

**UNDERSTANDING DYSLEXIA: THE INTERSECTION  
OF SCIENTIFIC RESEARCH AND EDUCATION**

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**HEARING**  
OF THE  
**COMMITTEE ON HEALTH, EDUCATION,  
LABOR, AND PENSIONS**  
**UNITED STATES SENATE**  
**ONE HUNDRED FOURTEENTH CONGRESS**

SECOND SESSION

ON

EXAMINING UNDERSTANDING DYSLEXIA, FOCUSING ON THE  
INTERSECTION OF SCIENTIFIC RESEARCH AND EDUCATION

—————  
MAY 10, 2016  
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# UNDERSTANDING DYSLEXIA: THE INTERSECTION OF SCIENTIFIC RESEARCH AND EDUCATION

TUESDAY, MAY 10, 2016

U.S. SENATE,  
COMMITTEE ON HEALTH, EDUCATION, LABOR, AND PENSIONS,  
*Washington, DC.*

The committee met, pursuant to notice, at 10:08 a.m., in room SD-430, Dirksen Senate Office Building, Hon. Bill Cassidy presiding.

Present: Senators Cassidy, Mikulski, Burr, Scott, Casey, Bennet, Murphy, and Warren.

## OPENING STATEMENT OF SENATOR CASSIDY

Senator CASSIDY. The Senate Committee on Health, Education, Labor, and Pensions will please come to order. Welcome to all. Thank you for being here.

Let me remark that Senator Bennett's funeral is this morning. So we've lost some of our colleagues who will be attending the funeral. Senator Hatch, who asked that I would note that he's going to be in Utah attending former Senator Bennett's funeral and wished he could be here and regrets that he cannot be here to introduce Ms. Hanrath. Under the circumstances, we understand.

This morning, we're having a hearing titled Understanding Dyslexia: The Intersection of Scientific Research & Education that, hopefully, will raise awareness and educate us on dyslexia, highlighting the importance of early identification of students with dyslexia, and ensuring that such students have access to evidence-based resources.

Senator Mikulski and I will each make an opening statement, and then introduce our panel of witnesses. Each panelist will have 5 minutes to summarize your testimony. We have a timer in front of you. Green light is go, yellow means you have 1 minute left, and red means I'm going to start pounding with my gavel. After our witnesses' testimony, Senators will each have 5 minutes to ask questions.

I am pleased to chair this hearing, and, again, I thank Senator Mikulski for co-chairing. I also thank my other colleagues who were in support of having this hearing.

We're discussing dyslexia, an issue very important to me, both as the parent of a dyslexic child and as a Senator. We have a great lineup of witnesses, including those who have personally addressed dyslexia.

Ameer Baraka, who is a friend, will speak about growing up with unrecognized dyslexia, without resources, but overcoming and eventually becoming an actor; David Boies, who overcame dyslexia, entering the most language-based of all professions, law; and Ms. Hanrath will speak of her daughter, who has been quite successful, but from the mother's perspective. Thank you, Ms. Hanrath.

There's a common thread in each family's testimony: a child who struggles to read and cannot. Often, the parent was dyslexic, too, and they relate. But a child frustrated by their inability to read, if a boy, acts out. If it's a girl, she becomes shy, embarrassed to read aloud in class. Afraid of being mocked. Think about the teacher who has that bright child struggling to read, but does not have the training or resources to help that child become the better student and achieve their fuller potential.

In October of last year, Senator Mikulski and I sponsored and the Senate passed a resolution that defined dyslexia as a, "unexpected difficulty in reading, highlighted by a gap between the individual's intelligence and their reading level." It's the bright child who doesn't read commensurate with their brightness. Put simply, in non-dyslexics, IQ and reading tend to track along the same line. In dyslexics, IQ is higher, and reading ability is lower.

Dyslexia is the most common learning disability, many will mention. According to NIH sponsored research, nearly 20 percent of us have dyslexia, whether you're watching on TV, in this room, in Congress, in your workplace. It's from all walks of life. The impact of dyslexia on an individual, a family, a school, and our society is tremendous.

What if I told you that by effectively addressing dyslexia, we could further prison reform by identifying students with dyslexia and providing science-based interventions? Or that we could get more bang from our Federal investments in education? Or that we could reach into the classroom and change the interaction between a dyslexic student and a frustrated teacher to a relationship between a learning, productive student and a fulfilled teacher?

The goals of this hearing are simple: to raise awareness of the scope and scale of dyslexia; to increase awareness of what precisely dyslexia is, as defined by science; and to highlight the importance of early identification of those who are dyslexic and giving these children the necessary evidence-based resources needed to succeed in school and beyond.

There are great schools for children with dyslexia, almost all of which are private, and if you can't afford the \$10,000 to \$50,000 a year, a family's options are limited. If the family is less wealthy, quite likely, they cannot afford to have their child's needs met. Perhaps that's the one thing that should be taken from this hearing. There's a correlation between your ability to have your child's needs accommodated and your wealth, and that's not good.

We've heard testimony from Governors, superintendents, and other school administrators that screening for dyslexia is not happening. Your child may be dyslexic, and it may not be discovered, despite the fact that we'll hear from Dr. Shaywitz that the achievement gap between a dyslexic and a typical reader is evident as early as first grade, and the gap continues into adolescence.

There are three public charter schools in the Nation that specialize in teaching dyslexics. I'm proud to say two are in Louisiana, the Louisiana Key Academy in Baton Rouge and the Max Charter School in Thibodaux. Parents choose to send their child to these schools, the goal being for the child to transition to a traditional public school as their reading difficulty is addressed.

There are also colleges that accommodate for students with dyslexia. Nicholls State University has the Louisiana Center for Dyslexia and Related Learning Disorders. I think Senator Alexander has a school in his State of Tennessee.

I mentioned about how addressing dyslexia can greatly impact the rates of incarceration. We know that many who are incarcerated are functionally illiterate. A study at the Texas State Prison in Huntsville found that 80 percent of prison inmates were functionally illiterate and 48 percent dyslexic.

The prevalence of dyslexia is 20 percent in the general population and 48 percent in the incarcerated population. If appropriate science-based strategies to teach and treat dyslexia are instituted, the effect on our future prison population could be profound.

Let me say, with all of this, there's been progress. Last year, Senator Mikulski and I sponsored a bipartisan Senate resolution which passed that calls on Congress, schools, and State and local educational agencies to recognize the significant educational implications of dyslexia that must be addressed. It also designated October 2015 as the National Dyslexia Awareness Month. We will reintroduce this resolution this year.

Representative Lamar Smith's Research Excellence and Advancements in Dyslexia Act, or the READ Act, ensures the National Science Foundation has dedicated funding for dyslexia research, and this past Congress was signed into law. The Every Student Succeeds Act creates a dyslexia-focused comprehensive center providing evidence-based resources for identifying students struggling with reading and the appropriate interventions to States, school districts, teachers, and parents.

Last, the U.S. Department of Education's Office of Special Education and Rehabilitative Services issued a Dear Colleague letter that specifically clarifies that nothing in Federal law prohibits the use of the word, dyslexia, in evaluation, eligibility determinations, and an individualized education program, or IEP, for students. Anecdotally, however, State and local educational agencies are still reluctant to specifically reference the word, dyslexia, denying dyslexics the specific services they need to succeed.

I hope these efforts are the first of many steps in the right direction. We've made great progress in the area of learning disabilities. We've seen that conditions like autism and dyslexia can be specifically diagnosed and that there are science-based interventions. We must continue efforts that all learning disabilities have the same science-based intervention.

If there's a call to action in this hearing, it's that science should begin driving policy. We have the dots. Now let's connect them.

I will now yield to Senator Mikulski for her opening statement.

## OPENING STATEMENT OF SENATOR MIKULSKI

Senator MIKULSKI. Thank you very much, Senator Cassidy. I'm delighted to co-chair this hearing with you on this very important issue of dyslexia. It's important to both you and I, it's important to the Congress, and it's surely important to the Nation. I would like to thank Senator Alexander, the Chairman, and the Ranking Member, Senator Murray, for allowing us to hold this hearing today and to focus on dyslexia and the understanding of it and the intersection of scientific research and education.

This is a very interesting hearing at many different levels. First of all, we're co-chairing. That, in and of itself, is very different, and the fact is that we see each other as, really, not a Democrat or a Republican, but we see each other as advocates for children and children who need special attention, and then what type of special education they need.

The second thing is that within the realm of Congress and the prickly atmosphere we sometimes find with each other, we would be regarded as an odd couple, because Senator Cassidy and I come from different parts of the country, we come from different political parties, and, occasionally, on our votes, even different political philosophies. Again, in this room, in this committee, we are focusing on the needs of children, and that doesn't know politics. It doesn't know the lines that separate us or divide us. Senator Cassidy is a physician. I'm a social worker. We bring those kinds of attitudes and skills to this table.

We look forward to hearing from our witnesses, and you should know that this will be a hearing where we really want to engage in a conversation with you on how we can best help these children that are facing these challenges. This won't be a harass and a harangue hearing. This will be an informational dialog, and I look forward to doing this.

I regard each and every one of you as experts at the table who come from very esteemed academic centers of excellence, Yale, Georgetown, Hopkins, Kennedy Krieger. There are other great centers of learning, and they're called the streets and neighborhoods where kids grow up, because as they face challenges, their education comes from the street.

The first teacher and the first learning center is in the home, and that's why it's so important that we hear from a parent who has actually lived these issues and tried to cope with the issues as well as how to get the best plan and the best opportunity. All of you are experts in different ways.

We expect a lot from our teachers, and I would like to salute our teachers. As we worked so hard on the Elementary and Secondary Education and No Child Left Behind and now our latest version of that, we believe that every problem could be solved if we had a highly qualified teacher in the classroom. We need highly qualified teachers in the classroom. There's no doubt about it. When a child walks into that classroom, the child brings a lot. They bring a lot from the home, their family history, their social situation, and so on. We expect a lot of our teacher, but the teacher should begin to expect some things of the larger community.

I support the schools with children who are trying to do the famous individual education plans. I forget how all those acronyms come together. The fact is this. You can have the best plan, but unless you can operationalize that plan, what does it mean? Because of the very nature of the unfunded mandate, where we only pay 10 percent of special education funding, and then we argue over title II and how we can even provide additional training for our teachers, school systems are hard pressed to have that individual education plan and to be able to operationalize it.

Today is not a day to talk about budgets. Today is a day to talk about children and science. But I do bring to your attention that special education is an unfunded Federal mandate, and we need to come to grips with that, and we need to come to grips with it across party lines, because I think one area that we could agree upon is that we should fund that and meet our obligation so that States and then local school systems could do what we told them to do. I urge my colleagues to think about that as part of an action plan.

Today is about dyslexia, a lifelong condition that affects the way the brain processes written and spoken language. It's considered the most important learning disability. I know that Senator Cassidy has gone into a lot of the information and a lot of the data that I won't say again.

The recent report from the National Center for Learning Disabilities highlights the many challenges our country faces when trying to meet the needs with dyslexia and other learning disabilities. These challenges include a lack of awareness and understanding among educators and even healthcare professionals, a lack of teacher training when they're in schools learning how to be teachers and then in the mentorship, and then a lack of scientifically based reading interventions and a lack of resources to accommodate it.

Today, I want to listen to the experts, those that are from officially designated learning centers, but also those that have been in the streets and neighborhoods and lived the life of being challenged by dyslexia, those who have been a mother trying to be on the phone, trying to be in the chat room, and trying to do everything that she could to make sure that her daughter had a fair shot at following her dreams and her passions.

I want to thank you for your consistent leadership and I look forward to hearing this testimony.

Senator CASSIDY. I'll now defer to Senator Murphy to introduce Dr. Shaywitz.

Senator MURPHY. Thank you very much. I'm eager to get to the testimony as well. I may have to step out to another hearing and come back. I'm very excited to introduce the expert of experts at the end of the table which is Dr. Sally Shaywitz from Yale University where she is the Audrey Ratner Professor in Learning Development at the Yale School of Medicine.

She has a long list of titles, including the Co-Director of the Yale Center for Dyslexia and Creativity. She's one of the leading researchers in this field, and as a physician, her research focus really has been on neurobiology and epidemiology, providing a scientific basis for understanding dyslexia. She has written more than 200 journal articles and chapters in books on this topic. I know that she

is a great source of counsel for both the Chairman of this hearing and myself, and I'm glad to have Dr. Shaywitz with us.

Senator CASSIDY. I'll introduce Mr. Baraka. Ameer is an actor and author from New Orleans who struggled to read his whole life. He didn't learn that he was dyslexic until age 23 and incarcerated. In prison, he earned his GED and was empowered to influence youth who struggled the same way as he. I'm eager to hear how he has used his stardom—he is now an actor—to steer children off the path to incarceration.

I'll defer to you, Senator Mikulski, to introduce Dr. Eden and Dr. Mahone.

Senator MIKULSKI. I'd like to introduce Dr. Guinevere Eden. She is considered to be a nationally recognized expert in dyslexia research and one of the very first to use brain imaging and MRIs to better understand the neurological basis for dyslexia. She's been supported both by NIH and NSF and currently directs the Center for the Study of Learning at Georgetown. She continues to investigate while she is actively involved in teaching graduate students, investigating all the sensory processes related to reading and how these may be different in individuals. She's going to bring a lot to us.

We also have Dr. Mark Mahone, who is a Baltimore guy through and through. He grew up in a neighborhood called Dundalk, which was very close to the one where I grew up. He's a pediatric neuropsychologist, and he is at the esteemed Kennedy Krieger Institute in Baltimore. This is an institution internationally recognized and dedicated to improving the lives of those, particularly children, with brain and other challenges.

What Dr. Mahone does is provide clinical services for young kids with neurodevelopment disorders, works on the training of psychologists and educators and physicians on these issues, and really is an expert on involving the study of brain behaviors in children with or without these neurodevelopment disorders. He currently serves as the Co-Director of the Center for Innovation and Leadership in Special Education, and he brings really great knowledge about what the children need, but what the systems that are supposed to help the children need to do. I'm very proud to bring he and Dr. Eden to the committee's attention.

Senator CASSIDY. I'll next introduce David Boies, who is the Chairman of Boies, Schiller, and Flexner. He has been selected as one of the 100 most influential people in the world by Time magazine in 2010. He has been named Global International Litigator of the Year by Who's Who Legal an unprecedented seven times and has received many prestigious awards and numerous honorary degrees. Mr. Boies is a former Hill staffer, having served as Chief Counsel and Staff Director for the Senate Antitrust Subcommittee and the Senate Judiciary Committee.

Thank you, Mr. Boies.

And, last, Ms. April Hanrath, a small business owner and a single mom of two adopted children from Salt Lake City. Ms. Hanrath has been recognized as a child advocate in Utah for her work on behalf of children like her daughter, Jocelyn, who is behind her, who has dyslexia and other learning disabilities. She is a parent

advocate with Understood, at *www.understood.org*, and attended the University of Utah before taking over the family business.

Thank you all, and now I'll ask Dr. Shaywitz to begin her testimony and the rest to follow in order.

**STATEMENT OF SALLY SHAYWITZ, M.D., CO-DIRECTOR, YALE CENTER FOR DYSLEXIA AND CREATIVITY, YALE UNIVERSITY SCHOOL OF MEDICINE, NEW HAVEN, CT**

Dr. SHAYWITZ. Thank you. Good morning, Senator Cassidy, Senator Mikulski, and other committee members. Thank you for the opportunity to speak with you about the science of dyslexia and share with you the tremendous scientific progress that has been made in dyslexia and its important implications for education.

The problem: Our Nation is in the midst of a national nightmare where substantial numbers of children are not learning to read, especially boys and girls from disadvantaged families. Just released, 2015 data from NAEP—I'm going to be showing a number of slides, and it would be helpful if people could see it.

[Slides Shown]

Senator MIKULSKI. We're looking at it right here.

Senator CASSIDY. We see it on the TV.

Dr. SHAYWITZ. Oh, great.

Senator MIKULSKI. Are you going to give us the NAEP 2015 High School Reading Scores? We've got it.

Dr. SHAYWITZ. Great. Just released 2015 data from NAEP, the Nation's report card, sends a loud warning signal. Here, outlined in yellow, the lowest achievers show large declines in reading, and, most alarming, the greatest drop in reading in two decades occurs, between 2013 and 2015.

Reactions from experts: We're stalled. We're not making any progress. We need something substantially different. Increasing scientific evidence strongly points to dyslexia as the explanation and potential solution to our education crisis.

As shown here, dyslexia puts all the pieces together. Dyslexia represents 80 percent to 90 percent of all learning disabilities and differs markedly from all others in that dyslexia is very specific and scientifically valid. Dyslexia is very common, affecting one out of five.

Initial descriptions of dyslexia as an unexpected difficulty in reading are today empirically validated. A major step forward is Cassidy-Mikulski Resolution 275, providing a 21st century definition of dyslexia incorporating scientific advances in dyslexia, especially its unexpected nature, and emphasizes the cognitive basis of dyslexia, difficulty getting the individual sounds of spoken language. It is not seeing words backward.

Resolution 275 represents a landmark in aligning science and education. Dyslexia is a paradox. The same slow reader is often a very fast and able thinker, giving rise to our conceptual model of dyslexia as a weakness in getting the sounds of words surrounded by a sea of strengths in higher level thinking processes.

Converging evidence has identified a neural signature for dyslexia. That is an inefficient functioning of those posterior left hemisphere reading systems. Our ongoing studies examine disruptions

in brain connectivity in dyslexia, the role of attentional mechanisms in reading, and the economic consequences of dyslexia.

Dyslexia is real. However, imaging cannot be used to diagnose individuals. The achievement gap between typical and dyslexic readers is large, occurs as early as first grade, and persists. Dyslexia has often dire consequences. Dyslexic students drop out of school at a significantly greater rate than their typically reading peers. As a consequence, they are often doomed to higher unemployment, lower earnings, and, as you heard from Senator Cassidy a few minutes ago, almost 50 percent of prison inmates are dyslexic.

In aligning education with science, certain principles emerge. One, given its high prevalence and scientific validity and harsh impact, dyslexia must be given prominence in reauthorization of IDEA. Schools must screen for and identify dyslexic students early. The dyslexic student should know his diagnosis and that he is smart.

Moving forward, implementation requires a model incorporating 21st century scientific knowledge about dyslexia as shown in this slide: a school climate where everyone is on board, and the word, dyslexia, is used; small classes; evidence-based methods; et cetera.

Where can this model be found? Independent schools for dyslexic students, for example, the Windward School in New York. However, the tuition is \$52,000, a tuition out of reach of most middle class and certainly disadvantaged children. Public charter schools—a new model serving dyslexic students. An example is the Louisiana Key Academy, LKA, in Baton Rouge. Schools like LKA bring a quality and hope to all dyslexic children so that disadvantaged children are no longer left behind.

I always think of people who are dyslexic—it reminds me of an iceberg, where you just see 10 percent—and we see the people who have succeeded, including my hero, David Boies, who is seated at this table—but we forget about the 90 percent that are unseen that are asking for help and could benefit from help.

Thank you.

[The prepared statement of Dr. Shaywitz follows:]

PREPARED STATEMENT OF SALLY SHAYWITZ, M.D.

