

# 1 What is dyslexia?

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## Introduction

In January 2009, a British Member of Parliament, Graham Stringer, caused something of an international storm by questioning the validity of the concept of dyslexia. Unlike the majority of critiques that have questioned the conceptual and diagnostic utility of this construct (e.g., Elliott & Gibbs, 2008; Stanovich, 1994), his criticisms, written on his website (<http://www.manchesterconfidential.co.uk/News/Dyslexia-is-a-myth> [retrieved October 5, 2013]), were far more direct and accusatory. Describing dyslexia as “a cruel fiction . . . no more real than the 19th century scientific construction of ‘the æther’ to explain how light travels through a vacuum,” he argued that the reason why so many children struggled with literacy was because they had been failed by the education “establishment.” Rather than admitting that poor instruction was at fault, he argued, a brain disorder called dyslexia had been invented. For Stringer, “to label children as dyslexic because they’re confused by poor teaching methods is wicked. . . . The sooner it is consigned to the same dustbin of history, the better” (ibid.). In response, the Chief Executive of the British Dyslexia Association stated on the association’s website: “Once again dyslexia seems to be making the headlines for all the wrong reasons. It is frustrating that the focus should be on whether dyslexia exists or not, when there is so much evidence to support that it does” (<http://dyslexiaaction.org.uk/news/mp%E2%80%99s-claims-dyslexia-cruel-fiction> [retrieved October 5, 2013]).

As this response acknowledges, questions about the existence or otherwise of dyslexia have raged periodically for many years. At first glance, this seems rather puzzling, as fascination with unexpected reading difficulties in individuals with high levels of intelligence and sound eyesight has been expressed for centuries (Shaywitz, 2005), and the topic has been extensively researched across a variety of disciplines.

Although the first account of “word-blindness” was produced in 1676 by the physician John Schmidt, much of the early published work appeared in the latter

part of the nineteenth century, a time when an inability to learn to read first became a medical concern (Campbell, 2011). Early investigations were largely concerned with examining difficulties that had been acquired as a result of some form of brain trauma. In 1872, Sir William Broadbent reported the case of a man who, following a head injury, lost the capacity to read, despite being able to write with little difficulty. Although he had good conversational skills and extensive vocabulary, he struggled to name objects presented to him. Broadbent asserted that the reading failure was a result of this more general difficulty in naming objects. Five years later, Kussmaul (1877) reported on the case of an adult patient with no apparent disabilities other than severe reading difficulties. Kussmaul coined the term “word-blindness” to describe the inability to read text despite sound eyesight, intelligence, and speech.

The term “dyslexia” was first used in 1887 by Rudolf Berlin, a German ophthalmologist, to describe a particular form of word-blindness found in adults, which, he argued, was caused by brain lesions. Berlin contended that severe damage would result in alexia, a total inability to read, whereas partial damage would most likely result in dyslexia, a significant difficulty in decoding written symbols. Here, the focus was on the effect of a physical trauma of some kind, “acquired dyslexia,” rather than that which develops naturally from a young age, “developmental dyslexia,” the focus of almost all of the dyslexia literature.

The idea that “word-blindness” could be a developmental as well as an acquired condition came somewhat later. As Shaywitz (2005) notes, this is unsurprising as the suddenness of an acquired loss is considerably more salient than the more subtle picture of unfolding developmental difficulties. In 1896, a paper on “congenital word-blindness” by a British physician, W. Pringle Morgan (1896), described a child of fourteen years of age who had failed to learn to read despite normal intelligence and good eyesight. Noting the boy’s other abilities, he observed: “The schoolmaster who has taught him for some years says that he would be the smartest lad in the school life if the instruction were entirely oral” (p. 1378). Morgan described two generations of one family with six cases that had strikingly similar symptoms and opined that the problem was congenital, involving a defective ability to store visual impressions of words.

