Dyslexia

Revisiting Etiology, Diagnosis, Treatment, and Policy

Julie A. Washington Donald L. Compton Peggy McCardle







Dyslexia Revisiting Etiology, Diagnosis, Treatment, and Policy

edited by

Julie A. Washington, Ph.D. Georgia State University Atlanta, Georgia

Donald L. Compton, Ph.D. Florida State University Tallahassee, Florida

and

Peggy McCardle, Ph.D., M.P.H.

Peggy McCardle Consulting, LLC, Tarpon Springs, Florida Haskins Laboratories, New Haven, Connecticut

with invited contributors



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Excerpted from: Dyslexia Edited by: Julie A. Washington, Donald L. Compton, Peggy McCardle Ph.D., MPH



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About the Editors

Julie A. Washington, Ph.D., Professor and Program Director in Communication Sciences and Disorders, Georgia State University, Atlanta

Dr. Washington is Co-Director of the Center for Research on the Challenges of Acquiring Language and Literacy and Chair of the Communication Sciences and Disorders department at Georgia State University. Her work focuses on understanding cultural dialect use in African American children, with a specific emphasis on the impact of dialect on language assessment, reading, and academic performance. Her work with preschoolers has focused on understanding and improving the emergent literacy skills necessary to support later reading proficiency in high-risk groups, with a special focus on the needs of children growing up in poverty in urban contexts. Dr. Washington is Principal Investigator of the Georgia Language Disabilities Research Innovation Hub, funded by the National Institutes of Health, Eunice Kennedy Shriver National Institute of Child Health and Human Development. This research hub is focused on improving identification of reading disabilities in elementary school-age African American children and includes a focus on children, their families, their teachers, and their communities.

Donald L. Compton, Ph.D., Professor of Psychology and Education at Florida State University and Director of the Florida Center for Reading Research (FCRR)

Dr. Compton was formerly Professor and Chair of Special Education and John F. Kennedy Center Investigator at Peabody College, Vanderbilt University. After earning a Ph.D. from Northwestern University's School of Communication Sciences and Disorders, he was a learning disabilities resource teacher in Skokie, Illinois. He was an assistant professor in the Department of Curriculum and Instruction at the University of Arkansas, then a National Institute of Child Health and Human Development (NICHD) postdoctoral research fellow at the Institute for Behavioral Genetics, University of Colorado-Boulder. From there he accepted a position at Vanderbilt University, and in 2015, he accepted his current position at FCRR. Dr. Compton is experienced in designing, managing, analyzing, and disseminating data from cross-sectional and longitudinal studies as well as randomized controlled trials (RCTs). His research involves modeling individual differences in the development of children's reading skills

About the Editors

and the identification and treatment of children with reading disabilities. Compton has served as Principal Investigator and Co-Principal Investigator on multiple NICHD and Institute of Education Sciences (IES) studies using RCTs to evaluate academic interventions for children with learning difficulties. He has more than 80 peer-reviewed publications and is on the editorial boards of the *Journal of Educational Psychology, Journal of Learning Disabilities, Scientific Studies of Reading, Reading Research Quarterly,* and *Exceptional Children.* Dr. Compton is the past president of the Society for the Scientific Study of Reading and currently serves as Associate Editor of *Scientific Studies of Reading.*

Peggy McCardle, Ph.D., M.P.H., President/Consultant, Peggy McCardle Consulting, LLC, and an affiliated research scientist at Haskins Laboratories in New Haven, Connecticut

As former Branch Chief at the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD), U.S. National Institutes of Health, Dr. McCardle developed and directed the research program in language, bilingualism, and biliteracy and various literacy and child development initiatives. Dr. McCardle is a linguist, former speech-language pathologist, and former university faculty member, and she currently works as a private consultant, science writer, and editor (including volume and thematic journal issue design and implementation). Her publications address various aspects of public health, developmental psycholinguistics, and human development. She is currently involved in various projects related to literacy, English language learners, early childhood, education and learning difficulties, and human–animal interaction.

About the Contributors

Ruben P. Alvarez, Ed.D., Program Director of the Language, Bilingualism, and Biliteracy Program at the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD), Bethesda, Maryland

Dr. Alvarez completed his doctorate in human development and psychology (bilingual development and neuroscience) at the Harvard University Graduate School of Education. Prior to joining the NICHD, he held a postdoctoral fellowship at the National Institute for Mental Health and was an assistant professor at the Laureate Institute for Brain Research and the University of Tulsa. The program he directs at NICHD supports research on all aspects of normative language development, bilingualism, and second-language acquisition, from infancy through early adulthood. Of particular interest is research with dual language learners, and children and youth learning English as a second or additional language.

Emily Binks-Cantrell, Ph.D., Clinical Assistant Professor, Texas A&M University, College Station

Dr. Cantrell is Clinical Assistant Professor and Program Coordinator of Reading and Language Arts Education and the Reading Clinic at Texas A&M University. Her research interests are in identification of reading problems and teacher knowledge.

Jennae Bulat, Ph.D., Director of the Teaching and Learning Team, International Development Group (IDG) at RTI International, Raleigh-Durham, North Carolina

Dr. Bulat specializes in early-literacy development and educational technologies, has a strong commitment to facilitating learning across all populations, especially among at-risk populations, and manages a team providing technical support to educational programs for all ages, across the globe. She also serves as RTI International's international education disabilities inclusion expert and has authored important RTI International tools to promote inclusive education and guide the production of low-cost, high-impact teaching and learning tools: *Learning Disabilities Systems Guide for Low- and Middle-Income Countries; School and Classroom Disabilities Inclusion Guide for Low- and Middle-Income Countries; Disabilities Inclusive Education Systems and Policies Guide for Low- and Middle-Income Countries; and Teaching and Learning Materials Development Production Handbook.*

Philip Capin, doctoral student, The University of Texas at Austin

Mr. Capin is a doctoral student studying special education with a concentration in learning disabilities and behavioral disorders. As a researcher for Meadows Center for Preventing Educational Risk and experienced special education teacher and certified school administrator, he has played a primary role in the development and testing of reading intervention programs for elementary and secondary schools. He has authored research articles addressing reading outcomes for students at risk for or identified with learning disabilities. His research interests include interventions for persistent reading difficulties, the role of treatment fidelity in reading interventions, and approaches to content-area reading instruction that support content acquisition and reading comprehension.

Anne Castles, Ph.D., Distinguished Professor of Cognitive Science at Macquarie University, Sydney, Australia, and Scientific Director of the Macquarie University Centre for Reading

Dr. Castles' research focuses on variability within individuals with reading impairments and in the causes of different types of dyslexia, including genetic, perceptual, and language factors. She is a Fellow of the Academy of Social Sciences in Australia (FASSA) and serves on the editorial boards of several journals, including *Scientific Studies of Reading, Cognitive Neuropsychology,* and the *Journal of Experimental Child Psychology.* In 2017–2018, she served as President of *Learning Difficulties Australia.*

Carol McDonald Connor, Ph.D., CCC-SLP, Chancellor's Professor in Education at University of California, Irvine

Dr. Connor investigates individual differences and the links between children's language and literacy development to better understand difficulties of atypical and diverse learners, including children with dyslexia. Her recent research focuses on individualizing students' classroom learning opportunities—from preschool through fifth grade, developing technology and interventions to improve teacher efficacy and students' literacy, math, and science outcomes. Awarded the Presidential Early Career Award for Scientists and Engineers (PECASE) in 2008, she is also a fellow of the American Educational Research Association (AERA) and American Psychological Association (APA), and a principal investigator funded by the U.S. Department of Education and the National Institutes of Health, including the Early Learning Research Network and the Florida Center for Reading Research Learning Disabilities Research Center. She is past Editor of the *Journal for Research in Educational Effectiveness* and Associate Editor for *Child Development* and *AERA Open*. Marie-France Côté, Ph.D., Professor, Department Didactique des Langues, Université du Québec à Montréal

Dr. Côté recently completed her Ph.D. with Dr. Robert Savage at McGill University. She has experience as a special education teacher and a reading specialist. Her research focus is on developing effective interventions for children at risk for or experiencing difficulties in learning reading and writing in elementary schools. To be specific, she has a strong interest in the cognitive mechanisms underlying transfer of learning and the development of effective interventions to support it in schools. Dr. Côté has also been involved in the training of elementary school teachers for more than 5 years in Montreal.

Peter F. de Jong, Ph.D., Professor of Psychology and Education in the Department of Child Development and Education, University of Amsterdam, The Netherlands

Dr. de Jong's research involves the acquisition of basic academic skills (reading, spelling and arithmetic) and the etiology, diagnosis, and treatment of learning disorders, in particular dyslexia.

Maria De Palma, M.A., Program Manager for the Learning Disabilities Research Program (LDRP), The Hospital for Sick Children, Toronto, Canada

During Ms. De Palma's 23 years with the LDRP, she has coordinated several systems-based research studies and is one of two program managers for Empower Reading. She has led the expansion of Empower Reading globally into low- and middle-income countries such as India and has trained and mentored teachers, onsite and remotely, to deliver Empower Reading in Indian resource centers and schools. Ms. De Palma is also a senior trainer and mentor for teachers in and across Canada and in the United States.

