Individualizing and Personalizing Communication and Literacy Instruction for Children who are Deafblind

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Abstract

Interviews, field notes, and 66 communication and literacy lessons, shared between 23 teachers and speech-language pathologists and 22 children who are deafblind (in the United States and the Netherlands), were analyzed to identify professional views and instructional strategies related to individualizing and personalizing instruction. All 66 lessons featured extensive individualization strategies; six were also personalized (e.g. they were about the child's experiences). Knowing the student and family, collaboration and continuity among professionals, understanding each student's unique communication, and adjusting instruction in the moment supported individualizing instruction. Shared experiences, memories, and emotions were central to personalizing instruction.

Key Words

Individualizing, personalizing, communication, literacy, interactions, deafblind

Introduction

Communication occurs when one individual sends a message to another and that message is received and understood (Downing & Falvey, 2015). Communication occurs long before language is developed with prelingual communication often expressed through body movements, vocalizations, objects, and gestures. Language requires the flexible use of abstract representations called symbols and adherence to rules for symbol use (Downing & Falvey, 2015).

Traditional definitions of literacy focus on reading and writing with language as a precursor. The Ministry of Education in the Netherlands has expressed concern about low literacy levels among individuals with disabilities and emphasized the need for literacy instruction (OCW, 2012). Since the reauthorization of the Individuals with Disabilities Education Act (IDEA) in 1997, United States (U.S.) school professionals are responsible to support student learning in the general curriculum, including literacy (Ruppar, Gaffney, & Dymond, 2015). Therefore, school professionals in the U.S. are required to teach literacy to students who have not yet acquired language. This federal mandate, coupled with the influence of new technologies, has blurred the distinction between communication and literacy, causing an expansion of the definition of literacy in the U.S. (Bruce, Nelson, Perez, Stutzman, & Barnhill, 2016; Emerson & Bishop, 2012). New definitions of literacy are inclusive of all learners (not just those who have achieved language) with literacy development beginning at birth (Parker & Pogrund, 2009; www.literacy. nationaldb.org/early-emergent literacy). Ruppar (2014) suggested that reading, writing, listening, and speaking are literacy tasks. Koppenhaver (2000) included skills such as 1:1 correspondence and object to symbol associations within the literacy curriculum. Literacy may be experienced through visual, auditory, or tactile modalities and may involve the use of highly individualized materials and equipment including low tech forms (such as pictures or objects) and high tech options (such as speech generating devices and videophone technologies) (Emerson & Bishop, 2012; Ruppar, Gaffney, & Dymond, 2015). Within this broader definition, partial participation is valued and communication is viewed as either supporting literacy or being part of literacy (McKenzie & Davidson, 2007).

The concept of individualization is a cornerstone of special education, as reflected in federal mandates such as the Individuals with Disabilities Education Act (IDEA) which requires an individualized education plan for each child (Westling, Fox, & Carter, 2015). The purpose of individualization is to "maximize every child's opportunities for optimal learning" (McCormick, Wong, & Yogi, 2003, p. 212). Individualization involves making decisions about placement, instructional targets, instructional approaches, assistive technology, instructional materials, and services based on thorough assessment of each child (Janney & Snell, 2011).

Children who are deafblind require individualized approaches to communication and literacy because they are a heterogeneous group of learners who differ by vision, hearing, ability, motor skills, health, experiences, and family background (Ferrell, Bruce, & Luckner, 2014).   Individualization within the area of communication includes consideration of receptive and expressive forms, selection of materials and technologies appropriate to each child, correct positioning, recognition of idiosyncratic communication, and the implementation of individually suitable instructional strategies. Deafblindness presents a barrier to learning through visual or auditory observation, thus many learners will need to access models of reading and writing through touch (Miles, 2005). Learners who develop literacy skills primarily through touch will require additional time for exploration of materials, to build concepts, and to develop an association between tactual experiences and communicative representations (Miles, 2005). Commercially produced books may be adapted by adding tactile elements to the text or by supplementing the book with a box of objects that correspond to the text for the purpose of supporting comprehension and engagement.

   Personalized communication and literacy activities are about the child and his life. For example, a personalized book about a trip to grandmother's house would capture the aspects of the visit that were most salient to the child. These aspects might be experiences that were particularly charged with positive or negative emotions. This is in contrast to commercially produced books that more generally talk about visiting grandmother, but do not necessarily emphasize the experiences that are most meaningful to a particular child who is deafblind. Personalized lessons that are grounded in experiences shared by both communication partners reduce memory load, thus supporting both meaning making and spontaneous communication (Kucirkova, Messer, & Whitelock, 2010; Martens, Janssen, Ruijssenaars & Riksen-Walraven, 2014)). Shared experiences are essential to affective attunement and to meaning making (Martens, Janssen, Ruijssenaars & Riksen-Walraven, 2014). The sharing of memories and positive interactions has been linked to the achievement of literacy (Janes & Hermani, 2001).

