Communication During Physical Activity for Youth who are Deafblind: Research to practice

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Abstract

Communication is a barrier to accessing physical activity and recreation for many people who are deafblind (Lieberman & MacVicar, 2003; Lieberman & Stuart, 2002). The purpose of this study was to observe effective communication strategies used during four physical activities for youth who are deafblind. Communication during physical activity was analyzed over two summers during a one-week sports camp with eight participants with four different modes of communication. Three themes emerged from the data collected: 1) the importance of allowing time for environmental exploration; 2) the individual and familiar people are essential resources; 3) conceptualizing activities as discrete or continuous emerged as a way of thinking about activity.

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Introduction

Research has established that there is a fundamental need to focus on communication skills for participation in normal daily life activities including physical activity and recreation for individuals who are deafblind (Tedder, Warden, & Sikka, 1993; Stremel and Schultz, 1995). However, the provision of effective communication can be problematic. Lieberman and Stuart (2002) found that communication was a major barrier to participation in activities for adults who are deafblind; Lieberman and MacVicar (2003) reported a similar finding for children who are deafblind. Communication with individuals who are deafblind may include sign language in close proximity, sign far away, tactile sign, or a combination of sign and speech; finding communication partners who are skilled in sign and in adapting their signing style and method to the needs of the individual can be challenging across all environments. When considering the intricacies of communicating with someone deafblind while they are engaged in physical activity, which often involves the use of the hands, the issues become even more significant.

In addition to a potential communication barrier, there are other barriers to involvement in satisfying physical activity and recreational activities for adults who are deafblind (Lieberman & Stuart, 2002). Those barriers include lack of opportunities (Lieberman & Houston-Wilson, 1999) and lack of confidence (Shapiro, Lieberman, & Moffett, 2003). Research conducted with adults who are deafblind showed that those adults were unsatisfied with their current level of recreation (Lieberman & Stuart, 2002). Furthermore, parents of children who are deafblind were not satisfied with their children's current level of recreation inside and outside the home (Lieberman & MacVicar, 2003).

Related specifically to children with visual impairments, complications in physical activity for children with visual impairments also include fear of movement and difficulty in establishing trust with others (Lowry & Hatton, 2002). In addition, lack of experience with complex sport activities severely limits sport participation in later life for children with visual impairments (Ponchillia, Strause & Ponchillia, 2002). While these studies were not conducted with children who are deafblind, there are implications from this research for those children. Children and youth who are deafblind must mange not only the effects of a visual impairment but a hearing impairment as well. The potential that findings from Lowry and Hatton (2002) and Ponchilla, Strause, and Ponchilla (2002) would in some way apply to children who are deafblind seems a reasonable one.

Lieberman (2002) has shown that recreational activities fulfill a variety of needs for individuals who are deafblind such as socialization, fitness, and normalization. Additionally, recreation helps facilitate communication and is an essential part of transition from school to vocational life for youth who are deafblind (Haring, Haring, Breen, Romer & White, 1995; Huven & Siegel 1995; McNulty, Mascia, Rocchio, & Rothstein, 1995). Finally, recreation can be a means of reducing physical, social and psychological isolation (Haring et al, 1995;

Mar & Sall, 1995; McInnes, 1999). Clearly being physically active is a powerful strategy to support children and youth who are deafblind. However, a lack of experience in physical activity and recreation coupled with communication barriers results in isolation and limited opportunities to engage in physical activity for youth who are deafblind.

Purpose

The purpose of this study was to observe effective communication methods in use with youth who are deafblind during swimming, track and field, tandem biking, and gymnastics. Authors collaborated with participants in problem solving related to communication during physical activity as requested. However, no particular method was taught. The focus was on identifying what effective methods were in use at the time of the study.

Methods

Participants and Setting

The setting for the camp was a college campus in the northeast United States. Authors observed participants as they engaged in a variety of physical activities at a one-week developmental sports camp for youth and young adults who are visually impaired, blind, and deafblind. The camp was designed to provide opportunities for skill development in a wide range of physical activities and sports for youth who often did not have those opportunities in general education settings. To that end, instruction and opportunity to practice was provided for activities including beep baseball, goal ball, judo, track and field, swimming, canoe and kayaking, tandem biking, and gymnastics.

