A Legal Approach to Sharing Health & Education Data

Getting to Yes: Creating an Intergovernmental Agreement for Data Sharing Between the Chicago Department of Public Health and Chicago Public Schools
Introduction

A growing body of research indicates that education and health are inextricably linked. Improving student health outcomes related to asthma and other chronic illnesses leads to improved academic performance and attendance, and the reverse is also true—higher educational attainment creates opportunities for better health.\(^1\)

This connection between education and health outcomes makes the Chicago Department of Public Health (CDPH) and Chicago Public Schools (CPS) natural partners in improving the lives of all children in Chicago. Education was a major focus of CDPH’s Healthy Chicago 2.0 plan, which is building a movement to bring city agencies together to address the root causes of poor health in Chicago. Similarly, CPS, the fourth largest school district in the country, has made it a priority to focus on improving student health. In 2010, they formed the Office of School Health and Wellness to remove health-related barriers to learning and in 2017, passed an updated school wellness policy to promote healthy environments for students. CDPH and CPS have a long history of collaborating on interventions with shared goals. In 2002, CPS entered into several intergovernmental agreements with CDPH, providing limited sets of student data to CDPH on a case-by-case basis so that they could more effectively deliver a variety of health services for students, like monitoring school-based dental and vision programs and conducting health research related to childhood obesity and vaccinations. In 2009, with funding from the Otho S. A. Sprague Memorial Institute, the two agencies established a Chief Health Officer position that reports to both CPS and CDPH and is now funded by both agencies, helping to further streamline efforts that bridge the health and education sectors. These collaborative efforts helped set the stage for an innovative intergovernmental agreement between CDPH and CPS that allows them to share their data on an ongoing basis with a common vision of improving students’ well-being. The story behind this process is documented in this brief.

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A History of Sharing Data

One of the roles of the school district is to provide assistance to parents and guardians in meeting state requirements with a variety of health services, including dental, vision and hearing.

To do so, CPS often partners with CDPH to provide services in schools that parents and guardians may not be able to obtain within their communities. For example, once school-based dental exams and vision screenings are conducted, CDPH uses data from CPS to offer case management and quality assurance services to ensure that students receive referrals for follow up dental care and vision exams.

In addition, CDPH routinely analyzes student health data collected in schools and shares the results with CPS so that district administrators can better understand the underlying medical issues that lead to chronic absenteeism, behavioral issues, and poor academic performance and adjust students’ educational environment appropriately.

CDPH epidemiologists can also use educational data to track student health outcomes and conduct more robust analyses to examine relationships with other related factors. Together, both entities are interested in understanding the impact of policy changes, such as whether implementing new standards for screen time, physical activity, and nutrition in early childhood centers results in lower obesity rates as children enter kindergarten.

Although the two entities have already spent over a decade implementing intergovernmental data sharing agreements, they lacked a broader legal agreement that would allow the school district and health department to share relevant data on a
routine, ongoing basis. As a result, every time CPS and CPDH partnered on a new project that required data from the other entity, they would have to obtain approval from the Chicago Board of Education and City Council. Considering how often CDPH and CPS identify a need to share information and resources, staff envisioned a pathway to align and streamline data sharing efforts that would ultimately result in a more efficient process.

A New Legal Approach

Motivated by the desire to move projects forward that would improve health and educational outcomes for Chicago students, CPS and CDPH set out in 2015 to develop an agreement that was broad in scope and would act as an umbrella to share commonly used data types between the two entities.

The Family Educational Rights Privacy Act (FERPA) is a law that requires schools to have written permission from the parent (or an adult student) in order to release information from a student’s education record for most purposes. This often creates barriers—real and perceived—to data sharing. However, CDPH and CPS were able to develop an agreement to allow data sharing without consent by relying on an exemption under FERPA, and a provision within FERPA that allows the district to share student identifiable information without parental consent to a contractor, consultant, volunteer or other party to whom they have outsourced institutional services or functions.

At CPS, the Office of Student Health and Wellness was the lead department involved in developing the intergovernmental agreement. They also worked key staff in collaboration with the Law, External Research, and IT departments. Adding to the momentum, a new Medical Director was appointed within the CDPH Office of Adolescent and School Health. Her programmatic goals were closely aligned with the effort, so she served as a liaison between the attorneys at both agencies to ensure that the agreement was moving forward in a timely manner.

