

JUNE 23, 2021

# DATA-SHARING BARRIERS TO ACCESSING SPECIAL EDUCATION

PREPARED BY

THE COLLABORATIVE FOR CHILDREN'S HEALTH POLICY

*With funding from  
The Center for Bioethics and Medical Humanities  
The Feinberg School of Medicine  
Northwestern University*



The Collaborative  
for Children's  
Health Policy

## Contents

Executive Summary.....	2
Background: IEPs and 504 Plans .....	5
Evaluation for Eligibility .....	6
Role of Pediatric Providers.....	8
Legal Considerations .....	9
Literature, Interviews, and Data .....	11
Policy and System Responses .....	13
Conclusion & Next Steps.....	15
Appendix 1: Accessing Special Education Services in Illinois .....	16
Appendix 2: Regulations and Resources .....	17
Reference List.....	18

## Executive Summary

**Purpose:** The Collaborative for Children’s Health Policy is a statewide organization composed of over 700 stakeholders<sup>1</sup> that focus on the health and wellbeing of children. The Collaborative has a goal of ensuring that children with disabilities, who have had a right to a free education for decades, exercise that right. However, the Collaborative has determined that Illinois lags behind other states in some areas of equitable educational practices for students with disabilities, particularly for children aged 6-21. In addition, minorities in Illinois have less access to the “least restrictive educational environment” than non-minorities.

As this paper will show, access to appropriate services and supports is heavily dependent on parents’ and guardians’ ability to navigate a very complex system and to advocate for their child. Part of this challenge is the parents’ role in communicating their child’s needs to the school district and acting as a go-between for health care providers and school districts.

This white paper seeks to lay out these concerns, to describe the reasons underpinning them, and to offer possible solutions. We focus on opening up more fluid data-sharing between health care providers and schools to reduce the burden on the parent. This is one way to increase access and decrease inequality.

**Background on IEPs & 504 Plans:** Individualized Education Programs (IEPs) and 504 Plans are the primary mechanisms helping children with disabilities secure accommodations and services in schools. Federal laws establishing and reauthorizing these programs include the Individuals with Disabilities Education Improvement Act of 2004 (IDEA), the Rehabilitation Act of 1973, and the Americans with Disabilities Amendments Act of 2008. These laws establish the right to a free, appropriate, public education (FAPE) in the least restrictive environment (LRE). IEPs and 504 plans have many similarities but key differences as well. IEPs are typically harder to obtain due to more specific eligibility requirements and may involve more people due to services or specialized instruction not offered in a 504 plan.

**Evaluation for Eligibility:** Both IEPs and 504 Plans require children to be evaluated for eligibility before a plan can be created. Schools screen students and authorize an evaluation when warranted. A parent or guardian can also request an evaluation, though many do not know about this right. If a parent or guardian requests an evaluation, the school is required to respond within a specific time period, either authorizing the evaluation or stating why it is not warranted. In the latter case, parents/guardians can appeal. During an evaluation, a trained professional must use appropriate, validated assessments.

**Role of Pediatric Providers:** Pediatric healthcare providers often contribute to creating IEPs and 504 Plans in several ways. Foremost is by identifying special needs during routine well child visits. Healthcare providers may refer parents to social workers or resources necessary to learn about the law and pursue an evaluation. Providers can also directly educate parents and guardians on their child’s eligibility for an IEP and/or 504 Plan, and their rights in advocating for those plans. Before communicating health

---

<sup>1</sup> Founding members include Ann & Robert H. Lurie Children’s Hospital of Chicago, EverThrive Illinois, the Illinois Chapter of the American Academy of Pediatrics, Start Early (formerly the Ounce of Prevention), and Voices for Illinois Children. Lurie Children’s Hospital drafted this White Paper.

information to the child's school, health providers must obtain the parent or guardian's consent. Communicating with the school can be in the form of a letter or, more powerfully, attending an IEP meeting at the request of the parent/guardian which could potentially occur via telehealth. Because they are not reimbursed for this, however, providers do not attend IEP meetings as often as they would like. Healthcare providers can also serve as evaluators at school-based clinics or on a contractual basis with the school.

**Legal Considerations:** Federal and state laws impose requirements on the sharing of health information. For instance, the Health Insurance Portability and Accountability Act (HIPAA) allows a provider organization to share protected health information (PHI) upon authorization by the patient, or for certain other authorized purposes. On the school side, the Family Educational Rights and Privacy Act (FERPA) and the Illinois Student Schools Records Act similarly imposes requirements on the school's ability to share education information about a student with other parties. Additionally, all Illinois, there are additional requirements for information that is often deemed sensitive or highly confidential. For instance, the Mental Health and Developmental Disabilities Confidentiality Act is an Illinois law that places further limitations on physicians, psychologists, nurses, and others sharing information about mental health services provided, unless they first obtain parental written consent to share the specific mental health treatment information. Schools must still provide accommodations and services to students with disabilities, including free, appropriate public education even during the COVID-19 pandemic, regardless of whether the school provides in-school or remote teaching.

