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Leveraging brain science for impactful advocacy and policymaking: The synergistic partnership between developmental cognitive neuroscientists and a parent-led grassroots movement to drive dyslexia prevention policy and legislation

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ABSTRACT

Reading proficiency is crucial for academic, vocational, and economic success and has been closely linked to health outcomes. Unfortunately, in the United States, a concerning 63% of fourth-grade children are reading below grade level, with approximately 7%–10% exhibiting a disability in word reading, developmental dyslexia. Research in developmental cognitive neuroscience indicates that individuals with dyslexia show functional and structural brain alterations in regions processing reading and reading-related information, with some of these differences emerging as early as preschool and even infancy. This suggests that some children start schooling with less optimal brain architecture for learning to read, emphasizing the need for preventative education practices. This article reviews educational policies impacting children with dyslexia and highlights a decentralized parent-led grassroots movement, Decoding Dyslexia, which centers the voices of those directly impacted by dyslexia. It utilizes civic engagement practices, advocacy and lobbying on local, federal, and social media platforms, and strong partnerships with scientists to drive systems-level change in educational practices, leading to dyslexia prevention legislation across the U.S. The ongoing partnership continues to address the profound gaps between scientific findings and policymaking to drive systems-level change for contemporary challenges in educational practices within a learning disabilities framework.

1. The dyslexia paradox

Every child has the right to learn to read well. Proficiency in reading plays a vital role in achieving academic, vocational, and economic success and has also been closely linked to health outcomes (Irwin et al., 2007). In the United States, a concerning 63% of fourth-grade children are reading below the expected grade level, with approximately 7%–10% being identified with a disability in word reading, termed developmental dyslexia. Many of these children go unnoticed within the educational system for several years until they experience repeated challenges with learning to read. This delayed recognition can have detrimental effects on a child's overall long-term development. In addition to persistent academic struggles, difficulty learning to read often significantly impacts other aspects of a child's life, such as social-emotional development and mental health. For example, challenges in learning to read have been associated with a higher risk of developing anxiety and depression and increased externalizing behaviors such as peer aggression (Dahle and Knivsberg, 2014; Hendren et al., 2018; Mugnaini et al., 2009).

Furthermore, the level of education an individual attains is heavily influenced by reading proficiency and serves as a crucial predictor of overall health and longevity (Johnston, 2019; Vernon et al., 2007). Individuals with dyslexia are less likely to pursue postsecondary education programs (Horn et al., 1999) and more prone to involvement in the criminal justice system (Moody et al., 2000). Reports indicate that up to 75% of incarcerated individuals lack high school completion and/or exhibit low literacy skills (National Center for Education Statistics, 2014). Moreover, incarcerated individuals who engage in educational programming within the justice system are less likely to re-offend upon release (Davis et al., 2013). On a broader scale, the U.S. Department of

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Labor estimates that illiteracy imposes a substantial cost of approximately $225 billion per year on the American economy due to lost human productivity. It has been projected that elevating all adults in the U.S. to the equivalent of a sixth-grade reading level could boost the Gross Domestic Product by 10%, equivalent to around $2.2 trillion (Rothwell, 2020).

Given these detrimental numbers and the fact that the number of struggling readers nationwide has remained unchanged over decades, (National Center for Education Statistics, 2022) a preventative approach to reading disabilities should be a priority for all stakeholders, including caregivers, educators, and especially policymakers. However, when it comes to learning differences, including dyslexia, for decades, educational systems were primarily focused on a reactive, deficit-driven, "wait-to-fail" model instead of on the development and implementation of preventive approaches (Ozernov-Palchik and Gaab, 2016; Ozernov-Palchik et al., 2016; Gaab and Petscher, 2022). Consequently, children's reading difficulties often go unrecognized until late elementary school, and in many cases, even later or never (Ozernov-Palchik and Gaab, 2016). To date, dyslexia is generally diagnosed after the most effective time for intervention has passed, which can be termed the "dyslexia paradox". (Ozernov-Palchik and Gaab, 2016) This reactive approach poses significant challenges. Up to 70% of below-average readers in first grade continue to struggle academically through eighth grade, and children identified with a reading disability in second grade rarely catch up without intensive intervention (Landerl and Wimmer, 2008; Shaywitz et al., 1999; Juel, 1988; Torgesen, 1997). Additionally, children facing reading difficulties in the third grade are more likely to encounter ongoing challenges throughout their educational journey (Francis et al., 1996). Early identification is crucial because interventions are considerably more effective when implemented in kindergarten or first grade (Torgesen, 1997). According to Wanzek and Vaughn (2007), (Wanzek and Vaughn, 2007) word reading interventions yield significantly better results when administered in early compared to late elementary grades.

The increased effectiveness of interventions in 4–6-year-olds can be attributed to several factors. One factor has been illustrated by several studies reporting that narrowing the gap between poor readers and proficient readers becomes more challenging in the higher grades of elementary school (Shaywitz et al., 1999; Juel, 1988; McNamara et al., 2011). Another factor has been grounded in brain research, primarily in the fact that the brain is highly malleable and plastic in young children, especially when it comes to oral language development, which serves as the foundation for subsequent reading acquisition. Brain research focusing on the developmental trajectories of typical and atypical language and reading development has been fundamental to the synergistic partnership between developmental cognitive neuroscientists and Decoding Dyslexia, a parent-led grassroots movement. By utilizing scientific evidence, including results from developmental cognitive neuroscience, grassroots organizations such as Decoding Dyslexia developed evidence-based advocacy strategies on behalf of children with dyslexia and reading disabilities which subsequently led to the passage of many dyslexia policy legislations across the U.S.

