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2019 Legislative Year

OPPOSE SB 276 Immunizations: medical exemptions

California Legislator,

Educate. Advocate., a non-profit organization providing resources and support for students with exceptional needs and their families across California, strongly opposes Senator Pan's proposed legislation, SB 276, to restrict medical exemptions. We believe this bill fosters discrimination of students with exceptional needs and their family members.

Discrimination of Students with Exceptional Needs

The proposed bill will create additional burden for students with exceptional needs and their families both emotionally and financially, harming their access to education by discouraging school districts from providing special education services to students who do not meet new medical exemption requirements.

- Students with Individualized Education Programs and 504's, with and without medical exemptions are being excluded from school and denied special education services based on immunization status
- Proposed medical exemption guidelines violate ADA and CA Civil Rights Act (Unruh) statutes by excluding medical conditions and genetic information which qualify as disabilities

Discrimination Using Personally Identifiable Health Information

The bill also mandates the creation and maintenance of a statewide database, to include approved medical exemption requests.

- Personally identifiable health information of students with exceptional needs *and family members* will be included in a medical exemption database
- Databases are at risk for 'hacking', exposing confidential medical information to insurance companies, higher education institutions and future employers, who may discriminate based on pre-existing conditions and disabilities
- The database will have no opt-out feature, currently available in the California Immunization Registry
- The United States Congress has already discussed inclusion of immunization exemptions in a database and were counseled, by a member of the CDC Advisory Committee on Immunization Practices, that doing so was not appropriate

Request

Educate. Advocate. urges you to oppose SB 276 by voting 'no' or abstaining.

Thank you for the opportunity to state our concerns and we look forward to hearing from you on this issue that affects nearly one million students with exceptional needs in California.

PO Box 1011 Guasti, CA 91743 (909) 285 4269
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History of SB 277 and Students with IEP's & 504's

Current State of Special Education in CA

According to the California Department of Education, **771,000 students with exceptional needs are currently enrolled in California schools (1 in 10)** and receiving special education services (12.5% of all CA students). This translates to \$4 billion in special education state expenditures annually.

The Legislative Analyst's Office states that 85% of special education funding is distributed according to a student attendance formula, as required by AB 602. Since AB 602's passage in 1997, inclusion or "mainstreaming" of students with severe disabilities has doubled, in line with placement in the least restrictive environment, as mandated by the federal IDEA.

AB 428 notes that the share of California students receiving special education was virtually flat from the 1997-98 school year through 2007-08 school year, then grew notably over the last decade. The share of students diagnosed with autism has increased at an especially fast rate, more than doubling over that time period.

Total state and federal funding for special education has declined due to the drop in overall student attendance. During this period, however, total **special education expenditures have increased, largely driven by the growing number of students receiving special education coupled with some students requiring more intensive services.** As a result, local general purpose funding has been covering an increasing share of special education expenditures, rising from about 45% ten years ago to about 60% today. This increase has resulted in cost pressures to school districts.

If SB 276 is implemented, special education expenditures will continue to increase, but attendance formulas will be impacted by the exclusion of students with exceptional needs, adding further stress to district budgets incurred from due process, ADA and OCR violations. California will fall further behind the federal push for inclusion and be forced to face the legal and budgetary consequences.

Current Discrimination: SB277, IEP's & 504's

Despite California Health and Safety Code (CA HSC §120370) and the federal Individuals with Disabilities Education Act (IDEA) explicitly providing an exemption for children with Individualized Education Programs (IEP's) to continue to receive services, regardless of immunization status, Educate. Advocate. regularly receives complaints and requests for assistance from families who have children in special education who have been discriminated against; excluded from enrollment, attendance and services due to immunization status.

Districts are unilaterally modifying students' placements from the least restrictive environment without IEP meetings, parental consent or providing prior written notice.



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These complaints range from refusal to assess a child with a disability, to providing therapies at local parks and libraries, denying a free and appropriate public education to students in the least restrictive environment, secluding and isolating them from their general education peers.

Financially burdened, these families are unable to hire special education advocates and attorneys to inform their districts and instead, seek medical exemptions to ensure their child does not go without the services necessary to their education.

Students with exceptional needs on 504 plans via the 1973 Rehabilitation Act are not afforded the same protection as those eligible for special education under IDEA and must obtain medical exemptions to meet SB277 requirements.

Educate. Advocate. believes that narrowing eligibility criteria for medical exemptions and establishing a database constitutes discrimination against students with exceptional needs with Individualized Educational Plans (IEP's) and 504 plans.

Discrimination: Narrowing Medical Exemption Criteria

Both the Americans with Disabilities Act (ADA) and the Unruh Civil Rights Act of California afford discrimination protections to students with exceptional needs in school settings, whose disabilities impact major life activities.

