

The Right to Write: Even if I Can't Hold a Pencil

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Abstract

All students need to learn written expression skills, including students who have severe and multiple disabilities. This project covers not only the why, but the when and how to teach written expression for students with the most severe learning challenges including intellectual, physical disabilities and deaf-blindness. There is a growing body of evidence-based practice that demonstrates writing is an important part of literacy instruction. Staff who work in school systems need more training because there are still many barriers for students with significant disabilities in learning not only to read, but also write.

The Right to Write: Even if I Can't Hold a Pencil

In education we work extensively on vocabulary, grammar and language development to promote communication and literacy skills for students' ultimate success. In special education we have even begun doing this for students who have significant challenges and use augmentative and alternative communication (AAC). However, do we expect students to only use these skills verbally? Verbal communication allows for sharing thoughts and ideas with someone in the near vicinity. We should expect these same students to use these same skills to communicate distantly, with others who may not be in the immediate area at that exact moment in time (Sturm, Cali, Nelson & Staskowski, 2012). We work toward teaching all other students to be able to communicate distantly. We expect all other students to write letters, email, fill out forms, make grocery lists, to do lists and fill in a planner.

In its essence, literature is about communication. It is about sharing thoughts, feelings and ideas with others who may not be right here, right now to hear the words coming out of one's mouth. This project report will review and explore why educators must provide comprehensive literacy instruction that not only includes reading, but also writing. Although, less well documented than reading, writing is a part of comprehensive literacy instruction. All students have the right to have access to a comprehensive literacy instruction through language development and the generative writing process. These same students also need the educators, backed by appropriate supports and training, and to have 'can-do' attitudes to help them overcome barriers of accessibility. All educators need to have a broader view of written expression and the writing process in order to provide appropriate instruction, which can facilitate and demonstrate continuous progress toward meeting state standards and assessments. Most of all, we need to teach all students regardless of the severity of his or her learning

challenges not only to read but to write, in order to meet each person's basic human right to use language and literature to develop a social-emotional connection to a larger community of people.

All Students have Rights

All humans have the right to communicate making needs and wants known to others. In an attempt to express these ideas, a person may have the power to enrich his own life and possibly other's lives by sharing a message. All students regardless of the severity of their physical, intellectual or sensory impairments have rights supported by many governing bodies. These bodies range from federal and state laws to national and international organizations.

Rowland and Schweigert (n.d.) summarized the Communication Bill of Rights that appear in guidelines of the National Joint committee for the Communication Needs of Persons with Severe Disabilities, "all people with a disability of any extent or severity have a basic right to affect, through communication the conditions of their existence. All people have the following specific communication rights in their daily interactions...Have access at all times to any needed A.A.C. and other A.T. devices...Be communicated with in ways that are meaningful, understandable and culturally and linguistically appropriate" (Rowland & Schweigert, n.d., p. 2) Although, IDEA (2004) makes it clear students of all abilities and needs are to have a Free and Appropriate Public Education, by having access and being able to participate in the general education curriculum, the "Communication Bill of Rights" takes the idea a step further into human rights.

According to the National Agenda for the Education of Young Children (NAEYC), educational team members are reminded, "IEP teams also must consider the method or methods for teaching blind and visually impaired children, including those with other disabilities, how to

write and compose”. According to the Path’s to Literacy website (NAEYC, 2015, *para* 1), “All children, including those with multiple disabilities, should be given an opportunity to include "writing" in their daily routine.” “One of the principles of the “No Child Left Behind Act” of 2001 is that students with disabilities have a fundamental right to have access to the same high quality education as their peers without disabilities” (Carroll, 2014, p.1). This right to access the curriculum is the foundation of a Free Appropriate Public Education (FAPE). However, teams may be confused by what *access* and *appropriate* may look like for some students with the most unique learning needs.

The National Center on Deaf-Blindness has posted a *Bill of Rights* for literacy instruction by Yoder, Erickson, and Koppenhaver (1997). This *Bill of Rights* states that regardless of the severity of any person’s disability, s/he has the right to learn to read and write in whatever form that is “meaningful, culturally and linguistically appropriate” (p.1) to provide access to the literature (Yoder, Erickson, & Koppenhaver, 1997). It goes on to proclaim that all individuals including those with the most involved disabilities, have the right to be educated by “teachers and other service providers who are knowledgeable about literacy instruction methods and principles. These methods include but are not limited to instruction, assessment, and the technologies required to make literacy accessible to individuals with disabilities” (Yoder, Erickson, Koppenhaver, 1997, p.1). The right to comprehensive literacy instruction is based on, “principles include, but are not limited to, the beliefs that literacy is learned across places and time, and no person is too disabled to benefit from literacy learning opportunities” (Yoder, Erickson, Koppenhaver, 1997, p.1).