2. The typical and atypical reading brain

The act of reading is a cultural invention with a history dating back approximately 5400 years (Wolf, 2008). Given its relatively recent emergence, it is highly unlikely that specific brain regions or neural mechanisms evolved exclusively for reading (Wolf, 2008; Dehaene, 2004). Instead, it has been hypothesized that brain regions or mechanisms originally developed for other perceptual and cognitive functions were repurposed to accommodate reading, often termed the "neuronal recycling" hypothesis (Dehaene, 2004). Over many years, research within the field of developmental cognitive neuroscience has shown that proficient reading is predominantly supported by left hemisphere brain areas, as evidenced by research in both children and adults (Ozernov-Palchik and Gaab, 2016; Ozernov-Palchik et al., 2016; Martin et al., 2015). These areas include the inferior frontal cortex, responsible for phonological and semantic processing of words; the temporoparietal cortex, crucial for grapheme-phoneme conversion; as well as the occipitotemporal cortex, essential for letter and whole-word recognition (Eden et al., 2016). For individuals with dyslexia, research has consistently revealed structural and functional atypicalities in these brain regions that process reading and reading-related information (Ozernov-Palchik and Gaab, 2016). Specifically, in reading-related brain areas, reduced gray matter volume, (Richlan et al., 2013) hypoactivation observed in response to reading-related functional magnetic resonance imaging (fMRI) tasks, (Richlan et al., 2011) and weaker functional connectivity (Martin et al., 2015) have been reported in individuals with dyslexia compared to peers without reading challenges. Additionally, white matter tracts connecting these brain regions have displayed atypicalities; notably, reduced microstructure has been consistently observed in the left arcuate fasciculus (AF) as well as the superior longitudinal fasciculus (SLF) and inferior longitudinal fasciculus (ILF) (Vandermosten et al., 2012a). Interestingly, these differences have been reported regardless of the children's general cognitive abilities, (Tanaka et al., 2011) supporting the discontinuation of the discrepancy model, a widely used diagnostic model that allowed a dyslexia diagnosis only if an individual shows a discrepancy of one standard deviation between their reading ability and general cognitive abilities (e.g., an I.Q. measure) (Fletcher et al., 1994).

3. Brain characteristics of dyslexia in preschoolers and infants

Despite a vast body of research outlining atypical brain characteristics in individuals with dyslexia, for many years it remained unclear if the observed structural and functional atypicalities in reading-related brain regions are (a) the underlying cause of dyslexia, (b) the result of the daily struggles with learning to read, or (c) a consequence of reduced reading experience that often accompanies reading difficulty. To start answering these questions, research has employed reading-level-matched designs, which compare a cohort of children with dyslexia characterized by low reading scores for their grade to younger children who exhibit similar reading levels than the children with dyslexia but whose scores are considered on grade level. For example, a study indicated that children with dyslexia displayed similar reductions in activation of left temporoparietal and occipitotemporal regions, as well as reductions in gray matter volume in the left temporoparietal cortex when compared to both children of the same age and those matched for reading level (younger by 2–4 years) (Hoeft et al., 2007). This observation was reinforced by another study demonstrating atypical gray and white matter morphology shared among children with various types of reading disabilities (e.g., poor comprehension, poor decoding), suggesting that distinct reading experiences within the realm of reading impairments do not alter the neural foundations of reading disability (Eckert et al., 2017). In summary, these findings suggest that brain atypicalities reported for children with dyslexia indicate fundamental structural and functional differences in brain regions specific to reading.

While these findings were important for understanding that children with dyslexia are not just delayed in maturation, which implies that they may eventually catch up without any intervention, it remained unclear if these brain atypicalities observed in elementary school represent a (neuro)biological predisposition that is already present in preschool-age children prior to the onset of formal reading instruction, possibly emerging as early as infancy.

To answer this open question, we conducted a series of cross-sectional and longitudinal studies in children prior to the onset of reading instruction, as did other laboratories around the globe (see overview in (Ozernov-Palchik and Gaab, 2016)). Importantly, these studies oversampled children with a familial risk for developing reading difficulties to examine atypical and typical developmental trajectories with sufficient sample sizes. Family studies suggest that dyslexia is strongly heritable, occurring on average in 45% of children with a first-degree relative with dyslexia (Snowling and Melby-Lervåg, 2016). We demonstrated that the hypoactivation in key regions of the reading network during phonological processing, as previously observed in school-age children and adults with dyslexia can be detected in preschoolers with a familial risk of dyslexia (FHD+) prior to reading onset (Raschle et al., 2012). Similarly, FHD+ children compared to preschoolers without a familial risk of dyslexia (FHD-) exhibited reduced gray matter volume indices in left occipito-temporal and temporo-parietal regions and the left fusiform gyrus. Furthermore, activation and gray matter volume indices in these key regions correlated positively with pre-reading skills (Raschle et al., 2011). Using diffusion tensor imaging (DTI), FHD+ children exhibited reduced fractional anisotropy (FA) in the left arcuate fasciculus, a main tract connecting posterior and anterior parts of the reading network at pre-, beginning, and fluent reading stages (Wang et al., 2017). Although FHD+ status leads to a heightened risk, we observed that the rate of FA development within the arcuate fasciculus measured longitudinally from kindergarten to mid-elementary school was faster for subsequent good versus struggling readers regardless of their familial risk status (Wang et al., 2017).

