



Kelly Howard
Before the
Education Committee

Regarding:

S.B. 317 An Act Concerning Dyslexia

March 1, 2016

Good Afternoon Co-Chair Senator Slossberg, Co-Chair Representative Fleischmann and other members of the Education Committee. My name is Kelly Howard, mother of Zoey and Katie Howard. Thank you for the opportunity to address you today on the proposed bill listed above.

This will be my third time submitting testimony to the Education Committee related to Dyslexia Legislation. My family and I are so very grateful for the changes we have made here in Connecticut related to Dyslexia legislation (H.B. 5562 & S.B. 1054).

As we address the most critical piece of the equation ***Practice Standards for Teachers of Reading***, I can't help but ponder what I consider to be good advice from my father (an Engineer), "do it right the first time! If you do not take your time to do it right the first time, whatever it is you are trying to do will always have problems later on down the road."

This has been good advice to me, it has applied to so many situations I would be faced with during my life both professionally and personally. I am in support of Senate Bill No. 317, An Act Concerning Dyslexia - with the following amendments: Comprehensive teacher preparation using evidence based curriculum and content (graduate level) MUST take place in our CT Institutions of Higher Education, regarding the literacy instruction for students with Dyslexia. Teacher preparation must align with evidence based standards that are proven to be effective. IDA Knowledge and Practice Standards for Teachers of Reading, should be aligned with the Remedial Reading (102) Endorsement. "A Course" in Dyslexia – is NOT SUFFICIENT. If one course was all that was needed to serve Dyslexic children, sign me up for that course I would gladly take it to help my child. In fact I would pay for every Special Education teacher in my district to take it. We all know it is not this simple. As it is currently written Senate Bill No. 317, An Act Concerning Dyslexia is NOT comprehensive enough to provide the needed supports. As you the Education Committee contemplate all the testimony you will receive, I ask that you please remember my father's advice, do it right the first time! If you do not take your time to do it right the first time, we will have problems later on down the road.

On February 18, 2016 H.R.3033 - Research Excellence and Advancements for Dyslexia Act was signed into law. This bill passed both the Senate and the House **unanimously**. I would like to draw your attention to SEC. 4. Dyslexia.

(a) In general.—Consistent with subsection (c), the National Science Foundation shall support multi-directorate,professional development for teachers and administrators of students with dyslexia, curricula and educational tools needed for children with dyslexia, and implementation and scaling of successful models of dyslexia intervention. Research supported under this subsection shall be conducted with the goal of practical application.

Teachers are the first step in the process. We need to invest in our teachers! If we do not properly address teacher training at higher education, we are not addressing the underlying issue and we will continue to perpetuate the same issues over and over.

Currently we are asking the towns to provide that teacher training. With our towns facing shrinking enrollment, skyrocketing special education costs eating up school budgets, do we honestly think towns are going to willingly



invest in good quality teacher training? School budgets can't support it. What do you think is happening? Most school districts are paying for **cost effective** training that can be completed in a short amount of time.

As parents we jump through hoops to have our children's disability diagnosed, then go through the process of getting an IEP in place. What good does that IEP do if the very people we are entrusting to deliver our children's educational needs, do not have the proper training to address their disability? Dyslexia is the most prevalent language based disability a teacher will face. We need to give them the tools they need to do their job. Instead we are setting them up for frustration and failure. That is why it is critical to address the root cause, teacher training. The good news is the research has already been done. We have all the resources we need right here in Connecticut as it relates to Dyslexia!

We have internationally renowned Haskins Laboratory, their mission: Haskins Laboratories is an independent, international, multidisciplinary community of researchers conducting basic research on spoken and written language. Exchanging ideas, fostering collaborations, and forging partnerships across the sciences, it produces groundbreaking research that enhances our understanding of—and reveals ways to improve or remediate—speech perception and production, reading and reading disabilities, and human communication.

Haskins Laboratories has long-standing, formal affiliations with the University of Connecticut and Yale University. We also have collaborations and partnerships, both formal and informal, with other institutions and groups around the world.

We have the Yale Center for Dyslexia and Creativity, their mission: The Yale Center for Dyslexia & Creativity serves as a nexus for research on dyslexia, and is as well a leading source of advocacy and information to better the lives of people with dyslexia.

Our mission is to uncover and illuminate the strengths of those with dyslexia, disseminate the latest innovations from scientific research and practical advice, and transform the treatment of children and adults with dyslexia.

