Data Sharing Across Child-Serving Sectors:

Key Lessons and Resources

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CONTENTS

SEC. 1. PURPOSE

Evidence shows that investments in the early years can improve lifelong health and well-being.[1] In response, multi-sector community collaborations seeking to optimize health for children and families are emerging across the country. However, community collaboratives, even at their early stages, face fundamental questions about data sharing among the various sectors and quickly raise the necessity for a data strategy to guide planning efforts.

Developing a data strategy is an opportunity to bring community partners together to advance shared goals, improve coordination across sectors and systems, identify needs and gaps, and assist in measuring progress. It can catalyze dialogue about the intended purpose of data sharing, as well as clarify the specifics related to data priorities, data collection, data-sharing infrastructure, and data reporting among state or community partners in order to achieve jointly defined shared outcomes.[2] Developing a data strategy across sectors reveals complex legal, technical and partnership challenges that can be overcome.

Communities find that working together to articulate the value of data collaboration and identify the multiple purposes for data sharing between partners and communities is a useful step.[3] For example, a data strategy addresses questions such as: will data be used for coordinating services, monitoring progress toward population health outcomes and identifying program gaps; what data is most relevant; how will data incorporate an equity lens; what data sources and gaps exist; what legal requirements are involved; and what technical challenges are present? The process of developing a data strategy allows partners to explore language and discuss definitions such as what are the shared outcomes, the short- and long-term measures, and the indicators of success. Moreover, this process builds trust and commitment as an important foundation for the inevitable challenges ahead.

This issue brief summarizes key lessons learned and bright spots in navigating data partnerships with a focus on child-serving sectors. In addition, it includes an Appendix with resources that were compiled based on suggestions from key informant interviews, input from members of the Collaborative on Accountable Communities for Health for Children and Families, and a scan. This brief is intended to serve as a resource to amplify and strengthen the efforts of emerging and existing multisector collaborations, such as the Center for Medicare and Medicaid Innovation's (CMMI) Accountable Health Communities Model, broader Accountable Communities for Health Initiatives, CMMI's Integrated Care for Kids, and Racial and Ethnic Approaches to Community Health, through an exploration of data-sharing partnerships across: 1) health and education; and 2) health and early childhood sectors.

SEC. 2. FOUNDATIONAL READINESS FACTORS AND OVERCOMING BARRIERS TO SUCCESSFUL DATA SHARING

Lessons from case studies utilizing early childhood data, a few key informant interviews, and presentations during a meeting of the National Academies Collaborative on Accountable Communities for Health for Children and Families[1] point to specific readiness factors to developing an effective cross-sector data-sharing strategy. This section briefly highlights a few key foundational readiness factors, including building trust, establishing champions, and aligning goals and establishing shared measures.

Trust

Establishing trusting relationships among partnering organizations and community members is a key foundational element.[4-9] To build trust, partners should have a joint understanding from the outset that building cross-sector relationships takes time and necessitates strong engagement from community members — including children and families — with lived experience. For example, the trust-building process resulted in a three-year investment for a community in Indianola, Mississippi, working to strengthen educational and health opportunities for children and families in that region.[9] Efforts to change the data culture in Indianola were successful as a result of not only continuous engagement of community members, but also increased transparency around project goals — which was key to building trust.

Champions

Another important readiness factor is identifying leaders who can champion efforts over time and navigate the local context. For example, in Philadelphia, the mayor's commitment to universal, publicly funded pre-kindergarten led to long-term investment in an integrated data system, requiring multiple city agencies to combine their data to coordinate client services across agencies.[4] And Oregon's health and education cross-sector model was facilitated by state and local leader buy-in for cross-sector joint accountability efforts.[7] In each of these examples, champions understood and valued the contributions of each sector and helped to catalyze action.[7]