While it has been demonstrated that preschool-age children at risk for dyslexia exhibit atypicalities in both brain function and structure, it remains unclear whether these atypicalities arise from 1) atypical brain development starting in utero most likely influenced by susceptibility genes, 2) atypical brain development over the first few years of life in interaction with language development and likely influenced by environmental variables, or 3) a combination of both factors. Infant and toddler neuroimaging has gained increasing attention for insights into early brain development and the neurodevelopmental origins of typical and atypical development and may be a more reliable measure than infant behavior which can be hard to measure and often unstable (Turesky et al., 2021). These studies have also supported the notion of early atypical brain development in infants and toddlers with a familial risk for developing reading difficulties, including dyslexia, and those with no risk but who subsequently develop atypical reading skills (Molfese, 2000; Lyytinen et al., 2005; Guttorm et al., 2005; Zuk et al., 2021a). For example, several studies have reported atypical neural responses to basic speech sounds in FHD+ newborns/infants (Guttorm et al., 2005, 2010, 2001; Lyytinen et al., 2015, 2004a, 2004b) and in newborns/infants later characterized as having dyslexia and poor reading abilities (Molfese, 2000; Lyytinen et al., 2004a; van Zuijen et al., 2013; Leppänen et al., 2012). Neural responses to basic speech sounds in infants have also been linked to later language/reading development in toddlerhood and elementary school, but these brain-behavior relations varied depending on FHD classification (Guttorm et al., 2005; Leppänen et al., 2012; Lyytinen et al., 2004c). Furthermore, using a support vector machine classifier, distinguishing patterns of functional connectivity in the left fusiform gyrus between FHD+ and FHD- infants were observed in our laboratory (Yu et al., 2022). We also showed that some of the previously observed white matter alterations in the left arcuate fasciculus (Wang et al., 2017; Steinbrink et al., 2008; Hasan et al., 2012; Vandermosten et al., 2012b) in individuals with dyslexia can be detected in FHD+ compared to FHD- infants (Langer et al., 2017). Further bolstering the importance of early brain structure and function to subsequent reading development, we showed that both functional connectivity and white matter organization in left temporo-occipito-parietal regions in infancy predicted language outcomes five years later (Zuk et al., 2021a; Yu et al., 2021). Overall, these studies have suggested that some of the differences in left-hemispheric brain structure and function which are characteristic of dyslexia can be observed before the start of reading instruction and may therefore represent a (neuro)biological predisposition likely linked to atypical brain development as early as in infancy. In essence, these neuroimaging studies could show that some of these brain differences are present before a child begins learning to read and may start to develop as early as infancy. This implies that some children who will struggle to learn to read most likely start their first day of formal schooling with a brain architecture that is less optimal for learning to read than that of their peers, which underlines the importance of early identification and intervention to ensure successful reading acquisition.

4. The role of science in policymaking in education

Although neuroimaging research has been invaluable in establishing the biological basis of dyslexia and other reading difficulties, neuroimaging technology does not have the ability to screen or diagnose dyslexia on an individual level, nor is it likely that this will be the case in the future. Furthermore, many research studies have shown that the neural correlates of reading develop in interaction with environmental influences, including variables such as the home literacy environment or the socioeconomic background of the child's family (Turesky et al., 2022; Powers et al., 2016; Ozernov-Palchik et al., 2019; Torppa et al., 2022). At this time, it is impossible to fully disentangle genetic, neurobiological, and environmental factors influencing typical and atypical reading development. That said, many behavioral studies using longitudinal design have established behavioral precursors of typical and atypical reading acquisition starting in preschool. It is important to note that previous endeavors to characterize dyslexia through a singular deficit lens proved unsuccessful. Instead, most researchers have embraced a multi-factorial etiology with various genetic, neurobiological, and environmental risks interacting with protective factors, resulting in distinct profiles along a continuum of severity of reading outcomes (Ozernov-Palchik et al., 2019; Catts and Petscher, 2021). Many studies examining potential behavioral risk factors in children prior to the onset of formal schooling have been identified (Landerl et al., 2013; Elbro et al., 1998; Scarborough, 1998; O'Connor and Jenkins, 1999; Lyytinen et al., 2001; Catts et al., 2001, 2015; Pennington and Lefly). These include measures of oral language, print knowledge, and more general cognitive-linguistic factors. Nevertheless, behavioral measures in young children can often be unstable. Brain imaging can provide a more objective measure and is often less susceptible to explicit and implicit biases. Furthermore, the brain areas, tracts, and networks that subserve reading develop long before preschool and school-age, with the most rapid development in infancy. Studies examining the development of and potential differences in pre-reading measures (e.g. phonological processing) in infancy are scarce and often lack longitudinal designs. Previous work, including ours, has repeatedly shown associations among infant brain features, early longitudinal trajectories of brain structure/function, and subsequent reading outcomes (Yu et al., 2021; Zuk et al., 2021b; Wang et-al.). It is important to note that while we expect that understanding early brain mechanisms and trajectories has the potential to inform early identification and intervention in the future (e.g., windows of neuroplasticity or increased growth, or the identification of more/less optimal time windows for intervention) it should not be suggested that brain correlates can be used for directly identifying children at risk or tailoring interventions to specific brain mechanisms.