Morgan’s paper acted as a stimulus for a flurry of case studies, most notably by a Scottish ophthalmologist, James Hinshelwood, who gathered data on several cases involving both acquired and congenital word-blindness. The children he reported on in a classic text, *Congenital Word-Blindness* (Hinshelwood, 1917), were typically male (as were the majority of similar cases of this period [Stephenson, 1904]), intelligent, had sound eyesight, and performed well on oral tasks.

Following an autopsy on a patient whose progress he had monitored for several years, Hinshelwood (1902) located the cause of reading disability in the

angular gyrus. He suggested that the primary disability was visual memory for words and letters and advocated one-to-one training designed to increase visual memory as the preferred form of intervention. Noting the embarrassment and ridicule often experienced by poor readers in the classroom, he commented:

It is a matter of the highest importance to recognise as early as possible the true nature of this defect, when it is met with in a child. It may prevent much waste of valuable time and may save the child from suffering and cruel treatment. When a child manifests great difficulty in learning to read and is unable to keep up in progress with its fellows, the cause is generally assigned to stupidity or laziness, and no systematised method is directed to the training of such a child. A little knowledge and careful analysis of the child's case would soon make it clear that the difficulty experienced was due to a defect in the visual memory of words and letters; the child would then be regarded in the proper light as one with a congenital defect in a particular area of the brain, a defect which, however, can often be remedied by persevering and persistent training. The sooner the true nature of the defect is realised, the better are the chances of the child's improvement. (Hinshelwood, 1902, cited in Shaywitz, 2005, pp. 21–22).

In their historical account of learning disabilities – a term that includes a number of specific areas of problematic functioning, including reading disability – Hallahan and Mercer (2001) observed that groundbreaking work largely shifted from Europe to the United States during the 1920s. With the increasing trend toward mass education and the issues that resulted in conjunction with the dissemination of the idea of universal literacy (Grigorenko, 2011), many researchers found themselves with the responsibility not only of understanding and explaining children's academic and behavioral difficulties but also of taking a lead in assessment and remediation techniques, particularly in relation to reading disabilities (Hallahan & Mock, 2003).

Leading clinical researchers at this time were Samuel Orton and Grace Fernald. Fernald was a clinician who employed a multisensory approach for those with reading difficulties and sought to evaluate the success or otherwise of her techniques by maintaining detailed case records of her clients' progress. Despite the rather anecdotal mode of evaluation, still largely the case for multisensory approaches today, such techniques have an intuitive appeal and continue to be popular among specialist dyslexia teachers (see Chapter 4). Orton, Fernald's contemporary, was a neurologist who became best known for his work on educational intervention, in particular multisensory approaches and an emphasis on phonics. Orton attempted to understand the origins of reading difficulties, introducing a number of ideas that added to contemporary understandings. Like his intellectual predecessor, Hinshelwood, he was interested in areas of the brain that might be influential but believed those other than the angular gyrus were involved. He suggested that reading difficulties were primarily the result of poor cerebral dominance in which the

nondominant hemisphere stored a different representation to that of the dominant one. This explained the common tendency for cases to exhibit letter and word reversals, and the use of mirror reading and writing. To reflect a shift from an emphasis on purely visual deficits, Orton recommended that the term “word-blindness” should be replaced by “strephosymbolia,” which in Greek means “twisted.” His work proved highly influential and promoted much theorizing on various visual mechanisms held to be responsible for reading difficulties.

Early research pioneers sought to understand a condition that continues to pose significant problems for many individuals and challenges to those who seek to help them. Their puzzlement over the particular problems encountered by a small number of children would appear sufficient to refute any suggestion that dyslexia/reading disability is merely the consequence of poor teaching. Since then, more than a century of research activity has provided incontrovertible evidence that some children experience particular difficulties that render the reading process highly problematic. The original belief of these early clinicians that the difficulty was caused by a visual pathology has now been largely rejected in favor of language-based origins (see Chirkina & Grigorenko, in press, for details of similar conclusions that were arrived at rather earlier in the Soviet Union), although, interestingly, the conception of dyslexia as essentially a visual problem is still widely held by the general public (Christo, Davis, & Brock, 2009). Interestingly, the role of underlying visual processes in reading disability is gaining significant researcher interest once again (Stein & Kapoula, 2012).

