

Appendix E

Title V Partnerships, Collaboration and
Coordination

MCH/CSHCN Data Reporting

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Levels of cooperation scale

Networking: information sharing

Linkages: agreements which include referrals, intake, interagency consultations, monitoring referral outcomes, and participation in joint planning meetings which usually do not involve sharing of funds.

Collaboration: specific formal agreement to accomplish common purposes including specific allocations of staff time and funds, quantities of services, timeline, use of each other's sites, joint staff trainings and co-sponsorship of events

Integration: formal horizontal or vertical affiliation or merger of agencies with resultant structural and leadership changes

External MCH Partners

Partners	Description of Partnership Activities	Level of Cooperation
Utah chapter - American Academy of Pediatrics	Perinatal mortality review, Utah Women and Newborns Quality Collaborative, Zika Surveillance, Intervention and Referral Program, EHDI/CMV/CHAP articles for their "Growing Times" newsletters	Networking
Utah chapter - American College of Obstetricians and Gynecologists	Perinatal mortality review, Utah Women and Newborns Quality Collaborative, Survey dissemination, CMV Working Group, Newborn Hearing Screening Advisory Committee	Networking
Utah chapter - American College of Certified Nurse-Midwives	Perinatal mortality review, Utah Women and Newborns Quality Collaborative	Networking
Utah Midwives Organization	Utah Women and Newborns Quality Collaborative, CCHD/EHDI/CMV/NBS Presentations to UMO Annual Conference, Zika Surveillance, Intervention and Referral Program, Utah Birth Defect Network, Critical Congenital Heart Defect (CCHD) Screening program	Networking
Association of Maternal and Child Health Programs	Zika Surveillance, Intervention and Referral Program, Utah Birth Defect Network, Critical Congenital Heart Defect (CCHD) Screening program	Networking
Association for Utah Community Health	Zika Surveillance, Intervention and Referral Program working with providers to create a protocol for identifying women at risk for Zika virus and educating providers on the established protocol for getting	Networking, Collaboration, Integration

	their patients tested. Creating workflow process for submitting the necessary data during the pregnancy and through 2 years of age on the children who mothers tested positive for Zika virus. Utah Birth Defect Network has provided information on birth defects and prevention of birth defects, as well as multivitamins in some cases, Critical Congenital Heart Defect (CCHD) Screening program reviewing the CCHD protocol and necessary follow-up should a child fail their CCHD screening.	
University of Utah Hospitals and Clinics	Perinatal Mortality Review, Utah Women and Newborns Quality Collaborative, Zika Surveillance, Pregnancy Risk Line/Mother to Baby, Intervention and Referral Program, Utah Birth Defect Network, Critical Congenital Heart Defect (CCHD) Screening program, Newborn Hearing Screening Advisory Committee, Audiology Working Group	Networking, Collaboration, Linkages
Intermountain Healthcare	Perinatal Mortality Review, Utah Women and Newborns Quality Collaborative, Zika Surveillance, Intervention and Referral Program, Utah Birth Defect Network, Critical Congenital Heart Defect (CCHD) Screening program, Newborn Hearing Screening Advisory Committee, Audiology Working Group	Networking, Collaboration, Linkages
UDOH Preparedness Coordination Meeting	Zika Surveillance, Intervention and Referral Program working with our partners to create state plans for care of pregnant women testing positive for Zika virus and subsequent follow-up for the babies through 2 years of age.	Networking, Collaboration
Department of Substance Abuse and Mental Health Services	Perinatal Mortality Review, Utah Women and Newborns Quality Collaborative	Networking
Utah Maternal Mental Health Collaborative (recent name change to Postpartum Support International Utah - PSUIUt)	Maternal mental health policy work	Networking, Collaboration
University of Utah Department of Psychiatry	Utah Registry of Autism and Developmental Disabilities, Autism Prevalence estimates and etiology	Collaboration