Eileen Dombrowski, Early Childhood Development Specialist, RTI International

Ms. Dombrowski focuses on ensuring that early childhood programming meaningfully includes children with disabilities, and she supports teachers to provide the differentiation of instruction these children need to be successful. Prior to joining RTI International, Ms. Dombrowski was a policy and programs specialist at Easter Seals, where she advocated for increasing funding for programs that affect children with disabilities and their families. She started her career as an early childhood special education teacher and has taught in public schools in Washington, DC, and Baltimore City. About the Contributors

Ms. Dombrowski was a Peace Corps volunteer in Romania (2006–2008) and a Peace Corps response volunteer in The Gambia (2010–2011).

Margaret (Peggy) M. Dubeck, M.Ed., Ph.D., Senior Literacy Researcher at RTI International, International Education Team, Washington, District of Columbia

Dr. Dubeck holds an M.Ed. at George Washington University as part of the Peace Corps Fellows program and a Ph.D. in reading education from the University of Virginia. She did postdoctoral work at the Harvard Graduate School of Education. Interested in literacy in readers with dyslexia learning in multilingual contexts, Dr. Dubeck has expertise in multidisciplinary randomized controlled trials, tracer studies, piloting, implementation, evaluation, analysis, and dissemination. She has created, modified, and established the technical adequacy of literacy, math, attention, and affective instruments in multiple languages. Her literacy interventions, designed for schools, community programs, and individualized settings, include teacher and student materials, trainings, supportive technology, and measures of fidelity.

Kristy Dunn, doctoral student in special education, University of Alberta, Canada

Ms. Dunn has 15 years of experience as an elementary teacher in mainstream and special education classrooms and is the Reading Research Project Manager in the Reading Research Laboratory. Her recent research interests include the early identification and remediation of reading difficulties in English language learners and the contribution of executive functioning to academic achievement. Her previous work has examined the cognitive profiles of gifted readers and the PASS (planning, attention, simultaneous, and successive) processes that predict superior reading and mathematics performance.

Hank Fien, Ph.D., Associate Professor in School Psychology, Department of Special Education and Clinical Sciences (SPECS), College of Education, and Director of the Center on Teaching and Learning (CTL), University of Oregon, Eugene

Dr. Fien is an expert on reading and mathematics development in young children and on instructional design. He is Director of the National Center on Improving Literacy and has been Principal Investigator and Co-Principal Investigator on 16 Institute of Education Sciences (IES) and National Science Foundation grants. Dr. Fien has 62 publications in refereed journals and is a standing member of the IES Reading, Writing, and Language review panel.

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Barbara R. Foorman, Ph.D., Francis Eppes Professor of Education and Director of the Regional Educational Laboratory Southeast and Director Emeritus of the Florida Center for Reading Research, Florida State University, Tallahassee

Dr. Foorman's research focuses on language and reading development, instruction, and assessment.

Nadine Gaab, Ph.D., Associate Professor of Pediatrics at Boston Children's Hospital and Harvard Medical School and faculty at the Harvard Graduate School of Education, Harvard University, Cambridge, Massachusetts

Dr. Gaab received her Ph.D. from the University of Zurich, Switzerland, and conducted doctoral research at the Harvard Medical School and postdoctoral work at Stanford and the Massachusetts Institute of Technology. She primarily works on early identification of children at risk for language-based learning disabilities (e.g., developmental dyslexia), their environmental and genetic influences, and the neural correlates of reading development. She develops and implements screening practices for young children, working at the intersection of developmental cognitive neuroscience, clinical/educational practice, and public policy, focusing on early identification and implementation of real-world changes for struggling readers, in collaboration with numerous public and private schools. For more info, please see http://www.gaablab.com.

Brian Gearin, Co-Lead of Dissemination at the National Center on Improving Literacy and doctoral student, University of Oregon, Eugene

Mr. Gearin's research is broadly focused on the development of executive function and on reading and mathematics achievement. He is particularly interested in how educational policies support student development in these areas. His research has appeared in outlets such as *Journal of Education Policy, Educational Policy,* and *Trends in Neuroscience and Education.* Mr. Gearin is pursuing a Ph.D. in quantitative methods in educational research in the University of Oregon's Department of Education Methodology, Policy, and Leadership.

George Georgiou, **Ph.D.**, Professor of Special Education at the University of Alberta, Canada, and Director of the Reading Research Laboratory

Dr. Georgiou has published extensively on the cognitive and environmental bases of reading development and disabilities. Research interests include early identification and remediation of reading difficulties across languages. He has trained both preservice and in-service teachers to teach and assess different aspects of reading with a particular focus on phonemic awareness, About the Contributors

phonics, fluency, vocabulary, and reading comprehension. Over the last 8 years, he and another contributor to this volume, Dr. Parrila, have trained more than 500 primary and secondary teachers in Edmonton, and the schools that have participated in their professional development program have demonstrated measurable growth over time (in particular decreasing the number of poor readers requiring additional services).

Anne M. Hayes, Ed.M., Independent Consultant

Ms. Hayes has more than 20 years of technical expertise focusing on disability-inclusive development, inclusive education, gender equity, and human rights, working in more than 30 countries in Asia, Africa, Eastern Europe, Latin America, the Caribbean, and the Middle East. She is lead author for *Literacy for All: How to Use Universal Design for Learning to Promote Literacy Skills for Students with Disabilities,* supported by United States Agency for International Development (USAID). She was previously Senior Technical Advisor at Perkins School for the Blind; Director of Collaborative Initiatives, World Bank Global Partnership on Disability and Development; and Disability and Gender Specialist, USAID. Currently she is an independent consultant supporting disability-inclusive development and inclusive education programming for various non-governmental organizations, contractors, United Nations agencies, and organizations for individuals with disabilities.

R. Malatesha (Malt) Joshi, Ph.D., Professor, Texas A&M University, College Station

Dr. Joshi serves as Editor of *Reading and Writing: An Interdisciplinary Journal* and the monograph series "Literacy Studies: Perspectives from Cognitive Neurosciences, Linguistics, Psychology, and Education." From 1980 to 2002, Dr. Joshi directed six highly successful North Atlantic Treaty Organization Advanced Study Institutes in Europe on the topics of neuropsychology, cognition, and literacy, which helped to bring various fields together. Active internationally in education and literacy research he has served as a visiting research scholar in China, Germany, Taiwan, and New Zealand. Dr. Joshi has published numerous books and scientific papers and has received several awards. He is a Fellow of the American Educational Research Association (AERA). His research interests focus on teacher knowledge and literacy development among monolinguals and second language learners.

Devin M. Kearns, Ph.D., Assistant Professor of Special Education, Department of Educational Psychology, Neag School of Education, University of Connecticut, Mansfield

About the Contributors

Dr. Kearns is a research scientist for Haskins Laboratory and the Center for Behavioral Education & Research (CBER). Dr. Kearns researches reading disability—including dyslexia—in elementary- and middle school-age children. He also teaches educators the most effective strategies for supporting students with serious reading problems. He is an investigator on multiple projects to prevent and remediate reading difficulties funded by the Institute for Education Sciences, the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development, and other national and local organizations.

Young-Suk Grace Kim, Ed.D., Professor, University of California at Irvine, and Faculty Associate, Florida Center for Reading Research, Florida State University, Tallahassee

Dr. Kim holds an Ed.D. from Harvard University and is a former primary and secondary school classroom teacher. Her research interests include development and instruction of language, cognition, and literacy skills as well as dyslexia and dysgraphia across languages and writing systems. She has conducted several large-scale longitudinal studies and intervention work supported by the Institute of Education Science, the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development, and the National Science Foundation, as well as the National Research Foundation of Korea. A recipient of the Presidential Early Career Award for Scientists and Engineers and research and teaching awards, Dr. Kim serves as Associate Editor for the *Journal of Educational Psychology* and as an editorial board member for several journals.

Saskia Kohnen, Ph.D., Clinical Director, Macquarie University Reading Clinic, and Senior Researcher, Department of Cognitive Science at Macquarie University, Sydney, Australia

Dr. Kohnen's research interests include typical and atypical reading and spelling development and the assessment and treatment of reading and spelling difficulties. Her clinical work focuses on translating research into practice.

Nicole Landi, Ph.D., Associate Professor of Psychological Sciences at University of Connecticut, Storrs, and the Director of EEG Research at Haskins Laboratories, New Haven, Connecticut

Dr. Landi's research seeks to better understand typical and atypical reading and language development through the use of multiple cognitive neuroscience methodologies (magnetic resonance imaging and electroencephalography) and genetic analyses. Through this work, her lab hopes to xviii

identify neurobiological and environmental mechanisms that contribute to individual differences in reading and language skill and to the complex etiology of disorders such as dyslexia, specific comprehension deficit, and developmental language disorder.