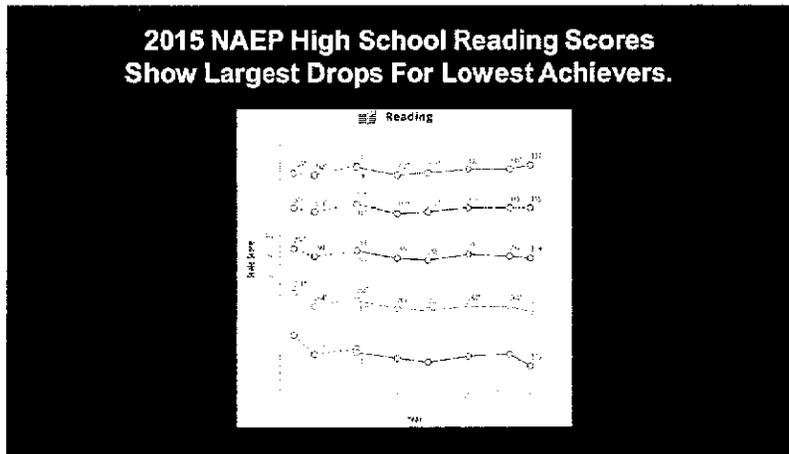
UNDERSTANDING DYSLEXIA: THE INTERSECTION OF SCIENTIFIC RESEARCH  
& EDUCATION

DYSLEXIA: EXPLANATION AND POTENTIAL SOLUTION TO THE EDUCATIONAL CRISIS

Good morning Senator Cassidy, Senator Mikulski, and other committee members. Thank you for the opportunity to speak with you about the science of dyslexia and share with you the tremendous scientific progress that has been made in dyslexia and its important implications for education.

THE PROBLEM

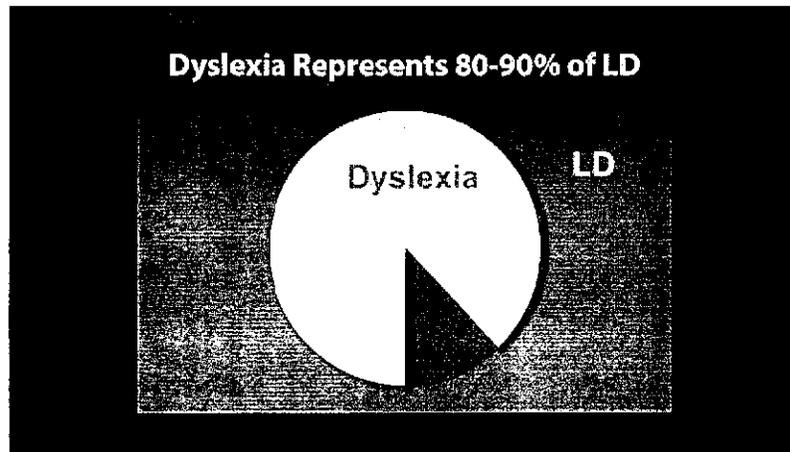
Our Nation is in the midst of a national nightmare where substantial numbers of children are not learning to read, especially boys and girls from disadvantaged families.



**(Slide 1)** Just released 2015 data from NAEP, the Nation's report card, sends a loud warning signal.

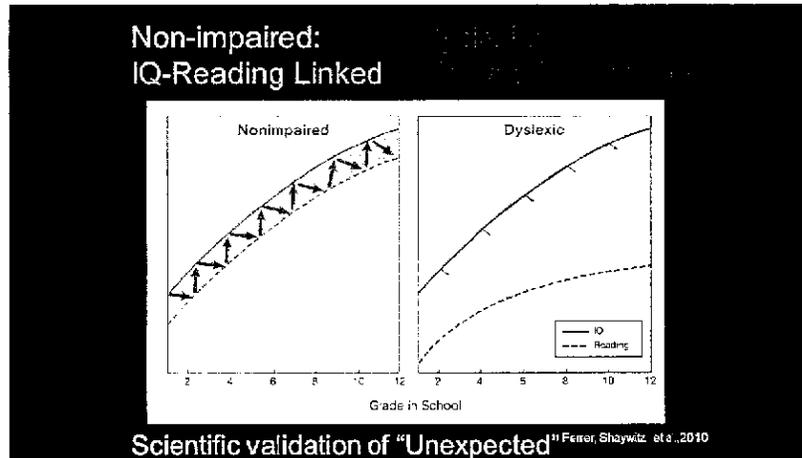
Here on the lower right—the lowest achievers show large declines in reading and, most alarming, the greatest drop in reading occurs between 2013 and 2015. Reactions from experts: “We’re stalled . . .” “We’re not making any progress.” “We need something substantially different . . .”

Increasing scientific evidence strongly points to **dyslexia as the explanation and potential solution to our education crisis.**



Dyslexia represents 80 percent to 90 percent of all learning disabilities (**Slide 2**) and differs markedly from all others in that dyslexia is very specific and scientifically validated.

**Prevalence:** Dyslexia is very common, affecting 1 out of 5.



**Unexpected Nature: (Slide 3)** Initial descriptions of dyslexia as an "unexpected" difficulty in reading are today empirically validated.

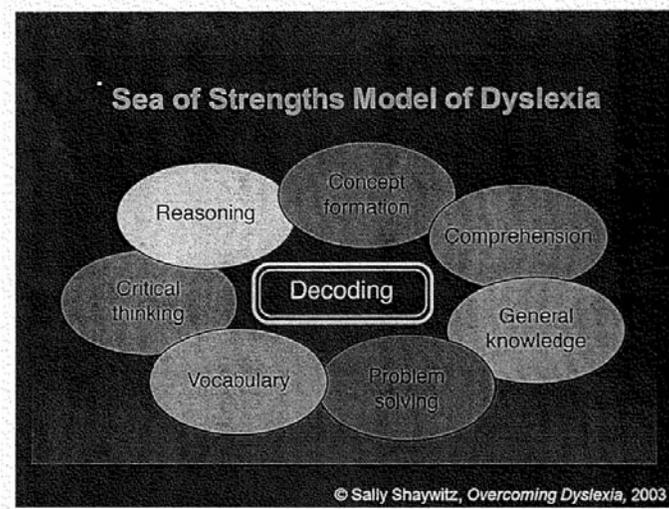
**Cognitive Basis:** Dyslexia is a difficulty within the language system, more specifically, the phonological component of language—it is not seeing words backwards.

### The 21<sup>st</sup> Century Definition of Dyslexia (Cassidy-Mikulski US Senate resolution 275)

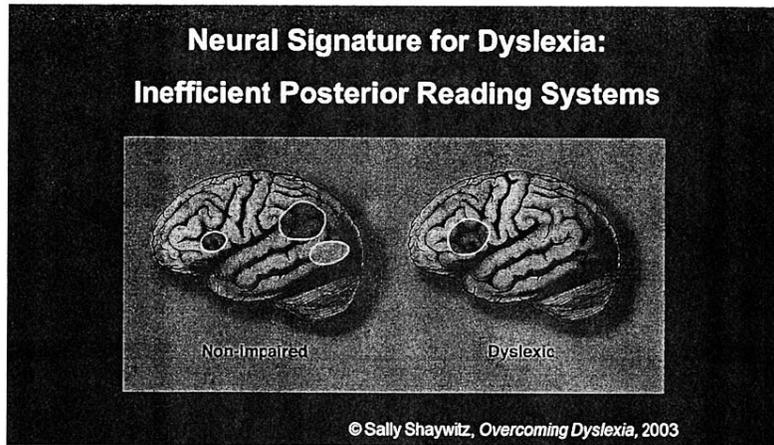
#### *Major Step: Aligning Science & Education*

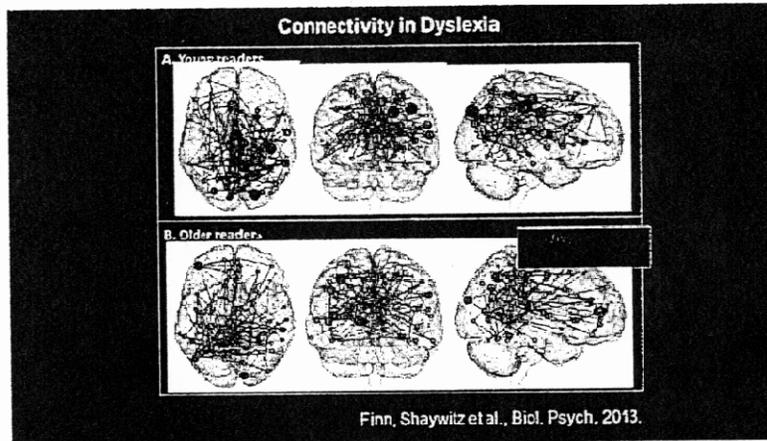
- 1) an *unexpected* difficulty in reading for an individual who has the intelligence to be a much better reader; and
- 2) due to a difficulty in getting to the individual sounds of spoken language, which affects the ability of an individual to speak, read, spell, and often, learn a second language.

A major step forward is Cassidy-Mikulski Resolution 275 (**Slide 4**) providing a 21st century definition of dyslexia incorporating scientific advances in dyslexia, especially, its unexpected nature, and represents a landmark in aligning science and education.

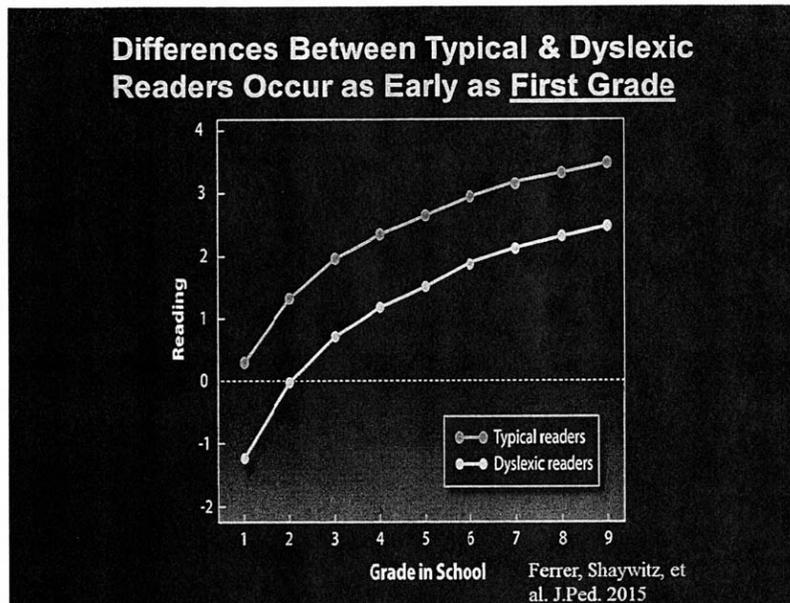


(Slide 5) Dyslexia is a paradox, the same slow reader is often a very fast and able thinker.

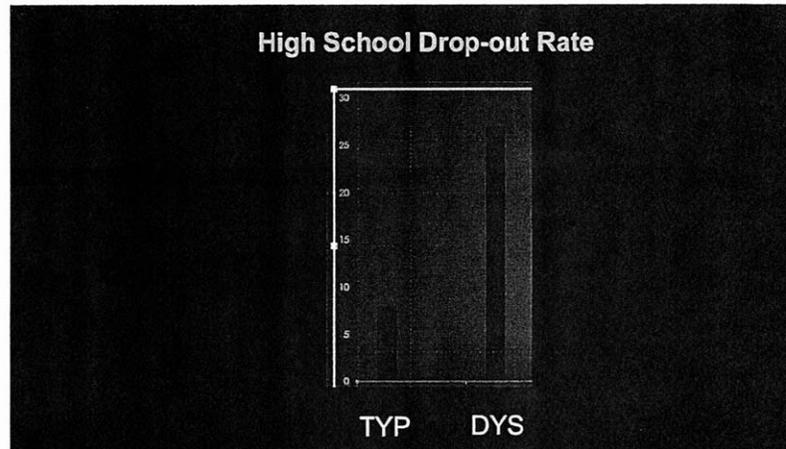




Neurobiology: Converging evidence has identified a neural signature for dyslexia—(Slide 6) that is, an inefficient functioning of those posterior, left hemisphere reading systems and (Slide 7) disruptions in connectivity.



**Early identification of dyslexia critical: (Slide 8)** The gap between typical and dyslexic readers is large, present by first grade and persists.



**High Cost of Dyslexia:** Dyslexia has often dire consequences (**Slide 9**). Dyslexic students drop out of high school at a significantly greater rate than their typically reading peers.

As a consequence they are doomed to higher unemployment, lower earnings, and significantly higher rates of anxiety and depression. Studies indicate that almost 50 percent of prison inmates may be dyslexic.

**In aligning education with science certain principles emerge:**

1. Given its high prevalence + scientific validity + harsh impact—dyslexia must be given prominence in reauthorization of IDEA.
2. Schools must screen and identify dyslexic students early.
3. The dyslexic student should know his diagnosis (dyslexia) and that he is smart.

**Moving forward—Implementation—requires a model incorporating 21st century scientific knowledge about dyslexia; for example:**

- School climate—everyone at school on board, use the word dyslexia.
- Small classes.
- Evidence-based methods.
- Knowledgeable, flexible, caring teachers.
- Consistency in instruction across all classes.
- A community to join—know they are not alone.

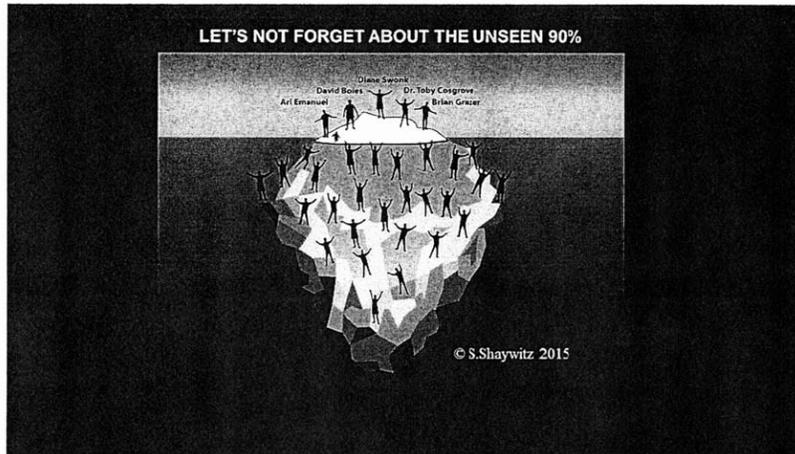


**Specific solutions: where can this model be found?**

- Independent schools for dyslexic students, (Slide 10) example, the Windward School in New York. (Slide 11).



- Clearly, a tuition out of reach of middle class and disadvantaged children.
- Public Charter Schools serving dyslexic students. (Slide 12) An example is the Louisiana Key Academy in Baton Rouge. (Slide 13)



**A school like LKA brings equality and hope to all dyslexic children so that disadvantaged children are no longer left behind. (Slide 14)**

Senator CASSIDY. Thank you, Dr. Shaywitz.  
Mr. Baraka.

**STATEMENT OF AMEER BARAKA, AUTHOR/ACTOR,  
TERRYTOWN, LA**

Mr. BARAKA. Good morning, Senators and panelists. I want to thank you for taking your valuable time to listen to my message. We are coming up on an important Presidential election, and I know your time is important.

I am also not oblivious to the challenges we face as a country. One such challenge is the lifelong curse of dyslexia. One out of five live with this challenge each day of their lives. Many will never reach their full potential and enjoy this great country as you and I do. Many people have lost the will to believe because the enemy, dyslexia, has forced them into the shadows. Today we have found a new way to address this enemy once and for all.

For many years, I allowed dyslexia to control my life by robbing me of my God-given potential. Can you imagine in my early teens never wanting to be anything but a drug dealer? Neither my mother nor my school teachers were able to diagnose the reasons why I had trouble learning. In my mind, pursuing a more formal education was irrelevant. I knew early in life that being a dentist, a physical therapist, or a lawyer was out of my reach because I could not read.

I turned to quicker pathways out of the New Orleans projects. I saw men in my community making ways for themselves without having to read by selling drugs. My defeatist attitude seemed to outweigh the positive values my grandmother tried to teach me. There were many more ingredients that helped me make my decision to sell drugs, for example, having my mother and siblings call me names such as dumb and stupid. Using names such as these can cause any child to feel hopeless and lost.

You will notice that I never mention my father in this presentation. That's because he left when I was 3 years old to chase his dreams of finding a better grade of heroin to use. It was the perfect storm for me. I chose to succumb to my environment while both my brother and sister excelled in school. I didn't care about my future or anyone else, because I thought I was a dummy like my mother and my siblings said.

I became a street thug and full of anger because I felt cheated out of an education. I went to school just because I had to as a kid. Many Fridays, I would malingering because I couldn't pass the spelling test, or I would sleep in a project hallway until school was out just to avoid embarrassment. I pushed myself into a hole, and I couldn't get out of it. My teachers had to know that I couldn't read. My young mother ran the streets and didn't seem to value my education.

What became the final thing that caused me to pledge my allegiance to the lies of the streets was a girl. I was in sixth grade and a girl I liked was in my class. It was our first week of school. We were in English class and the teacher called on me to read out loud. My palms began to sweat. It felt like drops of blood on my forehead. I couldn't pronounce any of the words and the teacher made me continue, knowing I couldn't read. Some students laughed while others looked in amazement.

From that day forward, I knew that school wasn't the place for me, and the young lady never really liked me much from that day forward. The streets became my classroom, and looking back, the lessons I learned were shameful. I shot and killed a young person because the streets taught me that that is how you resolve conflict. After my release from prison at 15 years of age for manslaughter, I got back into the drug game, still never learning to read. I ended up doing prison time as an adult.

I ran from the law for 4 years as a fugitive because I was facing 60 years for drug distribution and I was guilty. I ended up doing 4 years because, by God's grace, a jury found me guilty of a lesser charge. At age 23, I entered into a prison correctional facility reading at a third grade level. I didn't feel so bad because many of the men there were just like me. We all read poorly. After reading the autobiography of Malcolm X, I discovered that he dropped out in seventh grade and still made something of himself. I thought for the first time in my life that I could accomplish something too. I worked hard, writing down each word I couldn't pronounce. I just kept memorizing words and writing letters and reading short books.

A GED teacher noticed that I struggled with phonics and had me tested. He asked if my siblings could read. I told him that my siblings went to college. After testing me, he said I had a reading disability and it could be corrected if I was willing to work hard. I would write words down wrong so I sat in the front of class and double checked my answers. I worked for 4 years trying to attain my GED. My reading ability surged and I was ready for the test. I passed and started helping others in math and vocabulary.

Since my release from prison, I went on to model for clothing lines such as Nike. Also, I went to acting classes and worked with Academy Award winners Jessica Lange, Kathy Bates, Angela Bas-

sett, Forest Whitaker, Blair Underwood, Hill Harper, and many others. I have produced four independent films and written my first book titled *The Life I Chose: The Streets Lied to Me*. It is meant to inspire others who are just like I was, hiding in the shadows and not getting help. It is also for those who believe that dealing drugs is a way out. Today there are schools available to help kids fight and dyslexia, schools like the Cassidys have.

Thank you for your time and consideration.

[The prepared statement of Mr. Baraka follows:]

PREPARED STATEMENT OF AMEER BARAKA

Good morning Senators. I want to thank you for taking your valuable time to listen to my message. We are coming upon an important presidential election and I know your time is important. I'm also not oblivious to the challenges we face as a country. One such challenge is the life-long curse of dyslexia. One out of five people live with this challenge each day of their lives, so many will never reach their full potential and enjoy this great country as you and I do. Many people have lost the will to believe because the enemy, dyslexia, has forced them into the shadows. But today we have found a new way to address this enemy once and for all.

For many years, I allowed dyslexia to control my life and rob me of my God-given potential. Can you imagine in your early teens never wanting to be anything other than a drug dealer? Neither my mother, nor my school teachers, were able to diagnose the reasons why I had trouble learning. In my mind, pursuing more formal education wasn't relevant. I knew early in life that being a dentist, physical therapist, or lawyer was out of my reach because I couldn't read. I turned to quicker pathways out of the New Orleans projects. I saw men in my community making a way for themselves, without having to read, by selling drugs. And my defeatist attitude seemed to outweigh the positive values my grandmother tried to teach me. There were many more ingredients that helped me make my decision to sell drugs, for example, having my mother and siblings call me names like "stupid" and "dumb." Using names such as these can cause any child to feel hopeless and lost.