**Literature, Interviews, and Data:** IEPs and 504 Plans are quite prevalent: among those aged 6 to 21, 9.5% of students nationally and 10% of students in Illinois have an IEP. A further 2.5% of Illinois students have just a 504 Plan. Children aged birth through 36 months of age served under Part C account for 3.5% of children in this age group nationwide and 3.8% of children in Illinois. While a large number of students are receiving accommodations and services under these plans, challenges remain. Parents report that the process of securing a service plan is exhausting and makes them feel disempowered. Even well-written plans may not be fully implemented for a variety of reasons that frustrate parents. Finally, inequalities exist. Illinois students with IEPs spend less time in regular classrooms than their peers nationwide; these figures are even worse for African American and Hispanic/Latino students. Nationwide, students with disabilities are more likely to be suspended than are non-disabled students.

**Policy & System Responses:** While most policy and system responses do not directly address the issue of data sharing in regards to IEP and 504 Plan development, models from other systems can be illustrative. Chicago Public Schools and the Chicago Department of Public Health built a comprehensive data-sharing agreement for mutual benefit. Other cities and counties have had similar collaborations. Additionally, 11 states have created ways for schools to use their health department's immunization information system, eliminating the need for the schools to independently determine whether students have all necessary vaccinations. Health information exchanges provide another possible avenue for data sharing (though Illinois does not have a health information exchange). Similarly, the databases for special education and Medicaid waivers could be designed to "speak" to each other.

**Conclusion & Next Steps:** The Collaborative for Children's Health Policy proposes to identify an efficient means of facilitating the exchange of information between healthcare providers and schools to promote IEP and 504 Plan development for school age children in Illinois. Possible solutions include:

1. Recommend the expansion of the ICARE (vaccination) data system in Illinois.

2. Advocate to allow schools to gain access to the data available through health information exchanges.
3. Build a new system for efficiently sharing the appropriate amount of data between schools and health care providers, in a secure manner.

Each strategy has advantages and disadvantages. The importance and support of parental consent is essential. The Collaborative for Children's Health Policy's will evaluate these strategies in light of the context provided in this white paper and their own expertise.

## Background: IEPs and 504 Plans

While most people working with children are familiar with Individualized Education Programs (IEPs), and many are familiar with 504 Plans, this section provides a basic introduction to these key concepts.

Individualized Education Programs, or IEPs, arose from Part B of the Individuals with Disabilities Education Act, which has origins in the 1970s and was most recently updated in 2004. The law is designed to ensure children who have disabilities that affect their ability to learn can access a free, appropriate public education (FAPE) in the least restrictive environment (LRE). In practice, however, this does not always happen.

504 Plans, which get their name because they are described in section 504 of the Rehabilitation Act of 1973, aim to provide accommodations for children who have disabilities or medical problems interfering with their education so they can access free, appropriate public education. Children with 504 Plans may not experience learning disabilities but may need help with a medical condition during the school day. For example, children with asthma would have 504 Plans to assure they have access to a rescue inhaler at schools. 504 Plans do not require annual meetings and the development and evaluation of individual educational milestones, so they are less involved than IEPs.

Students may have either or both plans. Table 1 shows similarities, while the chart on the next page shows differences.

### Box 1. IEP and 504 Plan Similarities:

Right to a free, appropriate, public education

Children should be educated in the least restrictive environment possible

Federal laws with state regulations implemented at the district level

Parents must be notified if a plan is developed and the plan's contents

Accommodations and services made based on individual's needs and characteristics

Schools not receiving federal funding (such as private K-12 schools) are exempt

**Table 1: Key Differences between IEPs and 504 Plans**

	<b>IEPs</b>	<b>504 Plans</b>
<b>Legislation</b>	Individuals with Disabilities Education Act (IDEA)	Rehabilitation Act of 1973, Americans with Disabilities Amendments Act of 2008
<b>Definition of Covered Disability</b>	Specific categories of disabilities (14 nationwide, 13 in Illinois) mentioned, including specific learning disability, autism, hearing impairment, and others	General Disability definition: "physical or mental impairment that substantially limits one or more major life activities"
<b>Parent or guardian involvement in decision-making</b>	Parents/guardians must be involved, per Federal law	Though parents/guardians are not mentioned in Federal requirements, their participation is required in Illinois
<b>Specific goals for the student's achievement</b>	Set annually with progress towards those goals evaluated at least annually	Not required
<b>Re-evaluation</b>	A full evaluation is required every 3 years. Review is required at least annually	At least every 3 years or whenever there is "significant change in placement"
<b>Higher Education</b>	Stops at the end of high school education	Continues through higher education and includes most private universities because they receive federal funding

## Evaluation for Eligibility

Schools may use the same referral and evaluation process for both IEPs and 504 Plans, or they can use separate processes. The information in this section comes primarily from IEP documents.

Illinois school districts must have processes in place to screen children under the age of 5 to identify those who may need special education and/or Early Intervention services. The extent to which parents are aware of this service and that schools respond to these requests is not known. For school-age children, districts are required to monitor students' eligibility, but they do not have to do an annual screening process.

