
September 2017

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Recommended Citation

Perez, Joshua W. (2017) "The Test That Changed His Life," *The Idea of an Essay*: Vol. 4 , Article 30.
Available at: https://digitalcommons.cedarville.edu/idea_of_an_essay/vol4/iss1/30

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The Test that Changed His Life

Joshua Perez

Introduction

A boy is born with severe cerebral palsy and cannot speak. Many around him, like those surrounding so many other non-vocal children, have initial assumptions that non-vocalism is synonymous with non-literacy. As he grows older it becomes apparent although he is non-vocal, he is far from non-literate. His teachers notice strengths and weaknesses in his literacy, and wish to understand the factors playing into such things, though the published literature regarding this subject only increases their confusion. Phonological tests show his strengths and weaknesses, but find no patterns between said weaknesses and gender, age, education type, years in

school, or virtually anything else. It is in this situation, when answers could decide the flourishing (or lack thereof) of this child's literacy, that his teachers see the pathetic lack of specific tests designed for him. To have a more specifically designed test for people like him could exponentially increase the progress of his literacy, and those like him. Phonological awareness tests specifically designed for non-vocal



children with cerebral palsy are a necessary step in evaluating and developing their literacy skills. This is clear because of the ability for these tests to highlight key issues in the children's literacy, as well as discrepancies correlating to a variety of independent factors.

A Common Misconception

Cerebral Palsy, commonly abbreviated as "CP," refers to a group of disorders affecting a person's ability to move. CP is caused by damage to the developing brain either during pregnancy or shortly after birth. CP affects people in a variety of ways, such as body movement, muscle control, muscle coordination, muscle tone, reflex, posture and balance. Although CP is a permanent condition, some effects can improve or worsen over time. CP has known correlations with visual, learning, hearing, speech, epilepsy and intellectual impairments (What is Cerebral Palsy, 2015).

Though many may be inclined to connect non-vocal children with non-literate children, it is well documented this is a false assumption. Non-vocal children, particularly with cerebral palsy, are commonly spoken to as if they have no perception of spoken word, or mature conversation. Not only would speaking to these children be ironic in the very nature of believing they cannot comprehend such words, but the assumptions of such things are absurd. Numerous studies have been done in order to find any causation or correlation





between the inability to speak in children with cerebral palsy and literacy. It is well established that children with CP who do not speak still have intact language comprehension, so long as they have no additional cognitive impairments (Bishop & Robson, 1989; Bishop, Byers-Brown, & Robson, 1990; Duffy, 1995). Though there is high correlation between severe cerebral palsy and the presence of

other disorders, the inability to speak in a person with CP is usually due solely to motor impairment, hence, having nothing to do with cognitive ability.

Clearly, although it should, at this point, be well established that non-vocalism and non-literacy are different, the idea of literacy playing a role in phonological abilities predicts children with severe CP who cannot speak should have impaired speech perception, since they would have never had the chance to acquire articulatory code (Card & Dodd, 2006, p. 149).

Although numerous studies have been done to evaluate this idea, results are inconsistent with each other. Two large studies, interestingly, contrast in results regarding the phonological awareness abilities of two groups of children with cerebral palsy: those who speak, and those who do not (Card & Dodd, 2006). In one of the studies, Bishop and Robson (1989) found no differences between a child with CP who could or could not speak on measures of rhyme judgement and short term memory. On the other hand, Vandervelden and Seigel (1999) found that nonspeaking children with CP have phonological processing difficulties in multiple tasks.

Multiple studies assume that the connections between understanding and producing speech involve a variety of different abilities. Because of this, a deficit in one area at a given point may affect both input and output functions. This is important because it begs the question if some phonological abilities are gained only through speech. For example, it is clear that Connor can read. This is known because teachers can ask him to read a passage, and then ask him questions about it which he can answer through use of his iPad or various other methods they have developed. However, if Connor's classmates developed certain aspects of literacy solely from the acquisition of speech, is he less of a "good reader?" Some argue that children with some sort of speech difficulty often have difficulties with associated phonological awareness.

Inconsistencies

The mere presence such inconsistencies justifies a need for more specific phonological analysis tests for non-vocal children with CP, who, like Connor, will flourish much more in the classroom if specific strengths and weaknesses can be more objectively addressed.