In many pieces of literature there is continuous evidence to support the principle that literacy is a learned process even for people who have significant disabilities, including

intellectual, physical, sensory and even deaf-blindness. According to Downing and MacFarland (2010), “The question is not whether students can learn, but how much they can learn and with what types of instruction and support” (p. 2). Regardless of the severity of any individual’s disability, with systematic instructional supports all students will show progress in literacy instruction (Cooper-Duffy, Szedia & Hyer, 2010; Erickson, Hatch & Clendon, 2010; Wollak & Koppenhaver, 2011).

Standards of Practice/ Assessment

In addition to the laws and organizations that support literacy instruction, there are standards of practice and assessments that guide our decisions in the realm of education. Districts are under pressure to meet guidelines for Common Core State Standards and educating students to pass statewide assessments. According to Sturm, Cali, Nelson and Staskowski (2012), “despite an emphasis on improving writing instruction for typically developing beginning writers, students with disabilities continue to lag behind their peers on a statewide and national writing assessments” (p. 298). In addition, Sturm et al. (2012) proposes, “children with the most severe and complex disabilities may not even be represented in these national data (National Assessment of Educational Progress) because they were not considered to be writers” (p. 298). Sturm et al. (2012) explained, based an extensive review of literature, that there are no existing measures sensitive enough for atypical writers. So that leaves us asking the question that Cooper-Duffy et al. (2010) asked, “how can teachers teach academics that link to SCOS (Standards Course of Study) so that students with cognitive disabilities can not only understand but make yearly progress” especially since “the reality is many students with significant cognitive disabilities are not fully included in the general education classrooms” (p. 31)?

The primary goal of the CCSS (Common Core State Standards) is to “provide clear

consistent framework to prepare children for college and the workforce”, (Carroll, 2014, p. 1). All students including those with special education needs are expected to work toward meeting CCSS, even students with the most significant learning challenges are expected to participate in general education curriculum with accommodations and supports (Carroll, 2014). It is important for educators to be able to show progress with written expression for students with significant disabilities and that we need adequate tools to show this progress over time (Hanser, 2006); Sturm, Cali, Nelson & Staskowski (2012).

Without this kind of legal, legislative and evidence based practice, “students with severe and multiple disabilities risk remaining beginning writers for life” (Sturm, Cali, Nelson & Staskowski, 2012, p. 301). Having “access to the general education curriculum means having the opportunity to learn the same academic content as typical peers for student’s grade level. Because of the strong focus on functional curriculum in the last two decades, educators need resources to know how to teach this content” (Browder & Spooner, 2006, p. 10) and provide real access to general education curriculum.

In addition to the rights and standards we are trying to meet in the school system, teachers must use the tool of collaboration to make a student’s educational experience successful. According to Downing (2005a), “the cohesiveness of a student’s program is placed in jeopardy when professionals stay within clearly defined boundaries and work independent without knowledge of what other team members are doing with a student” (p. 205). Janey and Snell (2011) remind us that for effective collaboration it is important to have a.) Clearly defined roles and responsibilities, b.) Agree on strategies for communication especially in relation to instruction and support for the student and c.) Have team meetings with ground rules, rotating roles and specific agendas.

Increased Language and Literacy Development

In our efforts to teach literacy to all students, it is universally recognized that language development is at the core of becoming a literate person. Copper-Duffy, Szedia and Hyer (2010) summarize the work of Smith, Demarco & Worley (2009) recommending teaching students language and vocabulary because... “(d) students have a right to know all kinds of words and (e) the words will increase a student’s conversational skills and make it possible to communicate with others” (p. 34). The meaning of language develops through these shared experiences of communicating (McDonnell & Copeland, 2011). When we use the same language system to communicate with the student that we expect the student to communicate with us, it increases comprehension (Jones & Bailey-Orr, 2012).

