Colorado Immunization Information System

A Summary of Policy, Operations and Systems

Recommendations from Stakeholders

May 2014

Executive Summary

The Colorado Immunization Information System (CIIS) is a population-based, computerized registry that is an integral program of the Colorado Department of Public Health and Environment (CDPHE). This system collects and disseminates consolidated immunization information for Coloradans of all ages by electronically tracking individuals' immunizations, allowing for an ongoing and complete record that ensures they receive all recommended vaccines in a timely manner. As of May 2014, CIIS held approximately 45.3 million immunization services for 4.2 million individuals.

CIIS enjoys strong support among Colorado's vaccine providers, as well as other important stakeholders. It has become a valuable tool for healthcare providers and public health agencies who administer immunizations, for other public health service providers such as the Women, Infants and Children (WIC) program, and for schools and child care facilities.

The Colorado Children's Immunization Coalition (CCIC) received a grant from The Colorado Health Foundation to conduct a strategic planning and stakeholder engagement process to develop recommendations that could enhance and expand the capacity and functionality of the CIIS. This process included: 1) development of an "environmental scan" on the history and current state of CIIS; 2) convening of Colorado immunization and child health experts to identify common CIIS expansion goals and objectives; and 3) producing a visioning document that offers key recommendations for priorities over the next three to five years.

CCIC contracted with Health Management Associates (HMA), a Denver health consulting firm, to facilitate the stakeholder engagement process and develop a visioning document based on the outcomes of the stakeholder meetings. Stakeholders were invited to participate based on state-level leadership and expertise in immunizations, public health, informatics and technology, pediatrics, family medicine, healthcare delivery and payment and other relevant expertise. CCIC, CDPHE and HMA formed a planning committee to oversee the process and provide strategic direction. In addition to creating the stakeholder recommendation document, HMA also created an environmental scan reflecting the history and background of CIIS so stakeholders would have some knowledge and context within with to discuss the future.

The environmental scan and series of facilitated discussions were used to determine the key recommendations for priorities that focus on enhancing and improving CIIS capacity and functionality over the next three to five years. Through this process, the stakeholders established the following prioritized recommendations:

Priority #1 – Optimize CIIS Performance

This priority includes eliminating the provider waitlist for electronic connectivity, improving system performance for all users, ensuring CIIS data are as accurate and as timely as possible, and increasing provider participation.

Priority #2 – Include Newborn Hearing/Screening (NBH/S) Data in CIIS

This priority includes making both NBH/S data collected by CDPHE available to authorized users through CIIS and ensuring that the data is accurate, as well as serving as a model for how CIIS could work with other partners and data subject matter experts in the future.

Priority #3 – Implement Enhancements for Women, Infants and Children (WIC) Staff to Use CIIS

This priority includes continuing and expanding the coordinated effort between CIIS and WIC toward one of CDPHE's 10 Winnable Battle objectives (increasing the percentage of children who are up-to-date on their diphtheria, tetanus and acellular pertussis (DTaP) immunizations upon school entry), making WIC-specific reports available in CIIS to program experts in WIC, and ensuring adequate ongoing CIIS resources to manage WIC user access.

Priority #4 – Improve Functionality and Expand Access to CIIS for Schools & Child Care Centers

This priority includes continuing to provide technical assistance to schools and child care centers that participate in CIIS, understanding the level of resources required for CIIS to successfully support such a varied and diverse group of users, pursuing appropriate options to work within the specific regulatory requirements and consent management rules that schools and child care centers have, and building strong and effective partnerships. It also includes identifying ways for CIIS to most effectively support newly enacted Colorado law, HB14-1288, which requires schools and child care centers to provide immunization and exemption rates upon request.

Achieving a high level of consensus among such a diverse group speaks to the fact that stakeholders recognize both the broad and deep importance of CIIS, and see the value in setting aside individual agendas and differences to support a common set of goals to ensure its success. However, even with this list of priorities upon which all key stakeholders agree, there remain significant implementation challenges to achieve the end goals. These include limited resources – money and personnel – policy and regulatory requirements, and the bureaucracy of working through multiple state and federal agencies, all while continuing to meet current and future mandates and maintaining ongoing operations. It is critical for CIIS to have broad support for each of these recommendations to ensure necessary funding, build essential partnerships, and establish the required legal and regulatory authority, as necessary, to successfully accomplish them within the proposed three to five year timeframes.

There is progress being made on many of the items on the above list. Several of the most critical IT solutions are underway and have approved budgets. Still, it will be important for stakeholders to continue to support a focus on all of the priorities identified here until each is achieved. To that end, stakeholders can use this report to discuss the recommendations with their own associations, organizations and constituencies to strengthen united support for CIIS' needs and make sure appropriate resources are available. This includes:

- Sharing this document with others in their organizations for meaningful discussion about the importance of immunizations and CIIS.
- Discussing these recommendations with their various professional associations, to encourage dialogue around support for good immunization policies, programs and systems.
- Meeting with legislative representatives and public officials on the importance of thoughtful immunization policy and funding support for CDPHE/CIIS.
- Using this document as a mechanism to "evaluate" new technologies and policy/program changes to help understand how and where they should fit into the priority list.
- Stakeholders agree on the value of the CIIS and want to see it enhanced to its optimal functionality. Investing in operations, systems, and policy improvements today will make CIIS an even more valuable tool that provides an essential infrastructure system for supporting up-to-date immunizations for all Coloradans, decreasing rates of vaccine-preventable disease and improving health outcomes.

Table of Contents

Acknowledgements

Funding

Overview of the Project

The Colorado Immunization Information System (CIIS) is a population-based, computerized registry that is an integral program of the Colorado Department of Public Health and Environment (CDPHE). This system collects and disseminates consolidated immunization information for Coloradans of all ages by electronically tracking patients' immunizations, allowing for an ongoing and complete record that ensures patients receive all recommended vaccines in a timely manner. As of May 2014, CIIS held approximately 45.3 million immunization services for 4.2 million individuals.

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Stakeholder Engagement Process

Stakeholder meeting structure and outputs

The stakeholder engagement process was designed to provide recommendations for expanding and enhancing CIIS capacity and functionality over a proposed three to five year timeframe. A series of five stakeholder meetings was conducted over approximately seven months. The purpose of these meetings was to facilitate in-depth discussions and visioning with stakeholders regarding current, emerging, and new uses or applications for CIIS, and to prioritize the "wish list," as well as to discuss pros/cons, operational challenges, interoperability with other health information technology (HIT) initiatives in Colorado, barriers, and recommendations on policy and funding needs to accomplish the identified priorities.

The **first meeting** focused on an overview of CIIS and perspectives from other states and national IIS work.

- Diana Herrero, MS, Deputy Director of the Immunization Section at CDPHE, provided an overview of CIIS.
- Therese Hoyle, BS, Chair of the Board, Every Child by Two, discussed her experience with the immunization information system (IIS) in Michigan and gave a brief overview of the national IIS picture.
- Mary Beth Kurilo, Director of the Oregon ALERT Immunization Information System, and current Board President of the American Immunization Registry Association (AIRA), presented on the Oregon ALERT IIS.
- Stephanie Denning from HMA gave a short review of the history and background of CIIS based on the environmental scan paper.