   Personalized literacy activities must also be individualized to support access and engagement.

   Since the field of deafblindness has not yet adopted the term *personalized literacy*, it may be helpful to present emerging research evidence from outside the field. Kucirkova, Messer, Sheehy, & Flewitt (2013) described an iPad application used to create stories about a child's personal experiences in the home and other contexts that were familiar to the child. "Unlike most stories found in commercially produced books, highly personalized stories are customized for a particular child, intrinsically relevant to the child's social-cultural experience and aligned with the child's personal experiences" (Kucirkova, 2013, p. 116).

Commercially produced texts include content that may be culturally unfamiliar (Janes & and Hermani, 2001), especially to families of minority ethnic groups. In contrast, personalized texts ensure that the content is familiar to the reader. Janes and Hermani (2001) supported parents to develop both individualized and personalized stories. They found that minority children in their study and their parents preferred these texts and that parent reading behaviors improved when sharing personalized stories. Enjoyable interactions are central to literacy achievement and personalized stories evoked greater positive emotions in their study (Janes & Hermani, 2001). The sharing of positive memories evokes positive emotion, increases engagement, and supports spontaneous communication (Kuckirkova, et al., 2010).

The field of deafblindness has long emphasized the importance of personalized literacy lessons (albeit without using the term personalized literacy). Examples include: offering choices that are grounded in the child's preferences and experiences (Miles, 2005), story boxes (when they are about the child's experiences) (Lewis & Tolla, 2003), personal schedules (also known as anticipation shelves) (Crook, Miles, & Riggio, 1999; Miles, 2005), experience stories (also known as memory books) (Durando, 2008; Miles, 2005), interactive home school journals (Bruce & Conlon, 2005), and drawing or writing about one's personal experiences (McKenzie & Davidson, 2007).

This article shares findings from a larger international collaborative research study about communication and literacy for children who are deafblind involving sites in the United States (U.S.) and the Netherlands. The institutional research review boards at the authors' three universities approved the study. This article will focus on how teachers and speech-language pathologists discussed instructional strategies for individualizing and personalizing communication and literacy instruction and which strategies they applied in instruction. Additionally, we will share findings about the types of lessons that were personalized in our study.

Methods

Participants

The sample in this study was purposive, targeting professionals in schools that were in geographic locations near the work sites of the three researchers. The adult participants were 23 teachers and speech-language pathologists in the Netherlands (n = 7), Midwest U.S. (n = 9) and Northeast U.S. (n = 7). The school professionals were licensed and had at least two years experience working with children who are deafblind. The 22 participant children (Netherlands (n = 8), Midwest U.S. (n= 6), Northeast U.S. (n = 8) were 3-21 years old and deafblind. Only children who were deafblind (with measurable hearing and vision loss) and exhibited intentional behavior (acting meaningfully on objects) or intentional

communication (expressing for the purpose of having an impact on another person), with a vocabulary of no more than 40 words or signs were included in our study.

Data Sources

This study included three data sources: observations, field notes, and interviews. The school professionals were asked to select three lessons that best exemplified their efforts in communication intervention and literacy instruction with each child, resulting in 66 lessons that were observed and videotaped. Field notes included observations about the lesson and context, as well as the teacher's name for the lesson. Interviews were conducted with each professional and recorded. This paper will share the responses of 23 teachers and speech-language pathologists to the following interview question: Can you speak about how you individualize or personalize communication and/or literacy (translated as "geletterdheid" in Dutch) instruction for your students? We did not define the terms individualize and personalize, allowing professionals to determine if they viewed these concepts as being one in the same or distinct.

Data Analysis

Constant comparative analysis, a grounded theory approach to data analysis was used in this study. The observation videos of each lesson were viewed three times by two raters who worked independently at each site. The purpose of the first viewing was to gain an understanding of the lesson in its entirety. Notes were taken during the second and third viewing, followed by open coding (coding at a highly specific level to identify each instructional strategy) and axial coding (identifying themes or categories). The two raters then discussed their coding to develop the consensus document for each site, as well as conducting the axial coding. Across site analysis was then conducted by two of the researchers (at different sites) based on the consensus documents from each site.

Field notes included a list of lessons (as reported by the professionals and verified in the analysis of the observation video tapes). Field notes were used to determine which lessons were examples of personalized literacy, those lessons that were directly about the child's life and personal experiences.

