

Section of Women's, Children's, and Family Health (WCFH) Programs
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Alaska Birth Defects Registry (ABDR)

Established in January 1996, the Birth Defects Registry is a passive surveillance system that is utilized to provide statewide information on the prevalence and trends of birth defects among Alaskan infants and children.

- The ABDR is a confidential population-based surveillance system of birth defects reported to the registry using International Classification of Diseases codes.
- Defects are identified by medical providers and data aggregators (such as Medicaid) who are required to report birth defects to the Division of Public Health by querying their systems for specified conditions on a systematic basis.
- The ABDR is a multiple source surveillance system. Reports are linked to birth records to insure an unduplicated count of defects.
- Reported prevalence and defect estimates are calculated by birth year. Trends, distribution, and factors associated with each condition are monitored in order to assess and evaluate potential etiologies and the effect of preventive interventions.
- Condition specific reports are standardized and made available online at http://dhss.alaska.gov/dph/wcfh/Pages/mchebi/abdr/Data_Reports.aspx

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Alaska longitudinal Child Abuse and Neglect Linkage project (ALCANLink)

Upon completion of two pilot studies, the ALCANLink project was officially operationalized in 2015. ALCANLink was initially developed through a three-way partnership between a local funder, the Alaska Department of Health and Social Services, and the University of North Carolina at Chapel Hill. Unlike other projects in the US that link entire birth records with child welfare records, ALCANLink integrates only those records that were sampled and who subsequently responded to the Pregnancy Risk Assessment Monitoring System (PRAMS) survey. PRAMS samples approximately 1 in every 6 live births among Alaska resident mothers. Using probabilistic linkage methodology the 2009-2011 PRAMS records are integrated with child welfare, vital records, child death review, permanent fund dividend, CUBS, Birth Defects Registry, and others annually.

- By integrating Alaska PRAMS to other administrative records through a process called data linkage we can begin to answer prospective, population-based questions about the probability (or likelihood) that children born in Alaska will be reported, substantiated, or other experience other outcomes due to maltreatment.
- Annual estimates provide an indication of occurrence but do not provide an accurate picture of the number of children in the population who become involved with the child protection system throughout their early years. Prior to the ALCANLink project we had no data source to measure the cumulative risk in the population over time.
- The purpose of this project is to develop an understanding of the cumulative risk or child burden of reported maltreatment experienced during childhood in Alaska and to facilitate comprehensive epidemiologic investigation to describe who, what, when, where, and why maltreatment occurs over a child's lifecourse.

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Childhood Understanding Behaviors Survey (CUBS)

This is a mail and phone follow-up survey to PRAMS that interviews mothers of three-year-old children who completed the PRAMS survey after their child was born. The CUBS program began sending out surveys in 2006.

- Topics covered on CUBS include child development, nutrition and eating habits, general and specialized health care utilization and access, and child care, as well as items specific to maternal experiences.

- The goal of CUBS is to fill the gap in public health knowledge about the health behavior and early childhood experiences of young Alaskan children before they enter school. By re-interviewing mothers who completed a PRAMS survey, CUBS analysts can evaluate factors present at birth or early life that increase risk for later adverse childhood outcomes.
- If you ever have a client who asks about CUBS, encourage them to fill out the survey.
- For data requests or questions about CUBS, contact the CUBS Coordinator.

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Maternal Child Death Review (MCDR)

The Maternal Child Death Review Program (formerly known as the Maternal Infant Mortality Review and Child Death Review) was established in 1989. The initial goal was to reduce infant mortality. The goal was later expanded to include maternal and child deaths. The MCH Epi Unit coordinates on-going expert committee reviews of every infant, child (<age 18 years), and maternal death in Alaska. Case files available for reviews include medical records, autopsy reports, death scene investigation reports, and other records as available and appropriate. The committee identifies factors that contributed to the death and makes recommendations about how to prevent future similar deaths.

- The ultimate objective of MCDR is to reduce maternal, infant and child mortality and morbidity. Other objectives are to
 - Identify preventable causes of death and develop recommendations for public health interventions
 - Educate health care providers regarding preventive, diagnostic and therapeutic contributors to death
 - Educate the public regarding the causes of mortality and the public's role in prevention.

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Maternal and Child Health Indicator Surveillance Project (MCH-ISP)

The goal of the project is to provide data on national and state-specific maternal and child health (MCH) indicators to promote and improve the health and well-being of mothers and children in Alaska.