The **second meeting** was comprised of brainstorming ideas for CIIS and creation of a priority list.

- Stakeholders identified multiple ideas and then voted on each to create a list of the top priorities on which to concentrate in subsequent meetings.
- The group used the following "filters" to evaluate each idea:
    - It improves patient care or care at the point of service, or it is a direct benefit to the patient.
    - It has public health and population health benefits.
    - It has research benefits.
    - It is politically feasible.
    - What is the prevalence of the occurrence? Is there a potential for impact?
    - Is CIIS the best or only way to get the data?

Based on the identified list of priorities from the second meeting, the **third meeting** focused on information technology solutions and needs for each priority.

Similarly, the **fourth meeting** covered operational challenges (people, money, rules/regulations/policies) related to each of the identified priorities.

The **final meeting** focused on validating the information about each of the priorities, refining and combining some priorities, and ensuring that all the relevant information about each was captured accurately to reflect the group's input.

The ultimate output of the stakeholder meetings is this visioning document, which is meant to offer key recommendations from stakeholders, prioritized by opportunities, risks, capacity, feasibility, costs and benefits, for the next three to five years.

Participating Stakeholder List

The stakeholder listed below includes all of the organizations and individuals who participated in the meetings. As much as possible, participants were asked to commit to all of the meetings for continuity of the process; however, if a particular individual was not able to attend a meeting, they often sent a substitute to ensure the broadest possible engagement across the represented organizations.

Participant	Organization
Alicia Cronquist	Colorado Department of Public Health and Environment
Dr. Ally Kempe	Children's Hospital Colorado
Dr. Art Davidson	Denver Health
Dr. Brian Gablehouse	American Academy of Pediatrics
Brigitte Boyd	Colorado Department of Public Health and Environment
Caroline Koehler	Kaiser Permanente Colorado
Carrie Bandell	Colorado Access
Chris Wells	Governor's Office of Information Technology
Cody Belzley	Colorado Children's Campaign
Dana Erpelding	Colorado Department of Public Health and Environment
Dara Hesse	The Colorado Health Foundation
Dean McEwen	Denver Health
Diana Herrero	Colorado Department of Public Health and Environment
Dianna Anderson	Governor's Office of Information Technology
Edie Sonn	Center for Improving Value in Health Care
Elaine Lowery	Colorado Children's Immunization Coalition
Emma Carpenter	Health Management Associates
Erica McKiever	Colorado Department of Public Health and Environment
Heather Shull	Colorado Department of Public Health and Environment
Heidi Baskfield	Children's Hospital Colorado
Joan Henneberry	Health Management Associates
Jonathan Mathieu	Center for Improving Value in Health Care
Dr. Judith Shlay	Denver Health
Kate Kiefert	Governor's Office of Information Technology

Kathy Patrick	Colorado Department of Education
Katya Mauritson	Colorado Department of Public Health and Environment
Kaye Boeke	The Colorado Health Foundation
Kelly Joines	Colorado Regional Health Information Organization
Lynn Trefren	Colorado Department of Public Health and Environment
Mary Brown	Quality Health Network
Dr. Matt Daley	Kaiser Permanente Colorado
Dr. Rachel Herlihy	Colorado Department of Public Health and Environment
Sara Odendahl	Aponte & Busam Public Affairs
Sara Schmitt	Colorado Health Institute
Dr. Sean O' Leary	Children's Hospital Colorado
Shari Bohn	Walgreens
Stephanie Denning	Health Management Associates
Stephanie Wasserman	Colorado Children's Immunization Coalition
Steve Murchie	Envision Technology Partners
Dr. Suzanne Cooper	American Academy of Pediatrics
Tanya Weinberg	The Colorado Health Foundation
Tracey Campbell	Center for Improving Value in Health Care

Priorities Identified by Stakeholders

As noted above, each stakeholder meeting was dedicated to one or more topics related to CIIS. Over the course of the meetings, there emerged a final list of four priorities that stakeholders recommended should be the focus of CIIS over the proposed three to five year timeframe. Stakeholders all agreed that Priority #1 ranks the highest in the order of priorities, with the others of generally equal importance.

Priority #1 – Optimize CIIS Performance

1. Mitigate time delays and eliminate the wait list for providers' electronic connections to CIIS.
2. Maintain consistent performance for real-time, bi-directional electronic data exchange.
3. Address the underuse of CIIS – providers reporting all current and historical immunizations for all ages within a stated time period following vaccine administration. (The group noted that this issue could be corrected to some degree if the first two issues are addressed.)
4. Ensure data in CIIS is as accurate as possible. Data accuracy should be monitored before, during, and after submission to the registry.
5. Ensure greater ability to use CIIS data for population analytics to support targeted program investments and interventions.

Priority #2 – Include Newborn Hearing/Screening (NBH/S) Data in CIIS

1. Make NBH/S data collected by CDPHE available to authorized users through CIIS.
2. Ensure that the NBH/S programs (the data owners) are performing data quality checks on the NBH/S data on an ongoing basis.

3. Expand the model the NBH/S partnership exemplifies. This model is a partnership where the program subject matter experts who collect and own the data will work closely with the CIIS team to disseminate the data to authorized providers in an easily accessible and user friendly way.

Priority #3 – Expand Access to CIIS for Women, Infants and Children (WIC) Staff

1. Expand the coordinated effort of giving WIC staff access to immunization information in CIIS and adding WIC enrollment data to CIIS. This activity supports CDPHE's Winnable Battle of increasing the percentage of children who are up-to-date for diphtheria, tetanus and acellular pertussis (DTaP) immunizations upon school entry.
2. Provide access to WIC-specific reports in CIIS.
3. Expand the model the WIC partnership exemplifies. Under the model, WIC program experts plan for resources and provide most of the support for training and support for its staff, and CIIS acknowledges and plans for CIIS resources needed to manage user access.

Priority #4 – Improve Functionality and Expand Access to CIIS for Schools & Child Care Centers

1. Continue support for schools that participate in CIIS to view immunization records and add patient demographic and historical data, such as previous immunization records, when they have parental/guardian consent to do so. Similarly, continue support for child care centers to view immunization records.
2. Acknowledge that the universe of users is much more varied for schools and child care centers, and all have different IT systems (or no IT system) and different levels of technological proficiency, which requires more and different kinds of technical support from CIIS.
3. Recognize and plan for the fact that such a broad group of users requires significant support for managing user access on an ongoing basis, and to ensure security and appropriate use.
4. Pursue appropriate options to work within the specific regulatory requirements and consent management rules that schools and child care centers have, including the Family Educational Rights and Privacy Act (FERPA), and the Health Insurance Portability and Accountability Act (HIPAA) and any other regulations.
5. Build the necessary partnerships for schools and child care centers to be successful in using CIIS.
6. Utilize CIIS to ensure access to exemption and immunization rates for schools and child care centers in accordance with Colorado HB14-1288[1].

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[1] HB14-1288 was not signed into law until after the completion of the stakeholder meetings. However, stakeholders were aware of the bill and discussed how CIIS could be used to support implementation should the bill, which requires licensed daycare facilities and schools to provide data on immunization and exemption rates upon request, be enacted. See below for a more detailed description of HB14-1288.