What I am trying to emphasize is, we have the resources right at our finger tips. We have the opportunity to do something great here in Connecticut. These kids are so very intelligent. Let's teach the way they learn. I am driven by my daughter Zoey, and our families experience with Dyslexia. A lot has changed in the past two years, however it does not diminish our initial experiences going through this process.



My daughter Zoey Howard is an 8 year old Fraternal Twin. She is currently in third grade attending Ann Antolini School in New Hartford, Connecticut. She was diagnosed in first grade (January 2014) with a Language Based Learning Disability/Dyslexia and Expressive Language Disorder.

The first signs of learning based difficulties arose in preschool at Zoey's year-end assessment. She had great difficulty retaining the alphabet and names of shapes. The Director of the program was very concerned about the results. I would later find out these were the first early identification red flags of Dyslexia. My husband and I would not know about Dyslexia until approximately 1 year later.

The following year Zoey and her Sister Katie began a half day Kindergarten program at Bakerville Consolidated Elementary School in New Hartford. Zoey and Katie were in the same class. The school used the "Dolch" method to memorize high

frequency words. Part of their program was a requirement to memorize 25 "popcorn" words. Pop because they frequently pop up. Katie learned the words with relative ease. Zoey struggled and struggled. Neither my husband nor I knew what was wrong. We tried everything. Zoey could remember some of the words Monday and then forget them by Wednesday. At first I thought she was just being lazy and I would get upset. I would tell her let's just keep practicing. I had no idea what she was going through. It was such a difficult task for her. I even told her when she could get all the words memorized I would take her to NY City to buy an American Girl Doll. I was desperate to get her to learn these words!

It was in November 2013 the time of the Teacher Parent conference that we learned something was wrong. I remember going into that conference so happy thinking I was going to be told how smart my girls were. Instead the teacher looked at Tim and I and asked if we wanted the good news or the bad news? Foolishly, we took the good news first. Katie was learning well and at the high end of her class. As for Zoey, her teacher said, "I do not know what is going on."

It was like an out of body experience for me as Zoey's teacher walked us through the work she had been doing with my daughter, explaining to us what she was experiencing. Here we had one child doing so well while the

other struggled. The teacher told us a story about a circle time experience in which she call on the kids to answer various questions. Being selected is a real honor and the kids clamor to be picked. In this instance, the teacher picked Zoey but Zoey could not answer the question. The other kids were all yelling “I know it; I know it; pick me.”

Katie got so upset she yelled at her sister, “Zoey, you know this. I know you know this. Just answer the question.”

I could feel the pain and embarrassment my little girl must have felt. It went on and on. The last story the teacher told us was about an independent timed test she had given the class. They were to write down a few of the so called ‘popcorn’ words in a simple sentence and draw a picture. She told me Zoey froze, that she was confused and didn’t know what to do. She looked around to her friends and tried to see what was on their papers. The teacher said she could see Zoey struggling but it was meant to be an independent assignment. She knew it was uncomfortable for Zoey but she could not do anything. All I could think was how awful my poor little girl must have felt. I wished I could have been there with her. I kept picturing her young little face looking for help. The teacher asked us if we noticed anything before. My mind raced back to the conversation I had with the Director of her preschool. I immediately started to feel panic.

This teacher was so on the ball. When she explained to us what she was seeing she was so clear and to the point. She was very careful and never implied anything, but she clearly made it apparent we needed to pay attention. She told us she spoke to the Special Education Teacher about Zoey and they implemented extra help. Zoey would be working with a Paraprofessional.

(I feel it is important to note here, because of this teacher’s early identification and very detailed description of Zoey’s difficulties; after months of research I came to believe that Zoey had Dyslexia. Looking back the signs were so clear to me.)

After the conference, I went and sat in my car and cried. I felt like someone had punched me in the stomach. I was completely devastated. I began to question myself and everything I had done as a parent up until this point. After all I must have done something wrong. Maybe it was because I worked and I did not stay home with the girls? All I knew was I had to do something fast, I was not going to let my child fail. Poor Katie; that night when we got home from the conference we could not even celebrate her achievement the way we should have. I regret that now. I was so worried about Zoey.

Within a few days I reached out to a friend of mine who had a business called Little Hands Big Ideas. She teaches children sign language and intensive reading. The fees were \$100 an hour. It was a lot, but we were desperate. I hired her to work with Zoey in the morning before Kindergarten then she would drop her off at school for me. Zoey worked with Colleen through the end of the school year in mid-June.

