Effective Special Education Advocacy in the United States

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by

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Preface

Agreed upon practices for identifying and accommodating students who are "at risk" are few to none. This pushes us to further study the nature of identification and diagnosis of potentially at-risk members of a group to reach a critical end: how can we increase the rate at which students with special learning needs are identified and fairly accommodated?

With software becoming more widespread and complex there are increasing risks associated with vulnerable code and unknown exploits; additionally, as software becomes more complex, vulnerable code and malicious activity are increasingly difficult to detect. Under Dr. Yuan Tian, and in collaboration with teams at UCSB and Google, my Capstone Research involves the use of deep learning methods to answer the following: how, if at all, can we use semantic and syntactic data on a group to determine which members are vulnerable? We come to understand that, much like the human mind, the nature of software security is infinitely complex and therefore lacks any single solution or algorithm for "correctly" screening code and identifying vulnerabilities.

United States federal law guarantees all students, regardless of their learning needs, access to an "equal and appropriate" public education. Our public education system fails to deliver on this promise to a striking population of our nation's youth: most students are either being overlooked completely or are left with unaddressed needs in their education. The existence of such students is troubling and leads us to consider the relevant perspectives and actions of all participants involved: Federal and State governments, school districts, educators, parents, and other advocates. These considerations are made with the goal of identifying and understanding characteristics of effective special education advocacy in the United States public education system.

Effective Special Education Advocacy in the United States

The Individuals with Disabilities Education Act (IDEA) is a federal law that guarantees a free appropriate public education to all children ("About IDEA", 2020); yet, our nation has no standardized process for dealing with identification or accommodation of special learning needs. There are huge disparities among U.S. states in the percentage of students who receive special education services: ranging from 6% to 15% (Camera, 2019). This doesn't stem from a significantly larger population of in-need students in high-percentage states; rather, it comes from each state having their own process to allocate special education funding to districts.

A model such as this is not conducive to a fair and just education for all Americans when considering those with special learning needs, as students in states with more fair funding policies are more likely to achieve accommodations (Parker, 2019). As a result, research continues to show that parents frequently experience difficulty in obtaining appropriate services for their in-need children (Zagona, 2019). Because of the importance and complexity of any child's mental state, a personal effort must be made on their behalves by an advocate: either a parent or trained professional.

The glaring importance of the role advocates in preserving the rights of our nation's youth leads us to further investigate the characteristics of effective advocacy. Even with a professional advocate trained in obtaining special education services, over 40% of parents were unsatisfied with their child's accommodations after an IEP meeting(Goldman, 2020). Uusitalo-Malmivaara (2012) shows that failing to provide special learning needs students with appropriate accommodations can be detrimental to their happiness, school performance, and social skills.

The Federal Government is the entity that implemented IDEA with the agenda of providing fair and free education to all children in the United States. It is the responsibility of States to implement IDEA: they seek public trust and support and must allocate special education funding to districts (DoE, 2020). School districts must administer the programs within budget constraints (Burke, 2018). Educators are intermediaries between the schools and families, and should work to provide students and families with adequate opportunity and education. Parents typically strive to provide their children with the most favorable academic and personal life experience (Siddiqua, 2017), but many underserved groups are disadvantaged in this effort. There are also some dedicated advocacies who work for the interests of individuals and families who need special education services (Uusitalo-Malmivaara, 2012).

To be able to effectively implement IDEA, each in-need student must have an advocate who builds a trusting relationship with the family and child, understands the rights of the child and communicates them to the parents, provides effective and appropriate expertise, appears in person to fight for the rights of the student, and works to understand the student on a human level. I will limit my research to cases involving United States Public Schools within the past 10 years.

No government official, school administrator, or teacher should have total diagnostic and prescriptive power over a child's education: instead we must work to identify and execute effective advocacy on behalf of each child in need.

Review of Research

Some of the most significant published scholarship pertinent to my studies are reports of research by Dr. Meghan Burke (2017) and Dr. Samantha Goldman (2020), of the University of

Illinois and Assumption University, respectively. They are some of the only researchers working to understand the dynamics of the advocacy process: they have several studies documenting the perspectives of advocates, families, and schools regarding their experiences with advocacy process.

There are also several researchers who have focused on documenting parents' experiences during the special education process. There is negative sentiment around the fact that IDEA was created to help states and school districts meet their legal obligations: to educate children with disabilities and to pay part of the extra expenses of doing so; however, there is no mandate or discussion of properly educating parents to understand the intricacies their specific states' special education system (Jones, 2020). Regardless of legislation or court rulings, researchers continue to find that parents experience difficulty engaging in discussions with school personnel to obtain services for their child with disabilities (Zagona, 2019).