You will notice, I never mention my father in this presentation. That's because he left when I was 3 years old to chase his dreams of finding a better grade of heroin to use. It was the perfect storm for me. I chose to succumb to my environment while both my brother and sister excelled in school. I didn't care about my future, or anyone else, because I thought I was a dummy like my mother and siblings said I was.

I became a street thug and full of anger because I felt cheated out of an education. I went to school just because I had to as a kid. Many Fridays, I would "malinge" because I couldn't pass the spelling test, or I would sleep in a project hallway until school was out just to avoid embarrassment. I pushed myself into a hole that I couldn't get out of. My teachers had to know that I couldn't read. My young mother ran the streets and didn't seem to value my education. But what became the final thing that caused me to pledge my allegiance to the lies of the streets was a girl. I was in sixth grade and a girl I liked was in my class. It was the first week of school. We were in English class and the teacher called on me to read out loud. My palms began to sweat. It felt like drops of blood on my forehead. I couldn't pronounce any of the words and the teacher made me continue, knowing I couldn't read. Some students laughed, while others looked in amazement. From that day forward, I knew that school wasn't the place for me, and the young lady, never really liked me much from that day forward. The streets became my classroom and looking back, the lessons I learned were shameful. I shot and killed a young person because the streets taught me that is how you resolve conflict. After my release from prison at 15 years of age for manslaughter, I got back into the drug game, still never learning to read. I ended up doing prison time as an adult.

I ran from the law for 4 years as a fugitive because I was facing 60 years for distribution of cocaine and I was guilty. I ended up doing 4 years because, by God's grace, a jury found me guilty of a lesser charge. At age 23, I entered into a prison correctional facility reading at a third grade level. I didn't feel so bad because many of the men there were just like me. We all read poorly. But after reading the *Autobiography of Malcolm X* and discovering that he dropped out in seventh grade and still made something of himself, I thought for the first time in my life that I could accomplish something too. I worked hard, writing down each word I had trouble pronouncing. I just kept memorizing words and writing letters and reading short books. A GED teacher noticed that I struggled with phonics and had me tested. He asked

if my siblings read well. I told him they went to college. After testing me, he said I had a reading disability and it could be corrected if I was willing to work hard. I would write things down wrong so I sat in the front of class and double checked my answers. I worked for 4 years trying to attain my GED. My reading ability had surged and I was ready for the test. I passed and started helping others in math and vocabulary. Since my release from prison, I went on to model for clothing lines such as Nike. Also, I took acting classes and worked with Academy Award winners Jessica Lang, Kathy Bates, Angela Bassett, Forest Whitaker, Blair Underwood, Hill Harper and many others. I have produced four independent films and written my first book titled "The Life I Chose: The Streets Lied to Me." It is meant to inspire others who are just like I was, hiding in the shadows and not getting help. It is for those who believe that dealing drugs is a way out. Today there are schools available to help kids fight and defeat dyslexia. Schools, such as the one Senator Cassidy and his wife have created, provide a model for what could be a solution. In my opinion we can stop people from allowing the dyslexia to rob them of all that this great nation has to offer. If we understand this enemy, we can work to prevent it from stealing our most fundamental asset, our youth. We need to remember that 1 in 5 has dyslexia and dyslexia is 80 to 90 percent of the LD or learning disability community. The science about dyslexia, where the problem is in the brain, may be the key to reversing the curse of dyslexia that is now plaguing this great country.

Senator CASSIDY. Thank you.  
Dr. Eden.

**STATEMENT OF GUINEVERE EDEN, D.Phil., DIRECTOR, CENTER FOR THE STUDY OF LEARNING, GEORGETOWN UNIVERSITY MEDICAL CENTER, WASHINGTON, DC**

Ms. EDEN. Thank you, Senator Mikulski and Senator Cassidy, for inviting me to speak to you today. The research I'll be describing is largely emerged from the field of neuroscience and uses brain imaging technology to study the brain's structure and function. This research has resulted in tremendous advances in our understanding of the human brain, how it perceives information, how it learns, remembers, builds knowledge, and how it performs skills that are unique to humans, such as reading.

Reading, a cultural invention that allows us to represent speech in symbolic form, involves a coordination of the brain's language areas with visual and auditory systems. At Georgetown University, with support from NIH and NSF, we have studied brain activity with functional MRI while participants process words. This allows us to noninvasively characterize the developmental trajectory of reading acquisition in children and also to understand the brain basis of reading in different writing systems and in different languages.

Researchers have learned that acquiring reading changes the brain's structure and function. It is thought that learning to read involves co-opting of brain regions involved in language and visual object recognition and that these become recycled into a reading network. In other words, children's brains change as they learn to read.

Brain imaging has also heightened our understanding of dyslexia. The field has grown rapidly and made significant contributions. It has helped people understand that the brains of children and adults with dyslexia are different. Their struggles with reading are not because they are stupid or because they are not trying hard enough. There is an explanation for their reading difficulties. There should not be a stigma.

Researchers have also examined the impact of intensive reading intervention. We have learned that children and even adults with

dyslexia not only make gains in reading, but also show measureable brain activity changes and plasticity. One of our studies has shown that some of the same brain areas that are used for reading are less engaged when children with dyslexia solve arithmetic tasks, highlighting the far-reaching consequences of dyslexia and the connection to other forms of learning disabilities.

Sometimes we make novel discoveries with brain imaging for which there are no obvious indicators from behavioral studies. For example, we found that the brains of females with dyslexia do not conform to the neurobiological model of dyslexia that was largely derived from studies in males. This might have important implications for diagnosing and treating females with dyslexia.

Dyslexia runs in families, and genetic researchers have utilized brain imaging to examine the brains of those who carry the dyslexia associated genes. Taken together, researchers have made significant advances in characterizing the brain basis of dyslexia. However, the exact mechanism of dyslexia, how it comes about, is not yet fully understood and requires further research. Also, the information gained has not been applied as well as it could be.

For example, the fact that dyslexia is heritable, with roughly a 40 percent chance of your child having dyslexia if you have dyslexia, is greatly underutilized when it comes to early identification. This critical information is a warning sign, and there should be a place to note it on the questionnaire of an entering kindergartner. This, together with the child's performance on behavioral measures tapping skills known to predict later reading outcome, such as phonemic awareness and letter naming, can be used to signal that a particular child is at risk for difficulties in learning to read.

On the other hand, imaging is not used to identify the child who has dyslexia. Brain imaging is used in research studies involving groups of participants. However, parents often ask for a brain scan in their child because they see the difficulties in their child with reading, and they worry that the school is not recognizing the problem, and they hope that a brain scan will provide some information.

I understand such parents' quest for objective information because my own daughter recently had trouble reading and exhibited anxiety and avoidance around reading, which she described as a stupid activity. While the school was not concerned about her gradual decline, I was, and we pursued early intervention focused on phonemic and orthographic awareness. Her improvement, measured objectively by standardized tests, now manifests in her reading for pleasure.

For parents of struggling readers, it's a challenge to determine if there is a problem and what to do about it. Parents have to educate themselves and navigate a complex educational system. They stay up late at night to try and make sense of the scientific research and how it applies to their child.

Fortunately, there are resources to support families of children with learning issues, such as the website, [understood.org](http://understood.org). Here, the information is provided online, accessible to parents and educators, and tied to the findings of current research. This is one example of how those involved in understanding dyslexia can engage in a common language. However, much needs to be done by researchers

and educators to jointly harness the knowledge of teaching and learning to benefit the children with dyslexia.

Thank you.

[The prepared statement of Ms. Eden follows:]

PREPARED STATEMENT OF GUINEVERE F. EDEN, D.PHIL.

Thank you, Chairman Alexander and Ranking Member Murray, for holding this hearing and for the invitation to speak to you today about the intersection of scientific research and education in dyslexia. Thank you Senator Cassidy and Senator Mikulski for co-chairing today's hearing.

BRAIN IMAGING TECHNOLOGY: ADVANCES IN UNDERSTANDING THE BRAIN BASES  
FOR READING AND DYSLEXIA

The research I will be describing today has largely emerged from the field of neuroscience. The ability for scientists to use brain imaging technology to non-invasively study the brain's structure and function has resulted in tremendous advances to the understanding of the human brain, how it processes sensation, how it learns, how it remembers, and how it builds knowledge. Neuroscientists have been able to produce maps of brain regions underlying cognition and, importantly, skills that are uniquely human, such as reading.

Reading, a cultural invention that allows us to represent speech in symbolic form, involves a coordination of the brain's language areas with the visual and auditory systems. At my center at Georgetown University, we have studied brain activity with functional MRI (fMRI) while participants process words.<sup>1</sup> We use this approach to characterize the developmental trajectory of reading acquisition<sup>2</sup> and to study reading in different writing systems<sup>3</sup> and in different languages.<sup>4</sup> In the cognitive neuroscientific community, there has been an explosion in the use of brain imaging for the purpose of visualizing the reading brain. Unlike other areas of cognition, reading is a uniquely human skill and cannot be ecologically simulated using animal models. The non-invasive nature of fMRI allows scientists to study children (around or even prior to the time that they begin to read) and to study them repeatedly so that brain changes over time can be captured.

What researchers have learned is that the process of learning to read changes the brain's structure and function. People who never had the opportunity to learn to read manifest a different pattern of brain activity and have differences in brain anatomy compared to those who do learn to read.<sup>5,6</sup> It seems that learning to read involves co-opting of brain regions involved in language and visual object recognition, and these become "recycled" into a "reading network." In other words, as teachers are bringing about critical literacy skills in children through formal education, the children's brains change above and beyond the changes that occur based on maturation.

Research also indicates that the brain needs to make some adjustments when becoming a reader, not only re-allocating brain functions from processing common objects to processing letters and words, but also adapting new rules. So while it is OK for objects, such as a chair, to be recognizable as the same object when it is viewed from the right or from the left, this is not OK for mirror letters such as p and q, and b and d. While these may look like the same object with mirror-reversal to a beginning reader (who will confuse them), successful reading acquisition requires that they become recognized as representing distinctly different letters.<sup>7</sup>

Brain imaging technology has also heightened our understanding of dyslexia. Since our first implementation of functional MRI to study dyslexia in 1996,<sup>8</sup> the field has grown rapidly and made significant contributions to the science of dyslexia. While researchers had already been using MRI to scrutinize brain structural differences in dyslexia, functional MRI has allowed researchers to visualize brain activity in groups of people with and without dyslexia.

For example, functional MRI has been used to look at word processing and reading in children<sup>9</sup> and adults<sup>10</sup> with dyslexia. It has also been used to examine other functions that are not involved in reading, but may be affected in dyslexia (either as a part of having dyslexia, or as a consequence from having dyslexia).<sup>11</sup>

Using brain imaging, researchers have also examined the impact of intensive reading intervention. We have learned that adults with dyslexia not only make gains in reading, but also show brain plasticity, as demonstrated by increases in brain activity.<sup>10</sup> Brain anatomy is also malleable; in another study we found that reading intervention resulted in growth of brain tissue in children.<sup>12</sup> Together, these studies illustrate how reading gains in people with dyslexia are brought about by complex physiological and anatomical brain changes.

Researchers are also evaluating to what degree brain imaging data can foreshadow the amount of reading gains that are made in children down the road,<sup>13</sup> similar to prior work in which researchers identified behavioral measures such as rapid naming and phonemic awareness to be predictive of later reading outcome.<sup>14</sup>

Some of the same brain areas that are compromised for reading are also underactive when children with dyslexia solve arithmetic tasks,<sup>15</sup> highlighting the far-reaching consequences of dyslexia and their complex connection to other forms of learning disabilities.

Interestingly, through brain imaging research we sometimes encounter brain-based observations for which there were no obvious indications from behavioral studies. For example, we found that the brains of females with dyslexia do not conform to the neurobiological model of dyslexia that was largely derived from studies of males.<sup>16</sup> This might have important implications for diagnosing and treating females with dyslexia.

Together, brain imaging research has become an important tool for understanding reading and is a leading contributor in addressing the multitude of theories that have been proposed to explain dyslexia.

#### THE INTERSECTION OF SCIENTIFIC RESEARCH & EDUCATION

While researchers are careful to assess what is directly causing the reading problems and to distinguish these brain differences from those that are a consequence or a byproduct of whatever is causing the dyslexia,<sup>17</sup> it has become clear that children who eventually have dyslexia are likely to exhibit early signs of brain differences,<sup>18</sup> much like specific behavioral measures in young children are lower for those who eventually go on to have dyslexia. This is not surprising given the brain-behavioral relationships and the fact that dyslexia is heritable. Scientific evidence supports genetic involvement, and a connection between dyslexia-associated genes and differences in brain activity.<sup>12 13</sup>

Despite the fact that dyslexia often runs in families and there is research to explain genetic involvement, this knowledge is greatly underutilized when it comes to early identification. When a parent has dyslexia, the chances that their child has dyslexia are significantly higher, approximately 40 percent. Having this information provides a critical piece of information for educators and health care providers to consider when confronted with a child who is experiencing difficulties in learning to read, or even better, prior to that point. As such, a family history of reading disability should be noted on questionnaires for entering kindergartners along with health conditions (allergies, asthma) and home language environment. A family history of dyslexia can be very predictive of children at risk for reading difficulties<sup>20</sup> and, together with early behavioral measures of skills known to predict later reading outcome (such as phonemic awareness and letter naming<sup>21</sup>), can be used to signal that a child is at risk for difficulties in learning to read.

How else can we harness this knowledge to help children with dyslexia? Brain imaging research has helped people understand that the brains of children and adults with dyslexia are different. Their struggles with reading are not because they are stupid or because they are not trying hard enough. This helps children, parents, and teachers understand that there is an explanation for their reading difficulties. There should be no stigma.

Brain imaging has helped scientists characterize dyslexia, and investigations are ongoing to refine theoretical brain-based models. However, these studies are conducted in a research setting and involve groups of participants. They are generally not conducted in a single person, and brain imaging is not used to make a determination of whether a specific child has dyslexia. Parents and teachers, however, often think that it does. Parents wish for a brain scan in their child because they see their child's difficulties with learning to read and often feel that the school is not recognizing the problem. They wish that they could get a picture of the child's brain to put in front of the teacher to "prove" they have dyslexia as a way to get more help for their child. However, brain imaging data cannot be used in this way.

Parents have difficulties in gauging whether there is a problem with their child's reading abilities and, if so, what to do about it. I have personally been in this situation recently when my daughter in 1st grade seemed to have trouble sounding out words and reading fluently. This became especially worrying when she exhibited anxiety and avoidance around reading, showing clear frustration and describing it as stupid activity. I quickly realized the difference between my understanding of how reading is evaluated (using standardized tests that tap into a range of reading skills, such as decoding, fluency, and comprehension, and skills that support reading, such as phonemic awareness, rapid naming and working memory) and how it is measured in the school (text-reading accuracy using a story with a picture pro-

viding content clues). And I learned that as long as she reads at grade level, even if her performance continues to drop throughout the school year, and even though her level of reading is not aligned with her potential, she will be described as a normal reader. As such, the perspective on a child's performance when it comes to reading is very different in terms of the setting (home or school) and depending on the observer, because different observers use different contexts and have different goals. Recognizing the importance of early intervention, I arranged for my daughter to receive explicit instruction that bolstered both her phonemic (sound) and orthographic (visual word form) awareness over the summer. As a result of this, she moved from scoring at the 16th percentile as a 1st grader to the 75th percentile as a 2d grader on a standardized measure of reading accuracy, and she is thriving.

Not all parents have the resources or knowledge to intervene early. Learning to read is complicated, and for parents of a struggling reader, it is very challenging to determine if there is a problem and what to do about it. Fortunately, there are resources that are helpful to parents, teachers, and students. For example, the Web site *Understood.org*, a free, comprehensive online resource to support families of children with learning and attention issues (for which I serve as an expert contributor), can be a lifeline. Here, parents can access the information on early warning signs and learn what to do and how to take action. The information is provided in clear terms, while remaining tied to current scientific knowledge.

Overall, the science of dyslexia has made significant advances. However, academic researchers, even those working in classrooms, are bound by academic practices to publish in specialty journals, which in turn can be inaccessible, physically and conceptually, to those who directly operate as educators in the field. Consequently, teachers may not be implementing approaches that have been proven to be successful by rigorous research studies. Conversely, researchers may be pursuing theories that are not relevant to real classroom settings. As such, there remains a physical and cultural distance between academic research and educational practices.

Some agencies have addressed this problem. The National Science Foundation's Science of Learning Centers are a notable example of creating an environment to integrate knowledge across multiple disciplines, establishing common ground for conceptualization and connecting research with educational challenges. However, the dialog between science and the classroom is still far too limited. Academic and educational institutions will need to embrace a cultural change that facilitates jointly tackling the collective complexity of dyslexia, and engaging a common language and a common understanding of how to harness the knowledge of teaching and learning to the benefit of children with dyslexia.

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Senator CASSIDY. Mr. Boies.

**STATEMENT OF DAVID BOIES, CHAIRMAN, BOIES, SCHILLER,  
AND FLEXNER, LLP, ARMONK, NY**

Mr. BOIES. Thank you, Senators Cassidy and Mikulski, members of the committee.

I am dyslexic. I'm a father of two dyslexic sons. I know from personal experience the obstacles that dyslexia can cause in terms of early education. I also know from personal experience, both my own and my sons, that while dyslexia is a permanent condition, it does not have to be a permanent disability. It does not have to interfere with the ability of a child to realize their full potential to become a functioning, productive member of society.

What's critical is that dyslexia be identified and the children with dyslexia get the help that they need at the time they need that help. That help can be in several forms. It can be help in learning how to read around the disability of dyslexia. There is tutoring, there is training that can help people improve their reading. In addition, if they understand that they have dyslexia and they understand that there is this problem with reading, they can focus on alternative ways of getting information. Dyslexia is an input problem. It makes it difficult to get information in a particular

way. There are alternative ways to get information, and, most important of all, dyslexia is not a processing problem. It doesn't have anything to do with how well you think, how good your judgment is.

The third thing that early identification can do is it can help children understand that they're not dumb, that they're not stupid, that they can achieve. That can be sometimes the most important thing that a child can understand, that they are not consigned to being slow for the rest of their lives.

There comes a time when nobody cares how fast you read. Nobody comes to me as a lawyer and wants to know how fast do I read. They want to know: can I analyze the law, can I present a case, can I cross-examine a witness, can I exercise judgment, can I help them solve legal problems, how well do I think, what's my integrity, what's my character, how hard do I work?

Dyslexia doesn't have anything to do with those qualities. Those are the qualities that make a person successful. Those are the qualities that help somebody achieve and contribute to society. What children with dyslexia and what parents who have children with dyslexia need to understand is that this can be a temporary problem. It's not easy. There's an enormous amount of work that has to be done. No matter how much help we give children, they're going to have to really work harder than their peers. That training and working hard can serve them very well later in life. My son, Christopher, was tutored 4 days a week, every week, for 10 years. He had to learn to manage his time. He had to learn to adapt to that additional burden. That time management skill serves him extremely well as a lawyer today.

He always did well in school, if he could get in, which was hard because he did very poorly on standardized tests. Standardized tests test what people with—who don't have dyslexia. It tests them pretty well. It doesn't test people with dyslexia at all, because what it's doing is it's testing skills that they don't have, and not the skills that are important.

Reading and how much information and how many facts you've accumulated may be a proxy for your intelligence and how you will succeed in life if you don't have a disability in reading. If you have difficulty in reading, those standardized tests don't test your potential at all. We know we're testing the wrong things. We know that when we test reading, when we test how much vocabulary you have, we know that those aren't really life skills. We use those as a proxy, and they're not a bad proxy for people who don't have dyslexia. But for people who have dyslexia, they are a terrible proxy.

What we have to do is we have to educate the educators, and we have to have the patience, and we have to give people the help that they need so that they can achieve their potential, and that can be done.

Thank you.