At school Zoey was getting extra with a paraprofessional and her Teacher. At this point, Zoey told me **she did not like school anymore.** She did not want to go back. She just wanted to go to camp. It must have been hard for her. My husband also told me a sad story. He took the morning off so he dropped Zoey off at Colleen’s for her tutoring session. He said Zoey was so excited in the morning; she put on her usual big puffy fairy party dress for school and a fancy headband with a big bow. Tim said when he pulled up to Colleen’s house; he looked in

the rear view mirror at Zoey in the backseat. Zoey took a deep breath (out of frustration) and lowered her head. Tim said it was the saddest thing he ever saw. Zoey slowly took off her headband, paused for a moment like that and then reached out her little hand out to him and gave him the headband. She said she didn't feel like wearing it anymore. Then with a lowered head and a sad face she got out of the car and went into Colleen's house. Tim said it was not Colleen; Zoey liked her. It was that she had such difficulty learning to spell it was uncomfortable for her.



Despite her difficulty learning to read, Zoey loved books. In fact my husband and I noticed something weird. In the morning we would find all these books in a pile on the floor in front of the book case in the girls' bedroom. We were not sure which one of them was doing it. It was one night after everyone went to bed I heard something so we went down to the girls room. There was Zoey with her little head lamp on going through the book shelf. One by one she would pull a book out, open it try to read it then throw it in the pile on the floor and pick another one. After a while of watching her we asked her what she was doing? She said she wanted to see if she could read. We would often find books in her bed in the morning.

I started to do a lot of research trying to figure out what was going on with Zoey. I found the National Center for Learning Disabilities, NCLD. From there I made the connection to Dyslexia. They had a lot of information and checklists. I could see similarities in the symptoms the teacher explained to us and what

I was reading. In the mean time we had another meeting with Zoey's teacher.

That was the first time I brought up Dyslexia and it was like I said a four letter word. She clearly got uncomfortable talking about it. So I did not press it. She recommended we have Zoey tested for a learning disability. She said this will identify her weaknesses and the best way to teach her. She said that we would have to make a request for the evaluation. All the time she spoke to us it was as though she was being very guarded or at least that was my impression. She could not just come out and tell us what she thought. I remember thinking to myself, "Please just tell me!! I promise I won't get mad!" Instead I just followed her lead; it was all I could do at the time.

It is important to note here, we can now use the word Dyslexia in PPTs!

I formally requested an evaluation for Zoey. Before we started the testing I told them I had a concern about Dyslexia. Again they all gave me the same reaction. My concerns were documented. I told them my younger brother had it, though I did not know much about it. They noted my concern and scheduled the testing. When the results came back we had another meeting.

At that meeting, they discussed the results of their respective evaluations and made recommendations. We were all on the same page. They were setting up an IEP for Zoey in Kindergarten. I had never heard this term

before. In fact they were using a lot of terms I had never heard before. At this point in time I felt like I did not understand what they were talking about. The conversation was whizzing around my head. It was as though I had to attend a board meeting at work and I never prepared for it. I was not comfortable with this not understanding what was going on. I had to blindly trust them. From that point forward I vowed to myself I was going to make it my responsibility to understand everything for my daughter's sake.

I soon realized that Zoey would have to be labeled as Special Education to get the help she needed. I knew it was the right thing to do, but I got choked up as I fought back tears. It hit me my child was going to be in special education. Her teacher reached out to me and said, "it is okay; you are doing the right thing." They told me I had to sign a form and that they were going to create an IEP for Zoey. Again this was unfamiliar to me. I signed it. There was a list of 2 PPT Recommendations. I will never forget this. The first sentence read Zoey qualifies for special education services as a student with a **Learning Disability**. And then our journey began.



The people performing Zoey's evaluation were not specifically trained in 2013 (when they did her evaluation) to screen for Dyslexia, to identify Dyslexia. If I listened to the School, Zoey would have gone undiagnosed

for Dyslexia. However, fortunately this was not the case.

I spoke with my pediatrician about getting Zoey tested for Dyslexia. He recommend a good Doctor to do a Neuropsychological Evaluation. He told me to call Dr. Isenberg at Connecticut Pediatric Neuropsychology Associates. This was in July; the first appointment I could get with Dr. Isenberg was January 8, 2014.

We were at the end of Kindergarten; the next step was first grade. Zoey was so scared of school at this point, she was clinging to Katie. I felt this would hold Katie back. She also started to get angry with Katie because she was able to learn. I knew in my heart the girls would have to be separated. It was difficult but we did it. Zoey became very upset about it. She came home from school and said, "Mommy did you tell them to split us up? Now I am afraid that Katie and I will never be together again." I looked at her sad little face, she was so upset, and I could not tell her the truth. She would never understand. I said, "No, Zoey; the school separated you two." It would have hurt her more if I told her the truth. At 5 years old, she would not have understood.