The audiotaped interviews were fully transcribed at each site (in English and in Dutch). Open coding and axial coding were based on the full transcripts (McHatton, 2009). The primary researcher at each site conducted open coding by creating a document that listed all of the key ideas from their site interviews, keeping ideas at a highly specific level. One researcher then conducted the initial axial coding, looking for families or themes for each site and across sites. A second researcher then examined these themes with the original data from each site. The two researchers discussed what was missing and reached consensus on the coding.

Results

While individualization was evident in all of the observed lessons, only six of the 66 were identified as personalized lessons (about the child's life or personal experiences). Of the six personalized lessons observed, one was a music lesson (in Midwest U.S.) that included frequent repetitions of the student's name in the context of encouraging turn taking with a drum. Three were schedule lessons about the child's day (one in the Netherlands and two in Northeast U.S.) and two were experience stories about the child's personal life (both in the Midwest U.S.). Note that in their interviews some teachers and speech-language pathologists named additional personalized lessons that they did not select for observation.

Findings on Individualization

Video analysis supported the identification of practices to individualize the lessons. Only findings on individualization of the six lessons that were identified as also being personalized are shared here. All six of the personalized lessons featured either 1:1 or 2:1 staffed lessons. In the 2:1 staffed lessons one professional served in the teacher role and the second professional physically supported the student. Individualization strategies included positioning, use of appropriate equipment (such as standers, adapted seating, slant boards, hearing aids, eyeglasses) and materials selection (which considered the child's levels of vision and cognition). Close physical proximity was common due to the deafblindness. Individualized strategies for engagement (including how to direct the student's attention) were evident. For example, during a schedule lesson in the Netherlands, the teacher was able to direct the student's attention by pointing. The professionals were concerned about student comprehension and utilized strategies such as consistency within lesson routines, repetition, comprehension checks, and wait time.

Often, the length of wait time included consideration of the child's visual latency. During one schedule lesson, the teacher let the student know that the lesson was finished and then did not move or sign anything else to her. This provided an opportunity for the student to demonstrate comprehension and to initiate the next step in her daily routine (without any cues from her teacher). Professionals acknowledged and then individualized their responses to student arousal and emotion. For example, in the music lesson, the teacher (from Midwest U.S.) voiced the emotion she observed in her student, "You're getting all excited" and "I like it when you smile." Feedback to students was individualized to be meaningful to each. One teacher ignored loud vocalizations because she understood the student's anxiety, and instead concentrated on re-establishing calmness. Reinforcement

was expressed in different communication forms, including verbal and sign comments and the gesture of high five.

Adult communication was an important area for individualization.   Professionals individualized their own communication by using forms that were accessible to the child and by adopting a pace and vocabulary that were individually appropriate. Some teachers and speech-language pathologists used very specific language within a lesson, which was repeated daily. For example, during a schedule lesson one teacher in northeast, U.S. began with, "First you have _____(name of activity)" and then continued to use other key words and phrases (such as *next* and *last*).   Conversation involved different forms of communication (such as visual and tactual signs, verbalization, and objects) and conversation length varied by child and activity. Professionals were responsive to each student's communication, which varied in form and complexity. For example, in the music lesson the teacher responded to a clicking sound made by the student. During an experience story about planting, the student shook her head and the teacher voiced "no way" (which matched the student's distaste about touching dirt). During the schedule lesson in the Netherlands, the teacher paired drawing and verbalization to extend the conversation length.

Axial coding of the interviews resulted in the following themes about the concept of individualization: (1) knowing student and family, (2) individualizing lessons, (3) collaboration and continuity, (4) interactions and communication, and (5) teaching in the moment. The theme of *knowing student and family* included remarks about the importance of getting to know the student and family. Respondents indicated that getting to know the student was accomplished through observing the child and interacting with the child, not by relying on paperwork. Some respondents reported specifically what they wanted to know including the student's strongest modality for learning, what the student likes, and what the student understands. A quote on learning modalities from a teacher in the Netherlands follows: "Well, I look first which is the main modality in communication for this student. One is more focused on vision and the other more on the auditory, or on touch or smell."