[The prepared statement of Mr. Boies follows:]

PREPARED STATEMENT OF DAVID BOIES

Millions of children and their family members suffer from the consequences of dyslexia. Most of those consequences are unnecessary; they are the result of a failure to timely recognize and properly treat those children.

Recognizing the presence of dyslexia, and understanding what it is (and is not) is critical to enabling children with dyslexia to realize their potential and enjoy the happy, productive lives of which they are capable.

Dyslexia's primary effect is to make it difficult for someone who is dyslexic to read as easily, and as fast, as they otherwise would. That effect is challenging enough. Reading is one of the most important ways by which we ordinarily acquire information—and it is the primary way most students, particularly in grade school, learn what they are tested on. Moreover, reading (particularly, again, in grade school) is valued, and tested, in its own right.

Consequently, the ability to read becomes both the gateway to how students do on the tests by which they are judged by their parents, peers, teachers, and themselves and itself a marker for their success.

Recognizing dyslexia early can enable students to receive both training that can improve their reading skills and help in using other ways of acquiring information.

My dyslexia was not diagnosed until I was in my 30s and my reading skills in school were poor. I did not read essentially at all until late in third grade. However, my father was a high school history teacher and, including by attending his classes, I was fortunate to learn early the value of listening as a way of acquiring information.

Recognizing dyslexia early has another, perhaps even more important, benefit. One of the most corrosive consequences of dyslexia is that its effects (difficulty in reading, poor scores on standardized tests) are often misinterpreted as low intelligence.

Dyslexia is an input issue; it makes it difficult for people to read conventionally, and hence acquire information that way. It does not limit judgment or intelligence, or the ability to process information. In fact, there is some data that suggests dyslexia may be positively correlated with creativity.

In school, particularly early grades, the ability to acquire information, and particularly the ability to read, is often treated as the equivalent of intelligence. Students who are slow in reading, and who accordingly fail to quickly acquire the information that conventional exams test, are too often classified by their teachers, their parents, and themselves as “dumb”, “stupid”, or simply inadequate.

Difficulty in reading, and poor results on exams, can of course be due to lower than average intelligence, but the difficulty in reading that is caused by dyslexia has nothing to do with, and is not at all correlated with, intelligence.

Difficulty in reading caused by dyslexia will inevitably affect a student's performance on examinations testing what a student has learned from reading assignments. But again this is not a reflection either of intelligence or the ability to learn—it is merely a reflection of the difficulty in learning in a particular way at a particular speed.

Confusing an input problem (difficulty in reading) with a processing problem (low intelligence) not only prevents steps to solve the problem but also further erodes the student's confidence, and even their sense of self-worth; it can discourage a student from continuing to try, and discourage a student's teachers, and even parents, from continuing to try to encourage and help.

Failing to timely recognize and properly understand and treat dyslexia has three consequences. First, children fail to get the help and training that can improve their ability to acquire information. Second, the lack of such help and training causes the child to fall further and further behind. Third, as the child falls further and further behind, and because the problem is perceived as a lack of intelligence that will follow the child throughout life, the child (and the child's teachers and families) become discouraged, and too often give up.

Recognizing the real issue can enable the child to receive the help needed to improve reading skills and to learn to use alternative means for acquiring information. Even more important, it enables everyone to understand that the problem is largely temporary; success in life depends on judgment, intelligence, integrity, and commitment—not on how fast a person reads.

Even though my dyslexia was not diagnosed early, I was fortunate. Growing up in a small Midwest farming town in the 1940s reading was not a metric by which young boys measured their self-worth. My parents, both public school teachers, were supportive and my father in particular helped me learn by a combination of what I would now call lectures and what I have since come to recognize as Socratic dialogs.

It is much harder for today's young people who grow up in a time where there is academic competition to get into “junior pre-kindergarten” (which, of course, is the year the student spends in school before “senior pre-kindergarten”, which in turn is the year the student spends in school before kindergarten).

There is so much emphasis on early learning and testing that students can be forgiven for concluding by the time they are teenagers that they will either be masters of the universe or abject failures based on how their academic progress to that point has been evaluated. Both, of course, are likely wrong. But the perception can derail both from reaching their potential.

The debilitating effect that dyslexia can have on a child's confidence and sense of self-worth is aggravated by the fact that the very time reading and input most dominate reasoning and judgment in conventional test results, is the very time children are at their most vulnerable.

Recognizing that the difficulty in reading dyslexia causes can be mitigated by training, that alternative ways of acquiring information can be emphasized, and that dyslexia does not imply anything about a person's ability to reason, analyze, or communicate can give students the patience to continue to work and achieve, and give their teachers and parents the patience to help and support them.

Today some students whose families (and schools) can afford the best in testing are fortunate in having their dyslexia identified, understood, and treated early. However, the vast majority of students with dyslexia are not so fortunate. Their future, and the future contributions they can make to our society, is at severe risk. That risk is preventable.

Dyslexia is not an indication of, and need not affect, the ability of a person to succeed in life. There are many well-known examples, and many, many more unknown examples, of people with dyslexia who are highly effective, productive, successful, members of society. Success in life is not a function of how fast a person can read. Life is rarely a timed test; even when it is, it is rarely if ever based on reading speed.

We need to recognize this reality. We need to enable children, teachers, parents, and test administrators to recognize this reality. And we need to provide the resources and guidance that will help, not impede, children from reaching their potential. They deserve it. And our country needs it.

Senator CASSIDY. Dr. Mahone.

**STATEMENT OF MARK MAHONE, Ph.D., ABPP, DIRECTOR, DEPARTMENT OF NEUROPSYCHOLOGY, KENNEDY KRIEGER INSTITUTE, BALTIMORE, MD**

Mr. MAHONE. Good morning, Senator Cassidy, Senator Mikulski, fellow members of the panel. Thank you for the opportunity to speak with you this morning.

Dyslexia is currently the most prevalent educationally handicapping condition in the United States. It's twice as common as ADHD, 10 to 15 times as prevalent as autism. It affects an estimated one in five individuals nationwide. Even more importantly, many students show symptoms of dyslexia, including slow and inaccurate reading, weak spelling, or poor writing. Whether or not they meet full criteria for special education, most students benefit from systematic, explicit instruction in reading, writing, and language methods.

The problem is that many students are not getting access to this structured literacy instruction. As a result, there's an alarming achievement gap. As was mentioned earlier, the NAEP data—I have results from 1998 through 2013—fourth grade data from the NAEP showed that 9 percent of students with disabilities scored proficient in reading, compared to 26 percent of nondisabled peers. Both of those statistics are unacceptably low.

But is the prevalence of dyslexia so high that it can explain these high rates of school failure? I would assert that it's no, but there are other reasons. First, it is that pre-service teacher training programs routinely fail to provide teachers with the information based on the scientific literature about how learning occurs and also what gets in the way of learning, based on what we know from the neu-

rosiences, from the behavioral sciences, and from the educational sciences. This leads to a translational gap.

When teachers enter the field without prerequisite training, they must get the training on the job. They get it through supervision, mentoring, and from professional development. Getting training that way is expensive, inefficient, and burdensome to the schools and to the teachers themselves. It also places the responsibility for training teachers on the local school systems rather than on the institutes of higher education.

Second, a complicating factor in working with students with dyslexia is that pure dyslexia is often the exception rather than the rule. Students with dyslexia often have associated behavioral, motivational, and social-emotional problems and other conditions that interfere with the implementation of otherwise routine, evidence-based practices. Addressing the reading problem alone instead of the needs of the whole child leads to incomplete and ineffective care.

Third, individuals at the local education level in leadership positions often don't have the training, knowledge, and background to effectively and appropriately advocate for policy changes that will help translate what we know from the science into educational practice at the local school level, and especially as it relates to students with dyslexia.

There are other additional concerns, and I want to highlight some of those. Despite the best efforts of our scientific community, there is still heterogeneity in terminology that has become an impediment to achieving consensus in identification, treatment, and epidemiology. We know that dyslexia is a neurobiologically based developmental disorder. It occurs along a continuum rather than as a discreet entity.

We define it most often by low reading achievement. In the scientific literature, however, there are differences in where the cut point comes or how low someone has to perform in reading before it becomes dyslexia, with differences ranging from the 5th percentile up to the 25th percentile. Not surprisingly, when there are differences in the literature, the behavior, the learning, the neurobiological correlates, and genetics of dyslexia all look different depending on how it's defined.

As we move forward with implementation of ESSA, it's critical for the scientific and educational communities to work toward a common language for identification in studying dyslexia with efforts toward a more specific terminology. This consistency extends to implementation of response and intervention.

Finally, early detection of dyslexia is critical. But I must say we need to proceed with caution. The mission of early detection presents us with a conflict that requires awareness of the developmental appropriateness of reading expectations and reading instruction for a significant proportion of kindergarten children.

We know how to identify early risk factors for dyslexia. As scientists, educators, and policymakers, we must distinguish between unexpected and unwarranted failures in reading achievement. In other words, considering early detection, we must determine whether a problem represents true dyslexia or the risk for it, or a brain that is just simply too young and not yet ready to read.

This is particularly important because in the last 20 years, even before Common Core standards, we have gone to a system in which kindergarten is the new first grade. There are emotional and motivational consequences associated with developmentally premature educational expectations for children who experience failure this early, and the risk is exacerbated in boys, who develop later than girls upwards of a year, on average, by kindergarten.

Thank you.

[The prepared statement of Mr. Mahone follows:]

PREPARED STATEMENT OF MARK MAHONE, PH.D., ABPP

THE PROBLEM(S)

*An Achievement Gap*

Approximately 13–14 percent of students in the United States (more than 6 million children) are identified as having a handicapping condition and receive special education services in school. Half of those identified for special education are classified as having a *Specific Learning Disability*, and approximately 85 percent of those having a primary learning disability have a learning disability in reading and language processing (i.e., *dyslexia*). As many as one-third of all students may have symptoms of dyslexia, including, but not limited to, slow or inaccurate reading, weak spelling, or poor writing. Not all meet full criteria for a “disability,” or will qualify for special education, but most benefit from systematic, explicit instructions in reading, writing, and language (also known as structured literacy instruction).

In my home State of Maryland, the 2015 standardized assessments revealed that those students enrolled in special education performed dismally low. On the Partnership for Assessment of Readiness for College and Careers (PARCC) assessment for grade level 10, only 7.1 percent of students in special education met or exceeded expected performance level (i.e., Level 4 or 5) for literacy, compared to 39.7 percent of all students (*which is still unacceptably low*). These results are similar to national statistics for children with disabilities. Recent data from the National Assessment for Educational Progress (NAEP) for fourth grade achievement show a significant, long-standing difference between all students and those with disabilities. From 1998 to 2013, 8.6 percent of students with disabilities scored proficient in reading versus 26 percent of non-disabled peers (*also unacceptably low*). The achievement gap for students with disabilities is especially prominent in schools with limited resources such as those in the Baltimore City Public School (BCPS) system, where the majority of the students come from low-income families and the need for services far surpasses available resources (BNIA, 2012). Moreover, according to the 2014 Department of Education Report to Congress on the Implementation of the Individuals with Disabilities Education Act (IDEA), only 10–15 percent of students with individualized education programs (IEPs) exit the special education system by returning to regular education.

*Why Students Fail*

Why is it that so many students (with otherwise adequate intelligence) struggle or fail academically in today’s schools? In particular, why are so many children failing when it comes to learning to read? Is the prevalence of dyslexia so high it can explain such high rates of school failure? I assert that the answer is *no*.

There are a variety of (often inter-related) reasons, for academic failure, including: (1) poverty/disadvantage, (2) poor instructions, (3) childhood trauma (including neglect and abuse), (4) psychopathology, (5) chronic psychosocial stress, (6) illness or injury, and, the focus of my testimony, (7) highly prevalent neurodevelopmental disorders (i.e., dyslexia and Attention-deficit/Hyperactivity Disorder—ADHD). The wait-to-fail model typically associated with current educational practices, where students first have to underperform in order to receive the necessary educational interventions, suggests students with disabilities may be at risk from early on in their educational lives.

*Opportunity-to-Learn*

One potential explanation for this persistent achievement gap is the differential in the opportunity-to-learn (OTL), or the quantity and quality of instruction for students with disabilities compared to their non-disabled peers. Reduced OTL exists for students with disabilities despite increased access to the general education setting and curriculum (Eckes & Swando, 2009). Moreover, there is a demonstrated OTL

differential for students with disabilities and their non-disabled peers, even within the same classroom (Kurz, et al., 2014).

#### *Prevalence of Dyslexia*

Dyslexia is *highly prevalent*. It is not just the most common learning disability, but *the most common developmental disorder*—twice as prevalent as ADHD, and 10–15 times as prevalent as autism. The International Dyslexia Association (IDA) reports that dyslexia affects an estimated 8.5 million school children and *one in six* individuals nationwide.

#### *Societal Risks Associated with Academic Failure*

Up to 76 percent of students with learning disabilities will be suspended at least once (Fabelo, et al., 2011). The presence of a learning disability also confers a greater risk for school dropout (Cramer, et al., 2014), especially among low-income students, and a well-documented connection exists between school dropout and incarceration (National Center on Secondary Education and Transition, 2012). According to the National Disability Rights Network (2012), it is estimated that as many as 50 percent of inmates have some type of disability. In the juvenile justice system, this number is estimated to be up to 75 percent. Moreover, approximately 75 percent of youth under age 18 who have been sentenced to adult prisons have not completed 10th grade. Within the juvenile justice population, 70 percent suffer from learning disabilities and 33 percent are reading below the 4th grade level (Coalition for Juvenile Justice, 2001). Given these observations, appropriate (and thorough) early identification and provision of evidence-based intervention for children with learning disabilities, especially dyslexia, represents a *public health priority*.

#### *Problems with Current Educational Practices*

While there are undoubtedly a variety of reasons behind the persistent achievement gap among children with disabilities (and dyslexia specifically), I assert that there are *three critical problems* with current educational practices that contribute most prominently to the chronically (and unacceptably) low performance and underlie this public health crisis.

*First*, pre-service teacher preparation programs fail to routinely train educators to fully understand *how learning occurs* in children (and conversely, what processes get in the way of learning) using current knowledge from the developmental, behavioral, and neuroscience literature. As a result, the strategies and techniques being implemented by teachers of children with disabilities are often not based on available *scientific evidence* (i.e., a “translation gap”).

*Second*, despite (often intensive) intervention, students with dyslexia often continue to have significant *associated problems* (e.g., behavioral, motivational, psychiatric) that interfere with learning and with routine educational interventions. Addressing only the reading problem instead of all of the needs of the child leads to incomplete and ineffective care.

*Third*, individuals in local educational leadership positions (i.e., those who make decisions regarding policy, training, and curricula) often do not have the training and knowledge to appropriately advocate for *policy changes* that ultimately benefit the behavior and learning of students with dyslexia.

### ISSUES COMPLICATING THE CARE OF INDIVIDUALS WITH DYSLEXIA

#### *The Trouble with Terminology*

Despite best efforts by the scientific community, heterogeneity in terminology and definitions remains an impediment to achieving consensus in identification, treatment, and epidemiology. For the purposes of my testimony, I consider *dyslexia* to be equivalent to (or interchangeable with) a developmental learning disorder (or specific learning disability) in reading (i.e., reading disability or disorder). In other words, dyslexia is one type of (specific) learning disability.

The Individuals with Disabilities Education Improvement Act of 2004 uses the term *Specific Learning Disability*, defined as:

“A disorder in one or more of the basic psychological processes involved in understanding or in using language, spoken or written, that may manifest itself in an imperfect ability to listen, think, speak, read, write, spell, or do mathematical calculations. The term *includes* such conditions as perceptual handicaps, brain injury, minimal brain dysfunction, dyslexia, and developmental aphasia, while it *excludes* children who have learning problems that are primarily the result of visual, hearing, or motor handicaps; of mental retardation (now known as intellectual disability); of emotional disturbance; or of environmental, cultural, or economic disadvantage.”

The 2013 guidelines outlined in the American Psychological Association's Diagnostic and Statistical Manual of Mental Disorders (DSM-5) use a slightly different term: *Specific Learning Disorder*. According to the DSM-5, diagnosis is made using a synthesis of the individual's history (development, medical, family, education), psychoeducational reports of test scores and observations, and response to intervention. Thus, the DSM-5 criteria reflect a *hybrid model* of identification. Importantly, the guidelines also reflect recognition that individuals may "grow into" their learning deficits; thus, functional problems may not be fully manifested until a later age. The definition of *dyslexia* used by the International Dyslexia Association—IDA (and also adopted by the Eunice Kennedy Shriver National Institute of Child Health and Human Development—NICHD), is as follows:

"Dyslexia is a specific learning disability that is *neurobiological in origin*. It is characterized by difficulties with accurate and/or fluent word recognition and by poor spelling and decoding abilities. These difficulties typically result from a deficit in the phonological component of language that is often unexpected in relation to other cognitive abilities and the provision of effective classroom instruction. Secondary consequences may include problems in reading comprehension and reduced reading experience that can impede growth of vocabulary and background knowledge."

The DSM-5 provides more specific guidelines in its criteria than the IDA. DSM-5 criteria for a Specific Learning Disorder in *reading* includes difficulties with learning and using academic skills, as indicated by the presence of at least one of the following symptoms that have persisted for at least 6 months, despite the provision of interventions that target those difficulties:

- (1) inaccurate or slow and effortful word reading (e.g., reads single words aloud incorrectly or slowly and hesitantly, frequently guesses words, has difficulty sounding out words); or,
- (2) difficulty understanding the meaning of what is read (e.g., may read text accurately but not understand the sequence, relationships, inferences, or deeper meanings of what is read).

#### *Dyslexia is Defined by Low Achievement in Reading—But How Low?*

Implied (or stated specifically) in the aforementioned definitions is the notion that dyslexia is a *neurobiologically* based developmental disorder that affects the brain's ability to receive, process, store, and respond to information. Although not specifically stated, dyslexia is considered to occur along a continuum, with variability in severity and characteristic features, rather than as a discrete, dichotomous entity. Put simply, in most cases, dyslexia refers to instances in which an individual's reading achievement unexpectedly falls at the low end of the normal distribution of all readers. Except in cases of very low overall intellectual level, this "low achievement" model of dyslexia is not tied to the child's overall IQ, and does *not* require a "significant discrepancy" between the individual's IQ and reading achievement. Conversely, the model also does not imply that individuals with dyslexia have exceptionally high IQ, or compensatory "strengths" in other cognitive or academic skill areas.

Unfortunately, while the low achievement model of dyslexia is fairly well-accepted in the scientific community, there is less consensus as to the threshold for defining low reading achievement as dyslexia, with distributional "cutoff" scores ranging from as low as the 5th percentile to the 25th percentile. Not surprisingly, the scientific literature yields different findings with regard to the cognitive and behavioral phenotypes, neurobiological correlates (e.g., neuroimaging, electrophysiology), and genetics of dyslexia depending on how it is defined.

Additionally, given that the Federal definition of a Specific Learning Disability in reading used in determining eligibility for special education services leaves considerable room for local interpretation (e.g., relative to the criteria for Intellectual Disability), school districts across the U.S. demonstrate considerable inconsistency in diagnostic practices. Although clearly not the intent of the Federal law, *in practice*, it is not uncommon for a child receiving special education services for dyslexia in one school district to move to another district and be declared suddenly "ineligible" based on the new district's *interpretation* of the criteria.

#### *Developmental Course of Dyslexia*

Dyslexia is acknowledged as a developmental disability. That means those with "symptoms" of reading problems do not *necessarily* have a disability. Specifically, a disability is considered to occur when one's personal limitations (often biological in nature) produce a significant disadvantage when attempting to function in one's society. Thus, a learning disability is necessarily considered within the context of the environment, personal factors, and individualized supports. It implies that there is a "mismatch" or discrepancy between one's own biology and demands of the environ-

ment (considering all available supports). As a developmental disability, it is acknowledged that this discrepancy (and the functional impact) associated with dyslexia can change over time.