Goal Alignment and Shared Measurement

Goal alignment and shared measurement should be pursued following the establishment of trust among key champions and stakeholders who are at the table with a shared understanding of how each sector contributes to success. Clear identification and alignment of goals should be considered before embarking on shared measurement (i.e., an agreed upon set of measures between two or more sectors) and joint accountability (i.e., use of one or more measures to hold multiple sectors accountable).[10] To illustrate, the Chicago Department of Public Health and Chicago Public Schools devoted time at the outset to create a shared-values proposition where each sector identified data and expertise they could bring to the partnership (see Section 3 for further details). Before entering into a formal data-sharing agreement, two important foundational steps that contribute to success are the establishment of shared goals among true collaborators and creation of accountability structures.[2,7]

1. The Collaborative on Accountable Communities for Health for Children and Families is organized by the National Academies Forum for Children's Well-Being under the leadership of Nemours Children's Health System and Mental Health America. The goal of the Collaborative is to catalyze and support community health models that will nurture healthy and resilient children and families. The Collaborative held a meeting on May 29, 2019, which included presentations on developing a data strategy and data sharing across child-serving sectors.

Overcoming Barriers

The existence of the above readiness factors helps to facilitate successful data-sharing arrangements. However, barriers still remain. Legal considerations related to the Health Insurance Portability and Accountability Act (HIPAA), 42 CFR Part 2, and the Family Educational Rights and Privacy Act (FERPA) often serve as barriers — both real and perceived — to cross-sector data sharing, particularly between education and health sectors. Despite these barriers, communities and states are finding innovative ways to work collaboratively to address complex health and social needs of children and families while still ensuring compliance with these important privacy laws. In particular, communities have noted that involving the legal team early on in the relationship-building process is a critical step.[11] Additionally, the resources presented throughout this brief and in the Appendix can assist communities with addressing barriers to cross-sector data sharing.

The Health Insurance Portability and Accountability Act (HIPAA) is a federal law that provides data privacy and security provisions for safeguarding protected health information.

The Family Education Rights and Privacy Act (FERPA) is a federal privacy law that gives parents certain protections with regard to their children's education records, such as report cards, transcripts, disciplinary records, contact and family information, and class schedule. The law applies to all schools that receive funds under an applicable program of the U.S. Department of Education.

SEC. 3. COMMUNITY DATA SHARING BRIGHT SPOTS

Some innovative communities have been at the forefront of sharing data across the education and health sectors, as well as the early childhood and health sectors. Below are community spotlights and links to relevant tools and templates that communities have used to navigate HIPAA and FERPA and successfully share data across sectors. To access additional resources and toolkits, please visit the Appendix at the conclusion of this brief.

Health and Education

- **Washington, DC** — Washington's public schools, public health department and the Medicaid agency have improved coordination to more effectively collect student health information from families and support students in developing healthy habits. The agencies developed a Memorandum of Agreement (MOA) that allows them to share and combine their data (student enrollment files, records of health form submissions, Medicaid enrollment status, and records of well-child and dental visits) to develop a more complete picture of student health needs. Based on the data, Medicaid managed care organizations (MCOs) can identify and partner with high-need schools to connect children in need of well-child visits and dental visits to needed services. Additionally, MCOs use the data to help inform their outreach efforts to their student beneficiaries.[12] For example, after school nurses administer a vision screening, thanks to the data-sharing agreement, MCOs are informed when a child has vision issues and then can reach out to families to encourage follow-up appointments.[13] *Learn more*.

- **Wilmington, Delaware** — Nemours Children's Health System (Nemours) has a partnership with school nurses that enables nurses, with parent/guardian permission, to log onto NemoursLink, a web-based portal to Nemours' electronic health record, where they can see a child's plan of care and information about almost every visit to the Nemours/Alfred I. duPont Hospital for Children or a Nemours duPont Pediatrics office. For example, the school nurse can see current medications, scheduled appointments, procedures performed, diagnosis information, treatment plans, and care instructions after an injury, illness, surgery or hospitalization. According to a Delaware school nurse, "It is so nice to be able to feel that you have the whole picture. After all, our goal is to treat the whole child."[11] School nurses may only view a child's records if a parent or guardian has signed an *authorization form* that is HIPAA and FERPA compliant in advance. For added safety, Nemours keeps track of everyone who uses NemoursLink and what they view. Nemours enrolls between 1,400 and 1,700 students/patients into the program annually.[14] *Learn more*. The implementation guide for Nemours' Student Health Collaboration is available on the *Nemours Website*.