According to Downing and MacFarland (2010), “Teachers need to develop specific skills and knowledge...in many areas...including communication skill development in order to implement them in various school settings” (p. 2). By using these communication skills and expecting students to use communication in various school settings students with significant disabilities learn “both academic and non-academic skills” (Downing & MacFarland, 2010, p. 2).

Some students who have not yet learned a formal communication system often demonstrate a wide range of socially acceptable and unacceptable behaviors. These behaviors can range from pointing, pulling and gesturing to hitting, biting and screaming. Yet, Downing (2005a) tells us, “unconventional behaviors should be seen as a cry for help—for someone to listen to the individual and that person learn—and not as a reason to wait for “better” behavior to emerge” (p. 17). This behavioral communication can be shaped into a variety of expressive forms. Some of these expressive forms include more recognizable gestures, pointing, manipulating items, using pictures or electronic devices. Foley, Koppenhaver and Williams

(2009) explain that writing is just another form of communication that is a social activity requiring physical, linguistic and cognitive resources. If behavior is communication, writing is just another behavior that needs to be taught systematically.

Although not everyone learns to *read* in a traditional manner, but *all* “benefit from acquiring emergent literacy skills”(pp. 65-66), creating written expression is important for all students because it opens important avenues for communication (Browder, Courtade-Little, Wakeman & Rickelman, 2006). Communication is done through symbols. These symbols come in a variety of mediums: auditory (words we speak), visual (written, pictures, etc.) tactile (braille, works of art, etc.) and gestural (pointing and other movements we use to send messages). The symbols students use for literacy experiences can be anything from standard print, typing, pictures, icons or even objects. The process of using these symbols within a social context will give meaning to communication. When we as educators allow students to arrange “symbols and understand how these meanings change as a result of audience, context and purpose”, then we give opportunities for students to develop meaning through the construction of the written expression (van Kraayenrood, Moni, Jobling, & Ziebarth (2002). “Writing serves as a way to learn language and communication” (Musselwhite & Hanser, 2003, p. 4).

There is a reciprocal relationship between reading and writing; one enhances the skills of the other, (Bird, Cleave, White, Pike & Helmky, 2008). Students who have access to appropriate literacy instruction, inclusion support combine with appropriate assistive technologies and good collaborative teaming will show progress in language and literacy skills over time (Cooper-Duffy et. al 2010, Erickson, Hatch & Clendon, 2010; Hanser, 2006; Sturm, Cali, Nelson & Staskowski 2012).

Literacy Research

For decades the importance of literacy instruction for students who use AAC has been discussed, but putting the necessary information in to practice continues to be a challenge, especially in the area of writing (Musselwhite & Hanser, 2003). Erickson and Koppenhaver (1995) discussed how one project they reviewed had eight students in three different specialized classes for teaching students with significant disabilities showed a “consistent lack of progress” (p. 677). “Despite an emphasis on improved writing instruction for typically developing beginning writers, students with disabilities continue to lag behind their peers on statewide and national writing assessments” (Sturm et al., 2012, p. 298).

There are virtually no studies on writing instruction for students with significant intellectual disabilities (Erickson, Hansen, Hatch & Sanders, 2009; Sturm et al., 2012). The research that is available on students with significant disabilities for literacy instruction focuses on the reading aspects of literacy skills. This research is more descriptive rather than experimental and is focused on skill instruction that is disconnected from the larger writing interventions, (Wollak & Koppenhaver, 2011). Despite the lack of research, Wollak and Koppenhaver (2011), “found little to suggest any real differences in what is effective” (p. 4) for literacy instruction between students with and without disabilities.

Comprehensive Literacy Instruction

Using literacy skills involves a) communication, b) listening & understanding, c) reading, and d) writing; all require careful planning instruction for a student’s success (Downing, 2006). Downing (2006) reminds us that writing instruction is an important part of comprehensive literacy instruction. We must remember “students with significant intellectual disabilities can make progress in conventional literacy when they have access to comprehensive instruction” (Erickson, Hatch & Clendon, 2010, p. 8) because “emergent literacy is a function of experience

rather than development” (Erickson, Hatch & Clendon, 2010, p. 5).

