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Interagency, Cross-Sector Collaboration to
Improve Care for Vulnerable Children:
Lessons from Six State Initiatives

Research and Consulting in the Fields of Health and Human Services Policy, Health Economics
and Finance, Program Evaluation, Data Analysis, and Health System Restructuring

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ACKNOWLEDGEMENTS

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HEALTH MANAGEMENT ASSOCIATES

The HMA team is over 200 colleagues in 21 locations, with experience that spans the healthcare industry and stretches across the nation. Dedicated to serving vulnerable populations, we assist policymakers, providers, health plans and communities in navigating the ever-changing healthcare environment with a focus on making publicly funded programs like Medicaid and Medicare operate more effectively. With knowledge drawn from the front lines of healthcare delivery and reform, we work shoulder-to-shoulder as partners with our clients to explore innovative solutions to complex challenges.

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GLOSSARY OF ABBREVIATIONS

ACA: Affordable Care Act
ACO: Accountable Care Organization
CCO: Coordinated Care Organization
CDC: Centers for Disease Control and Prevention
CHCS: Center for Health Care Strategies
CHIF: Child Health Information Intake Form
CMMI: Center for Medicare & Medicaid Innovation
CMS: Center for Medicare & Medicaid Services
Council on Children and Families: The Council
CYSHCN: Children and Youth with Special Health Care Needs
DDS: Department of Developmental Services
DOC: Declaration of Cooperation
DOH: Department of Health
DPHE: Department of Public Health and Environment
DSHS: Department of Social and Health Services
DUA: Data Use Agreement
ECCS: Early Childhood Comprehensive Service
EL Hub: Early Learning Hub
EL: Early Learning
FERPA: Family Educational Rights and Privacy Act
HCA: Healthcare Authority
HCP: Health Care Program for Children with Special Needs
HCPF: Department of Health Care Policy and Finance
HIPAA: Health Insurance Portability and Accountability Act
HMA: Health Management Associates
HRSA: Health Resources and Services Administration
IAA: Interagency Agreement
IDEA: Individuals with Disabilities Education Act
MCH: Maternal and Child Health
MCHB: Maternal and Child Health Bureau
MCO: Managed Care Organization
MIECHV: Maternal, Infant, and Early Childhood Home Visiting Program
MIS/DSS: Management Information System/Decision Support System
MMIS: Medicaid Management Information System
MOA: Memorandum of Agreement
MOU: Memorandum of Understanding
MRT: Medicaid Redesign Team
NYS: New York State
OHA: Oregon Health Authority
PRISM: Predictive Risk Intelligence System
RCCO: Regional Care Collaborative Organization
SAMHSA: Substance Abuse and Mental Health Services Administration
SIM: State Innovation Model
VBP: Value Based Payment

I.   EXECUTIVE SUMMARY

There is growing acknowledgement that children and youth with special health care needs (CYSHCN) and other vulnerable populations can best be served through a coordinated approach across the myriad programs and agencies that touch them, including Medicaid, Public Health, Behavioral Health, Education/Early Learning, Human Services and others. However, states face structural, operational, financial, regulatory, and cultural challenges to breaking down traditional silos to achieve interagency, cross-sector collaboration.

Some states have made progress in overcoming these barriers, recognizing opportunities for state-level interagency collaboration and taking steps to address aspects of fragmentation and duplication of services for vulnerable children. Whereas most of the collaboration efforts examined here emerge from the health sector and focus specifically on CYSHCN, others are truly cross-sector and take a broader view of vulnerable children – with participants entering the collaboration through the "doors" of education, child welfare, mental health, juvenile justice, or labor and income supports.

This report describes six programs in five states that implemented collaboration mechanisms such as interagency councils and task forces, data sharing agreements, and new departments or full-time equivalents focused on fostering communication and coordination across programs for vulnerable children. Their achievements include: better identification of CYSHCN and more children/families with a shared care plan (Colorado care coordination data sharing pilot); "flagging" of CYSHCN for targeted outreach (Washington's CYSHCN cross-agency data system); increased health screening and dental visit form completion in public schools (D.C.'s data sharing across Education, Medicaid, and Health departments); a common developmental screening metric for health and early learning systems (Oregon's alignment of Health and Early Learning), a new interactive website for families of vulnerable children to navigate services across health, education, and human services (New York's Council on Children and Families), and a cross-sector ten-point plan for improving long term outcomes for young children enrolled in Medicaid (New York's First 1000 Days on Medicaid initiative).

While each state's environment and experiences are unique, common strategies and lessons across the programs studied suggest the following recommendations may help other states promote interagency collaboration:

- Inspire the Governor to launch a collaborative initiative as a statewide priority, establish cross-agency goals, and hold state agencies accountable;
- Select and nurture collaboration leaders with a broad view of 'health and well-being,' and the ability to foster relationships; consider cross-system leadership;
- Establish sustainable collaboration structures and resources (e.g., cross-agency council, dedicated staff, and technical advisory committee) through legislation, interagency agreements; tailor these tools and resources to the scope of the initiative, as narrowly targeted efforts require less new infrastructure and investment;
- When targeting CYSHCN, incorporate the family/youth/child voice on an ongoing basis, in conjunction with advocacy efforts that train and support families for participating in policy and program planning;

- Align with other state initiatives and federal grant opportunities; such efforts will leverage funding and be mutually reinforcing and more likely to gain broad support;
- Use robust project management techniques stressing transparency, inclusion, and realistic timelines;
- Establish common metrics, goals, and incentives across programs and agencies, with legal and technical guidance to facilitate data sharing and overcome obstacles;
- Build standards and requirements for collaboration into managed care contracts and other systems, with monitoring and consequences for non-compliance;
- Invest in and assist local collaboration activities, where service provisions actually take place.

More broadly, efforts are needed to expand the concept of "health and well-being" to promote greater collaboration across sectors, agencies, and programs, and better coordinated services for CYSHCN and other vulnerable populations and their families.

II.   CURRENT ENVIRONMENT

Lack of Coordination of Services for Children and Youth with Special Needs

Children and youth with special health care needs (CYSHCN) are served by a patchwork of public programs with different but often overlapping services, coverage regions, age bands, and eligibility criteria. Children with chronic physical, developmental, behavioral or emotional conditions require services from multiple programs, entities, and systems of care, including Medicaid, Public Health/Maternal and Child Health, Education/Early Learning, Social and Human Services, Mental Health and Substance Use, Foster Care, Criminal Justice, and others. Coordination and planning of care across the various programs is often limited due to the siloed nature of agencies that serve CYSHCN, created and reinforced by different policies and gaps or overlapping and unclear responsibilities, lack of uniform definitions or eligibility criteria, financial constraints, lack of communication channels across agencies, and lack of data sharing or connectivity between data collection systems.

These challenges often do not get adequate attention at the policy level because CYSHCN are a relatively small population with lower total costs compared with adults and the elderly—even though CYSHCN often have extensive individual needs, many being met by non-health public agencies. Further, management of childhood chronic or complex conditions may have a "return on investment" many years into the future, and therefore is often not viewed as a priority.[1]

Moreover, with states increasingly shifting "specialty" populations eligible for Medicaid from fee-for-service into managed care plans, there is the potential for better coordination or "management" of care. However, some families and advocates are concerned that in managed care CYSHCN may face restrictions on benefits and access to specialists with whom they've had long term relationships. State experience also demonstrates that transitions to managed care do not automatically result in enhanced coordination across the many medical and non-medical services CYSHCN often need.

Benefits of Interagency Collaboration and Federal Support

For CYSCHN and other populations with complex needs, cross-system collaboration and coordination have the potential to: reduce duplication and fill in gaps in services; promote a more holistic approach to addressing needs spanning different sectors; support families in navigating complicated systems and accessing services; leverage funding to pay for existing and potentially additional services; build capacity in the care system; and improve health outcomes, independence, and quality of life.

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[1] Breslin, K. (2017, Winter). Improving Children's Health by Focusing on Value. *Behavioral Health News*, 4, 32. Retrieved from http://www.mhnews.org/back_issues/BHN-Winter2017.pdf; and Bailit Health. (2016, July 13). Value-Based Payment Models for Medicaid Child Health Services (Rep.). Retrieved https://www.uhfnyc.org/assets/1503

> *"Cross-sector collaboration can increase efficiency and capitalize on natural networks and multidisciplinary interactions to improve service delivery and outcomes for clients."*[2]
>
> *Oregon Health Authority Handbook, 2017*

With a growing voice of families and advocates, a wide variety of federal requirements, initiatives, and grant programs have been implemented that promote state or local coordination and integration of services for children, some targeting specific subpopulations. Examples include:

- State Title V coordination agreements (Section 509(a)(2) of Title V of the Social Security Act and Section 1902(a)(11) of Title XIX[3]
- State Interagency Coordinating Councils required under the Individuals with Disabilities Education Act (IDEA) (20 USC §1441; 34 CFR §600-605)
- Title 42 of the United States Code Public Health and Social Welfare Section 438.208 on "Coordination and continuity of care" (42 CFR 438.208)[4]
- State Implementation Grants for Integrated Community Systems for Children with Special Health Needs
- Maternal and Child Health Bureau (MCHB) Early Childhood Community System development grants
- MCHB Family to Family Health Information Centers and grants
- Substance Abuse and Mental Health Services Administration's (SAMHSA's) Project Launch, Agency for Children and Families
- Early Childhood Comprehensive Service (ECCS) grants (funded by the MCHB since 2003)
- Affordable Care Act's (ACA) Section 2703 Health Homes
- Administration for Community Living/Center for Medicare & Medicaid Services (CMS) No Wrong Door systems[5]
- ACA's Maternal, Infant, and Early Childhood Home Visiting Program (MIECHV) to help state home visiting programs connect families to early education, early intervention, and health care services.[6]

Findings from federal programs to enhance coordination highlight the importance of: statewide planning and broad-based partnerships, aligning programs at the state and local levels, developing

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[2] Oregon Health Authority: Public Health Division. (2017, April). *The State of Collaboration: A Handbook for Cross-Sector Partnerships between Oregon's Coordinated Care Organizations and Early Learning Hubs*. Retrieved from http://www.oregon.gov/oha/PH/HEALTHYPEOPLEFAMILIES/BABIES/HEALTHSCREENING/ABCD/Documents/OHA-9410-HUB-CCO-Handbook-Final.pdf

[3] These provisions require that State Medicaid agencies enter into interagency agreements with their Title V agencies.

[4] This section delineates requirements for states to coordinate care through their contracts with managed care organizations (MCOs), including identification, assessment, and development of treatment plans for those with special health care needs.

[5] No Wrong Door. (n.d.). Retrieved from https://nwd.acl.gov/ and Medicaid. (n.d.). No Wrong Door System and Medicaid Administrative Claiming Reimbursement Guidance. Retrieved from https://www.medicaid.gov/medicaid/financing-and-reimbursement/admin-claiming/no-wrong-door/index.html

[6] Health Resources & Services Administration, Bureau of Maternal and Child Health. (2017, June). Home Visiting. Retrieved from https://mchb.hrsa.gov/maternal-child-health-initiatives/home-visiting-overview

metrics for measuring progress for the targeted populations, supporting engagement and leadership of participants and families in developing programs and policies, disseminating successful strategies, and adopting new policies for sustaining the changes.[7]

Despite efforts at the federal, state, and local levels, experts and family advocates report that actual integration across programs and agencies is uneven at best and highly variable across the states.

III.   STATE-LEVEL INTERAGENCY COLLABORATION

Purpose of Study and Methodology

The purpose of this study was to identify and examine promising state interagency efforts, and assess key ingredients, challenges, and lessons for other states. The objective is to promote collaboration across systems serving CYSHCN or other vulnerable populations that could reduce fragmentation and duplication of services, improve coordination of and access to needed services and supports, and ultimately improve health outcomes and contain costs.

To identify state interagency efforts, HMA conducted an environmental and literature scan[8]; and interviewed experts, advocates, and state officials (listed in Appendix B). Though not an exhaustive search or evaluation, the scan identified a number of examples with some apparent success though few quantifiable outcomes. In consultation with the Lucile Packard Foundation for Children's Health, six state programs representing diversity in state size, and in levels and scale of collaboration were selected for further study. HMA conducted structured interviews with state officials and advocates (listed in Appendix C), and reviewed websites, reports, and other relevant materials. HMA also interviewed individuals with state agency experience and advocates at the national and state levels to better understand barriers to collaboration.

A Closer Look at Six Cross-Agency Collaboration Efforts in Five States

The six programs examined for this study are delineated in Table 1 and individually profiled in Appendix A. The Colorado and Washington State programs focus specifically on CYSHCN; the program in the District of Columbia (D.C.) and the two in New York state are broader, targeting at-risk, low-income, and vulnerable children and youth participating in Medicaid and other public programs.

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[7] Clemmons, N., Friedrich, S., Segar, H., & Sprangers, K. (2013). *Impact Evaluation of the State Implementation Grants for Integrated Community Systems for Children with Special Health Needs* (Rep.). Retrieved from http://www.jsi.com/JSIInternet/Inc/Common/_download_pub.cfm?id=14231&lid=3
Family Voices. (2016, June). *Family-to-Family Health Information Centers Data Report* (Rep.). Retrieved from http://www.fv-ncfpp.org/files/9214/6770/7783/2014-2015F2FReport_06-27-2016-r.pdf
Johnson, T. (2017, September). *Improving Systems of Care for Children with Special Health Needs: Resources and Policy Options* (Rep.). Retrieved from http://www.ncsl.org/documents/health/ChildrenSpecialNeeds17.pdf
[8] This search was broader than programs for CYSHCN in order to identify strategies and lessons that could apply across populations and sectors.

TABLE 1. STATE PROGRAMS WITH INTERAGENCY COLLABORATION	
Colorado **Data Sharing Pilot for Care Coordination**	Data Use Agreement (DUA) among Medicaid, Health Departments and Regional Care Collaborative Organizations (RCOOs) piloted by the "Team 4C" cross agency collaboration that allows sharing of client lists to determine overlap between care coordination services for CYSHCN, and enables care managers to confer and better coordinate care
District of Columbia **Data Sharing for School Health Form Completion and Targeted Outreach**	Data sharing among the public schools, Medicaid, and the Health Department identifies gaps in well child visits and dental visits, and school health form completion; results in targeted outreach to families, directing dental care providers to high-need schools, and improved service coordination by Medicaid health plan care managers
New York **Council on Children and Families**	State-level council has authority to coordinate state health, education, and human services systems; mediates across agencies to address gaps or conflicting responsibilities, and staffs/facilitates monthly cross-systems meetings, Governor's Early Childhood Advisory Council, and special projects and programs
New York **First 1000 Days on Medicaid**	Medicaid-led effort, chaired by a state education leader, convenes many state agencies and stakeholders in four collaborative work group meetings between August and October 2017; goal is to develop agenda for enhancing access to services and improving outcomes and school readiness for young children on Medicaid
Oregon **Coordinated Care Organizations (CCO)-Early Learning Alignment**	The Oregon Health Authority and the Early Learning Division of the Oregon Department of Education (ODE) work closely to promote alignment for children 0-5, including a common developmental screening metric; a Child Systems Collaboration Coordinator facilitates coordination related to policy, measurement and technical assistance efforts across Oregon's regional CCOs, early learning hubs and public health systems
Washington State **CYSHCN "Flag" in State Data System**	A state Department of Health and Medicaid joint effort to better link local health department, Neurodevelopmental Center, maxillofacial review board and some newborn screening program data that can identify children with special health care needs (CYSHCN) to the Medicaid agency's Provider One system, creating a CYSHCN "flag" that is transmitted to MCOs and the state's web-based Predictive Risk Intelligence System (PRISM) care coordination support tool

Mechanisms/Models

State-level interagency collaboration can occur at the planning, policy, operations, and service levels. The selected states use a wide variety of mechanisms. Each program's approach is unique and varies in scope, structure, funding source, and other dimensions, but they also share many common elements, summarized in Table 2 below.

TABLE 2. KEY MECHANISMS FOR COLLABORATION	*Colorado* Data Sharing Pilot	*D.C.* Data Sharing for School Health	*New York* Council on Children and Families	*New York* First 1000 Days of Medicaid	*Oregon* Medicaid/Early Learning Partnership	*Washington* CYSHCN Flag in State Data System
Umbrella of Existing Legislation	X	X				X
New Legislation or Executive Orders			X		X	
Grant Award/ Federal Funding	X				X	X
Council/Committee	X	X	X	X	X	
New Department/Entity			X			
New Staff Position(s)			X	X	X	
DUA-Data Sharing	X	X				X
MOA/U	X	X			X	X
Advocate Participation			X	X	X	
Informal Staff Communication	X	X	X			X

New Entities for Collaboration

Ongoing or temporary interagency councils, work groups, committees (including Children's Cabinets) designed to promote coordination and alignment of services provided by the agencies that serve children can be broad or targeted in their roles, e.g., on kindergarten readiness, transitions for youth with disabilities, or individuals with developmental disabilities. These coordinating bodies may initiate or recommend other mechanisms listed below, such as development of common performance measures and incentives that promote working together to achieve goals. Shared metrics also establish a more holistic approach to children's health and well-being. Even without establishing a new entity, programs could share committee or program staff from multiple agencies, or two agencies could work together on a staff level to develop a shared enrollment process, data collection process, or individualized care plans.

