Autism System Development

**Mission:** To identify needs and promote available state wide services to assist families and individuals with autism and their caregivers.

**Performance Measures:**
1. Analyze current data collected by URADD and disseminate data throughout Utah.
2. Partner with the Utah Autism Initiative to identify system gaps and address needed improvements in services.

**Outcome Measures:**

**URADD data projects:**
- An In-Depth Analysis of the Association Between Labor Induction/Augmentation and Autism Spectrum Disorder - Dr. Erin Clark and Dr. Christina Herrera Obstetrics/Gynecology at the University of Utah.
- Analysis of an Autism-Centric Support and Vocational Program for Young Adults with Autism Spectrum Disorder (ASD) - Sorensen Impact Center at the University of Utah on behalf of the Columbus Community Center.
- Cooperative agreement between the Utah Department of Health, on behalf of URADD and the University of Utah on behalf of its Utah Resource for Genetic and Epidemiological Research was updated and renewed.
- Provided URADD Data to the Autism Council of Utah, The Utah State Board of Education, Columbus Community Center, Utah Valley University, and the Utah Autism Initiative.

**Utah Autism Initiative:**
System gaps identified and recommended improvements by UAI:
- M-Chat R/F screening in underserved populations.
  - Provide M-CHAT R/F Screening to children who do not have a Primary Care Physician at Early Intervention Programs and Local Health Departments.
- ASD Assessment wait times exceeding 6 months.
  - Use the ASD Services list created by the Autism Systems Development Program to reduce wait times.
- Service cliff for individuals with ASD over 21.
  - Creation of a state plan to address the end of services for individuals with ASD over 21 year of age.
Child Health Advanced Records Management (CHARM)

Mission: To provide secure, child-specific, integrated public health information that is accessible to health programs and professionals that have a specific need for this information.

Outcome Measures:

1. Increased by 339%, the number of children who completed hearing screening as a result of receiving a hearing screening alert through the CHARM system. In 2016, there were 528 alerts generated, and 417 of those children completed the screening (79%). Therefore the percentage went from 18%-79%, which is a 339% increase.

2. Increased/expanded the number of health care databases connected with CHARM and/or information shared from 6 databases to 8 databases with CHARM now sharing information with the Fostering Healthy Children and WIC programs. This would have been 9 if the ONC-HIE project to send hearing screening alerts from the EHDI Program through CHARM to the cHIE was fully implemented. However, a number of technical issues delayed this project. It is expected to be completed in 2017.

3. Access to the CHARM button was provided to all (100%) of the non-Intermountain Healthcare Providers/users that use USIIS. Therefore, users that have access to the CHARM button increased significantly above the 10% target.

4. The matching rate for calendar year 2104 was a 76% match rate. The 79% baseline used was a 2014 mid-year match rate. Therefore, the baseline number used in the performance measure should have been changed from 79% to 76% going into the 2015 year. If the 76% baseline from the 2014 calendar year is used, the matching rates between Vital Records, CHARM, and the Hearing Screening Program improved from 76% in 2014 to 77% in 2016, but were still below the 85% target.

5. Increased by 33%, the percentage of health care providers (from 60-80 health care providers/users) accessing/using the CHARM Web Interface for treatment purposes and care coordination of children. This was due to the addition of a new private provider clinic, and Newborn Screening Heel-stick, Fostering Healthy Children, and WIC Program users.
Critical Congenital Heart Defect (CCHD) Screening

Mission: To create a safety net for all babies born in Utah by educating health care providers, improving the screening process, and creating a statewide data collection system.

Performance Measures:
1. Ensure 91% of newborns in Utah receive CCHD screening between 24 - 48 hours after birth.
2. Provide education and outreach to 100% of birthing facilities who report "Not Screening" 20% or more of their births given the CCHD screening protocol.

Outcome Measures:
1. We achieved this measure each year with 92.6% of infants being screened on average each year as reported by vital records.

<table>
<thead>
<tr>
<th>Year</th>
<th>Pass</th>
<th>Pass %</th>
<th>Fail</th>
<th>Fail %</th>
<th>Screened</th>
<th>Screened %</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>2014</td>
<td>11,495</td>
<td>91.9%</td>
<td>16</td>
<td>0.1%</td>
<td>1,001</td>
<td>8.0%</td>
<td>12,512</td>
</tr>
<tr>
<td>2015</td>
<td>47,729</td>
<td>92.2%</td>
<td>95</td>
<td>0.2%</td>
<td>3,930</td>
<td>7.6%</td>
<td>51,754</td>
</tr>
<tr>
<td>2016</td>
<td>47,952</td>
<td>93.1%</td>
<td>92</td>
<td>0.2%</td>
<td>3,488</td>
<td>6.8%</td>
<td>51,532</td>
</tr>
<tr>
<td></td>
<td>107,176</td>
<td>92.6%</td>
<td>203</td>
<td>0.2%</td>
<td>8,419</td>
<td>7.3%</td>
<td>115,798</td>
</tr>
</tbody>
</table>