Because one of CDPH’s primary roles would be to conduct the ongoing data analyses, they led the effort to identify which data elements should be included under the agreement. Staff across various CDPH offices—including Maternal, Infant, Child & Adolescent Health; Informatics and Health IT; Innovation; and Epidemiology—made a list of all the current and potential use cases for educational data. Gathering input from several CDPH departments ensured that they could cover all their bases and remove potential data sharing barriers that may be encountered down the road.

The DASH project led by CDPH, which uses a predictive model to identify young children at risk of being lead poisoned, was one of the initiatives that helped determine which data elements and potential data applications should be included. Other use cases included analyses of body mass index (BMI) data, determining immunization coverage levels, and informing chronic disease prevention and treatment programs. More broadly, CDPH envisioned that the data could be used to identify groups or areas in need of resources, guide intervention development and implementation, and evaluate the impact of programs and policies on health outcomes, absenteeism, and school performance.
Specific data elements identified that would be transferred between CPS and CDPH include:

- Demographics data
- Immunization data
- Data from physical exams
- Chronic disease data
- Academic data
- Birth data
- Vision and hearing data
- Oral/dental data
- Social determinants data (e.g. homelessness, eligibility for financial assistance, school mobility, truancy, suspensions, behavioral misconduct)

After CPS attorneys reviewed the list of desired data fields, most of the data elements requested by CDPH remained in the final draft. After two years of development, the intergovernmental agreement was signed, providing a more standard data reporting framework and timeline that would benefit both parties long-term.

Tips to Get to Yes

For other communities interested in taking a similar data sharing and legal approach, CDPH and CPS shared key elements for success.

- **Identify leaders who can champion the effort:** Staff from both agencies emphasized the importance of building relationships with key influencers. For example, CDPH capitalized on a critical moment when a new Medical Director was appointed within the CDPH Officer of Adolescent and School Health. She was able to act as a liaison between the two entities, continually championing the effort and moving it forward.

- **Bring resources to the table:** CDPH epidemiologists have the expertise to conduct in-depth, robust data analyses that can be used to improve student outcomes and lower costs. This capacity made the data sharing partnership a win-win because CPS could take advantage of complex analytic expertise within CDPH, and CDPH was able to gain access to CPS data that could help them better understand and pinpoint health inequities among children in Chicago Public Schools.

**FIVE TIPS TO GET TO YES**

1. Identify leaders who can champion the effort
2. Bring resources to the table
3. Build trust by clarifying how data can be shared publicly
4. Consider if the project qualifies for a FERPA exemption
5. Identify shared values among participating partners
• **Build trust by clarifying how data can be shared publicly:** CDPH agreed that before any analyses of CPS data would be published, the publication had to be approved by both parties. This action helped alleviate concerns from CPS about releasing de-identified data that would reveal sensitive information, such as obesity or immunization rates at specific schools.

• **Consider if the project qualifies for a FERPA exemption:** The intergovernmental agreement focused specifically on data sets that would support CDPH in providing services that directly help advance CPS’ educational mission. As a result, it was eligible for a FERPA exemption which allowed the school system to share student information, as long as data was being used with the intent to improve educational efforts. Learn more in this [blog post](#) from the Network for Public Health Law.

• **Identify shared values among participating partners:** The intergovernmental agreement was based on a set of specific short-term, mid-term, and long-term goals that were of value to both the health and education sectors, with students’ needs as the primary focus. Clearly defining measures of success based upon outcomes for children helped foster alignment and buy-in across both agencies.

**Conclusion**

It’s clear that healthy students are better learners, and with the intergovernmental agreement in place, both parties are excited about the possibilities for using a variety of data sets to help Chicago students succeed. In 2018, CDPH agreed to conduct data analyses related to body mass index (BMI) and dental/oral health which will inform CPS policies and programs. CDPH will also continue to monitor outcomes related to school hearing, dental, and vision programs.

Although FERPA’s regulations can sometimes discourage communities from taking action, this Chicago collaboration provides one potential pathway for developing a proactive data sharing and services agreement with the education sector that eliminates common roadblocks to implementing health programs in schools while protecting students’ privacy.

**REFERENCES**


2. 34 CFR §99.31(a)(6)