> *"Navigating the legal and practical roadblocks to establishing data-sharing arrangements can be daunting and complex. For example, there are real data-sharing barriers related to HIPAA and FERPA — but there are perceived barriers as well. Training, cross-agency communication and developing shared goals can be important tools to identifying the best way to work through these. Examining bright spots where states and districts have succeeded in working through these challenges can also offer important insights into how to advance this work in your community."[5]*
>
> *— Alex Mays, Senior National Program Director, Healthy Schools Campaign*

- **Chicago, Illinois** — The Chicago Department of Public Health (CDPH) and Chicago Public Schools (CPS) worked together to improve childhood education and wellness. To achieve their joint goals, CPS and CDPH developed several agreements to share limited sets of student data on a case-by-case basis to better inform their interventions for students. Specifically, CPS has a history of partnering with CDPH to provide services in schools (e.g., vision and dental services) that parents and guardians may not be able to obtain elsewhere. CDPH uses data from CPS to ensure that students receive referrals for follow-up services and analyzes student health data collected in schools and shares the results with CPS to help administrators understand the medical issues that lead to chronic absenteeism, behavioral issues, and poor academic performance. Instead of seeking permission each time data sharing was warranted, CPS and CDPH developed an umbrella data-sharing agreement that would allow the exchange of information for commonly used data types without prior consent based on an *exemption* under FERPA.[15] More about this effort including "5 tips to get to yes," can be found at *dashconnect.org*.

Health and Early Childhood Sectors

- **Philadelphia, Pennsylvania** — The City of Philadelphia placed a Data Management Office within Health and Human Services to create an integrated data system (IDS) that ties together vital statistics, demographics (including geography), service use, and some outcomes — 5,200 variables in total — for every child born into the system.[16] The IDS is governed by a legal framework to protect the linked data while making it accessible for appropriate uses. Stakeholders have used the IDS to: 1) stratify children based on risk and ensure that every child receives an appropriate level of tiered intervention, 2) evaluate the effectiveness of social policies or programs, and 3) decide where to target new programs and to plan new community-wide initiatives to comprehensively meet the needs of children and families. The IDS approach was effective in part because it allowed different stakeholders to ask different kinds of questions — from whether children in need were receiving certain services to how risk clusters in places — beyond a general use indicator set or dashboard. Out of this work came the *Actionable Intelligence for Social Policy at University of Pennsylvania* to support other cities in creating and using IDS.

- **Provo, Utah** — Statewide, Utah's State Advisory Council on Early Care and Education launched the initiative Early Childhood Utah, which includes implementation of an *Early Childhood Integrated Data System (ECIDS).*[17] ECIDS brings together data across programs that serve young children and their families from birth to age eight. To implement the ECIDS, Early Childhood Utah secures data use agreements and aligns data systems with different programs across the state. Early Childhood Utah also increases rates of screening using the Ages and Stages Questionnaires®, third edition (ASQ®-3), and the Ages and Stages Questionnaires®: Social-Emotional, second edition (ASQ®:SE-2), to better identify early needs. Help Me Grow Utah in Provo connects children and families with child- and family-serving programs through pediatrics and interfaces with the ECIDS. Together, these programs will give stakeholders in Utah a better understanding of the developmental and mental health needs of young children, which services they are receiving, and their impact, to better coordinate and plan intervention strategies as well as understand the return on investment. Federal funding can support states in establishing their own ECIDS, as explored below.

  > *"Data has become essential for decision making across early childhood systems. Most people ask can I share data between the health and education sectors rather than asking how. In my experience, there are no barriers that can't be overcome when all parties have a united, shared vision and are willing to work together."[21]*
  >
  > — Colleen Murphy, Project Director, National Institute for Children's Health Quality

- **Yamhill, Oregon** — *Yamhill Community Care* is both the Coordinated Care Organization (CCO) for the region under the Oregon Health Authority and the Early Learning Hub under the Department of Education.[18,19] CCOs are designed to coordinate Medicaid services for a geographic area. Early Learning Hubs are funded to bring together child-serving sectors in a region to improve rates of kindergarten readiness — in addition to providing early childhood services such as home visiting and supports for children experiencing developmental delays. Because both efforts are housed within a single backbone organization, the Yamhill CCO can more easily integrate data across sectors to target services to families and plan new initiatives. Yamhill CCO is currently working to ensure coordinated services across families based on need and building capacity for evidence-based whole-family interventions in each sector.[20]

SEC. 4. FREE TECHNICAL ASSISTANCE ON SHARING DATA

The U.S. Department of Education (ED) funds several programs that provide free technical assistance (TA) on data sharing. The resources listed in this section provide support for states and communities through online trainings, videos and presentations.