"Parking Lot" Issues Identified by Stakeholders

Over the course of the meetings, stakeholders identified several issues that were important to many of in the group, but not high enough on the list of final priorities to be included in the key recommendations. However, the group agreed that they should be acknowledged and revisited at some point in the future.

Data Collection for Body Mass Index (BMI)

During the second meeting, stakeholders discussed a variety of desired functionality for CIIS and voted as a group on a final list of priorities to pursue as key recommendations. One of the important functions that did not make the final priority list was using CIIS to collect and disseminate BMI data.

There are two BMI projects currently underway: a pilot conducted between CDPHE, Denver Health (DH), Kaiser Permanente, and High Plains Community Health Center; and a project conducted by Denver Public Schools. Dr. Arthur Davidson, of Denver Health, who has been a key leader on the first pilot, noted in a presentation to the stakeholder group that the data collection/distribution model used by their project and the data collection/distribution model used by CIIS are very different. CIIS pulls data into a single repository, while the "federated" model they are using for their BMI project pulls data from multiple sources through a clearinghouse, and each participating partner has greater ability to control the data – what data is collected and who gets to see it or use it.

Ultimately, the group did not include BMI on the final priority list. Instead they believe that BMI is available through other sources that may be more appropriate for those who need the information, and they want to see additional data from the on-going pilot projects.

Data Collection for Multiple Child Health Indicators

In addition to the discussion of BMI, the group debated whether CIIS also could or should serve as a central repository for other child health indicators such as oral health data, and diseases such as diabetes and asthma. Again, in the end it was decided that while these are important and should not be set aside completely, at this time there are other priorities that must be addressed now to ensure the optimal availability of the information currently in CIIS to those who need it. The group further noted that by doing so, it could pave the way for CIIS to be used for other kinds of information, such as these child health indicators, if a better solution is not available through other systems such as the Colorado Regional Health Information Organization (CORHIO) or Quality Health Network (QHN). CORHIO is a nonprofit, public-private partnership designated by the State of Colorado to facilitate health information exchange (HIE); QHN is a non-profit HIE supporting providers on the Western Slope of Colorado.

Data Collection for Developmental, Social-Emotional and Autism Screening in Early Childhood

Along these same lines, stakeholders noted universal screening for developmental delays, social-emotional issues, and autism. These screenings are an important element of a comprehensive public

health approach in early childhood and there are significant gaps in the use and coordination of the information which undermines the purpose and effectiveness of screening and ultimately its usefulness to physicians, families, and the delivery of services. There are three primary areas of concern:

- Uniformity of Screening Tools Used
- Data Collection and Reporting
- Coordination of Information

These last two points are relevant for future CIIS discussions. There is currently no central system to collect and report the type of screenings completed, the screening outcomes, and the tracking of referrals/follow-up to the referral source. Screening information lacks standardization; it is driven by an individual practitioner's preferences or individual agency policies. Development of universal reporting requirements, easy access to the data by providers who need it, and the ability for multiple providers to share the information could help coordinate service delivery and positively impact development for these vulnerable children. A more in-depth discussion of this topic is available as Appendix B.

Consumer Portal for Immunization Information

In addition to making it easier for providers and users such as schools and child care centers to access immunization information, there was discussion of the need to make immunization information more accessible to the public. The group talked about how it would be useful to have a public website or portal so anyone, such as a parent, could look up a single immunization certificate. However, because CIIS does utilize unique identifiers such as Social Security Numbers or a universal Master Patient Index, it was determined that the portal idea would be better placed with a system such as CORHIO or ideally back with a provider's electronic health record (EHR).

Using CIIS data for Public Health Interventions and Data Integration

Stakeholders discussed the importance of using CIIS data for research and public health interventions. While discussed as a priority, CDPHE is working to determine the saturation of immunizing providers by county through analyzing data from the All Payor Claims Database. Once this information is determined, county immunization rates will be available for analysis. Stakeholders acknowledged the importance of using this information to identify communities with low immunization rates for targeted interventions. The group also discussed integrating immunization information with other public health data to give CDPHE, other state agencies, and researchers the ability to look at more robust sets of population health data. This would allow greater targeting of specific initiatives focused by geography, by specific population groups, or by specific types of need.

Review of Priorities Identified by Stakeholders

This section will review in greater detail each of the four priorities the stakeholder group recommends and what it expects to be included in each. The IT, operational, policy/legislative, and funding issues associated with each priority will be covered in the following section, *Addressing the Challenges Across Priorities*.

Priority #1 – Optimize CIIS Performance

Connectivity and System Performance: The stakeholder group reiterated in almost every meeting that the most important focus for CIIS should be optimizing its current performance before making any new additions to the system. "Optimization" included eliminating the backlog of providers waiting for electronic interfaces between their EHRs and CIIS, as well as improving performance for the two providers currently participating in real-time, bi-directional messaging and adding other providers who also want to participate in real-time, bi-directional messaging. The significant number of providers unable to connect electronically means some providers may not be submitting data to CIIS at all, or doing so through manual data entry as they await connectivity. Neither is optimal for ensuring maximum participation and timely, accurate data. At this time, only Children's Hospital Colorado and Kaiser Permanente Colorado (Kaiser) are connected via the real-time, bi-directional gateway. In addition, Kaiser has experienced slow response times through the messaging gateway; sometimes it has taken more than an hour for Kaiser to receive responses to their queries. There are other provider groups that have expressed interest in real-time data exchange, but the current CIIS real-time gateway architecture and security approach have been obstacles for rolling new providers onto real-time messaging.

Timely and Correct Reporting: Another important part of optimizing CIIS performance is receiving timely reporting from providers of all immunizations for all ages following vaccine administration. To a large degree, stakeholders believed issues of timely, accurate data could be mitigated by addressing the connectivity and performance problems. As noted above, when a significant number of providers either are not participating or are participating through manual data entry because they are waiting for electronic connectivity from their EHRs, there are gaps in the data available through CIIS. Implementing interfaces for the list of providers waiting for electronic connectivity will make reporting to CIIS easier and more efficient, which should encourage more providers to participate in CIIS and increase both the number of immunizations reported in general and the timeliness of reporting. The viability of mandating providers to report data to CIIS is discussed later under *Policy and Regulatory Issues*, in the *Addressing the Challenges Across Priorities* section of this document.

Quality, Actionable Data: Stakeholders want the current immunization data to be more "actionable" for CDPHE, providers, and others working to improve immunization rates across Colorado. For example, creating aggregated immunization data reports available via the CDPHE website would allow more people to access and use important immunization data. CIIS can be used to pull data for tracking and management of vaccines administered, as well as by providers to run their own immunization rates by age. Timely reporting by all providers would allow CIIS data to be more actionable for a broader range of users.

There are several reasons CIIS data cannot be used as broadly as many stakeholders would like, including:

- Incomplete Data
  - The backlog of providers waiting for electronic connectivity creates gaps in what is reported and when it is reported.
  - Some providers may not report all of the immunizations they administer.