Utah Population Database	Utah Birth Defect Network - reporting all children with birth defect cases, Utah Registry of Autism and Developmental Disabilities - Autism Prevalence estimates and etiology	Linkages
National Birth Defect Prevention Network	Utah Birth Defect Network serves and participates in all committees to improve birth defect surveillance, research, and prevention.	Networking, Collaboration
Utah March of Dimes	Utah Birth Defect Network	Networking
Utah West Nile and Zika Virus Coordination Meeting	Zika Surveillance, Intervention and Referral Program working with our partners to create state plans for care of pregnant women testing positive for Zika virus and subsequent follow-up for the babies through 2 years of age.	Networking, Linkage, Collaboration
Utah School for the Deaf Parent-Infant-Program	Newborn Hearing Screening Advisory Committee; Referral, enrollment and data linkages	Networking Linkages
Utah Regional Leadership Education in Neurodevelopmental Disabilities (USU Department of Communicative Disorders and Deaf Education / University of Utah School of Medicine, Department of Pediatrics)	Coordinating Infant-Pediatric Audiology Program; mentoring trainees and leadership projects; providing clinical experiences; planning content and teaching didactic sessions	Collaboration
UPIQ/Medical Home Portal	Providing and updating content for the Medical Home Portal; Newborn Hearing Screening Advisory Committee	Networking
Help Me Grow - Utah	ASD Screening, Zika Surveillance, Intervention and Referral Program, Utah Birth Defect Network, Critical Congenital Heart Defect (CCHD) Screening program	Collaboration

Other Programs with UDOH

Other UDOH Programs (funding source)	Description of Partnership Activities	Level of Cooperation
Office of Home Visiting (Other federal)	Newborn Hearing Screening Advisory Committee	Integration
Abstinence Education/Personal Responsibility Education Program (Other federal)	Local Health Departments	Integration
Pregnancy Risk Assessment Monitoring System (Other federal)	An ongoing, population-based surveillance system to collect data on women's experiences before, during and after pregnancy. Funded by CDC, this project provides Title V programs with important data for needs assessment and population outcomes.	Integration
Utah Birth Defect Network (UBDN) (MCHBG, other federal)	A statewide, population based surveillance system identifying children born with major structural malformations and referring to Baby Watch Early Intervention program. Established linkages with Newborn Hearing Screening program, Utah Office of Vital Records, and Utah Population Database. The UBDN also focuses on preconception health in collaboration with the Maternal Infant Health program and the Power Your Life campaign.	Integration, Linkage
Critical Congenital Heart Defect Screening (state)	Collaboration with the Utah Birth Defect Network to create a safety net for babies born in Utah by educating health care providers, improving the screening process, and creating a statewide CCHD screening and data collection system. Linkages established with Utah Office of Vital Records, Newborn Hearing Screening, Child Health Advanced Records Management (CHARM), and hospital systems.	Linkage, Integration
Zika surveillance, referral, and intervention (other federal)	Collaboration with the Utah Birth Defect Network to identify children born with Zika associated birth defects through rapid ascertainment. Collaboration with the Utah Bureau of Epidemiology to identify pregnant women testing positive for Zika virus and following them throughout their pregnancy and the child through 2 years of age. Linkages established with Utah Office of Vital Records, Newborn Hearing Screening, Baby Watch Early Intervention, Local Health Departments, and Association for Utah	Integration, Linkage, Collaboration

	Community Health Centers.	
WIC (Other federal)	Newborn Hearing Screening Advisory Committee; Looking for Lost to Follow-Up EHDI infants within the WIC system Disseminates educational messages to clients from other MCH programs.	Integration Networking Linkages
Office of Health Disparities (state)	Collaboration on issues related to health disparities, provides consultation on culturally and linguistically appropriate services, implementing programs addressing sub-optimal birth outcomes among Utah's Pacific Islander population.	Integration
Baby Watch/Early Intervention (state)	Utah Birth Defect Network referral of children with down syndrome; Autism Systems Development Program; Newborn Hearing Screening Advisory Committee; EHDI Data Sharing	Networking Networking Linkages
Integrated Services Program (MCHBG)	Newborn Hearing Screening Advisory Committee; Autism Systems Development Program; Participating in EHDI Learning Communities; Care coordination for EHDI infants and their families; Utah Children's Care Coordination Network; Medical Home Portal Advisory Committee; Employment Partnership; Utah Disabilities Advisory Committee; University Developmental Assessment Center	Networking Linkages