- The project gathers, analyzes and summarizes epidemiological data on MCH indicators for Alaska. Data are gathered from local, state and federal agencies, including existing surveillance projects within the MCH Epidemiology Unit.
- The project contributes to the Alaska MCH Data Book publications.
- The program is a resource for anyone needing MCH data for grant applications, project planning, program evaluation, and needs assessments.
- For more information on how MCH-ISP can work for you, contact the Coordinator.

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Pregnancy Risk Assessment Monitoring System (PRAMS)

This is a survey of mothers of newborns that has been on-going in Alaska since 1990. It collects all kinds of information about behaviors and circumstances of Alaskan mothers and their infants surrounding the pregnancy and postpartum period.

- Outside of what Vital Records can provide, PRAMS is the only source of population-based data on maternal and infant issues for Alaska. Unintended births, breastfeeding, domestic violence, prenatal substance use, and depression are just some of the topics covered in PRAMS.
- If you ever have a client who asks about PRAMS, encourage them to fill the survey out.
- If you need data on maternal or infant issues, check with the PRAMS Coordinator.

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Adult Health Unit

Kelly Keeter, MPH, Health Program Manager III, Unit Manager, 907-269-3461

Breast and Cervical Health

The State of Alaska Ladies First program pays for breast and cervical cancer screening and diagnosis for Alaskans 21-64 years old who meet program eligibility requirements.

- Program Eligibility Guidelines:
 - Ages 21-64;
 - Who meet income guidelines based on family size and monthly income (250% of federal poverty rates, updated annually);
 - Who don't have insurance;

- Whose insurance will not pay for breast and cervical cancer screening;
- Who have insurance but can't afford the deductible (after deductible is met, insurance is responsible for payment).
- Patients are enrolled through contracted providers, and by calling the 1-800-410-6266 in order to determine eligibility. 1-800-410-6266, 907-269-4662 are contact numbers for Ladies First. Fax number is 907-269-3414.
- Ladies First pays for breast and cervical cancer screening from the first Pap and Mammogram up until a diagnosis of cancer is determined following USPSTF, ACOG and ASCCP guidelines.
- Ladies First can pay for HPV testing when done as a cancer screening tool.
- Enrollees who are screened through Ladies First and need treatment for breast or cervical cancer, or a pre-cancerous cervical condition requiring treatment, are referred into BC (Breast and Cervical) Medicaid. This allows enrollees who would not normally be eligible for Medicaid access to Medicaid to pay for treatment.
- Ladies First works with providers to help improve cancer screening in their offices by offering quality improvement resources and distributing evidence based materials to motivate patients towards screening.
- Ladies First works with partners to increase cancer screening rates statewide by linking resources. Examples would be in linking outreach activities to imaging centers to increase mammography services.

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Family Planning

The Family Planning Program funds comprehensive family planning and related reproductive health services for low income women, men, and teens.

- The federal Title X Family Planning Services Grant funds clinical family planning and related preventive health services, supplies, counseling and education at the Anchorage Health Department Reproductive Health Clinic in Anchorage, and the non-profit Kachemak Bay Family Planning Clinic in Homer.
- The Federally funded Title V Family Planning Program maintains a formal contract with the City and Borough of Juneau for Nurse Practitioners who offer family planning and related reproductive health services at Juneau School-based Health Centers.

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Women's Health Program

The Women's Health Program promotes resources and initiatives designed to improve the health of Alaskan women of all ages. Activities include:

- Providing the public with reliable information about healthful living and its role in reducing the incidence of chronic and preventable conditions.
- Promotion of evidence-based clinical practices based on nationally recognized guidelines, including those published by the U.S. Preventive Services Task Force and the Centers for Disease Control and Prevention, to providers of women's health care through multiple venues, including live webcasts, and statewide and regional conferences.