Ryan Lee-James, Ph.D., Assistant Professor, Communication Sciences and Disorders, Adelphi University, Garden City, New York

Ryan Lee-James is an assistant professor in the Department of Communication Sciences and Disorders at Adelphi University and a speechlanguage pathologist certified by the American Speech-Language-Hearing Association (ASHA). Her work contributes to the larger body of research that is focused on better understanding the impact of African American English dialect use on assessment and treatment of language disorders for children reared in poverty.

Maureen W. Lovett, Ph.D., C-Psych., Senior Scientist in the Neurosciences and Mental Health Program at The Hospital for Sick Children, Toronto, Canada, and Professor of Paediatrics and Medical Sciences, the University of Toronto

Dr. Lovett's research focuses on questions about the effective remediation of decoding, word identification, fluency, and reading comprehension deficits in struggling readers in elementary, middle, and high schools. As Co-Principal Investigator of the Institute of Education Sciences-funded Center for the Study of Adult Literacy, she is developing interventions for adult literacy learners as well. She and her team are also involved in knowledge translation initiatives: Their Empower Reading interventions are now used to teach struggling readers in school districts in four Canadian provinces.

Kristina Maiorino, B.A.

Ms. Maiorino holds a bachelor's degree in psychology from McGill University. After her graduation, she worked as coordinator of McGill's bilingual acquisition lab for a year, and then taught English abroad for 2 years. On her return to Montreal, she worked in many research labs focused primarily on language and literacy, collaborating on a variety of projects that studied language attrition through electroencephalography, bilingualism in adopted children through functional magnetic resonance imaging, and, most recently, coordinating a response-to-intervention study with struggling elementary school readers.

Matthew H. C. Mak, doctoral student, Department of Experimental Psychology, the University of Oxford, Oxford, England

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About the Contributors

Mr. Mak's research interest lies in the interface of language and memory. He is investigating the mechanisms that underlie long-term orthographic memory formation and how various factors, such as context and sleep, promote this process. He also has a long-standing interest in dyslexia and developmental language disorders and an ongoing collaboration with speech therapists to investigate the memory deficits associated with those disorders. Prior to arriving at Oxford, he obtained a M.Phil. in applied linguistics at the University of Cambridge, where he worked on a project that examined the relation between statistical learning and spelling proficiency in a second language.

Joan Mele-McCarthy, D.A., CCC, Executive Director of The Summit School, Edgewater, Maryland

Dr. McCarthy is Executive Director of The Summit School, a school designed for students who have dyslexia and other learning differences. Prior to holding this position, she served as a special assistant to the Assistant Secretary for Special Education/Rehabilitation Services in the U.S. Department of Education and worked on policy issues related to the connections between special education and general education, and English language learners and disabilities. She also has served on university faculties in departments of communication sciences and disorders, owned/directed a private practice that provided direct intervention and school consultation, and worked in public schools. Her work is focused on language-based learning differences and special education policy.

Brett Miller, Ph.D., Program Director, *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD)

Dr. Miller oversees the Reading, Writing, and Related Learning Disabilities research portfolio at the NICHD, National Institutes of Health, that focuses on developing and supporting research and training initiatives to increase knowledge relevant to the development of reading and written-language abilities for learners with and without disabilities. Dr. Miller also co-directs the Language, Bilingualism, and Biliteracy research program, which focuses on language development and psycholinguistics from infancy through early adulthood; bilingualism and/or second-language acquisition; and reading in bilingual and/or English-language learning children and youth.

Kate Nation, Ph.D., Professor of Experimental Psychology at the University of Oxford and a Fellow of St John's College, Oxford, England

Dr. Nation's research is concerned with language processing, especially reading development. She is interested in how children learn to read words and comprehend text, and more generally, the relationship between

About the Contributors

spoken language and written language. A key aim at present is to specify some of the mechanisms involved in the transition from novice to expert. She also studies language processing in skilled adults, addressing the issue of how skilled behavior emerges via language learning experience, and reading processes in individuals with developmental disorders that influence reading and language. For more information visit http://www .readoxford.org and follow on Twitter @ReadOxford.

Elizabeth S. Norton, Ph.D., Assistant Professor at Northwestern University, Evanston, Illinois

Dr. Norton leads the Language, Education, and Reading Neuroscience (LEARN) Lab at Northwestern. Her research combines behavioral and brain measures and seeks to understand typical development as well as reading, language, and neurodevelopmental disorders. As a former high school teacher for students with dyslexia, she is particularly interested in understanding individual differences and working toward early identification and intervention for reading disabilities.

Rauno Parrila, Ph.D., Professor of Educational Studies, Macquarie University, Sydney, Australia

Dr. Parrila has co-edited a book on theories of reading development and published more than 100 research papers that have mostly focused on different aspects of home literacy practices, reading acquisition, and reading disabilities. He is the past Editor and Associate Editor (2008–2009) of *Scientific Studies of Reading*. For more than 20 years, Dr. Parrila has trained hundreds of preservice and in-service teachers in Canada to teach reading to struggling readers, and he worked with Dr. Georgiou on developing and delivering professional development on literacy for K–9 teachers.

Nicole Patton Terry, Ph.D., Olive & Manuel Bordas Professor of Education and Associate Director, Florida Center for Reading Research (FCRR), Florida State University, Tallahassee

Dr. Patton Terry's research concerns young children with and without disabilities struggling to acquire language and literacy skills, especially those from culturally and linguistically diverse backgrounds and those living in poverty. Her research has been supported by diverse organizations, including the Spencer Foundation, National Institutes of Health, Institute of Education Sciences, and The Annie E. Casey Foundation. She currently serves as a board member for the Society for the Scientific Study of Reading and an associate editor for the *Journal of Learning Disabilities*. At FCRR, she directs The Village—a division that creates and

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maintains research partnerships with diverse community stakeholders to promote reading achievement and school success among vulnerable children.

Yaacov Petscher, Ph.D., Associate Director at the Florida Center for Reading Research, Tallahassee, and Deputy Director of the National Center on Improving Literacy

Dr. Petscher's research interests include the study of cross-sectional and longitudinal individual differences in literacy, psychometrics, reading assessment, and research design. He has co-authored more than 150 peerreviewed publications, book chapters, books, and technical reports, and his work has been recognized by awards from the Society for the Scientific Study of Reading, the International Literacy Association, the American Educational Research Association, and the International Society for Technology in Education. He presently serves as an associate editor for the *Journal of Learning Disabilities* and *Elementary School Journal* and as an editorial board member for other educational journals.

Jay G. Rueckl, Ph.D., Senior Scientist at Haskins Laboratories, New Haven, Connecticut; Director of the University of Connecticut's Brain Imaging Research Center, Storrs; Associate Professor of Psychological Sciences, and Associate Director of the Variable Vowel Collaborative, a National Institutes of Health Learning Disabilities Hub

Since earning a Ph.D. in experimental psychology at the University of Wisconsin, Dr. Rueckl has used behavioral experiments, neuroimaging, and computational modeling to study the neurocomputational processes underlying reading and reading acquisition in a variety of languages (including English, Hebrew, Spanish, and Mandarin) and in ages ranging from beginning readers to young adults.

Elinor Saiegh-Haddad, Ph.D., Professor of Applied Linguistics at Bar-Ilan University, Israel

Dr. Saiegh-Haddad is senior advisor to Israeli authorities in education and technology and has been actively involved in L1 Arabic and L2 English curricula and textbook development. She holds graduate degrees from Reading University, England (M.A.), Bar-Ilan University, Israel (Ph.D.), and the University of Toronto (Rothschild postdoctoral fellow). She maintains strong interest in studying language and reading development and disability in Arabic and focuses on the role of diglossia and the linguistic distance between Arabic written and spoken dialects on literacy. She also studies reading development in English as a second language with a focus on cross-linguistic differences in language and About the Contributors

orthography. She has published a large number of articles on reading development in these contexts and is co-editor of the *Handbook of Arabic Literacy* (Springer, 2014).

Joseph Sanfilippo, M.Sc., Ed.M., medical student, Queen's University, Kingston, Canada, and research student working under Dr. Nadine Gaab at Boston Children's Hospital, Massachusetts

Involved in the Gaab Lab for several years, Mr. Sanfilippo is currently the lab's full-time research coordinator. Sanfilippo has coordinated several projects investigating cognitive, language, literacy, and brain development, including a large-scale longitudinal infant dyslexia study in Boston, as well as several international studies (e.g., Bangladesh, Brazil, South Africa). His interests lie at the intersection of medical science and education, including the investigation of the neural bases of language and literacy development, and the implications of this research for practice and policy.

Robert Savage, Ph.D., Professor and Head of the Department of Psychology and Human Development at University College, London, England

Dr. Savage has experience both as a school psychologist and as a classroom teacher and maintains a strong interest in making schools effective learning places for all children. He has published more than 100 research articles exploring children's early reading and spelling strategies. His work includes studies of the neurocognitive processes that are used in reading and spelling, and he is particularly interested in preventing early reading and spelling problems by better teaching of phonics. Together with Drs. Georgiou and Parrila, he is developing and testing a professional development program that helps teachers understand and use phonics effectively to support typically developing and struggling children.