- **Protecting Student Privacy.** In addition to online trainings, ED offers an opportunity to request a training on FERPA, which may include FERPA as it relates to HIPAA and data sharing. Communities have a range of options regarding how to receive TA and the level of intensity, available on the *DOE website*.

- **Common Education Data Standards (CEDS).** CEDS is an initiative of ED that seeks to standardize different aspects of data collection and governance to improve integration and, ultimately, usability. CEDS also offers the opportunity to request assistance on its *main page*.

- **Statewide Longitudinal Data Systems (SLDS) Grant Program.** *SLDS* is funded by ED to assist states in better capturing longitudinal data on children. SLDS offers TA from the State Support Teams, which offer expert advice from states that have been leading data integration projects.

SEC. 5. CONCLUSION

Sharing data across the health, education and early childhood sectors can help to improve care coordination and ultimately promote healthy development and wellness for children and adolescents. Long-standing, trusting relationships built on shared goals, engaged champions, a solid data strategy, and dedicated resources help lay the groundwork for successful collaborations. While privacy laws can present challenges to data sharing across sectors, tools, templates and TA are available to help interested communities navigate these laws and achieve collective success. As communities continue to pursue transformative approaches to promoting health and well-being, whether through Accountable Communities for Health or other models, a greater focus on cultivating health during childhood and adolescence that involves cross-sector partnerships will be essential. Communities that have set forth on this journey can avail themselves of the tools and expertise that early innovators have developed in order to accelerate their progress and advance transformation.

APPENDIX

The following resources were compiled based on suggestions from key informant interviews,[5,6,21] input from members of the Collaborative on Accountable Communities for Health for Children and Families, and a scan.

General Data-Sharing Resources

- *All In: Data for Community Health Network*
  All In is a learning network of communities across the country that are testing new ways to systematically improve community health outcomes through multisector partnerships to share data. The network offers a variety of TA, including reports, toolkits, webinars, subject matter experts, and an online portal for additional discussion and peer learning.

- *All In: How and Why Communities Are Using Data to Drive Community Health Improvement*
  This chapter, *All In*, provides an overview of the All In network, which includes multisector data-sharing initiatives focused on reducing health disparities. It also includes insights and recommendations for using data included in the All In and Data Across Sectors for Health (DASH) databases to advance individual and community health.

- *Dashconnect.org*
  The Robert Wood Johnson Foundation launched Data Across Sectors for Health (DASH) to highlight the challenges and opportunities in connecting information systems and sharing data across sectors. DASH aims to support community collaborations in their efforts to address locally determined problems, implement health improvement activities through sharing data, and identify lessons that can be applied locally and shared with other communities.

- *Data Across Sectors for Health (DASH) and Network for Public Health Law (NPHL) Legal Resource Bibliography*
  This resource houses over 100 papers, toolkits, and other materials aimed at helping local organizations share data across sectors. Categories of resources include privacy, confidentiality, FERPA exemptions, data de-identification, informed consent and policy documentation.

- *Unlocking the Value of Data Sharing Series: A Look Across Five Sectors*
  This series of papers provides an overview and framework for reaching out to stakeholders or potential partners from other sectors that may share your interest in collaborating and sharing data to improve community health. Following the introduction, a series of five sector-specific papers provides more context on the incentives, challenges, and benefits of data sharing for a specific type of stakeholder within each sector.

- *The Integration of Early Childhood Data*
  The purpose of this report is to help states refine their capacity to use existing administrative data from early childhood (EC) programs to improve services for young children and families. It includes key considerations when integrating and linking EC data based on the best practices from the field and lessons learned from eight states that are actively engaged in developing integrated EC data systems.

