

Privacy and Ed Tech for Students with Disabilities

Speaker #1: Meghan Whittaker and Ace Parsi @ National Center for Learning Disabilities

Meghan Whittaker

NCLD's Mission: to improve the lives of 1 in 5 children and adults who struggle with learning and attention issues by:

- Engaging with parents with online resources and community with Understood.org
- Building the capacity of educators to support all struggling learners
- Develop young adult leaders who can advocate for themselves and their peers
- Informing local and national policy efforts to ensure equal opportunity access
- Strengthening the field through innovative research and collaborative partnerships

NCLD manages understood.org which is partnered with 15 nonprofit parents to provide free comprehensive resources that are meant to empower parents and children with learning and attention issues. This is also a great resource for scholars who are not informed to get a basic understanding on policy that can be created.

History of Student with disabilities

- Before 1975 there were state laws that prohibited children with disabilities attending public schools
- Today 71% of children with learning disabilities or ADHD are in general education classrooms
- From a legal perspective there are three laws that need to be focused on which create a framework; the basis of each of the laws is an anti-discrimination policy that states that all children should have equal access regardless of disability.
 - Individuals with Disabilities Education Act of 1975
 - This was the biggest law that protected students with disabilities; the foundation of special education in the US which affords students with disabilities access to education at public schools
 - Core provisions:
 - Schools must
 - Find and evaluate (at no cost) every student in need of special education
 - Provide a free, appropriate education to those students who qualify through an individualized education program (IEP)
 - IEPs can provide:
 - Specialized instruction
 - Multisensory reading instruction
 - Related services
 - Speech, language, occupational therapy
 - Accommodations
 - Extended time, written class notes
 - Assistive technology

- Audiobooks, recorders
- Parents have the right to
 - Participate in the evaluation and IEP process
 - Legal resource if they disagree with the school for what they propose as an education path for the child
- - Americans with Disabilities Act of 1990 and Rehabilitation Act (504) of 1973
 - Civil rights laws, they are not as extensive as IDEA
- Who are the students?
 - ~6 million students with disabilities in public schools today, ages 5 through high school
 - The most common are
 - Specific learning disabilities
 - Speech or language impairment
 - High incidence disabilities –largely in general education classroom spending most of the day. In those classrooms really interacting the most with general education teachers
 - Students with 504 plans
 - More than 70% spend most of their day in general education classrooms – however, the general education teachers are not specifically taught how to handle or take care of children with disabilities
 - 70 % of teachers in elementary schools say that they face a lack of resources needed to provide instruction related services and support to children with disabilities
 - About 1/3 of teachers believe sometimes what people call a learning disability or attention issue is really just laziness
 - There is a real misunderstanding about what it means to have a disability. The lack of knowledge and understand can turn into a stigma
 - This creates a misconception which can turn into low expectations of the children. More than 85% of students with disabilities are able to meet the same level of ability with general students if they are given reasonable accommodations
 - These low expectations in turn become less access to general content/ education which has consequences that follow them throughout their lives
 - There is a diversity in education and ways that people learn and there is an error where students are not able to engage with the material in a way that is catered to their personal style (designed education)

Ace Parsi

- The interaction between technology and privacy issues as related to students with disabilities

- Personalized learning initiatives
- Benefits of Ed Tech for students with disabilities
 - Technology can:
 - Help identify and pinpoint student needs
 - Increase accessibility and reduce stigma by decreasing barriers to learning
 - Difference sources of opportunities
 - Improve achievement, engagement, and outcomes
 - Increase accountability by providing more detailed data on student performance
 - Different measures of achievement to get a wholistic measure of how a student is doing
 - Reduce costs by increasing efficiency
 - Technology can also:
 - Fail to identify disability by ignoring social cues of disability
 - Decrease accessibility and increase stigma by not accounting for accessibility and/ or singling students out
 - Reduce achievement, engagement, and outcomes
 - Decrease accountability through proprietary data and lack of subgroup accountability
 - There often isn't access to proprietary data
 - Increase costs by adding inefficiency
 - The lack of accessibility can result in the opposite of desirable outcomes
- Disability and Ed System challenges
 - Defining technology; the usages
 - Accommodations
 - Read aloud, things that provide students access to the curriculum
 - Learning enhancement
 - Does it help or hurt engagement with the students within the classroom, does the technology hurt or help the students
 - Learning environment
 - Virtual schools or blended programs, what is the environment in generally like
- Key considerations for disabilities
 - The interplay of anonymity, personalization, and accountability
 - The more we personalize data the more we remove the anonymity from students with disabilities because the sample size in schools is generally low
 - However this does not mean we should be more lax on accountability and holding the school accountable for student outcomes
 - Effectiveness for which students under circumstances?
 - What type of technology is being used? How do we measure effectiveness? For what students?