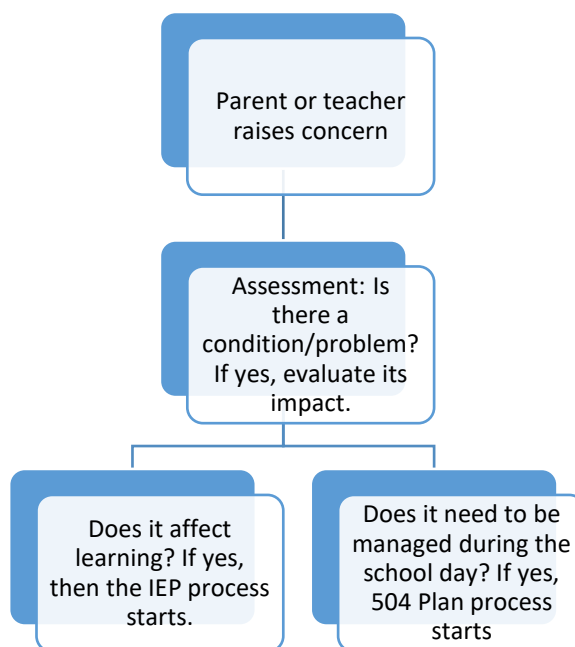
In addition to the screening process, "Requests for evaluation may be made by a parent of a child, an employee of a State educational agency, another State agency, a local school district, or a community service agency."<sup>i</sup> Note, however, that health care providers and mental health practitioners are not included in this list. What providers can do is provide a letter that the parent or guardian can give to the school requesting an evaluation. Additionally, a request for an evaluation does not need to be honored if the district does not believe an evaluation is warranted. In this case, they must notify the referring party of their decision not to evaluate, which the parent or official can then appeal.

Once a decision has been made to evaluate the child, the parent or guardian must give consent to have the child evaluated in Illinois. The evaluation must be completed and the eligibility conference to determine eligibility and develop an IEP must take place within 60 school days of the parent or guardian providing consent.

Evaluation must use multiple, valid and appropriate measures to identify whether and to what extent a child has a disability. The person administering them, typically a school official or a contracted agent, must be trained in their use. The parent or guardian can also obtain a private evaluation. The school then convenes a conference to review evaluation results, determine whether a student is eligible for an IEP, and develop the IEP. All IEP meetings must include parents/guardians, the student if the parent/guardian decides so, a general education teacher, a special education teacher, a school administrator, evaluation personnel, and others with knowledge or expertise about the student. The latter category can include people the parent/guardian invites, such as a healthcare provider.

If the parent or guardian disagrees with the evaluation, they can request an independent educational evaluation conducted by someone not affiliated with the school district, at the district's expense. These evaluations are often conducted by a health care provider, typically a pediatric specialist such as a pediatric neurologist or a cognitive psychologist. If the district refuses to pay for the external evaluation,

**Figure 1: Process for IEP/504 Plan Determination**



or if they allow the independent evaluation but still determine the student is ineligible for an IEP, they must let the parent/guardian know in writing of the decision. At that point, the parent/guardian can obtain a due process hearing to appeal the decision.

#### *504 Plans*

The procedures are less clearly defined for 504 Plans. In the Illinois State Board of Education publication, “Educational Rights and Responsibilities: Understanding Special Education in Illinois,” which is over 200 pages, just six pages are dedicated to 504 Plans. The exact identification process is not detailed in the ISBE document. Thus, schools have much more discretion in how they conduct 504 Plan evaluations.



## Role of Pediatric Providers<sup>ii</sup>

Healthcare providers, particularly primary care pediatricians, play important roles in relation to schools. A critical role is in securing appropriate education services for their patients through an IEP and/or 504 Plan. When a clinical examination reveals that the child may have special needs or have a medical issue that requires management during the school day, the provider can refer the child to a specialist or psychologist for further assessment. They also can educate parents/guardians on IEPs and 504 Plans. Many parents/guardians are unfamiliar with these programs and may not realize that their child qualifies for accommodations or services under them.

The provider cannot disclose protected health information (PHI) to the school without first securing the authorization of the parent/guardian (for more information, see [Legal Considerations](#) below). Where appropriate, such as for teenagers, the patient's authorization should be secured as well. The American Academy of Pediatrics has developed a [referral form](#) that complies with both HIPAA and FERPA. Start Early has developed referral forms for [Early Intervention](#) and [Early Childhood Special Education](#).

One possible barrier related to forms is the signature process: many of them are printed and must be physically carried by the parent/guardian, while others must be faxed. For other forms, electronic signatures may not be accepted, creating additional steps for overworked providers.

When authorization has been obtained from the parent or guardian, the health care provider (typically a primary care provider, pediatric specialist, or child psychologist) may provide information to the school about how the student's condition may impact their education. While this can be done in a letter, the parent/guardian can also ask them to attend an IEP meeting, where their voice can be more powerful and persuasive. Providers can also offer suggestions on ways to accommodate the student, on ways to shape instructional efforts, and/or on services the student may require. However, they cannot mandate which accommodations, specialized instruction, or services the school provides.

A majority of pediatricians indicated they believe it is their role to identify children who may benefit from an IEP or 504 Plan and to educate parents/guardians, but, according to one study, a much lower percentage actually use screening tools or asked parents/guardians if they wanted help obtaining services for their child.<sup>iii</sup> The most substantial barriers are lack of reimbursement for these activities and insufficient training. Aligning incentives and training towards greater involvement therefore represents a promising opportunity.

Pediatric providers can fulfill other roles as well. They may assess a child's need for special education services if they are part of a school-based health center or a consultant/vendor for the district. However, there is a clear delineation about who can provide in-school medical services as part of an IEP: if the child requires medical care to attend school, that care can be provided by a nurse or other qualified person, but not a physician. Finally, if the school secures the authorization to share the results of educational assessments and other information about the student (such as school progress and behavior reports), the primary care pediatrician or specialist can use this information to inform clinical assessment and treatment. However, this level of information sharing back to the provider is the exception, not the rule.