- *U.S. Department of Education Privacy Technical Assistance Center*
  The Privacy Technical Assistance Center (PTAC) provides on-site technical assistance and/or presentations on privacy-related topics, including FERPA, at conferences or regional meetings. PTAC operates under contract with the U.S. Department of Education; all visits and presentations are provided free of charge. PTAC experts are available to meet in informal settings with state and regional school district and technology leadership to discuss K-12 privacy and data security concerns, and offer individual counseling regarding the privacy and security challenges districts are facing.

- *HIPAA or FERPA? A Primer on School Health Information Sharing in California*
  This resource guide provides information on navigating HIPAA and FERPA in school health programs, including school health centers, school-based mental health programs, school nursing services, and other types of health services delivered on school campuses.

- *HIPAA or FERPA? A Primer on Sharing School Health Information in Indiana*
  This primer provides an overview of the pertinent federal and state confidentiality laws when health care is provided on school sites and addresses frequently asked questions regarding sharing information.

- *Silicon Valley Regional Data Trust (SVRDT)*
  SVRDT brings together data from numerous public agencies that service children and families, including education (public school districts), public health, child and family services, mental health, juvenile justice/probation, and education technology companies. SVRDT provides a comprehensive understanding of factors contributing to student failure and success by applying advanced data analytics to create personal blueprints for students to clarify the factors in their lives that can improve the effectiveness of services and academic outcomes.

Tools and Templates

- *Model Consent Form for Families to Release Education Records (required by FERPA)*
  Sample consent form, in compliance with FERPA, drafted by the University of South Carolina.

- *A Model Agreement for School-Based Services*
  Sample agreement allowing the provision of school-based health services, in accordance with HIPAA and FERPA.

- *Data Sharing Toolkit* (starting on page 14)
  This document provides information about the language in federal regulations that allow school districts to share data for research purposes. It provides resources for school districts seeking to explore data sharing with program evaluators or third-party researchers.

- *School-Based Health Care Support Toolkit*
  This toolkit, created by the Ohio Department of Education, Ohio Department of Medicaid, Governor's Office of Health Transformation, Ohio Department of Health, and Ohio Department of Mental Health and Addiction Services, provides advice and resources to encourage the implementation of school-based health care.

- *How to Draft Successful Memorandums of Understanding and Data-Sharing Agreements*
  Public health research has shown that communities with cross-sector collaboration have better health outcomes among all their population. Improving and increasing cross-sector collaboration in public health can be facilitated by a memorandum of understanding (MOU). This chapter walks through the benefits, drawbacks, and examples of MOUs, as well as expands on the scope of services and terms and conditions of implementing MOUs.

- *Allegheny County Data Warehouse*
  This resource brings together client and service data from public human services data. Data sources include: behavioral health, child welfare, intellectual disability, homelessness and aging.

Case Studies

- *At the Intersection: Connecting Health and Education Data in School-Based Health Centers*
  This document provides information on the methods, challenges, and value of joining school-based health center data and education data to successfully improve health outcomes for children. Case studies show the successful or substantial implementation of this type of data integration.

- *Early Childhood Data Report*
  Best practices and lessons learned are detailed in cross-sector data-sharing initiatives of three areas: Indianola, Miss.; Ventura County, Calif.; and Philadelphia.
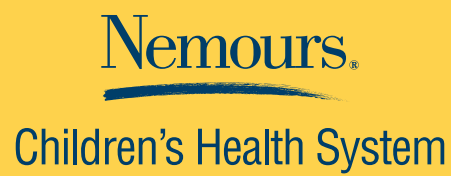
Measurement

- *Measuring Performance and Progress toward High Performing Medical Homes and Better Outcomes*
  This sourcebook includes a set of measures specifically designed to monitor high-performing medical homes for young children. These measures can be used under fee-for-service, managed care, or other financing arrangements for identifying and incentivizing such performance. The measures build on the Centers for Medicare and Medicaid Services Child Core set, with additional measures that relate specifically to the performance of medical homes for children in Medicaid and the Children's Health Insurance Program.

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