For most individuals with dyslexia, the functional deficits first have an impact in childhood, usually in the preschool or early elementary school years. For some, however, the manifestations and impact may not become evident until later in childhood, in the teenage years, or even in the adult years, even though the neurobiological basis of the condition is present earlier—a concept referred to as the “time referenced symptom” (Rudel, 1981). Nevertheless, in most individuals with dyslexia, the disorder manifests in a *persistent* functional deficit, rather than a developmental lag. The functional disability often persists over time, despite intervention efforts, and typically does not spontaneously remit with time or age. Among individuals with early-onset learning disabilities who have received consistent, high-quality intervention by early elementary school, deficits in word reading accuracy can improve; however, deficits in phonological processing, automaticity of word recognition, expressive language, and reading fluency tend to persist.

#### *It's Not Just Decoding: Reading Fluency and Processing Speed*

Reading fluency, or the ability to read words quickly either in isolation or text, is especially critical for older children who are required to learn from what they are reading. The lack of fluency increases demands on other processes, such as working memory, and results in difficulty with comprehension because higher-level processes have to compete with word decoding for the same time-limited resources, creating a bottleneck. Therefore, especially for older children, it is critical that they are not only accurate at word reading, but also efficient, automatic, and fluent readers. It is well-established that rapid automatized naming deficits (reflective of poor automaticity) are present in individuals with dyslexia; however, automaticity deficits are also observed in children referred for learning problems, whether or not they have dyslexia specifically (Waber, et al., 2000).

Dyslexia and ADHD represent the two most common childhood neurodevelopmental disorders. Approximately 35–40 percent of children with dyslexia have ADHD; while 35–40 percent of children with ADHD have dyslexia. As such, the two disorders co-occur more often than expected by chance (Couto, et al., 2009). The most parsimonious explanation for the co-occurrence is that they partially share genetic risk factors (Greven, et al., 2011).

To this end, scientists have identified a “multiple-deficit” model to explain the comorbidity between ADHD and dyslexia in which each disorder manifests multiple deficits—some specific and some shared (Pennington, et al., 2010). The ADHD model includes one unique predictor (response inhibition) and one shared predictor (*processing speed*), while the dyslexia model includes two unique predictors (phonological awareness, naming speed), and one shared predictor (processing speed). Here, processing speed represents the speed with which a task is completed with reasonable accuracy.

Children with ADHD (nearly 10 percent of students ages 4–17 years; Pastor, et al., 2015) commonly display slow processing speed (Jacobson, et al., 2011); however, slow processing speed is also observed in children with dyslexia (Willcutt, et al., 2005). Becoming a skilled reader involves adequate reading fluency, which is linked to efficient processing speed. Thus, while processing speed is separable from the core phonological deficit in dyslexia, it can influence reading fluency, even among individuals who can read single words accurately (i.e., those without “classic” phonological dyslexia), and can affect the development of more complex academic skills such as reading comprehension (Sesma, et al., 2009).

To this end, *processing speed* (a core skill underlying reading fluency) may represent a promising candidate for a behavioral “polyphenotype” (i.e., a phenotype constituting core deficits of more than one disorder), whose psychological makeup can account for comorbidity between common neurodevelopmental conditions and whose genetic architecture can account for the phenotypic correlations between these highly prevalent disorders (Gregorinko, 2012).

#### *Late Emerging Reading Disabilities and Reading Comprehension*

Approximately 41 percent of all students with dyslexia have *late-emerging reading disabilities*; that is, deficits are not evident until at least third grade. This pattern, sometimes known as the “fourth-grade slump,” can be associated with the transition from “learning to read” to “reading to learn,” and may also be related to reduced vocabulary development in students of low socioeconomic status backgrounds. From this point forward, curricula emphasize fluency and comprehension rather than more basic word recognition skills. Beyond third grade, students are also expected to be able to incorporate cause/effect sequences, goals/plans for characters, and con-

clusions that relate to final events to those at the beginning of the story (all higher-order cognitive skills). Children who received early intervention and showed improvement may start to struggle again with the increased demands and volume of middle and high school reading and when they are expected to work more independently.

Late-emerging reading disabilities are often associated with coexisting conditions, especially ADHD, the second most common developmental disability. It is clear that children who have early problems involving basic word recognition will most likely also have difficulty with reading comprehension; however, more recently, researchers have identified groups of children *without* reading basic word reading deficits who go on to have difficulties in reading comprehension, perhaps as a result of their associated executive function deficits (Sesma, et al., 2009). These children are considered to have “specific” reading comprehension disorders (Cutting, et al., 2009; Locascio, et al., 2010), and many also have associated ADHD. Working memory deficits (i.e., problems “holding” and manipulating information mentally) associated with ADHD can prevent students from monitoring what they read, as they are more susceptible to being distracted by detail when reading longer text—failing to “remember” main ideas. These findings challenge the long held “simple view” of reading (Hoover & Gough, 1990), which argued that reading comprehension was primarily the product of word reading and listening comprehension, and acknowledge the important contribution of higher-order “executive function” skills to the development of competent reading.

#### *Early Detection of Dyslexia—Proceed with Caution*

The 2016 Research Excellence and Advancements for Dyslexia Act (READ Act) (H.R. 3033) supports important research to further our understanding of dyslexia, including emphasis on better methods for *early detection and teacher training*. The Act specifies early identification of children and students with dyslexia, professional development about dyslexia for teachers and administrators, curricula development and evidence-based educational tools for children with dyslexia. As an educator, clinician and scientist, I applaud these efforts.

Nevertheless, when considering early detection of dyslexia (i.e., a developmental *disability*, as defined above), it is critical to distinguish between “unexpected” and “unwarranted” failures in reading achievement. In other words, when considering *early* detection, one must determine whether a problem represents true dyslexia or a brain that is not (yet) ready to read. To be clear, with informed assessment, risk for dyslexia can be identified early (often in the preschool years); however, we need to be very careful that we are not simply identifying children who are not yet biologically ready to read, but who have been pushed (too early) into academic demands. The scientific literature suggests that early (and accurate) identification of dyslexia and appropriate teaching of reading can prevent the experience of failure in children who are at risk. With appropriate interventions, the life history of students with dyslexia can be substantially “normalized” and secondary mental health issues averted.

In the last 20 years, however, even before NCLB, ESSA, Common Core Standards, or PARCC, there has been an alarming trend toward increasing early academic demands, such that Kindergarten is the “new first grade.” These practices ignore the child (and brain) development scientific literature as it relates to developmental readiness for academic demands. There are risks associated with developmentally premature educational expectations for the children who experience failure, and the emotional/motivational consequences of encountering premature reading and writing expectations may be long lasting. Moreover, the over-burdening of the already under-supported special education services with the “unready” now becoming indistinguishable from the truly dyslexic is yet another serious consequence. At the level of brain development, children forced prematurely to perform academic tasks may do so and appear to make progress, however, at the expense of using suboptimal circuitous pathways in the brain that ultimately may fail to support efficient and comfortable skill utilization in later years. This risk is exacerbated in young boys, whose physical maturation and brain development are at least a year behind that of same-age girls by Kindergarten entry (Eme, 1992; Lenroot, et al., 2007).

Thus, the (very appropriate) mission of early detection of dyslexia presents us with a conflict that requires awareness of the developmental appropriateness of reading instructions and reading expectations for a significant proportion of students in Kindergarten (or younger).

#### *“Pure” Dyslexia is the Exception, Not the Rule*

Most definitions of dyslexia specify that the observed difficulties in reading are not due to other physical, cognitive, or emotional exclusionary factors. The assess-

ments of these exclusionary factors are often complicated, because dyslexia commonly co-occurs with ADHD, language and other communication disorders, developmental motor coordination disorder, and other psychiatric disorders, including anxiety disorders and depression.

A sizable proportion of students with dyslexia have associated social-emotional problems, with estimates ranging from 38 percent to 75 percent (Bryan, et al., 2004). A recent meta-analysis revealed that approximately 70 percent of students with learning disabilities experience higher levels of anxious symptomatology than their peers without learning disabilities (Nelson & Harwood, 2011), raising the concern that many (if not most) students with dyslexia are at high risk for anxiety disorders that cause additional distress, reduce motivation, and complicate interventions (given the negative impact of anxiety on cognitive performance of all kinds). Students with learning disabilities are also at greater risk for developing depression, as they tend to struggle with self-esteem and are less socially accepted than students without learning disabilities (Maag & Reid, 2006), and some studies have shown a link between learning disabilities and increased rates of suicide (Bender, et al., 1999).

Given these associations, “pure” dyslexia is more the exception than the rule, and attention to the associated conditions and risks is of paramount importance.

#### WHAT NEEDS TO BE DONE

The prevalence, morbidity, and societal costs associated with dyslexia represent a major public health concern. In light of the problems cited above, I offer the following recommendations to support individuals with dyslexia and their families.

1. *Support Translational Educational Practices.* The wealth of scientific knowledge is often not accessible to front line teachers. Pre-service (undergraduate and graduate) and professional development training programs for teachers provide inadequate training in evidence-based practices for identification of dyslexia and intervention. If teachers are trained in evidence-based practices, they will use them. If they enter the field without this training, they will need access to professional development programs, along with supervision and mentoring, in order to use these programs with accuracy and fidelity.

2. *Strive for Consistency in Diagnostic Practices.* It is critical for the scientific and educational communities to work toward a common language and a common set of procedures for identifying dyslexia, with efforts aimed toward more specific terminology.

3. *Increase opportunity-to-learn (OTL) for students with dyslexia.* OTL is dependent on three interrelated classroom practices: (1) the amount of instructional time committed to the curriculum; (2) the use of evidence-based practices for teaching students with dyslexia; and, (3) classroom emphasis on best practices for supporting and developing high-order cognitive skills, such as problem solving, planning, and organizing thoughts and information (which are especially important, considering the comorbid conditions associated with dyslexia). Given the increased emphasis within classroom assignments and in standardized testing (such as PARCC) on integration of information, self-monitoring, and problem solving, competence in higher-order cognitive skills (executive functions) is critical to student success and to narrowing the achievement gap.

4. *Recognize the many forms of dyslexia.* Dyslexia should be considered to include not only difficulties in phonology, decoding, automaticity and word recognition, but also the (often later emerging) problems in reading fluency and comprehension.

5. *Support training of general educators.* Recognize that most children with dyslexia are taught primarily by general education teachers. It is critical to support inclusive practices in which special educators and reading specialists collaborate with general educators.

6. *Treat the whole child—not just reading.* Support efforts that allow acknowledge that students with dyslexia are at risk for psychosocial, language, motivational, academic, neuromotor, and psychiatric co-morbidities. By treating only reading problem, we reduce the chances for positive outcomes.

7. *Support use of developmentally appropriate methods for early identification.* It is critical that those involved in early identification of dyslexia understand the potential for misidentification of children who are prematurely placed into academically accelerated programs before their brains are developmentally ready.

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Senator CASSIDY. Ms. Hanrath.

**STATEMENT OF APRIL HANRATH, PARENT, SALT LAKE CITY,  
UT**

Ms. HANRATH. Good morning, Senator Cassidy, Senator Mikulski, members of the HELP Committee, fellow witnesses, and attendees. Thank you for giving me an opportunity to share my family's story of living with dyslexia. My name is April Hanrath, and I am the proud mother of Jocelyn, who is a senior in high school in our hometown of Salt Lake City, UT. I am also a parent advocate with Understood, a free comprehensive online resource for parents of children with learning and attention issues.

I am honored to share our journey with dyslexia as we have navigated through the educational system in Utah. I also recognize that we are not alone in this journey. Over 2 million children have learning disabilities, most of whom struggle with reading, and the National Center for Learning Disabilities estimates that another 15 percent of students struggle in school due to an unidentified learning or attention issue. I sit before you eager to tell our story, but hopeful that you will have an opportunity to meet parents from your States who face similar challenges and successes.

Through my testimony, I hope you will hear three messages come through loud and clear. First, it is critically important to identify learning disabilities like dyslexia in early elementary school. Second, we must support general and special educators by giving them training about dyslexia and learning disabilities, co-occurring issues, and necessary accommodations. Third, and most importantly, all of us must have high expectations for students with dyslexia.

Policymakers, educators, and families alike must recognize that students like Jocelyn are fully capable of excelling in school and college. My daughter, Jocelyn, is proof that when you hold students with dyslexia to high standards and provide them with the tools they need to succeed, they are able to fulfill their goals and dreams. Let me tell you a little about Jocelyn, who is sitting right behind me. Jocelyn is a driven, bright young woman who has excelled in school and soccer. In everything she does, she holds herself to a high standard, and failure has never been an option for

her. Yes, Jocelyn has learning disabilities, as she is dyslexic, but she has never used her challenges as an excuse to not achieve. In fact, it has only motivated her to work harder.

Next month, Jocelyn will graduate high school with a GPA of over 3.7. Next year, she will enroll in Highline Community College in Washington State with a soccer scholarship and an internship with the Seattle Reign, the professional women's soccer team. After that, she plans to finish college at a 4-year school to earn her degree in sports management with a sports psychology minor. To support her goals, I am proud to say that Jocelyn received the 2016 Allegra Ford Thomas Scholarship from the National Center for Learning Disabilities.

That's Jocelyn now, but over the past 13 years, we've had our ups and downs. When Jocelyn was in fourth grade, she was struggling with reading and started becoming withdrawn from school. At the end of fourth grade, Jocelyn was evaluated for special education and found to have an above average IQ with significant dyslexia, poor fine motor skills, and severe test anxiety. She has also had challenges with writing, known as dysgraphia; keeping herself focused and managing time, known as executive functioning; and difficulty with focusing, like ADHD. Looking back, I wish Jocelyn's needs were addressed earlier than fourth grade, a time when reading is an integral part of nearly every class in school. Starting in fifth grade and largely continuing to today, Jocelyn has received accommodations like extra time, oral testing, and using a computer rather than having to hand write assignments. These accommodations have made a huge difference for Jocelyn because they allow her teachers to teach her in a way that works for her. They allow her to show what she knows in a more accurate way.

For me, as her mother, what is of paramount importance is that Jocelyn has always been taught to the grade level she is enrolled in alongside her peers. Accommodations have allowed Jocelyn to access the grade level content, and even above grade level content. In fact, starting as a freshman and continuing throughout her 4 years at East High School, Jocelyn took honors and AP classes in addition to her regular classes.

It was an amazing special education teacher, Carrie Szumnarski, who helped Jocelyn navigate some challenging situations along the way. For example, when some of Jocelyn's teachers were unfamiliar with dyslexia, Jocelyn, Carrie, and I helped educate them to dispel the myth that dyslexia is a sign of a low IQ.

Or when some of Jocelyn's teachers were reluctant to give her accommodations, Jocelyn used the self-advocacy skills Carrie helped her develop to explain what accommodations are and why she needed them.

When some of Jocelyn's friends joked around about being dyslexic when they made mistakes reading aloud in class, Jocelyn used that opportunity to share that she was dyslexic and explain to them what it was like to be dyslexic.

Throughout our journey we have used all of these experiences to help others understand what dyslexia is and, more importantly, what dyslexia is not. Resources like the Understood.org and the National Center for Learning Disabilities have helped us along the way. These last 13 years have taught me that while the edu-

cational system is not created with dyslexics in mind, with the right information, training, and support, students with dyslexia can thrive.

I can say that I am a better mother and person because of our journey and that Jocelyn's future is limitless because she is an amazing young woman with much to give the world.

[The prepared statement of Ms. Hanrath follows:]

PREPARED STATEMENT OF APRIL HANRATH

Good Morning Chairman Alexander, Ranking Member Murray, Senator Cassidy, Senator Mikulski, members of the HELP Committee, fellow witnesses, and attendees.

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- Second, we must support general and special educators by giving them training about dyslexia and learning disabilities, co-occurring issues, and necessary accommodations.
- Third, and most importantly, all of us must have high expectations for students with dyslexia. Policymakers, educators and families alike must recognize that students like Jocelyn are fully capable of excelling in school and college.

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For example:

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Or:

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And:

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These last 13 years taught me that while the educational system is not created with dyslexics in mind, with the right information, training and support for students with dyslexia can thrive.

I can say that I am a better mother and person because of our journey and that Jocelyn’s future is limitless because she is an amazing young woman with much to give the world.

Senator CASSIDY. Thank you.

I get to ask questions first. We each have 5 minutes.

Dr. Eden, in your written testimony, you talk about how your daughter didn’t want to take that “stupid test.” She didn’t want to do it. There’s kind of a theme here that all these children who are dyslexic will say that they are—there’s this anxiety, et cetera. She actually read adequately so that she was not identified as needing intervention. Once you had the intervention, she went from 16th percentile to 75th percentile. I’m struck that she could have kind of moved around in the middle, never being recognized. It was only the concerned parent that was able to do so. Would you elaborate on that?

Ms. EDEN. Senator Cassidy, once you have children, you learn all sorts of things that you thought you knew as a researcher. One of the things that I learned is that the kind of testing that we do in the laboratory is very different from the kind of testing that goes on in the schools.

A child who has strong vocabulary skills can do very well in our school systems, and a child who is high-achieving otherwise can look OK when they’re reading text with pictures next to it. When you put them on standardized tests the way we use in our research to really understand fully all the different facets of reading, the different aspects of reading, you can see where there are weaknesses, and you can see that those are the weaknesses that are interfering

with her ability to learn and read the material that she is being given.

One of the things I certainly learned is it's such a complicated field, and for a parent, even a parent like me, who has served as the president of the International Dyslexia Organization, who runs a brain imaging center, I was stunned at how confused I was between the difference of what I saw in my child at home and in the school in using the kinds of testing that I was familiar with. People need to understand what those different things are and how we use all those different sources of information to identify and help our children.

Senator CASSIDY. Dr. Shaywitz, if the woman who does the research and is the president of the organization is confused regarding her daughter—I have a daughter, too, so maybe that's just an issue with daughters. That said, it kind of begs the question whether we should allow this to be discovered by a teacher observing, or whether it should be something we should screen for. How difficult would it be to screen children at first grade for the presence of dyslexia?

Dr. SHAYWITZ. I don't think it would be difficult. It should be mandatory. Too many children are being missed. As I showed in the slide, we reported in October on the basis of a longitudinal study that the achievement gap is not only present in first grade, but it's very large and it doesn't go away. There are many different—

Senator CASSIDY. That's not a reading gap. That is an achievement gap.

Dr. SHAYWITZ. That's correct, and it can be done—we at the Yale Center are just in the process of publishing a screening instrument that teachers can use and that takes a few minutes. There are other methods. The important thing is to think of it—it's not a developmental lag. It's not going to be outgrown. It's not because he's a boy or because he has a December birthday.

Too many children are missed, and that's really a tragedy, because, as we heard Ameer so eloquently talk about, what it feels like when you're in school and you have to read aloud and the reactions of the other children. Teachers have to recognize that and also listen to parents, because parents see the child and see the struggle when they get home. I don't think it would be difficult at all. The important thing is awareness, to be aware that it's already there, and then to take action.

Senator CASSIDY. Ameer, you were in public school—and Ms. Hanrath. Teachers—your child, you, were having difficulty reading. How did your teacher intervene, or did she or he intervene?

Mr. BARAKA. I never had a teacher to intervene. I was just sort of passed on from grade to grade to grade, and looking back, how awful that was, because someone should have taken notice that I could not read. I see those same patterns right now today. I deal with kids where I talk to the principal about kids who have dyslexia, and they can't do anything about it because there's no resources for those kids. Those kids are either kept back or just passed along, just like I was.

If we don't address this problem, I think we'll see a tremendous surge in violence, a tremendous surge in incarceration. If we do ad-

dress this problem, we can curtail the prison population and violence as well.

Senator CASSIDY. Ms. Hanrath, were your child's teachers prepared? How did they respond?

