

# Deaf-Blind Perspectives

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## History and Change in the Education of Children Who Are Deaf-Blind Since the Rubella Epidemic of the 1960s: Influence of Methods Developed in the Netherlands

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**T**he approach to education of individuals who are deaf-blind has changed significantly since the rubella epidemic occurred in the United States and Western Europe in the early 1960s. Prior to the epidemic, only incidental successes in educating children who are deaf-blind had been reported. In the United States, Samuel Gridley Howe wrote in a detailed manner about his student, Laura Bridgman, and Anne Sullivan reported on the enormous educational progress of Helen Keller. In Norway, Ragnild Kaata, a deaf-blind student, was taught to talk, and in France, Marie Heurtin received wide attention for the level of language she was able to attain. This article examines how methods developed in the Netherlands influenced later theories and practices in the education of these children and how those theories have evolved and changed over time.

Early educational methods were well documented and certainly inspired professionals who saw themselves confronted with the multitude of problems presented by children rendered deaf-blind by rubella. Since educators in the United States, at Perkins School for the Blind, had the longest history of deaf-blind education and already had established teacher training courses prior to the rubella outbreak, professionals in Europe turned to them for support. Young European educators of the deaf-blind were enrolled in teacher training programs in the United States and, together with the staff of the American Foundation for Overseas Blind (AFOB), used their newly acquired knowledge to establish eight training courses held from 1968 to 1975 in Sint-Michielsgestel (the Netherlands) and at the AFOB headquarters in Paris. Virtually all Western European countries participated in these six-to eight-week courses. The format of the courses was rather unique. As their colleagues observed, teachers of Sint-Michielsgestel demonstrated teaching techniques they had developed. After each session, a general discussion took place. Because of this early United States -Western European cooperation, the ideas of deaf-blind education that grew out of the AFOB courses at Sint-Michielsgestel found their way to newly founded programs in Scandinavia, Belgium, and Holland and to a lesser extent, Germany, France, and the UK.

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### What Were the New Ideas?

Traditional deaf-blind programs were mainly geared to children who were thought to have what was considered good educational potential. The curriculum emphasized classroom activities (e.g., development of sensory motor skills such as sorting objects and matching) and above all, the development of communication. This type of program was not appropriate for the "new" population of deaf-blind. Particularly in the rubella population, traditional classroom activities were overpowered by the motor clumsiness of this population. Training of motor skills was a prerequisite to the development of any form of formal communication, be it fingerspelling, speech or signing. As research substantiated these observations, a

program was developed with motor development as the central component. This approach was in line with the emphasis remedial education of that time placed on the development of gross and fine motor skills (Kephart, 1960; Bannatyne & Bannatyne, 1973; Bladergroen, 1971).

During the 1965 Kalundborg conference (Denmark), a film called "Motor Development in the Deafblind Education" was shown in which Jan van Dijk from Sint-Michielsgestel showed the beginning steps of deaf-blind education. Two parts of the film attracted wide attention. The young rubella population exhibited considerable delay in both their motor functioning and social skills. The majority of children in this group were withdrawn into their own body activities and therefore paid little attention to other people in their world including the teachers or parents who tried to come in contact with them. This was true both, of the children who were completely or almost blind and those with residual vision. There was, however, one way to successfully attract the children's attention: joining in their favorite activities (e.g., moving hands in front of their eyes, rocking, jumping or spinning around). This "moving-acting together" as Van Dijk called it, was in sharp contrast to approaches practiced with persons with cognitive disabilities in which these activities were stopped by taking their hands away from their eyes or even strapping them down. The co-active movement approach advocated by Van Dijk caught on because of its approach of "joining

in" with the child and following his or her attention and interest. It was truly a child-centered approach that included imitation of the child and giving him or her the lead, so he or she would not become totally dependent on the teacher's activities. In the coming theories of child development, this approach was to be called "feeling of competence" meaning fostering the feeling in the child that he or she can have an influence on the environment instead of being completely dependent upon it. In co-active activities, the educator literally feels what the child's intentions are. When moving and acting together the educator is able to perceive the topographically subtle tentative movements the child sends out and may act accordingly.