Eliane Segers, Ph.D., Professor, Learning & Technology, Behavioural Science Institute, Radboud University, The Netherlands

Eliane Segers is a professor of Learning & Technology at the Behavioural Science Institute at Radboud University, and she also has a chair by special appointment in Reading and Digital Media at Instructional Science at the University of Twente, both in The Netherlands. Her background is in cognitive science and speech technology, and she has a Ph.D. in social sciences (2003). Her research is focused on understanding individual differences in learning and reading, on learning in technology-based environments, and on optimizing learning in such environments via smart

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use of technological affordances. The main research focus is children in primary schools.

Christopher T. Stanley, Ph.D., Associate in Research in the Division of Quantitative Methodology and Innovation at Florida State University, Tallahassee

Prior to his current appointment, Dr. Stanley was full-time psychology faculty at Winston-Salem State University and, subsequently, Florida Gulf Coast University. Throughout his career, he has been involved on a variety of collaborative research projects and applied activities related broadly to human development and performance, including factors and outcomes in athletic, health, psychosocial, and educational domains.

Karen A. Steinbach, M.A., C. Psych. Assoc., Program Manager in the Learning Disabilities Research Program at The Hospital for Sick Children, Toronto, Canada

Ms. Steinbach has coordinated several multisite Eunice Kennedy Shriver National Institute of Child Health and Human Development- and Institute of Education Sciences-funded intervention research studies over a period of more than 25 years. In addition to her role in research, Ms. Steinbach co-leads the knowledge translation and dissemination initiatives of the evidence-based intervention Empower Reading; she collaborates with school districts in and across Canada and in the United States. She is particularly interested in the literacy outcomes of children in remote, disadvantaged communities and is responsible for coordinating and training teachers in the Cree School Board. She is also a senior teacher trainer and mentor for Empower Reading.

Elizabeth A. Stevens, M.A.Ed., doctoral student, The University of Texas at Austin

Ms. Stevens is studying learning disabilities and behavioral disorders. She received a master's degree in special education from the College of William and Mary and a reading specialist degree from the University of Virginia. She taught special education for 9 years in Arlington County Public Schools. Ms. Stevens currently coordinates a large-scale research project at The Meadows Center for Preventing Educational Risk and provides professional development to teachers in Texas and other states. Her research interests include diagnosis and remediation of learning disability, effective instructional practices for students with reading difficulty or disability, and the role of student explanations and discourse on student outcomes within mathematics and reading interventions.

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Carmen Strigel, Director of Technology for Education and Training at RTI International, Durham, North Carolina

Ms. Strigel's work focuses on technology for building capacity, collaboration, and information-based decision making in low- and middle-income countries. Ms. Strigel's passion lies in deploying technology at the intersection of desirability by users, feasibility in the context, and viability for sustainable use. She led the development of Tangerine, open source software facilitating continuous student assessment and program monitoring, which has been deployed in more than 60 countries and 100 languages to date. Specific to inclusive education, she has led groundbreaking research in Ethiopia using carefully designed technology to measurably improve teachers' inclusive instructional practices in regular reading classrooms. Concurrently, Ms. Strigel is conducting doctoral research in educational neuroscience at Johns Hopkins University.

Theodore (Ted) K. Turesky, Ph.D., Postdoctoral Fellow at Boston Children's Hospital (BCH), Massachusetts, and Harvard Medical School, Cambridge, Massachusetts

In graduate training at Georgetown University, Dr. Turesky examined the functional neuroanatomy of the motor system in development, aging, and developmental dyslexia; he was named the Karen Gale Excellent Ph.D. Student in Science. At BCH, he works on structural and functional brain development in early life adversity (e.g., poverty) and reading. His future work will focus on the biological and psychosocial risk factors mediating the relationship between poverty and brain development, and neural correlates of reading fluency and spelling. Dr. Turesky serves as Vice Chair on the Board of Directors for the American Tinnitus Association, providing expertise in neuroscience and advocating for noise health issues.

Sharon Vaughn, Ph.D., Executive Director of The Meadows Center, The University of Texas at Austin

Dr. Vaughn directs The Meadows Center, an organized research unit at The University of Texas at Austin. She is the recipient of the American Educational Research Association Special Interest Groups Distinguished Researcher Award, the International Reading Association Albert J. Harris Award, The University of Texas Distinguished Faculty Award, and the Jeannette E. Fleischner Award for Outstanding Contributions in the Field of Learning Disabilities from the Council for Exceptional Children. She is the author of more than 35 books and 250 research articles. Dr. Vaughn is Principal Investigator on several Institute of Education Sciences, *Eunice Kennedy Shriver* National Institute of Child Health and Human Development, and U.S. Department of Education research grants.

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Ludo Verhoeven, Ph.D., Professor, Psychology and Education, Behavior Science Institute at Radboud University, Nijmegen, The Netherlands, and Professor in Educational Policies and Innovation, The University of Curaçao, Willemstad

Currently President of the Scientific Society for the Study of Reading, Dr. Verhoeven's research focuses on language and literacy learning in typically and atypically developing children in culturally and linguistic diverse environments. He has a master's degree in psychology and special education from Radboud University and a Ph.D. in linguistics (honors degree) from the University of Tilburg. Dr. Verhoeven completed his postdoctoral work at the University of California at Berkeley and at Santa Barbara. He has co-authored more than 350 empirical papers in peerreviewed scientific journals and co-edited 20 books.

Kelly J. Williams, Ph.D., Assistant Professor of Special Education, Department of Curriculum and Instruction, Indiana University

Dr. Williams's research focuses on improving academic and post-secondary outcomes for students at risk for and identified with high-incidence disabilities. She is particularly interested in reading interventions for English learners and adolescents with reading difficulties and disabilities (e.g., learning disabilities) and interventions designed to reduce high school dropout and increase student engagement in school. Previously, Dr. Williams was the project coordinator at The University of Texas at Austin for an Institute of Education Sciences grant investigating the efficacy of a combined dropout prevention reading intervention for ninthand tenth-grade students with comprehension difficulties.

Henry Wolf VII, Ph.D., Student and National Science Foundation Integrative Graduate Education and Research Traineeship (IGERT) Fellow

Mr. Wolf is the founder of the Deep Learning Research Group at the University of Connecticut. His research involves using image recognition techniques (convolutional neural networks) in computational models of reading. Prior to pursing a Ph.D., Dr. Wolf earned a master's degree in teaching English to speakers of other languages from Teachers College, Columbia University and a bachelor's degree in international business and marketing from the University of Dayton (Ohio).

Dandan Yang, doctoral student, University of California at Irvine (UCI)

Ms. Yang is a second-year Ph.D. student at UCI's School of Education, specializing in Teaching, Learning, and Educational Improvement (TLEI). She holds a B.A. in English language and literature from China University of Mining and Technology and an M.A. in TESOL from the University of Southern California. Prior to entering this program, Ms. Yang taught English and Chinese to students with various linguistic and cultural backgrounds in both China and California. This teaching experience as well as the research practices in Professor Carol Connor's lab at UCI's School of Education led to her interests in language and the literacy development of young learners, executive functioning, and using game-based applications to assist students' learning.

Jason Zevin, Ph.D., Associate Professor of Psychology and Linguistics, the University of Southern California, Los Angeles

Dr. Zevin is affiliated with Haskins Laboratories as a Senior Scientist. He uses a combination of computational modeling, neuroimaging, and other techniques to study the processing of written and spoken words and other aspects of language.

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The Dyslexia Foundation and the Extraordinary Brain Series Symposia



n the late 1980s, The Dyslexia Foundation (TDF) was founded by William H. "Will" Baker in collaboration with notable researchers in dyslexia. The concept began in the late 1970s, then came to fruition in 1982, when, through the generosity of the Wm. Underwood Co. and the Baker family, the first Dyslexia Research Laboratory under the direction of Drs. Albert Galaburda and Norman Geshwind at Beth Israel Hospital, Harvard Medical School, Boston, Massachusetts, was established to investigate the neural underpinnings of dyslexia. In 1987, top researchers from cognition, neuroscience, and education were convened in a scientific symposium in Florence, Italy, where ideas were presented and discussed, with sufficient time to disagree, to identify research challenges, and to brainstorm solutions—and the concept of a dyslexia symposium series was born. In the fall of 1989, Baker established the National Dyslexia Research Foundation (later renamed The Dyslexia Foundation) to focus specifically on research. In 1990, the new foundation sponsored a second symposium in Barcelona, Spain. With it, the symposium series was designated as the Extraordinary Brain Series (EBS)!