## Legal Considerations

Laws at both the federal and state level impact the process of children obtaining an IEP and/or 504 Plan. Two major laws provide guidelines for sharing of information between health care providers and third parties, such as school officials: The Health Insurance Portability and Accountability Act (HIPAA), the Family Educational Rights and Privacy Act (FERPA) and the Illinois School Student Records Act.

Physicians, specialists, nurse practitioners, and physician assistants know HIPAA well. A key component of the law is the right for patients' information to be kept protected. Protected health information (PHI) includes identifying information about the patient, plus information about testing, diagnosis, treatment, etc. Beyond the purposes of treatment, payment, and healthcare operations, PHI may only be shared with express authorization of the patient (or their parent/guardian for children). Even within these bounds, the amount of information shared must generally be the minimum necessary to accomplish the purpose.

Even though treatments such as therapy may be included in an IEP, education itself is not considered treatment. Consequently, healthcare providers cannot disclose PHI to schools without the authorization of the child's parent or guardian. Healthcare providers are obligated to obtain consent to share information with the school. Many providers have the parent/guardian send a copy of the child's records to the school directly or may facilitate exchange, in-line with the authorization.<sup>ii</sup> While the authorization form is required by federal and state law, it does create an extra step that can be a barrier to a child getting an IEP.

FERPA similarly aims to protect an individual's privacy – in this case, a student's education records. Under most circumstances, the parent or guardian (or student, if they are at least 18 years old or in higher education) must give consent for any of the student's education records to be released to a third party. The law applies to public K-12 schools and nearly all colleges and universities. For K-12 schools, the health records that schools keep, including immunization records and notes by a school nurse, are considered part of the student's education record. Documents and information related to a student's special education under IDEA are also considered education records. Health records at a postsecondary institution are not considered education records if they are used only in the student's treatment and not disclosed to others except for treatment.<sup>iv</sup>

### Box 2. Key Privacy Laws

#### Federal:

Health Insurance Portability and Accountability Act (HIPAA)

Family Educational Rights and Privacy Act (FERPA)

#### State:

Mental Health and Developmental Disabilities Confidentiality Act

Illinois School Student Records Act

Illinois law creates further requirements for sharing mental and behavioral health information. The Mental Health and Developmental Disabilities Confidentiality Act (740 ILCS 110/)<sup>v</sup> allows a therapist (including psychologists, psychiatrists, social workers, physicians, and nurses providing mental health or developmental disability services) to communicate that the person in question is receiving services. The statute indicates "records" are items which cannot be disclosed without the authorization of the patient (ages 12-17) or the parent/guardian. It specifically does not include, "a reference to the receipt of mental health or developmental disabilities services noted during a patient history and physical or other summary of care," in the definition of "records."<sup>vi</sup> Given the ambiguity, therapists may err on the side of

caution and decline to disclose whether they are treating someone, for what condition, and for how long they have been treating them.

#### *Remote Learning during the COVID-19 Pandemic and Beyond*

The COVID-19 pandemic has resulted in many school districts shifting to fully remote or hybrid learning models. Some form of remote learning is likely to continue for some time. Regardless of the model, schools that offer any educational opportunities to the general student population must ensure that students with disabilities still have access to those opportunities. Consistent with the principles of IEPs and 504 Plans, schools should review each child's situation to determine how accommodations and services should be tailored to ensure they continue to have equal access.<sup>vii</sup> Equip for Equality has a [resource page](#) describing educational rights related to remote learning.

## Literature, Interviews, and Data

### ***Prevalence***

IEPs and 504 Plans have become major components of the American education system. In school year 2018-19, 7.1 million students aged 6-21 were served by the Individuals with Disabilities Education Act (IDEA), Part B. This represents 9.5% of all students in the US and its territories.<sup>viii</sup> In Illinois, approximately 298,000 students representing 10% of all students received services under IDEA Part B. An additional 51,000 students had only a 504 Plan, representing 2.5% of all Illinois students (this figure is for the 2015-16 school year, the most recent available).<sup>ix</sup> Nationally, there were 409,315 children aged birth up through 36 months of age served by IDEA Part C, representing 3.5% of all children in that age group. In Illinois, 17,030 children aged birth through 36 months of age served received supports IDEA Part C in Illinois, or 3.8% of all children in that age group in Illinois.<sup>x</sup>

### ***Inequities in Illinois***

Illinois lags behind the nation in assuring students are in the least restrictive environment. Illinois students aged 6-21 do not spend as much time in regular classrooms as do students nationally. Just 52.8% of students aged 6 to 21 with IEPs spend four-fifths of their day in a regular classroom (a US Department of Education measure for the least restrictive environment), compared with 64.0% nationwide.

The problem is worse for minorities. Black students aged 6 to 21 with IEPs in Illinois, the percent of students with IEPs who spend four-fifths of their day in a regular classroom is just 44.8%, compared with 59.5% of Black students nationwide and 55.8% of White students in Illinois. Among Hispanic/Latino students aged 6 to 21 in Illinois with IEPs, 53.8% spend at least four-fifths of the day in a regular classroom, compared with 62.4% of Hispanic/Latino students nationwide.<sup>viii</sup>

Discipline is a nationwide inequity issue. Students with disabilities are twice as likely as non-disabled students to be suspended, and they are more likely be suspended repeatedly. For students of color with disabilities, the inequities are even more stark: Black students with disabilities are more than three times as likely to be suspended as the general student population.<sup>xi</sup> While many factors contribute to these inequities, having better-quality IEPs and 504 Plans may reduce the inequities.