All campers were visually impaired and blind. In addition, a small number of campers had additional disability labels, including deafblindness. The campers who are deafblind were the focus of this study. Five young women and three young men who are deafblind were observed over the course of two years. Participants were teens and young adults ranging in age from 12 to 23 who are deafblind and used four different modes of communication. Those modes were sign language 6-8 inches from the face, tactile sign language, sign language in a small signing space 6-8 feet from the face, and tactile sign with speech. All participants reside in the United States. See table 1.0 for a review of each participant's pseudonym, gender, year(s) they participated in this research project, age, sensory status, and familiar communication method.

Table 1.0 - *Participant Description*

Pseudonym	Gender	Years at camp	Age	Sensory Status	Communication method familiar to participant
Beth	Female	1st, 2nd	12-13	cortical visual impairment and deafness	sign language 6-8 inches from face
John	Male	1st, 2nd	12-13	congenital total deafblindness	tactile sign language
Keith	Male	2nd	23	congenital total deafblindness	tactile sign language
Mary	Female	1st	19	total deafblindness, cerebral palsy	tactile sign language
Monica	Female	1st	19	deaf, low vision from Charge Syndrome	sign language
Bianca	Female	1st, 2nd	15-16	cortical visual impairment and deafness from Charge Syndrome	sign language 6-8 inches from face
Mark	Male	1st	20	2 degrees of central vision and deafness from Usher Syndrome	sign language in small signing space 6-8 feet from face
Chloe	Female	1st	19	total blindness hard of hearing	tactile sign and voice

Data Collection

Permission to conduct research was requested and received from the authors' Institutional Review Boards. All campers over 18 and the parents of campers under age 18 signed informed consent statements allowing observations and interviews. All consent forms were available in print, large print, and Braille. An assent statement was signed or read to campers under 18 and permission was granted by those participants. Campers' counselors, interpreters, and activity specialists were also interviewed. An oral consent script was read or signed to them, and oral or signed consent was granted by those counselors, interpreters, or and activity specialists.

Data collection included participant observation and interviews over two years. Each year included 7 days and 6 nights of camp; researchers conducted observations throughout the 8 hour activity days and conducted informal one to one interviews during the day and in the evenings with campers, counselors, interpreters, and activity specialists about communication during physical activity for the campers who are deafblind.

A schedule of each participant's daily activity was reviewed and observation plans made to ensure that each author observed each participant in at least two activities. This was done to ensure inter-rater reliability. Activities selected for this study were swimming, track and field, tandem biking, and gymnastics. An observation form was created for use in the field. It indicated the participant being observed, others involved in the communication process, the activity, the researcher conducting the observation, and room for field notes.

Authors observed participants, their counselors, activity specialists, and interpreters during activity sessions and conducted informal interviews with them. Rapport with participants was established by communicating a feeling of empathy and interest in the activities (Taylor & Bogdan, 1998). Authors and collaborated with them to provide communication opportunities during activity. At the end of each activity the authors met with each other and generated detailed field notes. Notes were recorded on the observation forms.

Participants and others were asked in informal interviews how they communicated during the activity, what worked, what did not worked, and what adjustments were made. Interviews were conversational and focused on identifying what facilitated communication when the youth was engaged in physical activity. Notes were taken immediately after each interview to facilitate as complete a record of the interview as possible.

Authors met several times each day to review emerging themes and plan the next day's observation schedule.

Data Analysis

Observation forms and notes from interviews were the primary data source. All information from the forms were typed verbatim and proofread for accuracy by two authors. Transcripts comprised a total of 100 pages of single spaced text. Interviews were a secondary data source and comprised a total of 70 pages of single spaced text. All data were read in undisturbed periods by each author to gain a sense of the totality of the data (Bogdan & Biklen, 1998). Data were coded and categories were extracted. The authors developed coding categories independently and compared their emergent codes. The majority of codes were similar. In cases involving codes not mutually identified, the authors reviewed the data

related to those codes and came to agreement about the codes to be used.

Findings

Three findings will be examined. Those are 1) the importance of allowing time for environmental exploration; 2) the individual and familiar people are essential resources; and 3) conceptualizing activities as discrete or continuous is an emerging way of thinking about activity.

