Colby's Growth to Language and Literacy: The Achievements of a Child who is Congenitally Deafblind

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Abstract

This article tells the story of how Colby, a young boy who is congenitally deafblind, developed language and literacy. Narrative is coupled with video to illustrate how the following four instructional approaches and interventions supported his development: (1) daily schedule, (2) home-school journal, (3) experiential based literacy, and (4) child-guided instruction. Both Colby's mother and his teachers developed individualized literacy lessons that were delivered with daily consistency. Repetition of highly interesting activities paired with consistent exposure to representations about those activities (expressed in objects, verbalizations, sign language, and braille) supported Colby to literacy.

Keywords
literacy, deafness, blindness, deafblindness

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This article shares the story of one boy's growth to language and literacy. Colby is a surviving twin, born at 24 weeks gestational age, with moderate hearing loss (in middle speech range) sloping to profound hearing loss (in the higher frequencies) and light perception only due to Stage 5 Retinopathy of Prematurity. This article will present narrative coupled with brief video clips of Colby at the ages of 4 years, 2 months and 8 years, 2 months (with the exception of the braillewriting video clip which was taken at 8 years, 10 months) to illustrate his language and literacy development. These videos also will illustrate the following instructional interventions and approaches that many special education professionals believe to be critical to the language and literacy development of children who are deafblind: (1) the daily schedule; (2) the home-school journal; (3) experiential based learning and literacy (including story boxes and experience books); and (4) child-guided instruction. Although this article tells the literacy story of a child who is deafblind, the interventions described are relevant to children with other disabilities.

Colby's Communication and Play at Four and Eight Years

At the ages of 4 years and 8 years, Colby was assessed using the *Communication Matrix* (Rowland, 2000) and the *Play Assessment Questionnaire* (PAQ) (Yoshinaga-Itano, Snyder, & Day, 1999). At the age of four years, he communicated at Level V: Concrete Tangible Symbols and Level VI: Single, Abstract Symbols on the *Communication Matrix*. Colby used whole and partial objects as representations, understood speech, and spoke in single word utterances. When presented with raised print letter magnets of his name and his mother's, he could usually identify his name. He loved to play with toys that produced auditory output including those that named letters and their sounds although he did not yet independently name letters. Data from The *Play Assessment Questionnaire* (PAQ) (Yoshinaga-Itano, Synder, & Day, 1999) indicated that he physically manipulated objects/toys, used toys to stimulate his senses, demonstrated knowledge of the function of some objects (such as putting a cup near his mouth), put two play objects together in the correct way, copied some movements, and performed two and three step sequences. A total communication approach including receptive and expressive experiences in speech, gesture, sign language, object symbols, raised letters, and braille was provided.

When Colby was almost 7 l/2 years old, his educational team expressed concern about his literacy development at his IEP meeting. The team wasn't confident that the years of daily braille exposure and tactual development efforts were guiding Colby to braille literacy. They agreed to continue the braille instruction with the annual goal that he would learn six braille letters. Less than five months later, something remarkable happened. Colby came to understand the power of braille as a system of symbols. Once he understood that each braille letter had its own sound and that braille letters could be combined, he experienced a rapid growth in braille literacy.

At the age of 8 years, Colby is communicating at Level VII: Combinations of 2-3 Abstract Symbols (on the Communication Matrix) and even beyond when expressing in speech. Colby combines abstract symbols and is now linguistic, communicating in multiword utterances and sentences. Colby continues to receive modeling and prompting to express himself in sentences of increasing complexity. He can both hear a word and spell it and name a familiar word when others spell it. Over the past four years, Colby has gained the following play skills according to the PAQ (Yoshinaga-Itano, Snyder, and Day, 1999): repeats actions on others, performs related play actions on self, brings related