2. We continue to provide education as requested to hospitals and midwives since this screening became mandated. Over this time period (2014 – 2016) we have worked with several hospitals who have reported 'Not Screening' 20% or more of their births each month on vital records. Since this screening was mandated on October 1, 2014 the number of hospitals in this category has declined as we would hope. In 2014 October – December there were 3 hospitals, in 2015 January – December there 7 hospitals, and in 2016 January – December there were only 2 hospitals.
Children’s Hearing Aid Program (CHAP)

**Mission:** To provide early access to hearing aids for hearing impaired infants and young children of financially eligible families, in order to maximize their communication and learning potentials.

**Outcome Measures:**

1. All children with a conclusive diagnosis of permanent or chronic hearing loss receive an ‘Interactive Notebook for Families with Children who are Deaf/Hard of Hearing’ which contains a brochure on CHAP and contact information for the program. In addition, pediatric audiologists are sent notifications and updates of the program through the Utah Consortium of Pediatric Audiologists and also through state-sponsored in-services and conferences. The CHAP advisory board members also share information to their respective professional contacts.

2. All applications are initially processed within one week; if all materials are turned in with initial packet, the application may be approved within one to two days. Approval may be delayed until all the necessary paperwork is turned in. If there is missing paperwork, an e-mail requesting the missing information is sent out immediately after the initial processing of the application.

3. Surveys are submitted annually to all pediatric audiologists who have referred to the CHAP program in order to gain input on the overall and individual aspects of the program. Surveys are also submitted annually to all families who have used the CHAP program in order to fund hearing aids for their Deaf/Hard of Hearing children in order to gain insight on the perceived positive/negative aspects of the program. The survey responses are then analyzed and changes are made as necessary in order to improve and update the program.
Cytomegalovirus (CMV) Public Education and Testing (CMV Public Health Initiative)

**Mission:** To educate women of child-bearing age in Utah on the risks of Cytomegalovirus (CMV) during pregnancy and to teach them strategies for CMV prevention; to facilitate the screening of eligible infants for the presence of congenital CMV infection that allows for early detection and intervention.

**Performance Measures:**
1. Increase by 5% (currently 58%) CMV testing-eligible infants that receive CMV testing.
2. Increase by 5% (currently 52%) CMV test results that are reported to UDOH.
3. Provide at least 5 education outreach activities by December 2015.

**Outcome Measures:**

**CMV: Outcomes 2016**
1. CMV testing for 2016 - 73% of eligible infants received CMV testing, an increase of 15%
2. CMV test results that were reported to UDOH by NBHS programs = 32% with an additional 44% found by UDOH in the CHIE and 24% found by UDOH from HELP2 and f/u calls.*
3. There were more than 5 educational outreach activities provided.

*Note: access to the CHIE and HELP2 has made significant improvements in the ability to record CMV tests results in a timely manner.
Early Hearing Detection and Intervention (EHDI)

Mission: Utah’s Early Hearing Detection and Intervention Program provides newborn hearing screening oversight to assure all infants born in Utah have access to early screening, identification and intervention for hearing loss.

Performance Measures:

1. Increase the percentage of Out of Hospital Births (OOHB) by 1% (currently 82%) with documentation of having received NBHS.
2. Decrease the time of the second hearing screening of newborns who fail the first hearing screening to rescreen within 21 days of birth.
3. Ensure 100% of infants who fail their second hearing screening have a diagnostic audiologic evaluation before 3 months of age.

Early Hearing Detection and Intervention (EHDI)

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Outcome Measures:

EHDI: Outcomes 2016

1. Home Births Screened in 2016: 89%, an increase of 7%
2. 86% of CMV eligible (failed 2 hearing screenings) infants were rescreened prior to 21 days of age
3. 84% of infants receiving a diagnostic evaluation were completed before 3 months of age
Fostering Healthy Children Program (FHCP)

**Mission:** To promote the health and well-being of children in foster care by assuring access to timely health care for children in Utah’s foster care system so their needs will be met in a timely manner.