- Differences between deploying technology for vision impaired and ADHD
 - Connecting accessibility rigor, and capacity
 - Is it worksheets that are just put on to computer screens or are we talking about developing a higher level of education? This is something that needs to be explored
 - Innovation outpaces policy safeguards for now
 - This is something that needs to be changed in further versions of IDEA or other laws that address the matter
- **Framework** on how to address how to bring technology into the classroom effectively
 - **Origin:**
 - High expectations for all should guide investment choices
 - Whether it is data systems or technology, it should account for all of the needs for all students and their higher learning needs
 - **Design:**
 - Disability experts are fully included in the design of products
 - Make sure that companies that are creating the platforms have the experts and user test beds with students with disabilities
 - **Procurement:**
 - Needs of all learners inform decision-making
 - States and districts should be explicit about what the specific purchase means with students for disabilities and the individuals charged with making the decision has the expertise to make it.
 - **Use:**
 - Practitioners are empowered to effectively use products to serve all learners
 - Make sure the teachers know how to use the systems
 - **Sustainability**
 - There is funding to expand and sustain the benefits of the tech investment for all learners
 - There has to be a system that continues to fund and does not make the same mistakes again and again
- **Recommendations**
 - Ensure data and student outcomes are transparent
 - Particularly regarding the production and the outcome of technology
 - Do not use personalization as an excuse to water down accountability or advance tracking
 - Make sure that they don't become a new avenue to tracking students and make sure that it is a way for students to access higher education
 - Don't procure technology without training educators to serve all students
 - Don't just look toward the average students in the middle but look toward the students on the margins

- Ensure systems accessibility: rigorous, technology and pedagogically accessible investments
- This is something that should be done at the front end rather than later when the technology is already implemented. This should be something that should be done from the start and carried throughout the project

Question 1: what are some specific examples of how edtech companies can help further their products with students with disabilities without running into any of the challenges above?

Answer: (Ace) the biggest thing is user testing and talk to developers about what the purpose of the technology is for, particularly with various disabilities. Make sure that disability experts are involved with the development of the technology, talk to students, educators, and parents to see what is needed the most.

Question 2: Who should stakeholders (teachers, companies, school districts etc) engage with in order to gain the disability expertise they need?

Answer: (Ace) NCLB is one but there are many other organizations out there that explicitly focus on accessibility, depending on the product that is being sought. There are many guidelines that are a good step.

Meghan: reach out to the community and parents about a lot of these decisions. The public wants a say and should have a say in the development of these technologies and the education of children.

Speaker #2: David Rubin, private practitioner who represents numerous school districts in NJ

Education for all handicap children act of 1975 and FERPA

FERPA was an attempt to balance access for families to get information about their children with the protection that other people who did not have a legitimate right to know would not get access to that same information

National School Boards Association Council of School Attorneys – a 3000 or so member organization of attorneys that advise school districts on the issues, including today's discussion

FERPA and State laws impose obligations regarding confidentiality and the security of data

- The most issues arise in the following situations:
 - General issue of electronic storage of student records (cloud storage), applying to all students
 - But this might be something that is more concerning for the privacy of special education children who may have more sensitive data

- There is little knowledge about where the data is going when it is sent to the cloud for the teacher to easily transfer between devices -- this may have implications where sensitive information is sent to an unsecure cloud service – there is a need to make sure that such cloud services are compliant with FERPA
 - Their practices should meet within the “School Official Exception” under FERPA that allows third parties to be included with the storage and collection of data
 - They must
 - Be controlled directly
 - Exercise functions that the school would do
 - Are monitored and will be held responsible if something wrong happens
- The increase use of web-based IEP development programs
- Communication electronically between special educators particularly when they are communicating about a special education child where it may contain sensitive information
- Proliferation of classroom apps
 - Many teachers are independently and with little or no oversight are implementing apps into the classroom
 - This may be done with the best intentions for the children and the desire to improve child outcomes however without any centralized decision-making approval process there often times very little awareness of the privacy implications of the data
 - Generally there is an acceptance of terms of service without an understanding of what any of the language means
 - If the teacher takes it upon themselves to download an app without prior approval and if the app is used to monitor student behavior there are a couple of problems
 - (1) who has made the educational decision that the app is acceptable to be used in the classroom? Is it consistent with the schools pedagogical approach?
 - (2) procurement issue – is there now a contract? Who is the contract between? Not the school district because the district is not being consulted
 - (3) where is the data going? Once the teacher has downloaded and used the app the data is being transferred and stored somewhere – the data is no longer within the control of the school district but out there somewhere in the universe
 - Training is the answer – there is a need to raise awareness as to the privacy/ data implications and the responsibilities that the staff and teacher holds