Unfortunately, inconsistencies and lack of correlative results do not stop at the research mentioned above. Studies show there must be some sort of factors which must be noted in terms of studying literacy in non-vocal children with CP. This is mostly due to the fact that they are not a homogenous group. First, they differ in severity and co-occurrence of other disabilities such as dyspraxia. Additionally, they differ in cognitive abilities, experiences with school, and the type of communication assistance they have or have not been given in the past. Moreover, there could be differences based on age, due to the fact that it correlates with the amount of literacy the children have been presented with. Also, problems occur sometimes in trying to make case studies because comparing children with a motor impairment with children with none makes it difficult to find controls, considering poor motor coordination is relative to those without poor motor coordination. Research shows that chronological age, school experience, gender, social class, and possibly the extent to which the child has motor constraints are of importance.

As time progresses, these various factors become increasingly important when specifying phonological tests further than the

relatively superficial level of any non-vocal child with cerebral palsy. Imagine a database with stored correlations per factor which apply to a specific child. To make this idea more clear, imagine Connor needs to take a phonological test. Instead of the usual case in which a teacher pulls the same exam out for Connor as he or she would for any other child, the teacher goes to an online database uploaded on his or her computer. With simple button clicks, the teacher is able to check through every factor which applies to Connor such as age, gender, severity of CP, etc. Such a database would have the ability to compile an exam specifically designed to test Connor's needs; clearly a much more fruitful exercise.

Case By Case

In order to conclude whether or not these factors play a role in the abilities of a non-vocal child with CP regarding literacy, they must be studied. One study uses 28 children, 14 Swedish and 14 Irish, who have CP, in order to outline their abilities in different phonological tasks. After studying memory tasks, letter knowledge, reading tasks, and spelling tasks, no large correlations show up. There is large variability in groups in terms of school experience and age. Of all of the tests, phenome blending and deletion seemed to

be the easiest. Scores on all of the reading tasks ranged from 0 to 100%. Spelling real words which were spoken orally proved to be the hardest task. Some students scored zero on all of the tasks, while others achieved 100% on every task (Larsson, Sandberg, & Smith, 2010). Although at first it may seem this would imply these factors do not matter, nothing could be further from the truth. Such results conclude the fact that



children, particularly these children with CP, have varying, case by case factors which cannot be limited to looking at one factor at a time. In other words, it may be that the factors play roles in literary ability when mixed with other factors, rather than on their own. Since it would be ridiculous to claim children only have one, single characteristic, pretending so for a series of studies is, expectedly, relatively unfruitful.

It is apparent that results in the multiple case studies reviewed here are largely varying. This does not mean, though, that Connor has a clear advantage for being a good reader (which he is) over other students who are younger, a different sex, or have different educational background. But how? It seems there must be some sort of factors involved in determining literacy levels of these children, many of whom have severe cerebral palsy, like Connor, but are not as good at reading. Another approach is to better understand the possibility of problems with the language comprehension tests used to measure skill level in phonology.

The number of factors contributing to literacy in non-vocal children with CP is a large one. There are two factors which seem notable, in addition to the others. The first is the children's parents. Due to the overwhelming amount of time someone with severe CP will spend with their parents throughout childhood, the role a parent plays in the children's lives is vital. More specifically, the attitudes they have towards their child receiving literacy help is important. Connor's parents have always put an emphasis on education and being a well-rounded person. Connors older brother, Liam, is an accomplished student, as is Connor's sister, Julia, who has autism spectrum disorder. One study shows that in overwhelming conclusion, parents want to help their children, but they need guidance, and usually much more information, as well as technical support for their child in regards to decision making regarding the alternative or assistive communication techniques their child will receive. A clearer understanding of the many factors which go into literacy and their outcomes enables parents to find the best means of educational assistance for their child (Wray et. al., 2014). Unfortunately, many parents do not understand the strengths and weaknesses of their children in the classroom. Specialized phonologic tests are not only productive in the classroom, but are productive in home and family settings.

Additionally, the communication skills of the child is extremely important. Though Connor is extremely vocal in his own ways, he cannot simply list his wants and needs like some other children can. Likewise, he cannot interact in terms of phonological analysis tests the same as child who can speak. Although there are some differences in communication of children with CP, there are strong patterns which emerge in various studies, regardless of age or developmental level. One study looks at various aspects of communication and tests them separately, concluding the strong patterns previously mentioned. The article also provides discussion on the implications of such study results. This article concludes various interventions are necessary in improving interaction patterns with some children, particularly in teaching things such as active participation and communicative interaction (Light & Lund, 2007). It should be noted these interventions are not necessary for all children with severe CP, which adds to the overall point that there are a large number of factors going into all of this. These overarching characteristics may be the best ways to begin phonological tests for non-vocal children with CP, since most of these children share the same issues. Starting with the same fundamental questions which then move towards more specific, case oriented questions may be fruitful.