Ms. HANRATH. My child's teachers did not even recognize she was dyslexic. Her first three teachers were first year teachers, and so they viewed her, the way that she read, as just the fact that she was young in her classroom. Her fourth grade teacher viewed Jocelyn as a behavior problem and said nothing about her dyslexia. She felt that Jocelyn perhaps was not as bright as the other children, and I knew that couldn't possibly be true. I actually took it upon myself to have her tested, and that's when I found out she was dyslexic.

Senator CASSIDY. I got you.

Senator MIKULSKI.

Senator MIKULSKI. Each and every one of these testimonies were so compelling, and we could spend all morning just talking to one of the people at the table. I want to thank you, really, for your contribution already.

I'd like to turn to Mr. Baraka. Sir, your testimony is so much like what we see in Baltimore. Dr. Mahone works at Kennedy Krieger, and if you look out the window at Kennedy Krieger over in east Baltimore, on one side, 12 blocks down, you look toward the harbor, and people are doing very well and very prosperous. If you look on the other side, it's usually in our poor neighborhood where drug dealing is going on.

We have real issues in Baltimore, and we're always accusing our schools as failing and our kids as failing. What you lived through is kind of what we hear every day.

Right, Dr. Mahone?

My question to you is here you are. You were a rough and tumble guy in the streets and neighborhoods, and they were—the streets became your friend, and the streets became your teacher. What would have helped you, and when, to make a difference?

Mr. BARAKA. In my opinion, early detection would have definitely deterred the road that I chose. Like I said, my brother and my sister were excellent students. They both went off to college.

If I had someone to put me in a program, such as the school that Senator Bill Cassidy and his wife has, I would have definitely—as I was walking from the hotel—I was telling a gentleman earlier—and I'm walking to the Capitol, and I'm looking at this vast amount of property and these big buildings, and I said, "Oh, my God. I could have been here." I could have been sitting where you are had someone caught me early on. I always knew—

Senator MIKULSKI. You're a Louisiana guy. You would have been him.

Mr. BARAKA. Yes, yes.

[Laughter.]

I don't want to take his job. I always felt as though I was someone, but it stayed dormant. When I got to prison, I guy told me how brilliant I was, because I was telling him about how—

Senator MIKULSKI. Who was this guy?

Mr. BARAKA. His name was Norman Spooner. He was an incarcerated person. I was telling him how I would get drugs from Cali-

fornia and bring them down, et cetera, and he said, "Man, you know what? You're brilliant. You are somebody."

Senator MIKULSKI. You are brilliant.

Mr. BARAKA. I never heard someone tell me that I was brilliant and that I was somebody.

Senator MIKULSKI. In prison, you read Malcolm X.

Mr. BARAKA. Yes.

Senator MIKULSKI. How did you get started in prison? Was there an evaluation of you in prison?

Mr. BARAKA. Yes.

Senator MIKULSKI. You read Malcolm X?

Mr. BARAKA. Yes. When you enter into a prison, you have to be tested. Everybody has to be tested, and I was found to be on a third grade level. I read Malcolm X's book. I floundered through that book, but I understood what Malcolm stood for, and I understood what Malcolm did. I was facing a 60-year prison sentence, and I said to myself—I said, "God, if I get 60 years"—which I was guilty—I said, "I'm going to educate myself some way, somehow, because I want to emulate Malcolm X. I want to do something for my people, because he did it." I saw that many people behind me were taking the same pathways, and it was a burden on me to get out of prison and tell young people, "This is not the way. This is not the way."

Senator MIKULSKI. Did prison teach you to read?

Mr. BARAKA. That's where I began—

Senator MIKULSKI. Were you self-taught in prison?

Mr. BARAKA. I was self-taught in prison, yes.

Senator MIKULSKI. There wasn't a program that said, "Well, this guy Baraka is pretty smart. He's reading at a third grade level." Was it, again, the sort of bigotry of low expectations—African American male, drug dealer, manslaughter—oh, we know that profile? You know how that narrative goes.

Mr. BARAKA. Yes. Absolutely. Absolutely.

Senator MIKULSKI. That stereotypical narrative.

Mr. BARAKA. Absolutely.

Senator MIKULSKI. Did anybody say, "OK. We've got that. Let's find out why."

Mr. BARAKA. No. There was no hope for me there.

Senator MIKULSKI. Was this a State prison?

Mr. BARAKA. Yes, a State prison.

Senator MIKULSKI. Do you feel—and this isn't meant to be peppering you. Just in my short time here left in the questioning, do you feel—because, unfortunately, prison is at the end of the pipeline. We would want this early screening so much sooner. Do you feel that for many of our men and women in prison, this is one of the areas that—if we want to prevent recidivism and do second chance, along with criminal justice reform—that, really, different kinds of evaluation when you come into prison would be helpful?

Mr. BARAKA. Absolutely.

Senator MIKULSKI. A real intervention.

Mr. BARAKA. Absolutely. This is a Titanic area, because, as I said, many guys in prison cannot read. You can make a lot of money when you can write letters. A lot of guys—there are some guys who can read and write, and they make a lot of money writing

letters for other guys. A lot of guys in prison are—I don't know if they're dyslexic, but they cannot read.

What I did was I wrote down words. I recall my lawyer telling me about the circumstances of my case, and he gave me a pen, and he said, "Write circumstances down." I could not spell that word. Every word that I know—I don't know about phonics. I can't break words down. I know that word because I've written that word down over—and said that word over and over and over again. I don't know anything about phonics. It's completely—it's out of my mind.

Senator MIKULSKI. It's not your thing.

Mr. BARAKA. It's not my thing. I don't know it. I know words because I've written that word down. I had a pile of words I would write down every day, just stacks and stacks of words, and go over them day to day.

Senator MIKULSKI. And then you memorized them.

Mr. BARAKA. Then I memorized the words. If we could get something like this in a prison institution and help men to build on their phonics, we could—again, as I said earlier, we can reduce that, because it gives you—when I learned to read, there was this joy, there was this hope that I am somebody, that I can do something.

It gives you encouragement. It gives you motivation to say, "You know what? I can read." That's one of the most powerful things in the world to do, is to read, to read. It is a blessing to read. Now that I read, I read all the time. I'm reading Sally's book. I'm excited about reading.

Senator MIKULSKI. Thank you very much. My time is up. I have many other questions for the witnesses. I hope we get a second round.

Senator CASSIDY. Senator Bennet.

#### STATEMENT OF SENATOR BENNET

Senator BENNET. Thank you, Mr. Chairman. Thank you very much for holding this hearing, and thank you to the panel for your excellent testimony.

Mr. Boies and Ms. Hanrath talked about the importance of early detection, and Mr. Baraka shared his views about the cost of not having early detection. I remember extremely well my parents sitting me down and telling me that I was going to repeat the second grade and my deep disappointment that my friends were leaving me behind. I remember the year I spent in that second grade classroom tracing letters that were glued to cardboard cards.

In the end, that hard work—as Mr. Boies talked about and Mr. Baraka also talked about, that hard work and the intervention allowed me to compensate for my dyslexia, and I'm sitting here today, partly, because of that early detection, and I wonder if the panel could talk a little bit about how we do a better job—we're doing a lousy job of detecting this—and how we share best practices across school districts and schools, and whether a far greater commitment by this country to early childhood education, a high-quality early childhood education, might actually help us wrestle with this problem as well.

I don't know who would like to go first. I'm happy to—Dr. Mahone.

Mr. MAHONE. I agree that early identification is really critical, and I agree that it should be something that all school districts have in place, and the truth is that it isn't happening in many school districts. And when it is, it sometimes isn't happening effectively.

I agree that it needs to be at the level of the local school system to implement it, but it also needs to be at the level of the leaders of those school systems to make sure it's implemented with fidelity appropriately and developmentally appropriately and to be able to translate the material that has been generated by the researchers here and at other places into the hands of the people who would be screening four- and 5-year-olds.

There's also the issue that we are moving toward more universal pre-K, and the dearth of training that we see in appropriate screening for dyslexia at the level of 5 years old or 6 years old—it's even more challenging when you get younger—and we don't have in place as good of programs for preparing our pre-K teachers to be ready to screen and work with children who may be experiencing some of the risk factors and some of the early signs of dyslexia that emerge sometimes as early as 4 years old and before and can be detected. Our pre-K teachers and our kindergarten teachers need to be trained in developmentally appropriate methods.

Senator BENNET. Dr. Shaywitz.

Dr. SHAYWITZ. Before we do any of that, there has to be greater public awareness of what dyslexia is. It's not just training people and administering a measure, but to understand the whole of it.

You mentioned you don't know phonics, but you read.

It becomes very, very important for teachers—as several of us here are physicians, we go to medical school, but then we do internships and residencies, where we take care of people under supervision. I think, in a way, that the education of educators needs to expand so that they learn in class, but they also learn from experience, so they see people who are dyslexic are not stupid and are not ignorant, and to be able to then use screening measures—they are available—and not to look at reasons—oh, well, this child is this, and this child is that—but to actually use the screening measures themselves.

Senator BENNET. Thank you. I'm running out of time here. As a former school superintendent, I also listened to some testimony today, from Dr. Mahone, about the importance of treating the whole child. Many children with disabilities talk about how they dread going to school, and they experience a level of stress, we heard about from Mr. Baraka, as a result of their disability.

I wonder whether you could talk a little bit about what the emotional and mental effects of learning disabilities are in young children and how we can better support the full range of children's needs.

Mr. MAHONE. Thank you. It's complicated because children with dyslexia can present with a complicated picture, including associated concerns and conditions ranging from anxiety and lack of motivation, and when you experience failure, it gets in the way of motivation. There are a number of risk factors that we know that go along with dyslexia, along with a number of conditions, real other

conditions that seem to coexist with dyslexia that complicate the picture.

It isn't as simple as just looking at the reading and looking at the experience of this child and why a child might be failing. A child might be failing for reasons that go beyond the dyslexia, including living in poverty, having poor opportunities to have really quality instruction, having other kinds of psychopathology that may interfere with learning in other ways. That's not dyslexia. It's something different, but, nevertheless, the result is poor achievement.

Senator BENNET. I'm out of time, Mr. Chairman, so I will yield back. Thank you.

Senator CASSIDY. Thank you.

Senator Murphy.

#### STATEMENT OF SENATOR MURPHY

Senator MURPHY. Thank you very much, Mr. Chairman and Senator Mikulski, for having this hearing.

Let me just add a story to the mix here. It's a constituent from Newtown, CT. She noticed early on that her son, Brian's, preschool years—during his preschool years, he had a speech delay and that Brian struggled to learn letters and early literacy skills in kindergarten, first, and second grade. Despite her concerns, and, frankly, her family's history of dyslexia, her son didn't receive an evaluation for special education services until the end of third grade.

This is standard, in part, because tests don't start until third grade. At this point, Brian's teacher told her that he didn't make any progress in reading between second and third grade, and he was way behind his peers already. Once he was evaluated, he was found to have ADHD, dyslexia, but also a high IQ, and he received specialized instruction and accommodation, but learning to read was rocky.

Eventually, Brian was able to decode words and read. He still struggles today. He's 19 years old, and he's doing well. He's studying mechanical engineering at the Rochester Institute of Technology, and he's a competitive speed skater. He's accomplished. He had to work and his parents had to work especially hard, because it took so long and they had to fight so hard to get him the appropriate programming.

I'm totally on board with the idea that we need to do better, that this is a crisis, as Dr. Shaywitz says, and I hear it every day in Connecticut. I guess here's my only question, and I'll pose it maybe first to Dr. Shaywitz and then ask Dr. Eden and others to remark on this.

What we know—and I'm sure it's been said—is that 80 percent to 90 percent of students with learning disabilities have dyslexia, and it's also, often co-occurring with other disabilities. How do we elevate and do better by way of treating dyslexia without minimizing other disabilities that kids walk into school with? How do we make sure that we do everything that you want us to do without picking dyslexia out of the pot of disabilities that kids are struggling with and have this debate end up in a result that robs Peter to pay Paul?

I know that that's a tension here, right? That's a tension, and so let me ask, in particular, Dr. Shaywitz and Dr. Eden to talk about that. How do we focus the attention on dyslexia while not misunderstanding the fact that there are a lot of other disabilities still that we can't ignore at the expense of tackling this epidemic?

Dr. SHAYWITZ. That's a great question. First of all, let me say that every child should get what they need. What's really important is that this hearing is about science informing education. When we have the science, we have to use it. If we have a drug for breast cancer and not for pancreatic, we can't say, "Well, we can't use it until we can treat all the cancers." We have to use it when we have it.

In the case of dyslexia, we have the knowledge. In my own mind—you're aware, Senator Murphy, that two children committed suicide in Connecticut because of their dyslexia. They were bright. They were in special ed. They were teased. They saw no future. We have to use the knowledge we have.

On the other hand, there are other disabilities, and they're important. We have to make sure the science progresses so it teaches us what we need to know to give the better—I would say optimal, but I know in policy it's the appropriate education to these children. We shouldn't hold the dyslexic children back because we don't have the knowledge to treat the others. We have to make sure we are maximizing the education of all the children who have disabilities.

As a mother and as a grandmother, I know how I worry and I care about my children and grandchildren, and mothers of all children, and fathers, feel the same way. We have to use the knowledge we possess and have to make sure we do it for all disabilities. When the knowledge isn't there—and for many of the disabilities, it's not there yet—we have to make sure that we work to ensure that we acquire that knowledge.

Senator MURPHY. Dr. Eden, a quick response?

Ms. EDEN. Thank you, Senator Murphy. The other thing to add here is that the focus on dyslexia in research has really opened a lot of eyes in terms of understanding about teaching reading in general. I would say that many children have benefited by there being more information about best practices about teaching reading.

Also dyslexia really serves as a model of understanding disorders more generally. How do you work with the school system? How is it that the research that has shown the kinds of measures that you can use to identify dyslexia early—why is it that they are in the hands of teachers, and when the teachers are given those and are using them, they're not using them the way the researchers intended? There's a communication—there's a gap here, that the tests are there, but they're not being implemented.

On the other hand, there are some individuals who are getting the help that they need. They go perhaps for expensive programs, but they also go for programs that are expensive and don't work. We have another very interesting problem here, which is that in the absence of knowledge, in the absence of research, in the absence of educating people, in the absence of people understanding what this is, parents will take it upon themselves to try everything

they can on the Internet, often at a high cost and with no benefit to the children.

These are all problems that you have with any kind of situation where a child is failing to reach their potential. Dyslexia serves as a model to help us understand the full range between education, the role of the parents, the role of the teachers, and the role of private enterprise, and how people need to be educated so those things can be optimized to actually help the child.

Senator MURPHY. Thank you.

Thank you very much, Mr. Chairman.

Senator CASSIDY. Senator Warren.

#### STATEMENT OF SENATOR WARREN

Senator WARREN. Thank you, Mr. Chairman, and thank you, Senator Cassidy and Senator Mikulski, for your passion, for bringing this issue up, and for your advocacy on behalf of those who are affected by it.

One area that I know that all of us are very much in agreement on is that we need education for biomedical innovations, the need for increased investments in research in this area. We've already learned a lot about dyslexia from research funded by the Department of Education, the National Science Foundation, the National Institutes of Health through the National Institute of Child Health and Human Development, which was a vision of President Kennedy.

Investments in research through these agencies mean that we now have some evidence-based interventions that are leading to improved educational outcomes for our kids with dyslexia across the country. There still is a lot that we don't know.

Dr. Mahone, I'd like to ask you about this. How would greater Federal investments in research like yours into the neurological underpinnings of dyslexia help us both intervene earlier and improve outcomes for our kids?

Mr. MAHONE. Thank you. We are on the verge of treating educational research and the translation between biomedical research and education in the same way we are looking at translational research in the field of medicine, meaning that we've learned a lot about the condition. We've learned a lot about the neurobiology of the condition, about the genetics of the condition.

The next question is: How do we translate what we've learned into practice that really gets at the root of the problem? We are on the verge of that right now. We have come a long way with a tremendous amount of support from the Federal Government to get to the research that we have right now. Going forward, we need continued support in order to continue to translate that into the day-to-day practice of our children and improve their lives.

Senator WARREN. Good. Thank you. I really appreciate you talking about this. Whether we're talking about Alzheimer's or ALS or cancer or dyslexia, we know that one of the smartest things that the Federal Government can do is invest in research. The NICHD supports neuroscience and learning intervention research to determine how to identify dyslexia early on and how to support the needs of students with learning disabilities.

Over the last 10 years, Congress has decimated the budget for NICHD, cutting its purchasing power by nearly 20 percent. Researchers are being limited because Congress won't give them the resources that they need. Right now, the Senate faces a critical choice, whether to come together in a bipartisan way to provide sustained, stable, and targeted increases for medical research at the NIH, or just to say, "It's too hard. Let's go on summer vacation."

Senator Cassidy and I have talked a lot about the importance of NIH funding, and I know we both agree on the urgent need to find a bipartisan way to get this done. I hope we can get there, because today's hearing is just one more example of why fixing our research funding problem is just too important for us to walk away.

Mr. Chairman, I have a second round of questions, but I'm glad to put it off and wait my turn, or I can do it now. Your choice.

Senator CASSIDY. We're going to have a second round.

Senator WARREN. Then I'll hold off.

Senator CASSIDY. You have a minute and 15 seconds.

Senator WARREN. I'll yield back and go to my next round. Thank you.

Senator CASSIDY. Senator Casey.

#### STATEMENT OF SENATOR CASEY

Senator CASEY. Thank you, Senator Cassidy and Senator Mikulski for having this hearing. We're grateful to have this opportunity. We don't often have the kind of opportunity we have today to focus on one issue in a very intensive way and to have a—we have a lot of great panels here, but this is, indeed, an all-star panel for a lot of different reasons. We're grateful for the opportunity.

I won't get to each of our witnesses, but I did want to start with you, Ms. Hanrath, to commend you for taking the time to be here today, for your testimony, and to bring your own personal story and that of Jocelyn to this committee. We learn a lot when we read about public policy and analyze data, and that's part of the learning process for us. It's all the more significant when you can bring your own personal story.

Jocelyn, I want to say to you congratulations on both your academic and athletic achievements. I always wanted an athletic scholarship in college. It just wasn't in the cards.

[Laughter.]

It's difficult to do one—to be recognized for one versus the other. To have both academic and athletic achievement is significant.

I want to ask you a more technical question about transition to college, transition to higher education. I did want to focus, first of all, on your three points, because sometimes we leave here and we've learned a lot, but then it begins to fade over time. It's important to remember those three concepts: identify, train, and set high expectations, all three critically important.

If I were adding a fourth, I'd say try to get a good mom, because I know that some children never have that opportunity to have a mom or a dad or a caregiver who is so engaged as you have been and to be that advocate. You've turned her into her own self-advocate based upon your testimony. We're grateful for that. We do

want to bear in mind those three core messages of identify, train, and set high expectations.

My question is more technical. My staff and I have heard from folks in Pennsylvania about this transition from high school to college and having strong transition services important to students with a learning disability. What's your experience with that? What can it tell us about either—not just your own experience, but what you would hope we would do to fill in some of the gaps if there are some?

Ms. HANRATH. Thank you, Senator, for the question. First of all, our experience is a bit different. Because Jocelyn is an athlete who is wanted, the transition has been very simple. We immediately started talking to the special education department, who was very open to whatever Jocelyn needed. They were willing to accept her IEP from high school, which is not common.

At so many colleges, the students are asked to go back and re-test in order to receive accommodations in college, which was shocking to me, because I am not a doctor, but when Jocelyn received her diagnosis, one of my first questions to the neuropsychologist was: If I get Jocelyn a lot of help, will she stop being dyslexic? She said, "No. She'll always be dyslexic." I couldn't understand why an IEP in a high school would not be adequate for a college to accept that as a learning disability.