parts together for a toy or game (grouping), makes sounds associated with specific toys, puts objects inside of toys, relates toys in purposeful ways to his own body (such as trying on hats, using a brush), brings toys and other objects to adults, and performs 3 or 4 step sequences in play routines. Colby's speech provides ample evidence of problem solving, memory of previous events, and associative thinking. Colby has achieved the following pivotal cognitive and social milestones that have been reported by researchers to be either precursors to or emerging at about the same time as symbolic expression in children without disabilities and children with disabilities other than deafblindness: joint attention (non-visual based), imitation, object permanence, means-end, self-recognition (of his name when expressed verbally and in raised print and braille), and categorization (by shape, size, location, and object function). Although he was not yet engaging in imaginary play at the time of the assessments, he began to exhibit such play about 5 months later (at about 8 l/2 years). Imaginary/symbolic play emerges at about the same time as symbolic communication in hearing and sighted children, but we do not have sufficient research to know its relative importance to the language development of children who are congenitally deafblind. Colby's early imaginative play included pretending that he was playing or interacting with objects when they weren't there. He also exhibited evidence of a sense of humor at that time. Early humor included putting his coat on backwards and deliberate misspelling of words.

The Daily Schedule

Colby's school program has always included consistent use of the daily schedule (also known as an anticipation shelf or calendar system). Although his schedule has changed over the years the process has remained the same. He has always participated in setting up his schedule in the morning and he has always gone to the schedule before and after each activity. Video clip #1, *Daily Schedule: 4 Years* depicts how Colby used his daily schedule at the age of 4 years. Most of his representations were mounted on painted tri-wall board and then each representation was placed within a separate section of the schedule display box. Mounting the representation may reduce confusion about when an object is an object and when it is a representation. The left to right display represents the sequence of time. The dividers used in Colby's schedule helped to separate each representation, making it easier for him to learn what was next (the first section to the right with a representation in it). At 4 years of age, only primary activities for l/2 day at a time were presented. His schedule included representations for activities that occurred every day. Such routine activities (and routines within activities) are extremely important to the development of anticipation, to mastery of the daily schedule, and to reducing the stress experienced by the child who is deafblind (van Dijk & de Kort, 2002). Each activity represented on Colby's daily schedule took place in a designated area of the classroom. This supported him to develop anticipation and associations between the representation, the designated area, and the activity being represented (Crook, Miles & Riggio, 1999). Most important, was how the schedule was used. The staff understood that each trip to the schedule box was a lesson in itself, an opportunity for an important conversation and that this was not to be rushed.

Please click VIDEOCLIP 1 in Associated Files on this article's site to download video. After downloading, the video will open in a new window.

Colby's use of the daily schedule at the age of 8 years is depicted in video clip #2,

Daily Schedule: 8 Years. Note that it is no longer necessary to have dividers between each representation. Each of his activities is represented by a small card that features braille labels, print labels, and in some cases, an object symbol attached with velcro. The print labels are provided so that unfamiliar adults (such as substitute staff) will know the meaning of each representation. This is important so that all adults use the same word when naming the representation. Colby still returns to his schedule after each lesson (to place the representation for the completed activity in the finished box) but the entire day can now be represented. Colby is using smaller object representations and he understands the meaning of those representations out of the context of the current activity because he has achieved distancing, the ability to use symbols separated in time and space from what they represent (Bruce, 2005). Braille is increasingly being integrated into his schedule and soon he will be using a portable braille schedule that depicts his entire day. Now that Colby is linguistic, he is very accepting of schedule changes. For example, on one day of observation his audiologist was absent and his play session was delayed. He gracefully accepted both of these schedule changes and participated in rearranging his schedule display with his teacher.

The daily schedule is not just a tool for transition; it is a tool for literacy. It is through the schedule that the child can learn to anticipate what will happen next and to have conversations about the day. The schedule can evoke the expression of varied communicative intents, such as requests for desired activities, comments about preferred and non-preferred activities, protests about the next activity, and questions about the activities. The daily schedule also promotes the development and sharing of memories. Hearing and sighted children have many opportunities to engage in conversations about print, children who are deafblind need adults to create opportunities for conversations about their object, print, and braille representations (Miles & McLetchie, 2008).

Please click VIDEOCLIP 2 in Associated Files on this article's site to download video. After downloading, the video will open in a new window.