Furthermore, while behavioral studies demonstrated ways to identify at-risk children early, scientific evidence highlighting the need for a preventative approach had previously been largely ignored by policymakers, state agencies, and school districts (Torgesen, 1997). Most of the implemented policies addressing struggling readers were designed within a "wait-to-fail" model, reinforcing the reactive approach in classrooms, namely the identification of children who already exhibit profound reading challenges. This is frustrating and counterproductive, especially given the fact that both the final report of the National Reading Panel (Adams et al., 2000) published in 1999 and the National Research Council report (National Research Council, 1998) published in 1998 concluded that in many cases, reading difficulties could be prevented with early identification and intervention (e.g., by identifying children at risk rather than children who already struggle) (Lyon et al., 2001). In order to understand why brain and behavioral research on reading development has often been neglected by policymakers, one needs to understand the history of policymaking in the field of education. It is important to recognize that political and educational policymakers at the federal, state, and local levels often lack a solid comprehension of the potential role that scientific evidence can play in developing and implementing education policies. While scientific research is widely acknowledged as essential in various policy domains, such as public health or agriculture, education has traditionally been perceived as more value-driven and reading instruction has its roots in other fields such as sociology. In this context, primary policy input has historically been derived from politicians and diverse special interest groups rather than education scientists. Despite amalgamated influences of groups grounded in sociology, social justice, or civil and disability rights, and possibly because reading is so critical to social and economic policies, many assumptions unsupported by science have influenced educational policy. That said, scientific evidence has been hard to access for stakeholders involved in policymaking, given the paywalls of academic publishing and the incorrect assumption that the local Alderman or Representative are somehow accessing the conclusions and recommendations of the latest peer reviewed studies within the field of reading research. Consequently, education policies have predominantly emerged within a political framework rather than a scientific one. Given these barriers, one can conclude that outreach efforts by scientists are necessary to be a catalyst for change but that these outreach efforts need to contain much more than the usual efforts that often are limited, in the case of neuroscientists, to bringing a brain to a preschool classroom and teaching young kids how to use a helmet.

In summary, education policy, like other political endeavors, has historically been influenced by diverse interest groups with varying perspectives. Scientists trying to impact the field of education will be most effective by recognizing the interest groups and policymakers and targeting outreach to those most invested in the process. That said, despite the ongoing significant influence of political input on education decision-making, as education and its policies inherently involve politics, there has been a noteworthy increase in the utilization of scientific evidence in shaping national reading policies. In 2005, reading researchers Reid Lyon, Sally and Bennett Shaywitz, and Vinita Chhabra (Lyon et al., 2005) wrote a paper outlining recent advances toward more evidence-based reading policies in the United States and how scientific research should inform instructional practices. Specifically, they state,

> "Over the past decade the root of certain education policies in the United States has shifted from philosophical and ideological foundations to the application of converging scientific evidence to forge policy directions and initiatives. This has been particularly the case for early (kindergarten through third grade) reading instructional policies and practices. The use of scientific evidence rather than subjective impressions to guide education policy represents a dramatic shift in thinking about education. Some education policy initiatives in the United States now reflect a reliance on findings from rigorous scientific research rather than opinion, ideology, fads, and political interests. Advances in brain imaging technology now make it possible to provide evidence of the impact of scientifically informed reading instruction on brain organization for reading" (Lyon et al., 2005; direct quote page 1).

5. Education policy initiatives addressing 'reading difficulties'

Historically, there have been laws designed to address learning disabilities within educational settings in the U.S. In 1969 the Children with Specific Learning Disabilities Act was enacted mandating support services for students with learning disabilities for the first time. Subsequently, we saw the Education for All Handicapped Children Act of 1975, which guaranteed a free, appropriate public education (FAPE) to children with disabilities in every state and locality across the country. While these early laws were important milestones of disability advocacy, scientific evidence was largely ignored in the early policymaking process. However, since the 1990's, federal Education Policy initiatives have started to slowly embrace reading research and engage scientists and experts for guidance. This started with the "Preventing Reading Difficulties Committee" of the National Research Council of the National Academy of Sciences, which was followed by the "National Reading Panel" (NRP) formed at the request of Congress in 1997. Together these provided some of the informational backdrop for the policies addressing "reading" and "reading disabilities" developed since the late 1990's, such as the Reading Excellence Act in 1998 and the Individuals with Disabilities Education Act (IDEA) of 1990, reauthorized in 2004. The Report of the National Reading Panel, in April of 2000, was particularly influential for passing the No Child Left Behind Act in 2002, which included the Reading First and Early Reading First legislation both based on the Report of the National Reading Panel (Adams et al., 2000). More recently, the Every Student Succeeds Act (ESSA) replaced the No Child Left Behind Act (NCLB) in 2015 and is now the main federal law for K-12 general education. In contrast to ESSA, which covers all children in K-12, the Individuals with Disabilities Education Act is a federal education law designed to find and evaluate students with disabilities in K-12. Under IDEA, schools find students eligible in one or more of 13 categories and provide access to instruction designed to meet the child's individual differences and needs (special education) and/or additional access to related services (e.g., speech therapy, and early identification and assessment of disabilities; IDEA Sec. 300.34, (U.S. Department of Education) accommodations, or assistive technology). However, despite the fact that all these policies and laws were designed to find children with disabilities, they have largely been elusive for reading because of the prevailing assumption in educational settings that you cannot determine reading disability/dyslexia risk until you have been exposed to reading instruction. As a result, IDEA policies, with respect to reading, in practice often only 'find' children who already struggle and who, if identified with a disability, then receive Free Appropriate Public Education (FAPE) through a formal Individual Education Plan (IEP). Newer policies such as Response to Intervention (RTI), which was introduced in the 2004 reauthorization of IDEA, or the more expanded policies introduced under ESSA to improve student outcome for all learners such as the multi-tiered system of supports (MTSS) are designed to prevent learning disabilities but, in practice, these policies are often implemented poorly on the local level, lack a focus on multifactorial factors identified by science, and often delay high-quality interventions (Reynolds and Shaywitz, 2009). More specifically, evidence-based reading curricula and products are essential to deliver high-quality instruction for developing reading skills in general education settings but do not replace the specific specialized instruction for students with an IEP under IDEA for reading disabilities. Special Education reading services are expected to be part of a Comprehensive Literacy Plan as defined in ESSA and IDEA. While many schools have MTSS, this system cannot be used to delay or deny an IEP for students with suspected disabilities (see (U.S. Department of Education, 2023)). Furthermore, it is important to state that a close alignment between general education curricula and intervention strategies lead to better outcomes (Stevens et al., 2020).