In Utah, for example, Jocelyn's special educator has a caseload of 40 students. Her transition work is basically a checkbox. Once a year, someone comes in, talks to Jocelyn for 5 minutes and says, "Are you going to college? Are you taking classes? Good job," check the box and that's all. There is not really anything given to us in Utah as far as transitioning to college.

Once again, because of Jocelyn's athletic accomplishments, when we talked to the athletic department, whatever she needed, she could have. It was very simple. It is not that simple for most kids, and it's impossible for them to, many times, re-test because the testing costs so much money to be able to access special education in college.

Senator CASEY. I appreciate that perspective. What we often try to do here by way of legislation but also by way of something much more substantial in the case of Every Student Succeeds—it was a great effort by this committee to take No Child Left Behind and reform it, shake it up, and change it, and a lot got done.

I was just looking at a list of things that might be applicable here: a center to develop assessment tools to support the identification of students with disabilities, including dyslexia; evidence-based instruction materials; professional development. We have the outlines of it, but I also want to make sure that we're not missing a piece when it comes to that transition, but, in particular, having that IEP not be adequate and having new evaluations done which might be difficult for a lot of families.

I'm out of time, but maybe what I'll do is pose a question for the record to the other witnesses so we can get at this issue.

Mr. Chairman, thank you very much.

Senator CASSIDY. We'll have a second round, and I'll begin.

Mr. Boies, first, I'm struck. In your written testimony, you speak about how your dad kind of would verbally teach you just a So-

cratic method, and so you didn't need to read, and you could just kind of download everything your dad knew about history. That sort of thing. Then you describe how your son for 10 years had 4 hours of tutoring every day. Now, that takes some courage and determination.

In your last paragraph, some students with families that can afford the best; they're fortunate to have their dyslexia identified, understood, and treated early. The vast majority are not so fortunate, and their future contributions are at risk.

Senator Warren and I mentioned briefly this is really an issue of middle-class economic opportunity. Your thoughts on this?

Mr. BOIES. The right to an education is one of the most basic civil rights that we have. That right should not be inhibited by the economic circumstances of a child's family. I have been very fortunate, and I could give my children the opportunity to be tested early, to get tutoring, to have all of the advantages that modern science can give.

Most children are not that fortunate, and we as a country are terribly wasting those resources. It is unfair to the child, and it is a disaster for this country in a global world to lose those resources. By identifying people early and by giving them the help and the hope that they need to succeed, we can give them that basic civil right of a decent education, and we're not doing that now.

Senator CASSIDY. I'm struck. It's not just someone like Mr. Baraka, who obviously has a tragic story but finished well. It's also Dr. Eden's daughter, who was a promising girl who was going to be allowed to achieve less because they did not know. If we have 20 percent and Dr. Mahone said there's not many districts screening. I'm not sure there's any districts screening. As best we can tell, there's not a single district that screens all incoming students for dyslexia.

If you've got a condition affecting 20 percent in one way or another—Mr. Boies, you're an attorney. You spoke of civil rights. Is it excusable that we're not screening? This is not 1 percent or 2 percent. The cost-benefit ratio here is pretty substantial.

Mr. BOIES. Senator, it's inexcusable, because we have the technique to do that. We can do that in a cost-effective way. It's a question of education. It's a question of commitment. We could do this for a fraction of what we spend on lots of other things that are much less important and much less critical to children and to our country. We have the ability to screen. We know how to do it. We could implement it in a cost-effective way. We're just not doing it.

Senator CASSIDY. I know that it costs about \$50,000 a year to incarcerate somebody. If you broke down the siloes and somehow said, "Well, heck, we could redirect some dollars," it would make quite a difference.

Mr. BOIES. It is the definition of penny-wise and pound-foolish.

Senator CASSIDY. Yes. Your child, if I may ask—was he identified early by a teacher, or was it just because of your family history that you knew to watch for early signs of dyslexia?

Mr. BOIES. It wasn't so much the family history. He was a twin, and his brother, Jonathan, was very verbal and in kindergarten was reading and very phrasal, and Christopher was struggling terribly. The sharpness of that comparison led us to have Christopher

tested, and when Christopher was tested, that was the time I was first diagnosed with dyslexia.

That testing led to the tutoring, led to the help, led to the hope, because he knew what it was. He knew it didn't affect his intelligence. He knew he could conquer this, and he did. As I say, he performed well in high school. He performed well in college, although we had a hell of a time getting into it, and he performed great in law school, although, again, his standardized tests—because he did not get accommodations—predicted that he would fail. He graduated from Yale Law School with honors. His LSAT would have predicted that he couldn't have succeeded.

Senator CASSIDY. The standardized testing option. I thought what you said was very provocative. I'll defer now to Senator Mikulski.

Senator MIKULSKI. Thank you very much. I want to associate myself with the remarks of Senator Warren in terms of the need for more biomedical research. Also I want to go back to my original remarks. We need to put that research into action, and then when you look at the way we do not fund programs like IDEA, then groups with learning challenges are pitted against each other for resources, the very things that we just talked about here earlier. We need a multifaceted approach here, just like we do with the children.

Dr. Eden, let me go to some of your research findings. I was struck by what you said, that there were different neurological aspects to girls compared to boys. Could you elaborate on that? In my early days in the Senate when I came here, women were not included in the protocols at NIH. This was 1986, not 1886. Working together across the aisle with Dr. Bernadine Healy, Dr. Ruth Kirschner, and so on, we were able to change that, which validates exactly this.

Could you tell us, though, what your findings are? Because you'd think the brain is the brain, that it's kind of—the brain is gender neutral.

Ms. EDEN. Thank you, Senator Mikulski. This is an example where brain imaging research really has a lot to add and we can get some insight, because brain imaging research has shown for years that the brains of women and men and boys and girls are different. They're different in their anatomy. There's difference in the hormones that bathe the tissue, and it also goes hand in hand with some of the differences that we observe in boys and girls as they develop early on.

The important part here is to recognize that early research, for reasons that aren't fully clear, often did focus more on boys. The deductions that were made from that research were that these were findings that were true for all individuals with dyslexia, and they were generalized to all people with dyslexia.

We're beginning to focus more on sex-specific differences, and the NIH now requires that when we submit research grants, that we consider biological variables such as sex so that we have very specific questions about—do the kinds of questions we're asking, the hypothesis that we're posing in our research—are they also addressing the issue that there are sex-specific differences, and is that part of our hypothesis. That's tremendously important.

Senator MIKULSKI. How has this manifested itself?

Ms. EDEN. What the real point here is, is that we don't fully understand how it's manifesting. It could be that—we know from cognitive neuroscience that sometimes we observe performance in males and females and they appear to be equal. Under the surface in the brain, the mechanisms that invoke to do those tasks are very different.

Then you ask the question: What happens if those mechanisms then interface with a learning disability? How do the female brains respond versus the male brains? We don't really—we don't have the answer to those yet, because we haven't done the research. Doing more research in that area is really very critical, and we'll see a lot more research because of the new NIH mandate.

Senator MIKULSKI. Thank you.

I'm going to turn to—let's hear it for the mothers with Ms. Hanrath. I'm going to call you like a nighthawk, because, obviously, you and other mothers and dads stay up at night, kind of cruising the Internet, avoiding scams and schemes, and yet trying to come up with approaches. Could you tell us what worked for you as a mother, even to know what to do and so on? You mentioned the group, Understood. Also, you paid for your own testing for your daughter, which was, obviously, extremely expensive.

What did you run into? How can we help—at least a pathway for moms and dads—regardless of social class or whatever, to do this? Could you elaborate on your personal exploration here on how to help your daughter? What helped? What were the obstacles? What was your best friend? Was it the Internet?

Ms. HANRATH. Certainly. At the very beginning, when my daughter was actually tested by the school district at the end of fourth grade. Her grandmother had died the week before they tested her. They came back with the results that she had an IQ of about 80.

Senator MIKULSKI. Eighty? Eight zero?

Ms. HANRATH. Eight zero, and that she would not ever succeed in school because she was not very bright. I said that is absolutely not true, and I found a neuropsychologist to redo the testing. Once that happened, then I had to go through the phase of—I always thought dyslexia meant you mixed up your letters. I had no idea that it was—

Senator MIKULSKI. Senator Cassidy, if I may—Ms. Hanrath, you said, “I found a neuroscientist.” You don't go to Craigslist for that, you know? You don't say, “Oh, well, let's go find a neuroscientist, after we get our refrigerator or toaster oven fixed.” Tell me, in other words, how did you do that?

Ms. HANRATH. I did that because I have an older son who also has learning disabilities, and he had a specialized tutor. I went to the tutor, and I said, “Who is it that I should have my daughter tested by?”

Senator MIKULSKI. I see. You were essentially on your own.

Ms. HANRATH. Yes. It was on my own.

Senator MIKULSKI. Did you have, where you live, an institution like Kennedy Krieger you could have turned to?

Ms. HANRATH. No, there really isn't anything in Salt Lake. There is a place at the University of Utah with graduate students, but I wasn't comfortable with that.

Senator MIKULSKI. Right. Here, we have Georgetown to turn to. We have Kennedy Krieger. We would have in New Haven the Yale Center and the Shaywitzes. But you were on your own, and you did this through a tutor.

Ms. HANRATH. Yes.

Senator MIKULSKI. And you got the results.

Ms. HANRATH. Yes. Then I decided that I had to come up with a solution. The neuropsychologist was wonderful. She gave me 23 pages of accommodations. When I went to my first IEP meeting, I took those 23 pages in, and I said, "I want you to accept all of these." No one argued with me. It was immediately attached to Jocelyn's IEP, and I kept those accommodations, and whenever Jocelyn needed a specific one, we invoked the IEP.

I was fortunate enough to have the money to have her tested. Unfortunately, I was not wealthy enough to have daily tutoring for Jocelyn, so I had to rely upon the school system, but mostly myself, my inventiveness.

Senator MIKULSKI. Could we ask about Understood and what that meant? Because, you see, what we have here is a path that—look at the struggle here. Could you just tell us about Understood?

Ms. HANRATH. I would love to tell you about Understood. I'm a single mom. At night, I would wake up. I was worried about Jocelyn. I didn't know what to do.

Senator MIKULSKI. So you were a nighthawk.

Ms. HANRATH. I was a nighthawk. I had to be, because I wasn't sleeping. I found this incredible website called Understood.com, and I could plug in the fact that Jocelyn was dyslexic and what age she was, and I could read about it. Then there were parent forums and I could talk to somebody at 3 o'clock in the morning, someone who understood where I was coming from and that would get back to me.

I could watch videos from experts. I could listen to archived sessions on dyslexia. I started to become educated, and education is the source of all power, and that's where my education came from.

Senator MIKULSKI. Thank you, Senator Cassidy. You are very generous. Thank you.

Senator CASSIDY. Senator Warren.

Senator WARREN. Thank you, Mr. Chairman.

Thank you, Senator Mikulski, for your remarks on research and the importance of making sure that we have adequate NIH funding.

Also, thank you, Dr. Eden, for reminding us of yet more reasons why this research is important.

I just want to ask—I want to turn to a slightly different issue here and talk a little bit more about what we're learning from the research and to training teachers for the classroom. This is a special topic for me, because I was a special needs teacher a long time ago.

Ms. Hanrath, let me start with you. First, congratulations on your daughter's graduation, impending graduation, from high school. I know you are very proud.

Jocelyn, way to go. It is good to have a success story here. We're delighted to have you here today.

In your testimony, you talked about the importance of supporting educators by giving them training about dyslexia and other learning disabilities. Can you talk just a little bit more about how important it has been to you and to your daughter to have special education teachers with the tools and training they need to support your daughter's learning needs?

Ms. HANRATH. Thank you, Senator. Without Carrie Szumnarski, there was no way we could have navigated through high school. She talked to Jocelyn's teachers. She gave Jocelyn confidence. She went to meetings with Jocelyn and I. She stood up for Jocelyn's rights. She knew things I didn't know. If we did not have Carrie, if Carrie was not educated, as I said, I do not believe the success would have happened for Jocelyn the way that it did.

I find it really frightening that so many teachers are not educated about dyslexia, that they assume that dyslexics are stupid people, that they shouldn't expect much of them. They need the education. They need to understand that dyslexic kids can do amazing things. They think outside the box. They're leaders by nature. It doesn't take much for accommodations. They don't have to cost a lot of money. Everything isn't high tech.

Please, please, find a way to let all teachers understand what dyslexia is and how they can help. It doesn't take much, but, once again, it requires an education.

Senator WARREN. Thank you. That's very important, Ms. Hanrath.

Maybe that means I can turn to you, Dr. Eden. How do we equip all teachers and all school leaders with the training and the development they need to serve students with dyslexia?

Ms. EDEN. Thank you, Senator Warren. That is, of course, the big question here, and that's where we will need more resources, and we need to make some changes in the way people think about their role in all of these things. It's very frustrating as a scientist to see.

There are tests that are out there that predict to a very high degree which children are at risk for reading. Those same research data have made it into benchmark tests that are in schools, in my daughter's school. When you ask the teacher how your child is performing on those tests, it turns out they haven't looked at those test results, probably because somewhere the research fell short in trying to apply this and to educate the teachers to use it effectively.

One of the problems we have in research is that we don't do enough to make sure that the findings that we have are implemented in a way that they are actually useful. Again, you've put in a lot of money. You have the information, but it's not going the full length to actually then benefit the child who needs those to be identified.

The other risk that we run here is that if we don't continue doing the research—remember, I said we don't have enough—we still don't quite understand how dyslexia actually comes about. Others will fill that void. Parents are online all the time. Doing an evaluation is expensive. You think that's expensive. Getting the treatment is really expensive.

Then you find an alternative. Maybe it's not quite as expensive. It's based on something that you can do at home. It's quick. You

don't have much time. You're trying to feed your child. You want them to do something for the little time you have in the evening. You use a quick fix. It appears to be something that has research behind it. You don't know. You're not a scientist. You didn't read the paper. Is it truly validated?

You grab onto another option. You've made a huge mistake. You've made a misinvestment. You've used something that actually isn't research-based, and if we don't do the research to actually investigate these programs, then there's no knowledge that we can put out there to guide parents about which avenue they should pursue.

All of these things have to be moved forward hand in hand. It's sort of interesting to hear how teachers learn from the Understood website things you would think they learn in the schools of education, but apparently they don't. Everybody has to buy in. Everybody has to understand it's an education, and everybody has to be ready to learn together and implement the knowledge that we have together.

Senator WARREN. Thank you very much, Dr. Eden. It's very important. I know from firsthand experience how much support teachers who work with special needs children need, and we owe it to them to have their backs in making sure they have the resources they need, and to have the resources in their professional development so they can be trained, so they can understand what they're dealing with here.

We already have a vehicle where we could be doing much more of this by investing more in title II of the new education law which supports teacher development. Let's face it, Congress needs to fully fund the Individuals with Disabilities Education Act. Senator Mikulski raised this in her opening statement, and she's exactly right about this.

Congress passed IDEA over 40 years ago to ensure that teachers would have the necessary resources to support students with disabilities. Although the program was designed to support 40 percent of the additional cost of educating students with disabilities, Congress has repeatedly failed to meet this commitment. That's why I sponsored the IDEA Full Funding Act last Congress. I would increase IDEA funding over 10 years until Congress fully meets this commitment.

I've sent letters to the Appropriations Committee about this. I intend to keep fighting for full IDEA funding until Congress lives up to our end of the bargain to support our kids with special needs and their teachers. Our children have already waited too long.

What I hear today is about everyone has a job. Our kids work hard if they have the opportunity to do it. Our mothers work hard. Our teachers work hard. Our researchers work hard. It's time for Congress to work hard and do our part, too, and make sure you have the resources you need.

Thank you for having this hearing. I really appreciate it, Senator Mikulski and Senator Cassidy. This is the kind of thing that we need to be doing to make Congress work for our children.

Thank you.

Senator CASSIDY. Thank you.

Again, thank you, Senator Mikulski.

Thank you, to all of the witnesses.

Thank you, to those in attendance.

There will be a reception afterwards if people wish to stay and linger and have further conversation. I'd like the witnesses—if they have something they wish they'd had a chance to say but didn't have a chance to say, they may submit it in writing and have it as part of the record.

The hearing record will remain open for 10 days for Senators to submit additional comments and any questions for the record Senators may have.

Thank you for being here today. The committee will stand adjourned.

[Additional material follows.]

## ADDITIONAL MATERIAL

## RESPONSE TO QUESTION OF SENATOR SANDERS BY DAVID BOIES

*Question.* Importance of Fully Funding IDEA—Today, our schools are being asked to do more with less. This is unfair for students, families and educators, especially in an environment of increased economic inequality where *over half* of all public school students come from low-income families.

States, local districts, and the Federal Government have a responsibility to ensure that our schools have the resources they need to provide every child an excellent education. Currently, over 30 States are spending less per student than they did before the recession. Further, we have yet to make up even 15 percent of the over 350,000 jobs cut by school districts due to the Great Recession. Making matters more challenging is the fact that schools are serving over 800,000 more students than they did in the year 2008.

We know that students with disabilities often need extra support. Congress passed the Individuals with Disabilities Education Act (IDEA) to ensure that students with disabilities had a civil right to education and that schools had the resources needed to meet the “excess costs” of providing special education services. Today, the Federal Government is far short of its obligation to fully fund IDEA, contributing *less than half* of the promised 40 percent contribution necessary to cover the “excess cost” of educating students with disabilities.

Mr. Boies, Ms. Hanrath, and Dr. Mahone, can you speak to the need of fully funding IDEA and how that would help schools better serve children with specific learning disabilities like dyslexia? Additionally, what extra challenges do low-income families face in trying to get the appropriate services for a child that has a disability? How can the Federal Government work to support low-income families that have a child with a specific learning disability like dyslexia and the public schools that serve these students?

*Answer.* The good news about dyslexia is that we know how to identify it, and once we identify it (particularly when we identify it early) we know how to provide children with the help they need to enable them to overcome the debilitating effects that untreated dyslexia can have.

Dyslexia, if properly identified and treated, need not limit a person’s potential. Dyslexia makes it difficult for a student to learn to read. Because reading is the primary way students, particularly in grade school, acquire information, if dyslexia is not identified and treated it can prevent students from acquiring the information they need to succeed in school. They, and their teachers and parents, often confuse their difficulty in learning with a lack of intelligence. This often leads the student, and the student’s teachers and even parents, to become discouraged, and to give up.

Identifying dyslexia enables us to provide students with training that improves their reading skills and their ability to acquire information in alternative ways. This in turn encourages students, and their teachers and parents, to stay the course. In addition, understanding that the problem is a limited input disability, not any deficiency in processing, and that as students progress in life, processing skills (i.e., what a person does with the information the person has), becomes more and more important, helps everyone to avoid getting discouraged and giving up. In life, judgment, character, and commitment are far more important to a person’s success than how fast a person reads; but without an understanding of what the problem is (and is not) too many people get discouraged and give up prematurely.

Identifying dyslexia will also permit students to get the extra time on standardized tests that is required to prevent those tests from massively understating those students’ knowledge and ability.

An increasingly large percentage of dyslexic students from well-to-do families, or who are fortunate to live in a particularly well-financed school district, are today identified, treated, and enabled to reach their ultimate potential.

The tragedy is that few children who come from economically disadvantaged homes and live in less well-financed school districts get the diagnosis and treatment they deserve. The help they need is practical. It is promised by the IDEA. But it is lost because of lack of funding.

Education is a basic civil right. Indeed it is a right that is essential to making other civil rights effective. By depriving dyslexic children of early diagnosis and treatment, our educational system (and our society) deprives these children of this basic civil right—and of the promise made to them in IDEA.

## RESPONSE TO QUESTIONS OF SENATOR SANDERS BY MARK MAHONE, PH.D., ABPP

First of all, I would like to thank the committee for the opportunity to provide testimony at the hearing on May 10, 2016, “Understanding Dyslexia: The Intersection of Scientific Research and Education.”