### ***Problems related to initial identification of concerns that may warrant an IEP/504 Plan***

Establishing a need for services and developing the plan (whether IEP or 504) takes sometimes a very long time. Parents describe the process as depersonalized and one in which they lack power.<sup>xii</sup> It can leave parents feeling exasperated and exhausted.<sup>xiii</sup> For IEPs, the requirement of including parents has positive and negative consequences. Their right to be present at the IEP meetings is assured, as the school cannot do anything to bar their participation. At the same time, this also means they have the burden of being present as well. For parents or guardians with limited time, this can be a barrier to their child's plan being developed and implemented.

### ***Problems related to the development of Plans***

Although schools and healthcare providers may transmit information to each other after obtaining parental consent, in practice, the parent/guardian frequently must ferry documents between the two entities (which does not require consent since the parent is the party sharing the documents). This creates an additional burden for families. A Lurie Children's intern conducted interviews with two parents whose children had service plans. One had an IEP, while the other had a 504 Plan. A key theme of both interviews was how much advocacy was required on the parts of the parents. One of the parents described how another parent with less knowledge of the school system would have found it difficult to secure services for their child. The other parent spoke about the tenacity required: "Once you hear no, you think that's it, but it's important to stay persistent and voice concerns. It was most difficult getting into the process and understanding the different facets of it but once the child has a plan it is not hard to navigate from there."

Research has shown IEPs often have goals and objectives that fail to address the problems identified. Moreover, many of the recommended interventions are not evidence-based, while evidence-based interventions are available but not included in IEPs.<sup>xiv</sup> Even if important services and accommodations are included in an IEP, they may not be implemented. For instance, parents and guardians report problems with ensuring busing with qualified personnel on board, such as having someone trained in the use of Diastat or seizure care, or who can support therapeutic behavior protocols that the child has in the IEP.

### ***Problems related to evaluation of Plans' effectiveness***

A group of researchers developed a standardized tool to evaluate IEPs, then used the tool to show that IEP quality was poor across a variety of student and school characteristics. They often lack specific, clear, measurable recommendations and benchmarks for evaluation.<sup>xv</sup> Without those benchmarks, it is difficult to track students' progress. If the parent or guardian can tell their child is falling behind, the lack of benchmarks makes it difficult to demonstrate that additional supports are needed.

## Policy and System Responses

There are few policy and system responses that specifically address data sharing for IEPs and 504 Plans. The ideas discussed in this section therefore respond to different challenges with possible applicability to data sharing for special education plans.

One local example is a collaboration between Chicago Public Schools (CPS) and the Chicago Department of Public Health (CDPH). Although the two agencies had worked together on several initiatives, such as CPS sharing vision screening information with CDPH for case management follow-up, data sharing was piecemeal and fragmented. They identified a need for a more comprehensive data sharing agreement that would lead to a more efficient process. Through a two-year project, they were able to navigate legal requirements, agree on which data would be shared, and decide how data would be reported to the public.<sup>xvi</sup> A key partner was Data Across Sectors for Health (DASH), an initiative led by the Illinois Public Health Institute and Michigan Public Health Institute with support from the Robert Wood Johnson Foundation.

Looking farther afield shows several other examples of collaboration:

- The Allegheny County Department of Human Services created a Memorandum of Understanding with Pittsburgh Public Schools to pool data and allow for better coordination of services.<sup>xvii</sup>
- The UC Berkeley Center for Healthcare Organizational + Innovation Research has produced a data-sharing toolkit based on the framework of Accountable Communities for Health.<sup>xviii</sup>
- A report from the School-Community Health Alliance of Michigan includes four case studies of cities and counties across the country that are in various stages of integrating health and education data in school-based health centers.<sup>xix</sup>
- The National League of Cities has a toolkit for building a coordinated data system for afterschool programs.<sup>xx</sup> An advantage of building a data system is that it allows for customization to meet the program needs more closely. A disadvantage is that it is the more labor-intensive and would likely take the longest to implement.

A challenge of many of the above examples is that they are restricted to the municipal or county level. Healthcare providers who work with patients attending multiple school districts may still run into obstacles even if one or two of their districts have a more efficient process.

A promising model comes from the sharing of immunization records across an entire state. All states have immunization requirements for childcare and/or school settings, and nearly all states have an immunization information system (IIS) to monitor vaccinations statewide. However, they vary significantly in how students' immunizations are recorded and communicated. The majority of states require schools or childcare facilities to collect proof of vaccination and report the information to the local education or health departments. Some, including Illinois, only require aggregate data, not individual records, to be shared. At the other end of the spectrum, eleven states allow schools to use the IIS to verify whether a child has received their vaccinations or not. In Arizona, the health department sends immunization information to local schools. In New Mexico, school nurses can go onto an IIS portal

to access vaccination records. A study suggests that having schools use the IIS would make the IIS more beneficial and reduce the record-keeping and reporting burden on schools.<sup>xxi</sup>