Clearly, there are many children who struggle to learn to read for reasons other than poor teaching. For this reason, the fact that there are some who question the value of the term “dyslexia” may appear puzzling, particularly to those for whom the existence of such difficulties is all too real. However, the primary issue is not whether biologically based reading difficulties exist (the answer is an unequivocal “yes”), but rather how we should best understand and address literacy problems across clinical, educational, occupational, and social policy contexts. Essentially, the dyslexia debate centers on the extent to which the dyslexia construct operates as a rigorous scientific construct that adds to our capacity to help those who struggle to learn to read.

### **Definitions of dyslexia**

Without an agreed-on definition that can be implemented reliably and validly, understanding the nature, causes, and best treatments for reading disability is unlikely. Similarly, an agreed-on definition is essential for practice. (Brown Waesche, Schatschneider, Maner, Ahmed, & Wagner, 2011, p. 296)

Somewhat paradoxically, defining dyslexia is seemingly both very easy and very difficult. It is easy, largely because most parties agree that the definition should principally concern the inherent and particular difficulties encountered by those who struggle to read text. It is difficult because the field has been unable to produce a universally accepted definition that is not imprecise, amorphous, or difficult to operationalize. As noted in the section-opening quotation, without a universally agreed-on operational definition, we cannot be sure that assessments are measuring the same thing, and as a result, there are likely to be serious doubts about any resultant diagnosis or classification (Siegel & Lipka, 2008).

One of the particular difficulties concerning definitions of dyslexia is that the term has variously been seen as different from, or synonymous to, several other labels that involve problems with literacy. These include specific reading retardation, reading difficulties, specific reading difficulties, reading disability, learning disability, unexpected reading difficulty, and specific learning difficulties. These overlap substantially and vary according to causal assumptions (Rice & Brooks, 2004). Thus, some (National Institute of Child Health and Development, 2007; Pennington & Bishop, 2009; Siegel & Mazabel, 2013; Wagner, 2008) do not differentiate between the terms “dyslexia” and “reading disability,” and many (e.g., Swanson & Hsieh, 2009) use the term “reading disability” as synonymous with a number of terms: “dyslexia,” “reading disorder,” “learning disabilities in reading,” and “specific reading disabilities.” However, many other researchers, clinicians, and educators seek to reserve the term “dyslexia” to describe a smaller group within the larger pool of poor decoders. Determining the particular constellation of difficulties that marks out such a subgroup introduces a further set of contested definitions and understandings.

The U.S. National Research Council (Snow, Burns, & Griffin, 1998) identified three broad reasons for reading difficulty. These concern (1) difficulties of understanding and using the alphabetic principle in order to develop accurate and fluent reading; (2) poor acquisition of the verbal knowledge and strategies that are important to comprehend written material; and (3) a lack of motivation to read. In general, those who use the term “dyslexia” are concerned with the first of these, although poor reading comprehension and a lack of motivation to read are often associated by-products of word-reading difficulties (Morgan, Fuchs et al., 2008), and the motivational problems of some poor readers are likely to affect their response to intervention (Vaughn et al., 2009).

While there appears to be a bidirectional relationship between reading and motivation, it is not clear to what extent this latter variable serves to moderate the impact of a preexisting difficulty (Catts & Adlof, 2011) although there is some evidence that high engagement in reading-related activities can serve as a protective factor for young children at risk of future reading disability (Eklund, Torppa, & Lyytinen, 2013). There is also some evidence that students with

reading disabilities tend to mix together in school peer groups, and this may result in lowered motivation and educational achievement, particularly for males (Kiuru et al., 2011).