To summarize, there is no doubt that previous behavioral research studies have significantly impacted policymaking related to reading, and current policies contain definitions and terminology taken directly from the NRP. These definitions and terminologies are accepted by Congress and written verbatim or summarized in laws NCLB, ESSA, laws for adult literacy, and in IDEA. They are referenced in legal cases and continue to guide policy on the federal, state, and local level. However, the focus has been primarily on remediating children who already qualify for specialized instruction based on IDEA. There has been less emphasis on the important questions of *why* some children have difficulty learning to read despite high-quality instruction and *how early* at-risk children can be identified, but these questions can inform the design of early identification and intervention methodologies. This is where research grounded in developmental cognitive neuroscience has its impact.

It is important to note that the federal structure of the United States leaves maintenance, operation, and decision-making for public schools (e.g., for educational teaching methods and instructional material), to the state, who then may defer it to local government. While congress does enact laws to govern equal protection or equal access to state or local education and can spend money to assist states in their obligations, it is restricted in how it can influence policies. Not surprisingly, parents and caregivers nationwide report that these laws are often not enforced on the local or even State level, especially not when it comes to invisible and misunderstood learning disabilities such as dyslexia.

6. Decoding dyslexia as a grassroots movement

As a direct result of the lack of support children received under these laws in their local school districts, a parent/caregiver-led grassroots movement started in New Jersey in 2011 and spread across the U.S. highlighting the legal obligations of "Child Find", a mandated part of IDEA that obligates the State to enforce and the local districts to provide a means of early identification of students with disabilities. This group, Decoding Dyslexia, is a decentralized group centering the voices of the people who are impacted by dyslexia and other reading disabilities (Ward-Lonergan and Duthie, 2018). It has 52 chapters in all 50 states, the District of Columbia, some Canadian Provinces, and Bermuda, as well as a chapter for military families (Fig. 1). Its members raise awareness of dyslexia through social media and local events and lobby state and federal legislators. Decoding Dyslexia has been the force behind state legislation related to dyslexia policy and early dyslexia screening mandates in all 50 U.S. states (see map here: https://improvingliteracy.org/state-of-dyslexia), and numerous journalistic articles have highlighted their success (e.g., TIME Magazine) (Luscombe, 2019).

The overall structure of Decoding Dyslexia across North America follows a bottom-up rather than top-down approach. Chapters for each state or region formed (or will form) locally, inspired by already established chapters and primarily through social media. There is no formal organizational structure, and the leadership is collaborative and flexible. Only three states are official 501(c)3 nonprofit organizations with a board to organize the Chapter. Other states are run as private organizations with a few co-founders and leaders with a publicly engaged following. Each Chapter generally has 3–5 state leaders assigned to a National Leadership Network. These leaders organize lobbying visits to Washington, DC ("Hill Days") and collaborate with the International Dyslexia Association, Understood.org, the National Center for Improving Literacy, and many other organizations and stakeholders. The connections can vary from state to state, but chapters often benefit from the strengths of others in the broader network. It is important to realize that one challenge of educational policy is that each State has its own educational culture and influencers in policy and in the public eye, as well as norms of traditions at play in the politics of policy for education.

Decoding Dyslexia Massachusetts was founded in 2012/2013. Its establishment was inspired by the initial Decoding Dyslexia New Jersey group which had shared a handbook and started connecting with state legislators in New Jersey. Decoding Dyslexia MA began to use social media as an outreach tool in 2013 with a first Facebook message that stated: "You have no idea what you are capable of until you try. – Unknown." Initially, the group leveraged the opportunity to engage with highly respected neuroscience labs that had established a presence and reputation in the dyslexia community through, for example, families participating in the lab's research studies or outreach efforts (e.g., conferences for parents and educators, presentations to Special Education Parent Advisory Councils in MA school districts). This was a priority for the Decoding Dyslexia Chapter in Massachusetts because local MA-based Higher Education institutions and teaching hospitals carry weight in households and at the MA state House. It was an obvious goal for Decoding Dyslexia Massachusetts to work, collaborate, and engage with local research experts in the field. However, not one university or teaching hospital is the go-to policymaker in MA. Some of the other state chapters' approaches were similar, while others had to develop new strategies. For example, Virginia Decoding Dyslexia leaders knew that connections to The University of Virginia (UVA) would enable them to get the ear of policymakers and that any policy change would be highly