The List Goes On

It is apparent there are a large number of factors in evaluating literacy in non-vocal children with CP. Many studies aiming to evaluate various factors in regards to specific phonological areas contradict each other. Because CP is a muscle and movement disorder, areas of sensorimotor functioning and literary skills are in need of constant study (Obrzut & Straub, 2009). It is clear that there are a seemingly infinite number of factors which are necessary to study in terms of understanding literacy in this setting better and more thoroughly. The reality remains that “non-vocal” and “illiterate” are not synonymous with each other, particularly in children with CP, and because of this truth, mixed with the seemingly infinite amount of factors contributing to the literary abilities of non-vocal children with CP, more specific language tests are absolutely necessary.

According to Geytenbeek et. al. (2010) language comprehension tests for children with severe CP are scarce. This is not only important for better understanding the various factors which help determine

literary abilities, but in order to have benchmarks for children in order to help them continue to learn. It is stated “A language comprehension test specifically designed for (young) children with severe CP is therefore warranted” (Geytenbeek et. al., 2010, p. 276).

A Precious Gem

In regards to the strong need for specific, case by case, phonological tests for non-vocal children with CP, it is extremely important to realize how great the gift of literacy is. To a spoken child, literacy is a beautiful means of understanding history, art, science, and day to day life. Although this is true for any child, for one who is spoken, these things are supplemental to the ability to speak, to sing and to present in the ways most accustomed to society. For Connor, literacy may be even more important. Literacy is one of the only means to communicate he has. Literacy is a means for him to tell stories, to share his accomplishments, and to learn and show understanding of an infinite variety of fields. Connor needs tests which can guarantee a fair, proper evaluation of his strengths and weaknesses. These tests may be the best hope for a continued education which allows him to continue doing what he loves. Connor continues to read, and to enjoy it. He continues to be a lover of school, which, regardless to the inability to hear him speak, is readily apparent.



References

Bishop, D. V. M., & Robson, J. (1989). Unimpaired short term memory and rhyme judgement in congenitally speechless individuals: Implications for the notion of “articulatory coding”. *Quarterly Journal of Experimental Psychology*, 41(A), 123 – 140.

Speechless individuals may have individual impairments due to supplemental cognitive issues. In this article, the judgements of memory and rhyme are evaluated through non-speaking individuals.

Bishop, D. V. M., Byers-Brown, B., & Robson, J. (1990). The relationship between phoneme discrimination, speech production, and language comprehension in cerebral palsied individuals. *Journal of Speech and Hearing Research*, 33, 210 – 219.

Non-spoken individuals with Cerebral Palsy may have impairments in language because they cannot develop an articulatory code. In this sense, these individuals have varying perceptions of language, hence, producing a language differing in specific areas than those who can speak.

Card, R., & Dodd, B. (2006). The phonological awareness abilities of children with cerebral palsy who do not speak. *AAC: Augmentative & Alternative Communication*, 22(3), 149-159 11p.

It is commonly assumed that an inability to speak leaves an inability to comprehend spoken language. Such a theory should predict that non-vocal children with cerebral palsy should have an impaired perception of speech due to the lack of opportunity to learn articulatory code. It has been shown, though, that in the absence of other cognitive impairments, most non-vocal children with cerebral palsy have intact language comprehension. This article presents a study of a range of speakers and non-speakers with cerebral palsy

should, therefore, conclude whether connections exist between speaking and the emergence of phonological awareness abilities.

Dahlgren Sandberg, A. (2001). Reading and spelling, phonological awareness and working memory in children with severe speech impairments: A longitudinal study. *Augmentative and Alternative Communication*, 17, 11 – 26.

Individuals who cannot speak generally use some sort of augmentative and alternative communication techniques in order to learn and produce language and literacy. This article looks specifically at the reading, spelling, and phonological awareness of those individuals.

Dahlgren Sandberg, A., Smith, M., & Larsson, M. (2010). An analysis of reading and spelling abilities of children using AAC: understanding a continuum of competence. *AAC: Augmentative & Alternative Communication*, 26(3), 191-202 12p. doi:10.3109/07434618.2010.505607

It is often the case that children and adults using augmentative and alternative communication underachieve in their development of writing and reading skills. Additionally, it seems that their disabilities in these areas are disproportional to other abilities in linguistic functioning. Since reading and writing skills are developmental, combining internal resources the reader carries with him or her, the mere presence of speech issues cannot be the only reason for reading and writing deficits which commonly occur. This paper uncovers relative strengths and weaknesses in children using AAC in a range of areas in order to find correlations between skills and experiences with the children's learning environments.