Some believe that not all of those who struggle to decode text should be considered dyslexic, with the relative influence of nature and nurture often seen as a key factor. Herein lies a critical conceptual and diagnostic issue: In what ways is it meaningful and potentially valuable to conceive of a dyslexic subgroup within a larger pool of poor readers who all find reading accuracy (and, for some, fluency) problematic?

The critical question in dyslexia research is not whether dyslexic people in particular differ from 'normal' readers. It is *whether dyslexic people differ from other poor readers*. (Rice & Brooks, 2004, p. 33; emphasis in the original)

It is important to recognize that the value of a definition may be tempered by its purpose. Thus, as Stanovich (1992) has noted, there are definitions that are designed to serve scientific purposes, with fairly strict scientific criteria, and others that are employed for determining the allocation of additional educational resources for students with learning difficulties of various kinds. Some definitions are used by advocacy groups to highlight specific learning problems and to gain formal legislative support. For such groups, strict conceptual rigor may not be desirable, particularly where its use to guide resource planning might lead to the reduction of services to those deemed to be in need of these (Kavale & Forness, 2003):

The highly restrictive definitions of the research community are resisted by school personnel, who often want the broadest definition possible in order to allow themselves discretion in providing services for children with generic school learning problems. (Stanovich, 1992, p. 279)

Irrespective of the breadth of the definition, it is widely agreed that the core problem of dyslexia – a difficulty in decoding text – should be contrasted with the ultimate goal of reading – taking meaning from the written word. While these two processes are clearly related, they each involve a number of different skills, and strengths and weaknesses may be found in either one or both of these processes. Some can understand considerably more of a passage of text than one would expect on the basis of their reading skills; others may decode well but take little meaning from the print before them. The term “hyperlexia” is used to describe the phenomenon where an individual’s word-reading skills are considerably higher than are their levels of reading comprehension, verbal functioning, or general cognitive functioning (Grigorenko, Klin, & Volkmar, 2003). Unsurprisingly, however, those who experience severe difficulties with decoding will usually experience associated problems of reading comprehension, in part because the effort that must be expended on decoding is likely to detract

from the capacity to focus on deriving meaning. However the dependence of reading comprehension on word recognition appears to be lesser for older children (Hulslander, Olson, Willcut, & Wadsworth, 2010). In other words, there appears to be some age-based dynamics in the relationship between decoding and comprehension. They appear to be more closely related at the beginning of the process of reading acquisition but are more dissociated at the later stages when comprehension becomes increasingly dependent on skills of inferencing, capitalizing on general knowledge and vocabulary, deriving meaning from context, and so forth.

Fletcher (2009) notes a shift from a conception of general reading disorder to a description of more specific forms of reading difficulty. A differentiation can be made between dyslexia – which, he contends, describes a difficulty in decoding single words – and other forms of reading difficulty involving problems of reading fluency and comprehension. The child with dyslexia will most likely encounter problems in all three domains because of the decoding “bottleneck.” For Fletcher, such individuals can be contrasted with a small number of nondyslexic poor readers who may demonstrate particular difficulties with fluency or comprehension but have few problems with single-word reading. Many people with reading difficulties succeed in overcoming the worst problems of decoding yet continue to struggle to read fluently (Biancarosa & Snow, 2006). (Note: The emphasis on single-word reading reflects the fact that, unlike for passages of continuous text, semantic and syntactic knowledge cannot be used to help decode the target words [Fletcher, 2009; Vellutino, Fletcher, Snowling, & Scanlon, 2004]).

