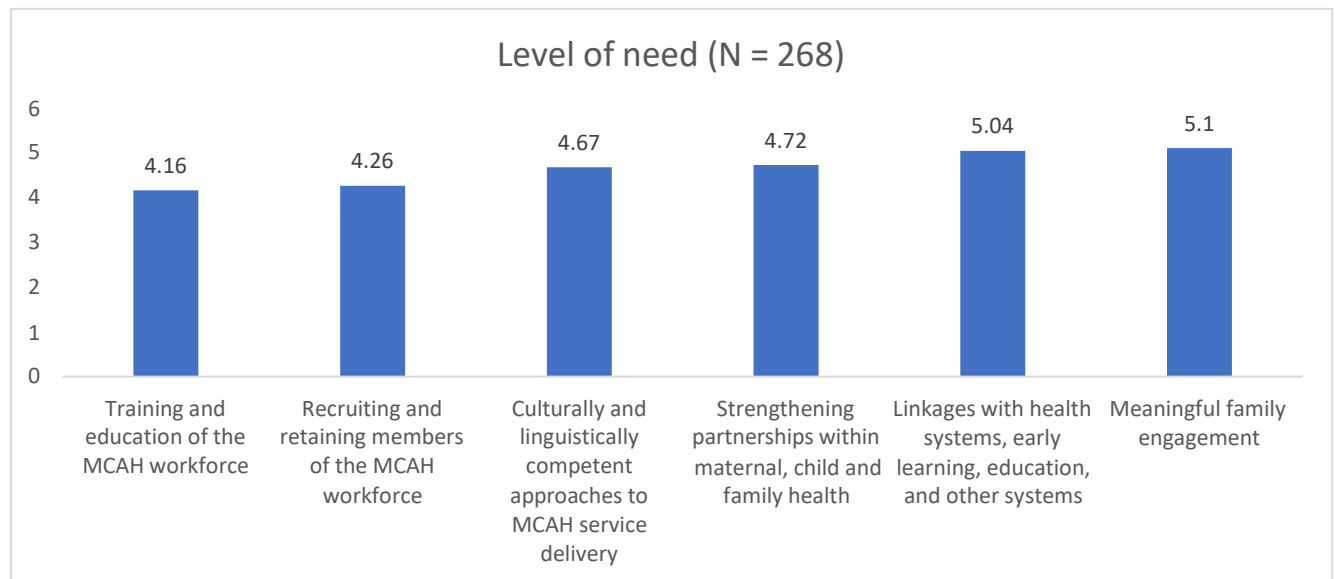
## Emerging / Cross-cutting (N = 279)



## Suggestions for other emerging needs:

- Adolescent access to insurance coverage without parental involvement (e.g. for homeless youth)
- Child abuse and neglect
- Childcare (accessible and affordable)
- Climate change and the impact on public health
- Comprehensive sex and reproductive education
- CYSHCN support in accessing services
- CYSHCN support in early childhood education
- Domestic violence/Intimate partner violence
- Drug use and misuse including marijuana
- Environmental health including environmentally safe neighborhoods
- Fetal Alcohol Spectrum Disorders
- Foster system
- Gender equity including using gender inclusive language
- Homelessness
- Homophobia and transphobia
- Housing, specifically for at risk youth and youth aging out of foster care
- Immigration policy and associated community trauma
- Immunization education
- Income equity including raising minimum wage
- Community-based programs for early childhood development
- Evidence-based maternity care
- Maternal education
- Maternal mortality and severe morbidity
- Mental and behavioral health including infant mental health and suicide prevention
- Paid family leave
- Parenting support and education
- Postpartum care
- Prenatal care
- Perinatal continuous and individualized care such as a doula services
- Racism and discrimination
- Reducing weight stigma and bias, particularly impacts on adolescents and children
- Reproductive health
- Safe routes
- Screen time
- Social connection
- Social media and the impact on youth
- Supports for fathers
- Tribal health and resources, not only through county sources
- Workforce development for MCAH and CYSHCN workforce