Five of the six programs we examined involve a new or existing interagency commission or committee, ranging in size, type and frequency of meetings depending on the scope and duration of the effort they were undertaking. For example, Colorado's cross-agency "Team 4C" was a two-year pilot that generated ongoing medical home policy and collaborative data sharing strategies that other committees adopted and fit into the state's continuing medical home policy development. In contrast, New York's Council on Children and Families has been promoting cross-system coordination for decades as an independent state entity.

The councils and committees typically included high-level officials, such as agency/department heads or their deputies, or officials responsible for CYSHCN at their agencies. If these individuals could not attend all meetings, they were involved at the beginning of the effort to build credibility and momentum, and looped back in when necessary for decision-making at key points. Informants emphasized the necessity of having decision-makers involved to help projects progress and address any barriers as they came up. Informants described informal staff communication and existing staff relationships across the various agencies as important to achieving their goals. Colorado and Oregon have a staff position dedicated to liaising across departments and understanding the roles of various agencies and departments, as well as networking with specific staff.

Stakeholder Engagement
Advocates and families/Medicaid enrollees were more likely to be directly involved in broader, long-term state collaborative efforts, such as those in New York and Oregon, than in more narrowly-focused data-sharing collaborative efforts in Colorado, D.C. or Washington State. Advocates and state officials highlighted the benefits of advocacy organizations training family representatives so they are equipped to participate alongside agency staff in policy work that is sometimes technical and unfamiliar. Different entities in states, such as managed care organizations, accountable care organizations, and state agencies, may have different approaches to and levels of family engagement. Some have longstanding mechanisms and others create new ones if they establish a new entity for collaboration.

Funding Strategies
Though initial and sustained funding is always a challenge, there are a wide variety of potential funding strategies for collaborative efforts, including grant funding, state general funds, federal match for certain eligible activities, or user fees (discussed further below). There are also potential ways to combine funds from different federal agencies or programs into a single funding stream so they can be used more easily at the point of service delivery. Shared funding strategies include:

- Blended Funding – combining financial resources into a single pool for reimbursing providers;
- Braided Funding – combining financial resources from various sources to pay for a service package for an individual, with tracking and accountability for each resource maintained at the administrative level; the funds remain separate but are joined at the end of the "braid";
- Sequenced funding – in some states, agencies are learning to make effective use of multiple funding streams through strategic sequencing of resources available at the individual level and ensuring that the right resource is available at the right point in time, with the potential for shared outcome reporting.

Several collaborative efforts studied are funded by new sources such as a grant or federal match (e.g. for a specific change to the Medicaid Management Information System [MMIS] in Washington State). New York's Council on Children and Families receives staff funding through the Office of Children and Family Services division, with specific initiatives and programs funded through varied federal, state, public and private sources. For example, development of its Multiple Systems Navigator Website was funded primarily from the New York State (NYS) Developmental Disabilities Planning Council.

Narrower collaborative tasks (e.g., related to data sharing) were often accomplished using existing staff and considered to be within the parameters of their job descriptions. Blended and braided funding was not commonly used, and interviewees often felt there was too much administrative complexity and too many grant restrictions to make these strategies feasible at the state level.

Interagency Agreements (IAAs) and Data Sharing

Interagency agreements include Memoranda of Agreements (MOAs), MOUs, Cooperative Agreements, Declarations of Cooperation (DOCs), and DUAs between state agencies or programs. IAAs define roles and responsibilities, ongoing communication, exchange of information or payments, joint staffing or other activities. The scope and implementation of IAAs across states vary widely, from establishing a broad collaborative effort (and regional partnerships) in Oregon to detailing data-sharing processes in Colorado and Washington State.

The exchange of information across programs or agencies can help identify and refer individuals who would benefit from the reciprocal agency's services, help to coordinate care, or facilitate evaluation and program improvements. Such efforts may involve new information technology infrastructure, tweaks to existing systems, or steps as simple as regularly exchanging spreadsheets between agencies.

In several of the states examined (Colorado, Washington D.C. and Washington State), agencies engaged in data sharing, which they accomplished without making major changes to or investments in their information technology infrastructure. Existing state or federal-level legislation provided the rationale for the data sharing – Washington, D.C. and Washington State framed their efforts as necessary for compliance with the agencies' legal obligations to coordinate care for CYSHCN broadly (in Washington State) or to collect health data on all students (in Washington, D.C.). Staff revisited these requirements for care coordination or information sharing, including those that are decades old, and re-evaluated what they entail given the technological capabilities that states and health plans have today (discussed in further detail in the state profiles in Appendix A). While typically narrow in scope, the DUAs were effective in improving identification and care coordination for CYSHCN.

Interagency data sharing requires addressing privacy laws including Health Insurance Portability and Accountability Act (HIPAA), Family Educational Rights and Privacy Act (FERPA) and Informed Consent issues. In fact, data privacy concerns and interpretation of HIPAA and FERPA were a major topic of discussion and collaboration in the states studied. State agencies had different understandings of the public health departments' data capabilities and authority to obtain information from, as well as share individual or population-level health data with, the Medicaid agency, health plans, and other systems. Developing a shared understanding of what was possible under the laws and how all those involved would comply with them required frequent communication among staff, leadership, and lawyers. These issues were revisited often as data-sharing efforts evolved and when leadership or staff changes took place.

Motivation for Collaboration

We identified a number of motivating factors behind the collaborative efforts examined, summarized in Table 3. All programs were motivated by recognition of duplication and lack of coordination across

agencies and programs. Many noted the difficulties identifying CYSCHN (or others with unmet needs) due to fragmentation of services between county public health or behavioral health organizations and Medicaid managed care plans, and lack of data sharing between entities serving CYSHCN, resulting in children "falling through the cracks."

But the impetus for collaboration was typically some *new evidence* of either poor outcomes from lack of coordinated services, or renewed discussion of the interconnectedness of health, education, economic, and social factors and their impact on long-term and adult health and well-being. Leaders understood that the traditional organization and financing of services do not acknowledge and address these realities. For example, New York's First 1000 Days initiative grew out of a growing body of evidence—summarized in an influential 2016 report—that the early days of a child's life are critical for development; adverse early experiences dramatically affect lifelong health and social outcomes; and social determinants of health disproportionately affect poor and minority children.[9] New research highlighting the importance of early child development on long-term health outcomes was an impetus behind Oregon's efforts to build bridges between health care and early learning programs.

Most of the programs studied were built on momentum and alignment with broader state transformation movements. The First 1000 Days is one of approximately 400 distinct Medicaid Redesign Team (MRT) initiatives that are built on the momentum established by early MRT accomplishments and a robust stakeholder engagement process. While Health System Transformation in Oregon was creating regional entities (CCOs) that are given flexibility and tied to state-level accountability metrics, the state legislated a similar Early Learning regional structure and mandated collaboration between the systems at the local level.

Some collaborative initiatives were propelled by the Governor or Medicaid director championing the effort. Interviewees highlighted that governors can set the tone for collaboration across agencies, funding priorities, and expectations for alignment of agency goals, as well as take concrete steps to establish new cross-sector entities and initiatives. The more narrowly focused collaboration efforts relied more on existing relationships across agency staff to encourage and facilitate communication and cooperation.

Federal funding or federal requirements spurred collaboration in half the programs. Colorado received federal funding from the National Maternal and Child Health (MCH) Workforce Development Center for technical assistance, which the state determined would focus on a partnership between the health department and the Department of Health Care Policy and Financing (HCPF). State officials in Washington State viewed a decades-old federal mandate for Title V and Medicaid to share data as providing authority to use local health department data to help Medicaid health plans identify CYSHCN for care coordination and outreach.[10]

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[9] Bailit Health. (2016, July 13). Value-Based Payment Models for Medicaid Child Health Services (Rep.). Retrieved https://www.uhfnyc.org/assets/1503

[10] 42 CFR 438.208, *Coordination and continuity of care.* This section includes requirements that states "Share with other MCOs, PIHPs, and PAHPs serving the enrollee with special health care needs the results of

TABLE 3. KEY MOTIVATORS FOR COLLABORATION	*Colorado* Data Sharing Pilot	*D.C.* Data Sharing for School Health Forms	*New York* Council on Children and Families	*New York* First 1000 Days of Medicaid	*Oregon* Medicaid/ Early Learning Partnership	*Washington* CYSHCN Flag in State Data System
Evidence/recognition of poor outcomes, duplication, interconnectedness	X	X	X	X	X	X
Governor/Leaders spearheading Effort			X	X	X	
Agency staff relationships, willingness to partner	X	X		X		X
Federal program, funding, requirement	X	X				X
Task force/ committee recommendations			X	X	X	
Legislation – establishing goal, collaboration requirement or entity			X		X	
Momentum – alignment or part of larger state transformation movement, coverage or managed care expansion	X			X	X	X
Advocate Influence			X	X	X	

Barriers and Challenges

State interviewees described grappling with barriers to their collaboration efforts; some were overcome while others continue to be challenges:

- **Turf issues:** Interviewees cited difficulties bridging the historical divides between programs and their staffs. For example, public health and Medicaid agencies have parallel roles and responsibilities and serve the same or similar populations, yet have limited communication about shared goals or strategies for special populations, such as CYSHCN. Others noted the significant mismatch in size and influence between the Medicaid program (considered the "Goliath") and other, smaller agencies and programs that don't have sufficient funding to collaborate on an equal basis.

- **Lack of regional alignment:** In Oregon, the regional CCOs that coordinate Medicaid services and the Early Learning Hubs were not fully aligned across the state, which made partnerships more challenging in some regions. In contrast, the first Colorado RCCO (comparable to CCOs or

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its identification and assessment of that enrollee's needs to prevent duplication of those activities."

Accountable Care Organizations (ACOs) to participate in data-sharing had the same service area as the tri-county health department, which helped to facilitate collaboration.

- **Privacy concerns and different interpretations of rules:** Varying interpretations of HIPAA (among health agencies) and FERPA (between school systems and other agencies) delayed collaboration in some states examined. State agency staff view this as an opportunity for states or the federal government to help clarify and align interpretations of what data could be shared and how. Such clarification should also address advocates' concerns about informed consent to data sharing, the importance of information security, and the necessary training and resources for any personnel using the data.

- **Changes in administration and agency leadership:** Where governors and agency directors drove collaborative initiatives, changes in leadership made continuation of the efforts more challenging. With new state priorities, support and funding declined for some programs over time.

- **Federal funding restrictions:** Rules that limit how federal funds could be used posed a challenge in some interagency collaborative efforts, deterring participants from braiding or blending funding. Administrative complexity was also a factor limiting the use of federal funding in some cases. Meanwhile, other efforts fit well with existing streams of federal funding – for example, a change to the MMIS in Washington State qualified for enhanced federal Medicaid match, while also allowing that system to better align with local public health data to identify CYSHCN.

- **Data system incompatibility, expense, and policy hurdles:** New information technology infrastructure or major changes that require substantial alterations to MMIS or other systems are time- and resource-intensive, and in some cases, require legislation. Several states therefore focused on more incremental and low-tech changes (e.g., securely sharing a spreadsheet) when they pursued data sharing.

- **Lack of robust stakeholder engagement:** Data confidentiality and the technical nature of some collaborations were often the rationale for state agencies to not actively include family representatives in planning the initiatives. Some efforts to make technical changes to better identify CYSHCN were felt to be so narrowly targeted that a major stakeholder engagement process was not necessary. One state informant noted that limited engagement of racial/ethnic minorities has led to missed opportunities to reduce disparities in services and outcomes. In other states, interviewees praised advocates' efforts to train family members, so they could participate in cross-sector councils and advisory groups.

Accomplishments

The accomplishments of the study states' collaboration efforts varied in degree and form. While there were no specific metrics used to quantify the extent of collaboration or the impact on health outcomes, interviewees reported positive effects on interagency cooperation and coordination. Some projected that there may be measurable effects in the future.

Better Collaboration and Communication across Agencies to Address Gaps

The interagency efforts fostered collaboration and communication to help meet their respective goals. In Washington D.C., the collaboration among the public schools, health department, and Medicaid

agency developed a MOA based on the schools' statutory obligation to collect student health information, enabling them to share and match data to determine whether students who are covered by Medicaid have completed well-child medical and dental care visits and submitting their required school health forms. The process identifies not only children with incomplete forms, but also those who could benefit from outreach from their Medicaid health plans. The data-sharing promotes targeted outreach to families and to schools, enables the agencies to better direct contracted dental care providers to high-need schools, and identifies care gaps to be addressed by Medicaid health plan care managers. The health plans can more effectively plan health promotion and education events, and engage students at school-based health centers and through Head Start. Over a three-year period, the three state agencies doubled the number of complete and submitted health screening and dental visit forms to about 40 percent of health forms and 30 percent of dental forms. Interviewees acknowledge there is much work still ahead, however, and their goal is 100 percent completion.

The NY Council on Children and Families (Council) was charged with a broader task: coordinating state health, education, and human services systems to better serve children and families. The Council improved collaboration and communication across state agencies by convening commissioners, directors, and other key staffers in monthly cross-systems meetings, committees, workgroups, and advisory councils. With more than 40 years of history, the Council has been gradually breaking down the barriers to interagency communication and is a vehicle for child/family advocacy organizations to offer input and feedback to state agencies. Its achievements include reducing the number of out-of-state placements of children with high needs, mediating when two agencies cannot determine which one is responsible for children with complex needs, and developing a Multiple Systems Navigator website to help families who rely on multiple programs.

Following the release of the 10-Point Agenda comprising action steps, it is expected that the First 1000 Days on Medicaid effort will continue to implement at least some of the recommendations. The final agenda may include regulatory changes, managed care organization (MCO) contract modifications, and other areas affecting multiple departments and sectors.

Oregon achieved improved communication and coordination across its state early learning and Medicaid systems, as well as at the regional level between CCOs and Early Learning (EL) Hubs (see text box).

Portland, Oregon's CCO and EL Hub Partnerships

Working under three similar Memoranda of Understanding, the Coordinated Care Organization (CCO), Health Share of Oregon, and three Early Learning Hub (EL Hubs) covering the tri-county Portland Metro area meet monthly as a collaborative group and have successfully implemented many initiatives, including but not limited to the following:

1. *Developmental Screening: Children 0-3 receiving developmental screenings is a state-wide pay- for-performance metric for CCOs and a program requirement for all the early learning system partners. The CCO offers data to the EL Hubs to identify zip codes and school districts with low screening rates, which guides targeted outreach including working with through community parent groups. The CCO promotes developmental screening across its clinical delivery system, and multiple partners are working together to adapt and translate screening tools so they are more culturally appropriate and effective. Screening rates have improved.*

2. *Help Me Grow: As developmental screening rates increase throughout the region, the growing need for coordinated referrals will be met by the implementation of Help Me Grow, a national model that improves early life health outcomes by promoting screening practices across disciplines, identifying children at risk of delay, and linking families to services. This model is being implemented as a partnership between the CCO, Providence Health and Services, the three counties, and the leadership of each of the regional Early Learning Hubs*

3. *Early Kindergarten Enrollment: Ensuring that "children are ready for school and schools are ready for children" is recognized as important for long term health and education outcomes for children. Data indicated that in low-income communities, families often enrolled their children on the first day of school, making it difficult for schools to adequately prepare and to engage families in events supporting school readiness. A collaborative Kindergarten Enrollment Campaign included community outreach to talk to parents in various languages about the importance of enrolling their children early. The campaign was successful and the schools offer kindergarten "boot camp" to help children who did not attend preschool to catch up for kindergarten. The CCO shared these enrollment campaign messages across their networks to help the three EL Hubs reach wider audiences.*

Inclusion of Children and Families' Voices

Effective involvement of children and families and their advocates was a key accomplishment of some state efforts, particularly where new entity was established and charged with interagency collaboration. All states have active advocacy communities, and state agencies typically had various mechanisms for gathering family input but needed to create more opportunities for families to directly participate. The New York Council on Children and Families, for example, includes family and youth at regular meetings to help motivate state agencies, as well as identify challenges families experience while navigating multiple systems (see text box).

NY Council on Children and Families: Including Youth and Families at the Table

Authorized to foster cross-sector coordination, in 2007 Council staff organized a retreat for its member Commissioners representing a wide array of state departments and offices serving children and families. They also invited families and youth to "tell their stories" about the challenges navigating multiple systems. Based on what they heard, the Commissioners decided that families and youth would be partners in their ongoing work.