Much of the literature on reading in international journals has had a strong Anglocentric focus, although this situation is being redressed with studies of reading difficulties in other languages now appearing more widely in prestigious international journals. Nevertheless, it has been argued that current knowledge has largely been derived from a highly idiosyncratic, “outlier” orthography (i.e., English) that has only limited relevance for a universal science of reading (Share, 2008). In transparent languages, the main reading difficulty tends to center on reading fluency rather than accurate word reading. In contrast, the complexities of letter-sound correspondence in the English language have resulted in a heavy focus on accuracy and a corresponding neglect, until relatively recently, of fluency in relation to both reading research and classroom instruction. Currently, the precise nature of reading fluency, its causal mechanisms, and whether the many features that are associated with it represent a single construct or a range of abilities are unclear. It remains to be seen whether greater interest in fluency, something that ‘involves every process and subskill involved in reading’ (Wolf & Katzir-Cohen, 2001, p. 220), will reduce the current emphasis on single-word reading in English-language speakers.

Recognition of the advantages of greater specification of different forms of reading difficulty would appear to be reflected in the recent psychiatric classification literature. The draft revision to the fifth version of the American Psychiatric Association's *Diagnostic and Statistical Manual* (DSM-5) originally suggested the replacement of the term "learning disorder" with that of "dyslexia" in order, it was stated, to render APA terminology consistent with international use. It was proposed that the term "dyslexia" should be employed to describe difficulties in reading accuracy or fluency that are not consistent with the person's chronological age, educational opportunities, or intellectual abilities.

In an update (May 2012), however, the draft proposals were amended. The diagnosis of *Learning Disorder* was now to be changed to *Specific Learning Disorder*, and the various named types of learning disorder (including dyslexia) were no longer recommended. The key reason for this was the variety of international conceptions and understandings of dyslexia (and other similar terms such as dyscalculia) that exist (Tannock, personal communication). Within the overarching category of *Specific Learning Disorder*, clinicians are required to specify for a given individual which particular domains of academic difficulty and their subskills are impaired. For *reading*, the particular skills identified are word reading accuracy, fluency, and reading comprehension. A second literacy-related domain, entitled *written expression*, includes spelling, grammar and punctuation, and clarity or organization of written expression.

One of the key difficulties of those who have tried to produce a definition of dyslexia concerns the extent of its inclusivity. Even relatively general definitions have been criticized as too inclusive by some groups and too exclusive by others. For example, a British Psychological Society (BPS) Working Party sought to provide what was described as a *working*, rather than an *operational*, definition (Reason, 2001). It is not immediately apparent exactly what this distinction means in practice, but it is likely that members of the Working Party were wary of producing a definitive account that might be subject to challenge in the courts or elsewhere in relation to specific cases. The BPS definition links accuracy and fluency together as follows: "Dyslexia is evident when accurate and fluent word reading and/or spelling develops very incompletely or with great difficulty. This focuses on literacy learning at the "word" level and implies that the problem is severe and persistent despite appropriate learning opportunities" (British Psychological Society, 1999, p. 64).

In the United Kingdom, the government-sponsored Rose Report (Rose, 2009) definition, geared primarily to a professional audience, took a similar stance: "Dyslexia is a learning difficulty that primarily affects the skills involved in accurate and fluent word reading and spelling" (p. 30). The highly general



nature of this definition was subjected to criticism by the House of Commons, Science and Technology Select Committee (House of Commons, 2009) on the grounds that “[t]he Rose Report’s definition of dyslexia is . . . so broad and blurred at the edges that it is difficult to see how it could be useful in any diagnostic sense” (paragraph 71, p. 26).

As previously noted, general definitions of this type can result in mutual dissatisfaction from otherwise opposing camps. On one side are those who think that such conceptions are too inclusive and spuriously include nondyslexic poor readers. On the other are those who believe that these are overly exclusive and rule out recognition of those “true” dyslexics who do not present with significant decoding problems but instead have other manifest forms of difficulty that stem from the condition. Situated within the former camp are those who believe that there are marked differences at the cognitive level between dyslexics and other poor readers. For such individuals, broad definitions fail to permit appropriate differentiation between these two groups (Herrington & Hunter-Carsch, 2001; Thomson, 2002, 2003). Thomson (2002) criticizes the BPS definition because, in his opinion, descriptive definitions of this kind downplay the importance of diagnosis, something he considers crucial for determining the most appropriate form of intervention.