Allow time for exploration and instruction

Allowing time for the camper to explore the environment and equipment and to receive one to one instruction - with an interpreter as needed - emerged as a theme for communication during activity. We found campers benefited from using activity time to explore the setting and equipment before beginning direct skill instruction. Other campers who have visual impairments or who are blind and are hearing used less time to become familiar with the environment and equipment.

Swimming

In swimming, campers were typically familiar with the setting and most equipment (which included kickboards, noodles, hula hoops, floating balls, and weighted balls). Skill instruction typically took longer for campers who are deafblind than for campers with visual impairments alone. For example, Mark is an advanced swimmer and was in a small group of swimmers learning the breaststroke. When asked how his lessons were going, his instructor said “It’s going well, but it takes so long to explain to Mark. He is behind the rest of the group.” When asked why, she said “Mark needs to be out of the water to have things explained. It takes a long time.” Others swimmers in his group could stay in the deep water and hold the sides of the pool while an instructor gave direction from the deck. For Mark, that was not effective. The result was Mark taking a longer time than his peers to receive instruction.

Track and Field

In track and field, there were many instances that included taking time to explore equipment and the sequence of movement. One example of what can happen if time for exploration and instruction is not provided is reviewed here. Holly and John went to the long jump lane and sand pit. Holly guided John to the end of the asphalt lane and faced the sand pit in front of them. She asked him to jump – and he did, straight up and back down. If he had been given the opportunity to explore his environment he would have understood that there was a sand pit in front of him and that the request was for a long jump not a vertical jump. Holly realized that he did not understand the expectation. She stopped to talk with John about jumping and different ways to jump. She guided him to the end of the lane and they touched the sides of the lane all the way to the end, then felt the sand pit at the end. She explained that the jump she wanted him to try is “not up and down, no, it’s long jump.” After this review he jumped from the lane into the sand pit, each time jumping farther into the sand.

Tandem Biking

In tandem biking, John took time to explore the tandem bike and helmet. This process included several steps. First, he chose a helmet from a box of helmets. He touched each and tried on several before finding one that fit well. Holly guided his hands and provided support for him to snap the buckle on the chinstrap. She guided him to tandem with a standard bike seat in the back and recumbent front seat with a seat

belt. She explained that this was the bike he would ride, and that another counselor Mitch would ride with him. Mitch straddled the bike, holding it upright by the handlebars from the rear seat.

Holly guided John to the bike and explained that Mitch was standing at the back; the seat was for John to sit on. John ran his hands along the front wheel and front seat, found the grips for his hands. He continued to feel the bike and touched Mitch, feeling the position of Mitch's body as he held the bike. John pointed to the empty front seat and then to himself. Holly affirmed that that was where he would sit. He put on the helmet Holly had waiting for him, seated himself on the bike, and fastened the seat belt. Holly explained that he needed to put his feet in the toe clips and that Mitch would hold the bike up. She guided his legs to the pedals. She explained that she would be waiting for him when he was done, and Mitch would ride with him. He reached his hand back to feel for Mitch's hand; he felt Mitch's hand and settled in to ride.

Gymnastics

In gymnastics**,** the environment included a variety of surfaces and equipment. Equipment in the gymnastics room included a tumble track (a long rectangular trampoline), uneven bars, a chalk bin for coating the hands, a balance beam with foam pads at each end, a vault and spring board, a foam pit (to land in when practicing vaulting), a trampoline, and a floor exercise floor. On the floor exercise floor were various foam wedges, cylinders, and large squares. In addition there were a variety of mats around the room –some thick, some thin, some stacked on top of each other; underneath the mats was a wooden floor. These pieces of equipment merited time and attention by the campers who are deafblind to explore and understand the name and use of each before beginning instruction related to using the equipment.

For example, in his first session in gymnastics Keith spent 40 minutes exploring the floor exercise area. He sat on the floor and bounced lightly with his legs; he walked up and down a large foam wedge, he touched and smacked the uneven bars and felt them vibrate, he touched and tasted the chalk. He walked around the room with his counselor, slowing changing the surfaces he walked on. He experimented with each surface, bouncing a little here and there, reaching down to touch the mats or floor, sitting on some surfaces before resuming his exploration. This is all necessary even though it takes time.