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Child and Adolescent Health Unit

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Adolescent Health

The Adolescent Health Program seeks to promote positive youth development and prevent or reduce negative health outcomes, with a focus on:

- Managing community grants on unintended pregnancy prevention and healthy relationships promotion
- Working with health care providers to bolster youth-friendly clinical and other health services
- Implementing primary prevention strategies to reduce violence, specifically, sexual assault, bullying, and teen dating violence
- Emphasizing the importance of family, school and community involvement and strength-based approaches to support youth;
- Working with school and public health nurses to increase evidence-based sexual and relationship health education in schools
- Collaborating with stakeholders throughout the state to promote overall adolescent health and wellbeing;
- Coordinating the Youth Alliance for a Healthier Alaska- a statewide youth advisory committee;
- Implementing the Fourth R Curriculum in schools across Alaska, in partnership with the Department of Education and Early Development. The Fourth R teaches healthy relationship skills and empowers adolescents to make healthier decisions about relationships, sexual behavior, and substance use; and
- Providing technical assistance, trainings, and resources on healthy relationships, peer education, teen pregnancy prevention, youth development, and more for parents, teachers, and adolescent service providers

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School Nursing/School Health Services

The School Nursing/School Health Program seeks to promote optimal health and safety, and educational achievement, to all children in the State of Alaska regardless of their health status or special needs. The School Health Services Program supports comprehensive school health services ideally provided by professional school nurses. Over 133,000 children attend Alaska's 54 public school districts. Federal laws mandate that each child has a right to a free and appropriate public education in the least restrictive environment. .

Key components of the program are:

- Clinical consultation, technical assistance, policy development and analysis, professional development in the areas of school nursing practice, case management of children with chronic diseases, and school health services.
- Maintain continuous quality improvement and documentation/data collection standards including uniform data points throughout the state.
- Support and provide resources, and consultation for school districts without school health services
- Consultation and collaboration with national and state organizations promoting school health including the National Association of State School Nurse Consultants, National Association of School Nurses, Alaska School Nurses Association, American School Health Association
- Collaboration with the Department of Education and Early Development, Department of Public Safety, Division of Public Health (Section of Epidemiology and Section of Chronic Disease Prevention and Health Promotion), Division of Behavioral Health and the Alaska Mental Health Board to coordinate school health programs and promote the CDC Whole School, Whole Child, Whole Community model at the state and local level.
- Inter- and intra-agency collaboration and partnering for school based health clinics, immunizations, infectious disease management, school environmental health, disaster preparedness, medical home promotion and communication, continuing nursing education, and planning for students with chronic conditions and special health care needs.
- Leadership of the School Health Nurse Advisory Committee to address current issues in school nursing practice, attain consistent school nursing practice across Alaska via the development of evidence-based guidelines for practice, and to increase the understanding of the role of the school nurse in student success
- Development, coordination, and provision of CNE contact hours for school nurse professional development, trainings, and webinars
- Review state school screening guidelines and make recommendations based on current best practice
- Promotion of comprehensive well child preventative health visits that include developmental assessments as well as annual dental exams and screening.

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Oral Health

The Alaska Oral Health Program is funded by a Health Resources and Services Administration grant to Support Oral Health Workforce Activities. Activities include:

- Convening a broad-based oral health coalition to provide an advisory role for the oral health program and improve coordination and collaboration between public and private health systems.
- Coordinating development of a state oral health plan.
- Supporting a Dental Consultant to provide clinical and strategic guidance
- Supporting Christian Health Associate to provide dental care services to underserved citizens.
- Encouraging school nurses to promote dental home and annual oral health screenings.
- Increase continuing education for school nurses on school dental screening

Summary data and the state oral health plan is available at <http://www.hss.state.ak.us/dph/wcfh/Oralhealth/>

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Perinatal and Early Childhood Health Unit

Christie Reinhardt, Health Program Manager III, Unit Manager 269-4762

Perinatal Health

This program provides consultation and technical assistance on pre-conception, maternal and perinatal health and birth outcomes to public and private health care providers across Alaska, and leadership to improve health care systems. The focus is on population-based activities and infrastructure building. Activities include:

- Identifying areas for improvement in perinatal standards of care and supporting development of policies and protocols.
- Partnering with health care providers and administrators to improve perinatal outcomes; supporting and collaborating with organizations that promote perinatal health.
- Developing, implementing, and evaluating initiatives to improve perinatal health including:
 - Alaska Infant Safe Sleep Initiative
 - Maternal, Infant, and Early Childhood Home Visiting Program
 - Decreasing substance use during pregnancy
 - Implementing a perinatal quality collaborative in Alaska
 - Promoting evidence-based screening tools
 - Alaska Breastfeeding Initiative that trains clinicians on evidence-based lactation and infant nutrition
- Providing professional education opportunities through participation in conference planning, distribution of materials, and sharing MCH data.
- Preparing information for issues of public or legislative concern.