Using writing skills “involves many different skills including spelling, individual words, constructing sentences and creating text. All are important in a comprehensive literacy program” (Smith, 2006, p. 5). Although it is crucial for AAC users to have phonemic instruction so they can translate their thoughts into a written form, we need to be thoughtful about what information are asking beginning AAC writers to juggle (Musselwhite & Hanser, 2003). Our students who are AAC users need all the skills required for writing, but this is a lot to add onto also physically accessing their individual communication method, either high or lite tech. Regardless of the student’s needs, they need structure and support in the ongoing process, “to improve the quality of the students writing” and in order to improve the quality, we need to “increase the quantity of their writing” (Wollak & Koppenhaver, 2011, p. 6). Which brings us back to making sure there is adequate structure and support to assist students with juggling all the demands of the writing process.

The process of teaching writing is about helping students understand that they are communicating with someone they can’t see at the moment. Students need to understand that “writing is about conveying one’s own thoughts on paper” (Wollak & Koppenhaver, 2011, pp.14-15). When staff model the act of writing to “show its function and purpose and to model writing using the same alternative pencils their students use” (p. 3) we can increase the quality of our writing instruction (Hanser, 2006). With quality comprehensive literacy instruction that involves writing our students will show they are more eager and capable of being writers (Wollak & Koppenhaver, 2011). “Writing is particularly important for students with disabilities because it enhances communication, increases independence and makes a unique contribution to literacy learning” (Wollak & Koppenhaver, 2011 p. 1).

A good comprehensive literacy program is “like a mosaic being constructed. There are many components that go into the development, but the final product is the result of careful planning and implementation of the plan. With good materials, planning and experiences we can help students with complex learning needs develop their own uniquely beautiful literacy mosaic” (Smith, 2006 p. 6).

“Generating written text is communication” (Musselwhite & Hanser, 2003, p. 4). “Given the power of writing as a means of communication, we can no longer afford to overlook it or assume it will develop at a future time” (Hanser, 2006, p. 3). An “AAC user’s talking can be writing or with enough opportunities writing can help them with talking” (Musselwhite & Hanser, 2003, p. 4). When we integrate technologies in a well-organized, theory-based program that is developed around a student’s unique literacy learning needs, we can create learning opportunities where a student will “write better and enjoy it more” (Wollak & Koppenhaver, 2011 p. 18). However, “unlike spoken language” literacy “skills require explicit instruction” (Smith, 2006, p. 2).

In situations where writing is meaningful, it is also interactive and entertaining, (Downing, 2005b). When students with significant literacy learning needs are “actively creating print” they are learning about writing and the writing process (Hanser, 2006, p. 3). By asking students with significant disabilities to be actively involved in constructing their own language and print it in environments where there are other students with more literacy skills, the students with severe disabilities will develop more meaning from their written expression, (Erickson, Hatch and Clendon, 2010). This ongoing, generative process causes students to build “rich relationships among concepts and linking to prior knowledge to new information, actively constructing meaning and transferring experiences and knowledge to new situations” (Larson,

2014, p. 113). Is this not what we are striving for with literacy instruction in the first place? As educators, we want students to develop the “complex mosaic” that being literate allows (Smith, 2006, p. 2).

Why do Educational and Support Staff Need more Training?

There are many barriers like historical practices, attitudes and a lack of understanding about what technologies to access and when. As stated previously, for students with the most severe disabilities, it is difficult to show measurable progress especially academic instruction. The history of special education teachers has not required them to teach a “Standard Course of Study” when the students display significant cognitive disabilities, instead these students were taught “life skills” (Cooper-Duffy et al., 2010). This educational practice in itself is a barrier that needs to be overcome.

In education we face many obstacles everyday. Some of these barricades are an innate part of the individuals that we have the opportunity to educate and sometimes the people supporting the student inadvertently and unknowingly create barriers. There are issues such as needing extra time for health care routines, therapies (Hanser, 2006), decreased opportunities, low expectations, under prepared professionals (Wollak & Koppenhaver, 2011), and “assumptions that children need to have specific ‘readiness’ skills” (Hanser, 2006, p. 1). As Erickson & Koppenhaver (1995) state, “it is difficult for you to learn to read and write, many of the people closest to you do not view you as a capable learner and there are no models of best practice in providing you with appropriate literacy instruction” (p. 677).