Some very useful information can be found in research studying factors that contribute to happiness and success of students with special learning needs. Research shows that, compared to regular education students, students in public school special education programs perceived themselves as having less control at school and reported lower levels of happiness (Smith, 1987). Uusitalo-Malmivarra (2012) has also contributed a great deal to the study of happiness and success in special education students. Her research documents psychological, school-related and demographic factors that impact happiness of in-need students. This research, along with many other studies, continuously show us that the quality of a student's education is directly correlated to the amount of personalized teaching and attention they receive (Kohn, 2008).

In any research regarding education reform it is important to note the historical controversy around the idea of a "traditional" versus "progressive" education system. Franklin

Bobbitt, who introduced some of the early traditions of curriculum studies, approached education with the goal of increasing overall student learning while maintaining the minimum cost to society (Mohamed, 2020). He believed it is in the best interest of society to push students to align with and adapt to whatever blueprint society and educators deem fit. This school of thought is not conducive to fair treatment all because we recognize that this "all" consists of unique children with their own stories that must be addressed. Bobbitt's views also conflict with those of Alfie Kohn: one of the most influential proponents of progressive education.

Alfie Kohn believes that those who advocate for a "traditional" education can be grouped with those who advocate for education standardization today: the ideas and values that some may believe guide a "proper" education come from "outdated policy that have calcified into conventions" (Kohn, 2008). Kohn is responsible for many studies that help us better understand the ideal education to be one that allows a student to grow and learn according to their specific strengths and needs. He rejects the idea that students can be reduced to numbers based on any evaluation: humans require understanding and support in a way that no tool or system can provide. He notes that the idea of a "perfectly progressive" education is impossible to define; however, this acknowledgement supports his greatest contribution to education: we cannot try to perfect the idea of education in a one-dimensional manner because the idea of driving one definition of perfection is not only dangerous but detrimental to human progress and growth.

The research performed by these individuals, among many others, is a great way to understand the nature of advocacy. I aim to extend their studies to isolate the aspects of advocacy that are most effective in reaching favorable outcomes in terms of student happiness and success.

Characteristics of Great Advocacy

Family Trust

It is necessary for advocates to build strong relationships with the families they serve to set the stage for a successful advocacy process. Representatives for The Arc of the U.S. concur (MediSked & Arc, 2018), stating that successful individual advocacies build relationships with the families they serve before any other actions are taken. Burke (2017) studied 33 graduates who completed the Volunteer Advocacy Project (VAP) training: all 33 agreed that their successes required personal connections with the family. Colombo (2019) and Wellner (2012) are both educators who agree that advocates must establish relationships to access parents' lived experiences and discover useful patterns in order to improve the effectiveness of the parent-advocate team.

Peter and Pam Wright, of *Parenting with Special Needs Magazine*, discuss that experienced parents view building relationships with an advocate as a kind-of information gathering period for all parties involved. Families are able to become acquainted with the advocate, their values, and to what degree they will able to understand their child (Wright, 2010). This allows parents to course-correct if need be and otherwise provides them with confidence in the level of care their child is receiving. Finally, educator Tracy Gershwin (2020) discusses the family-professional partnership in the context of special education advocacy to be one that is grounded in trust and equity: she notes research that documents a correlation between a trusting family-advocate relationship and student improvement in multiple areas of interest.

Communicate History and Situation

        An advocate must understand the child's history and current situation, and clearly communicate this to parents. Siddiqua (2017) explains that parents frequently voice their struggles with the disorganization of information involved in the special education process. Burke (2017) shares accounts of VAP advocates who note that educating parents on their child's situation and documentation is imperative for them to gain the knowledge and confidence to act as productive members of the IEP team. Educators Kerry-Henkel & Eklund (2015) observe that the required documentation for a special education case, which may exceed 50 pages, can interfere with such parental involvement. They recommend simpler writing, graphic organizers, explanations of jargon, and other guidance for helping parents better understand these documents. Educated parents better understand their child's situation and make more effective advocates.

Provide Expertise

        Advocates must provide families with expertise to the best of their ability, and be willing to refer to other services when necessary. According Burke (2017), effective advocates are disability experts and strategic planners; Trainor (2008) concurs, adding that they are also intuitive thinkers and agents of change.

        It is important to understand what services you, as an advocate, can provide and to be transparent. An advocate must be prepared to recommend legal representation if necessary (Gehring, 2020). The American Speech-Language-Hearing Association (2021) explains that, without presenting parents the opportunity to discuss legal considerations of their child's

situation with an attorney, an advocate may leave the family disadvantaged in the future when handling a due process situation.