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Pediatric Subspecialty Clinics

WCFH contracts with medical specialists to bring them to regional centers or communities where there are no local providers with specialty expertise. This makes specialty care more accessible for those who need it. Local health practitioners are invited to facilitate coordination of care.

The Metabolic Genetics Clinic offer services for individuals diagnosed with metabolic genetic disorders:

- Most patients see are diagnosed with a metabolic disorder through the Newborn Bloodspot Program
- Children with changes in body chemistry, such as extremely high or low protein, fat, or sugar levels in their blood are referred to the Metabolic clinic
- Patients are seen to monitor their disorder and provide nutrition evaluation and counseling

The Neurodevelopmental/Autism Clinic offers screenings, diagnosis, and consultations for children with neurodevelopmental conditions. Autism screening clinics have been added around the state to reduce the number of children needing to travel to for a full diagnostic evaluation.

Process for referral:

- Contact the program manager/coordinator to request a 1-page referral form, if needed.
- Fax the completed referral form with all medical records relevant to the referral reason to the program manager. Complete information will expedite the scheduling process.

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 Sue Armstrong, Neurodevelopmental Clinic Coordinator, 264-6281, sue@alaskachd.org

Newborn Hearing Screening

The State of Alaska Early Hearing Detection and Intervention (EHDI) Program is committed to the National EHDI 1-3-6 Goals: newborn screening before 1 month of age, diagnostic assessment before 3 months, and intervention services before 6 months. The Alaska mandate for universal newborn hearing screening and intervention went into effect in January 2008.

- All birthing hospitals in Alaska are screening newborns. Hearing screening equipment was placed at public health centers in three communities with high out of hospital births and in four midwifery centers in communities experiencing obstacles to screening at their local hospital. Information on where an infant can receive a hearing screening or location of pediatric audiology services can be obtained from the State EHDI Program.
- All newborn hearing screening results, including missed screenings, are reported into a secure web-based data system. Newborn hearing results are reported weekly and audiology (diagnostic) results are reported on a monthly basis.
- If parents or primary care providers do not know if an infant had a hearing screening, or passed their screening, this information can be obtained from the database through the State EHDI Program.
- Parent support is available for children diagnosed with a hearing loss through a parent navigation grant with the Stone Soup Group.
- The EHDI Advisory Committee meets 3x/year to discuss any issues or concerns about the screening program and updating any changes to protocol

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Newborn Bloodspot Screening

The Newborn Bloodspot Screening program screens for more than 30 metabolic disorders, endocrine disorders, abnormal hemoglobins, and cystic fibrosis. Educational presentations are conducted for the medical community when requested.

- Follow-up includes ensuring abnormal screens are not closed until a diagnosis is made or the case is closed with a normal screen. The program also provides technical assistance to birthing facilities on proper specimen collection.
- Children diagnosed with a metabolic disorder through the screening program are seen in the state sponsored Metabolic Clinics and have their diets monitored by a metabolic nutritionist.
- A DVD was produced on one of the conditions when a high prevalence was found in the Alaska Native population., CPT1A Arctic Variant. The DVD is sent to each family with an infant diagnosed with this condition to provide education on how to care for their child.
- The Newborn Bloodspot Advisory Committee meets twice a year to discuss issues, concerns, and proposed changes to the screening panel.

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Autism, Neurodevelopmental Disorders

In 2007, the State of Alaska's Section of Women's Children and Family Health (WCFH) collaborated with programs and agencies statewide in response to the Governor's Council on Disabilities and Special Education five-part autism strategic plan. In partnership, a system of care for children with autism spectrum disorder and other neurodevelopmental conditions was built which includes improved screening, intervention, diagnostic, and treatment services statewide.

- Pediatric neurodevelopmental outreach and autism screening clinics are held in up to 8 rural Alaska communities. In collaboration with tribal health, local health providers, families, and community agencies, patients are referred and seen by a developmental specialist and supported by a parent navigator.
- In collaboration with tribal health and the UAA Center for Human Development, WCFH sponsors a Project ECHO on autism and other neurodevelopmental and behavioral disorders. Project ECHO will serve as a tele-education tool for primary care providers serving children with these conditions. Using technology, primary care providers throughout the state will have access to content experts who can provide feedback and consultation as a part of learning. The goal is to develop more capacity in Alaska for diagnosis and providing ongoing care.
- Partner with or fund on projects related to workforce development such as training for Applied Behavioral Analysis, Family Navigation, and developing a family advisory council.