- Student records are no longer just in paper form anymore, sometimes the information will never see paper ever, it is created and stored in a electronic format that need to be kept private
 - This is one of the biggest challenges because there are so many actors that need to be educated on the privacy implications of the various applications of different technologies and devices
 - There is an issue of security in addition to privacy
- Contracting
 - There is a need that the contracts are being clearly written so that all of the parties agree on:
 - Who owns the data
 - How to get the data back from the vendor if the agreement terminates
 - Proper vetting procedures regarding the security of the data and that there are security measures in place
 - Etc
 - The information that is being collected is very important and school districts should considered including lawyers and legal minds when interacting with technology because there are enormous legal implications
 - Procurement of services should be reviewed for their legal implications
- Angel Sense
 - A GPS tracking device that is frequently used in NJ purchased by parents with children with special needs that is used to keep track of the students throughout the day
 - Some of the devices have a “listen in” feature that allows the parents to listen to whatever is going on around the child
 - There are some privacy concerns because this allows the parents to listen to whatever is happening including what is happening during special education classes and the interaction with the teacher, what are the privacy rights of the teacher?
 - There is potential for deactivation by the company – the school district got the president of the company on the phone to change their standards of practices
 - When dealing with ed tech companies, vendors should be open to conversations with the district and school board lawyers in order to protect the privacy of all parties involved

Question 1: how does FERPA interact with IDEA privacy requirements?

Answer: FERPA protects all students, IDEA is a small subset that protects special education students. FERPA fits into IDEA because it keeps information private and accessible only to people with legitimate interests including parents, school members and child welfare. The way that FERPA interacts with IDEA is that it makes the right of access and the right of privacy double, especially for special needs children.

Question 2: At what point does having or collecting information about a student's disability carry into HIPAA? As an EdTech vendor, if a school flags a student in the product as an IEP student, is that vendor now obligated to be HIPAA compliant in addition to FERPA?

Answer: generally speaking if you are compliant with FERPA, there is nothing more that you need to be worried about under HIPAA because you will generally be compliant. There are a lot of state requirements that should be checked.

Amelia: FERPA has a specific exemption for information that would be covered under HIPAA. If the information is part of the education record, FERPA is the law that rules even if HIPAA would apply otherwise.

Speaker # 3: Melissa Lazaro @ Lexplore

What is Lexplore?

- a clear view of reading
 - it is an eye tracking device (Toby Eye Tracking Device)
 - this is used in gaming
 - Features and benefits
 - Real reading
 - 2 minute assessment
 - High accuracy
 - Auto-aggregated data
 - Cloud portal
 - Ease of use
 - Behind the scenes AI/ Machine learning is used to create a model that predicts child's reading ability using a 30 year study at Karolinska Institute in Stockholm Sweden
 - This program helps identify children with reading disabilities as quickly as possible
 - Determine different reading levels in less than 2 minutes
 - Allows for the company to see the cognitive function of the student's brain in order to predict the readability
 - It allows for the educator to understand in what ways the child needs help
- There is great concern about literacy around the country and the product helps identify students at any different reading level
 - This is not a diagnostic tool
 - This is something that is used to help the teachers identify how to instruct the children
- Educators have said they need
 - Clear, real time data to guide the most effective instruction
 - More time for teaching – less time testing, only two minute assessment that allows for focus on children

- Easy assessment which is better for the kids
- What information is being collected?
 - High level data reporting from a district level all the way down to the exact student
 - Recordings include
 - Fixation time (time spent decoding a particular word)
 - Eye movements while reading
 - Any type of regression
 - Fluency rate
 - Comprehension rates
 - RAM score and grade level equivalent
 - Reading test, results analysis, recommendations, and results
 - Silent reading scores
 - Voice of the student reading
 - Psychologist evaluation or teacher information
 - Gender, socioeconomic status, race, etc
 - Cognitive functioning
- Privacy protections
 - FERPA and GDPR Compliant
 - Ensure central point of responsibility for data security
 - Upload testing materials to a central system directly
 - Ensure encryption and two step authentication
 - Create layers of authority in central system
 - Ensure personal agreement with subcontractors
 - Create policies and procedures for handling student testing and assessment
 - Suggestions that are followed
 - Uploading testing materials through essential systems directly in a centralized location
 - Graduated level of access, only need to know basis are able to access the student data

Question 1: There has been push back against biometric data collection from children, how is this company thinking about privacy in the context of the type of information? Is biometric data something considered?

Answer: Generally, the company complies with GDPR which is generally higher of a standard than the U.S.. The data is anonymized and there are barriers to access for the data. However, there is no direct approach right now to cover biometric data.