The EBS symposia began as think tanks of researchers who were encouraged to discuss, disagree, and explore new possibilities. Many have called these symposia the best research meetings they have ever attended because of the depth of discussion and exchange of ideas afforded by a 5-day think tank. Each symposium resulted in a volume to share the research presented and the ideas that grew out of the symposia's deliberations. Educators from independent schools for students with learning differences, interested in hearing the latest research and witnessing these cutting-edge discussions, began to attend and to contribute as TDF sponsors to the meetings. Hearing their cry for bringing current research to their classrooms, in a then-novel outreach activity, TDF instituted 1-day annual educational meetings held on the campus of Harvard Medical School, where educators and allied health practitioners could hear about current research directly from researchers. In 2007, at the 10th EBS symposium in Brazil, educators asked so many questions and were so eager to share their research needs with the researchers present that these educators were given a forum during the meeting, and the research-to-practice efforts of TDF took on a new, higher level. Since that time, educators and practitioners are heard and participate in each EBS symposium, and the interactions among them and researchers have been rich and rewarding. Although it had been part of the TDF philosophy to include not only senior, established researchers but also promising early-stage researchers as

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participants in the symposia, this has also accelerated. At the 11th symposium in Taiwan, in 2010, Taiwanese researchers invited their graduate students and postdoctoral fellows to display posters of their work during the meeting. Since that time, those invited to present or moderate sessions at EBS symposia are also invited to bring junior colleagues, postdoctoral fellows, and graduate students and to have them present posters—both displaying the posters and giving a very brief explanation of their work during one special session at the symposium.

Over the 3 decades of the existence of TDF and EBS, major strides have been made in not only dyslexia and reading research itself (many researchers have commented that their best new ideas and great new collaborations have grown out of their participation in EBS symposia), but these meetings have also provided a safe venue for the exchange and development of research-to-practice ideas, the mentoring of many new and emerging researchers, and content for the continuing and expanding 1-day research-to-practice meetings for educators and practitioners, which are live-streamed in real time and archived for later viewing.

This volume celebrates the 17th symposium in the EBS. The series volumes make accessible to all researchers and practitioners the thoughts of scholars across various disciplines as they tackle various aspects of the behavior, neurobiology, and genetics of dyslexia and of learning to read and write. The following is a listing of TDF symposia and the related volumes to date:

- I. June 1987, Florence, Italy. Symposium Director: Albert M. Galaburda. Galaburda, A. M. (Ed.). (1989). *From reading to neurons*. Cambridge, MA: Bradford Books/MIT Press.
- II. June 1990, Barcelona, Spain. Symposium Director: Albert M. Galaburda.

Galaburda, A. M. (Ed.). (1993). *Dyslexia and development: Neurobiological aspects of extra-ordinary brains.* Cambridge, MA: Bradford Books/Harvard University Press.

- III. June 1992, Santa Fe, NM. Symposium Director: Paula Tallal. Chase, C., Rosen, G., & Sherman, G. F. (Eds.). (1996). Developmental dyslexia: Neural, cognitive, and genetic mechanisms. Mahwah, NJ: Lawrence Erlbaum Associates.
- IV. June 1994, Kauai, Hawaii. Symposium Director: Benita Blachman. Blachman, B. R. (Ed.). (1997). Foundations of reading acquisition and dyslexia: Implications for early intervention. Mahwah, NJ: Lawrence Erlbaum Associates.
- V. June 1998, Kona, Hawaii. Symposium Director: Drake Duane. Duane, D. (Ed.). (1999). *Reading and attention disorders: Neurobiological correlates*. Baltimore, MD: York Press.

- VI. June 2000, Crete, Greece. Symposium Director: Maryanne Wolf. Wolf, M. (Ed.). (2001). *Time, fluency, and dyslexia*. Baltimore, MD: York Press.
- VII. June 2002, Kona, Hawaii. Symposium Director: Barbara Foorman. Foorman, B. (Ed.). (2003). *Preventing and remediating reading difficulties: Bringing science to scale*. Baltimore, MD: York Press.
- VIII. October 2002, Johannesburg, South Africa. Symposium Director: Frank Wood.

Multilingualism and dyslexia. No publication.

- IX. June 2004, Como, Italy. Symposium Director: Glenn Rosen. Rosen, G. (Ed.). (2006). *The dyslexic brain: New pathways in neuroscience discovery*. Mahwah, NJ: Lawrence Erlbaum Associates.
- X. June 2007, Campos do Jordão, Brazil. Symposium Directors: Ken Pugh and Peggy McCardle.
 Pugh, K., & McCardle, P. (Eds.). (2009). How children learn to read: Current issues and new directions in the integration of cognition, neurobiology and genetics of reading and dyslexia research and practice. New York, NY: Psychology Press, Taylor & Francis Group.
- XI. January 2010, Taipei, Taiwan. Symposium Directors: Peggy McCardle, Ovid Tseng, Jun Ren Lee, and Brett Miller.
 McCardle, P., Miller, B., Lee, J. R., & Tseng, O. (Eds.). (2011). Dyslexia across languages: Orthography and the brain-gene-behavior link. Baltimore, MD: Paul H. Brookes Publishing Co.
- XII. June 2010, Cong, Ireland. Symposium Directors: April Benasich and Holly Fitch.

Benasich, A. A., & Fitch, R. H. (Eds.). (2012). *Developmental dyslexia: Early precursors, neurobehavioral markers, and biological substrates.* Baltimore, MD: Paul H. Brookes Publishing Co.

XIII. June 2012, Tallinn, Estonia. Symposium Directors: Brett Miller and Laurie Cutting.

Miller, B., Cutting, L., & McCardle, P. (Eds.). (2013). *Unraveling reading comprehension: Behavioral, neurobiological, and genetic components.* Baltimore, MD: Paul H. Brookes Publishing Co.

- XIV. June 2014, Horta, Faial Island, The Azores. Symposium Directors: Carol Connor and Peggy McCardle.
 Connor, C. M., & McCardle, P. (Eds.). (2015). Advances in reading intervention: Research to practice to research. Baltimore, MD: Paul H. Brookes Publishing Co.
- XV. June 2016, Saint Croix, U.S. Virgin Islands. Symposium Directors: Albert Galaburda, Fumiko Hoeft, and Nadine Gaab.

Galaburda, A. M., Gaab, N., Hoeft, F., & McCardle, P. (Eds.). (2017). Dyslexia and neuroscience: The Geschwind-Galaburda Hypothesis, 30 years later. Baltimore, MD: Paul H. Brookes Publishing Co.

- XVI. May 2018, St. Petersburg, Russia. Symposium Directors: Elena Grigorenko and Yury Shtyrov.
 Grigorenko, E., Shtyrov, Y., & McCardle, P. (Eds.). (2020). All about language: Science, theory, and practice (Неделя языка: наука, теория, практика). Baltimore, MD: Paul H. Brookes Publishing Co.
- XVII. June 2018, Cathedral Peak, Drakensburg, South Africa. Symposium Directors: Julie A. Washington and Donald L. Compton.

Washington, J. A., Compton, D. L., & McCardle, P. (Eds.). (2020). *Dyslexia: Revising etiology, diagnosis, treatment, and policy.* Baltimore, MD: Paul H. Brookes Publishing Co.

SECTION I

Setting the Stage

An Overview and Introduction to the Volume

Julie A. Washington, Donald L. Compton, and Peggy McCardle

nterest in the root causes, diagnosis, and treatment of dyslexia has a long history, dating back to the late 19th century, when the term Ldyslexia was first coined. The earliest characterizations of children with dyslexia described them as "bright, intelligent and quick" and as having "text blindness" despite intact intellect and speech. Understanding of dyslexia improved exponentially in the 20th century. In the United States, the study of dyslexia was buoyed by the establishment of the Specific Learning Disabilities Act of 1969 (PL 91-230), which was followed by, and included in, the Education for All Handicapped Children Act of 1975 (PL 94-142), a federal law mandating free appropriate public education for all children. Since being renamed the Individuals with Disabilities Education Act (IDEA) of 1990 (PL 101-476) and later the Individuals with Disabilities Education Improvement Act (IDEA) of 2004 (PL 108-446), reauthorizations of the federal law have included 1) expanded definitions of reading disability, 2) increased access to the general curriculum for all students, and 3) guidance for identification and intervention for children struggling with learning disabilities. These changes in the law over time have resulted largely from new advances in the research base.

On a global level, the identification and study of dyslexia and, by implication, the education of children struggling to learn to read have not kept pace. A 2014 report by Dyslexia International confirmed that in wealthier nations such as the United States and the United Kingdom, where public education is available for all children, identification of children with dyslexia and subsequent intervention services, though not perfect, are more likely to occur. In contrast, children in impoverished countries are more likely to go undiagnosed and have their symptoms unaddressed, contributing to significant illiteracy rates. The report cited five major reasons for the gaps in addressing dyslexia in these countries, where public services are more limited: 1) limited knowledge about dyslexia, including its characteristics and treatment; 2) limited teacher training; 3) lack of awareness of cost-effective, modern solutions; 4) poor leadership for establishment of public policies; and 5) a global shortage of teachers. Importantly, many of these same variables have affected the identification of dyslexia in impoverished children in wealthy nations as well.