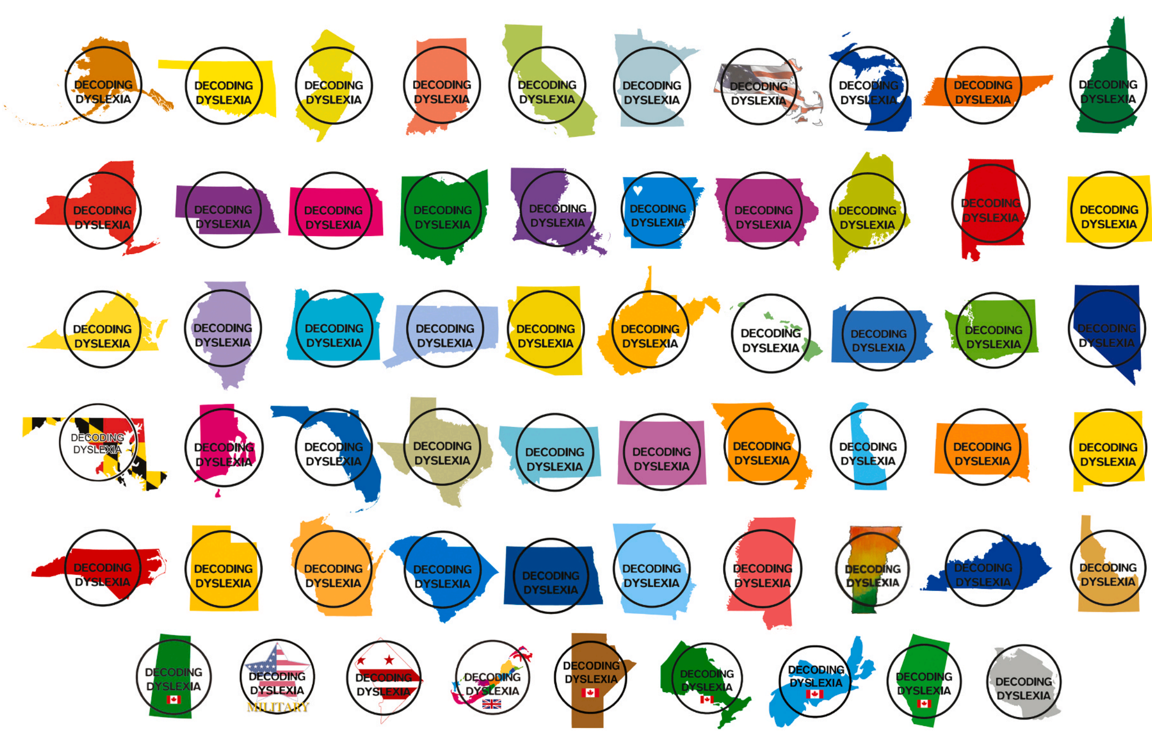

Fig. 1. Logos representing Decoding Dyslexia chapters.
Figure by Nicole Mitsakis and Deborah Lynam, Decoding Dyslexia Leadership Network

dependent on UVA support. Many other states did not have the "local" scientists on the team because there was no research or expert connection to make. For example, Decoding Dyslexia Alaska struggled to find experts as speakers to testify for their advocacy. In Alaska, Decoding Dyslexia's strength lay in skilled dyslexia practitioners and informed parents. The Alaska chapter engaged leaders from the Massachusetts and Arkansas chapters to attend their state hearings, enabling them to show that very different states had similar incarnations of the same problem. Each Chapter leverages its own network for the best state-level policies of engagement and advocacy. The Decoding Dyslexia leaders from New Jersey, Maryland, Virginia, Massachusetts, Texas, and Pennsylvania had physical proximity and/or strong legislative connections to participate in and plan events in Washington D.C. and unified group lobbying involving many Decoding Dyslexia chapters took place as early as 2014 and started to get some traction in 2015. The Dyslexia Guidance released by the Office of Special Education and Rehabilitation Services (OSERS) in October 2015 was the affirmation advocates needed to continue, despite the costs of personal time, energy, and funds to create change in education for students with dyslexia. Overall, one can summarize that the structure of Decoding Dyslexia was responsive to the way that policy evolves in the U.S. and partnerships with researchers provided the necessary knowledge base for the advocacy and policy work.

Today, Decoding Dyslexia Massachusetts maintains a strong and close partnership with local developmental cognitive neuroscientists, reading researchers, and developmental psychologists. Together, they ensure that the knowledge of scientific advances arrives at the Massachusetts State House and other state legislatures across the country through advocacy and direct engagement in the political process. This partnership is especially important because policy should be made centering the voices of the people who are impacted and many scientists in these fields do not have the lived experience of people facing adversities related to learning disabilities, and therefore should not inform or drive policies without considering how these policies affect individuals with learning disabilities and their families.

7. Bridging science, advocacy, and policymaking

Following decades of well-intentioned federal initiatives that still failed their children and employing the collective communication power of the internet and social media, parents of struggling students started to collaborate, initially to help their own children and later to seek systemic change. Parents/caregivers across the country, mainly organized under local Decoding Dyslexia groups, summarized and shared the scientific knowledge gained through reading research including (developmental) cognitive neuroscience and built a large grassroots initiative to improve reading outcomes. This unprecedented movement pushing for educational policy reform worked to connect parents/caregivers, researchers, and policymakers on the national, state, and local levels. Without funds or fundraising, this grassroots effort convinced the federal government to issue Dyslexia Guidance in 2015 (Yudin, 2015). By 2022, nearly every state had adopted some dyslexia policy. What did these parents and caregivers have that enabled such a powerful shift in educational policy? Parents and caregivers embraced scientific evidence and closely collaborated with researchers across various disciplines. As a result, a palpable shift in general education and in reading instruction for all students is now happening across the country. Utilizing results from educational science, developmental psychology, (developmental) cognitive neuroscience and other disciplines, often summarized as "the Science of Reading", helped to emphasize to legislators that learning differences are often not identified until childhood, but diverging trajectories of brain development may be present as early as infancy and therefore that children need to be identified early to prevent detrimental academic, mental health, vocational, and economic outcomes. The push towards 'preventative education' approaches has not only impacted early identification of at-risk children, they also have been shown to inform instructional and intervention approaches and can prevent academic and psychosocial harm caused by reading difficulty.