Speaker #4 Linette Attai @ Playwell LLC

Data Privacy for All Students

- Key requirements
 - Vendor compliance
 - Protection of personal information

- Confidentiality
 - Transparency
 - Parent/student rights
 - Consent
 - Access
 - Review
 - Amen
- Similarities and differences between the different types of regulations/ laws
 - IDEA specifics that are not found in FERPA
 - Protect PII across the lifecycle of the data
 - Designate a privacy officer
 - Provide employee training
 - Maintain record of those with access to PII
 - Physical destruction or removal of personal identifiers
 - Inform parents when the information is no longer needed
 - Destroy at the request of parents, with limitations
 - Note: This is essentially permissive for companies to keep de-identifiable information
 - However, there are issues and risks here
 - Note: that the laws are not limited to specific markets or industries, this can be something that can become applicable to any entity that comes into contact with the threshold of the regulation
 - Complaints and repercussions of not follow the law
 - Appropriate corrective action
 - May include compensatory or monetary reimbursement
 - Potential for damages under section 504 if disability is known and not addressed
 - Withdrawal or withholding of funding
 - Precluded from providing data to technology provider for 5 years
- When advertising/ marketing for particular needs of students (particularly disabled students)
 - Be careful when marketing to schools
 - It must be truthful
 - Understand the repercussions of what happens when a teacher who relies on the promises of the marketing campaign
 - If the product does not perform as designed and a complaint is filed under FERPA for example, that may sweep broadly
 - A lack of knowledge and fluency as to the requirements can be damaging all around
 - Make sure to conduct efficacy studies
 - Caveat claims appropriately

- Note about Connecticut Law – student privacy law has been updated and particular contract provision are required
 - Exceptions to contract provisions in the law in certain limited situations
 - If the technology is deemed necessary and unique to address a need and a contractor cannot meet certain requirements of the law. The district has made a reasonable effort that meets the requirements of the CT law but the vendor complies with FERPA and HIPPA and the board cannot find a replacement and the parents sign off on the usage of the technology – then the district is permitted to bring the technology into the classroom without meeting all of the standards of CT contracting provisions
 - Untested provision (became effective in June 2018) there is no known information about the law and therefore it is unknown what the limitations are
 - Consider potential repercussions
- Transparency and trust
 - Privacy compliance program is a fundamental business requirement
 - Understand the education ecosystem, laws, implementation practices, customer challenges and market requirements
 - Communicate clearly and be accurate
 - Commit to ongoing monitoring and improvement of the compliance program

Question 1: As an EdTech vendor our pursuit of strongly engaging content activities (visual, requiring keyboard dexterity etc) sometimes seems to comply with accessibility standards with WCAG, what is a good litmus test or general guidelines with how to handle seemingly conflicting priorities? In short, is it acceptable or possible to demonstrate to schools the vendors efforts by way of efforts without having every box check in the WCAG standard?

Answer: (David) The office of civil rights have gotten into the business of policing website accessibility standards and have over the last few years have been taking a position that websites need to be accessible to all. Good faith efforts may not be the legal standard to accessibility, it might not be enough to get you there – sufficiently accessible applies to whatever law is in place and whatever that law is you will need to meet it and good faith may not get you there. There are standards that need to be met and they should be met, there is no participation effort.

Question 2: A lot of districts have been dealing with legal mandates for more accessibility on their websites for people with disabilities and the practical implication to those requirements are posting least information online or removing access – how do we balance the rights of people with disabilities with transparency, privacy and limited budgets?

Answer: (David) under the current administration, OCR is taking a less aggressive position on compliance. There is more leniency and practicability. There is a shift in the way that the federal government is imposing burdens on school districts.

(Linette) OCR has been getting an extremely high volume of complaints in this area, so they are being challenged by the balance of requirement and reason with addressing the valid complaints.

(Meghan) While there is some concern with balancing, but districts should be making smart investments that allow for all people to have access and there is an important to uphold the standards. There needs to be innovative ways instead of just withdrawing from the mode of posting online. Hopefully, as districts move forward there will be more ways to tackle the issue.

Question 3: LEA's Costs and resources when they are creating a website can be high, what resources should be used to take action?

Answer: WCAG (Website Content Accessibility guidelines) and AEM Center provide a lot of resources and materials.

Question 4: There are more and more cases where parents and students are getting in trouble for recording what is happening at school, often in the context with students with disabilities – how should private implications of those types of accommodations be evaluated?

Answer: (David) Where students are coming in with recording devices attached, there is a lot of state law that applies with regard to consent. NJ is a one party consent state so it depends on the state. Often the situation arises that records are occurring because the recording arises where there has been a mishandling by an educator. The law is generally unsettled where the student's need to have recording devices and its relation to privacy concerns.

Question 5: Texas passed a law in 2015 that all special ed classrooms have video and audio recordings if any person in the district requests it?

Answer: This is a policy choice that Texas thinks this is a good thing – however Texas is an outlier and most likely will not be the trend throughout the country. There is concern for the privacy of the teacher and the privacy of other students in the classroom, especially because there is no option for the other students to opt out.