Home-School Journal

At the age of 4 years, Colby's home-school journal included one page for each special lesson or service (such as Gross Motor Activities or Speech). On each page there was a braille and print label at the top, an auditory device (with a message about that activity) placed in the middle and an object symbol at the bottom. The object symbols used in his daily journal were initially introduced in the context of his daily schedule lessons. The development of this journal is more fully explained in Bruce and Conlon (2005). As you view video clip #3 on the journal (taken when he was four years old) at http://escholarship.bc.edu/education/tecplus/vol2/iss1/art3 you will notice that he did not read braille or spell. He did display an emerging understanding that there was some sort of association between the object symbol and the braille. This was evident when his mother voiced "and that's what you did in Gross Motor" as she coactively supported him to touch the object symbol and then he independently reached up to touch the corresponding braille. This understanding resulted from daily exposure to both forms of representation and the guidance of adults who showed him that both the object and the braille represented the same thing.

Video clip #4 displays Colby's use of the home-school journal at the age of 8 years (*Home-School Journal: 8 Years*). The journal pages primarily consist of individual braille words, so that Colby can remove them and rehearse their spelling, with the addition of a

few object symbols that are much smaller than those used when he was 4 years old. The journal pages are created each afternoon, sent home for his mother to review with him and then reviewed again the next morning in school. This creates opportunities to talk about the concepts of today and yesterday and when he was pre-lingual these lessons supported the development of distancing. This effort is an important family-school collaboration that helps everyone to be aware of the vocabulary that is being emphasized while offering Colby multiple opportunities to rehearse his vocabulary. Repetition of experiences paired with repeated exposure to the corresponding representations (objects, verbalization, and braille) has been central to the success of Colby's literacy program.

Please click VIDEOCLIP 4 in Associated Files on this article's site to download video. After downloading, the video will open in a new window.

Experiential Based Learning and Literacy

Adults select commercially produced books that are of interest to Colby. When he was younger, switches with objects adhered to the top were used with books that had repetitious phrases. Colby learned to anticipate when those phrases would appear and to activate the switch at the correct time in the story. Such experiences with repetition support vocabulary development (Bloom, 1993).

Commercially produced books were made more personally relevant through the creation of story boxes (containers with objects that correspond to key events, objects, and characters in the story that are particularly interesting to an individual child). One of his favorite story boxes was for the book *Goodnight Moon* (Brown, 2007). Colby used the objects to perform actions described in the book, such as making his cow jump. Like experience books (see discussion below), story boxes can also be used to support conversations about important events in the child's life.

Colby enjoys creating books about his experiences with his teachers. Sometimes these experience books are about special events at school such as a holiday party. Colby's experience books integrate the use of object symbols and braille. Each page features a print label at the top followed by the object symbol and then a braille sentence at the bottom of the page. The objects that appear in the book are the same real objects that he experienced tactually during the activity or special event. Two of his favorites are the *Holiday Jubilee* book (because it shares an important memory about a school party that his mother attended) and the *Fourth of July* book. Colby is an active participant in the creation of these special books. He collects the object representations with his teacher or parent and he co-constructs the books. Most of these books include at least one object symbol that provides him an opportunity to perform an action. For example, a small accordion in his *St Patrick's Day* Party book can be detached for play. He has a special shelf of these books at school and during his literacy sessions he is offered the opportunity to select one or two to read with his teacher. Video clip #5, *Experience Books: 8 Years* displays his classroom teacher sharing one of his experience books about a 4th of July celebration. Effective experience books focus on one experience/activity and feature pages that are based on the aspects of the activity that are most interesting to the child so that the child is motivated to read the book often, thus providing opportunities to rehearse vocabulary and share memories.

Please click VIDEOCLIP 5 in Associated Files on this article's site to download video. After downloading, the video will open in a new window.

Colby's mother has always made language and literacy fun for Colby by pairing active experiences with literacy lessons in the home. In video clip #6, *Experiential Based Literacy* (taken at the age of 8 years), Colby learns about the concepts of small, smaller, smallest, big, bigger, and biggest by pairing an experience with a balloon pump with a braille literacy activity. Such real-life high interest experiences make literacy come alive for children while incorporating principles of child-guided instruction such as the importance of emotion and action to language development (discussed later).

Please click VIDEOCLIP 6 in Associated Files on this article's site to download video. After downloading, the video will open in a new window.

Spelling in braille is part of Colby's current literacy program although he continues to enjoy spelling by using toys that feature raised print letters. Long before Colby was a braille reader, his teachers created a Word Wall. They constructed word cards that featured braille while allowing Colby to have an opportunity to build his words with the plastic print letters he was already familiar with. These were used on a large whiteboard. At this point in his development, objects were also incorporated into the Word Wall lessons. Colby very much enjoyed tracing the plastic letter and braille letter shapes but his understanding of this early reading/spelling lesson came from the real objects that were integrated into the lessons.