Be Present

It is imperative for advocates to be present, in person, to assist children and parents in their communications with the school. Zaretsky (2008) documents feelings of parents who are versed in the advocacy process: they feel it is necessary, if an advocate wishes to have the greatest impact, for them to accompany parents to meetings with school administrators. Goldman (2020) agrees, noting that parents express reduced stress and increased satisfaction with IEP meeting results when they had been accompanied by a professional advocate.

Uusitalo-Malmivarra (2012) notes that in-person support (in an advocacy setting such as IEP meetings) has direct impact in increasing student happiness and success in their long-term educational experience. School special education staff report often wanting to suggest different accommodations for a student, but don't because of their perception on how colleagues may feel about the suggestion (Jones, 2020). Advocates who are present during IEP meetings are able to bring up strategies and suggestions that the school can recognize as appropriate, but may not have otherwise had the intuition to execute.

Understand the Student as a Human

When thinking about education, we often fail to properly consider what is most important: the "student". It is important to understand the bias that we hold when we think of this word.

The idea of education has been politicized and abused throughout history. The United States Education System, with countless others, has continuously subjected marginalized groups to inferior learning conditions, all the time in some ignorant way feeling they were doing the "right thing". Researchers in education now understand that there is no process or algorithm to define the "right way" of education (Pak, 2001). There is no way to quantify the human mind or experience, and therefore no way for any individual or group to standardize an education or system to align with their perspective of "right".

Franklin Bobbitt rejected ideas of derailing the performance of schools by catering to those who did not meet his definition of academic performance (Mohamed, 2020). He was, however, a white male in a time where ideas such has his contributed to the continued plight of growth and unity in our nation. His ideas may have been valuable to those deemed as important at the time, but they are now not only outdated but toxic in their disregard for human difference.

Alfie Kohn (Salovita, 2019) supports this idea in his research regarding perspectives of classroom teachers towards students with special needs. He finds that most of these educators are not consistent or confident in their judgement of what treatment is appropriate for a specific student of theirs with special learning needs. The lack of confidence in those who know the student best and are expected to facilitate conversation regarding student needs makes us further question any standardization in the education system, especially in processes for identifying those in need.

Dr. Abraham Verghese, Professor for the Theory and Practice of Medicine at Stanford University Medical School, helps us further understand the importance of the human in his explanation of the "IPatient" concept (Verghese, 2008). Dr. Verghese argues that, in medicine, the technology that we are developing, which is necessary and useful in some situations, is also

pushing us to treat patients as purely quantifiable and digitizable entities. He argues that, both in training and application, technology is giving professionals illusion of productivity and control when in reality it is becoming a crutch that encourages laziness and complacency. There is no way to provide comforting and personal human care through computers. In one journal, he notes the unintended consequences of nationwide implementation of electronic medical records (Verghese, 2018). Although intended to increase productivity and accessibility of information, this implementation resulted in a significant loss of important social rituals: not only did this loss impact motivation and positive culture, but impacted the cohesion and level of care that was able to be provided by hospital staff.

The "IStudent" concept is one analogous to this in the context of education. The IStudent is the student in the perspective of the system: they are their scores, their attendance, their skills, and their failures. The issue with this idea, and with the increasing use of data and test in over-analyzing student progress, is that the data will only limit what we are able to tell about the student (Neel, 2006). As we focus on this mean of what set we push our child to align with, the individual needs and characteristics of that child gets lost: in turn, classifying students as data will only continue to fail us in fully understanding for what they are: human.

Conclusion

Through exploration of the experiences and perspectives of involved parties, I have been able to identify five characteristics of great special education advocacy. It is undoubtable an advocate will be better suited to help a child succeed if they strive to embody these characteristics; however, recognition of these traits leaves us far from a solution to the problem of fairly accommodating all students in United States public schools.

What we can learn from this study is that it is almost impossible to implement any effective advocacy without understanding and supporting the student. We also learn that the parent of this student, who should understand and support them more than anyone, is more often than not significantly disadvantaged in their effort to do so. In light of these learnings, the obvious course of action is to ensure that each and every student, regardless of their identified learning needs, is advocated for by an educated adult who supports and understands them.

Diffusion of responsibility is undeniable in most systems or groups. It is also, to some degree, acceptable and natural in many situations. It is unacceptable, however, for the actions of any system or individual, or lack thereof, to strip a child of their opportunity to succeed.

Expecting a system to care for a child is like expecting a square peg to fit in a round hole. Each and every child is different and deserves to be understood and heard for their needs which they cannot voice.

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