## Public Health System (N = 271)



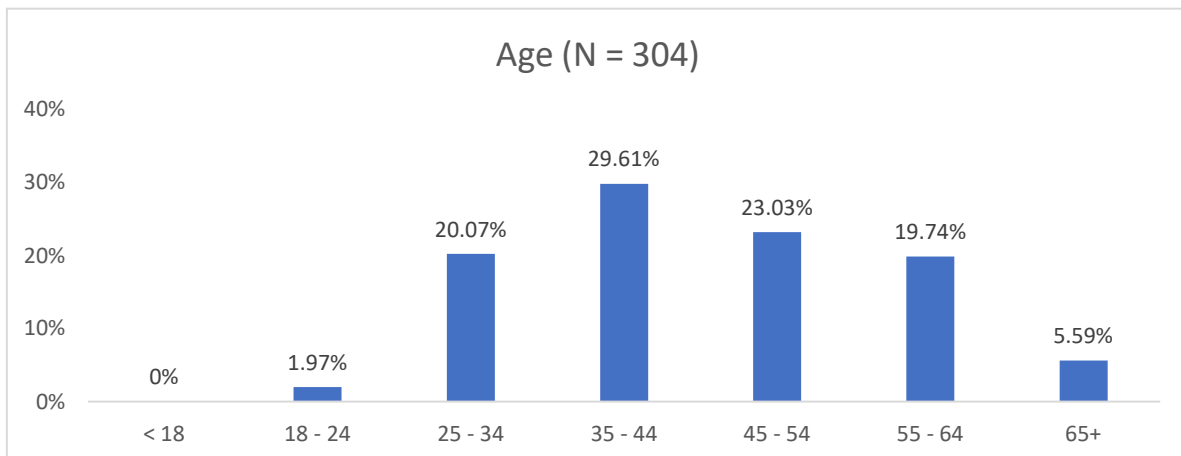
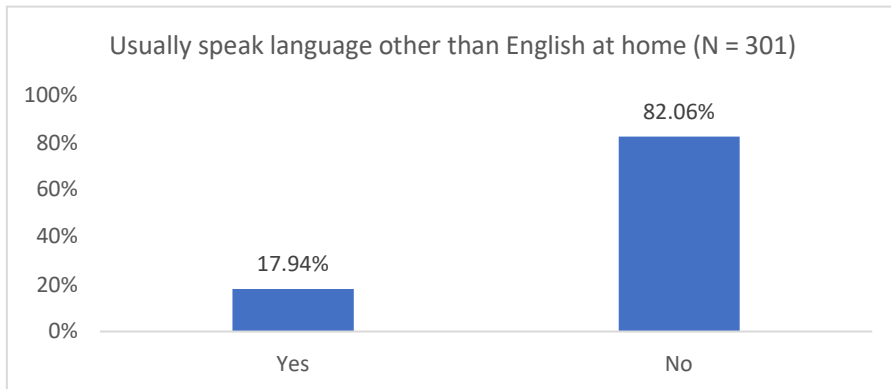
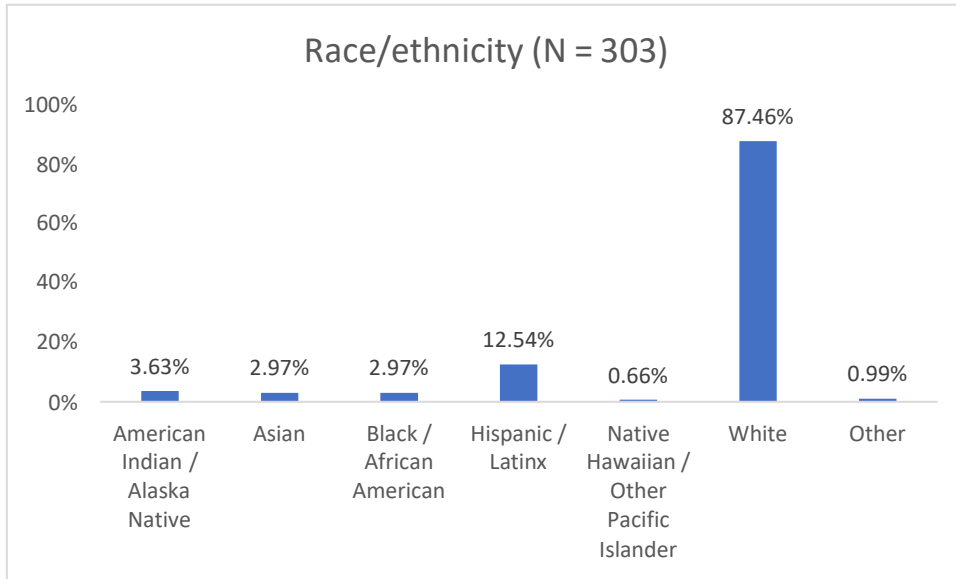
### Other suggested system needs:

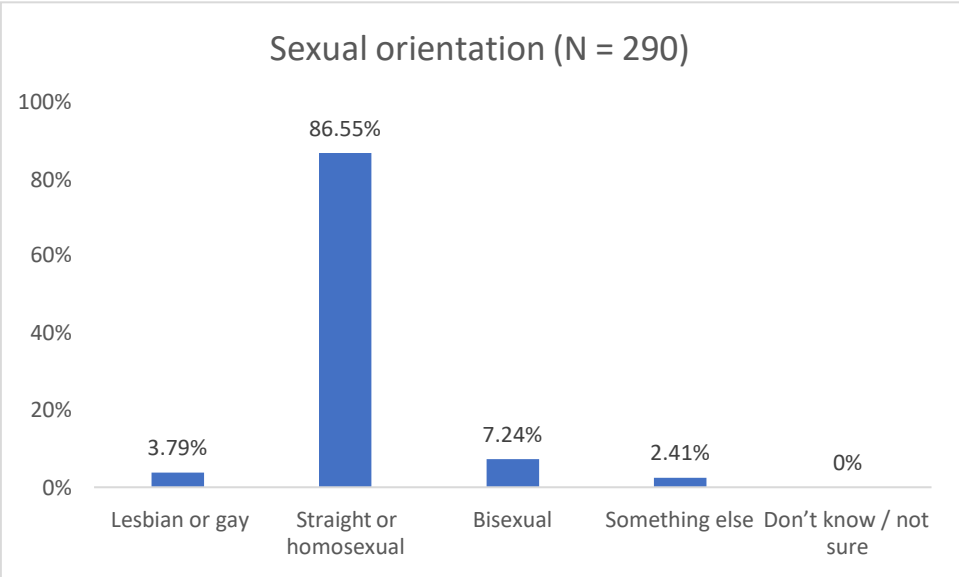
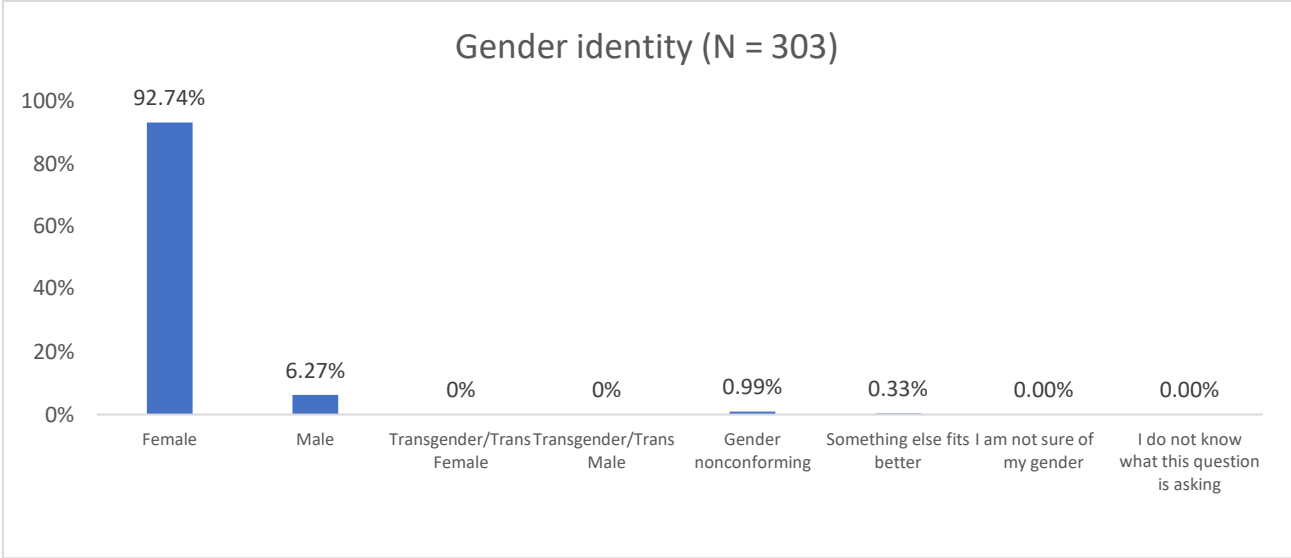
- Adolescent self care
- Breaking down silos of work in MCAH
- Childcare workforce is undertrained
- Closer links/coordination with CCOs
- Cross agency coordination and alignment of services
- Development of meaningful relationships with CCO
- Development of new partnerships outside of MCAH and CYSHCN system
- Development of partnerships with other systems such as self-sufficiency and higher education
- Ease of use of systems due to high turnover, which makes things confusing for clients and other providers.
- Exploration of innovative and non-traditional delivery of services should be explored
- Gentle, non-cry it out sleep education to parents of babies
- Incarceration of parents
- Integrated oral health care
- Integrating services into existing programs/partnerships
- Lifting up/Funding local initiatives led by people of color, LGBTQ, people with disabilities, and youth.
- Mental health support/services for low income families and non-English speakers
- More human development education in schools (K-12) as well as for professional educators, paraprofessionals and parents/lay people.
- Partnering with Tribes and having local support for Tribal initiatives that address MCAH issues or shared priorities
- Partnerships that expand beyond government agencies
- Policy, system and environmental change



- Racism, discrimination, and implicit bias in MCAH system
- Reflective supervision and support for MCAH and CYSHCN workforce
- Respite care services for new parents and parent of CYSHCN
- Rural health and access to services
- Support for parents with substance abuse issues
- Support to mixed status families
- Trauma-informed labor and delivery advocates
- Workforce development and training for MCAH and CYSHCN workforce

## Demographics (N = 344)





Other sexual identities specified:

- Pansexual
- Polysexual
- Queer

# Appendix C: OCCYSHN Needs Assessment Report, Chapter 1

## How are Oregon Children and Youth with Special Health Care Needs Faring?

Summary of Findings, October 2020



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