*The Council created a Senior Staff, Family, and Youth Partners Workgroup that includes state agency staff, family, and youth representatives and meets monthly to address cross-system challenges. The work evolved, and with a grant from the Developmental Disabilities Planning Council, it developed the web-based Multiple Systems Navigator tool (*http://www.msnavigator.org/)*, launched in 2016, which provides extensive resources spanning health and human services systems as well as information and support for families to use them.*
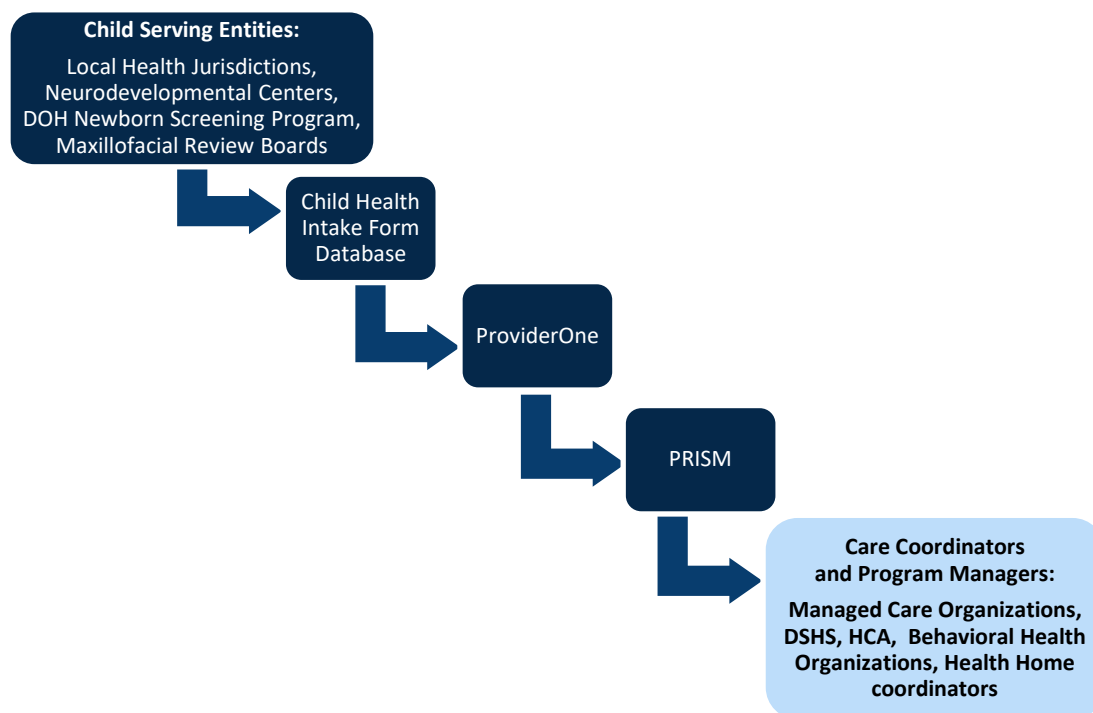
Developing and Improving Tools to Identify and Assist CYSHCN:

Across the various interagency models, states created and improved upon tools to identify and assist CYSHCN and better coordinate services. These tools included shared data identifying CYSHCN in Colorado and Washington State (see text box), and Oregon's Universal Referral Forms. The NY Council on Children and Families' Multiple Systems Navigator Website is an interactive tool that allows users to access health, education, human service and disability information for youth, family members, and caregivers to better navigate the various systems of care. States hope to build on these tools in future efforts.

The Colorado Department of Public Health and Environment (DPHE), HCPF – the Medicaid agency, Tri-County Health Department, and one of Colorado's RCCOs, effectively Medicaid ACOs, formed the Colorado Care Coordination Collaborative to better align the provision of care coordination services by various agencies and programs at the state and local levels. The participants developed a DUA that allows them to share client lists (via Excel spreadsheet rather than a new IT system) to determine overlap between care coordination services the programs provide to CYSHCN. The number of Medicaid enrollees with a shared care plan between a family and one other entity (e.g., the MCO or county health department) increased from 40% to 82% over five quarters.

Washington: Linking CYSHCN Flag to Predictive Risk Intelligence System (PRISM)

The state Department of Health (DOH) worked with the Medicaid agency (HCA) and the Department of Social and Health Services (DSHS) Research and Data Analysis (RDA) division to better link local health department data that can identify CYSHCN to the Medicaid agency's Provider One system, creating a CYSHCN "flag" that is then transmitted to the state's web-based PRISM data system and MCO data systems. Washington built on the state's existing data sharing agreements that underlie its extensive PRISM data system. The Medicaid program and care coordination staff at MCOs, behavioral health organizations, and others can access PRISM, a web application maintained by DSHS. Identifying CYSHCN enables all who use to the system to better leverage the web application to support care coordination for high-risk Medicaid enrollees.

Child Serving Entities:
Local Health Jurisdictions,
Neurodevelopmental Centers,
DOH Newborn Screening Program,
Maxillofacial Review Boards

Child Health
Intake Form
Database

ProviderOne

PRISM

**Care Coordinators
and Program Managers:**

**Managed Care Organizations,
DSHS, HCA, Behavioral Health
Organizations, Health Home
coordinators**

Source: Washington State Department of Health, September 2017

Sustainability and Next Steps

Recognizing that there are constraints on staffing, resources, and political capital, agencies sought to develop models that were sustainable. In some cases, they established the initiatives using existing budgets and staff, in other cases the programs are funded through a variety of grant and state program sources that must be renewed or replaced over time. All of the programs studied are planning next steps, including the following.

Increasing Use of and Improving Existing Tools to Identify CYSHCN

States that developed tools to better identify CYSHCN are focused on improving these tools and increasing the numbers of individuals utilizing them. In Washington State, both the health and Medicaid agencies intend to build upon and increase utilization of data from its PRISM system. This includes meeting with Medicaid health plans to discuss how they use the CYSHCN flag and exploring other ways to use data from PRISM.

The collaborating partners in Washington, D.C., outlined further steps toward the goal of collecting completed health screening and dental visit forms, including minimizing the administrative burden on providers. The agencies would like to implement an electronic submission process or portal in which providers can complete and submit the forms at visits rather than having the parents and students submit the forms.

As the New York Council on Children and Families' Multiple Systems Navigator Website is fairly new and the public is not fully aware of its capabilities, the Council intends to increase awareness of the tool among families, social workers, and care coordinators through outreach in the form of presentations, webinars, conferences, and local libraries.

Increasing Collaboration and Building on Programs

States that established new entities to foster collaboration among agencies intend to expand their programs. In Oregon, the state will further align the CCOs and the EL Hubs and connect them to the local public health systems. Working with the Office of Health Analytics and the state's Transformation Center, the Child Systems Collaboration Coordinator plans to expand technical assistance and implement kindergarten readiness measures, and identify linkages in early childhood metrics across the systems. Colorado intends to build upon its pilot and replicate it across the remaining RCCOs by embedding the program within the Title V Medical Home. There are now five public health agencies working on that project, three of which have agreements in place with their RCCO; one is becoming a delegated practice and the other is in the process of negotiating an agreement. While the cross-agency committee disbanded in late 2016, a subset of the participants formed a Title V policy workgroup that continues to work to improve internal systems and processes to support shared care plans among all entities involved in coordination patient care. Findings from the pilot have also contributed to broader efforts in the state on medical homes, State Innovation Model (SIM), and behavioral health/primary care integration, which will be a feature of new regional care collaborative entities that the state is developing to replace RCCOs.

Lessons: Key Ingredients for Collaboration

Key factors that contribute to successful collaboration, based on the six programs' experiences, are summarized in Table 4.[11] (While there is some overlap with the "motivating factors" discussed above, here we focus on ingredients for ongoing collaboration.) Sustainable structures, such as state legislation,

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[11] Defining successful collaboration was primarily based on program-specific process outcomes and key informants' input. None of the programs tried to isolate and measure the impact of the collaboration aspect of their initiatives. Lack of measurable outcomes for CYSHCN further precluded quantitative assessment of success.

commitment of resources, and establishment of cross-agency committees, were deemed essential factors in all six programs examined. Some type of interagency agreement to share data, with common metrics and goals, played a critical role in most of the programs. Other ingredients that were essential to establish and sustain the collaborative efforts are: state directives and/or assistance to collaborate across systems at the regional or local level (such as data sharing or leveraging/sharing resources); strong leadership and buy-in from "above" (e.g., Governor, Medicaid director) and "below" (e.g., state agency staff, families and advocates); and effective project management techniques emphasizing transparency and realistic timelines and goals.

TABLE 4. KEY INGREDIENTS/FACTORS FOR SUCCESSFUL COLLABORATION	*Colorado* Data Sharing Pilot	*D.C.* Data Sharing for School Health Forms	*New York* Council on Children and Families	*New York* First 1000 Days of Medicaid	*Oregon* Medicaid/ Early Learning Partnership	*Washington* CYSHCN Flag in State Data System
Governor as champion - Setting priority, accountability, influence over agency directors ("trickle down")			X	X	X	
Sustainable structures - State requirements or reinterpreting federal requirements - Commit resources/funding - Cross-agency (or neutral) committees/ councils with ongoing communication, full-time equivalent devoted to collaboration -Established through legislation or other mechanism	X	X	X	X	X	X
Interagency agreements -MOU, data sharing agreements -Legal guidance on interpretation of privacy rules - Needs monitoring and enforcement to be effective	X	X			X	X
Common metrics and goals - Shared measures and objectives - Incentives to meet shared goals	X	X		X	X	
Relationships, leadership, buy-in, willingness to partner - Leaders promote buy-in from above and below, using evidence of interconnectedness - Agency staff connections - Medicaid, as largest player, sets agenda and brings resources	X	X	X	X	X	
Alignment with and building on other state efforts -Leverage and build on other state programs or initiatives, federal funding opportunities	X		X	X	X	X
Project management techniques - Transparency, communication - Realistic goals and Timelines			X	X	X	
Strong stakeholder/advocacy engagement -Incorporation of family/youth/child voice on ongoing basis			X	X	X	
Local implementation and Buy-In - Shared local activities - Shared resources/funding easier at local level	X	X	X	X	X	X

IV.   RECOMMENDATIONS TO STATES

The common themes, strategies, and lessons across the programs examined can be translated into recommendations to other states wishing to strengthen cross-sector collaboration to improve services for CYSHCN and other vulnerable populations.

Governor should establish collaboration as a state-wide priority with cross-agency goals and hold agencies accountable.

To become a priority and have greater chance of success, a collaborative initiative should: be championed by the Governor, specify high-level goals that require collaboration from multiple agencies, and hold agency leaders accountable to the Governor's office for achieving those goals.

Select and nurture collaboration leaders with a broad view of 'health and well-being' and ability to foster relationships; consider cross-sector leadership.

Selection of individuals to lead the initiative should be based on: demonstrated commitment to a collaborative approach and reaching across sectors; ability to foster relationships and promote buy-in among staff and stakeholders; and an understanding of the multiplicity of factors and programs affecting the health and well-being of the targeted population. Staff who have family members who are CYSHCN are both knowledgeable about the challenges facing families, and may be particularly suited to build connections across agencies.

The state Medicaid agency, as the "biggest player" with the largest budget, could set the agenda and provide resources, while inviting leaders and participants from other sectors. New York's Medicaid-led First 1000 Days initiative selected an Education leader to chair the collaborative effort, ensuring cross-sector participation and input. Planners and advocates should also highlight the growing body of evidence on the social determinants of health, the return on investment of taking a holistic approach to addressing complex needs, and the benefits of leveraging resources to meet mutual goals.

Establish sustainable structures and resources for collaboration through legislation and interagency agreements.

The following types of state-level mechanisms and supports could help to implement and sustain collaborative efforts:

- Legislation establishing the program/initiative that relies on or requires collaboration across agencies and departments;
- MOUs or other type of interagency agreement among different agencies specifying the roles, responsibilities, and mechanisms for coordination, resources and directives for monitoring adherence;
- A cross-agency committee or council with specific goals, timelines, and regular meetings to ensure ongoing communication and promote coordination; a technical advisory committee could support implementation;

- A designated full-time equivalent, preferably with staff, whose sole responsibility is to facilitate cross-sector collaboration.

Table 5 provides links to sample MOUs that have been developed or used to promote collaboration in serving vulnerable children and youth. The authors do not endorse any particular sample, but suggest that state planners of the relevant agencies or programs examine existing MOUs, seek legal counsel, and tailor an appropriate MOU to meet their needs and goals. More narrowly targeted efforts require less new infrastructure and investment.

TABLE 5. SAMPLE MOUs	
California: Template for Memorandum of Understanding between [Plan] and [County] California Children's Services (CCS) Whole Child Model Program, 2017	http://www.dhcs.ca.gov/services/ccs/Documents/WCM_MOU_Template_111917.pdf
California: Model Health Care Program for Children in Foster Care Memorandum of Understanding, 2000	http://www.dhcs.ca.gov/services/HCPCFC/Documents/Section1.pdf pages 9-12
Oregon OHSU: Sample MOU for the Provision of Services and Referrals Related to the Child Health Team	https://www.ohsu.edu/xd/outreach/occyshn/programs-projects/upload/MOU-Template-Child-Health-Team.pdf
Texas Department of Assistive and Rehabilitative Services and the Texas Education Agency: Early Childhood Intervention MOU, 2014	https://tea.texas.gov/WorkArea/DownloadAsset.aspx?id=25769805534
Iowa Head Start and Iowa Department of Education: Interagency Memorandum of Understanding, 2002	https://www.educateiowa.gov/sites/files/ed/documents/MOU%20Early%20Child%20Special%20Education.pdf
North Dakota: MOU Concerning Cooperation and Collaboration in Providing Services to Students with Disabilities Ages 16-21, 2011	https://www.nd.gov/dpi/uploads/63/MOU.pdf

When targeting CYSHCN, incorporate and support the family/youth/child voice on an ongoing basis.

Family members and advocates should be included as partners and committee members in planning, implementation, and monitoring. The beneficiary voice at the table can ensure that the interests and needs of CYSHCN are represented and remain central in both targeted and broader health and early childhood activities. The states studied noted the importance of family participation and efforts to provide support and training for family representatives to be effective participants. Though families of CYSHCN often have extensive experience with and understanding of the systems they have navigated as part of their children's care, they may not be familiar with the operational, technical, or policymaking processes involved in interagency collaborative efforts. Families participating on advisory groups and councils should also receive payment for their time, and reimbursement for expenses, such as travel and childcare.

Align with other state initiatives and leverage federal funding opportunities.

Aligning with or building interagency collaboration into other state priorities accelerates and promotes buy-in, funding, implementation, and sustainability. Coordination of services for CYSHCN across programs, for example, could be framed as part of broader state Medicaid expansion or transformation initiatives or data modernization activities.

Service integration efforts could also leverage federal grant opportunities, and in fact federal grants drove collaboration efforts in some programs examined. For example, Oregon's collaboration efforts were supported by Center for Medicare & Medicaid Innovation (CMMI) State Innovation Model (SIM), Early Childhood Comprehensive Systems (ECCS) and Race to the Top, Early Learning Challenge grants. The NY Council on Children and Families' ECCS Impact Initiative was also funded through a grant from the Health Resources and Services Administration, Maternal and Child Health Bureau (MCHB); its Head Start Collaboration Project was supported by the federal Office of Head Start. Colorado's technical assistance for data sharing was supported by the National MCH Workforce Development Center.

Federal programs supporting value-based payment (rewarding better outcomes) and addressing social determinants of health could support state cross-sector initiatives. MCHB Family to Family grants and federally funded State Councils on Developmental Disabilities could support training for CYSHCN families on advisory councils and cross agency collaboration.

Use robust project management techniques stressing transparency and inclusion.

Successful interagency and cross sector initiatives require inclusive and transparent project management, with realistic goals and timetables. Regularly scheduled and frequent communication across designated staff from the relevant departments should be frequent and ongoing. Broad input from stakeholders can facilitate a true collaborative process. For example, stakeholder engagement is a foundational management process for New York's MRT activities; staff intentionally invite and incorporate feedback into program development. Project management work plans, slides and minutes from meetings with stakeholders are publicly available and additional input is invited and taken seriously.

Establish common metrics, goals, and incentives, with legal and technical guidance to facilitate data sharing.

Existing or new data sharing or data use agreements between agencies and programs provide guidance for information exchange that can help identify CYSHCN, gaps in services, and opportunities for coordinated outreach and care management. Legal guidance should be sought to find agreement across agencies on interpretation of HIPAA and FERPA privacy rules. At the same time, states should acknowledge and address families' interest in being informed about data sharing across systems and their concerns about signing blanket consent documents allowing information flow across agencies.

There is room to be creative in interpreting federal requirements or addressing technical challenges. For example, Washington State's shared PRISM database is a relatively low-cost, web-based alternative to

an integrated electronic health record and in some ways (e.g., home and community-based services assessments, other non-health data) has more potential to capture a wider range of variables. Public health departments, Medicaid, and Regional Care Collaborative Organizations in Colorado's DUA that allowed them to share client lists—via relatively simple Excel spreadsheet rather than a new IT system—to determine overlap between care coordination services the programs provide to CYSHCN. This allows care managers serving children to communicate to better coordinate care.

Technical assistance should be built into all data sharing efforts. To the extent agencies/programs can share data, states can work toward establishing similar metrics and goals across programs or sectors. A New York Medicaid planning process first identified long term goals and then stepped back to establish a cross-sector framework with shared metrics and goals including some outside of the traditional health care-oriented goals. In Oregon, a Medicaid incentive metric for Developmental Screening was adopted as a program requirement for Early Learning Hubs. The financial incentive, Pay for Performance, to conduct developmental screenings encourages Medicaid CCOs to collaborate with the Early Learning Hubs and other systems to identify and reach out to the targeted population. However, additional work is needed in developing and adopting core sets of indicators to measure processes and outcomes around health and family well-being.

Build guidance and stronger requirements for coordinating services into managed care contracts and other systems.

States can build stronger requirements or incentives into Medicaid managed care contracts regarding health plans' care management and coordination with other systems. For example, some Medicaid health plans' care managers attend Individualized Education Plan or 504 planning meetings[12] and participate in coordinating transitions of care between facilities or programs, even if not involving medical services. Through contract language and pay-for-performance incentives, states could expand these practices to become the norm. Similarly, regional early learning entities could be required to collaborate across multiple systems, as in Oregon. Importantly, adherence to these requirements must be monitored, with consequences for non-adherence.

States that transition this population to managed care must monitor it closely to assess the impact on CYSCHN and to identify gaps as well as best practices for ensuring continuity of care, coordination of care and access to specialists. Effective strategies could be incorporated into both MOUs between agencies, and managed care contract standards.

Invest in and assist collaboration activities at the regional and local level.