Similarly, health information exchanges (HIE) provide another possible model for the creation of IEPs and 504 Plans. Health Information Exchanges allow health care professionals and patients to appropriately access and securely share a patient’s medical information electronically.<sup>xxii</sup> However, then-Governor Rauner ended the statewide HIE in 2015, partially due to competition from regional HIEs.<sup>xxiii</sup> More recently, the Central Illinois HIE ceased providing services in 2019 after many members indicated its services were redundant.<sup>xxiv</sup>



Another point of potential collaboration is to allow the Medicaid waiver systems “speak to” the education systems—for example, any children with developmental disabilities enrolled in Early Intervention should be auto-registered with PUNS upon graduation from EI (sort of like motor voter systems). Likewise, any students who gets an IEP later than preschool, if it is related to a developmental disability, should be auto-registered with PUNS and be evaluated for Medicaid eligibility. Physicians should be copied on such determinations.

Document design and sharing should also be coordinated. Currently, the types of psychological assessments used in schools are not necessarily the same ones required when a child is being evaluated for home- and community-based services (HCBS) waiver by the Department of Developmental Disabilities within the Department of Human Services (DHS)—in theory, if a child with a developmental disability (DD) has an IEP, the documentation of the DD has been made. DHS should accept school-based evaluations, rather than conducting additional new ones; it is wasteful to duplicate, and unnecessary. To the degree that the two systems (IEP and DD waiver) could overlap, rather than duplicate, we would save money, time, and error.

Likewise, if there were ways for health systems and schools to share health information, families would spend a lot less time on forms, some of which are still done on paper. This is a barrier—it is time consuming for families and for physicians, and often falls out of sync with the child’s annual physical date. If there were some ways to register for some auto-updates with medical homes for kids with IEPs, that would again save time, effort, and ensure more seamless delivery of services.

## Conclusion & Next Steps

This white paper explores the link between data sharing between schools and health care providers in an effort to expand access to free, appropriate, public education in the least restrictive environment. Illinois lags behind national trends in access to special education services, and there is significant inequity in access to these services and supports.

Children in Illinois schools who have or need IEPs and 504 Plans are not always receiving the most appropriate accommodations and services, are not spending as much time as their peers in integrated classrooms and are disciplined disproportionately. The burden on parents to act as advocates and facilitators of information flow is substantial. The process of being assessed and establishing an appropriate IEP can be overly technical, not user-friendly, and lacking in evidence-based practices that would actually address children's needs.

Tackling all of the challenges would be beyond the scope of a single initiative. The Collaborative for Children's Health Policy will instead focus on one important issue: facilitating the exchange of information between healthcare providers and schools to promote the appropriate identification of and planning for youth in special education, and thus reducing the burden on parents.

Policy and system responses could include:

1. Recommend the expansion of the ICARE data system in Illinois. ICARE is the data system that is used to track immunizations for children. In addition to ICARE, Illinois Early Intervention may offer a framework that could be replicated or expanded.
2. Advocate to allow schools to gain access to the data available through health information exchanges. These data are shared routinely between health care providers, but because special education coordinators are not health care providers, they do not have legal access to the system.
3. Build a new system for data sharing between schools and health care providers. Among the three options, this solution would require the greatest lift in terms of resources and advocacy but is appealing because the system could be tailored for the needs of children needing IEPs and 504 Plans.

Each of these solutions has significant advantages and drawbacks, in which both legal and technical challenges overlap. Take, for example, the expansion of ICARE. Special education coordinators are not considered health care providers from the perspective of HIPAA and so do not have access to the system. What legal or policy solutions could the State of Illinois adopt to allow them direct access to students' health data? The ICARE technical infrastructure is not robust enough to handle this expansion. What technical solutions are required to enable special education coordinators access to ICARE?

Facilitating an easier flow of information between healthcare providers and schools should allow for more timely and more accurate assessments of a child's needs and strengths, and help the IEP or 504 Plan team specify more appropriate services and accommodations. Doing so will also help them spend more time in integrated classrooms and reduce the use of punitive discipline.



## Appendix 1: Accessing Special Education Services in Illinois

### **Child Find** (ISBE regulation [226.100](#))

If school district concludes individual evaluation is warranted, requirements for evaluation apply.

### **Evaluation Procedures** (ISBE regulation [226.110](#))

#### *Requesting an initial evaluation*

"A request may be made by a parent of a child or by an employee of a State educational agency, another State agency, a local educational agency, or a community service agency."

## **DEVELOP EVALUATION REQUEST FORM**

District must respond within 14 school days after receiving request (See ISBE form [34-57A](#))

*If District conducts an evaluation:*

Within 14 school days:

In consultation with parent, complete a **domain review** (ISBE form [34-57B/C](#))

After domain review is completed, parent signs **consent for evaluation** (ISBE form [34-57B](#))

Within 60 school days after receiving signed consent for evaluation:

District must **complete the assessments** identified on the domain review form ([34-57B/C](#))

District must **convene an eligibility conference** (See [34-57D](#): Parent/Guardian Notification of Conference)

*If District determines not to conduct an evaluation:*

Within 14 school days:

District must provide written notice to parent (Written Notice Requirements – [34 CFR 300.503\(b\)](#) and [Notice of Procedural Safeguards](#))<sup>1</sup>

### **Eligibility/IEP Conference**

**At the conference**, the District must complete an IEP Conference Summary Report. See [ISBE IEP Forms \(34-54\)](#)

If the IEP team determines the child is eligible, the IEP team must **develop an IEP**.