Overall, this is an exciting time for dyslexia research. Developing knowledge in areas such as genetics, brain imaging, cognitive psychology, and intervention has expanded understanding of dyslexia considerably over the past approximately 15 years. Despite these advances, there

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An Overview and Introduction to the Volume

continue to be as many disagreements as there are agreements about the definition, etiology, diagnosis, and treatment of dyslexia. For example, researchers generally agree that early detection and intervention are critical, that dyslexia is a specific learning disability with a phonological basis, and that children with dyslexia benefit from ongoing assessment and support. On the other hand, the neurological and genetic bases of dyslexia have provided exciting insights and discoveries but no universal consensus regarding the nature of brain or gene processes. Of importance for the The Dyslexia Foundation (TDF) Extraordinary Brain Symposium (EBS) 17 and this volume, which is based on it, there are also significant gaps in the development of knowledge about dyslexia. In particular, little is known about the basic learning mechanisms underlying dyslexia and how these interact with important sociodemographic variables such as language (or dialect) differences, poverty, or cultural differences. The impact of these variables on the manifestation and treatment of dyslexia in affected populations in the United States and across the globe is the next important frontier in dyslexia research. The absence of this information represented a critical omission in the work of TDF to develop a comprehensive understanding of dyslexia and its sequelae.

Thus, the goal of the 17th TDF Extraordinary Brain Symposium and this volume was to revisit the current foundational knowledge base about dyslexia, including its etiology, diagnosis, treatment, and public policy status. We were seeking ways to expand this knowledge base to include children who are impoverished, who are culturally diverse, and who speak various languages or whose dialects differ significantly from the standard. Expanding the research focus to include understudied populations is important as researchers and educators seek to develop a comprehensive definition and strategy for addressing dyslexia worldwide. The integration of understudied groups and issues into current research, and expansion to include the unique challenges and gifts that these children bring to the understanding of dyslexia, are crucial both to research and to improving practice and influencing public policy; all of which must include input from the practice community. Therefore, we also sought to forge strong links between members of the research and practice communities and to present information that is accessible to policy makers, who represent key stakeholders who can provide the necessary leadership to move both research and practice forward.

This volume is organized into six sections, each concluding with an integrative commentary that highlights cross-cutting themes from the chapters in that section and sometimes from other chapters in the volume. In addition, several chapters cross-reference to chapters in EBS Volume XVI, *All About Language: Science, Theory, and Practice* (Неделя языка: наука, теория, практика; Grigorenko, Shtyrov, & McCardle, 2020), which addresses the state of knowledge of language—both spoken and written—and the importance of research on language development and disorders

to better understand dyslexia, reading research, and practice. As in that volume, each chapter begins with a summary of the chapter's contents in nontechnical language so that readers can preview the information prior to reading the entire chapter. We hope that this will increase the accessibility of each chapter and commentary.

Section I sets the stage for the subsequent chapters and commentaries in this volume. It consists of this introduction and a chapter by Miller and Alvarez that addresses the history of National Institutes of Health (NIH) funding and presents a preliminary analysis of that funding and resulting advances in the field.

Section II, "Basic Etiology and Learning Mechanisms," consists of five chapters addressing brain bases of dyslexia and reading disabilities (Landi) as well as efforts at diagnosis (de Jong), early detection (Gaab, Turesky, & Sanfilippo), and information on learning mechanisms that underlie reading ability (Rueckl, Zevin, & Wolf; Nation & Mak). Norton's integrative commentary points out the common viewpoints presented across these chapters regarding current questions about etiology and assessment of dyslexia, calling for multidisciplinary teams to bring together the rigorous methods represented in each chapter, to accurately identify and successfully intervene for children who struggle to read.

The three chapters of Section III, "Linguistic Differences and Reading," explore how a child's language background and status as a bilingual or bidialectal speaker affects learning to read and the detection of and intervention for reading disabilities. Saeigh-Haddad addresses the topic in relation to Arabic diglossia, and Washington and Lee-James address the identification of reading disabilities in children who speak dialects that differ from those used in classroom instruction, especially African American children. Connor, Kim, and Yang discuss personalization of literacy instruction for children with varying linguistic and socioeconomic status backgrounds and children with severe learning difficulties. Foorman, in her integrative commentary on these chapters, notes the common theme of missed opportunities for students with linguistic differences or weak oral language skills and the overriding theme that oral language matters in learning to read, a theme also emphasized throughout the chapters in Grigorenko and colleagues (2020).

Identification and treatment are taken up in Section IV. Castles and Kohnen present cognitive approaches to identification, whereas the other four chapters address intervention. Williams, Capin, Stevens, and Vaughn discuss reading comprehension interventions for students with dyslexia; Savage and colleagues address interventions for those at risk for dyslexia; and Verhoeven and Segers present information on reading fluency and intervention. In an integrative commentary, Kearns covers three themes from these chapters—theoretical models of brain processing, the integration of word meaning in word-reading instruction, and the need for individualization of instruction.

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Five chapters on research and practice make up the fifth section, on research and practice. Bulat and colleagues offer an international perspective, describing their approach to dyslexia screening in low-resourced and multilingual contexts, and Petscher and colleagues offer specific considerations for selecting screening tools. Lovett, Steinbach, and De Palma discuss their experiences in scaling up evidence-based interventions, and Joshi and Binks-Cantrell argue for changes and improvements in teacher preparation for reading instruction. Finally, Mele-McCarthy discusses what inclusion really means, the necessary reciprocity of research and practice, and the relations of research, policy, and legislation to impact classroom practice. Patton Terry points out that across the chapters it is clear not only that knowledge matters to bridging the research-to-practice gap and improving reading achievement but also that such knowledge can be improved, impeded, or supported and that knowledge is equally critical to research, practice, and policy.

The last section is the book's finale. Section VI consists solely of Compton's chapter, which presents next steps—what the field must undertake across programs, disciplines, and approaches to provide effective interventions and instruction for all children.

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- Individuals with Disabilities Education Act (IDEA) of 1990, PL 101-476, 20 U.S.C. §§ 1400 *et seq.*
- Individuals with Disabilities Education Improvement Act (IDEA) of 2004, PL 108-446, 20 U.S.C. §§ 1400 et seq.

CHAPTER 2 Investing in Our Future

Examining Programmatic Investments in Dyslexia Research

Brett Miller and Ruben P. Alvarez

SUMMARY

To improve the lives of individuals with dyslexia and their families, the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) has invested in learning disabilities research for more than 50 years. Based on a 1987 report to the U.S. Congress on this investment and research needs, a center-based program focused on learning disabilities was initiated in 1989 (Interagency Committee on Learning Disabilities, 1987). This chapter begins to examine the current and historic investment of the National Institutes of Health (NIH) and NICHD at the intersection of language and literacy research utilizing newer data visualization tools. Our analysis of research support for language and literacy research, inclusive of learning disabilities, spanned across four NIH institutes from 1975 to 2017. As expected, the investment of each institute mirrored its mission (e.g., mental health, neurology), but the vast majority of work on dyslexia and reading disabilities classification and diagnosis was clustered within the learning disabilities centers. In addition, in a separate social network analysis of researcher co-authorship, we suggest that this analytic tool can successfully capture shifts in co-authorship, reflecting trends such as an emerging integration of neurobiological and genetic research in dyslexia; application of machine learning and other approaches to analyzing neurobiological data; and nascent integration of imaging, genetics, and computational modeling. Overall, our conceptualization and analyses of the history of investments in literacy shows that the work supported has resulted in advancements and changes in the dynamics of the field and how it conducts research. Arriving at more general conclusions will require the use of more extensive social network analyses in future efforts.

INTRODUCTION

Improving the lives of individuals with dyslexia and their families remains a cornerstone of the learning disabilities investment at the NIH.

The opinions and assertions presented in this article are those of the authors and do not purport to represent those of the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development, the U.S. National Institutes of Health (NIH), and the U.S. Department of Health and Human Services. Correspondence concerning this article should be addressed to Brett Miller, *Eunice Kennedy Shriver* National Institute of Child Health and Human Development, National Institutes of Health, 6710B Rockledge Dr., Suite 2345, Bethesda, MD 20892. E-mail: brett.miller@nih.gov

Investing in Our Future

The NICHD has invested in dyslexia and reading-related research for over 50 years (e.g., Lyon, 1998) and initiated a center-based program in 1989 (National Institutes of Health, 1988). This chapter focuses on our efforts to conceptualize and link historic investments in literacy to advancements and changes in the dynamics of the field and how it conducts research.

The NICHD investment supports research and training initiatives designed to enhance understanding of the development of reading and writing skills throughout the life course. The NICHD programs emphasize research on typically developing individuals as well as individuals who struggle or have a learning disability (e.g., dyslexia). The NICHD investment is complemented by investments in other parts of the NIH, primarily those that emphasize older adults (National Institute of Aging; NIA), individuals with speech and language disorders (National Institute of Deafness and Communication Disorders; NIDCD), the relationship of language and literacy development to mental health (National Institute of Mental Health: NIMH), and individuals with acquired forms of reading problems (National Institute of Neurological Disorders and Stroke; NINDS). The Reading, Writing and Related Learning Disabilities research program at the NICHD emphasizes the development of prevention, remediation, and instructional/intervention approaches to improve literacy by utilizing a confluence of methodological approaches to understand the behavioral, genetic, and neurobiological foundations of literacy development and its manifestation over time. In recent years, the portfolio has included a substantial emphasis on understudied populations and research topics (RFA-HD-12-203, 2012; RFA-HD-17-003, 2016). This research portfolio is complemented within the Child Development and Behavior Branch by the Early Learning and School Readiness and Language Bilingualism and Biliteracy research programs.