Individualization of each lesson and activity was reported to be important. *Individualizing lessons* included teaching at the correct level for each student, meeting each student's needs, and respecting each student's interests. Several respondents indicated the importance of selecting activities that were motivating to the student, as in the following quote from a teacher in the Netherlands: "Yes, definitely choosing the activities which are interesting for the students and/or which they are motivated." Some of the professionals provided specific examples of lessons that they individualized by level of instruction, such as memory books, schedules and calendars, and conversation maps.   One respondent mentioned that individualizing included consideration of the level of instructional support, such as the need for 1:1 support. Another mentioned the need to individualize instruction

through the selection of materials while another specifically mentioned individualizing the selection of books. Two teachers remarked that individualization involved adapting materials. Individualizing lessons also included the selection of teaching strategies and decisions about the use of repetition, prompting, and the amount of wait time required by each learner. Several teachers mentioned the need for tactile strategies for learners who are deafblind.

Several comments were made within the theme of *collaboration and continuity*. One professional remarked that stable staffing patterns were important to continuity when individualizing instruction. Stable staffing and collaboration among staff supports continuity of programming, including effective individualization. Professionals in the Netherlands and Midwest U.S. pointed out that collaborating with others was helpful to learning how to individualize for specific students. One professional in the Midwest U.S. mentioned the importance of teaching peers so that they can also interact with the student who is deafblind.

The theme of *interactions and communication* included comments on understanding the unique nature of each student's communication and sharing that knowledge with others. Sharing with others is also an aspect of the theme of collaboration and continuity. Professionals remarked about the importance of individualizing communication forms/modes as exemplified in the following two quotes: "I individualize by understanding my students' communication modes, understanding their thresholds, and knowing, especially it's very important to just know their interests" (professional in Northeast U.S.) and "Multimodal in first instance, then stay on using more forms…, and then to observe which fits the best with this student" (teacher in the Netherlands). One professional mentioned offering individualized choices during interactions. Two professionals remarked that individualizing interactions included modulating the amount of emotion and excitement that the professional displayed, based on the needs of each student.

Much emphasis was placed on individualization that must occur in the moment as part of an instructional approach that capitalized on child-guided methodology. Ideas included adjusting instruction in response to the student and responding to the student's initiations in the moment. This meant departing from the original instructional plan, as indicated in the quote from a teacher in the Netherlands:

'We work, of course, already very individual with every student, and then it is important to observe at the moment what the student initiates. It is difficult to prepare, because you have to adapt to the mood and to the interest of the student. If you don't do that, you miss a chance'

Adjusting to the student's changing activity level was also mentioned as part of teaching in the moment.

Emotion was central to the responses about teaching in the moment, especially among professionals in the Netherlands. This included being attuned to the student's emotions and adapting to the child's changing moods. One professional asserted the importance of making interactions fun:

'*How can you make the click together-because it has to be fun. Yes, it is my work, but it has to be fun for both of us. If it is not fun then nothing happens.*'

Decisions about retelling and reliving shared experiences also occur in the moment and are highly individualized. Finally, one professional mentioned the importance of trying new things as this may be helpful to learning how to individualize instruction for students.

Findings on Personalization

Video analysis of the observations and review of the field notes supported the identification of lessons that met our definition for personalization. Personalization strategies included frequent use of the child's name in the music lesson, making experience books with the child pairing the book with an actual experience, and elaboration of parts of the experience book to which the child displayed greater interest and positive affect. A teacher in the northeast, U.S. remarked:

'*So, try to do the same thing with all the kids, as much as possible, let them make books, to make them experience the concepts themselves through these kinds of books. I think that's one way I try to personalize. Repeated readings of experience books may support the child's memory of these personal and shared experiences.*'

Axial coding of the interviews resulted in the following response themes: (1) types of lessons, (2) instructional procedures, and (3) the importance of experience. When asked about how they personalize instruction, teachers and speech-language pathologists identified *specific lesson types*, such as personalized literacy books, experience stories, memory books, daily schedules, and social stories (although these were not necessarily the lessons they selected for observation). Two teachers who were not currently using personalized literacy materials mentioned specific examples of using personalized books in the past. Professionals also mentioned *instructional methods* and *procedures* such as making books together (both gathering materials and co-construction of personalized literacy products), using the child's name or name symbol during instruction, and considering what the child likes and dislikes when planning lessons. Responses about *experience* included

grounding lessons in the child's experiences, sharing experiences with the child, and retelling and reliving experiences shared with the child. In the following quote, a teacher includes commentary about both individualizing and personalizing literacy instruction across communication forms:

'We have kids doing icons. We have kids doing sign. We have kids that are using objects. We have kids doing books that are texturized and are very simple, simple texts. Then we have kids who don't need the texture, but they might just need icons. We have books that are personalized for each kid, where it's like individual experiences they've had. That way they can relate to them and then make sense and use that information.'.