In September when school started I notified them I wanted to have Zoey tested for Dyslexia. We had a meeting with our PPT Team in September 2013; I told them I scheduled the Neuropsychological Evaluation. The Director of Special Education told me flat out they would not pay for it. Again I did not know if I did not agree with the schools evaluation that I could request that she be reevaluated. That is my fault for not completely understanding a Parent's Guide to Special Education.

In January 2014 we had Zoey's Independent Evaluation. Our insurance did not cover this; they told us the school should be providing it, it is an Educational Cost. We knew that was not going to happen, we had to pay the \$2,500 at the time of the visit. They were very clear about this. We just had the evaluation and received the report. We also paid for an extra consultation with our PPT Team to discuss the results of the report. Dr. Isenberg made a lot of suggestions. When he met with Tim and I to go over the results, he told us that Zoey was

going to need a lot of one on one intervention. He said because she was identified so early, we could have a positive outcome.

We hired a tutor trained in both the Orton-Gillingham and Lindamood Bell methodology working with Zoey three days a week after school (\$75 dollars an hour.).

Upon getting the detailed report from Dr. Isenberg Tim and I hired an advocate from SpEdCT. It was becoming very overwhelming for me. I was trying to stay on top of the latest Dyslexia research as well as continue to inform myself on Zoey's rights for FAPE. When we met with the PPT Team after going through Dr. Isenberg's results I requested a full record review and reading evaluation from Literacy How. Dr. Isenberg told us what was wrong, now we need a road map to get Zoey on track.

The town agreed to pay for this. I am very thankful. This evaluation is the single most important thing we have ever done for Zoey. Literacy How came to the school and observed the teachers working with Zoey. They also performed specific testing and gave us 19 specific recommendations. The two most important... "Zoey requires continued use of a research-based, multi-sensory, systematic and explicit reading program to strengthen her decoding, word recognition, encoding and reading fluency skills. This program is essential to help close the gaps in reading so that Zoey can reach her full potential. Whatever multisensory language (MSL) program is chosen, it must be delivered intensively, meaning 5 days a week, for a minimum of **90--120** minutes each day. Examples include, but are not limited to, Wilson Reading System, Orton-Gillingham or Nanci Bell's Seeing Stars Program.

2. If a specific program is chosen for Zoey to participate in, the individual(s) who work with Zoey (i.e., special education teacher and speech and language pathologist) **must have authentic training in that program** so that the program is carried out with fidelity. If they are newly trained in a program, they will require a mentor/consultant to assist with initial program implementation.



Zoey has the new 2015 IEP form with an X next to SLD –Dyslexia.

Tim and I continue to have Literacy How do Independent Progress monitoring. We continue to keep up on the latest Dyslexia research. Zoey participated in the BILD study up at MIT in October 2014 at the Gabrieli Lab. They did a FMRI brain scan (we were given a free copy) and other assessments. We also took Zoey up to TUFTS University, where she participated in a study by Dr. Melissa Orkin the Director of the Center for Reading and Language Research.

At the end of the day the experts basically all say the same thing. These kids just need early identification and a good multisensory language (MSL) program delivered intensively. The person delivering it **must have authentic training in that program** so that the program is carried out with fidelity. If Teachers are newly trained in a program, they will require a mentor/consultant to assist with initial program implementation.

Require that our teachers have Dyslexia training through professional development and higher education. If it is not a requirement it will not happen.

Before I close I would like to emphasize how expensive it was to get the right help for Zoey and we are still not there. Insurance has not covered any of this. Fortunately we were able to do this on our own with great sacrifice. Many families may not have the resources to have their child tested; due to expense may not be able to afford tutoring. Consequently, the child will struggle, possibly fail and not receive the proper training needed to succeed. No child deserves this.

The State Legislation has the power to bring Dyslexia front and center in the educational system and provide Dyslexic children with the education they so richly deserve.

I am in support of Senate Bill No. 317, An Act Concerning Dyslexia - with the following amendments: Comprehensive teacher preparation using evidence based curriculum and content (graduate level) MUST take place in our CT Institutions of Higher Education, regarding the literacy instruction for students with Dyslexia. Teacher preparation must align with evidence based standards that are proven to be effective. IDA Knowledge and Practice Standards for Teachers of Reading, should be aligned with the Remedial Reading (102) Endorsement. "A Course" in Dyslexia – is NOT SUFFICIENT.

As a resident in the State of Connecticut, I request your support of the Dyslexia legislation.

Respectfully,

Kelly Howard

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