Because service provision and coordination occur at the local level, states should provide guidelines and technical assistance to local agencies to promote shared local activities, communication, and cross-system learning, while also allowing some flexibility to innovate. In some cases, states can encourage

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[12] Section 504 of the Rehabilitation Act of 1973 is a civil rights law enumerating protections for individuals with disabilities, including in schools. Students who qualify under the law must have a 504 plan detailing how their school district will make accommodation. Students who qualify under the more stringent IDEA are eligible for special education services and must have an individualized education plan instead.

and facilitate shared governance, risk-assessments, common forms, and potentially blended funding and shared staff at the regional or local level.

Recommendation Checklist

❐ *Use the transition to managed care as an opportunity to address fragmentation and test effective strategies*
    ❐ *Build guidance and requirements for collaboration into managed care contracts and other systems*
❐ *Enhance engagement with stakeholders and seek executive and legislative support*
    ❐ *Governor should establish collaboration a state-wide priority with cross-agency goals and hold agencies accountable*
    ❐ *Select and nurture collaboration leaders with a broad view of 'health and well-being' and ability to foster relationships; consider cross-sector leadership*
    ❐ *Establish sustainable structures and resources for collaboration through legislation and interagency agreements*
❐ *Align and build on other initiatives and infrastructure*
❐ *Leverage federal funding opportunities*
❐ *Structure efforts at multiple levels*
    ❐ *Invest in/assist collaboration activities at the local level, where services are delivered*
❐ *Support and train families to participate in health plan and statewide advisory committees*
❐ *Assess opportunities to coordinate Health and Education*
❐ *Use robust project management techniques stressing transparency and inclusion*
❐ *Establish common metrics, goals, and incentives, with legal and technical guidance to facilitate data sharing*
❐ *Conduct activities for state staff to learn from other agencies and other states*

Conclusion

There is growing acknowledgement that CYSHCN and other vulnerable populations can best be served through a coordinated approach across myriad programs, agencies, and levels of government that touch them. Various federal initiatives and grant programs encourage a more holistic approach, offering flexibility to promote integration of behavioral and physical health, or to address social determinants of health.[13]

However, states face structural, operational, financial, regulatory, and cultural challenges to breaking down traditional silos to achieve interagency, cross-sector collaboration. Some states have made progress in overcoming these barriers, implementing mechanisms such as interagency councils and task forces, data sharing agreements, and new departments or full-time equivalents focused on bridging or

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[13] Olson, S. (2015). *Proceedings for the 2015 Symposium: Designing Systems That Work for Children with Complex Health Care Needs* (Rep.). Retrieved
http://www.lpfch.org/sites/default/files/field/publications/symposium_proceedings.pdf

filling gaps across programs. Their achievements include: less duplication and more children/families with a shared care plan (Colorado), identification of more CYSHCN for targeting/outreach (Washington State), more health form completion and dental services in schools (D.C.), a common developmental screening metric for health and early learning systems (Oregon), a new interactive website for families to navigate services across health, education, and human services (New York), and a ten-point plan for improving long term outcomes for young children enrolled in Medicaid (New York).

Examining these promising state examples has uncovered both unique and common strategies, accomplishments, and lessons. Though each state has a unique environment and dynamics, the recommendations presented here could be considered and adapted by other states. They could help shape future state policies and activities toward more effective and high-value systems of care and improved health outcomes for CYSHCN and other vulnerable populations.

Despite progress in some states, greater efforts are needed to expand the concept of "health and well-being," develop metrics to measure process and outcomes, and eliminate the barriers to true coordination of services for CYSHCN and other vulnerable populations, and their families.

APPENDIX A: STATE COLLABORATION CASE STUDIES

1. Colorado: Data Sharing Pilot

Data sharing pilot to better align care coordination efforts for CYSHCN among Medicaid, Health Departments and Regional Care Collaborative Organizations

Model or mechanisms: Data sharing pilot for CYSHCN among Medicaid, Health Departments and Regional Care Collaborative Organizations as part of the Colorado Care Coordination Collaborative (Team 4C)

State/Local Agencies: The Colorado Department of Public Health and Environment (DPHE), Health Care Policy and Finance (HCPF – the Medicaid agency), Tri-County Health Department, and one of Colorado's Regional Care Collaborative Organizations [(RCCOs, effectively Medicaid Accountable Care Organizations (ACOs)]

Motivation: Better align care coordination efforts among the state and regional entities providing services to CYSHCN

Accomplishments: Developed a Data Use Agreement (DUA) to share client lists to determine overlap between care coordination services the programs provide to CYSHCN, allowing care managers to communicate and better coordinate care.

Challenges: Aligning agencies' interpretations of HIPAA to make the data sharing possible

Lessons: Importance of organizations' willingness to partner and provide input, and collaboration at all levels – state, local, and provider—rather than top-down requirements

The Colorado Department of Public Health and Environment (DPHE), Health Care Policy and Finance (HCPF – the Medicaid agency), Tri-County Health Department, and one of Colorado's Regional Care Collaborative Organizations [(RCCOs, effectively Medicaid Accountable Care Organizations (ACOs)], formed the Colorado Care Coordination Collaborative (Team 4C) to better align the provision of care coordination services by various agencies and programs at the state and local levels. Medicaid, Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) and the state Health Care Program for Children with Special Needs (HCP)[14] program, which provides services to some children and youth with special health care needs (CYSHCN) through local health departments, all provide services to children who need care coordination, but without necessarily coordinating across programs. As part of this effort, the participants developed a Data Use Agreement (DUA) that allows them to share client lists (via Excel spreadsheet rather than a new IT system) to determine overlap between care coordination services the programs provide to CYSHCN. This allows care managers serving children to get in touch to better

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[14] HCP was formerly called the Health Care Program for Children with Special Needs. Located within local public health agencies throughout the state, HCP programs use nurse-led teams with special knowledge of the needs of medically complex children to provide care coordination, resources and access to specialty care, regardless of diagnosis or income. Most services are provided at no cost to families.

coordinate care. The Collaborative ended in late 2016, but the data sharing and resulting care efforts to better align coordination have continued to build on the pilot.

Collaboration Model and Mechanisms

- **State Agencies involved**:
  - DPHE (the state-level agency and the HCP program specifically for CYSHCN), HCPF and its contractors, RCCOs (primarily Colorado Access).
  - DPHE operates the Title V Maternal and Child Health (MCH) block grant, which was one of the funding sources for this effort.
  - The entities formed Team 4C, a two-year pilot program, to solidify the collaboration.
- **Non-state agencies involved**:
  - The Tri-County Health Department, which serves more than 1.4 million residents in part of the Denver metropolitan area and uses Title V funds to provide HCP care coordination services to CYSHCN
  - RCCOs including Colorado Access and others, which receive per-member-per-month payments to provide care coordination to their members. The RCCOs are in the process of a state re-procurement that will create Regional Accountable Entities that integrate physical and behavioral health.
- **Positions:**
  - No positions were added to state agencies or other participants – existing staff participated in these activities in addition to their regular duties.
- **Data Use Agreements**
  - The participants developed a DUA that allows them to share client lists for children enrolled in Medicaid who are receiving care coordination (via Excel spreadsheet rather than a new IT system) to determine the overlap between care coordination services provided by the programs. Previously, 60% or 70% were receiving duplicated services by multiple agencies, largely without shared care plans across entities. The goal was to develop policies and processes to better communicate across entities to optimize the use of resources and reduce duplication of services.
  - The partners intentionally did not initially specify exactly which data fields would be shared. This needed to be worked out among participants as the data agreement was developed, based on interpretation of Health Information Portability and Accountability Act (HIPAA) by both the state agencies and the other entities involved.
  - No legislation or executive action was necessary, but could be in the future if data sharing or other activities expand.
- **Committees, Structures**
  - The collaborative operated primarily through a 12-person committee representing all participants that met monthly in person. Participants had varying roles at their agencies and organizations, but by design the committee included staff who were senior enough to have decision-making authority and participants who would be responsible for implementation at their respective organizations.
- **Communication**:

- o The committee held monthly meetings, which were not open to the public, and participants communicated outside these as needed.
  - o **Leadership across agencies –** The committee included staff who were high-level enough to make decisions during the meetings, to break through any logjams. It did not include the directors of the RCCO and the public health agency in the beginning. However, they were subsequently added.
  - o **Local level engagement** – Local health departments, RCCO, and contractors participated in all meetings. Once data sharing began, care coordinators could contact each other to discuss specific care plans for patients. The group instituted case conferencing sessions to discuss shared clients and identify opportunities for systems improvements (for example, using a care plan to clarify roles).
  - o **Family engagement –**
    - ▪ RCCOs have family advisory committees, which are made up of Medicaid members who provide guidance and input into policy and procedural work.
    - ▪ Local Public Health departments have trained family leaders, who go through a family leadership training institute. They are involved in the delivery and policy around care coordination.
    - ▪ Youth advisors employed by the health department engage other youth around services for CYSHCN.
- **Data sharing –**
  - o Medicaid contracts with the RCCOs across the state, but does not specify that the RCCOs have to use the same data systems. RCCOs have their own data systems, so the opportunity to share state-level data is limited to the state health information exchange. Local public health departments are not currently sharing information with the HIE, though a pilot has been established with one local agency to identify opportunities to do so. There was an obvious need to increase data sharing across these parties for enrollees who need care coordination.
  - o The parties developed a DUA that allows them to share client lists (via Excel spreadsheet rather than a new IT system) to determine overlap between care coordination services the programs provide to CYSHCN.
  - o Future efforts will explore further data sharing opportunities as part of efforts to enhance care coordination and reduce duplication of services among the many entities that serve CYSHCN, such as broader Data Use Agreements.
- **Funding arrangement** – The Health Department receives the state's maternal and child health block grant (Title V) funding. It is required to spend 30% on the CYSHCN population, of which this effort is part.
  - o Some state general funds for CYSHCN are also used, though a specific breakdown was not available.
  - o The funding is not "braided" across agencies, but participants would consider the funding braided within agencies.
  - o Colorado received federal funding from the National MCH Workforce Development Center to receive technical assistance, which was used for the interagency partnership.

Motivation and Development

- Colorado decided the technical assistance funding would focus on a partnership between the health department and HCPF. Medicaid was providing care coordination services for all Medicaid members within each region through contractors. HCP, the statewide program that provides care to CYSHCN at a variety of income levels, also provides such services to people under age 21. Three quarters of children being served by HCP were already enrolled in Medicaid, and others were eligible for Medicaid. This was an opportunity to align services and roles, referral systems, responsibilities and explore how to share information.

- The partners established the Colorado Care Coordination Collaborative, a collaboration between HCPF, DPHE (at state and local levels), and Colorado Access, one of the RCCOs, in 2014. It incorporated state-level entities and local implementation, with the Tri-County Health Department serving as the local implementing entity. It serves more than 1.4 million people in Adams, Arapahoe and Douglas Counties – a substantial part of the Denver metropolitan area.

- Tri-County and Colorado Access served a high-population area that overlapped almost perfectly, making it a promising area for the pilot. For two years, they piloted how to align care coordination services across Medicaid, health departments, and HCP. The collaboration included developing a DUA across the RCCO and Local Public Health Departments to share information on the clients who were receiving care coordination services across the three programs.

Barriers and Challenges

- The DUA template was provided by Colorado Access, and the participants worked to align their interpretations of HIPAA and make the data sharing possible. Public health departments, the Medicaid agency and RCCOs had different interpretations of what was permissible. Developing agreements using the Public Health Authority, with which other participants had limited experience, required working through differing approaches and perspectives on data sharing and how agreements could be developed. Public Health Authority is designated in statute and the state board of health further defined the core public health services for Colorado, guiding the agencies' role across the state. Local health departments that were Covered Entities (health care providers that already comply with HIPAA requirements for electronic data exchange) were more prepared to participate. This highlighted the importance of establishing—and sometimes renegotiating—shared understanding of the law.

- Significant work was required at the beginning of the partnership to engage local partners that may not typically be engaged with state level policy efforts and prepare them to participate. DPHE used its implementation framework to create a readiness tool to help partners identify whether they were ready to implement the data sharing. This was very helpful to support self-assessment.

Accomplishments

- As part of broader medical home policy efforts in the state and as a result of this collaboration, participants are more focused on connecting care coordinators to one another and finding ways to monitor coordination and its effects on outcomes. The data sharing allowed them to identify

specific patients whose care should be better coordinated, as well as barriers to better coordination at the most granular level.

Next Steps and Sustainability
- The sustainability plan is to embed the program in Title V Medical Home work to maintain the partnership and replicate the process more broadly among RCCOs. Title V and state general fund funding will be used. The state used the pilot to develop the strategies for its MCH Medical Home priority work (under Title V). There are now five public health agencies working on that project, three of which have agreements in place with their RCCO, while one is becoming a delegated practice and the other is in the process of negotiating an agreement.
- While the committee disbanded in late 2016, a subset of the participants formed a Title V policy workgroup, which continues to work to improve internal systems and processes to support shared care plans among all entities involved in coordination patient care.
- Findings from the pilot have contributed to broader efforts in the state on medical homes, State Innovation Model (SIM) and behavioral health/primary care integration, which will be a feature of new regional care collaborative entities that the state is developing to replace RCCOs. Many stakeholders and efforts are looking at how to do whole-person care, so this was a timely effort.
- The desired next steps are to get to a point where they can collect data to show the clinical impact of care coordination, which payers will want to know even more in the new, highly integrated environment.
- The participants have maintained the partnership at Tri-County and now five large Local Public Health Agencies are working with their RCCOs to develop Data Sharing Agreements. They look at the pilot's policy and process for communication, referrals and sharing data. This process has also been expanded to children's primary care clinics (which are delegated practices of their RCCO) to further align care coordination for CYSHCN.
- This effort helped to lay the groundwork for future partnerships between primary care, specialty care, and public health.
- Once the rebidding of the new Medicaid entities is complete, new data sharing efforts are likely to emerge to further support integrated care. All participants are interested in examining what is possible.

Lessons: Key Ingredients
- Action at all levels – state, local, and provider—produced results better than the state imposing new requirements without true collaboration. Implementing agencies' input was valuable.
- In-person meetings needed to include people who were high-level enough to make decisions about key issues (or attend a few meetings and could be brought back in to help resolve issues/challenges). Involving high-level leadership initially helps commit the agencies to the collaborative's mission, and then they can be called on at a later point to assist with challenges or major decisions even if they are not at every meeting.
- Willingness to partner is the overarching key ingredient.
- There is also a staffer at the DPHE Health System Unit whose sole job it is to facilitate communication and align efforts between DPHE and HCPF. HCPF also has a counterpart who

works with the DPHE staff person. They know "who to call" and exactly what the relationships are, facilitating effective communication between the agencies.

- Having the same staff largely working on the effort all the way through was also very beneficial. These staff know and trust one another, know the history of the effort, are committed to it, and communicate effectively.
- Momentum and timing are key. This effort aligned well with a variety of other state efforts to better integrate care and federal opportunities (e.g. SIM) to do so, as well as Medicaid priorities.
- DUAs need to be broad enough for the agencies to talk to each other regarding the clients and their services and have flexibility in how to do that, but specific enough to allow them to discuss the data in detail. Care coordinators need to be able to discuss specific patients.
- Centers for Disease Control and Prevention (CDC) and Health Resources and Services Administration (HRSA) resources are useful to reinforce that the public health authority is an important partner and they can form a DUA with others. Non-public health agencies may not be familiar with Public Health Authority or its potential scope, and the process of building understanding and support for this authority is ongoing.
- HIPAA interpretation can be subjective; a statewide approach or template that could help all participants be comfortable with a consistent interpretation would be beneficial.
- Key informants felt that the braided funding concept should come from the federal level as a mandate in order to increase its use, as well as an interpretation of how agencies can partner so that all participants can be better aligned.

2. District of Columbia: Data Sharing for School Health

Data sharing agreement between the schools, Medicaid, and the Health Department to improve school health form completion, targeted outreach and service delivery

Model or mechanisms: Memorandum of Agreement to share school health form data across entities to improve health form completion, targeted outreach and service delivery

State (District) Agencies: The District of Columbia Public Schools (DCPS), Department of Health (DOH), Department of Health Care Finance (DHCF, the Medicaid agency)

Motivation: The school system's statutory obligation to collect student health information, and low rates of health form completion and well-child visits

Accomplishments: Completion of the two types of school health forms approximately doubled over about three years, enhancing: identification of students with incomplete health forms and who need preventive or additional care; identification of schools needing stronger outreach for well-child visits and oral health services; and health promotion/education events and individualized family outreach by MCOs

Challenges: Addressing barriers related to FERPA and HIPAA laws that protect privacy of school heath data, in part by clearly communicating how the data sharing was required by the relevant laws and that it would be strictly limited

Lessons: Meeting the statutory requirement for schools to collect student health information provides the framework to share data, while meeting the needs and obligations of multiple agencies to improve child and adolescent health

The District of Columbia (D.C.) public schools (DCPS), health department, and Medicaid agency developed a Memorandum of Agreement based on the schools' statutory obligation to collect student health information. This agreement has enabled them to share and match data to determine whether students who are covered by Medicaid have completed well-visits and their required school health forms. The process helps to identify not only children whose forms are not complete, but also those who have not received appropriate visits and could benefit from outreach from their Medicaid managed care organizations (MCOs), which also receive the data. Using the data, D.C. can identify schools with high Medicaid populations and where students are not receiving annual well-child or dental visits. The data sharing promotes targeted outreach to families and to schools, enables the agencies to better direct contracted providers of dental care to high-need schools, and improves coordination of services by identifying care gaps to be addressed by care managers. With 96 percent of children in the district insured, the effort aims to increase the proportion of children receiving the appropriate care that is already covered. As of October 2017, 49 percent of DCPS students were enrolled in Medicaid out of

48,531 total DCPS students under age 21, making the Medicaid population central to efforts to increase completion of wellness visits and the related forms.[15]

Collaboration Model and Mechanisms

- **District-level Agencies involved**: The District of Columbia Public Schools (DCPS), Department of Health (DOH), Department of Health Care Finance (DHCF, Medicaid agency) are the only entities involved in this project. Because of concerns about the confidentiality of the data and discussions about data sharing that would be involved, outside stakeholders were not included.