**After the conference**, the District must provide the parent with a notice regarding the conference recommendations. See Parent/Guardian Notification of Conference Recommendations ([34-57E](#))

The Parent must sign **consent for services** (only upon initial provision of special education and related services). See Parent/Guardian Consent for Initial Provision of Special Education and Related Services ([34-57F](#))

**NOTE:** No later than 3 school days prior to a meeting to determine a child's eligibility for special education and related services or to review a child's IEP, the local education agency must provide the child's parent or guardian copies of all written material that will be considered by the IEP team at the meeting so that the parent or guardian may participate in the meeting as a fully-informed team member. ([105 ILCS 5/14-8.02f](#))

<sup>1</sup> See [Parent Guide – Educational Rights and Responsibilities: Understanding Special Education in Illinois](#)

<sup>1</sup> See [ISBE Special Education Required Notice and Consent Forms](#)

## Appendix 2: Regulations and Resources

### **Federal**

*Individuals with Disabilities Education Act* (IDEA) [20 U.S.C. Section 1400 et seq.](#)

IDEA regulations [34 CFR Part 300](#)

*Family Educational Rights and Privacy Act* (FERPA) [20 U.S.C. Section 1232g](#)

FERPA regulations [34 CFR Part 99](#)

Student Privacy Policy Office [studentprivacy.ed.gov](http://studentprivacy.ed.gov)

Center for Parent Information & Resources [parentcenterhub.org](http://parentcenterhub.org)

[Right to Receive a Complete Explanation of IDEA's Procedural Safeguards](#) (August 1, 2020)

### **Illinois**

*Illinois School Student Records Act* (ISSRA) [105 ILCS 10/1 et seq.](#)

See [Section 5](#) (Parent right to student records)

See [Section 6](#) (Release of student records)

ISSRA regulations [23 Ill. Admin. Code Part 375](#)

*Illinois School Code*, [Article 14](#) (105 ILCS 5/14-1 et seq.)

See [Section 14-8.02](#) (Identification, evaluation, and placement of children)

See [Section 14-8.02f](#) (Individualized education program meeting protections)

Illinois State Board of Education (ISBE) Special education regulations [23 Ill. Admin. Code Part 226](#)

See [Section 226.110](#) (Evaluation Procedures)

[Notice of Procedural Safeguards for Parents/Guardians of Students with Disabilities](#) (ISBE, November 2018)

### [ISBE Special Education – Parent Rights](#)

[Parent Guide](#) – Educational Rights and Responsibilities: Understanding Special Education in Illinois

[Illinois Student Records Keeper for Parents of Students Who Receive Special Education Services](#)

*Illinois Mental Health and Developmental Disabilities Confidentiality Act* [740 ILCS 110/1 et seq.](#)

See [Section 4](#) (access to records)

Transforming School Discipline Collaborative TSDC) <https://www.transformschooldiscipline.org/>

## Reference List

- <sup>i</sup> Special Education Department. *Educational rights and responsibilities: Understanding special education in Illinois*. Illinois State Board of Education. 2020. <https://www.isbe.net/Documents/Parent-Guide-Special-Ed-Aug20.pdf>
- <sup>ii</sup> Lipkin PH, Okamoto J, Council on Children with Disabilities, Council on School Health. The Individuals with Disabilities Education Act (IDEA) for children with special needs. *Pediatrics*. 2015;136(6), e1650-e1662. <https://doi.org/10.1542/peds.2015-3409>.
- <sup>iii</sup> Shah RP, Kunnavakkam R, Msall ME. Pediatricians' knowledge, attitudes, and practice patterns regarding special education and individualized education programs. *Acad. Pediatr*. 2013;13(5), 430–435. <https://doi.org/10.1016/j.acap.2013.03.003>
- <sup>iv</sup> Joint guidance on the application of the Family Educational Rights and Privacy Act (FERPA) and the Health Insurance Portability and Accountability Act of 1996 (HIPAA) to student health records. *US Department of Health and Human Services and US Department of Education*. 2008. <https://www2.ed.gov/policy/gen/guid/fpco/doc/ferpa-hippa-guidance.pdf>
- <sup>v</sup> Mental Health and Developmental Disabilities Confidentiality Act, § 740 ILCS 110. <https://www.ilga.gov/legislation/ilcs/ilcs3.asp?ActID=2043&ChapterID=57>. Accessed August 2020.
- <sup>vi</sup> Taylor SJ. Privacy of mental health records in Illinois: The Mental Health & Developmental Disabilities Confidentiality Act. *Illinois State Bar Association*. 2016;2(3). <https://www.isba.org/sections/mentalhealth/newsletter/2016/04/privacymentalhealthrecordsillinoism>
- <sup>vii</sup> Questions and answers on providing services to children with disabilities during the Coronavirus Disease 2019 outbreak. *US Department of Education*. <https://sites.ed.gov/idea/files/qa-covid-19-03-12-2020.pdf>. Published March 2020. Accessed September 2020.
- <sup>viii</sup> IDEA Section 618 Data Products: Static Tables, Part B: Child Count and Educational Environments. *US Department of Education*. <https://www2.ed.gov/programs/osepidea/618-data/static-tables/index.html>. Updated June 15, 2020. Accessed September 2020.
- <sup>ix</sup> Civil Rights Data Collection, 504 Plan Estimates for Illinois. *US Department of Education*. [https://ocrdata.ed.gov/StateNationalEstimations/Estimations\\_2015\\_16](https://ocrdata.ed.gov/StateNationalEstimations/Estimations_2015_16).
- <sup>x</sup> IDEA Section 618 Data Products: Static Tables, Part C: Child Count and Settings. *US Department of Education*. <https://www2.ed.gov/programs/osepidea/618-data/static-tables/index.html>. Updated June 15, 2020. Accessed September 2020.
- <sup>xi</sup> Losen D, Hodson C, Ee J, Martinez T. Disturbing inequities: Exploring the relationship between racial disparities in Special Education identification and discipline. *Journal of Applied Research on Children*. 2014;5(2). <https://digitalcommons.library.tmc.edu/childrenatrisk/vol5/iss2/15>
- <sup>xii</sup> Zeitlin VM, Curcic C. Parental voices on Individualized Education Programs: ‘Oh, IEP meeting tomorrow? Rum tonight!’. *Disability & Society*. 2014;29(3), 373-387. doi:10.1080/09687599.2013.776493
- <sup>xiii</sup> Thompson T. The special education charade. *The Atlantic*. <https://www.theatlantic.com/education/archive/2016/01/the-charade-of-special-education-programs/421578/>. Published January 3, 2016. Accessed September 2020.
- <sup>xiv</sup> Spiel CF, Evans SW, Langberg JM. Evaluating the content of Individualized Education Programs and 504 Plans of young adolescents with attention deficit/hyperactivity disorder. *Sch Psychol Q*. 2014;29(4):452-468. doi:10.1037/spq0000101
- <sup>xv</sup> Ruble LA, McGrew J, Dalrymple N, Jung LA. Examining the quality of IEPs for young children with autism. *J Autism Dev Disord*. 2010;40(12), 1459–1470. <https://doi.org/10.1007/s10803-010-1003-1>