This success story is focused on reading disabilities and most specifically on dyslexia. To apply similar models to other policy areas, one needs to understand how Decoding Dyslexia has been so successful and how partnerships between parents/caregivers and researchers were formed. These parents/caregivers, as activists and often with previous experience in civic activity, understood that policy for education is very difficult to drive from the top and that local control of school budgets and decisions for policies are passed by local political policy makers, the town/city, and in some places, citizens vote in town meetings. Although schools in this millennium are often million-dollar enterprises and have expanded their service offerings from breakfast and lunch to academic, social-emotional, and even mental health services and further account for an average of 1/3 or more of a local budget, its policies are still determined through local town meetings and school committees. School Boards or Committees are locally elected officials who rely on the professionals in the schools to inform and guide the process. Parents and community members are the constituents of the Boards/Committees as the schools serve their children. Many members of Decoding Dyslexia have experience with civic engagement and know that district advocacy is essential. They use whatever political levers they can to impact district, state, and federal policy. They also realized that science can provide a powerful tool in the advocacy process, especially given the more recent shift to more evidence-informed policymaking in education.

As stated above, the partnership between Decoding Dyslexia Massachusetts and local reading researchers, including developmental cognitive neuroscientists, started with Decoding Dyslexia reaching out to local researchers in the Boston area. They did this by organizing meaningful lobbying opportunities such as going to the Massachusetts Institute of Technology to raise awareness as part of highlighting the Proclamation for Dyslexia Awareness Months (sponsored by every Massachusetts Governor since 2012), lighting up the Zakim bridge in Boston in red for dyslexia awareness month, planning Statehouse lobbying visits with affected families, or coordinating participation in public hearings for bills affecting systemic change at the state level. Furthermore, they created opportunities for researchers to share scientific evidence, and through these opportunities labs highlighted results indicating that brain alterations in children with dyslexia are already observable prior to the onset of formal reading instruction, which shifted Decoding Dyslexia's focus from a reactive to a proactive mission. This started a long-term partnership that led to the passing of the Massachusetts screening legislation in 2018 and, subsequently, the Massachusetts Dyslexia Guidelines, co-developed by the Departments of Elementary and Secondary Education (DESE) and Early Education and Care, to implement specific requirements of the 'An Act Relative to Students with Dyslexia.' This Act inserted the wording "dyslexia and other neurologically based disabilities" to current law that already itemized screening requirements for vision and hearing and therefore required DESE and the Department of Early Education to issue guidelines to assist districts in developing screening policies and procedures for students who demonstrate one or more potential indicators of a neurological learning disability including dyslexia (Department of Elementary and Secondary Education, 2015). While Decoding Dyslexia was the driving force and worked closely with policymakers and advocates to draft and introduce the bills, scientists assisted by (a) providing lectures in the Massachusetts State House, (b) drafting and editing scientific evidence used in the advocacy process and within the legislative bills, (c) working closely with Special Education Parent Advisory Councils (SEPAC) to raise awareness through scientific talks, (d) disseminating and translating new scientific findings relevant for advocacy and the legislative process, (e) sharing social media posts to add credibility and scientific evidence to the cause, (f) being interviewed in documentaries related to dyslexia and reading disabilities more broadly, (g) becoming board members on private schools focusing on learning disabilities to disseminate science, (h) attending congressional hearings, and (i) developing educational technology that enables more accurate and efficient screenings (e.g. see www.earlybirdeducation.com), among many other actions and initiatives. That said, it is important to note that this partnership was built on high mutual respect between the scientists and Decoding Dyslexia which was the foundation for their team efforts and enabled priceless and fruitful knowledge building on both sides.

8. Next steps, applications, and open questions

This article highlights that partnerships between grassroots caregiver organizations and researchers can be a powerful policy driver. Research in developmental cognitive neuroscience indicates that individuals with dyslexia show functional and structural brain alterations in regions processing reading and reading-related information, with some of these differences emerging as early as preschool and even infancy. This suggests that some children start schooling with less optimal brain architecture for learning to read, emphasizing the need for preventative education practices. This knowledge can be utilized as a basis for policy changes using a bottom-up process.

However, it is important to note that brain measures have been and can be misused (e.g. see the concepts of neuromyths) (Torrijos-Muelas et al., 2021) and have further been shown to lead to public misconception (e.g., see (McCabe and Castel, 2008); Weisberg et al., 2008). Nevertheless, we argue that brain imaging in this particular context has its legitimate value as a knowledge basis that can drive policy. More specifically, evidence from neuroimaging can provide insight into the development of atypical reading skills starting as early as infancy, identifies similarities in atypical brain correlates across several developmental periods which is difficult to do with behavioral measures in this age range, and can add additional, more objective evidence that atypical reading development starts long before the onset of formal reading instruction.