Family/Consumer Partnerships

Family/Consumer Partnership	Nature and substance of the partnership	Members of partnership (including number, compensation, training)	Issues being addressed	Impact of the partnership
Utah Parent Center	Collaboration	2 Parent Consultants and Utah Family Voices Director/EHDI Liaison (\$62,500 annual contract from HRSA EHDI grant)	Parent-to-Parent Support; Increasing EHDI Follow-Up	This allows for peer information sharing and support at the time of deaf/hard-of-hearing diagnosis identified through the EHDI system; and, support through the completion of the EHDI 1-3-6 process including timely CMV testing.
Newborn Hearing Screening Advisory Committee	Networking	We have eight deaf adults/parents of deaf children who are members of our committee.	EHDI systems/protocol reviews; providing family perspective for EHDI decisions, etc.	These individuals provide valuable input on all aspects of the EHDI program - through the screening, diagnostic, early intervention, and CMV testing process.
CSHCN Advisory Committee	Networking	CSHCN Programs Parents	Review needs identified by families and family input on projects being worked on by CSHCN programs	Families provided their perspective on projects CSHCN is working on.
Autism Council of Utah	Networking	Parents of Children with ASD	Review of available resources and needs from families	Parents of children with ASD provide the ASDP Program with updates on available resources, issues facing individuals with ASD in the community and networking opportunities.
Utah Autism Initiative	Networking	Various stakeholders from the ASD	Ongoing needs assessment from the	This network allows the program to maintain an understanding of

Intermountain Healing Hearts	Networking	Community Families of children with a heart defect	ASD Community Utah Birth Defect Network, Critical Congenital Heart Defect (CCHD) Screening program	the needs of the community. Interacting with families who have had a child born with a heart defect and providing resources as requested
Utah Down Syndrome Foundation	Networking	Families of children with down syndrome	Utah Birth Defect Network, Critical Congenital Heart Defect (CCHD) Screening program	Interacting with families who have had a child with down syndrome and providing resources as requested
National Birth Defect Prevention Network Parent Advisory Group (PAG)	Networking, Collaboration	Parent representatives (2 Utah parents) and NBDPN members	Utah Birth Defect Network	Working to increase awareness of birth defects for the public and medical community audiences
Utah Fetal Alcohol Coalition	Networking, Collaboration	Parents, Utah Department of Health, University of Utah, Parents Empowered, Utah Department of Alcoholic Beverage Control, Division of Child and Family Services, Division of Substance Abuse and Mental Health, Utah Parent Center, Utah Substance Abuse Advisory Council, Commission on Criminal and Juvenile Justice, Weber Human Services	Utah Birth Defect Network, MoteToBaby, Maternal Infant Health Program	To promote effective, life-long interventions for those affected by prenatal exposure to alcohol and their families.
Utah Newborn Screening Advisory	Networking	Families, Utah Department of Health,	Utah Critical Congenital Heart	The committee allows the program to maintain an understanding of

Committee Meeting		University of Utah Healthcare, Community Providers, Parent Support Groups, ARUP	Screening program	the needs of the community.
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Utah Department of Health - Health Status Updates

Autism Prevalence, Breaking News, Apr 2019
Adolescent Health Trends, Oct 2018
Critical Congenital Heart Disease Screening in Utah, May 2019
Cross-Cultural Education and Training of Oral Health Education Institutions in Utah, Breaking News, Dec 2018
E-cigarette Use Among Pregnant Women, Jan 2019
Oral Health Care and Pregnancy, Sept 2018
Reasons for Not Having Health Insurance Before Pregnancy, Breaking News, Oct 2018
Seal Your Smith School Based Sealant Program: Addressing Oral Health Disparities in Children, Dec 2018
Reducing Preterm Birth, Nov 2018
Testing Infants Who Do Not Pass Newborn Hearing Screening(s) for Congenital Cytomegalovirus (CMV) Infection, May 2019
The Status of Women's Health in Utah, Special Edition 6 (May 2019)
Trend in Overall Cesarean Rate, Community Health Spotlight, Jan 2019