- **School Health Requirements Interagency Committee**: Comprised of representatives from DOH, DCPS and the Medicaid agency, as well as other agencies like the Office of the State Superintendent for Education that are typically focused on child and adolescent health with oversight of health services at their respective agencies, the committee meets quarterly to discuss a wide range of issues relating to school health. This interagency collaboration was a major topic of the committee's efforts as it was being developed, though the key participants already knew each other and also communicate outside the structure of the formal meetings through email/phone follow-up associated with them.

- **Memorandum of Agreement for Data Sharing:** Signed in January 2014, the Memorandum of Agreement (MOA) allows the three agencies to share data to promote outreach for health services and target resources in schools. While ensuring compliance with FERPA and HIPAA, the MOA stipulates each agency's contributions:
    o DCPS: student enrollment file, Universal Health Certificate (UHC) and Oral Health Assessment (OHA) submissions (which also capture lead screening and immunization results).
    o DHCF: Medicaid status, the date of the last well-child visit and dental visit, and MCO assignment.
    o DOH: Universal Health Certificate completion and date of exam (for care provided through school nurses).

   Twice annually, DCPS sends the school enrollment file and school registrars' data on completion of the UHC and OHA submissions to the Medicaid agency, which matches the data with Medicaid enrollment files and claims information on well-child and dental visits claims submission (i.e., was a service paid for by the Medicaid program). The Department of Health also shares its school-based oral health program data with the Medicaid agency as another source to confirm dental visits billed to Medicaid. The Medicaid agency sends back a matched file to DCPS, which allows both agencies to see which Medicaid-enrolled children have had visits and which have submitted the required forms, as well as who has not. The Medicaid agency also shares this information with the Medicaid managed care organization outreach staff. It is all exchanged via Excel spreadsheets.

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[15] Quick, C. and Sonosky, C. (2016, October). *DC: Bridging the Data Divide [PowerPoint Slides]*. Department of Health and Department of Health Care Finance. Retrieved http://www.ashaweb.org/wp-content/uploads/2016/10/ACL10.pdf

- **Collaboration on Outreach**: The Medicaid agency shares information with the Medicaid managed care organizations in which students missing their forms or who did not receive the recommended care are enrolled, enabling the health plans to conduct outreach directly to families. DCPS can also identify schools where well-child or dental visits are particularly lacking, and better direct resources to meet those needs.
- **Communication**: School Health Requirements Interagency Committee quarterly meetings are supplemented by email and phone contact on an on-going basis. Many of the staff who originally collaborated on this effort are still in positions with the District government, so they have strong relationships which have been valuable over the course of the project.
- **Shared funding**: The project was conducted using only existing agency funding; staff carry out the work as part of their existing roles. DCPS views the effort as necessary to fulfill its obligations to collect statutorily required health information from all students.

Motivation and Development

- This effort grew out of DCPS and interagency discussion of how to increase submission of completed UHC and OHA forms, as well as completion of the well-visits they capture. In the course of these discussions, the agencies concluded that the statutory requirement for DCPS to collect the information included in these forms for all students, enacted in the Student Health Care Act of 1985, requires this enhanced collaboration. This was the driving force of the effort and determinant of its scope.[16] The three agencies share goals to meet health needs of DCPS students, seeking to ensure that children receive needed care, and with up to 96 percent of children in the District insured, nearly all care for low-income students can be billed and reimbursed by Medicaid or another payer.
- Prior to this effort, lack of data sharing and collaboration resulted in duplication of efforts and inaccurate data regarding receipt of basic health services by DCPS children, as well as a lack of coordinated, targeted outreach to address unmet needs.
- The key staff attending quarterly meetings developed the Memorandum of Agreement (MOA) between the three agencies to share data to promote outreach for health services and target resources in schools; Programmatic Staff from each agency worked to develop language, shepherd through Agency approval processes; District Privacy Officers and General Counsels were included to ensure Health Insurance Portability and Accountability Act (HIPAA)/Family Educational Rights and Privacy Act (FERPA) compliance, which was the most time-consuming part of the effort.

Barriers and Challenges

- Participants needed to overcome barriers related to FERPA and HIPAA laws that protect privacy of school heath data, in part by clearly communicating how the data sharing was required by the relevant laws and that it would be strictly limited (i.e., it could not be used explicitly to pursue

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[16] DCPS is required to collect the following information: UHC (including lead screening and immunization data) and OHA forms.

the Medicaid agency's goals of increasing recommended visits – these benefits were incidental to the legal justification).

- Two years ago, the team needed to address barriers within and changes to the school system's student information system in order to ensure that the required data was flowing smoothly. For example, registrars needed to enter form completion data on a timely basis so that it could be shared, and updates to the data system temporarily interfered with the data flow. DCPS successfully worked with colleagues at the schools to improve the internal data process. Real-time feedback to the schools about the impact of the data sharing and barriers helped ease any disruptions related to the changes.

Accomplishments

As a result of this effort, completion of the UHC and OHA forms approximately doubled over about three years, to about 40 percent for UHC forms and 30 percent for OHA forms. The agencies ultimately seek 100 percent compliance.

The DCPS-DOH-DHCF Data sharing also helps facilitate the following:

- Identification of students who submitted incomplete health forms, who need preventive or additional care.
- Organization of health promotion and education events by MCOs, as well as individualized family outreach.
- Identification of schools that receive increased outreach for well-child visits and oral health services.
  - o Schools were prioritized for the DOH school-based oral health program on gaps.
- Identification of school principals and nurses that need strategies to increase efforts to improve health and wellness.
- Tailoring of outreach to schools with school-based health centers and Head Start Programs.
- Managed care collaboration: DHCF developed MCO-specific data snapshots; MCOs receive school enrollment information for their members. They can then target outreach to students at schools with school-based health centers and those enrolled in Head Start programs, as well as plan health events and education efforts, using member school enrollment data.

Next Steps and Sustainability

- In the future, DCPS would like to institute electronic submission of UHC forms, which could enable providers to complete and submit the forms at the visit, further increasing completion. The current system, which requires parents and sometimes students to secure and submit the forms adds administrative complexity and barriers.
- Ideally, the partners would enhance their ability to track the impact of completed wellness care. They would like to collect data to tie increased completion of wellness care to student-level impact on academic indicators (this is not yet underway and would likely involve additional data sharing that is not covered under existing agreements).
- They would also like to further enhance student-level coordination of care in order to increase access to wellness services.

Lessons: Key Ingredients

- Meeting the statutory requirement for schools to collect student health information provides the framework to share needed data, while meeting the needs and obligations of multiple agencies to improve child and adolescent health.
- The critical steps in this partnership, according to the participants, were to:[17]
    - Identify the problem to be addressed, identify the partners that have the needed information, identify goals based on the information exchanged and how it can be used, identify the potential barriers (in this case FERPA[18] and HIPAA[19]),
    - Develop an agreement that addresses the barriers: identify the institutional requirements of each partner and applicable laws, regulations and limitations on data use, convene participants regularly, "cull down" the effort to the key areas of agreement that will work for all participants, seek approval from the respective agencies, obtain approval and implement the data sharing, and continue to meet and communicate during implementation.
- Key informants advised other states considering similar approaches not to be deterred from exploring such an effort by potential challenges involving HIPAA and FERPA, because these requirements can be met through persistent effort and collaboration.

Resources

Charlissa Quick and Colleen Sonosky, "DC: Bridging the Data Divide," Department of Health and Department of Health Care Finance, October 2016. http://www.ashaweb.org/wp-content/uploads/2016/10/ACL10.pdf

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[17] Quick, C. and Sonosky, C. (2016, October). *DC: Bridging the Data Divide [PowerPoint Slides]*. Department of Health and Department of Health Care Finance. Retrieved http://www.ashaweb.org/wp-content/uploads/2016/10/ACL10.pdf

[18] Protects privacy of students' educational records, including: Student information, including immunization records, school health records, etc.; Information about what school a student attends, attendance data and academic data

[19] Requires covered entities to protect individual health records and identifiable health information. Includes conditions on uses and disclosures that may be made without consent, including: public health activities, legal obligations and institutional requirements, and care coordination

NEW YORK

Various vehicles have been used to promote interagency collaboration related to vulnerable children in New York State, each with successes and challenges. The following summarizes information about two strategies: *Council on Children and Families*, and *First 1000 Days on Medicaid Initiative*.[20]

3. New York: Council on Children and Families (The Council)

A neutral government entity established in the 1970s to facilitate interagency collaboration

Model or Mechanisms: *Council to coordinate state health, education, and human services systems to better serve children and families; reports directly to Governor's office*

State Entities: Departments of Health (DOH), Education (SED), Labor (DOL); Offices of Children and Family Services (OCFS), Mental Health (OMH), People with Developmental Disabilities (OPWDD), Alcoholism and Substance Abuse Services (OASAS), Temporary and Disability Assistance (OTDA), Aging (OFA), Probation and Correctional Alternatives (OPCA); Division of Criminal Justice Services (DCJS); Justice Center for the Protection of People with Special Needs Health (JCPPSN)

Motivation: Recommendation by a state commission addressing gaps in care; created through legislation

Accomplishments: Council brokers responsibilities between agencies/programs for children falling through cracks, involves families/youth in policy discussions, reduced out-of-state placement of children, convened Early Childhood stakeholders to provide strategic direction to state, launched Multiple Systems Navigator website, others.

Challenges: Changes in governors' and agencies' priorities, reduced staffing

Lessons: Importance of Governor as champion of collaborative initiative, strong working relationships across agencies, buy-in among state leaders and county officials

Established in 1977, the Council is authorized to coordinate state health, education, and human services systems to better serve children and families. The Council focuses on structural issues and works with state, local, public and private organizations to facilitate interagency collaboration. For example, the Council is notified when a child or youth seems to "fall through the cracks" between various agencies/programs meant to serve them, and mediates across agencies to address gaps or conflicting responsibilities. Among other activities, the Council provides leadership, staff support, and facilitates monthly cross-systems meetings with senior agency staff and youth and family advocates, staffs and co-chairs the Governor's Early Childhood Advisory Council, and recently developed a Multiple Systems

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[20] Another cross-sector initiative, not examined in this report, is the Health Homes for Children. See https://www.health.ny.gov/health_care/medicaid/program/medicaid_health_homes/health_homes_and_children.htm

Navigator Website. The Council is now part of the state's Office of Children and Family Services (OCFS), but the Executive Director reports directly to the Governor's office.

Model and Mechanisms
- **State Agencies involved**: Members of the Council include the commissioners and directors of the following New York State entities:
  - Office of Alcoholism and Substance Abuse Services (OASAS)
  - Office for the Aging (OFA)
  - Office of Children and Family Services (OCFS)
  - Division of Criminal Justice Services (DCJS)
  - State Education Department (SED)
  - Department of Health (DOH)
  - Justice Center for the Protection of People with Special Needs (JCPPSN)
  - Department of Labor (DOL)
  - Office of Mental Health (OMH)
  - Office for People with Developmental Disabilities (OPWDD)
  - Office of Probation and Correctional Alternatives (OPCA)
  - Office of Temporary and Disability Assistance (OTDA)
- **Non-state agencies involved**: The Council staff work with advocacy organizations, regional entities, and other stakeholders as appropriate to the specific initiatives.
- **Statutory Authority**: The Council was created under Governor Carey by Chapter 757 of the Laws of 1977. Social Services Law Article 10-C establishes the Council and its membership and specifies the Council's powers and duties, including obtaining assistance and data from other agencies: "Utilization of other agency assistance… To effectuate the   purposes of this article, any department, division, board, bureau, commission or agency of the state or of any political subdivision thereof shall, at the request of the chair, provide to the council such facilities, assistance and data as will enable the council properly to carry out its powers and duties and those of the chair." (NY Soc Serv L § 483-A [2015])
- **Committees, Initiatives:** The Council currently leads, coordinates, and provides staff support for multiple collaborative committees, workgroups, advisory councils, and projects including:
  - **Senior Staff and Family and Youth Partners Workgroup** that includes state agency staff, family, and youth representatives and meets monthly to address challenges impacting children and families and share successes.
  - Under a 5-year federal **Early Childhood Comprehensive Systems (ECCS) Impact grant,** the Council is using a Collaborative Innovation and Improvement Network (CoIIN) approach to increase age-appropriate developmental skills among 3-year old children in select communities by 25 percent.
  - The Council staffs and co-chairs the **Early Childhood Advisory Council,** with Governor-appointed members representing state agencies, advocacy groups, foundations, higher education, unions and other organizations; this council provides strategic direction and advice to the State on early childhood issues.

- o Additional initiatives can be found at: http://ccf.ny.gov/council-initiatives/ , including The Coordinating Council on Children with Incarcerated Parents, Every Student Present, Fetal Alcohol Spectrum Disorder Workgroup, Head Start Collaboration Project, and others.
- **Funding**: In addition to staff funding through the OCFS, initiatives and programs are funded through varied federal, state, public and private sources. For example, the Multiple Systems Navigator Website was funded primarily from the New York State (NYS) Developmental Disabilities Planning Council. The Council's Head Start Collaboration Project is funded through the federal Office of Head Start. Its Early Childhood Comprehensive Systems Impact Initiative is funded through a 5-year grant from the Health Resources and Services Administration, Maternal and Child Health Bureau. The Council's KIDS COUNT activities are supported by the Annie E. Casey Foundation.
- **Communication:**   The Council holds monthly meetings with agency staff and scheduled monthly, quarterly, or as-needed meetings for specific committees.

Motivation and Development

- In the 1970s, based on recommendations by a state commission studying public assistance and social services programs, a bill establishing the Council was drafted and signed into law by then Governor Carey in 1977. The support of the Governor encouraged the agencies to participate.
- The Council was established as an independent Executive Agency and in 2003 the Council became part of the OCFS, which is an executive agency of the New York state government. This change occurred for administrative reasons. The Council's Executive Director continues to report directly to the Governor's office.

Select Accomplishments

- A new concept in 1977, the Council was an acknowledgement that vulnerable children and families interact with multiple programs and agencies, each with different rules, policies, and eligibility criteria that can be confusing and result in gaps in critical services. The Council "identifies where there are mixed messages and instructions between the agencies. It listens to the constituents and the providers," and makes recommendations to improve alignment, according to a key informant.
- The Council has become recognized for helping the most vulnerable children and youth in complex situations. For example, the Council may receive a referral re: a child needing a new residential placement, and the OPWDD and OMH cannot determine who is responsible, the Council will mediate, bringing the two divisions together to collaborate, and ensure a placement for the child.
- The Council is credited with bringing families and youth "to the table," establishing monthly meetings that include agency staff and youth and family representatives. The Council is a vehicle for child/family advocacy organizations to offer input and feedback to state agencies.
- Various Council activities and programs have reduced out-of-state placement of children, convened Early Childhood stakeholders, facilitated a "train the trainers" model, and had numerous other varied accomplishments over its 40-year history.

- The **Multiple Systems Navigator website**[21], launched August 1, 2016, is an interactive tool that offers user-friendly access to health, education, human service and disability information for youth, family members and caregivers who rely on support from multiple systems

Barriers and Challenges

- Changes in priorities along with general downsizing of government have led to decline in Council staffing from a high of 55-60 in the late 1980s to 16 staff in 2017.
- Participating agencies also have competing priorities, limited staff and resources. With staff turnover, new staff across state government are often not aware of the Council or its role.
- The NYS SED is not an executive agency and therefore does not report to the Governor, but rather to the New York State Board of Regents. Over the years, the Executive Director of the Council has relied on relationship-building to encourage Education department SED cooperation in cross-sector activities and dialogue.
- Cross-agency collaboration and coordination are hindered by "turf" issues and different, sometimes conflicting philosophies, regulations, and policies across agencies and programs.
- Braided and blended funding from different sources was possible when more discretionary funding was available, but most federal sources are now restricted to specific programs or services. On the local level, however, shared funding to improve service coordination is more feasible.
- The Multiple Systems Navigator website was released in 2016, but appears to require additional dissemination and publicity to fully reach the targeted audience.

Next Steps and Sustainability

- The Council continues to be funded through OCFS and various grants and program-specific funding streams.

Lessons: Key Ingredients

- Governor as "champion": Support from the Governor and reporting to the Governor's office enhance clout and encourage engagement among state agencies, departments, offices, etc. The Governor's office can be helpful by applying pressure on the agencies. However, if an entity is established through an executive order, there is risk that the next governor will not continue or prioritize the effort.
- Leadership and Relationships: Strong leadership from the Council's executive director and her ability to establish working relationships with agency leaders and staff, have been keys to successful collaboration. It is important to have buy-in from "above and below"–among state agency leaders, county level officials where collaborative efforts are often implemented, as well as the governor's office.
- Neutral Player: Maintaining a role as a *neutral player* that prioritizes the best interest of children, youth and families—rather than representing or favoring one department over

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[21] http://www.msnavigator.org/

another—is important for the collaboration facilitator's standing and bringing the agencies together.