In the latter camp are those who believe that descriptive definitions that focus on reading wrongly exclude from the diagnosis those who have other symptoms of dyslexia. Thus Cooke (2001, p. 49) was “in no doubt” that parents, teachers, and adult dyslexics would be concerned that the BPS definition could exclude those whose reading was no longer highly problematic but who nevertheless struggle with a range of problems such as being personally disorganized, experience difficulty filling in forms correctly, or find mathematical or musical notation problematic (a group, according to Cooke, that is sometimes misguidedly known as “compensated dyslexics”). In similar vein, she is also critical of the focus on reading at the word level on the grounds that this emphasis may exclude those whose primary difficulties concern reading fluency and comprehension.

If we wish to define dyslexia in a way that is more discriminating than that employed in the BPS or Rose solutions, the definition would need to be framed in a fashion that embodies either symptoms, causality or prognosis (Tønnessen, 1995). Symptoms refer to “observable and/or measurable signs of underlying conditions and processes. When we describe reading behaviour or reading achievement without reference to their underlying causes, then we are at the symptom level” (Tønnessen, 1997, p. 80). Symptom-based definitions of dyslexia may be inclusionary or exclusionary; the presence of the condition may be signaled by the absence of certain symptoms or by the presence of others.

Heaton and Winterton (1996) suggest that there are many reasons why a child may experience difficulties in learning to read. Key factors are:

- low intelligence
- socio-economic disadvantage
- inadequate schooling
- physical disability (e.g., visual or hearing difficulties)
- visible neurological impairment which goes beyond reading and writing
- emotional and behavioural factors which might affect attention, concentration and responsiveness to teacher direction
- dyslexia.

On such a basis, dyslexia could be defined and identified by the absence of the other six factors listed (Lyon, 1995). However, the field has tended to move away from identification on the base of exclusion (Lyon & Weiser, 2013) largely because when we seek to operationalize the construct on the basis of this conception, problems rapidly emerge.

As is discussed in some detail later in this chapter, the use of IQ for diagnostic purposes in dyslexia has been the subject of much debate and is now largely discredited. It would appear that for intellectual abilities to be considered as an exclusionary factor in a diagnosis, the individual would need to be functioning at a level sufficiently low to be considered to be “mentally retarded” – that is, scoring two or even three standard deviations below the mean on an IQ test. Such a perspective would imply that those with IQs no further than two standard deviations below the mean (typically, 70+) would not be automatically excluded from the possibility of a diagnosis of dyslexia. Such a view clearly differs from others (e.g., Nicolson & Fawcett, 2007), who consider dyslexic children to have average or above-average intelligence. Thus, these researchers are critical of a study by White et al. (2006), in which some children scoring below an IQ of 90 form part of the dyslexic sample, because this might lead to the inclusion of some with “no discrepancy between their reading and general performance” (Nicolson & Fawcett, 2006, p. 260).

Socioeconomic disadvantage is another highly problematic criterion, primarily because its use as an alternative explanation for reading difficulties could reduce the possibility of a diagnosis of dyslexia in poor readers from impoverished backgrounds (Rutter, 1978). Clearly, negative environmental circumstances, particularly disruptive early life experiences resulting from extreme poverty, and low levels of parental education will have a strong effect on the development of children’s language and literacy (Hartas, 2011; Herbers et al., 2012). Wolf (2007), for example, cites a study of an impoverished Californian community (Hart & Risley, 2003) in which by the age of five, some of the children studied would have heard 32 million fewer words spoken to them than the average middle-class child. Socially disadvantaged children are less likely to have high levels of print exposure in the home, a resource that, while