Video clip #7, *Spelling: 8 Years* shows how words that are part of Colby's daily experiences become his spelling list. He substitutes "f" for "s" in this video clip because he does not hear these sounds as being different. Colby has recently learned that when just one letter changes in a word it can become another word or it may no longer be a real word. This knowledge has resulted in a great deal of word play and experimentation with spelling. When spelling, Colby seeks opportunities to share what he knows about words and what they represent and his teacher uses this time to gently scaffold his understanding. Daily experiences with real objects paired with consistent rich verbal descriptions are central to the language and literacy development of the child who is blind or deafblind.

Please click VIDEOCLIP 7 in Associated Files on this article's site to download video. After downloading, the video will open in a new window.

Colby's speech reflects how he associates one experience with another. For example, in video clip #7 he mentions "walking class" (after spelling the word "walk) and then remarks about being careful with fans. This might sound like an out of place comment to someone who doesn't know him but he is actually associating messages he's heard about being careful during Orientation and Mobility lessons with hearing the same message about touching fans. Because he often expresses without using a complete sentence, adults must be mindful about his experiences across environments so that they can recognize the meaning behind his speech and then support him to expand his comments.

The creative use of literacy materials supports the child to generalize the meaning of representations. For example, Colby can identify the shapes of real objects (such as reporting that the air conditioner is a large rectangle during one observation). Finding

shapes in different environments reinforces this knowledge. His understanding of other representations for shapes is then supported by the use of homemade and commercial literacy materials, such as the thermoform (raised plastic) representations in the *Tactile Treasures books* (Poppe & Elder, 1997). So, varied materials present concepts (in this case, shapes) in slightly different ways, expanding how the child thinks about each concept while supporting generalization.

Colby is now writing in braille. He uses both the Perkins braillewriter and the braille overlay for the Intellikeys program. Videotape#8: *Braillewriting: 8 Years, 2 Months* depicts his use of the braillewriter. Although his braille lesson was on reading and writing words that begin with "p," he asserted his interest in writing, "Valentines Day" which his teacher accepted because he had already brailled several words that began with "p." Colby's braille teacher has always used the "shared agenda" strategy when working with him. This means that while he is allowed to do some of what he wants to do in braille sessions, he is also expected to meet some of her expectations. Early braille lessons began with a "Colby paper" (on which he could braille one letter repetitively or invent his own spellings) for the experience of producing braille quickly and a "Wendy paper" (when he was expected to write more conventionally). When writing with Intellikeys he reads the braille letters and presses them to form the spelling of each word. This allows his teacher to assess his spelling when there is no demand to recall the correct finger configurations on the braillewriter keyboard.

Please click VIDEOCLIP 8 in Associated Files on this article's site to download video. After downloading, the video will open in a new window.

Child-Guided Instructional Approach

The child-guided instructional approach has been the foundation of Colby's communication and literacy interventions at home and at school. Although the child-guided approach is used with typically developing children and with children who have other disabilities, it has a different tenor when we think of its application to children who are deafblind. Hearing and sighted children learn a great deal incidentally through their distance senses of vision and hearing. Even though most children who are congenitally deafblind have some functional vision or hearing, very little incidental learning occurs. Learning in children who are congenitally deafblind occurs in the context of close physical proximity with a trusted adult and the sense of touch and shared physical experiences are central. Adults play a critical role in establishing trust by being extremely responsive to the child and then gently inviting the child to learn about the world beyond his immediate body space.

In early childhood, child-guided interactions start and end with the child. The child shows a readiness for interaction, the child's contributions are accepted and when the child is ready, the adult gently scaffolds the child's learning. Early interactions end by returning to what the child can do independently. Inherent to child-guided assessment and instruction is respect for the child's integrity as a learner. Adults do not impose, but respond to what the child is ready and interested in learning. Adults do not rush the child to the next stage of development but seek to expand what the child knows to new materials, new people, and new settings in a sensitive manner that respects the child's interests and readiness.