Essential resources

Individuals who are deafblind have unique communication needs and a varied background of experiences. A theme that emerged from this literature was the importance of familiar people being available, and treating the person as an expert about their needs.

Swimming

In swimming, one author observed Keith with his counselor Albert. Albert knows Keith well and sees him daily. The author asked Albert if Keith had experience with bobbing in the water. He said yes, and that the signal they used for going under was to "hold his hand and squeeze it, then go under yourself, and he will go under after you." Albert demonstrated that it worked well, and then the author completed the same sequence with Keith.

Track and Field

In track and field, the authors observed Bianca and her counselor Karen preparing to run on the track. An interpreter who had not been to track with them was preparing to go with them, and positioned

herself in front of Bianca. Bianca angrily signed "move!" and refused to run. The interpreter asked her what was wrong; Bianca did not answer and ignored her. Her counselor Karen said "Bianca, I know, let me explain to her." She turned to the interpreter and explained that Bianca liked to run with no one in front of her; Karen ran behind her and shouted verbal cues to her from behind her. The interpreter and Karen turned to Bianca and explained that now they were ready to run with Bianca in front and they all started their jog. Without Karen to explain and mediate, the interpreter would have needed additional time and support to understand what Bianca expected and preferred. Karen's growing familiarity with Bianca made her a valuable resource after only a few days of living and engaging in activity with her.

Tandem Biking

In tandem biking, Beth had two counselors she worked with, Sue – who has a visual impairment – and Sarah, who is deaf. The adults expected that someone with vision would ride with her, and Sarah prepared to join Beth on the bike. Before getting on the bike, Sarah asked her who she would like to have ride with her. Sarah was surprised when Beth asked that Sue go with her. Beth explained why she chose Sue to ride with instead of her counselor Sarah: "Because Sue can hear, so if someone yelled out stop or there was a car we could hear it. With Sarah we would not be able to hear those things." Beth and Sue rode successfully together on the closed track. Allowing Beth to choose for herself gave her the opportunity to request something the adults did not expect or plan to provide for her.

Gymnastics

In gymnastics, John asked one author to "throw" him while they were bouncing on the tumbletrack. The author asked John to explain, and he asked her again to throw him. At a loss, the author turned to Holly. She was standing to the side and observing, and was familiar with John and his environment at home. She joined them on the track and explained to John that while his family would throw them on their trampoline at home, people at camp would not because there was not room to throw him safely. Without that insider knowledge, the author would not have known what he meant. These examples demonstrate that the participant and familiar people are essential in developing communication during activity.

Discrete and continuous activities

A third theme emerging from this research is the difference between activities that include natural breaks and those that do not. We term activities with natural breaks "discrete activities:" they include a clear beginning and end to the skill or activity. Natural breaks in activity provide communication opportunities – for discussion about adjustment in the performance of the physical skill, soliciting input from the camper about their comfort level with the activity, and encouragement. Examples of discrete activities include shot-put, long jump, goal ball, beep baseball, archery, and bowling.

Activities that do not include natural breaks we call "continuous activities." These are activities with no clear ending point. Examples include swimming, running, rock climbing, canoeing, and tandem biking. In addition to continuous activities are activities in which both hands are engaged in activity and are not available for communication. When students who are deafblind have both hands occupied it is difficult to receive information if they are tactile learners, and it is difficult to express

information at all. This must be considered when planning communication as it interferes with expressive and receptive communication which can affect the acquisition of skill information.

Continuous skills must be punctuated with breaks for communication. In other words, continuous activities must be modified into discrete activities to allow necessary breaks. What we found in this research was that it is necessary to think deliberately about when and where communication can take place during activity. If explicit attention was not given to the issue, communication breakdowns occurred.

Swimming

In swimming, instruction in shallow water can occur while standing in the water. However, being in deep water is problematic for communication, demonstration, and feedback. One interpreter commented about working with Mark in deep water: "instruction needs to be on the deck when he can put his glasses on. And that's where instruction should be done. After that point, once he's in the water, it's difficult to understand." A second interpreter had a similar comment about interpreting for Beth: "what works for her is to have as much instruction as possible on the deck." The way to incorporate breaks for swimming instruction in deep water is to plan to have the student come out on deck for instruction when needed. This way, the continuous activity of swimming can be broken into discrete instructional sets with breaks for instruction.