- Inaccurate Data
  - While an individual's immunization information may not necessarily change very often, his/her demographic information can, which can cause issues with creating accurate reminder/recall lists or generating immunization rates at the geographic and provider levels.
  - There are always a certain number of user errors – data gets keyed incorrectly or information is missing – which require manual intervention to correct.

Given these challenges, it is difficult for CIIS, CDPHE, or others to use CIIS data for statewide or targeted analytics to support immunization policy development and program investments. It also limits other organizations such as local public health agencies, health systems, insurance carriers, and academic researchers for whom such information would be very valuable. Stakeholders believe that by improving its connectivity and performance issues, CIIS can mitigate many of these data problems, which then would allow it to focus on making the data more useful for a broader audience. Additionally, the group felt that CIIS needed additional resources to perform quality assurance to support the growth of data in CIIS, as well as the user communities inputting and accessing that data.

Other Items Discussed: The group also discussed that having access to timely electronic death records is important for CIIS to help ensure accurate data. Death records need to be linked to CIIS the same way as electronic birth records, and there is work underway to complete this link sometime in late 2015.

Priority #2 –Allow Access to Newborn Hearing/Screening Data through CIIS

Much of the required functionality to make NBH/S data available through CIIS is already built, although, as with any new program, there will be ongoing updates/upgrades needed over time. Stakeholders also noted that it would be beneficial for providers to have more standardized data collection and definitions for NBH/S results. To some extent, the group noted that work on this priority can be done in parallel with Priority #1 core functionality; however, they felt it should not take staff or resources away from that work.

There are differences between NBH and NBS, and recent changes within CDPHE have moved the NBS functions and oversight to the Laboratory Services Division (LSD), while NBH functions and oversight remain with the Prevention Services Division (PSD). This adds a layer of effort to ensuring that all NBH/S data displayed in CIIS is accurate and that both of the data owners (LSD and PSD) have ongoing processes in place for data quality checks. However, NBH has been a leader in terms of testing and roll-out of connecting its data with CIIS, and the hope is to use what it has done as a model for NBS and other possible data that could be made available through CIIS. For example, the NBH team serves as the

data collection and quality subject matter experts, and provides support for CIIS to ensure that the correct NBH data is available in a timely manner. They will also oversee provider training and determine who should have access to the NBH data.

There is a robust telephonic notification system already in place for abnormal NBS test results; having the information available through CIIS will be an additional way providers can access this information. While CIIS already has connectivity for NBH data, it must build the same for NBS, which is slated to happen in 2014 through upgrades CDPHE's Informatics Unit will make to the system. Additionally, NBS results are available to hospitals and providers connected to CORHIO. CIIS could potentially import NBS data from CORHIO since it is already connected to the Lab. Physicians among the stakeholder group expressed how important it is for them to have easy, timely access to NBH/S data and that getting it through CIIS in the same way they are able to access immunization information would be helpful to them.

Priority #3 – Expand Access to CIIS for WIC Staff

WIC staff work with thousands of Colorado's low-income mothers and children each year, and are in a position to help ensure these children are accessing important health services, including immunizations. Connectivity with WIC creates synergies within CDPHE because it helps to promote CDPHE's broader Winnable Battle goal of increasing the percentage of children who are up-to-date on their DTaP immunizations upon school entry. Specifically, WIC staff are now benefiting from the clinical decision support offered by CIIS to better identify children who are behind on their vaccines so they can refer those children to immunization providers.

WIC users that wish to participate have been trained how to use CIIS. WIC provides the majority of support for its users, with the exception of managing user access, which CIIS staff must do. Now that WIC staff has read-only access to CIIS, WIC has made changes to its operational processes to streamline some activities. As WIC staff grows more accustomed to using CIIS, there is potential that WIC will look to have additional CIIS functionality available. For example, there are management reports in CIIS that would likely be of use to WIC, but they currently are not being run because WIC is just getting up and running with the initial CIIS capability and does not yet have the capacity to use them. CIIS will need resources to be able to support additional functionality and users as WIC identifies new ways its teams can use CIIS.

Priority #4 – Improve Functionality and Expand Access to CIIS for Schools & Child Care Centers

The final priority identified by the group relates to functionality and accessibility for schools and child care centers. While schools and child care centers today can use CIIS to verify the immunization status of individual students, the process could be improved. If schools and child care centers could use CIIS to create lists of their students who are up-to-date on immunizations and those who still need records and/or immunizations, or those who have exemptions, verifying immunization status would be much easier for both schools/child care centers and parents.

Stakeholders agree that while this is a significant priority for CIIS and one with tremendous potential value, it also is the most complicated to work through because it requires navigation of three complex agencies – public health, human services and education – and the bureaucracies, technologies and legal issues associated with each at multiple levels. However, while implementing this priority would mean a significant investment in up-front work, the group felt that once organizational policies and procedures are in place, operations would be relatively easy to manage with adequate personnel. Additionally, better coordination and collaboration with schools and child care centers further supports the CDPHE Winnable Battle of increasing the percentage of children who are up-to-date for DTaP upon school entry.

For this priority to be truly successful, there would have to be greater cooperation among several state agencies, each of which has oversight of different groups involved – specifically CDPHE, the Colorado Department of Human Services (CDHS) and the Colorado Department of Education (CDE). Greater connectivity and access to expanded functionality for schools and child care centers could be facilitated through special data use agreements and memorandums of understanding between and among these state departments. It also for CDPHE to coordinate more with the Department of Health Care Policy and Financing (HCPF) because Medicaid plays such a large part in providing insurance coverage for a significant proportion of Colorado children, and has developed approved data-sharing agreements with schools so they can bill Medicaid for services provided to their students with Medicaid.

There are conversations between CDPHE and CDE about options to help increase schools' use of CIIS. For example, there may be ways for CIIS to upload publicly-available student directory information (currently used by HCPF to estimate the number of Medicaid children in each school and for billing Medicaid for services to eligible children) to link patients in CIIS with the school district and school they attend. It is unknown if there is a comparable student directory for child care centers that CIIS could upload. CIIS also is considering exploring the feasibility of interoperability with the data systems some school districts use, such as Infinite Campus. Such linkages would make it easier for schools to run immunization rates for their students. However, the stakeholders agreed that this work would need to come after CIIS addresses the electronic interface waitlist for healthcare providers.

In addition to the operational issues, there are legal and regulatory issues that must be addressed for schools to use CIIS more effectively. For example, FERPA is a federal law that protects the privacy of student education records and gives parents and students age 18 and older certain rights with respect to their or their children's education records. HIPAA is the federal law protecting individually identifiable health information held by covered entities (including child care centers) and their business associates, and gives individuals a number of rights with respect to that information. The Privacy Rule is designed to balance disclosure of health information needed for patient care and other important purposes with individual privacy rights.

The infrastructure and potential users among public schools, private schools and child care centers that may want to participate in CIIS are varied. Each of these entities has different IT systems (or no IT system at all), different levels of staff support available to use the system, and different levels of staff with technological proficiency to use systems like CIIS. Such a broad group of users requires a great deal of support to manage access on an ongoing basis, to ensure security, to provide technical assistance for

appropriate and efficient use, and to ensure accuracy of data entry. Changing the way schools and child care centers can access and use CIIS information could reduce the administrative burden they currently have and improve their ability to provide timely, accurate immunization information to parents who need it, as well as to meet enrollment requirements.