Since SB 277, many schools have refused to accept medical exemptions from students with exceptional needs outright or concluded the medical condition stated is insufficient; a direct violation of the ADA [936 CFR §301(a)] by imposing additional eligibility criteria that screens out disabled individuals.

Genetic Disorders & Medical Conditions as Disabilities

Disabilities are often the effect of genetic abnormalities or inherited medical conditions. Unruh [CA GOV §12926] defines disability as including "Genetic Information" and "Medical Conditions" and defers to the ADA when the definition of "Disability" would result in a broader protection of civil rights:

"Genetic Information" and "Medical Condition" and "Disability"

*"(g) (1) "**Genetic information**" means, with respect to any individual, information about any of the following:*

*(A) The **individual's genetic tests.***

*(B) The **genetic tests of family members** of the individual.*

*(C) The **manifestation of a disease or disorder in family members** of the individual.*

(2) "Genetic information" includes any request for, or receipt of, genetic services, or participation in clinical research that includes genetic services, by an individual or any family member of the individual...

*(i) "**Medical condition**" means either of the following:*

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(1) Any health impairment related to or associated with a diagnosis of cancer or a record or history of cancer.

(2) **Genetic characteristics.** For purposes of this section, “genetic characteristics” means either of the following:

(A) Any scientifically or medically identifiable gene or chromosome, or combination or alteration thereof, that is known to be a cause of a disease or disorder in a person or that person’s offspring, or that is determined to be associated with a statistically increased risk of development of a disease or disorder, and that is presently not associated with any symptoms of any disease or disorder.

(B) **Inherited characteristics that may derive from the individual or family member, that are known to be a cause of a disease or disorder in a person or that person’s offspring, or that are determined to be associated with a statistically increased risk of development of a disease or disorder, and that are presently not associated with any symptoms of any disease or disorder....**

*“n) Notwithstanding subdivisions (j) and (m), if the definition of “disability” used in the federal Americans with Disabilities Act of 1990 (Public Law 101-336) would result in broader protection of the civil rights of individuals with a mental disability or physical disability, as defined in subdivision (j) or (m), or would **include any medical condition not included within those definitions, then that broader protection or coverage shall be deemed incorporated** by reference into, and shall prevail over conflicting provisions of, the definitions in subdivisions (j) and (m).”*

SB 276 requires that the medical exemption request provide sufficient medical evidence that the immunization is contraindicated by CDC guidelines.

Narrowing the eligibility criteria for medical exemptions, which does not take into account genetic and medical conditions contributing to disabilities, such as MTHFR mutations, will result in students in special education being denied exemptions, contradicting their private physicians’ recommendations.

If students with exceptional needs’ previous exemptions are revoked based on the new standards in SB 276 and denied exemptions going forward, district liability and due process filings will substantially increase, putting at risk the already insufficiently funded special education budgets.

Discrimination and Confidentiality: Medical Exemption Database

Currently, medical exemptions are required to list the specific medical condition warranting the exemption. This information is contained within the exemption, itself, maintained in the educational record and protected by the Family Educational Rights Protection Act (FERPA).

Personally Identifiable & Health Information of Students with exceptional needs & Family Members



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The database will include personally identifiable health information, such as the child's name, physician's name, specific medical conditions of the child and relevant family members, school and date of issuance.

Medical exemptions, for a child with exceptional needs, encompasses not only their diagnosis, but related disorders and often references their siblings' and parents' health disorders, as evidenced by the recent public records act request response, issued by the San Diego Unified School District, which included 486 medical exemptions.

Although FERPA requires that personally identifiable information be redacted, 20% of those released were not compliant and contained student names, ages, schools, physically distinguishable disabilities and characteristics, such as cochlear implants, organ transplants and chemotherapy treatments. This disclosed information makes the students' and family members' identities easily traceable.

Equally concerning is the detail of family members' personal health information, such as ALS diagnosis, psychiatric disorders, epilepsy, autism spectrum disorder and disclosure of student's special education eligibility, indicating their IEP's and diagnosis, including OCD, ADHD, sensory processing disorder, neurological and developmental delays, etc.

Of valid concern, is a future employer, insurance company or higher education institution gaining access to the database and utilizing the medical information contained therein to discriminate against a disabled student or their family members.

No 'Opt-Out' & Database Integrity Concerns

With no language providing for 'opt-out' of the proposed medical exemption database or sharing of the information stored in the database, as is available with the current California Immunization Registry (CAIR) (http://cairweb.org/images/docs/CAIR_Decline_Eng.pdf) serious confidentiality risks are prevalent.