Discussion

The six lessons that were identified as being both individualized and personalized represented three different lesson types: one music lesson that created frequent opportunities for active performance by the child and repeated use of her name, three schedule lessons that were about the child's daily life and individualized to each child's needs, and two experience stories. Additional lesson types were shared in the interviews (such as day books, journals, and conversation maps). Miles (2005) advised professionals to support children who are deafblind to participate in as many of the typical functions of literacy as possible. She discussed the functions of memory use and coping with emotions, among other literacy functions. Personalized stories (also known as experience books) and journals support the child to build memories, while making fewer cognitive demands because the content is familiar. Journals and conversations about the daily schedule may support children in the function of coping with their emotions as they grapple with preferred and non-preferred activities on the daily schedule and memories of those activities in their journals.

Ruppar (2014) discussed four types of teacher literacy decisions: (1) setting, (2) topic, (3) materials, and (4) activity. The teachers and speech-language pathologists in this study considered these aspects when individualizing lessons. In their lessons, setting included positioning, equipment, and staffing considerations. When selecting the topic and activity, some of the professionals talked about considering the child's interests and even creating activities about the child's personal experiences, as a means of personalizing literacy. Others talked about the need to leave their instructional plan behind to respond to the child's interest in the moment. This is a foundational principle in educating children who are deafblind through a child-guided approach. Consideration of the child's interests is important to grounding conversations (Nelson, van Dijk, McDonnel, & Thompson, 2002) and activities that are grounded in the child's interest, actually promote communication (Miles, 2008).

During the interviews all 23 teachers and speech-language pathologists made comments about how to individualize communication and literacy lessons. Some used the terms individualize and personalize interchangeably in describing their actions that were unique to each child, but not necessarily about the child's life (e.g. not actually personalized, according to our definition). Several professionals differentiated individualizing and personalizing instruction, while others did not. Across all three sites professionals identified these elements of individualizing instruction: knowing the child (through interactions and collaboration), consideration of child's preferred communication forms and learning modalities, teaching at the correct level to meet the child's needs, pacing, and wait time.

Some site differences emerged in the interviews. Professionals in the Netherlands made unique comments about emotional attunement, adapting in the moment, and drawing. These professionals shared more detailed descriptions of how they worked with specific students. One professional in the Midwest U.S. made a unique comment about how individualizing changes over time (corresponding to the changing needs of the student). Professionals in the Netherlands and Midwest U.S. commented on regulating their emotions and energy levels to each child's needs. Professionals in the northeast, U.S. most often mentioned specific lessons and were the only group that discussed individualized selection of commercial texts. Both professionals in the Northeast U.S. and the Netherlands mentioned how they would individualize specific lessons, although their terms for these lessons may have differed (schedules, calendars, experience stories, conversation maps).

Limitations

Sample size is a limitation of this study. The study included 23 teachers and speech-language pathologists who served 22 children who are deafblind. The sample was also purposive, resulting in some of the adult participants being familiar to the researchers. Although 66 lessons were observed we focused on just the six that were both individualized and personalized in this article and on the one interview question that addressed the concepts of individualizing and personalizing instruction.

In presenting our preliminary findings at the Deafblind International Worldwide Conference in Romania in 2015, we invited audience input on the meaning of personalizing literacy. Participants asserted that personalizing instruction might occur in the moment, such as when the teacher draws on shared memories to support a student to connect to concepts in a commercially produced literacy text. Since personalizing in the moment would be more difficult for an outsider to recognize, it is possible that we under-identified the number of lessons that were personalized.

Conclusion

The meaning of literacy has been extended beyond the traditional definition of reading and writing. Literacy instruction no longer excludes learners who are prelinguistic. One of the primary purposes of this article is to differentiate the meanings of individualized instruction and personalized instruction in the area of communication and literacy for learners who are deafblind. While some of the educators in this study used the terms "individualize" and "personalize" synonymously we propose that these terms have distinct meanings. Individualized instruction occurs when instruction is provided at the correct level and utilizes strategies that are most suitable to the needs of each child. Personalized instruction focuses on the child's life experiences, with attention given to what is most salient about each experience from the child's perspective. Often these experiences are shared with others who may later share memories with the child. In this study, knowing the student and family, collaboration and continuity among professionals, understanding each student's unique communication, and adjusting instruction in the moment supported were important to individualizing instruction. Shared experiences, memories, and emotions were central to personalizing instruction.

We suggest that effective interaction and instruction will require the enactment of the principles of individualization and personalization by professionals who are highly sensitive and responsive to the changing needs and interests of each child who is deafblind. Future research can extend this preliminary investigation by learning more about how professionals in different cultures and across different languages view the constructs of communication, literacy, individualization, and personalization.

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