Addressing the Challenges Across Priorities

Resources – Funding, Personnel and Time

Particularly in recent years, Colorado's state agencies – including CDPHE - have been squeezed especially hard by the economic recession and shrinking revenues, but also have been expected to meet greater demand for services. Although CIIS has an annual funding source through state general funds that supports basic systems and program operation needs, that funding has not been adequate to allow CDPHE to achieve the optimal capabilities of CIIS as quickly as stakeholders would like.

Each of the priorities listed above comes with new operational costs, although some technological solutions may actually reduce costs in the long run. When functionality is added or enhanced, sometimes changes are made to policies and regulations (at every level), or when new users are added, there are commensurate operational costs. Through the stakeholder process, the group estimated costs associated with achieving the list of priorities that is above the current level of operational funding CIIS receives through the state general fund. For simplicity, cost estimates were rated as: Low = less than $100,000; Medium = $100,000 to $500,000; High more than $500,000.

IT Goods and Services

Each of the priorities requires some level of IT support- whether hardware, software, or non-labor services such as data storage, transmission bandwidth, etc. Several of these IT needs have at least some level of approval and/or funding already. A Low, Medium or High cost estimate is assigned to each based on either costs that have already been identified or cost estimates derived from similar work projects and products. The estimates are meant only to provide a high-level picture of what it will take to implement a priority.

For Priority #1, CIIS already has a contract in place to implement the iSIIS Vision software product, which includes a number of components:

- **IIS Outreach Management System (OMS)**: Manages all clinic, school, and vendor information, including online enrollment and user training requests. This module will replace the current paper-driven CIIS Letter of Agreement process.
- **Immunization Data Exchange Service (IDx)**: Provides self-serve, automated HL7 file testing related to EHR integration, and monitoring of Meaningful Use status.
- **VFC Outreach Management System (VFC OMS)**: Provides trend analysis for VFC provider enrollment and corrective action management following VFC site visits.
- **Support Ticketing System (STS)**: Documents CIIS issue resolutions and Help Desk tracking services.
- **Stage 2 Meaningful Use tracking functionality:** Automates provider communications, and allows CIIS staff to see: (1) which providers have registered their intent for immunization reporting; (2) which providers have passed the self-serve HL7 testing phase; (3) and real-time status updates for all providers actively engaged in the on-boarding process.

Additionally, CIIS already has approval to move forward with the implementation of a new real-time, bi-directional interface for improved real-time, bi-directional messaging for which it has already developed a Request for Proposal (RFP), as well as secured a no-cost extension from the Centers for Disease Control and Prevention (CDC) to retain previously awarded grant funds until completion of the project.

Cost estimates for the iSIIS Vision software were in the **Medium** range and the new real-time, bi-directional interface also was estimated to have a **Medium** cost. Both have already been approved through the budgeting process.

Other Priority #1 IT needs identified by stakeholders include:

- **An externally accessible data warehouse** to store data so that the most frequently requested and resource-intensive reports can be run outside of the CIIS production environment, and so external users could run their own reports without compromising CIIS performance (e.g., Jefferson County running an immunization rates report on all 11 – 19 year olds can impact system performance because the cohort is so large). Envision Technology Partners, Inc., the vendor who supports the WebIZ registry product for CIIS, has built a similar data warehouse for another WebIZ client. It might be possible for Colorado to benefit from "reuse" of some of this work, but would still require significant funding to create. Estimated costs = **Low to Medium**, depending on ability to build from existing work done by Envision.
- **Full inventory management for electronic reporters** – Providers who electronically submit their immunization data to CIIS have no way to decrement their vaccine inventory within the immunization registry except by manually entering the required information into CIIS. Enabling auto-decrementing of inventory through electronic data exchange is a programming enhancement that would need to be implemented by CIIS/CDPHE IT staff. While the Inventory Module was part of the baseline WebIZ software implemented in 2011, it was not until the Vaccine Ordering Module rollout for Vaccines for Children (VFC) providers that the Inventory Module became so important for providers. All ordering VFC providers use the CIIS Inventory Module to manage their VFC-funded vaccines, including receiving vaccine shipments, creating adjustments to line items (e.g., wasted or expired doses), and reporting the number of doses administered in their clinic over a given time period. The Inventory Module directly increases vaccine accountability and stewardship. Estimated costs = **Low**.
- **Expand connection to CORHIO.** Although there was not a lot of conversation in the meetings about the relationship between CIIS and CORHIO, stakeholders did acknowledge there should be more intentional discussion about how the two can collaborate more and potential leveraging of opportunities between the two entities. For example, enhanced connectivity between CIIS and CORHIO could allow many more providers to access CIIS information they need, without having to build interfaces directly with CIIS. However, providers will still be required to build interfaces with CORHIO. Estimated costs = **unknown** until better defined.

Some of the other IT needs identified by the group that could support all of the priorities include:

- **Forecasting algorithm updates** – CIIS and Envision continue to update the algorithm to meet the current ACIP recommendations. This is an ongoing effort, as the ACIP recommendations change

based on available data. Maintaining and upgrading the forecasting algorithm is part of the annual maintenance and support that Envision provides. The forecaster is tied into the bi-directional HL7 messaging gateway, so when a provider queries for a record, CIIS returns the vaccine history and vaccine recommendations for the patient in the response message. Estimated costs = **Low**, since much of the algorithm updates are part of maintenance and support.

- o Additionally, there are scenarios where providers have given vaccines that, while "not right" (e.g., outside of licensed product usage), are not exactly "wrong" (e.g., the dose would not have to be repeated). CDPHE Immunization Section staff have been researching and documenting these kinds of scenarios, and it would be useful to incorporate this logic into the forecasting algorithm. However, this kind of enhancement to the algorithm has a potentially hefty price tag and would require additional funding to implement. Estimated costs = **Unknown** until better defined.
- o There is also technology being explored on the national level that seeks to create a single web service that providers and EHR systems could use to access standardized forecasted immunization information. For example, ICE, a product developed by HLN Consulting, LLC, is under consideration by Denver Health for use in its immunization registry. However, until and unless there is more discussion about some of these, it would be difficult to know how to determine anticipated costs to implement. Estimated costs = **Unknown** until better defined.

- **Medicaid billing module** – The WebIZ product includes an optional Medicaid billing module. Boulder County Public Health is currently the only organization using this module in Colorado as they have their own local instance of WebIZ separate from the state's version. The Medicaid billing module is not "turned on" or programmed for CIIS generally, and it would require some programming to make it functional at a broader level. Implementation of the Medicaid billing module is slated to begin in early 2015. Expanding the Medicaid Billing module to allow providers to bill other health plans would require significant programming and funding to implement. Estimated costs = **Medium**.
- **Connectivity with school district systems such as Infinite Campus.** There are opportunities for CIIS to work better with schools and child care centers, but there needs to be a clearer understanding of what technology solutions could support this and what it might take to implement them. Because there is still so much work to be done on the policy, regulatory and legal fronts, it may be more prudent to first iron out those issues then look at what technology is needed to support what can be done. Estimated costs = **Unknown**, until better defined.