As we've seen with the San Diego Unified public records release, personally identifiable information is included in many medical exemptions and the integrity of a database is unreliable.

In December of 2018, the San Diego Unified School District notified families that between January and November of 2018, phishing emails were utilized to gain access to the district's network, including the student database, which offered complete access to personal identifying, health, grade and scheduling information.

(<https://drive.google.com/file/d/1timPjP0VTyzxjtNVyCLUWbtZ5MIMFOgq/view>)

This event validates our concern addressing discrimination related to personal health information of disabled persons when confidentiality is compromised.

Database Logistical Legal Limitations

PO Box 1011 Guasti, CA 91743 (909) 285 4269
<http://educateadvocateca.com>
educateadvocateca@educateadvocateca.com
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Discussion of an Immunization Information System (IIS) is not new and many states, including California, have created county and statewide immunization registries, which will ultimately be required to adhere to a national standard, developed by the CDC.

However, the databases are designed to maintain immunization information, adhering to both FERPA and HIPAA guidelines and providing access via health information exchanges to other IIS participants.

The inclusion of immunization information in such a database has been examined by the United States Congress previously.

Congressman Waxman (D) introduced the Comprehensive Child Immunization Act in April of 1993. During the congressional hearing process, creation of a database that incorporated exemptions was discussed and addressed by a CDC Advisory Committee member:

*“Another concern is that the data elements to be included...be only those required to track a child's immunization status. **Additional information, such as history of adverse reactions, any vaccine contraindications present for this child, and any religious or legal exemptions that may pertain for an individual child are not appropriate for inclusion in a national system.** The child's medical record should contain this information.”*

- *Dr. Ed Thompson, member of the CDC Advisory Committee on Immunization Practices and acting State Health Officer for Mississippi*
(https://archive.org/stream/comprehensivechi00unit/comprehensivechi00unit_djvu.txt)

The Network for Public Health Law, Public Health Law Center at William Mitchell College of Law, offers insight on this matter via their memorandum on the legal issues related to sharing of state immunization information system (IIS) data, highlighting prevalent limitations within current state immunization registries, which would be further convoluted by adding an additional layer of complexity with medical exemptions.

*"If a school provides individually identifiable information to the IIS, with the exception of directory information, the IIS is limited in re-disclosure of this information. **An IIS may not share most school-entered information with providers, health plans, or others that have access to the IIS.** Immunization Information Systems may filter school-entered information from medical providers. For example, if a school adds a varicella to a student's immunization record in the IIS, the physician managing this student's health care would not be allowed to see the varicella dose added by the school. The provider would have to receive this information from the parent or from the previous provider. Similarly, absent consent, an IIS cannot provide most school-entered information to another IIS."*

(<http://www.astho.org/Public-Policy/Public-Health-Law/Cross-Jurisdictional-Sharing-IIS-Data/>)

This claim is substantiated by FERPA redisclosure statutes (34 CFR §99.3)

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§ 99.33 What limitations apply to the redisclosure of information?

(a)

(1) An educational agency or institution may disclose personally identifiable information from an education record only on the condition that the party to whom the information is disclosed will not disclose the information to any other party without the prior consent of the parent or eligible student.

(2) The officers, employees, and agents of a party that receives information under paragraph (a)(1) of this section may use the information, but only for the purposes for which the disclosure was made.

Logistically complex and legally jeopardizing, the creation of a medical exemption database risk far outweighs the benefit.

Conclusion

A student with a medical exemption cannot unilaterally be considered 'unvaccinated'. As evidenced by the San Diego Unified School District sample, nearly 20% were issued for sufficient immunity levels (currently, the law requires that titer tests be accompanied by a medical exemption), many more for delayed schedules due to health conditions and several more exempt for live virus immunizations only due to immunosuppressive treatments.

This bill is unnecessary and insufficient to address the concerns raised by Senator Pan regarding issuances of medical exemptions and introduces additional risk and liability for California school districts. Current avenues via the Medical Board of California and Department of Public Health provide adequate means of addressing the Senator's apprehensions.

SB 276 encourages discrimination of students with exceptional needs via documentation and maintenance of personal health information in a statewide database and severely limiting the scope of physicians to issue medical exemptions to immunization, abolishing consideration for disabilities that limit major life activities for students.

The proposed bill will create additional burdens for students with exceptional needs and their families both emotionally and financially, harming their access to education by discouraging school districts from providing special education services to students who do not meet new medical exemption requirements.

For these reasons we urge you to oppose or abstain on SB 276.

Sincerely,

Kristie Sepulveda-Burchit
Executive Director, Educate. Advocate.

PO Box 1011 Guasti, CA 91743 (909) 285 4269
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educateadvocateca@educateadvocateca.com
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