Barriers like language delays, physical and sensory impairments limit the access to appropriate technologies and contribute to the struggles with the development of literacy skills (Wollak & Koppenhaver, 2011). Smith (2006) shares, “we know that many individuals who use

AAC find reading and writing difficult, we know that this struggle is not simply a direct consequence of severe speech impairment. It usually reflects a combination of factors, including the resources individuals bring to the learning task, but also their experiences and the instruction they receive” (p. 2). When literacy instruction does occur, it is often limited to instruction in sight words, copying, handwriting, and grammar exercises, this in combination with learning difficulties consequently cause a disconnectedness from the learning needs and can create a negative attitude about reading and writing (Wollak & Koppenhaver, 2011). General educators should realize they have a critical missing piece in current education programming for children with severe disabilities: literacy expertise (Erickson & Koppenhaver, 1995).

Another blockade, especially for AAC users learning to write, is they are “forced to keep using pencils that aren’t working” for them (Musselwhite & Hanser, 2003 p. 6). As educators we need to be aware of many varieties of technology options or at least how to get assistance to access the many options that are available. For a student to make progress and to motivate the student to keep trying to succeed, we need to provide the right tools.

So if there are barriers, then it is the educators’ duty to build bridges. We can build bridges with tools like, positive attitudes, providing real access to curriculum content, having high expectations and using effective writing instruction for students with significant learning challenges. When we do this as educators, we can change lives.

“When students with significant disabilities are included in general education classes, neither instructional nor social participation should be forfeited” (Janey & Snell, 2011, p. 229). This takes serious planning and collaboration to implement. Ideally the most effective adaptations meet two criteria: (a) they facilitate both social and instructional participation in class activities and (b) they are only as specialized as necessary (Janey & Snell, 2011). In order

for teams to collaborate successfully, they need to be good listeners and be able to provide feedback to strategies materials and equipment that is suggested (Eagan, 2015, para. 3).

“Collaborations should focus on increasing the student’s independence, success in the classroom, positive communication and all while preparing the student for a successful and independent future” (Eagan, 2015 para. 8),

“We must find the means through which all children can interact with print in an environment filled with the same high expectations and ongoing opportunities afforded to typical peers” (Hanser, 2006 p. 1). As educators we need to be compelled to presume students with severe disabilities are competent and capable by having high expectations and adapting only as much as necessary (Janey & Snell, 2011; Jorgenson & Lambert, 2012). In other words, only adapt what must be adapted from the general curriculum to provide accessibility to the content without changing the core purpose of the activity.

If we have expectations and provide access for students with emergent reading and writing skills, then these skills can be developed into more conventional reading and writing skills (Erickson, Clendon & Hatch, 2010). When educators build bridges with these kinds of tools, “providing access to early writing activities with appropriate alternative pencils can facilitate the literacy learning that previously was not thought possible” (Hanser, 2006, p. 3).

“Access to the content is not adequate unless it is mediated by instructional design specific to the student” (Erickson, Clendon & Hatch, 2010, p. 3). We must have an instruction for method of writing (Browder, Courtade-Little, Wakeman & Richelman, 2006) no matter what style it is, pencil and paper, typing, software with word prediction, icons or objects. “The challenge is... to foster an atmosphere rich with ongoing models, meaningful writing opportunities and alternative writing tools that support the emergent writing development in a manner that parallels their peers

without disabilities” (Hanser, 2006, p. 1).

Probably the biggest obstacle that students need to overcome is a limited or narrow view of what written expression and the writing process can look like. As educators we need to increase the breadth of our view about written expression. We need to have a broad interpretation of what written text looks like: letters, words, pictures, graphics or a combination (McDonnell & Copeland, 2011; Musselwhite & Hanser, (2003). “Writing must be viewed more broadly as communication. Writing is generating novel thoughts and translating them into print” (p. 6) regardless of what forms the written expression may take (Musselwhite & Hanser, 2003).

The writing process is a very complex task that educators require students to perform on a regular basis. Many different things can interfere with the writing process because there are so many things to deal with in the process like sensorimotor, language and cognitive demands. (Musselwhite & Hanser, 2003; Sturm et al., 2012,). However, “writing is a learned process and used most effectively within meaningful and motivating contexts” (Foley, Koppenhaver & Williams, 2009, p. 93). It is a process designed to allow a student to “compose authentic text for a variety of reason and audiences” (Foley, Koppenhaver & Williams, 2009, p. 93). Therefore we need to be intentional in our systematic instruction. We need to decide what is more important at a particular stage of writing for a student. Is it, “generating ideas and planning, or worrying about syntax and punctuation?” (Musselwhite & Hanser, 2003 p. 5).