A number of the potential IT solutions identified would still need to be funded, either through state dollars or other external sources. There are opportunities for collaboration with other partners who could shoulder some of the costs, but other expenses would fall largely on CIIS. Additionally, as there are policy program and technology changes, CIIS may determine there are better, more appropriate, or less expensive alternatives that would allow it to accomplish the same goals as the technology solutions they currently are pursuing. CIIS will need the flexibility to be able to adopt or adapt to these new solutions if and when it is feasible.

Personnel

IT systems and solutions are only one part of the operational costs of making these enhancements to CIIS. A second potentially larger and more complex cost is paying for the people necessary to do the work to successfully implement and support CIIS. In addition to having enough personnel to manage the workload, more important is having the personnel with the right knowledge, skills, and experience. As functionality and different kinds of users are added to CIIS, there is a commensurate need for professionals to support the work, both short-term and ongoing.

For example, CIIS will need additional people who can perform the following:

- Programming (in various languages and systems);
- Data analysis;
- Quality reviews;
- Project management;
- Legal and policy reviews; and
- User outreach, training and technical support.

Given the current state budget and the constant scrutiny of state agency staffing, hiring a lot of new people to support added CIIS functionality and user groups is likely not feasible. There are relevant, specific State Personnel rules/statues that direct hiring practices. For some needs, it would be better to use independent contractors and/or vendor staff, particularly for very specialized work or time-limited projects. There also are opportunities to leverage personnel from partnering programs to provide training, outreach and promotion for their specific users or information as CIIS has done with NBH/S and WIC. Similarly, CIIS can explore shared personnel resources with partners such as other state agencies, HIEs, and other partners. Depending on the number and type of staff needed and how much staff support CIIS might be able to leverage from partners, personnel costs likely would be **Medium** to support both implementation and ongoing operational requirements for all of the priorities.

Timeline

Particularly when it comes to technology and systems such as CIIS, it is difficult to keep up with the volume and pace of changes. This is true for both marketplace and technology changes, but also true because CIIS must respond to federal and state mandates that can take priority over other projects identified in its strategic plan and that may be added with new federal and/or state legislation. Furthermore, growing demands for faster access to increasing amounts of immunization information means that CIIS staff are almost always behind the curve working to catch up with what stakeholders want and need. While this paper is not meant to be a project plan for CIIS, it does provide stakeholder recommendations as to how CIIS can prioritize activities to best support functionality and services that offer the most value to users. Further, as the stakeholder group discussed in several of the meetings, the recommended priorities identified should ideally be accomplished in the next three to five years to ensure that CIIS provides the level of value users expect and need.

Finally, the group acknowledged that this list of priorities represents a point in time; there will be changes in the outside world that will require CIIS to adapt these recommendations and priorities from time to time to accommodate the variations that will occur over the three to five years.

Policy and Regulatory Issues

As mentioned in several of the priorities, there are potential policy, legislative, and regulatory issues that CIIS may need to address to be able to fully implement the recommendations. These policy issues can be addressed through minor changes to current statutes and/or regulations, although there is always the possibility of significant pushback from anti-immunization organizations and privacy advocates for anything related to CIIS. There also are needs for additional funds, which will require both approval within the CDPHE budget, as well as legislative action and approval.

Mandatory Reporting

From a broader policy perspective, stakeholders noted that a key priority for CIIS data is ensuring data completeness and accuracy. It is becoming more difficult to obtain complete immunization information for an individual, given that many people receive immunizations in non-traditional places (e.g., grocery/drug store pharmacies and special health fairs), patients are increasingly mobile and move from provider to provider, and there are relatively high rates of personal immunization exemptions. CIIS participating providers do sign Letters of Agreement that stipulate reporting requirements including the timeliness of data entry/reporting; however, CDPHE has no resources to ensure they consistently report in a timely manner, and some providers choose not to participate in reporting at all.

Tightening CDC, VFC, and 317 vaccine requirements, particularly related to tracking patient eligibility to receive publicly-funded vaccines, has been difficult for both CDPHE and providers to meet. As federal budgets continue to constrict, there is likely to be even greater scrutiny on ensuring only eligible individuals receive publicly-funded vaccines. This will require more sophisticated VFC eligibility tracking and sharing among various agencies, including between CDPHE and HCPF for Medicaid clients, as well as tracking children who churn on and off new qualified health plans, which are required to cover vaccines under the Affordable Care Act.

Stakeholders in this process all believe that to eliminate the above issues, ultimately a mandatory reporting requirement that would include reporting on VFC eligibility status, would be the best public policy. However, they also agree that it may not be a feasible path to take at this time. There are other options for mitigating the problems of a voluntary reporting system and increasing provider participation. For example, additional vaccine administration reimbursements could be offered to Medicaid providers who participate in CIIS and report all immunizations in a timely manner. Since all recommended vaccines are now required as "essential health benefits" under qualified health plans sold through Colorado's health marketplace, Connect for Health Colorado, there may be new opportunities to work with private insurers to encourage more of their providers to participate in CIIS via enhanced immunization administration rates or incentives. It should be noted that one of the most effective methods to ensure timely and complete reporting by VFC providers is to require reporting to CIIS as a condition of participation in the VFC Program. A provider would not be allowed to order VFC vaccines if

vaccines were not reported. A recent change in the VFC Program allows states to include this requirement for ordering VFC vaccines in their provider contracts.

House Bill 1288

On May 21st, 2014, Governor John Hickenlooper signed HB14-1288, into law. It goes into effect on July 1st, 2014, and among other things, requires all schools and licensed child care centers in Colorado to provide immunization and exemption rates upon request. In the Board of Health rule 6 CCR 1009-2, a school is defined as, "A public, private, or parochial nursery school, day care center, child care facility, family care home, Head Start program, kindergarten, or elementary or secondary school through grade twelve, or a college or university." The definition excludes "a public services short-term child care facility (e.g., child care center in a court building), a 'guest' child care facility or ski school, a college or university which offers courses off-campus or on-line, or are offered at colleges or universities which do not have residence hall facilities."

Colorado law allows parents to exempt their children from school-required immunizations based on a medical, religious or personal belief (C.R.S. 25-4-903). Currently, exemption information is not consistently tracked in a standard way in CIIS. One review of a school district's data in Colorado found that up to 60% of children with an exemption on file at the school actually had a shot administration date recorded in CIIS.

HB14-1288 is meant to provide data transparency around exemption rates, and will be an important tool for helping parents make informed decisions about where to send their children for daycare or school, especially a medically fragile child that must rely on herd immunity for protection against vaccine-preventable illness. Ensuring that licensed child care centers and schools have access to up-to-date immunization and exemption rates through CIIS will be key to ensuring full implementation of the law.