**Performance Measures:**

1. Correlate documentation of immunizations in SAFE database to the Utah Statewide Immunization Information System (USIIS) on all children entering care.
2. Assure 90% of all children have received the immunizations needed to meet school requirements.
3. Ensure 100% of families are mailed the CDC recommended immunizations by Health Data Reports.
4. Ensure completion of the Health Status Outcome Measure (HSOM) by contacting the parent of the child in foster care according to the acuity schedule within 14 days.
5. Ensure 100% of all children ages 4 months to 5 years receive an initial developmental and social emotional screening and repeat yearly until age 5.
6. Ensure 100% of identified files for further services are referred to Early Intervention/Head Start.

**Outcome Measures:**

1. 94% of children received immunizations and immunizations were correlated between SAFE and USIIS.
2. 100% of children were mailed the CDC recommended immunization report from USIIS with HDR.
3. Year 2014-96% of HSOMs were completed within 14 days. Year 2015-91% of HSOMs were completed within 14 days Year 2016-92% of HSOMs were completed within 14 days.
4. All children ages 4 months to 60 months were mailed the ASQ/ASQ-SE development screening tool.
5. From the returned ASQ/ASQ-SE screening tools. 100% of those identified to require further services had referrals made to EI/Headstart.
Integrated Services Program

Mission: To provide coordinated care planning, education and resources to CSHCN and their families to assist them in making informed decisions about primary and specialty health care, behavioral health and social services to help meet their needs during the pediatric life cycle through transition to adulthood

Performance Measures:
Medical Home
1. Increase by 20% CSHCN who receive coordinated, ongoing, comprehensive care within a Medical Home by September 2017.
2. Promote Medical Home concept to providers around the State.
   a. Survey at least 50% of pediatric providers/practices to assess level of “medical homeness” by December, 2015.
   b. Provide at least one medical home/care coordination in-service monthly to interested providers (ongoing).

Transition
1. Increase by 1% youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence by September 2017.
2. Provide quarterly in-service regarding transition to adulthood to pediatric and family practice providers around the State (ongoing).

Care Coordination
1. Conduct a care coordination capacity inventory with pediatric providers/practices around the State. Establish a baseline by December 2015.
2. Provide “safety net” care coordination for CYSHCN who receive care in practices where care coordination may not be financially or physically feasible (ongoing).
   a. Establish baseline by December 2015, and; 
   b. Increase that number by 50% by September 2017.
3. Provide monthly in-service and training regarding medical home, transition, and care coordination to Integrated Service Program staff (ongoing).

Outcome Measures:

Medical Home
1. This performance measure is captured by response of Utah families to the National Survey of Children’s Health (last conducted 2009-2010) through which CYSHCN are identified. It is anticipated that survey data collected in 2016 will be compiled by year end FY2017.
2. a. By December 2015 Integrated Services Program staff had made contact with 16 pediatric clinics, 72 family practices, 1 community health center, 1 Navajo health center, and 4 Paiute health clinics outside the Wasatch Front area.
   b. In-service presentations for medical home and/or care coordination were made at School Districts, Community Health Centers, pediatric clinics, and Early Intervention facilities across the State.

Transition
1. This performance measure is captured by response of Utah families to the National Survey of Children’s Health (last conducted 2009-2010) through which CYSHCN are identified. It is anticipated survey data collected in 2016 will be compiled by year end FY2017.
2. Transition to adulthood in-service was provided to Community Health Centers Inc., Copperview Clinic, Utah Children’s Care Coordination Network (UCCCN), and 5 school districts.

Care Coordination
1. By December 2015, ISP staff had made contact with all non-Wasatch Front pediatricians and family practice providers (same list as Medical Home).
2. By December 2015, ISP had provided care coordination for 25 families (baseline); by April 28, 2017, ISP had provided care coordination for 785 families.
3. ISP meets monthly, at a minimum (sometimes 2x per month) to discuss cases; receive ongoing training and in-service; learn about partner organizations and services they provide; and quality and process improvement.
Kurt Oscarson Children’s Organ Transplant Fund

Mission: To support children under the age 18 who require organ transplants by providing financial assistance through an interest-free loan.

Performance Measures:
1. Increase tax preparer awareness.
2. Increase public awareness concerning organ donations.
3. Increase donations from tax payers.

Outcome Measures:
1. Provided awareness posters to approximately 200 tax preparers to post in office waiting rooms.
2. Provided 6 Facebook posts and 6 tweets to increase tax payer’s awareness.
3. Increase of donations to the Kurt Oscarson Children’s Organ Transplant Fund was received due to the promotion and awareness campaigns.

Newborn Bloodspot (Heelstick) Screening Program (NBS)

Mission: To provide a statewide system for early identification and referral of newborns with certain metabolic, endocrine, exocrine, immunologic or hematologic disorders that can produce long-term mental or physical disabilities or death if not treated early.