Reports

2019 Maternal, Infant, and Child Health Indicators in Utah
Cross Cultural Education and Training: Oral Health Education Institutions of Utah, Office of Health Disparities, UDOH, Aug 2018
Health Disparities by Utah State Legislative District – A Report published by the UDOH Office of Health Disparities, January 2019
Neural Tube Defects in Utah, 1995-2015, Jan 2019
Office of Health Disparities Strategic Plan, UDOH, Nov 2017-Dec 2020
Seal Your Smile: A Step Toward Combating Oral Health Disparities in Utah, UDOH, Office of Health Disparities, Sept 2018
Utah Adolescent Health Report, Bureau of Health Promotion, Utah Department of Health, 2017
Utah Primary Care Needs Assessment – Utah Department of Health, Office of Primary Care and Rural Health, 2018
Utah Suicide Prevention Plan 2017-2021, Violence and Injury Prevention Program, UDOH, 2017
Utah WIC Participant Satisfaction Survey, 2017-2018

Other

Child Injuries and Deaths, Violence and Injury Prevention Program, UDOH, 2014-2016
Hearing Screening. The Growing Times, Utah Chapter of the American Academy of Pediatrics, 2018
Maternal Mortality In Utah 2015-2016, Perinatal Mortality Review Update, Maternal and Infant Health Program, UDOH, July 2018
Utilization of Baby Watch Early Intervention program by Children with Congenital Heart Disease. The Growing Times, Utah Chapter of the American Academy of Pediatrics, Spring 2019.

Women of Childbearing Age Injuries and Deaths, Violence and Injury Prevention Program, UDOH, 2014-2016

Projects

It Takes a Village: Giving Our Babies the Best Chance, Office of Health Disparities, UDOH Oct 2018 - **An AMCHP Promising Practice**

Dyanne Tappin, M.D., MPH – AMCHP 2019 Poster Presentation: A Community Health Assessment of the Mental Health Concerns in Utah Refugee Women and Recommendations for Current Services and Programs

Contributions to Peer Reviewed Publications:

Kirby, A. V., Bakian, A. V., Zhang, Y., Bilder, D. A., Keeshin, B. R., & Coon, H. (2019). A 20-year study of suicide death in a statewide autism population. *Autism Research*.

MC Smid, N Stone, L Baksh, MP Debbink, BD Einerson, MW Varner, AJ Gordon, EAS Clark. (2019) Pregnancy-Associated Death in Utah: Contribution of Drug-Induced Deaths. *Obstetrics & Gynecology*, June;133(6), 2019.

International Society for Autism Research (INSAR) Poster and Presentations

Bakian AV, Mendoza D, VanDerslice J, Chen D, Coon H, Kingsbury C, Taxin N, McMahon W, Fraser A, Zhang Y, Bilder D., The independent, moderating and interaction effects of prenatal exposure to maternal smoking and ambient fine particulate matter on risk of autism spectrum disorder:

Amanda V. Bakian, PhD; William M. McMahon, MD; Chella Palmer, BS; Colin Kingsbury, MS; Noël Taxin, MS; Deborah A. Bilder, MD The Utah Registry of Autism and Developmental Disabilities A Population-Wide Data Resource for Environmental Epidemiology.

Amanda V. Bakian, PhD; Chella Palmer, BS; Colin Kingsbury, MS; Noël Taxin, MS; William M. McMahon, MD; Deborah A. Bilder, MD, Changes in the Prevalence of Autism Spectrum Disorder in Utah, USA: A Cohort Approach.