Data collection/sharing with schools and child care centers

Schools

While HB1288 will make it possible for people to get information about a specific school or child care center's immunization and exemption rates, there is still frustration and confusion among stakeholders and advocates regarding the sharing of immunization data by schools. The FERPA requirements which limit schools' ability to share data with CIIS have been a significant barrier to CIIS working with schools, and there have not been any significant breakthroughs in discussions between CDPHE and CDE about ways that both schools and the state agencies can work more productively within the intended parameters of the federal law. It will take a concerted effort, supported by senior leaders at both organizations to continue to move this dialogue forward. CIIS has the potential to be the source that provides the evidence of a child's vaccination status without requiring school to collect, store and manage vaccination records for the majority of their students. With the passage of HB1288, there may be more opportunities for new discussions focused on the common goals for education settings (schools and child care centers) and CIIS.

Child Care Centers

There was agreement among stakeholders that child care centers comprise a significant opportunity for CIIS since they are a key "collection point" of children during the time of their lives when they need the most immunizations (ages 0 – 6). However, the major hurdles with child care centers relate to the volume and variation of child care providers. There are more than 15,000 licensed child care centers in Colorado, and they range from small in-home providers to large, corporate centers. Their ability and know-how to interact with CIIS varies greatly and will require different kinds of technical support from CIIS staff. In addition to the licensed centers, there are also thousands of unlicensed child care centers who potentially could participate, although the stakeholders determined it is not feasible at this time to try to build capacity to support unlicensed child care centers. Again, HB1288 may create new possibilities for more discussions around enhancing and expanding CIIS capabilities to support child care centers in meeting the new law's reporting requirements.

Interagency

Finally, there are opportunities to improve coordination, collaboration and data sharing among state agencies, but it requires buy-in and prioritization from senior leadership in each agency. Data sharing agreements or MOUs between CDPHE, HCPF, CDHS, and CDE could help to smooth the way for each agency to better accomplish its own specific goals, as well as promote better coordination and leveraging of resources across agencies for similar and related work. For example, the CDE and HCPF share data on Student Medicaid Enrollment in order for schools to be able to bill Medicaid for medical services such as medication administration.

Next Steps: Disseminating the Recommendations

CCIC's charge in conducting these stakeholder meetings was to produce a "visioning document…for CIIS enhancement that offers key recommendations prioritized by opportunities, risks, capacity, feasibility, costs and benefits." The next step is to ensure the recommendations are disseminated as widely as possible and that stakeholders continue to support and advocate the recommendations.

Buy-in from Critical Sponsors

There are some key groups and individuals from whom it is critical to get buy-in and support for the priorities and recommendations identified through this stakeholder process. They include important sponsors and champions for immunization policy and funding such as:

- Board of Health
- CDPHE Leadership and Staff
- CCIC Board of Directors and Coalition Members
- Members of Colorado's Executive Branch
- State and Federal Agency Leaders
- School Administrators, School Boards and School Health Leaders
- Members of the Colorado General Assembly and other public officials
- Private foundations
- Immunization advocates and parents
- Major providers such as Children's Hospital Colorado, Kaiser Permanente Colorado, Denver Health, and other large provider groups that use CIIS
- Informatics vendors and other private sector interests

Having the backing of these valuable champions will give all stakeholders additional leverage to support efforts to address these priorities to improve and enhance CIIS functionality and value to all users.

Communications with Stakeholders

The report will be distributed as broadly as possible, and there are plans to present the recommendations to CDPHE leadership, the Vaccine Advisory Committee for Colorado, and CCIC members. In addition, the report will be shared via numerous listservs including the CIIS User Group, VFC providers, and school nurse lists. Additional opportunities will be pursued to share the report at local and state conferences and meetings.

The goal is for stakeholders to use this document as a means of united support for CIIS's needs and to help ensure that appropriate resources are available for achieving these recommendations. Important opportunities for stakeholders to explain the value and benefits of the priorities that were identified include:

- Sharing this document with others in their organizations for meaningful discussion about the importance of immunizations and CIIS.
- Discussing these recommendations with their various professional associations, to encourage dialogue around support for good immunization policies, programs and systems.
- Meeting with their legislative representatives on the importance of thoughtful immunization policy and funding support for CDPHE/CIIS.
- Using this document as a mechanism to "evaluate" new technologies and policy/program changes to help understand how and where they should fit into the priority list.

Ongoing Support for the Recommendations

Beyond sharing the information with stakeholders, one of the most critical factors to successfully move these recommendations forward will be to keep the stakeholders from deviating too far from the priorities outlined here. If different groups of stakeholders decide to focus efforts on issues or solutions that are not part of these recommendations, it will dilute the overall efforts to support successful implementation of these initiatives within the proposed three-to-five year timeframe.

On the other hand, there may be issues or activities such as CDC mandates and other needs that may arise due to unforeseen circumstances that should take priority over these recommendations. However, the purpose of creating a document such as this is to provide a recommended list of priorities that have the greatest value to the most stakeholders. Changing the recommended priorities, even when necessary to accommodate unexpected needs, will impact the ability of CIIS and its supporters to reach these goals in the desired time. It will be important to both acknowledge and account for any necessary changes in a way that clearly shows stakeholders why the changes were required, how they will change the prioritization of these recommendations, and how they will impact the timing of each desired outcome.

Conclusion

Through a series of several meetings over many months, a group of individuals and organizations invested in the importance of immunization policy, programs and systems in Colorado, came together and recommended what it believes should be the priorities for CIIS over a proposed three to five year timeframe. While there certainly was much strong debate and dissenting opinions at times, the group was remarkably consistent in naming the capacity and functionality in which it sees the most value for CIIS to accomplish. Achieving a high level of consensus among such a diverse group of stakeholders speaks to the fact that these stakeholders recognize both the broad and deep importance of CIIS, and see the value in setting aside individual agendas and differences to support a common set of goals to ensure its success.

Appendix A - Glossary of Acronyms and Terms

Acronym	Definition
ACIP	Advisory Committee on Immunization Practices
AIRA	American Immunization Registry Association
ALERT	Oregon's Immunization Information System
BMI	Body Mass Index
CCIC	Colorado Children's Immunization Coalition
CDC	Centers for Disease Control and Prevention
CDE	Colorado Department of Education
CDHS	Colorado Department of Human Services
CDPHE	Colorado Department of Public Health and Environment
CIIS	Colorado Immunization Information System
CORHIO	Colorado Regional Health Information Organization
C.R.S.	Colorado Revised Statutes
DTaP	Diphtheria, Tetanus and acellular Pertussis
EHR	Electronic Health Record
FERPA	Family Educational Rights and Privacy Act
HCPF	Health Care Policy and Financing (Colorado Department of)
HIE	Health Information Exchange
HIPAA	Health Insurance Portability and Accountability Act
HIT	Health Information Technology
HMA	Health Management Associates
HL7	Health Level Seven, a standard for exchanging information between medical applications.
ICE	The Immunization Calculation Engine (ICE) is a state-of-the-art open-source software system that provides clinical decision support for immunizations, commonly referred to as "immunization forecasting."
IIS	Immunization Information System
IDx	Immunization Data Exchange Service
iSIIS Vision	Proprietary Immunization Information Software
IT	Information Technology
LSD	Laboratory Services Division
NBH/S	Newborn Hearing and Newborn Screening
OMS	IIS Outreach Management System
PSD	Prevention Services Division
STS	Support Ticketing System
VFC	Vaccines for Children
WebIZ	A web-based, database-driven immunization registry system currently implemented in Colorado and many other states. A product of Envision Technology Partners, Inc.
WIC	Women, Infants, Children
317	Section 317 of the Public Health Service Act authorizes the federal