Duffy, J. (1995). *Motor speech disorders: Substrates, differential diagnosis and management*. St. Louis, MO: Mosby.

This article uncovers the various parts of motor

speech disorders, evaluating aspects from the first steps of recognition and diagnosis, to treatment and management.

Geytenbeek, J., Harlaar, L., Stam, M., Ket, H., Becher, J. G., Oostrom, K., & Vermeulen, J. (2010). Utility of language comprehension tests for unintelligible or non-speaking children with cerebral palsy: a systematic review Review. *Developmental Medicine & Child Neurology*, 52(12), e267. doi:10.1111/j.1469-8749.2010.03807.x

This article aims to identify and understand the utility of standardized tests on non-vocal children with cerebral palsy. Because children with severe cerebral palsy have severely limited mobility, impairments in expressive and receptive communication skills are prevalent in children with severe cerebral palsy. This requires an evaluation of comprehension in spoken and written language, particularly in standardized tests. Twelve standardized tests were identified for this experiment, all of which were developed for children without limited mobility. Only one of these tests was revised and used for children with severe cerebral palsy, hence, a language comprehension test specifically designed for these children is necessary.

Larsson, M., Dahlgren Sandberg, A. D., & Smith, M. (2009). Early reading and spelling abilities in children with severe speech and physical impairments: A cross-linguistic comparison. *Research in Developmental Disabilities*, 30, 77–95.

Because non-spoken individuals may develop articulatory code differently than spoken children, spelling and reading abilities may vary, in addition to possibly delayed onset. This article uncovers such implications in attempt to understand possible mechanisms for spelling and reading issues and probable solutions.

Lund, S., & Light, J. (2007). Long-term outcomes for individuals who use augmentative and alternative communication:

Part II – communicative interaction. AAC: *Augmentative & Alternative Communication*, 23(1), 1-15 15p.

The use of alternative and augmentative communication systems (AAC) has been widely researched. The participants in these various studies are in a wide variety of ages, though patterns show through all of them, particularly, patterns of interaction. This study evaluates the communication skills of seven young adult men who have used AAC systems at least 15 years. The study finds that interventions may be necessary in improving communication abilities with people using AAC systems, particularly in areas of active participation, social interactions, and communication functions.

Straub, K., & Obrzut, J. E. (2009). Effects of Cerebral Palsy on Neuropsychological Function. *Journal Of Developmental & Physical Disabilities*, 21(2), 153-167. doi:10.1007/s10882-009-9130-3

This article defines cerebral palsy as “a muscle and movement disorder that affects children and is the result of early brain injury.” The causes of these brain injuries may vary greatly, which is why children with cerebral palsy are considered a heterogeneous group. Specific areas of a child’s life is more affected due to the presence and severity of the CP. Specifically, areas of sensorimotor functioning, language and verbal skill, perceptual skill, learning, and memory are inhibited. This article explains the neuropsychology behind many of these issues faced by children with CP, and how they affect everyday life.

What is Cerebral Palsy? (n.d.). Retrieved April 05, 2016, from <https://www.cerebralpalsy.org.au/what-is-cerebral-palsy/>

This website aims to expose Cerebral Palsy openly in an attempt to have better communication and, decision making, and, most importantly, acceptance.

Vandervelden, M., & Seigel, L. (1999). Phonological processing and literacy in AAC users and students with motor speech impairments. *Augmentative and Alternative Communication*, 15, 191 – 209.

This article aims to evaluate the phonological abilities of people who use augmentative and alternative communication (AAC).

Wray, J., Edwards, V., Wyatt, K., Maddick, A., Logan, S., & Franck, L. (2014). Parents' Attitudes Toward the Use of Complementary Therapy by Their Children with Moderate or Severe Cerebral Palsy. *Journal Of Alternative & Complementary Medicine*, 20(2), 130-135 6p. doi:10.1089/acm.2012.0973

This article uses the parents of 32 children with cerebral palsy, ages 5-12, in order to discuss parents' attitudes towards the use of complementary therapy by their children. Results show that parents want to help their children, but have a lack of information. Additionally, they need guidance and practical support in order to make decisions regarding the use of complementary therapies. A clearer understanding of factors in their children's situations will assist in the proper decision as to what type of complementary therapy to use.