- 
- <sup>xvi</sup> DASH Bright Spot. A Legal approach to sharing health & education data. *Data Across Sectors for Health*. [https://dashconnect.org/wp-content/uploads/2018/05/DASH-Bright-Spot\\_Chicago.pdf](https://dashconnect.org/wp-content/uploads/2018/05/DASH-Bright-Spot_Chicago.pdf). Published May 2018. Accessed September 2020.
- <sup>xvii</sup> Fraser J. Framework for collaboration: The Memorandum of Understanding between Allegheny DHS and Pittsburgh Public Schools. *Allegheny County Department of Human Services*. <https://www.alleghenycountyanalytics.us/wp-content/uploads/2016/06/Framework-for-Collaboration-The-Memorandum-of-Understanding-between-Allegheny-County-DHS-and-Pittsburgh-Public-Schools.pdf>. Published March 2011. Accessed September 2020.
- <sup>xviii</sup> Rittenhouse DR, Ament A, Shortell SM. Accountable communities for health: Data-sharing toolkit. *UC Berkeley Center for Healthcare Organizational + Innovation Research (CHOIR)*. <https://cachi.org/uploads/resources/ACH-Data-Sharing-Toolkit-December-2016.pdf>. Published 2016. Accessed September 2020.
- <sup>xix</sup> Wright TD, Zimmerman JB, Knott R. At the intersection: Connecting health and education data in school-based health centers. *School-Community Health Alliance of Michigan*. [https://schoolhealthteams.aap.org/uploads/ckeditor/files/At-the-Intersection\\_Connecting-Health-and-Education-Data-in-SBHC.pdf](https://schoolhealthteams.aap.org/uploads/ckeditor/files/At-the-Intersection_Connecting-Health-and-Education-Data-in-SBHC.pdf). Published June 2013. Accessed September 2020.
- <sup>xx</sup> Institute for Youth, Education, and Families. Building management systems to coordinate citywide afterschool programs: A Toolkit for cities. *National League of Cities*. <https://www.wallacefoundation.org/knowledge-center/Documents/Building-Management-Information-Systems-to-Coordinate-Citywide-Afterschool-Programs.pdf>. Published 2012. Accessed September 2020.
- <sup>xxi</sup> Hedden EM, Jessop AB, Field RI. An education in contrast: state-by-state assessment of school immunization records requirements. *Am. J. Public Health*. 2014;104(10), 1993–2001. <https://doi.org/10.2105/AJPH.2014.302078>
- <sup>xxii</sup> Health Information Exchange. HealthIT.gov. <https://www.healthit.gov/topic/health-it-and-health-information-exchange-basics/health-information-exchange>. Updated October 2019. Accessed September 2020.
- <sup>xxiii</sup> Schorsch K. Rauner ends struggling health care initiative. *Crain's Chicago Business*. <https://www.chicagobusiness.com/article/20150922/NEWS03/150929963/gov-bruce-rauner-ends-struggling-illinois-health-information-exchange-initiative>. Published September 22, 2015. Accessed September 2020.
- <sup>xxiv</sup> Rath D. Central Illinois HIE shuts down. *Healthcare Innovation*. <https://www.hcinnovationgroup.com/interoperability-hie/health-information-exchange-hie/news/21078408/central-illinois-hie-shuts-down>. Published April 29, 2019. Accessed September 2020.