Investment in Literacy

The investment in literacy has fluidly evolved in response to field-driven and NICHD-specific programmatic influences. On the programmatic side, a major influence in the direction of the research portfolio derived from the proceedings of the National Conference on Learning Disabilities held in 1987 (Interagency Committee on Learning Disabilities, 1987). These proceedings were a product of an inter-agency committee on learning disabilities, convened by the NICHD, and mandated by the Health Research Extension Act of 1985 (PL 99-158), which called for review and assessment of federal research findings on learning disabilities. The committee produced a comprehensive report: *Learning Disabilities: A Report to the U.S. Congress* (Interagency Committee on Learning Disabilities, 1987). This report outlined major recommendations for the research field, including a need for a systematic research effort to develop valid and reliable definition and classification systems that could provide a theoretical, conceptual, and empirical framework for the identification of learning disabilities and how to

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distinguish them from other conditions. An outcome of this report was the initiation of the Learning Disabilities Multidisciplinary Research Centers in 1988/1989 (National Institutes of Health, 1988), which were integrative, multidisciplinary projects focused on learning disabilities—primarily dyslexia. This program, later renamed the Learning Disabilities Research Centers (LDRCs), retains its core focus on "etiology, diagnosis, prevention, treatment, and amelioration of learning disabilities" (p. 4) and richly integrative, transdisciplinary team-based projects. Beyond this core, the scientific foci evolved to meet the needs of the researchers, practitioners, policy makers, and families by inclusion of topics such as response to intervention (RFA-HD-04-027, 2004), writing and the relationship of oral language development and executive function skills to reading (RFA-HD-12-202, 2011), and inclusion of mathematical learning disabilities (RFA-HD-17-003, 2016).

In addition, in 2012, the NICHD added a higher risk investment titled the Learning Disabilities Innovation Hubs (LD Hubs). With the advent of the LD Hubs, the NICHD now explicitly and systematically works to address understudied or underserved populations and nascent, higher risk topics in learning disabilities science. These efforts allow for the development and evolution of these burgeoning research topics with the explicit goal of infusing and augmenting future NICHD investments such as the ongoing LDRCs and, more broadly, the field.

Analyzing the NIH Investment

Within the context of our reflections on the past, we aim to carve a path into the future. The remainder of this chapter highlights some of our initial efforts to examine the impact of research investments by the NIH at the intersection of language and literacy (topics addressed throughout this volume and the companion volume, All About Language: Science, Theory, and Practice (Неделя языка: наука, теория, практика) [Grigorenko, Shtyrov, & McCardle, 2020]). The effort originates from anecdotal and informal observations of enhanced connectedness between the language and literacy investments (operationalized here as reading and writing) that developed over time. (Despite the operational definition, the investment in literacy has been heavily weighted historically to reading and reading disabilities inclusive of dyslexia.) Our long-term goal was (and is) to link or align changes in these investments over time to objective measures demonstrating greater connections or intellectual exchange between these research communities. In the future, we plan to identify linkages and to provide a noncausal, interpretative framework to inform further hypothesis-driven data explorations in order to analyze the impact of investment on the field.

This chapter is a first step in the transition from informal observation to relating changes in time to structural investments in literacy and Investing in Our Future

language development research. We have begun this analytic process with reflections on the challenges faced in working with such retrospective analyses and illustrative examples of data visualization efforts currently underway, rather than a summative view of the investment and its potential impact over time. Thus, we focus on two illustrative analyses. The first shows the representational space of investments across the NIH and allows for initial face validity for the tool to reasonably map the conceptual space with the data available. The second analysis examines the ability to represent change in research collaborations over time; to illustrate, we examine the change in co-publication patterns for one investigator over time and qualitatively relate this to changes occurring in the field.

TWO ANALYSES OF NIH DATA

Our initial starting point was the guiding principle that the outcomes need to be objective and systematically available across the analysis period. Although literacy and language development are trans-NIH and transfederal agency priorities (e.g., the National Science Foundation and the Institute of Education Sciences, U.S. Department of Education), we focus our analysis on NIH-specific data sets. The NIH retains a range of administrative data on funded grant applications that is publicly available via the NIH RePort. Cross-agency versions of this tool are available via Federal RePorter, and some international data are available via World RePort, although this tool has fewer common fields with publicly available data and less consistent historical data available about funded awards than the NIH RePorter (NIH, 2018b).

Given the specificity of our research question to NIH-funded awards, we limited our initial analysis to NIH data. By restricting the scope in this manner, we could access and analyze 4 decades of data. We further limited our initial analyses to NIH-funded awards inclusive of institutes with substantive historic investment on children's and young adults' language and/or literacy development, specifically, the NICHD, NIDCD, NIMH, and NINDS. To ensure reasonable data quality, we limited the analyses to investments that received initial funding during fiscal years 1975 to 2017. (We based analysis of NIH awards exclusively on new applications, that is, approved applications that had not received prior funding.)

Data Search Tools

Federal RePORTER is a publicly available smart search tool found at https://federalreporter.nih.gov/ World RePORT can be found at https://worldreport.nih.gov/app/#!/; it is an international data search tool developed and hosted by the NIH. Miller and Alvarez

Generating the Data Set

To generate a data set that focused on language and literacy development, we applied several criteria in a multi-stage process. First, the search was limited to 23 funding mechanisms inclusive of grants and cooperative agreements. The only major exclusions from this list were training (T32) or mentored awards (e.g., fellowships, career development awards). The text-based search parameters included "language," "reading," or "dyslexia," with the goal of being more inclusive at this stage. One or more of the search parameters had to be present in the title, abstract, or aims of a funded application. (For some older data records, particularly in the 1970s and 1980s, one or more of these fields would not be present-typically missing either the abstract, aims, or both. These fields were not systematically recoverable by a more thorough search of the database, and so the criteria were applied to available fields.) Projects additionally had to involve human research, with either de novo data collection or use of extant human data sets, and could involve a combination of animal and human participant research in the same funded grant. Research projects involving animals only were excluded to maintain a focus on human research. One drawback of this exclusion is that historic investments in animal models of dyslexia (e.g., Galaburda, 1994) and language development (e.g., birdsong research) were omitted.

This process generated 2,165 funded applications. To ensure that funded applications included a meaningful focus on language, reading, or dyslexia, we reviewed titles and abstracts for these data records and only selected applications designed to inform our understanding of reading or language development; this review yielded 1,574 funded applications. We used this final data set to explore the conceptual space covered by the research investments during our selected time period (1975–2017).

The Analyses

To explore the data set, we used IN-SPIRE, visual document analysis software developed by Pacific Northwest National Laboratory, and Cytoscape, open source software for complex network analysis and visualization. These tools, combined with proprietary data of the NIH, allow for rich and varied linkages and representation of investments by the NIH to outcomes (e.g., publications, patents, drug approvals) and broader social network analysis (e.g., Bettencourt, Kaiser, & Kaur, 2009). As a first step, we focused on two central goals: 1) to illustrate the conceptual space of the language and literacy investment over time and 2) to utilize illustrative examples to identify the potential of mapping social network space for researchers involved in transdisciplinary dyslexia research.

To capture the language and literacy conceptual space at the NIH, the first analysis utilized a "galaxy" visualization of investments spanning across multiple institutes, including those from NICHD plus other

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relevant institutes at the NIH, specifically NIDCD, NIMH, and NINDS, as previously mentioned. With this visualization, which depicts more closely related grant topics closer to each other on a two-dimensional space, the goal was to map the conceptual space covered by the NIH investments and to verify the distinctiveness and areas of scientific intersection for the various institutes at the NIH that fund grants in language and literacy. We anticipated some overlap in areas of complementary interest, but we anticipated large segments of nonoverlapping scientific space mapped out by the various institutes' missions and/or scientific objectives. (Full descriptions of the mission or scientific objectives of each relevant institute can be found at NIH, 2018a.)

Mapping of Literacy and Language Investment at the NIH

From this exploration, some clear patterns emerge, which are in line with expectations. But first, we want to orient the reader to the figure. Our initial description of the findings focuses on funded applications that align conceptually on the vertical axis of the dimensional space in Figure 2.1. Starting near the top of the figure and working downward, there is a clear language research thread that transitions into more literacy-focused applications near the bottom half of the figure. This axis largely reflects investments funded by NIDCD and NICHD. Toward the top, the conceptual space primarily represents the investment by NIDCD, as can be seen by the descriptors that focus on hearing and audition, cochlear implants



genetic, reading disability, diagnosis, family, mental

Figure 2.1. Visualization depicting 1,574 literacy or language grants funded by the National Institutes of Health between 1975 and 2018. Each project is represented by a dot and is clustered by content similarity into a theme identified by peak labels.