Writing is part of daily living activities. It has many functions within the life of a single individual. We make to do lists, we make grocery lists, we send cards to friends, we email. In *Read, Write and Talk: a Practice to Enhance Comprehension* (Hartman, 2005) models writing for students, explaining that writing makes our thinking visible. When we use written expression, it “slows down the processing of letters, words and texts and consequently allows students with

disabilities to examine more carefully how print works” (Wollak & Koppenhaver, 2011, p. 1). By taking advantage of using text as a permanent form of communication, we can revisit, revise and reorganize our ideas to increase comprehension both for the reader and the writer (McDonnell & Copeland, 2011).

Social / Emotional connectedness

Communication requires social engagement. There are two parties involved in communication, a sender of a message and a receiver of that message. One can send a message, but if the receiver doesn't understand the method of the message or the meaning of the message, then the message is not really delivered or understood. Each party has to understand the meaning of the message and the method it is delivered in. For example, if you receive a written message in your native language, but you can't read, it doesn't matter if the message was given in your native tongue or not, you did not receive the intended communication. In other cases we send messages in words that are familiar to the listener, but in a new way or apply them to a new situation that is unfamiliar, the message can get confused and misunderstood. However, when both parties understand the meaning and method of the message, then communication occurs.

The purpose of reading and writing is to support communication, accessing information in the world and to conduct personal and work related business (Fosset & Mirenda, 2006), thus having information “to make decisions and choices, alter the environment and gain pleasure” (Alberto, Fredric, Hughes, McIntosh & Cihak, 2007, p. 234) in our everyday lives. “Restricted expectations coupled with a child's limited communication abilities, inhibit rich social interactions about the few print experiences children with significant disabilities have” (Hanser, 2006 p. 1). Therefore we must make literacy experiences meaningful. Literacy instruction is most effective within meaningful social interactions (Downing, 2005b, Downing, 2006). Some

social implications of developing written communication skills are having increased participation in the school, community and vocational settings (McDonnell & Copeland, 2011). Students also learn to see themselves as readers and writers and they gain “credibility within the school community” (Erickson & Koppenhaver, 1995, p. 679).

Since reading is a social act, students explode with ideas and construct meaning while they are engaged in real world reading (Erickson, Clendon & Hatch, 2010; Hartman, 2005). In addition, using “assistive and web based technologies, not only supported student learning and engagement, but also expanded their curriculum far beyond the classroom walls” (Wollak & Koppenhaver, 2011 p. 19). Literacy programs that were found to be highly engaging and motivating demonstrated students’ views about writing changed and they would seek out opportunities to read and write for their own purposes not related to school (Wollak & Koppenhaver, 2011).

By writing together, students establish relationships, have common experiences and develop a cultural identity together (Hagood, 2015, part I). Literacy “is not about reading, it is about building interactions/ engagement skills of students so that students can move forward on the literacy continuum” (King-DeBaun, 2006). “Throughout our lives writing helps us establish and maintain social relationships, share experiences and feelings, record personal events and insights and organize activities and events” (Wollak, Koppenhaver, 2011, p. 1). Is it not the point of education is to motivate students to such an extent they will seek out reading and writing on their own, for their own purposes?

Conclusion

“Writing is a place to hold your thinking!” (Hartman, 2005). “Reading and writing are a reciprocal process, one enhances the other” (McDonnell & Copeland, 2011, p. 511). “However,

if it” (*language and literacy*) “is left off the agenda as something that is only attainable once all the other skills have been put in place, then the journey to skills development is made unnecessarily arduous. From the outset, it is essential that language and literature are the center of the literacy intervention map”, (Smith, 2006, p. 6). It is necessary to have language and literature at the center of the intervention because it is the foundation for communication in any form. Without this communication taking form through a rich variety of mediums we lose or at least decrease the emotional connectedness with others in our world. Learning language, literacy and literature is about “exploring the wonder and richness of language, books and the power of self-expression. It is the point of learning to read and write – it is the prize!” (Smith, 2006, p. 6).

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