Colby's instruction is child-guided because it has always been based on his relative strengths. This required thoughtful reflection about how his sensory modalities play a role in his development and in the selection of

receptive and expressive forms of communication. Acuities and hearing thresholds do not tell the complete story about how a child will use his senses for learning. While Colby has no functional vision, he has functional hearing, which has improved over time. His mother noticed very early on that he was interested in auditory input so she purchased many of the toys that typically developing hearing children would use and later adapted them by attaching braille labels. Colby's instruction (at home and school) has always built on his interests with great consideration given to what motivates him. His interest in and attention to auditory stimuli guided the decision to provide experiences with toys that featured raised print letters that when touched named the letter and the associated letter sound. Colby's understanding of these plastic letters (that were later labeled in braille) preceded his understanding of braille letters, maintained his motivation to learn more about letters and letter sounds, provided him with rich information about phonics, and became the segue to braille literacy. Although this is not a common path to literacy for children who are congenitally deablind, it supported Colby's achievements in braille.

Colby's level of development has guided instruction. Assessment is critical to this process yet commercial tools provide limited information about what is appropriate to teach children who are congenitally deafblind. Van dijk and Nelson's recent work on child-guided assessment (with prelingual children) supports teachers to understand how to identify a child's best sensory modality for learning and how to teach when a child's learning state (also known as bio-behavioral state) is optimal (Nelson & van Dijk, 2002). The seven levels of communication depicted by Rowland (2000) or the five levels described by Crook, Miles, & Riggio (1999) can serve as useful guides to assessment and for the planning of developmentally appropriate language instruction for children who are deafblind. Of greatest importance is the daily ongoing assessment that guides instruction.

Child-guided instruction includes attention and sensitivity to the emotional state of the child (Rodbroe & Souriau, 1998) and to the role of bodily emotional traces (BETS) in language development and learning. BETS are the memories of the body in motion in tandem with the associated emotional experience (Daleman, Nafstad, Rodbroe, Souriau, and Visser, 2001). More than four decades ago Jan van Dijk wrote of the importance of movement to literacy development (van Dijk, 1965). Experiences of motion paired with highly charged emotional states support the development of memory and communication development in children who are congenitally deafblind. In video clip #5, *Experiential Based Literacy: 8 Years*, Colby's mother creates BETs when she uses the balloon pump to teach about relative size. This is a more active and emotionally charged instructional approach than simply touching and identifying the relative size of objects and it is an activity that he will seek again and again.

The pace of instruction reflects knowledge about Colby's individual characteristics. Appropriate pause has been used to elicit communication from Colby and to allow him to process information. Adults are also highly responsive to Colby's communication, expressed across forms (body language, verbalization, etc.) because he is the guide to conversation. When his verbalizations are not understood, his adult partners communicate an interest but also tell him that they don't understand and they ask him to either repeat or to use the word in a sentence.

Colby was taught a means to initiate joint attention with others so that he could lead a conversation as opposed to being put in a responding mode. This extended his opportunities to guide conversations with a greater number of partners and it provided an opportunity for him to express functions other than

answering and protesting. Even though Colby is already sitting in close proximity to his teacher, he establishes joint attention with her by gently reaching and touching her hand and then he directs her attention by taking her hand to show her something. (See video clip #4, *Home-School Journal: 8 Years* at 2.24 minutes.).

Child-guided instruction includes the recognition that the curriculum and the most effective strategies are determined on an individual, child-by-child basis. Adults learn how to teach each child by interacting with each child. Interventions such as the daily schedule (anticipation shelf), home-school journals, experience books, and story boxes have been used effectively with many children who are congenitally deafblind but they must be individualized to meet the needs of each child.

Conclusion

Because of Colby's incredible desire to learn and the thoughtful and persistent instruction provided by his dedicated mother, Amy Randall, and the teachers and related service professionals at the *Perkins School for the Blind*, he has achieved at a rate that has surprised us all. In his mother's words, " He has exceeded most of my expectations and he's not even 10 (A. Randall, personal communication, August 16, 2007)!" It is our hope that this story and the video images will serve as a powerful reminder to parents, teachers, and researchers that children who are congenitally deafblind have different paths to literacy and that persistent exposure to more abstract communication forms coupled with highly individualized instructional designs can result in amazing literacy gains and subsequently a higher quality of life.

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