Outcome Measures:
The Newborn Bloodspot (Heelstick) Screening Program (NBS) was transferred to the Utah Public Health Laboratory on August 1, 2016. For Newborn Bloodspot (Heelstick) Screening Program (NBS) outcomes, contact Kim Hart at kimhart@utah.gov
Technology Dependent Waiver Program

Mission: To provide home and community-based services for technology dependent, medically fragile individuals with complex medical conditions who would otherwise require care in a Medicaid enrolled skilled nursing facility.

Performance Measures:
1. Ensure 100% of initial and annual eligibility determinations are conducted for waiver applicants and participants using the process outlined in the approved State Implementation Plan.
2. Ensure 100% of waiver participants receive a plan of care that specifies the services needed to safely care for the individual at home and update the plan at least every 6 months.
3. Ensure 100% of waiver participants receive care coordination responsive to their needs and preferences.

Performance Measure 1:
Audit Response from Medicaid: All new waiver participants must meet level of care requirements as described in the State Implementation Plan (SIP) prior to receiving waiver services. Of the 15 new enrollees that joined the program in FY2015, (100%) were evaluated for level of care requirements prior to receiving waiver services.

Participants receiving services in the waiver program must continue to meet level of care requirements. Of the 92 participants to whom this measure applied, 92 participants (100%) had a record of a level of care re-evaluation having been completed within 12 months of the most current level of care evaluation and completed during the calendar month in which it was due.

A Level of Care form must be completed initially and annually thereafter to ensure that all Technology Dependent Waiver participants meet nursing facility level of care. Of the 102 participants to whom this measure applied, 102 (100%) had the level of care accurately documented on the Initial and Annual Level of Care/Freedom of Choice form.

Accurate documentation of the level of care evaluation requires clinical and/or medical records confirming the level of care criteria as described in the SIP. Of 108 participants, 108 (100%) had accurate documentation confirming the criteria as documented on the Initial and Annual Level of Care/Freedom of Choice form.

Performance Measure 2:
Audit Response from Medicaid: Information is secured about participant needs, preferences, goals, and health status as a part of the assessment process for care plan development. Of the 108 participants to whom this measure applied, 108 (100%) had Plans of Care that addressed all of the participant’s assessed needs.

All waiver services are furnished pursuant to the service plan which must be reviewed and updated at least every six months. Of the 103 participants to whom this measure applied, 100 (97.1%) had documentation of Plan of Care reviews and updates at least every six months. Five participants were not evaluated for this measure as they were newly enrolled and had participated on the waiver for less than six months during the review period, or left the waiver program before a six month review was required for FY2016. Three participants had care plans which were authorized for seven month spans.

Performance Measure 3:
Audit Response from Medicaid: Information is secured about participant needs, preferences, goals, and health status as a part of the assessment process for care plan development. Of the 108 participants to whom this measure applied, 108 (100%) had Plans of Care that addressed all of the participant’s assessed needs.

Plan of Care development incorporates input received from the recipient and/or the recipient’s legal representative during the assessment home-visit. Of the 108 participants reviewed, 108 (100%) had an assessment completed prior to updating the Plan of Care.
Utah Birth Defects Network (UDBN)

Mission: The Utah Birth Defect Network (UBDN) seeks to prevent birth defects and secondary disabilities by monitoring occurrence, conducting research, providing education and outreach.

Performance Measures:
1. Report CCHD screening data to birthing facilities quarterly, to ensure all Utah newborns are receiving this newborn screen per Health Code Statute 10-26-6.
2. Report yearly prevalence rates of certain birth defects through the Utah Indicator-Based Information System (IBIS).
3. Provide information to families as requested within 24 hours of each request.

Outcome Measures:
1. Since this screening was mandated there have been some challenges. Initially when this screening was mandated we worked with vital records to add Pass/Fail/NotScreened to the birth certificate. Over the course of this time period the Vital Records updated their reporting system which broke the system (Data Warehouse) by which we gather the information which took 6+ months to get corrected. This made it very difficult to get the data. The system modifications were completed in Late Fall 2016. We are currently are working to develop the reports for the hospitals. We did however publish a IBIS indicator on CCHD screening as initial step in making the data available. We have also been working with the hospitals individually if they request their data.

2. The two IBIS indicators we currently have available are Birth Defects: Overall and Birth Defects: Infant Mortality. Each indicator is updated each year in November.

3. It is our commitment to respond within 24 hours to all calls from families and providers. This commitment has continued throughout the entire time period.