	purchase of vaccines to vaccinate children, adolescents, and adults

Term(s)	Definition
Confidentiality	The obligations of individuals or groups who receive or use information to respect the privacy of individuals who are the subjects of the data.
Exemption from Immunizations	From C.R.S. 25-4-903: (2) It is the responsibility of the parent or legal guardian to have his or her child immunized unless the child is exempted pursuant to this section. A student shall be exempted from receiving the required immunizations in the following manner: (a) By submitting to the student's school certification from a licensed physician or advanced practice nurse that the physical condition of the student is such that one or more specified immunizations would endanger his or her life or health or is medically contraindicated due to other medical conditions; or (b) By submitting to the student's school a statement of exemption signed by one parent or guardian or the emancipated student or student eighteen years of age or older that the parent, guardian, or student is an adherent to a religious belief whose teachings are opposed to immunizations or that the parent or guardian or the emancipated student or student eighteen years of age or older has a personal belief that is opposed to immunizations.
Privacy	The rights of an individual to control how information about the individual is collected, used, and disclosed. The value of privacy derives from ethical principles of autonomy that imply individuals are entitled to some level of control over data, including health data, unique and personal to them.
Security	Technologic, physical, or administrative safeguards or tools designed to protect data, including health data, from unwarranted access or disclosure.

Appendix B - Issue Brief

CDPHE, April, 2014

Data Collection for Developmental, Social-Emotional, and Autism Screening in Early Childhood

Universal screening for developmental delays, social-emotional issues, and autism is an important element of a comprehensive public health approach in early childhood, and although screening is becoming more routine in pediatric and family practices, there are significant gaps in the use and coordination of the information. This undermines the purpose and effectiveness of screening and ultimately its usefulness to physicians, families, and the delivery of services. There are three primary areas of concerns.

1. *Uniformity of Screening Tools Used* - Effective screening processes begin with the use of reliable and valid screening tools that are able to correctly identify children who need further evaluation (Squires, 2000). Currently, there is no standardization of practice in which tools or parts of tools that are used to screen young children as part of developmental monitoring. This results in inconsistency of screening information which can be confusing to families and prohibits aggregated data analysis to effect systems change and improved service delivery. Requiring the use of standardized screening tools will improve the overall outcomes for families and the broader system.
2. *Data Collection and Reporting* – Underlying the ability for any system to analyze current practice and to develop innovation and improvements is a reliable data collection and reporting system. There is currently no central location to report on the type of screenings completed, the outcomes of screening, the tracking of referrals or follow up back to the referral source. Data collection and reporting of screening results can be integrated into the normal processes for well-child checks and developmental monitoring.
3. *Coordination of Information* - Effective screening processes must be understood as a valuable tool by all parties, including the physicians, family and the service delivery system. There must be feedback and coordinated communication whereby referring entities are informed of evaluation and service eligibility after referrals are made. Currently, the coordination of information is hit or miss because it is driven by individual practitioner's preferences or individual agency policies. Through the development of universal reporting requirements, ongoing communication and mutual benefit of information sharing, service delivery will be coordinated and the child's development will be positively impacted.

The effective use of universal screening and data collection is an essential element and precursor to an integrated early care and education (ECE) system. Without it, the health components of children will be absent, leaving an incomplete profile of a child's development. Colorado agencies must begin to fully integrate early screening and identification procedures with other early childhood data systems in order to provide families and funding sources with a robust capacity to meet the health and education needs of children. As identified in the Early Childhood Data Collaborative February 2014 report (www.ecedata.org), linkages between ECE and other data systems (e.g., K-12, health, social services) help policymakers and other stakeholders understand how children's experiences in these systems

contribute to their learning and development – and how policy changes can support the continuous improvement of these programs.

Background

Universal developmental screening is an effective way to identify young children at risk for developmental and behavioral difficulties who would benefit from early intervention services. Developmental screening is defined as a brief assessment procedure designed to identify children who should receive more intensive diagnosis or evaluation from local early intervention, health, or mental health agencies. Screening results are not diagnostic and screening alone does not determine eligibility. Effective screening processes begin with the use of reliable and valid screening tools that are able to correctly identify children who need further evaluation (Squires, 2000). Additionally, effective screening processes include feedback and coordinated communication whereby referring entities are informed of evaluation and service eligibility after evaluations are completed.

While screening for developmental delays, social-emotional issues, and autism is becoming a more routine practice, several issues have emerged that need to be addressed while our state continues to move forward in promoting universal screening for young children. Screening, early identification, referral, intake, evaluation and services are not each isolated activities but rather integral components of a single process. Providing a child with timely and appropriate services that support his or her optimal development requires close coordination between multiple child-serving systems. With the development and advancement of state health information exchanges under meaningful use requirements, it is an opportune time for states to expand data linkage efforts to include other systems of care beyond the medical provider. (SERIES: An Integrated Approach to Supporting Child Development, Summer, 2012)

The following issues are priorities with regard to a comprehensive and integrated screening data system:

Data and Reporting
There is a need for a consistent reporting location, a consistent process, and consistent data collected on developmental, social-emotional, and autism screening in Colorado. At least five points of data are needed as part of a comprehensive screening system: 1) if the child was screened; 2) results of screening; 3) whether an evaluation was completed; 4) entry into services; and 5) whether the child and family services were sustained. Currently, there is no standardized mechanism to track the data.

Data to Ensure Coordination of Efforts and Follow Up
While some tracking may occur in pediatric healthcare practices, tracking doesn't happen when screening occurs in early learning environments (e.g., Head Start, child care, preschool). There are various screening efforts, but no entity tying it all together. There is a need for integration of a paper-based referral process with an EMR and other electronic systems.

Information Sharing and Access

In order to prevent duplication of screenings, evaluations and services, there must be information sharing between all parties who are providing services to the family. This process needs to consider who would have access to screening data and how it would be shared.

Screening Data Integration Recommendations

1. Improve the uniformity of screening processes and outcomes for children and families.
2. Create a "centralized" database (or universal information sharing with appropriate safeguards) for screening information to be able to understand identification rates and results of screening that uses a phased approach to screening data collection that allows for movement toward an end goal of a comprehensive data system.
3. Shared agreement on data points to collect in screening and screening outcomes.
4. Ensuring a data system that:
    a. automatically populates screening completion and scoring so there is no or minimal manual data entry,
    b. is a central (not isolated to individual provider/organizational systems) mechanism in which completion of screening, scoring of screening, results of screening, referral information, and whether the child made it to the referral is captured,
    c. can be included in or exported to a child health record that begins at birth,
    d. assigns a unique identifier to each child in order to ensure that referral and ongoing health information can be followed,
    e. is usable across public and private insurance providers,
    f. has a clear process for authorized access and information sharing,
    g. is understood and promoted across providers of care to young children, and has a primary entity to tie screening efforts together,
    h. is mutually beneficial to those who screen and enter data, families and to service providers.