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(implicating populations with hearing impairments), and speech perception and production. Farther down on the figure, the intersection of scientific topics relevant to both NIDCD and NICHD becomes apparent: speech, processing, children, development, cognitive. This can be explained in part by the populations and relative balance of science in these applications, which may have differing levels of emphasis on populations at risk or meeting clinical diagnostic criteria for speech and language difficulties and representing the soft hand-off between research portfolios representing normative and at-risk populations versus those primarily reflecting clinically oriented populations. Farther down, the applications largely represent investment by NICHD with a focus on children's literacy, learning disabilities, and intervention (primarily reading).

A cornerstone of the literacy and language investments at the NICHD is its developmental focus, well represented on the vertical axis. On the horizontal axis of the dimensional space, we see anchors representing investments by NIMH and NINDS most clearly represented by the diagnosis, cognition, dyslexia, autism, magnetic resonance imaging (MRI) cluster on the left, representing some of the investments by NIMH, and in a second cluster on the right reflecting more NINDS-focused applications in the aphasia, treatment, stroke, patients, brain cluster. NIMH is primarily focused on mental health disorders, in particular the neurological and genetic foundations of these conditions (National Institute of Mental Health, 2015). This emphasis is reflected broadly in the cluster but, in particular, in the inclusion of autism and MRI in the conceptual labels. The NINDS emphasis on neurological disorders becomes apparent here with the conceptual emphasis on stroke, aphasia, brain, and patient populations. The general takeaway is that this representational space highlights clear emphases of the four major Institutes involved.

Perhaps less expected, the clusters that include diagnosis as a term are not as close in the dimensional space to other investments in language and literacy. This greater distance or separation may suggest that research on dyslexia and/or reading disability diagnosis is not as well integrated conceptually with other language and literacy research topics. Consistent with this interpretation, emphasis by NICHD on diagnosis of dyslexia and reading disabilities primarily occurs in the context of the investment in LDRCs and is largely absent outside of this investment. Note, the non-LDRC investment represents the majority of the investment by NICHD in literacyparticularly when considering number of grant awards. Likewise, there is an additional cluster that depicts "dyslexia, genetics, neurocognitive, computational," which could not be displayed due to space constraints for Figure 2.1. This additional cluster appears to the far left of the figure and is isolated in space from other clusters. In order to ensure legibility of the concept labels, we chose to highlight the conceptual space that excludes this cluster from the figure to magnify the main application clusters and their labels. No other cluster was excluded from Figure 2.1 representation.

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Research integrating genetics, neurobiology, and computational modeling occurs almost exclusively in the context of the LDRCs and LD Hubs and within our program projects. This confluence of methodological approaches generally involves larger teams and is more resource-intensive. It is perhaps not surprising that this work is less well integrated conceptually with other investments not funded as LDRCs or LD Hubs or as part of larger program projects, which in general require (or strongly encourage) transdisciplinary approaches to science. In addition, part of the explanation may involve the general lack of integration of computational modeling represented across investments. We have seen an increase in attempts to integrate these approaches in some recent grants, but such integrative studies are still the minority of our investment despite the potential for enhanced mechanistic understanding of dyslexia that computational modeling could provide (e.g., Rueckl, 2016; see also Chapter 6).

Co-authorship Network Analysis

Our second analysis illustrates changes in collaboration over time and serves as a starting point to examine the potential of social network tools to capture this relationship in the field of dyslexia research. To do this, we set two primary criteria: 1) The researcher must have a recent but consistent funding history at the NICHD so that substantive archival data can be brought to bear (i.e., more than 10 years of NICHD funding and two or more R01 or comparable awards, all post-2000), and 2) the researcher must have been and still currently be involved in NICHD-funded, team-based science applying multi-method data to inform reading development in order that we could examine changes in team dynamics over time. As our illustrative example of changes in collaboration over time, we mapped the collaboration network for Dr. Kenneth Pugh (key investigator).

As can be seen in Figure 2.2, we represent the co-authorship network based on journal publications associated with this investigator. That is, other investigators who co-authored three or more affiliated journal articles with the key investigator are represented with stronger co-publication networks, represented by thicker lines connecting the author to these investigators. The figure also shows the strength of the relationship of co-authors to each other for affiliated publications for which this investigator was also an author (and the paper was affiliated with an NIH-funded grant). The figure includes three co-author network spaces covering distinct nonoverlapping time periods: 2002–2008, 2009–2013, and 2014–2018. (Note that the data quality improves markedly beginning in 2008. This change is due to a 2008 NIH requirement to make all peer-reviewed journal articles associated with funded applications accepted on or after April 7, 2008, freely available through PubMed within 1 year of publication [Section 217 of the Omnibus Appropriations Act of 2009 [PL 111-8]; NOT-OD-08-033].) These time slices give a glimpse of the collaboration network supported through

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Figure 2.2. Co-author network based on the portfolio of *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD) grants of Dr. Kenneth R. Pugh demonstrating changes in scientific collaboration over time (2002–2008, 2009–2013, and 2014–2018). Nodes (circles) indicate authors and edges (lines) indicate co-authorship in a paper. Node size represents degree centrality or the number of edges (co-authors) a node has. Edge weight (width) represents the number of times the authors published together (i.e., the strength of the co-author relationship).

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NIH funding for this investigator. As a caveat, we are aware that the overall collaboration space for this investigator is larger than represented here, particularly since 2010. Inherent limitations of this analysis are, first, the sole reliance on publications associated with NIH-funded projects because some publications may not yet be published due to lag times in publishing, and second, that the analysis does not fully reflect all collaborations, particularly non–U.S.-based collaborations unaffiliated with an NIH award or represented in non-journal publications. Despite these limitations, we find that this representation tool effectively captures broader changes in collaborative networks over time for this key investigator, which we interpret as reflecting both changes in the projects he has been involved in over time as well as being consistent with broader changes in the types of transdisciplinary research conducted.

To illustrate, in the 2002-2008 period, the identified co-authorship network space largely represents neurobiological and behavioral sciences inquiries into the development of the reading circuit of the brain. For example, co-authors Constable, Frost, Fulbright, Gore, Mencl, Shaywitz, and Shaywitz were heavily involved in ongoing MRI projects during this time window. The dynamics of the collaborations changed from 2009 to 2013, associated with changes in the nature of the NIH-supported collaborations likely resulting from the expiration of a LDRC at Yale, where Drs. Shaywitz, Shaywitz, and Fletcher were more heavily involved, and the development of new collaborations to begin linking genetics to neurobiology and behavior (i.e., Grigorenko). Consistent with this evolution, in 2014–2018, we interpret these changes to reflect continued and increased collaboration with early career scholars (e.g., Preston, Molfese, Landi) making the transition to greater integration of computational modeling and advanced statistical approaches (e.g., Rueckl, Hancock, Hoeft) and continued integration of neurobiology and genetics (e.g., Grigorenko, Landi). (For a summary of recent work by these collaborators, see Chapters 3 and 6, this volume, and Chapter 3, in the complementary volume [Grigorenko et al., 2020]). We interpret this recent shift in co-authorship to reflect emerging integration of neurobiological and genetic research in dyslexia, application of machine learning and other approaches to analyzing neurobiological data, and nascent integration of imaging, genetics, and computational modeling (Rueckl et al., this volume). These shifts may also be associated with increasingly limited opportunities for funding for both larger programmatic efforts (i.e., program project investments that necessitate larger teams and integrative projects) and long-standing systematic lines of investigator-initiated funding via the standard investigator-initiated R01 grants.

CONCLUSION

These analyses represent our initial attempts to capture some of the potential impacts of investments from the language and literacy portfolios at the NICHD and beyond. Long-term, this data exploration, paired with future

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efforts, intends to elucidate how external funding (targeted and nontargeted) has served as an impetus to enhance collaboration in research in general and, more specifically, to enhance the interrelationship between language and literacy research. The NIH is a large historic funder of research on language and literacy, and various previous efforts have highlighted publications coming out of these investments, particularly in the literacy domain (e.g., Lyon, 1999; Lyon & Alexander, 1997; Lyon, Alexander, & Yaffe, 1997; McCardle, 2001; McCardle, Cooper, & Freund, 2005; McCardle, Cooper, Karp, & Houle, 2001; Miller & McCardle, 2011; Miller, McCardle, & Hernandez, 2010). Our long-term goal is to be inclusive of, but to extend descriptions of, publications to associate broader influence that investments may have in trends in the field-including influence on practice and usefulness in informing policy. In short, our goal is to capture the successes, and potentially the shortfalls, of the investment to advance our understanding of language and literacy as it relates to explicit (and implicit) goals of the relevant investment portfolios and their interrelationships and to inform strategic investments in the future. This effort is part of a broader, albeit informal, continuous improvement model to identify ways to maximize positive impact from short-, medium-, and long-term investments and to document these outcomes in objective ways. The NICHD is privileged to be the primary NIH Institute for literacy and related learning disabilities, but with this privilege comes the responsibility to show impact for investments. This analytic exploration is part of our continued effort to demonstrate and ensure this over time.

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