Track and Field

In track and field, throwing the shot, discuss or javelin and completing a long jump include natural breaks. Running can be discrete or continuous depending on the distance involved. In this research we found that running a single lap of the track (a quarter mile) or more was a continuous activity with little opportunity for communication. In one instance the authors observed Bianca, her counselor, and her interpreter arranging to run a half mile (two laps). Bianca did not want to stop to talk, and arranged with the counselor and interpreter that she would "run continuously" for the full two laps. Discussing this before the activity made it possible for Bianca to run without interruption.

Tandem Biking

In tandem biking, when John rode a double bike he chose the recumbent tandem with Holly in back. When he was on front Holly touched his back to let him know she was there. The interpreter touched his hand to let him know she was there. Holly said "alone or together," John said "together, yes." Touching his back while biking was one way to provide reassurance and touch during the activity. Over the course of the week Holly developed signals to give John information during biking. Those included a tap on the shoulder before slowing, touching the side of the shoulder when approaching a turn, choosing the side the turn was toward. Signs for "more" and "finish" were not possible given the fact that Holly needed to steer with both hands and John held his handlebars or seat with both hands. The spatial nature of both signs limited their use as well.

Instead, before beginning to ride, Holly discussed what John wanted by reviewing how many laps he wanted to ride before communicating again. They negotiated and agreed to ride 6 laps then stop the bike. After riding the 6 laps (1 mile), with Holly using the touches on John's shoulder before turns and the slowing signal, she stopped the bike and straddled the bike. Another counselor steadied the

bike as she reached over John's shoulder's to communicate. She asked if he wanted more or to finish, and he wanted more. They negotiated again to ride 6 more laps, and did so. After that series of laps John decided to stop.

Gymnastics

In gymnastics, most activities are discrete. We found that activities that included the use of both hands - like jumping to a front support on an uneven bar – were similar to continuous activity in that little communication was possible. In those cases, as in continuous activities, communication about the activity occurred before the movement began.

Implications for Practice

The purpose of this study was to determine effective communication methods in use with individuals who are deafblind during swimming, track and field, tandem biking, and gymnastics. The setting was a segregated camp for children and youth who are visually impaired or blind. Eight individuals who are deafblind were observed and interviews were conducted with the participants, their counselors, the interpreters and specialists about effective communication strategies. Three themes emerged and findings were described. Below is a discussion of how findings relate to current literature and recommendations for practice.

Allow time for exploration and instruction

Research has established the need for careful planning and added time, both in general interactions and in instruction for students who are deafblind (Best, Lieberman & Arndt, 2002; Downing & Chen, 2003; Gee 1994; Welch & Cloninger, 1995). For children who are blind, additional time – compared to the time children with vision need - supports the development of trust in the assisting adults; this is a crucial factor in enhancing confidence and a sense of security (Lowry & Hatton, 2002). Findings from this research confirm the need for *time to explore the environment and equipment*; the amount of time was often greater than the amount of time campers who are not deafblind needed. For example, it took John over 30 minutes to explore and understand what a horse was before he felt comfortable enough and understood the concept of riding the horse. Taking the time, energy and effort to establish successful communication and understanding during physical activities will improve skills, socialization and self-determination for individuals who are deafblind.

Essential resources

A second finding was to *ensure that the individual or people who are familiar with the individual are consulted* to avoid misunderstandings or miscommunication. Moving beyond oneself challenges a student's sense of security. Students must feel comfortable with and competent of their instructors in order to be willing to move outward and take risks (Prickett & Welch, 1998). The literature warns to be especially careful not to limit a students communication options because of instructor's preferences (Prickett & Welch, 1998). We know that instructors can inadvertently teach students to be helpless when they keep students in only passive roles (Prickett & Welch, 1998); it is important to support students in actively participating in decisions about communication.

In addition to familiar people, the individual is an expert resource about their preferences and needs (Bhattacharyya, 1997; Olson, 1998). These findings confirm the

work of several researchers who advocate the development of collaborative educational teams with different team members contributing their skills, knowledge, experience and ideas for program development and mutual support (Downing, 2002; Silberman, Sacks, & Wolfe, 1998; Welch & Cloninger, 1995).

