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DYSLEXIA & CREATIVITY
*Transforming dyslexia from a liability to an asset.*

# "Decoding Dyslexia" Organized in New Jersey

## "Decoding Dyslexia" Organized To Promote Dyslexia Awareness and Support in Public Schools

### By Liz Attebery

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Recognizing the need to provide accurate, evidence-based information about dyslexia to parents, The Yale Center for Dyslexia & Creativity recently hosted a conference in New York City: "Decoding Dyslexia and YCDC Working Together to Make a Difference." Ideas and strategies for raising awareness and tackling legislation were shared among 47 Decoding Dyslexia parents representing 23 states. YCDC Co-Directors Drs. Sally and Bennett Shaywitz spoke on the important role this growing, parent-led grassroots movement can play in shaping future dyslexia policy and the necessity of solidifying a common message focused on accurate evidence-based definition, diagnosis and interventions. The energy in the room was palpable. This movement is gaining momentum!

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Exemplifying the formation of Decoding Dyslexia state organizations, in the fall of 2011, a group of New Jersey parents of dyslexic children, frustrated by the lack of services and support available to their children in the public school system, decided to take matters into their own hands by joining together to address the problem. The impetus for their decision came from a train trip nine parents took to New York City. Strangers when the trip began, they had bonded by day's end through shared stories of struggles and frustration over their inability to get their children the help they needed in school. Before long, they held their first meeting, publicizing it on a Web site dedicated to helping children with special needs. The response was tremendous. "It didn't matter what town the parents were from or what their economic status was," said one of the group's co-founders, Kathy Stratton. "We all started sharing our stories and realized the many similarities we had. We felt that banding together would be the best way to make systemic changes."

Decoding Dyslexia New Jersey (DDNJ) describes itself as "a grassroots movement driven by New Jersey families concerned with the limited access to educational interventions for dyslexia within our public schools. We aim to raise dyslexia awareness, empower families to support their children and inform policy-makers on best practices to identify, remediate and support students with dyslexia in New Jersey public schools."

A major milestone in the growth and influence of DDNJ resulted when a busload of members, at the suggestion of Dr. Sally Shaywitz, co-director of The Yale Center for Dyslexia & Creativity, traveled to Washington, D.C., in spring 2012 to urge their Congressmen to join the Congressional Bipartisan Dyslexia Caucus. "We met in groups of three or four with 10 different New Jersey congressmen or their aides, told them our stories and our mission, and explained how it could apply on a federal level," said Stratton. "Eight of the congressmen joined the Caucus," she said. "Before that, not one New Jersey congressman had joined. It was a very successful and fulfilling trip."

Andy Kavulich, a founding member, describes his role in DDNJ as one of advocacy, awareness, and "sharing our story and our journey. The more we tell our stories, the more we can bring about change," said Kavulich, who participated in the Washington trip. He has had personal experience with the refusal of the educational establishment to recognize dyslexia. After watching his daughter struggle in school as a first-grader, he and his wife read everything they could about dyslexia, focusing particularly on Sally Shaywitz's book, Overcoming Dyslexia. When the daughter was diagnosed as dyslexic, Kavulich told the special services director in charge of special education in his district. His reply: “Dyslexia doesn’t exist in this district.” Kavulich testified to the Education Committee about the incident, saying it was like “getting a punch in the stomach, but that it also drives me to keep working to increase awareness of dyslexia and try to change educational policy so that it makes it better for these kids and their parents.”

Another founding member of the New Jersey group, Deborah Lynam offered her perspective . “There were so many other parents that it was exciting,” she said, “because we had never elicited such positive feedback before.” Lynam is the mother of three sons, two of whom are dyslexic and separated by six years. While the older boy was able to overcome his reading problems and take honors courses in high school, she lost precious time trying to get appropriate educational support for her younger son, who mixed up sounds and struggled with reading, spelling, and mathematical computation. The combination of teachers not trained in educating dyslexic students, and the method of teaching reading through a whole language program, a sight-based learning program with little systematic phonics instruction, put him considerably behind his peers. While he is now making good progress, and his school district has improved, Lynam said the local schools do not offer a balanced literacy program.