While the partnership between Decoding Dyslexia Massachusetts and local researchers has led to important policy changes, it is important to emphasize that the partnership and its development and processes described in this article are unique to the literacy and dyslexia space. While some of the approaches may be generalizable to other community efforts, it can never be a 1:1 translation. That said, many children with other learning disabilities, such as dyscalculia and developmental language disorder (DLD), are currently not identified early as practiced through the screening legislation for dyslexia (McGregor, 2020). While there are important milestones reached for DLD (Hendricks et al., 2019) and dyscalculia, more synergetic work between policymakers, advocacy organizations, and researchers is needed within the field of education.

Furthermore, it is important to emphasize that the partnership between scientists and Decoding Dyslexia was not at all restricted to developmental cognitive neuroscientists on the science side. Many scientists in various disciplines including developmental psychology, educational psychology, speech and language pathology, and genetics were part of this effort and provided important evidence related to the efficacy of early screening for dyslexia, its sensitivity and specificity, and changes needed for implementation and teacher training. While the developmental cognitive neuroscientists contributed important evidence highlighting underlying neural mechanisms of typical and atypical reading development or the evidence for atypical brain development predating the onset of formal education, they played a relatively small, but important role within the larger science community focusing on reading. Additionally, the existence of other likeminded organizations outside of Decoding Dyslexia enables the discourse between scientists, educators, and parents (e.g. Literate Nation, The Dyslexia Foundation, the International Dyslexia Association, The National Center for Learning Disabilities, The National Center on Improving Literacy, the Reading League and many more) and more collaborative work is currently underway (e.g., addressing evidence-based reading instruction in general education classrooms). Sadly, even now, with dyslexia screening legislation and regulations, many districts continue to avoid responsibility for early identification of at-risk children as well as identifying and diagnosing dyslexia. One reason that has been central to a lack of trust in the screening progress is the fact that no behavioral screening system is perfect. While sensitivity, specificity, classification accuracies, and other metrics have greatly improved in screening instruments over the last few years, false positive rates have been cited as one important reason why schools have resisted early identification and preventive measures. Many school districts are struggling economically and understandably, schools are trying to distribute resources to the children with the highest needs. However, it should be reemphasized that screening for reading disabilities has to be classified as a form of preventative medicine, or more precisely, "preventative education." Many screening instruments within the field of preventative medicine have similar rates of false positives including, screenings for depression, anxiety, breast cancer, or heart disease (Maxim et al., 2014). However, it has been established that, overall, preventative approaches are less expensive than health care needed to address subsequent diseases, which is the basic argument for preventative medicine. It can be acknowledged that there are circumstances and conditions when medical screening is contra-indicated or can potentially be harmful (Maxim et al., 2014) but this has been limited to screenings that have been shown to show no benefits to early treatment, are considered rare diseases/conditions or have been classified as a disease with no serious or minimal negative outcomes (Maxim et al., 2014). For reading difficulties, research points to the importance and benefits of early identification and interventions for at-risk students to improve remediation's effectiveness (e.g., effect size and time it takes to intervene) (Wanzek et al., 2018). Furthermore, it has been shown that early identification and remediation is economically superior over addressing the long-term effects of low reading skills and reading disabilities (Moll et al., 2023; UCSF Dyslexia Center and Boston Consulting Group, 2020; Karande et al., 2019; Fletcher et al., 2001). This is especially relevant since dyslexia intervention costs are not covered by health care insurance companies in many countries and given the high rates of mental health problems and negative vocational and economic outcomes associated with reading disabilities.

The ongoing partnership between scientists and Decoding Dyslexia and similar groups addresses the profound gap between the empirical findings and the implementation of "preventative practices" that enable the early identification of at-risk children for developing reading difficulties in educational settings and further seeks to address other contemporary challenges in educational and clinical practice and policy within both a general education and learning disabilities framework.

Most importantly, in the past, policy-related educational challenges have primarily driven which scientific questions were asked within the field of reading development and learning disabilities (Lyon et al., 2001) and not vice-versa. However, policy and practice decisions should be grounded in research and subjected to rigorous efficacy evaluations to evaluate the specific impact on the children and families to be served. Society should hold education policy and practice to the same standards as it does for medicine since the criteria for assessing evidence are not substantially different, and the considerations for determining the necessary research for implementing a specific policy or practice are not markedly distinct in education, medicine, or any other related fields (Lyon et al., 2001). Furthermore, we need to recognize the intricacy of translating scientific research results into policy and practical applications. Policies can potentially yield unintended consequences, especially if implementation barriers are not identified and addressed or the effects of anticipated changes are ignored. Newly designed evidence-based approaches may offer limited benefits or potentially harmful effects if the strategies for implementation lack capacity-building or a thorough understanding of the specific explicit or implicit rules and regulations at micro-, meso-, and macro-levels within the field of education (Lyon et al., 2001). Building partnerships between scientists, affected individuals and their families, policymakers, and educators and other community stakeholders is crucial for ensuring that scientific findings are at the center of policymaking and that we understand how to design policies based on these findings to elicit the systems-level change needed so that every child can learn to read well.

Declaration of generative artificial intelligence (AI) and AI-assisted technologies in the writing process

During the preparation of this work, the author(s) used ChatGPT to improve readability and use of the English language. After using this tool, the authors reviewed and edited the content as needed and take full responsibility for the content of the publication.

CRediT authorship contribution statement

Nancy Duggan: Writing – review & editing, Conceptualization. **Nadine Gaab:** Writing – review & editing, Writing – original draft, Supervision, Resources, Methodology, Investigation, Funding acquisition, Conceptualization.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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