In response to the followup questions posed by Senator Sanders, I am providing my responses below. The original questions are included for convenience.

*Question 1.* Dr. Mahone, can you speak to the need of fully funding IDEA and how that would help schools better serve children with specific learning disabilities like dyslexia?

Answer 1. The explicit intent of IDEA was to provide a free and appropriate education to all students, regardless of disability status. At the time that the original law (now IDEA) was passed, Congress committed to funding 40 percent of the excess costs of educating students with disabilities through grants to State education agencies (IDEA Part B). Presently, Federal appropriations only fund approximately 16 percent of these additional costs. While the proportion has increased slightly over the past 5 years, current levels remain far below the 40 percent goal.

I believe that it is unfair for the Federal Government to require local education agencies to provide “appropriate” services to all students with disabilities, but not appropriate sufficient support for implementation of these services. To this end, I believe it is critical for the Federal Government to increase appropriations to support implementation of IDEA, with the ultimate goal of fully funding the commitment made in 1975.

Recognizing that the number (and proportion) of all students who now qualify as students with disabilities has risen steadily since 1975, the emphasis in Federal funding should be toward early (and accurate) identification of students with disabilities and evidence-based intervention, with the goal of *reducing* the lifetime morbidity of these conditions and *reducing their ultimate cost* to the American education system. In other words, appropriations should target educational practices that have a high likelihood of reducing overall costs through better investment in screening and early intervention. These interventions will also increase the number of children who (for a variety of factors) are at risk for developing a disability, but because of better early intervention, do not go on to manifest the disorder, and are able to be fully educated in general education settings. This goal is especially true for children with specific learning disabilities such as dyslexia, as the methods for early screening and intervention, while well established in scientific literature, are not routinely translated into practice at the level of the local education agencies. This lack of translation leads to billions in extra educational and societal costs.

*Question 2.* Additionally, what extra challenges do low-income families face in trying to get the appropriate services for a child that has a disability?

Answer 2. Low-income families face a variety of additional challenges when attempting to secure appropriate services for a child with a disability. I will outline several of the key challenges below.

- Children from low-income families are more likely to live in poverty, which carries an increased risk for reduced access to healthcare, poorer nutrition, increased exposure to violence, and chronic traumatic stress—all of which have a direct, negative impact of brain development and ultimate learning potential.

- Many health insurance providers (including most of those contracted to provide medical insurance to low-income families) specifically *preclude* coverage for diagnostic assessments for autism spectrum disorders, specific learning disabilities, and intellectual disabilities, citing that these conditions are “the responsibility of the educational system and not healthcare.” This barrier effectively prevents effective access to early diagnostic assessment for these conditions, as schools do not routinely provide assessments until after a child has already demonstrated educational failure. Children from families with higher income are able to obtain these assessments privately on a fee-for-service basis—an option not available to low-income families.

- An alarming trend is that parents of students with disabilities who are not making progress now hire educational advocates to work with the local school system to obtain appropriate implementation of services. With few exceptions, this type of service is available only to families who can afford to hire these advocates. Low-income families are often not able to obtain such representation, and are left to advocate for themselves.

*Question 3.* How can the Federal Government work to support low-income families that have a child with a specific learning disability like dyslexia and the public schools that serve these students?

Answer 3. The Federal Government has begun to take steps toward supporting children with learning disabilities. For example, the Every Student Succeeds Act (ESSA) authorized a first-of-its-kind Comprehensive Literacy Center for parents and educators to better support children who are at-risk for challenges with reading, writing and language processing due to dyslexia or other disabilities. The goal of the Center is identify, develop, and deliver information to educators and parents to better meet the needs of students who may struggle with reading, writing, language processing, comprehension or executive functioning due to a learning disability like dyslexia. In December 2015, Congress passed a budget allocating \$1.5 million to the Comprehensive Literacy Center, which is expected that the Center will begin operating in 2017. While this is a start, it is unlikely to be sufficient to support the needs of low-income families. The achievement gap for students with disabilities is especially prominent in schools with limited resources, where the majority of the students come from low-income families and the need for services far surpasses available resources.

In addition to the goal of fully funding IDEA, it is also imperative that *all* certified/licensed teachers (including both general education and special education teachers) have appropriate pre-service training in evidence-based methods for identification and intervention of learning disabilities. Management of this requirement at the State and local level has proved insufficient. At present, most teachers entering practice do not have the requisite expertise or experience to provide evidence-based intervention to students with dyslexia. The result is that identification and treatment are delayed (or absent), and the biological “window” for optimal intervention begins to close before care is received. This is the framework for the “wait to fail” model.

The lack of training is not the fault of the teachers. It is typically not provided in pre-service/undergraduate training. Having a well-defined, *Federal* requirement for all licensed or certified teachers to have specific training and competence in identification and intervention with children with learning disabilities (who make up nearly half of all students with disabilities) is an initial step to ensuring reducing the achievement gap.

RESPONSE TO ADDITIONAL QUESTIONS OF SENATOR SANDERS BY MARK MAHONE,  
PH.D., ABPP

Thank you for the opportunity to respond to these excellent additional questions. The questions and my responses are below.

*Question 1.* When this committee considers the reauthorization of the Higher Education Act, what can we do to ensure that educators in-training—both those seeking to be general and special educators—get the training they need to support students with specific learning disabilities like dyslexia?

Answer 1. First, for pre-service teachers, one possibility is to set and enforce *national criteria* for pre-service teacher training that include required courses about developmental psychology, learner variability, differentiated instruction, and evidence-based interventions. There are established models for such national standards in fields such as medicine, psychology, social work, speech/language pathology, just to name a few. Pre-service teachers should also be taught to be wise and active consumers of published research. At present, this type of coursework is notably absent from the majority of undergraduate and graduate pre-service training programs. For general educators, many universities now require only *one* survey course addressing instruction for children with special education needs. Given that the majority of children with special education needs are taught primarily by general education teachers, this training is woefully inadequate.

Second, as noted above, national standards need to place significantly greater emphasis in pre-service training on the area of learner variability, emphasizing principles of Universal Design for Learning (UDL). UDL is a framework to improve and optimize teaching and learning for all people, and is built on the idea that instructional flexibility is a “standard,” and that systems and all classrooms are designed to accommodate all children and all learners. My home State of Maryland has implemented into its State law that school districts will use and emphasize principles of UDL in their curricular design. It is time for this emphasis to be at a national level.

Third, pre-service training emphasizes content knowledge; but there is insufficient emphasis on practical experience. As part of considerations for national standards for pre-service education, it is imperative that certified teachers entering the work-

force have sufficient pre-service internship experience with *high quality* mentor teachers. To that end, teachers in training need quality experiential activities early in pre-service education, not simply during the final year before graduating. To accomplish this goal, there will also need to be national standards for mentor teachers who supervise internship experiences.

*Question 2.* Furthermore, now that the Elementary and Secondary Education Act has been reauthorized, what can the U.S. Department of Education do to ensure that educators have ongoing and high-quality professional development that provides them with the tools to reach every student, including students with specific learning disabilities?

Answer 2. For in-service teachers, it will be critical to fund grants for instructional coaching, and encourage State Departments of Education to use *micro-credentialing* in order to reward teachers for seeking ongoing professional training. For example, a common practice at the State level is to provide a certification (or credential) for “Reading.” At initial glance, providing such a credential for those who teach reading seems like an excellent idea. Closer analysis reveals that such credentials are highly general, and may apply to the entire range of grades (pre-K–12). In other words, a teacher with a “Reading” credential may have expertise in teaching middle school students to read better, but may not have training or experience in teaching primary grade students how to read *initially*. Individuals with the “Reading” credential may also have little training or experience in teaching dyslexic students. Conversely, the micro-credential allows for specific standards and credentialing in specific areas, such as teaching students with dyslexia, or early literacy instruction. With these micro-credentials, States and districts can better match teacher expertise to needs of students. The process also allows for highly targeted continuing education among experienced educators. This model, like that set forth for national teacher certification, is also used in fields such as medicine, psychology, and speech/language pathology—all of which has established criteria for specialties and subspecialties.

Finally, continued and expanded funding should also be dedicated to improve the “What Works Clearinghouse” to be more accessible and user friendly for the front-line teacher. Created in 2002 by the U.S. Department of Education’s Institute of Education Sciences, the What Works Clearinghouse provides educators, researchers, policymakers, and the public with a central source of scientific evidence on what works in education to improve student outcomes. Its goal is to help decisionmakers contend with differing messages from research studies and product offerings.

#### RESPONSE TO QUESTIONS OF SENATOR SANDERS BY APRIL HANRATH

*Question 1.* Today, our schools are being asked to do more with less. This is unfair for students, families and educators, especially in an environment of increased economic inequality where *over half* of all public school students come from low-income families.

States, local districts, and the Federal Government have a responsibility to ensure that our schools have the resources they need to provide every child an excellent education. Currently, over 30 States are spending less per a student than they did before the recession. Further, we have yet to make up even 15 percent of the over *350,000 jobs cut* by school districts due to the Great Recession. Making matters more challenging is the fact that schools are serving over 800,000 more students than they did in the year 2008.

We know that students with disabilities often need extra support. Congress passed the Individuals with Disabilities Education Act (IDEA) to ensure that students with disabilities had a civil right to education and that schools had the resources needed to meet the “excess costs” of providing special education services. Today, the Federal Government is far short of its obligation to fully fund IDEA, contributing *less than half* of the promised 40 percent contribution necessary to cover the “excess cost” of educating students with disabilities.

Ms. Hanrath, can you speak to the need of fully funding IDEA and how that would help schools better serve children with specific learning disabilities like dyslexia? Additionally, what extra challenges do low-income families face in trying to get the appropriate services for a child that has a disability? How can the Federal Government work to support low-income families that have a child with a specific learning disability like dyslexia and the public schools that serve these students?

Ms. Hanrath, can you speak to the need of fully funding IDEA and how that would help schools better serve children with specific learning disabilities like dyslexia?

Answer 1. I am very proud of my daughter, Jocelyn, who just graduated high school with a 3.7 GPA and will begin studying sports management at Highline College in the fall. Jocelyn has learning disabilities and struggled throughout elementary school with reading, writing, test anxiety, executive functioning, and attention issues. Throughout elementary school, Jocelyn had several first-year teachers who thought she was simply unintelligent or a behavior problem. I knew that wasn't true. At the end of fourth grade, I had Jocelyn evaluated by a neuropsychologist and her school finally recognized that she had dyslexia and dysgraphia and provided her the rights and services she is entitled to under IDEA.

Starting in fifth grade and continuing throughout school, Jocelyn received extra time, oral testing, and the right to use a computer to type assignments. With the help of these accommodations and an amazing special education teacher who tutored and advocated for my daughter, Jocelyn was able to learn in general education classes with her friends. She even enrolled in AP and honors classes in high school. My family is not alone. There are 2.4 million students who, like Jocelyn, have specific learning disabilities and the majority of these students want to go to college.

The *President's fiscal year 2017 request* of \$11,912.85 million for IDEA grants to States would freeze funding at the fiscal year 2016 level, which is only 16 percent of the total per child cost. IDEA is critical to ensuring that all students are able to achieve their goals. Special education services are a civil right accessed by 6.7 million students with disabilities, and the number of students who need services does not decrease when Federal funding does. In order to ensure students and schools have the necessary resources, we need to fully fund IDEA State grants at the 40 percent level that Congress promised in 1975, and substantially invest in all IDEA programs.

*Question 2.* Additionally, what extra challenges do low-income families face in trying to get the appropriate services for a child that has a disability?

Answer 2. When Jocelyn was in fourth grade, the school tested her for special education the same week that her grandmother died, and reached the false conclusion that Jocelyn would never succeed in school because she just wasn't smart. I knew that my daughter struggled in school, but was very bright so I found a neuropsychologist and paid to have the testing re-done. The neuropsychologist diagnosed Jocelyn with dyslexia and other learning disabilities. I am a single mother and a small business owner and was fortunate enough to have the money to pay for Jocelyn's testing, but I was not wealthy enough to pay for daily tutors so I had to rely on the public school system, but mostly on myself.

Families living in poverty may not have the money to seek private help, or the time to educate themselves on learning disabilities and advocate for their child. This is especially disconcerting considering the *prevalence rate for learning disabilities* is higher for children living in poverty. Overall, students with learning disabilities are more likely to be boys, living in poverty, in foster care, homeless, African American, or Latino. Although learning disabilities do not correlate with intelligence, one-third of students with learning disabilities have been held back in a grade at least once, and students with disabilities—particularly African American and Latino boys—experience higher rates of school disciplinary actions, higher dropout rates, and lower graduation rates. For adults, the prevalence rate for learning disabilities is almost twice as high for individuals living in poverty compared to individuals above the poverty line, and only 46 percent of working age adults with learning disabilities are in the labor force. Yet, students with learning disabilities are enrolling in post-secondary education at the same rate as the general education population and express similar goals for college, employment, and life.

I was lucky that my daughter is a talented student-athlete so her college made it easy for her to get disability services using her high school IEP, and she earned a scholarship from the National Center for Learning Disabilities. This is not the case for most students with learning disabilities. Often, colleges make students pay for a new evaluation in order to receive services. Because these tests are so expensive, many students are just not able to get the supports they need in college. Even if the college recognizes that a student has a disability, the family may still have to pay extra, on top of regular tuition, to actually access services.

*Question 3.* How can the Federal Government work to support low-income families that have a child with a specific learning disability like dyslexia and the public schools that serve these students?

Answer 3. The biggest challenge that Jocelyn and I faced was the misconception that students with learning disabilities cannot learn. We're not alone. *Seven out of 10* parents, educators, and members of the general public incorrectly associate learning disabilities with intellectual disabilities and autism, and half think that

learning disabilities are the result of laziness. The vast majority of students like my daughter spend 80 percent or more of their school day learning alongside their peers who do not have learning disabilities. Research shows that children who spend more time in general education classrooms have improved outcomes. The practice of inclusion also reflects a core requirement of IDEA.

This means that it is critical for general education teachers to be trained on learning disabilities so that they can identify students as early as possible, hold them to high expectations, and address their unique learning needs. My daughter is proof that when you hold students with dyslexia, and other specific learning disabilities, to high standards and support them with the tools they need to succeed, they are able to fulfill their goals and dreams. To this end, the Federal Government can support low-income families that have a child with a specific learning disability by ensuring that schools are held accountable for *all* students' academic outcomes.

The Federal Government can support public schools by investing in IDEA, the National Center for Special Education Research (NCSE), and in programs designed to support all students, including high quality early learning programs, teacher quality grants, the Comprehensive Literacy Development grants, and evidence-based initiatives. As the Federal Government works to reauthorize the Higher Education Opportunity Act, streamlining and simplifying the documentation requirements for obtaining disability services will ensure that every student, regardless of her parents' income, is able to receive the supports they need to thrive in college.

RESPONSE TO QUESTIONS OF SENATOR CASEY BY GUINEVERE EDEN, D.PHIL.

*Question 1.* Dr. Eden, I know the majority of your research focuses on K–12 age children, but in your experience, how does support for students with dyslexia and other learning disabilities change when those students attend college?

*Answer 1.* While younger children with dyslexia struggle primarily with difficulties in decoding, high school and college-age students with dyslexia often struggle with reading fluency and reading comprehension, and also have difficulties retaining what they have read. Often they also struggle with spelling accuracy, slower handwriting fluency, limited writing vocabulary, or lower working memory capacity, which in turn can lead to difficulties with writing. This means that although these students may have the same ideas as their non-dyslexic peers, college students with dyslexia are at a disadvantage when it comes to writing academic essays. The amount of reading and writing is significantly greater than what students experienced in high school, further compounding the difficulties in making the transition from high school to college. For those students who also have Attention Deficit Hyperactivity Disorder (ADHD), the challenge of sustaining concentration and sticking with a storyline may be especially difficult.

While dyslexia persists into adulthood, the support for students with dyslexia and other learning disabilities changes when those students attend college. The Individuals with Disabilities Education Act (IDEA), which applies to K–12, no longer applies in college, and as such, special accommodations, individual instruction, and alternative testing are no longer in place. There are no Individual Education Plans (IEPs). Instead, the Americans with Disabilities Act Amendments Act (ADAAA) applies, and while this can provide a student with accommodations, the student will no longer have access to the range of services that was available while in grades K–12. Importantly, the college student with learning disability has to make a concerted effort to obtain these accommodations, which requires identifying the appropriate office at the college, submitting the necessary materials (usually a professional evaluation), and from then onwards activating and re-activating the support services and/or accommodations available to them throughout their studies. The degree to which a student seeks the help to which they are entitled will vary greatly and depend on their own advocacy skills. The transition to the college comes with significant change, including a reduction/absence of prior support mechanisms (parents and teachers who previously advocated on their behalf) combined with a new perspective on a personal identity formed within this new environment, which may cause the student to disregard their learning disability. Critically, *the student* has to secure the services because the college does not have a mechanism by which to identify students with learning disabilities. The number of college students with learning disabilities has been increasing, and it is therefore important that these students are given the tools that allow them to select the college that suits them best and to advocate for their academic and other needs throughout their studies.

The advice that students with dyslexia and other learning disabilities receive at college will vary depending on the institution. Some may provide input to help students identify courses that are more compatible with their reading and writing challenges or to substitute required courses. There are some colleges that specialize in

teaching students with dyslexia, such as *Landmark College in Vermont*. The choice of the college and the efforts made by the student to attain the necessary accommodations and support once they attend that college will play a critical role in their ultimate success. Taken together, the support for students with dyslexia and other learning disabilities changes a great deal when those students attend college, and the experiences will vary widely depending on the student and the college.

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*Question 2.* As we think about how best to support students during the implementation of the Every Student Succeeds Act do students who have dyslexia also struggle with other skills (in addition to reading) as well? What does brain research show about the relationship between dyslexia and other learning disabilities?

*Answer 2.* Students who have dyslexia often also struggle with other skills. For example, dyslexia (also referred to as reading disability) often co-occurs with dyscalculia (also referred to as math disability). This co-occurrence (referred to as “co-morbidity”) is significantly higher than what would be expected by chance, leading researchers to study the cause of their connection. It has been shown that difficulties in both reading and math may arise from a common weakness in working memory, processing speed, and verbal comprehension. Studies have also shown that the same phonological processing skills that are needed to succeed in reading are also needed to succeed in math. That is, these skills are important for successful reading *and* math. Further, the severity of difficulties in these areas and their combination will likely influence the manifestations of a child’s reading and math impairments. As such, researchers are viewing reading disability and math disability not so much as discrete groups, but rather as multi-dimensional, viewing performance on these skills along a number of continua. From an educational and policy perspective, this means that a child may appear to be impaired on reading using a cut point on a given standardized test of reading, yet the same child may also have difficulty in math, but this weakness may not have been tested sufficiently, or the child may fall just short of the threshold used to determine the disability. Implementation of the Every Student Succeeds Act should therefore take into account that when difficulties are identified in reading, the chances are high that there are weaknesses in math even though these may lie below the surface. Interventions need to be identified in consideration of all of these difficulties.

Results from brain imaging research are consistent with this approach, showing that children diagnosed with dyslexia have less brain activity in left hemisphere brain regions associated with reading, and children with dyscalculia have less brain activity in right hemisphere brain regions associated with math. However, children with dyslexia also underactivate the left hemisphere for some arithmetic procedures, even though they do not meet a diagnosis of dyscalculia. This means that while they did not exhibit obvious difficulties in math on behavioral evaluation, especially in the context of their severe reading problems, they nevertheless show signs of aberrant brain function during some math tasks. Neuroscientists are also investigating brain regions that have a more general role, such as supporting working memory, that are critical to both math and reading, and that may be contributing to the difficulties more generally, rather than the brain regions associated specifically with just reading or math. The outcome of this work is likely to aid in determining avenues for intervention for children with these learning disabilities.

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[Whereupon, at 11:55 a.m., the hearing was adjourned.]