Resources

Website: Council on Children and Families, http://ccf.ny.gov/

New York State Multiple Systems Navigator, http://www.msnavigator.org/

4. New York: First 1000 Days on Medicaid Initiative

Medicaid-led effort to develop a cross-system approach to addressing social determinants of health for children age 0-3

Model or Mechanisms: Medicaid-created work group, with cross-sector leadership (Education), using collaborative multi-stakeholder engagement process to develop ten strategic recommendations for improving long term outcomes for young children enrolled in Medicaid

State Agencies/Offices: Medicaid (in the Office of Health Insurance Programs (OHIP) within DOH) as lead, with Work Group members including representatives from other DOH offices, other state departments, and the Governor's office

Motivation: With Medicaid director as champion, recognition that Medicaid working with other sectors can play significant role in improving child development in first three years of life, affecting lifetime health and social outcomes

Accomplishments: Broad participation and input, resulting and development and release (pending as of December 2017) of actionable 10-Point Agenda

Challenges: Persistence of silo mentality across state departments, barriers to data sharing related to technical issues and privacy protections, high cost of expanding certain successful strategies

Lessons: Importance of Governor's, Medicaid director's, and cross-sector leadership; collaborative and trusting relationships; long term goals and metrics outside the traditional health care "box," and an inclusive and transparent project management process

In July 2017, the New York State (NYS) Department of Health (DOH) launched The First 1000 Days on Medicaid Initiative (First 1000 Days) as part of its Medicaid Redesign Team's (MRT) transformation efforts in New York. DOH recognized it "must take steps to ensure that New York's Medicaid program is working with health, education, and other system stakeholders to maximize outcomes and deliver results for the children [it] serves."[22] Though Medicaid-led, the initiative is a collaborative effort, bringing together stakeholders in a series of four work group meetings between August and November 2017 to develop an agenda for enhancing access to services and improving outcomes for young children on Medicaid. The initiative builds on leadership, membership, and work conducted by the MRT's Value Based Payment (VBP) advisory group on children´s health.[23] The First 1000 Days demonstrates two key levels of cross-sector collaboration:

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[22] New York State: Department of Health. (2017, December). First 1000 Days on Medicaid Initiative. Retrieved from https://www.health.ny.gov/health_care/medicaid/redesign/first_1000.htm

[23] Officially the Children's Health Subcommittee/Clinical Advisory Group (CAG), and also referred to as the Children's VBP Advisory Group the group was formed in late 2016 under the DOH's Value-Based Payment work group. It is comprised of state agency staff from multiple divisions/agencies, experts, and an array of stakeholders; the group has focused on the importance of social determinants of health in early childhood development.

- Strategic orientation: the Medicaid program recognizes it has a role to play in preparing children for success in schools; and
- Operational level: a state education leader was chosen to chair the Medicaid-led initiative, ensuring participation and goals beyond the traditional health care sector.

Model and Mechanisms

- **State Agencies and Offices involved**: New York State Medicaid (in the Office of Health Insurance Programs (OHIP) within DOH) as lead, with Work Group members including representatives from other offices within DOH as well as other departments. The first meeting included representatives from the State Office of Mental Health (OMH), Council on Children and Families/Office of Children and Family Services (OCFS), Office of Alcoholism and Substance Abuse Services (OASAS), State Education Department (SED), and Office of the Governor.[24]
- **Non-state agencies involved**: The Schuyler Center for Analysis and Advocacy, The Children´s Agenda, United Hospital Fund, Center for Health Care Strategies, and The Albany Promise. Work Group members represent a wide variety of advocacy groups, health care and children's service providers, health plans, New York City departments, and others. The meetings are open to anyone.
- **Work Group**
  - The First 100 Days' Work Group is chaired by the Chancellor of the State University of New York (SUNY), Nancy Zimpher, a national leader in educational issues and cross–system collaboration. Vice chairs are Kate Breslin, President and CEO of the Schuyler Center for Analysis and Advocacy, and Jeffrey Kaczorowski, MD, Senior Advisor, The Children´s Agenda, and Professor of Pediatrics, University of Rochester. The Director of the MRT Project Management Office, Kalin Scott, coordinates the initiative within OHIP.
  - The first Work Group meeting took place August 11, 2017, followed by instructions to the participants to submit recommendations that meet designated criteria:
    - Specifically address a foundation of health from the agreed upon framework
    - Be evidence based, or at least strongly evidence informed
    - Have measurable results, or include a viable strategy for collecting new data to measure results
    - Reach a large percentage of the affected population or be a targeted pilot with strong potential for wider adoption
    - Consider disparities in access, quality of care, and outcomes.
    - Have sufficient detail to be actionable and implementable by New York Medicaid and any relevant partners
    - Be affordable and cost-efficient given limited resources

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[24] Myriad offices and divisions in different state agencies and departments serve children and youth in New York state. The Medicaid program is administered by the state's *OHIP,* one of 12 offices within the *DOH.* The *Department of Mental Hygiene* is composed of several autonomous offices: the OASAS, the Office of Mental Health (OMH), and the Office for People with Developmental Disabilities (OPWDD). The Office of Children and Family Services (OCFS) is an agency of the New York state government within the Department of Family Assistance. The Education Department is headed by the Regents of the University of the State of New York.

- Consider the potential effect on various constituencies (including potential perverse incentives, political considerations)
    - o Webinars or meetings in September, November, and early December involved the following:
        - 14 issue area concepts presented on the September 25 webinar were eventually turned into 23 discreet policy proposals, which were presented and revised
        - Workgroup members were invited to score and rank the proposal based on: cost, cross-sector, feasibility, strength of evidence, and overall impact
        - The top ten proposals were further discussed and finalized, with public release of the 10-point Agenda pending as of December 6, 2017.
- A robust project management process monitors MRT-related activities and progress across DOH agencies. Because MRT is the Governor's signature initiative, all DOH agencies prioritize the MRT efforts.
- **Communication**: There are frequent meetings among the Medicaid Director, Commissioners and other state leaders. According to a key informant, this internal collaboration helps to prevent problems from arising and to ensure the agencies are "on the same page" when external stakeholders have a question or issue.
    - o The Deputy Secretary from the Governor's Office coordinated a call with department Commissioners, Deputy Commissioners, Executive Deputies, and staff (open to anyone in DOH and other agencies) before the initial First 1000 Days meeting to: describe the initiative's rationale, process, and any questions or concerns; welcome their participation in the Work Group process and provide the state MRT director's contact information to open up a dialogue; help break down silos by fostering relationships across agencies (outside of the Work Group).
    - o Monthly meetings for the Medicaid Director and Commissioners from agencies that are leading or on a team that is leading one of many MRT implementations, to keep each other informed and address issues. "They work very collaboratively, but there is always friction about money and how a program operates," reported a key informant.
    - o Overcoming traditional reticence to making drafts and preliminary versions public, the NY MRT website was created to be as transparent as possible. Project management work plans, slides and minutes from meetings with stakeholders are publicly available, and additional feedback is invited and taken seriously, according to a key informant. Operator-assisted phone calls are open to everyone. These practices have led to a "culture change" across agencies toward one that promotes information-sharing. It also resulted in efficiencies because less staff time is needed to answer calls and answer questions from stakeholders, according to a key informant.

Motivation and Development
- The First 1000 Days is one of approximately 400 distinct MRT initiatives (related to benefits, payment, enrollment, etc.) that are built on the momentum established by early MRT accomplishments and employ a robust stakeholder engagement process. NY State began its Medicaid Redesign initiative in 2011, bringing different stakeholders to the table to reexamine

the entire Medicaid program. Initial members included DOH's OASAS, OMH, and Office of Developmental Disabilities (ODD), and MRT invited input from other divisions and agencies as well as advocacy groups, providers, and other stakeholders. Early success saving $4 billion in the Medicaid program gave MRT planners and staff credibility among leaders within DOH and external groups, according to a key informant.

- While the state has deployed resources toward managing high cost/high need adults (given the potential opportunities for savings), there has been much less attention on children and particularly relatively healthy children. The First 1000 Days initiative grew out of a growing body of evidence that: the early days of a child's life are critical for development; adverse early experiences dramatically affect lifelong health and social outcomes; and social determinants of health disproportionately affect poor and minority children.[25] With encouragement from advocates, and direction and membership from the Children's VBP Advisory Group, the Medicaid director embraced the concept of taking a broad view and made it a priority. Leaders recognized that Medicaid can play a significant role in those early days of a child's life (along with parents/caregivers) and that it must be a cross-system effort with education.
  - o The process employed by the Children's VBP Advisory Group contributed to the cross-sector emphasis. The group began with identifying end result or "North Star" goals, which focused on healthy children (e.g., kindergarten readiness). It then stepped back to identify indicators that would measure goal achievement, and members realized that these metrics are overwhelmingly related to education. The group then identified ways that health care and Medicaid specifically could influence those metrics and goals. For example, leaders recognized that Medicaid billing and payment structures need to be modified and connected to broader contributors to health. They also acknowledged that results in terms of health outcomes and cost savings may not be seen in the short term.
- The First 1000 Days initiative also connected to various pilots in the state including the Albany Promise Collective Impact Initiative, intended to improve kindergarten readiness and educational outcomes.[26] Successful cross-sector collaboration at the local level encouraged state leaders to "try it" at the state level. Through the pilots, the Chancellor of SUNY (now Chair of the initiative), Medicaid Director, and Albany Promise director were already having conversations about VBP and the importance of cross-sector collaboration.
- New York is among six states participating in a learning group to identify and disseminate strategies to support healthy childhood development. In coordination with a Center for Health Care Strategies (CHCS) initiative titled, "The First 1,000 Days: Medicaid's Critical Role[27]," the group of state leaders identified key priority areas including integrating cross-sector data and

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[25] Bailit Health. (2016, July 13). Value-Based Payment Models for Medicaid Child Health Services (Rep.). Retrieved https://www.uhfnyc.org/assets/1503

[26] For more information see http://albanypromise.org/

[27] Supported by the Robert Wood Johnson Foundation and the David and Lucile Packard Foundation. See https://www.chcs.org/resource/first-1000-days-medicaids-critical-role/

shared metrics, and building state and community cross-agency partnerships (health, early childhood, child welfare, housing, etc.).[28]

Barriers and Challenges

- Despite progress, the silo mentality persists in some parts of state government. According to a key informant, it has been a challenge engaging the "Early Childhood world" of the OCFS in Medicaid-led discussions. Yet the children served by these systems are most likely to have long hospital lengths of stay and it will be important to work together.
- Technical issues and privacy protections create barriers to sharing of health information across systems.
- Developing 'solutions' that are not excessively costly is challenging; for example, home visiting to vulnerable new mothers is effective but expensive.

Accomplishments

- The first meeting was well attended by a wide spectrum of public and private agencies and stakeholders including the Department of Education (which does not "answer to" the Governor). The workgroup (over 200 members) met on November 1, and provided feedback and were invited to score and rank 23 proposals. The broad participation signals a recognition that myriad systems affecting children are interconnected, and a siloed approach is not beneficial to children.
- During a December 1 webinar, the top ten proposals were finalized, with a public release date of a specific and actionable 10-Point Agenda to be determined.

Next Steps and Sustainability

- Following the release of the 10-Point Agenda comprising realistic action steps, it is expected that the effort will continue to implement at least some of the recommendations. The final agenda may include regulatory changes, managed care organization (MCO) contract modifications, and other areas affecting multiple departments and sectors.

Lessons: Key Ingredients

- Governor's leadership: The Governor's establishing and prioritizing a collaborative initiative, with state agency and department Commissioners/leaders reporting to him, has been a key driver of the MRT initiatives including the First 1000 Days.
- Medicaid director as champion: Representing the largest payer in the state, the Medicaid director championing the collaborative approach has been instrumental to building partnerships and bringing state agency counterparts along.
- Cross-sector leadership: The Medicaid director strategically chose a high-level education leader to chair the First 1000 Days initiative. This brought the entire education sector (including the

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[28] Under a planning grant from the David and Lucile Packard Foundation, the Center for Health Care Strategies (CHCS) convened leaders from six states (Connecticut, Maryland, Minnesota, New York, Oregon, and Washington State) to identify and spread strategies to support high-risk, low-income families, prevent Automated Client Eligibility System, and improve the life chances, social determinants, and educational prospects of children. For more information see: https://www.chcs.org/project/medicaid-early-childhood-innovation-lab/

Board of Education, which does not report to the Governor and has traditionally been hard to partner with, according to a key informant) to the table.

- Personality and relationship: "Progress moves at the speed of trust" is preached by the Medicaid director, and the collaboration-centered philosophy filters throughout DOH and beyond, according to key informants. "When they have the commissioners around the table and send out policy guidance that is jointly signed, it communicates the mission and vision to the staff further down the flag pole." Further, the Medicaid director, the Chancellor of SUNY, and leader of the Albany Promise are all "big thinkers" and know each other personally, which has accelerated the collaborations.

- Starting with end-result goals: A planning process that first identified long term goals and then stepped back to identify metrics established a cross-sector framework with shared metrics and goals – including goals outside of the traditional health care-oriented goals.

- Inclusive and transparent management process: Stakeholder engagement is a foundational management process for MRT activities. Staff intentionally invite input and try to incorporate feedback, demonstrating that stakeholders' input is taken seriously. Making information publicly available further promotes trust and ongoing participation across stakeholders and sectors.
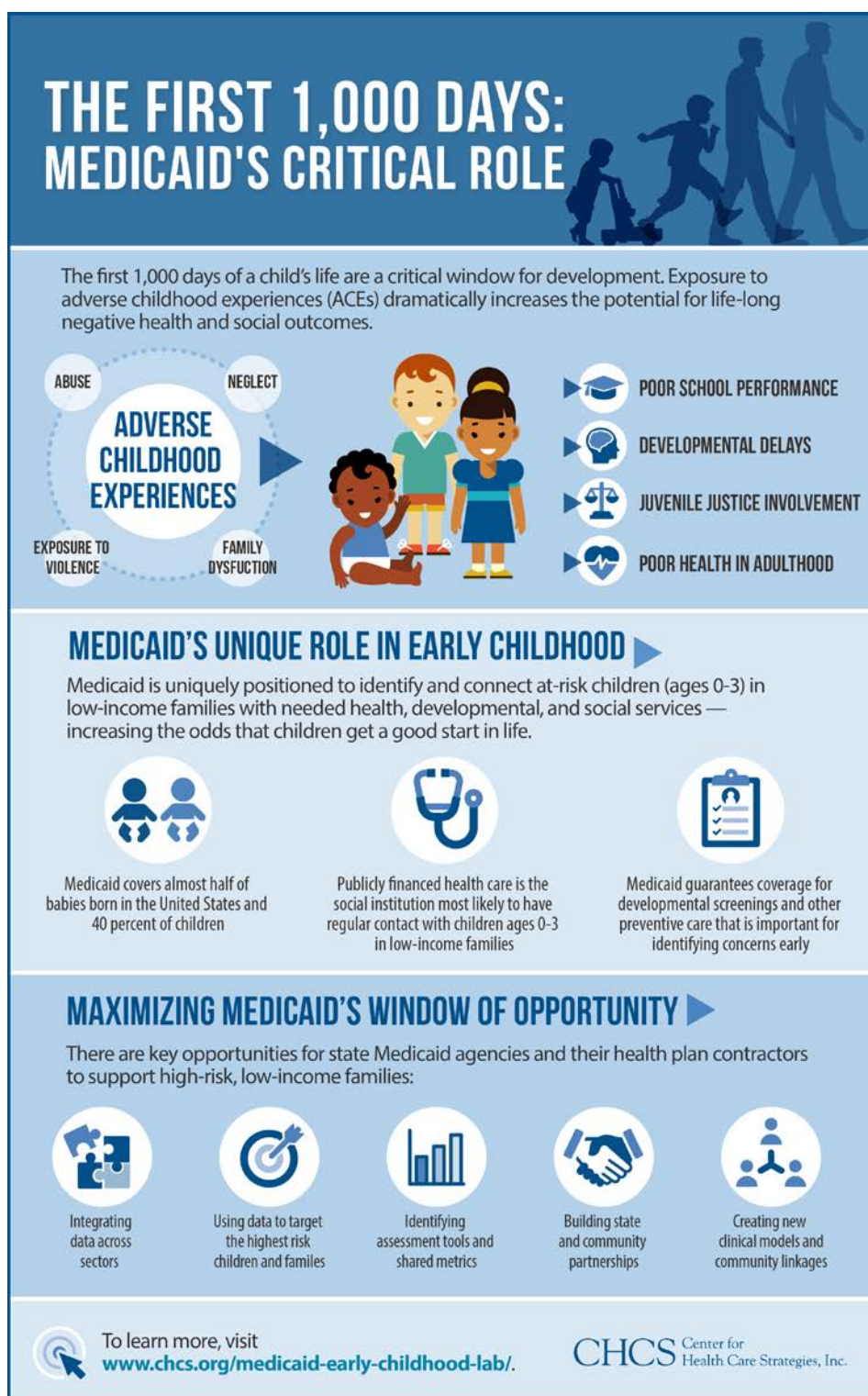
Resources:

The First 1,000 Days: Medicaid's Critical Role. Center for Health Care Strategies, June 2017. Available at: https://www.chcs.org/resource/first-1000-days-medicaids-critical-role/   - See graphic on next page

New York State Department of Health, First 1000 Days on Medicaid Initiative
https://www.health.ny.gov/health_care/medicaid/redesign/first_1000.htm

August 11, 2017 Work Group Meeting Materials:
https://www.health.ny.gov/health_care/medicaid/redesign/docs/2017-08-07_1000_days_final_deck.pdf

Value-Based Payment Models for Medicaid Child Health Services, Bailit Health, July 2016,
https://www.uhfnyc.org/assets/1503

THE FIRST 1,000 DAYS: MEDICAID'S CRITICAL ROLE

The first 1,000 days of a child's life are a critical window for development. Exposure to adverse childhood experiences (ACEs) dramatically increases the potential for life-long negative health and social outcomes.