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Children and Youth with Special Health Care Needs (CYSHCN) Program

The CYSHCN team works to enhance and integrate systems of care for CYSHCN through family and community partnership focused on the following activities:

- Assess pediatric systems to identify gaps and priorities
- Develop an [Alaska CYSHCN State Plan](#) using the 2014 "National Standards" framework
- Partner with local pediatricians and school districts to implement a cross-system electronic "Shared Plan of Care" for enhanced care coordination for CYSHCN
- Promote the concept and educate providers and policy makers on patient-centered medical home and care coordination
- Improve the process of Alaska CYSHCN as they transition from pediatric to adult medical care
- Support the All Alaska Pediatric Partnership in the implementation of Help Me Grow Alaska

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Early Childhood Comprehensive Systems (ECCS) Impact Grant

The primary purpose of the Alaska Early Childhood Comprehensive Systems Project (ECCS) is to facilitate the building and implementation of statewide comprehensive systems of care that supports family and community approaches to promoting positive early development and early school success for young children. This project is funded through a federal Health Resources and Services Administration (HRSA) grant.

- The project will support the Collective Impact approach to integrate service delivery and collaboration, resulting in improved child development and family wellness, measured by a 25% increase from baseline developmental skills in 0-3 year olds by 2021
- The work is focused in three place based communities: Kodiak Area Native Association (KANA), Norton Sound Health Corporation (NSHC) and Matanuska-Susitna (Mat-Su) Raising Our Children with Kindness (R.O.C.K)
- ECCS and the place based communities work collaboratively with Prentice Consulting and Alaska Center for Pediatrics (ACP) to increase education and use of the Ages and Stages Questionnaire (ASQ-3) as a standardized parent-completed developmental-behavioral screening tool and increase utilization of the ASQ Online System for data collection.
- [Help Me Grow](#) serves as a centralized system for the three place based communities; connecting at-risk children and families to needed services, completing developmental screenings, collecting and analyzing data, and offering provider outreach and education

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Parents as Teachers

The Parents as Teachers (PAT) program provides the information, support and encouragement parents need to help their children develop optimally during the crucial early years of life. Research suggests that from birth to 3 years and especially the first 6 months of life, the brain goes through the most critical stages of development; by age 3, a child will absorb and recognize about 1,000 words, which is two-thirds of the adult everyday speaking vocabulary; and by the age of 4, a child's brain will have grown to nearly three-fourths of its adult size. The goal of the PAT program is to increase parent knowledge of early childhood development, improve parenting practices, prevent child abuse and neglect, increase children's school readiness, and detect developmental delays and health issues.

- PAT offers parents research-based information on how children grow and develop; types of activities and toys that will foster learning and nurture development; methods of positive discipline; new techniques for problem solving; realistic expectations of child behavior; and attitudes that will raise children's self-esteem
- The PAT model includes individualized, strength based visits, a network of community resources for parent support, opportunities to share experiences, discuss problems, and support each other through group connections, and conducts developmental screening to help parents better understand their child's development and identify areas of concern.
- Parent Educators support families in understanding their child's strengths, identifying areas of concern and bridging the gap between available resources and families' needs

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Alaska Perinatal Quality Collaborative

WCFH coordinates the Alaska Perinatal Quality Collaborative (AKPQC) that launched in January 2019. The AKPQC is guided by a multi-disciplinary steering committee with representation from rural and urban regions of Alaska. The AKPQC drives state-wide continuous quality improvement (QI) through partnerships with health care facilities, health care and public health professionals, professional organizations, and patients/families to improve perinatal health outcomes in Alaska. Key activities of the AKPQC include:

- Partnering with the Alliance for Innovation on Maternal Health (AIM) program to engage all Alaska birth facilities and providers in collaborative QI to reduce severe maternal morbidity.
- Coordinating monthly coaching calls and quarterly learning sessions with AIM-participating facilities and providers.
- Reporting state-wide severe maternal morbidity outcomes measures to AIM and supporting facilities with process and structure measure data collection and reporting.
- Planning an annual face-to-face convening of AKPQC members and partners to learn from national experts and share facility successes and challenges with AKPQC initiatives.
- Developing a neonatal subcommittee and launching a data-driven neonatal initiative informed by facility and community needs.

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