Discrete and continuous skills

A final finding, *distinguishing between discrete and continuous skills*, provides a way of thinking about activity that explicitly addresses when communication will happen. There need to be clear beginnings, endings, and transitions for activities. Also, carefully task-analyze an activity keeping in mind the students particular sensory, cognitive and motor abilities-then consistently use the task sequence when teaching and performing the activity when performing with the student. Task analysis is the strategy of breaking a skill into component parts. For example, kicking a ball includes stepping toward the ball with the non-kicking foot, kicking with the kicking foot, making contact with the ball, rotating the hips, shifting body weight from non-kicking to kicking side of the body, and stepping forward with the kicking foot.

Continuous activity for people who are deafblind need to be carefully constructed to include planned breaks during the activity. If the activity is new the breaks may be closer together such as after three rotations on the bike, or after one width of swimming in the pool. Learning new skills that are continuous requires planning for instruction and feedback. Creating breaks that provide time for feedback and communication are necessary in order to increase knowledge of the skill and to address any concerns or questions the person has. As the learner becomes skilled and confident the continuous activity breaks can be spaced further apart.

Tips for teaching youth who are deafblind during activity

Activity area	Tip
Swimming	• For deep water swimmers, include time on deck for instruction • Remember that the pool environment includes lighting that may not be optimal and acoustics that make hearing challenging • Remember that hearing aids and cochlear implants are not worn during swimming; this affects what can be heard
Track and field	• Present equipment (tethers, guide wires, shot put, discus) and plan time for exploration before beginning instruction • Explore the area, including the whole track (and any obstacles on it), the long jump pit, and the throwing areas • Review safety rules about the throwing areas
Biking	• Allow time to explore the bike. • Review signals for starting, stopping, turning, and emergencies • Encourage the youth to choose a riding partner they are comfortable with.
Gymnastics	• Plan time for exploring the environment. There are many surfaces in the gym to experience. • Plan communication cues for movements that use both hands

Sport specific recommendations

In swimming, plan lessons to include time on deck for instruction. If swimmers are in deep water, assume that they will not be able to receive instruction while in the water, even when holding on to the side. Plan for them to leave the water for detailed instructions, or arrange signals before the swimmer enters the water.

In track and field, plan time for the youth to explore the setting and equipment. Understanding where and how to jump into the long jump pit is one example. A second is feeling a guidewire or tether used for independent running and exploring the beginning and end of the wire by walking the length of the wire. When preparing to teach shot put or discus, plan for the youth to walk onto the throwing area and pace off the area to be restricted for throwing only, and explain the danger of throwing outside of that area and of walking in that area when other throwers are present. For running, discuss the preferred guiding technique, the length of the run, and where to start and stop before beginning to run.

In tandem biking, plan for time to explore the bike, including both seats. Arrange signals for stopping, starting, slowing, and turning. Arrange and review a signal to use for emergencies or feeling unsafe or unbalanced.

In gymnastics, as in track and field, plan time for exploration and explanation of the setting and equipment. For activities that include the use of both hands – like front supports, handstands and headstands, hanging from rings and bars – plan communication cues before beginning the activity.

Taking the time, energy and effort to establish successful communication during physical activities will improve skills, socialization and self-determination for individuals who are deafblind. It is important to understand that it is a process and the product will come with careful planning, teamwork and patience.

Note

In this study the term “deafblind” is used to refer to individuals who are “unable to utilize their distance sense of vision and hearing to receive non-distorted information” (McInnes & Treffrey, 1997, p.2). As Smith (2002) and Brennan (2001) note, deaf-blind is a term that includes a wide range of experiences and does always not mean totally deaf and totally blind. The term “deaf-blind” has been used less frequently, especially since 1993, as “deafblind” has been adopted throughout the world (Aitken, Buultjens, Clark, Eyre, Pease, 2000). McInnes (1999) reports a similar shift dating to the 1990 Conference of the International Association for the Education of Deafblind People (since renamed Deafblind International). The international convention is followed and the term used is “deafblind.”

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