ABUSE   NEGLECT

ADVERSE CHILDHOOD EXPERIENCES

EXPOSURE TO VIOLENCE   FAMILY DYSFUCTION

POOR SCHOOL PERFORMANCE

DEVELOPMENTAL DELAYS

JUVENILE JUSTICE INVOLVEMENT

POOR HEALTH IN ADULTHOOD

MEDICAID'S UNIQUE ROLE IN EARLY CHILDHOOD

Medicaid is uniquely positioned to identify and connect at-risk children (ages 0-3) in low-income families with needed health, developmental, and social services — increasing the odds that children get a good start in life.

Medicaid covers almost half of babies born in the United States and 40 percent of children

Publicly financed health care is the social institution most likely to have regular contact with children ages 0-3 in low-income families

Medicaid guarantees coverage for developmental screenings and other preventive care that is important for identifying concerns early

MAXIMIZING MEDICAID'S WINDOW OF OPPORTUNITY

There are key opportunities for state Medicaid agencies and their health plan contractors to support high-risk, low-income families:

Integrating data across sectors

Using data to target the highest risk children and familes

Identifying assessment tools and shared metrics

Building state and community partnerships

Creating new clinical models and community linkages

To learn more, visit www.chcs.org/medicaid-early-childhood-lab/.

CHCS Center for Health Care Strategies, Inc.

Made possible with support from the Robert Wood Johnson Foundation and the David and Lucile Packard Foundation.

Source: Center for Health Care Strategies, Inc, https://www.chcs.org/media/Medicaid-Early-Childhood-Lab-Infographic_060917.pdf

5. Oregon: Health Care and Early Learning Partnerships

Close collaboration between Medicaid and Early Learning through committees, a children's health policy team and a full time Child Systems Collaboration Coordinator, with Coordinated Care Organization-Early Learning Hub collaboration on a regional level

Model or Mechanisms: State committees/teams promoting collaboration and shared metrics between Medicaid and Early Learning, a Child Systems Collaboration Coordinator and an Early Childhood policy person supporting collaboration within and across organizations; interagency agreements and some shared funding between regional Coordinated Care Organizations (CCOs) and Early Learning (EL) Hubs

State and Regional Entities: Oregon Health Authority (OHA), Early Learning Division (ELD) of the Oregon Department of Education (ODE), Department of Human Services (DHS), regional CCOs and EL Hubs

Motivation: New research highlighting the importance of early child development on long term health outcomes, leadership from Governor, ability to align state transformations of health system and early learning system

Accomplishments: Culture of collaboration at the state and local levels, common developmental screening metric for EL Hubs and CCOs, use of CCO data to identify opportunities for collaboration with EL Hubs

Challenges: Changes in administrations and priorities, budget constraints, lack of geographic alignment of CCOs and EL Hubs, discrepancies in resources between Medicaid and Early Learning, and data sharing constraints related to privacy rules and technical issues

Lessons: Importance of Governor championing collaboration, relationship-building, shared goals, and shared metrics across sectors

The Oregon Health Authority (OHA) and the Early Learning Division of the Oregon Department of Education (ODE) work closely to ensure coordination and alignment between these systems, with a focus on children from birth to age five. The Early Learning Council (ELC) and Oregon Health Policy Board (OHPB) provide policy guidance for these efforts, which are largely implemented on a regional level through 16 regional CCOs[29] and 16 Early Learning Hubs (EL Hubs), (although the CCO and Hub service regions are not necessarily geographically aligned). OHA's Director has a seat on the ELC, and cross-sector staffing within the OHA supports coordination across both systems.

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[29] Sixteen Coordinated Care Organizations (CCOs) for Oregon's Medicaid population, approved through a section 1115 waiver in 2012, are community-level entities that finance health care and are governed through a partnership of providers, payers that assume risk for Medicaid enrollees, and community-based organizations. The CCOs receive a global budget based on per member per month capitated amount, with a 4 percent withhold tied to meeting performance metrics.

Collaboration Model and Mechanisms

- **State Agencies involved**: OHA; Department of Education (Early Learning Division (ELD), Early Intervention/Early Childhood Special Education, others); Department of Human Services (DHS). While the ELD is within the ODE, its director is appointed by and directly reports to the Governor.

- **Non-state agencies involved**: Oregon Pediatric Improvement Partnership (OPIP), which has a family representative on its staff; Oregon Pediatric Society (chapter of American Academy of Pediatrics); Title V: Oregon Center for Children and Youth with Special Health Needs (OCCYSHN is Oregon's Title V-funded public health agency for Children and Youth with Special Healthcare Needs (CYSHN), part of Oregon Health & Science University's Institute on Development and Disability); the Children's Institute, an advocacy organization, participates on the ELC subcommittee; and others.

- **Child Systems Collaboration Coordinator**, a full-time position at OHA. The Coordinator splits her time between the Transformation Center (which focuses on health system innovation and quality improvement) and the Maternal and Child Health section of OHA's Public Health Division. Her work includes coordination related to policy, measurement and technical assistance efforts across Oregon's CCOs, early learning hubs and public health system.[30] In collaboration with numerous staff throughout the health and early learning systems,[31] this position supports:

  - Coordination across state agencies: daily contact with ELD staff, membership on ELD teams and committees, collective impact work on developmental screening and other shared early childhood measures; Maternal and Child Health (MCH) activities;

  - Coordination within OHA: coordination of early childhood efforts throughout OHA, including the Public Health Division, Transformation Center, Health Policy & Analytics Division, and Health Systems Division; work closely with the Public Health Home Visiting programs to support workforce development for early childhood professionals.

  - Coordination between regional CCOs and EL Hubs: provides resources, information, and technical assistance to local collaboration efforts, including *The State of Collaboration: A handbook for cross-sector partnerships between Oregon's coordinated care organizations and early learning hub;* also, responsible for identifying innovative regional collaborative models and sharing best practices throughout the state.

- In addition, an early childhood policy lead's responsibility includes coordinating/convening early childhood activities across the agency (which sometimes overlaps with early learning), staffing the prior ELC/OHPB joint subcommittee, coordinating and collaborating around agency level early childhood policy recommendations, and connecting with OHA leadership on early childhood policy opportunities

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[30] For more information on Oregon's Medicaid and Public Health collaboration, see: Case Study: Medicaid and Public Health Collaboration in Oregon, National Academy of Medicine, April 24, 2017, https://nam.edu/wp-content/uploads/2017/04/Medicaid-and-Public-Health-Collaboration-in-Oregon.pdf

[31] Other staff involved in this work include an early childhood policy lead in the Health Policy Unit and a Maternal & Child Health Manager/Title V Director (who is the OHA Director's designee to the Early Learning Council).

- **Legislation, Memoranda of Understanding (MOUs)**
  - o After cornerstone legislation establishing regional CCOs and then EL Hubs with similar region-based structures, legislative statutes promote collaborative relationships to improve outcomes for children and communities (ORS 414.629 and ORS 417.827).
  - o **MOUs and DOCs –** Memoranda of Understanding (MOUs) and Declarations of Cooperation (DOCs) establish working relationships and expectations for CCOs and EL Hubs to support one another's work to improve metrics and outcomes for young children. As a requirement of their contracts with the ELD, EL Hubs are expected to have MOUs or DOCs with CCOs, and to work across five sectors: Health, Business, Private Sector, K-12 System, Early Learning Services, and Human Services. Additionally, the ELD ensures that each EL Hub Governance Board includes representatives from each CCO in the Hub's service region. According to a key informant, "It wasn't ever the written MOUs that changed the collaboration model, but it was the intention behind these structures that led to the collaboration." The robustness of these relationships across the state vary, with many EL Hub and CCO relationships going above and beyond MOU or DOC agreements or work together on specific metrics. In the Portland area, the CCO and three EL Hubs serving the region have three similar MOUs that outline shared goals, and have successfully implemented many initiatives as a group (described in report).
- **Committees, Structures**
  - o Governor Kitzhaber established the 1) OHPB, the policy-making and oversight board of the OHA, as part of HB 2009 which created the OHA; and 2) ELC in 2011, the board/policy body for the Early Learning Division of ODE.
  - o In 2012 the committee leaders created a Joint ELC/OHPB Subcommittee (Joint Subcommittee) to work on statewide system for collaboration and supporting collaboration at the regional committee:
    - Shared goal is kindergarten readiness
    - Focused on how to identify metrics that could be shared across systems and ultimately be tied to incentives; one metric, developmental screening, was shared with EL Hubs
    - The Joint Subcommittee has not met since February 2016. Leadership changes have occurred in both sectors in the last two years, and as CCO-EL Hub collaboration is increasing at the regional level, statewide policy direction has decreased, according to a key informant.
- **Communication**:
  - o **At the policy board level**, monthly or bimonthly public meetings are held with much stakeholder attendance and staff- written reports to those policy bodies.
  - o **Leadership across agencies** met very regularly with very close working relationship among directors of Human Services and Early Learning, education department (to some degree), and (formerly) the Child Health Director representing the health agency.

Currently, DHS and OHA continue to have monthly coordination meetings, while meetings between OHA/ELD occur on as as-needed basis.

- o **Children's health policy team,** with representation from almost all divisions in the health agency (Mental and Behavioral health, Early Learning, Education Department, Health and Human Service, Child welfare, Disabilities) held staff-level meetings. These meetings have not continued, but two other groups with representation across the agency are an early childhood disparities team (met for 8 months to develop recommendations to OHA leadership); and a prenatal-to-5 team, staffed by child systems coordinator, with representation across the agency; this has less of a policy focus but still is a venue for cross-division work.
- o **Local level** engagement of EL Hub and CCO leadership; each generally includes a representative from the other on their boards. In the Portland region, the CCO and three EL Hubs meet monthly as a collaborative group.

- **Data sharing –** There are ongoing efforts to identify how to share data regionally to support better outcomes for children; e.g., capturing population-level Medicaid claims data and zip code-level data on developmental screenings and well-child visits to help the EL Hubs identify problem areas and target their efforts. The extent of data sharing between CCOs and EL Hubs varies across regions, and the ELD supports Hubs' data work through data requests to OHA.

- **Shared metrics** – A statewide workgroup (the Child and Family Wellbeing Metrics Workgroup) met from September 2014- September 2015 and was tasked with developing metrics that EL Hubs and CCOs could work on together. "For years, there has been this idea that if we share accountability for a metric, it would be a great way to drive collaboration," said a key informant. Building on this work, Oregon is now exploring possibilities for a school readiness measure that can be implemented in the health system. In a separate effort, a CCO incentive metric for Developmental Screening was adopted as a program requirement for EL Hubs.

- **Shared funding**-Various methods for integrating funding occurs, primarily at the regional level:
  - o Medicaid: CCOs receive money based on performance against incentive metrics – they can decide how to use that and sometimes use it in part to fund EL Hubs on a variety of efforts.
  - o State Education and Early Learning funds: At times, EL hubs used funding to train primary care practitioners on screenings using education dollars. Sometimes there was early learning money going to fund reading programs implemented on the health side.
  - o Federal grants (these have ended, though some received a no-cost extension): Center for Medicare & Medicaid Innovation (CMMI) State Innovation Model (SIM), Early Childhood Comprehensive Systems (ECCS) and Race to the Top – Early Learning Challenge grants helped support staff promoting collaboration across sectors, e.g., to train early learning and health care providers on screening.[32]

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[32] RTT-ELC was a grant to the Early Learning Division. OHA was a sub recipient for a project related to increasing developmental screening rates, which initially funded the Coordinator position. The Coordinator position is now jointly supported by General Fund and Medicaid match dollars.

- o Home visiting services bucket – looks different in every state, but funding comes from disparate sources. On the health side, many get federal match for case management and home visiting, and funding was braided (rather than blended) to assist Hub activity.

Motivation and Development

- Governor Kitzhaber – a physician – had strong relationships with key leaders in the state and beyond who focused on new research highlighting the importance of early child development on long term health outcomes; when elected in 2010[33], he created a transition team including a cross-sector state council on early learning (the ELC), with members with education and human services backgrounds. His administration included "a lot of movers and shakers,' said a key informant. "The governor was advocating for the advocates," according to another informant. Advocacy organizations, such as Children's First for Oregon were involved.
- While Health System Transformation was already underway, it made sense structurally to align it with an Early Learning System Transformation. During the time, the Medicaid system was being transformed and creating CCOs, the state legislated a similar Early Learning regional structure providing local flexibility while tied to state-level accountability metrics at the local level (EL Hubs). Collaboration between the Hubs and the CCOs is legislatively mandated.
- After legislation increased Medicaid coverage for children up to 300% of the federal poverty level, OHA created the Child Health Director position—a new, unique role to establish accountability and lead interagency state policies to improve children's health outcomes. A pediatrician with a public health background held the role for 4 years, spending at least 25-30% of time working directly with the ELD including sitting on their EL Council and internal executive committee. While OHA has not had a Child Health Director position since August 2015, much of the work and relationships established by the director continue.

Accomplishments

- The myriad efforts (above) established a "new norm for collaboration at the state and local levels," according to key informants. The new culture of collaboration is based on relationship building and consensus at the "vision level" that health and early learning need to be connected to improve Kindergarten Readiness and other outcomes. The Early Learning staff members are understanding the value and importance of health providers and vice versa. "It takes years of working together to develop a positive relationship and trusts," said a key informant. Collaboration between the regional CCOs and EL Hubs varies across the state but continues to grow.
- The collaboration established a common developmental screening metric for EL Hubs and CCOs. The financial incentive for CCOs, more concrete training for pediatricians on the screening, and CCO data helping to identify gaps in screening for the EL Hubs, have reportedly helped increase screening rates among 0-3 year olds within Medicaid from 21% in 2011 to 62% in 2016. Stakeholders are looking for more metrics to apply shared accountability.

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[33] Democrat John Kitzhaber, MD, served as Oregon's governor 1995-2003, 2011-2015, and briefly before resigning in 2015.

- Though unable to overcome data obstacles, CCOs and EL Hubs are using CCO data to identify opportunities for collaboration, e.g., finding gaps in utilization broken down by county and school district to conduct targeted outreach.
- One region where the CCO is the backbone organization for the EL Hub (Yamhill) has achieved improvements in coordination and intake around referral processes for all of the various community-based and early learning services. The fully integrated CCO/EL Hub has an effective system for triaging families using only one referral form, with a feedback loop back to the referring entity, and weekly or monthly meetings across the team of providers to match families into the most appropriate programs.

Barriers and Challenges

- Change in Governor with new priorities, high-level vacancies and new agency leadership have somewhat slowed the earlier efforts; this was accompanied by a budget shortfall that reduced staffing and increased competitiveness between agencies.
- The CCO and EL Hub regions are not aligned over geographic regions, making working partnerships more challenging.
- According to an informant, health plans or CCOs created by health plans have limited interest in major efforts related to children because they are not an expensive population, and children with special health care needs comprise a very small portion of their membership. Similarly, health plans/CCOs often do not focus on prevention, according to an informant who noted, "The prevention argument is lost on plans, yet prevention is the key to intergenerational change."
- Another informant noted that disability/family advocates in Oregon have been frustrated with the inability of the CCOs to provide adequate coordinated care for children with disabilities. Focused efforts targeting coordination for CYSHCN and families are needed.
- The "community voice," particularly among racial and ethnic subpopulations, is not as robust as it could be, according to a key informant, despite substantial work to engage communities around the state and legislation that created structures intended to ensure the family involvement. More work is needed to reduce disparities.
- There are substantial barriers to tying the same performance metrics to financial incentives across sectors, related to:
  - Different decision-making processes and timing of performance measurement across authorities and sectors;
  - Large discrepancy in resources between the CCOs and the EL Hubs; Early Education does not have the funding or capacity to fully pursue collaborative efforts. It does not have its own data system (in part because there is no "enrollment"), which is a major impediment in working with the CCOs. "They do not know their population," said a key informant. Early Learning has multiple small funding streams, so it has difficulties in coordination and looking at shared outcomes; even among CCOs funding is lacking for collaborative initiatives.
  - Technical data system constraints and privacy rules limit data sharing. Despite a fairly robust state-level database, there is limited Medicaid data and no education data. Further, "Health Insurance Portability and Accountability Act (HIPAA) and Family

Educational Rights and Privacy Act (FERPA) restrictions pose major challenges," said a key informant, precluding the sharing of patient-level data across sectors. Instead, there are a number of regions that have various forms of agreements that enable the EL Hubs to access aggregated data specific to developmental screening and care coordination for children at risk for developmental delays.

o Implementing shared metrics tied to financial incentives raises difficult questions such as: Who is accountable? What are the health aspects the CCOs can be held accountable for? What are the early learning components? What are the thresholds? How would money flow?

- The state gave significant flexibility to CCOs and EL Hubs to develop collaborations and evolve naturally over time; but the state's "hands off" approach may also result in slower progress and could benefit from greater sharing of best practices around the state, according to a key informant.