An integral part of the DDNJ mission is the group’s Web site, written and managed by Elizabeth Barnes, one of the founding members and the mother of an 11-year-old daughter with dyslexia. The site contains a wealth of information, ranging from the definition and identifying characteristics of dyslexia to books, articles, and films about the disorder; announcements of meetings, dyslexia-related conferences, and parent workshops; and instructions on contacting state senators and representatives to solicit their support of bills pending in the New Jersey Assembly and Senate. Barnes also manages the DDNJ Facebook page, which enables parents to network with others locally and nationwide. She says that DDNJ movement has expanded from eight founding members to 20 active participants and a statewide network of individuals taking small actions every day to help the cause.

What makes Decoding Dyslexia New Jersey work so well, according to Stratton, is mutual support among members and the lack of a hierarchy. “DDNJ is very targeted in its mission,” she said. “We have tasks and action items, but there are no officers. We all support one another’s ideas and efforts. There’s no jostling for ideas and there’s no ego in the group. If one person can write a letter and another can attend meetings, we’re very appreciative. Everyone contributes in his or her own way.”

Among those benefiting are Stratton’s 17-year-old son Brian Meersma, whom she describes as “severely dyslexic.” Brian is on the national advisory board of Bookshare, an online accessible library for people with print disabilities. By using Bookshare, Learning Ally, and other forms of assistive technology, Brian has become an outstanding student and an inspiration to others who struggle with dyslexia. Brian also shares his knowledge of assistive technology with others through presentations to parents, students, and educators, and through a blog featuring information on current products and trends.

DDNJ has spawned similar groups in 24 states and receives inquiries from interested parents in other states all the time. “We put out a manual on how we formed our group and how others could do the same and we publicized it on the Net,” said Stratton. “People come to us all the time for ideas and help.” “It’s exciting, but also overwhelming,” said Lynam, “because people often look to us to provide leadership. We let them understand that we’re not leaders; we’re just parents who are doing the work that they need to do in their own states.”

Recently, the group played a key role in another success story: the approval of several dyslexia-related bills by the Education Committee of the New Jersey Assembly in Trenton. Adding dyslexia to the special education code, as required in one of the bills pending in the New Jersey Assembly, is crucial, said Barnes recently. “If we get it in there, schools can’t tell us it doesn’t exist anymore.” Right now, dyslexia is included under the classification of “specific learning disabilities.”

Members of DDNJ credit fellow New Jerseyan Beth Ravelli with laying the groundwork for the progress made so far in bringing about positive change for students with dyslexia. When her daughter was in third grade and unable to read, Ravelli began working with local legislators to establish a Reading Disabilities Task Force to aid in the diagnosis, treatment, and education of children experiencing reading difficulties. The Task Force is now a reality and Ravelli’s daughter is a high school student with solid reading skills and plans to pursue a college degree.

While Ravelli is not part of DDNJ, the group has been a major supporter of her efforts. “Over 130 members turned out to attend the Task Force public hearing,” said Stratton. “There were multiple people and groups working in concert with one another, which is really nice. It was the recommendations of the Task Force,” she said, “that led to the writing of the recent bills.”


DD-NJ with Dr. Shaywitz, at Decoding Dyslexia conference

When asked her reaction to the successes in Trenton, Lynam said that in addition to the 12 people who testified at the Education Committee hearing, dozens submitted testimony and all of the DDNJ members called and wrote letters in support of the proposed bills. “When we wanted the parents of New Jersey to come through for us they did," she said, "but even if the bills become law, what really matters is how those laws are implemented. There needs to be a lot of follow-up, with integrity and fidelity." So is DDNJ on the home stretch? "No," said Lyman. "It's just the beginning. This is not about just one or two students. There's a real systemic problem in the public schools."

**All photos credit DD-NJ**