Next Steps and Sustainability

- Cross agency work is expected to pick up again when a new leadership positions at the Early Learning Division and OHA are filled and integrated in the work.
- In addition to continuing the collaborative developmental screening metric, a major focus is on kindergarten readiness. The Child Systems Collaboration Coordinator will be expanding the early childhood focused strategy into the technical assistance work that the Transformation Center provides to the CCOs. She will work closely with the Office of Health Analytics on implementation of early childhood metrics for the CCOs to identify the linkages and connections with the EL Hubs and Early Learning metrics.
- Through a statewide public health modernization process, the state is trying to improve alignment between the CCOs and EL Hubs and connect them to public health and the local public health systems.

Lessons: Key Ingredients

- Leadership from highest level (governor, agency director, or agency division head) to local level: "When you don't have the federal and state leadership, it is important to increase local engagement and diverse stakeholders," said a key informant.
- Legislation on cross-sector and coordination of services, with resources (after cornerstone legislation establishing EL hubs, CCOs, policy body): Policymakers put in legislation a requirement for cross-sector collaboration between EL Hubs and CCOs, school districts and business partners etc. Having a similar structure (regional CCOs and EL Hubs) is helpful but geographic overlap is a challenge
- Sustainable structures for both policy guidance and staffing to see the work through:
  o Cross agency governance committees at the state level can have a large impact if they are meeting regularly and have the right purview and goals.
  o A full-time position to lead interagency work (i.e., not added to other responsibilities), and with resources is instrumental; in Oregon, this was initially the Child Health Director role, this work continues with the Child Systems Collaboration Coordinator, early

childhood policy lead, Maternal & Child Health Manager/Title V Director, and other positions.

- Data sharing, common metrics, and incentives: Various EL Hubs and CCOs work together to improve their common goal of increasing developmental screening rates, which is a pay for performance metric for CCOs and a program requirement of many early learning system partners. Pulling and sharing data at the local level has been instrumental in understanding where additional outreach is needed.
- Strategic investment in early childhood health and learning: With significant health care funding, the CCOs are in a position to lead the discussion, devote resources, and establish early childhood as a priority across sectors.
- Local Relationships: With state-level support, numerous CCO-EL Hub collaboration strategies can and should be implemented at the local level, such as:[34]
  - Involve cross-sector representatives in the decision-making bodies (board, committees);
  - Regularly meet and communicate to keep each other apprised of activities, funding, issues of mutual concern; host roundtable discussions and brown bag lunches to build relationships as well as keep each other informed;
  - Build shared tasks and activities into strategic work plans, such as required Community Health Improvement Plans and outreach efforts;
  - Identify mutually relevant data and data collection processes, establish multi-disciplinary meetings between data professionals across the organizations, and develop standard release of information that allow data sharing;
  - Coordinate to co-host trainings and professional development for community partners;
  - Identify community partner efforts that align with both organizations and consider shared financial assistance that leverages resources;
  - Share staff by creating a complementary part-time position and share the expenses;
  - Apply for a collaborative grant for a fundable project that does not use existing financial resources of either partner organization.

Resources

Website: Early Childhood Developmental Screening, Early Childhood Systems Alignment, Oregon Health Authority, http://www.oregon.gov/oha/PH/HEALTHYPEOPLEFAMILIES/BABIES/HEALTHSCREENING/ABCD/Pages/early_childhood_systems.aspx

The State of Collaboration: A handbook for cross-sector partnerships between Oregon's coordinated care organizations and early learning hubs, Oregon Health Care Authority, April 2017,

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[34] Based on key informant interviews and Oregon Health Authority: Public Health Division. (2017, April). The State of Collaboration: A Handbook for Cross-Sector Partnerships between Oregon's Coordinated Care Organizations and Early Learning Hubs. Retrieved from http://www.oregon.gov/oha/PH/HEALTHYPEOPLEFAMILIES/BABIES/HEALTHSCREENING/ABCD/Documents/OHA-9410-HUB-CCO-Handbook-Final.pdf

http://www.oregon.gov/oha/PH/HEALTHYPEOPLEFAMILIES/BABIES/HEALTHSCREENING/ABCD/Documents/OHA-9410-HUB-CCO-Handbook-Final.pdf

Bridging Health Care and Early Education System Transformations to Achieve Kindergarten Readiness in Oregon, National Academy for State Health Policy, October 2014, http://www.buildinitiative.org/Portals/0/Uploads/Documents/102414%20Final%20BUILD%20Oregon%20NASHP%20Brief.pdf

6. Washington State: CYSHCN Flag in State Data System

Leveraging existing data sharing agreements to improve data linkage among local health departments, Medicaid and web-based data system to better identify children and youth with special health care needs (CYSHCN)

Model or mechanisms: Leveraging existing data sharing agreements across state and local entities to "flag" CYSHCN for care coordinators

State Agencies: Department of Health (DOH), Health Care Authority (HCA, the Medicaid agency) and Department of Social and Health Services (DSHS)

Motivation: With the transition of CYSHCN to Medicaid managed care several years ago, the health and Medicaid agencies saw an opportunity to apply a decades-old mandate for Title V and Medicaid to share data to improve data linkages to better identify CYSHCN

Accomplishments: Enhanced an existing tool for care coordinators that improves identification of CYSHCN, enhancing care coordination. The percentage of CYSHCN identified by DOH who are also identified in the Medicaid data systems increased from 40% to 90%

Challenges: Building linkages between health department and Medicaid data systems, requiring detailed technical efforts

Lessons: Effort aligned with state-level push for greater collaboration. Claims data can be meaningful as long as limitations are understood, and when fed into web-based multi-agency data sharing platform can be a powerful tool and is sustainable at a relatively low cost.

The state Department of Health (DOH) worked with the Health Care Authority (HCA, the Medicaid agency) to better link local health department, Neurodevelopmental Center, maxillofacial review board and some newborn screening program data that can identify CYSHCN to the Medicaid agency's Provider One system, creating a CYSHCN "flag" that is then transmitted to Managed Care Organizations (MCOs) and the state's web-based PRISM care coordination support tool. Washington first built on the state's existing data sharing agreements that underlie its extensive Predictive Risk Intelligence System (PRISM) data system. Care coordination staff at MCOs can access PRISM, a web application maintained by Department of Social and Health Services (DSHS), and sort data to identify CYSHCN. This enables them to better leverage the web application to support care coordination for children with special health care needs.

Collaboration Model and Mechanisms

- **State Agencies involved**:
    - DOH, HCA and DSHS
- **Non-state entities involved**:
    - Local health departments that serve CYSHCN including local neurodevelopmental centers, maxillofacial review boards, and some newborn screening.

- **DUAs/ Data Sharing:** The CYSHCN flag is visible both in the Medicaid enrollment file that MCOs receive and in the web-based PRISM application:
    - Through an existing data sharing arrangement with the DOH and HCA, data is combined from the local Child Health Intake Form (CHIF) database, which gathers claims data for CYSHCN who are receiving services through the local health departments, neurodevelopmental centers, the Department of Health's Newborn Screening Program, and the Maxillofacial Review, data sources which can help identify CYSHCN. The information is tracked in the Child Health Intake Form (CHIF) database, a requirement for the Title V Maternal Child Health Block Grant.
    - The key steps in this effort were:
        - Assuring that data systems for Children with Special Health Care Needs have a patient identifier shared by the state Medicaid Management Information System (MMIS)
        - Creating a flag in the MMIS that can be used in other applications
        - Including the flag in other data systems or extracts, including the monthly enrollment files to MCOs to enhance their internal systems and the PRISM care coordination application.
    - Beginning the Fall of 2015, the DOH asked the local health departments to begin collecting the ProviderOne number for all children in the CHIF system. This work—conducted through an existing data sharing agreement—enabled this local data to be better matched against ProviderOne, an information exchange program between the Automated Client Eligibility System (Automated Client Eligibility System, the MMIS) and HCA, to identify Medicaid CYSHCN. HCA changed its contracts with the local health departments to require them to use the same identification number for children as is used in Provider One, which improved the matching. Technical consulting to make changes to the Provider One interface to ensure that this happened smoothly required perhaps $60,000 to $80,000 in funding, which was eligible for a 90/10 Medicaid match.
    - Once Provider One incorporated DOH data identifying CYSHCN, that data flag was then shared with Research and Data Analysis (RDA) and DSHS to be uploaded into the larger PRISM system along with the other Medicaid data it incorporates. PRISM is a web application that can be accessed by care coordinators at MCOs. MCOs, behavioral health organizations, and leads for the Health Home program all have access to the flag and sorting function, but it was instituted primarily for use by MCOs. The CYSHCN flag can be viewed only by care coordinators who are responsible for triaging a Medicaid member for care coordination (currently 479 people). The Provider One data is also shared into MCOs' MMIS via the 834 enrollment file.
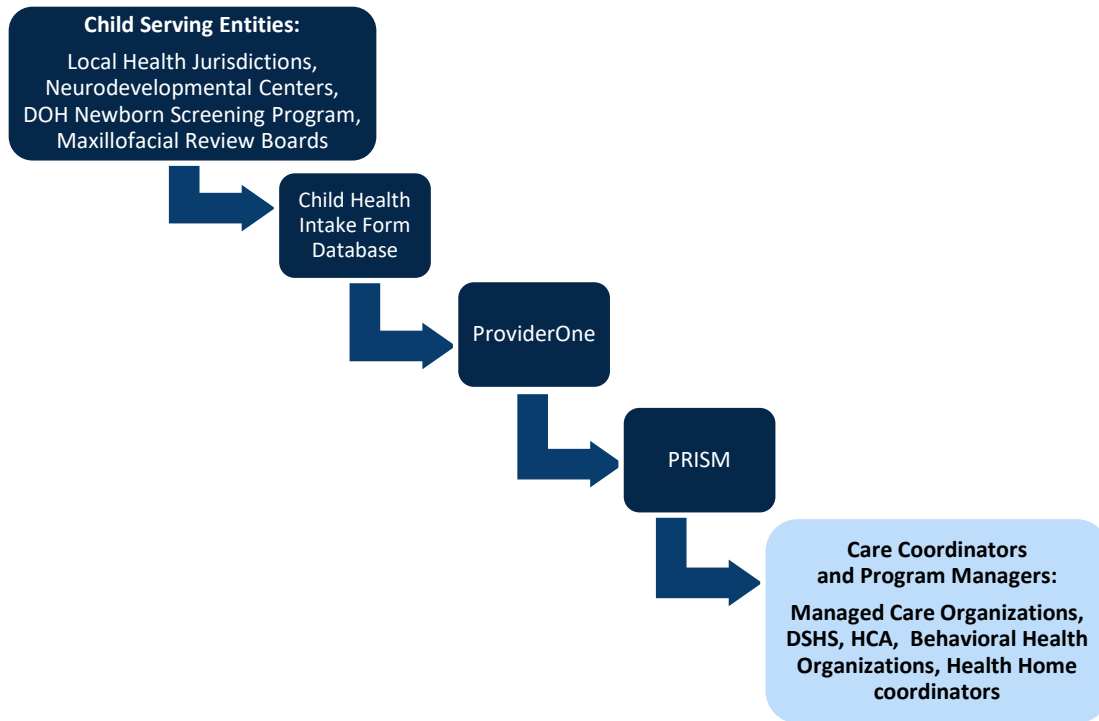
Source: Washington State Department of Health, September 2017.

- o PRISM includes information drawn from eligibility data, claims and encounter data, and long-term services assessments, including:
    - Key medical and behavioral health risk factors
    - Prospective hospital admission risk model
    - Medication adherence dashboard
    - Detailed eligibility and demographic data
    - Office visits
    - Prescriptions filled
    - Inpatient admissions
    - Outpatient emergency room visits
    - Long term care services
    - Skilled nursing facility services
    - Laboratory
    - Provider list with links to contact information
    - Mental health services
- o Access to the secure on-line PRISM system is limited based on the care coordinator's duties and employer, and data in the application cannot be transmitted further electronically.
- **Committees, Structures**
    - o Currently there is not a formal structure for ongoing cross-agency communication on Children with Special Health Care Needs. It is ad hoc based on need.
    - o When the effort to develop PRISM started, roughly ten years ago, there was a steering committee made of representatives from agencies to help develop it, including to address

how data sharing could be done while meeting Health Insurance Portability and Accountability Act (HIPAA) requirements.

- o   At this point it is so institutionalized that they only touch base if there is going to be a major change. Multi-agency contracts clearly define acceptable use of information and how it all meets HIPAA requirements.

- **Communication**:
  - o   **Interagency communication** – Currently communication is ad-hoc, without a formal structure. To achieve the changes to Provider One that allowed the CYSHCN flag, DOH staff met with HCA staff and made the case that this change was covered under the existing data agreements. DOH staff then worked on an ongoing basis with the MMIS staff to support making the tweaks necessary for the sharing to work smoothly.
  - o   **Local level engagement** – Local health jurisdictions hold quarterly meetings for each of four regions that provide CYSHCN services. The state health department coordinator for those meetings communicated to the field about the changes being made to use local data to flag CYSHCN in Provider One.
  - o   **Family engagement –** Managed care organizations engage with families through their established advisory structures.

- **Funding arrangement** – Agencies split the cost of PRISM out of their administrative budgets. Long-established MOUs enable the agencies to share the costs and are updated each budget cycle. The number of PRISM users has steadily increased, and growth is expected to continue. The Medicaid agency received a 90/10 federal match for the cost of changes to the MMIS that enabled the flagging of CYSHCN.

Motivation and Development

- This effort to better use information from local health departments to inform MCO efforts to identify CYSHCN built on the authority state officials saw in a decades-old mandate for Title V and Medicaid to share data.[35] Its implications have changed over the years as technology has evolved, but with the transition of CYSHCN to Medicaid managed care several years ago, the health and Medicaid agencies saw an opportunity to apply this requirement to better identify CYSHCN.

- The PRISM system already existed, staff across the publicly funded health care system knew how to use it, and there was broad support for maximizing its impact to improve care coordination.

- The effort, which began in Fall 2015, also aligns with the state's broader efforts to measure factors that affect health, including social determinants – there is a broad push to better utilize data across silos.

- The key to creating a better identifier for CYSHCN was to link DOH data to the MMIS in a more actionable way using a clear patient identifier, without necessarily establishing a new system.

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[35] 42 CFR 438.208, *Coordination and continuity of care.* This section includes requirements that states "Share with other MCOs, PIHPs, and PAHPs serving the enrollee with special health care needs the results of its identification and assessment of that enrollee's needs to prevent duplication of those activities."

This connection had been ineffective in the past, but once they got a better interface, it was effective.

Barriers and Challenges
- Finding ways to identify key linkages in the system that needed to be built was a challenge – connecting the DOH data with MMIS was central. It was a detailed process but persistence led to success.
- Getting clarity on what HIPAA allows and increasing the comfort level across agencies and users was a challenge in the initial development of the PRISM system, but that is now well-established. Contract language including data security and confidentiality details is the key vehicle for defining responsibilities, and user access is strictly controlled.

Accomplishments
- This effort created a useful tool that supports better care coordination through improved identification of CYSHCN for care coordinators. It could be enhanced in the future to incorporate more kinds of data.
- The percentage of CYSHCN identified by DOH who are also identified in Provider One increased from 40% to 90% by the Fall of 2016.

Next Steps and Sustainability
- This linkage is sustainable – there is no grant funding for the broader PRISM system, and key informants anticipate no problems with agencies budgeting for it.
- DOH would like to further assess how managed care organizations use the CYSHCN flag and any resulting improvements in service coordination. They met with the MCOs in 2016 to discuss strategies to use PRISM to improve care, and felt that many promising ideas emerged.
- They would like to incorporate more data sources, including on social determinants, from the many state data sources that are available.
- PRISM aligns with broader state efforts to synthesize data and use it to improve outcomes, across health, economic and other siloes. This will also mesh with likely increasing federal emphasis on paying for outcomes. Enhancing identification of CYSHCN is in line with exactly the type of efforts that statewide collaborations like this are intended to enable.

Lessons: Key Ingredients
- There is strong impetus at the state level, from the governor's office, for this type of effort, and this has been the case for many years. "In Washington State, we look for opportunities to collaborate," one interviewee said. Willingness to push tirelessly to maximize collaboration helped achieve the new linkages.
- This was in some ways not a dramatic departure from sharing of client demographic data that had occurred in the past – so it helped to be able to build on that.
- Key informants expressed that the type of data (claims primarily) that is shared through PRISM can be quite powerful. It is key to clearly define the limitations of this type of data and make clear to users that they must use their clinical judgment as well.

- Other states may be spending far more to create shared electronic health records systems, but PRISM is a relatively low-cost, web-based alternative. This is sustainable at a fraction of the cost of an integrated electronic health record and in some cases (e.g., home and community-based services assessments, other non-health data) has more potential to capture a wider range of variables.
- State agency staff who spearheaded this highlighted the value of their ongoing personal relationships across agencies. They also noted that many people who work on these issues are parents of CYSHCN themselves, adding a personal perspective that can help support this type of effort.

APPENDIX B: KEY INFORMANTS AND INTERVIEWEES

The authors are grateful to the following state officials, advocates, experts, and other individuals who generously shared knowledge and insights, informing the state collaboration profiles:

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- Cathy Kauffman, Principal, Health Management Associates and former Administrator, Office of Client and Community Services/Healthy Kids, Oregon Health Authority
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- Kate Taft, MPH, Associate Director, Child & Adolescent Health, Association of Maternal and Child Health Programs

- Margaret Tatar, Principal, Health Management Associates

- Karen Van Landeghem, MPH, Senior Program Director, National Association of State Health Policy