## Attachment Theory

Modern insights into child development have shown how well chosen the ideas of co-active movement were. Currently, a well-researched theory, the Attachment Theory, is gaining wide recognition. It appears that if a child's intentions, which may be subtly expressed through eyes, physical movements, and changes in breathing, are picked up on by the principal caregiver and responded to accordingly, the child will begin to feel that this is a safe person who can be trusted in times of need. In other words, a bond is established between child and caregiver which will serve as a "safe harbor" for the rest of the child's life.

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## Conversations

This idea of following the child's lead and responding to his or her intentions has only gained in prominence over the years. The same can be said about another theme of the 1965 film made at Sint-Michiëlgestel. A scene is portrayed in which one of the finest teachers of the deaf-blind, Mary Jurgens, communicates with a nonspeaking, nonsigning, deaf-blind boy. Co-actively, they are making a doll out of clay. Together they roll a kind of sausage representing the leg of the doll. Then Mary guides the child's index finger to point to the "sausage", then to her legs and to his legs, and finally to the missing part of the clay doll. He understands it, and with her help completes the clay doll including its leg. A conversation has taken place through pointing and referring to the situation (missing leg). The teacher has made herself understood by guiding the situation in such a way that the boy had to understand her intent. He added his part in the conversation by putting the leg in the right place. This is exactly what Van Uden, meant by having a conversation with a speechless (and nonsigning) deaf-blind child (1967). His conversational method has always been influential, not only for deaf, but also for children with deaf-blindness. Important features in this method such as turn-taking, mutual gaze or the looking to things together (e.g., child and educator or child and parent), and the use of pointing (deixis) have been found to be essential elements in the development of language, as was demonstrated in research that came out many years later (Ninio & Snow, 1996; Preisler, 1983; Volterra & Erting, 1990).

It goes without saying that such conversations must have a subject. Children who are deaf or nonverbal with hearing can be very clear about what it is they want to communicate about. They may look towards things, move towards something, or bring an object to a person. Most children who are deaf-blind do not show their intentions so clearly. Therefore in the early Van Dijk theory, the topic of conversation was elicited by making the experience very concrete. If the child participated in an activity he or she enjoyed such as swimming, an object associated with this activity was presented. Through pointing to the object, gesturing, and in some instances talking to the child, the experience was discussed: "you" (pointing); "me" (pointing with the child's finger and teacher's body); "swimming" (pointing to the water wings); "you" (pointing); "splash, splash" (co-actively splashing). A model of the swimming pool might be present with chlorinated water in order to depict the situation as vividly as possible. These objects called "objects of reference" were, and are, intended to serve as a concrete aid for engaging in conversation with the child.

## Objects of Reference

In his early work with deaf-blind children, Van Dijk and his coworkers stuck the objects of reference to wooden boards and sorted them according to conversation topics. Later the objects were also used to announce the activity (e.g., presenting the entire water wings or a portion to indicate actually going to the swimming pool). The use of the objects of reference for this function is now widely used with people who have all types of significant difficulties in communication. A group of special educators in the U.S. have expanded considerably upon the idea of the objects of reference. On a video tape, Rowland and Schweigert (1996) demonstrated step-by-step how the objects can be used.

## Calendars

From the same basic question of how to come into conversation with the child, grew the idea of calendars. By ordering the days/weeks/months according to their main activity and putting the objects of reference in the time order of the day/week/month, conversation can be enhanced. When the objects of a specific event are arranged in a box, they can serve as a support for the child's memory of episodes in his or her life. In a true conversation, both partners play an active role. By the nature of his sensory impairments, a child who is deaf-blind must be introduced into a situation which enhances expression, either through touching the objects, pointing to them, or having them arranged in a way that represents what the child has experienced. This gives the child the chance to be an active participant, rather than a person who is simply handed objects and is then compelled to proceed to the activity the objects refer to.

## Play

Our Russian colleagues have made us aware of how objects of reference can be included into the development of play in children who are deaf-blind. Since the political barriers were eliminated, western deaf-blind experts have become aware of how much Russian deaf-blind education has to offer. The educational practices described here could be enriched by including play activities in a methodical manner. In the Russian method of deaf-blind education, one starts by depicting the child's experience through the use of dolls. The child is asked to make compositions that resemble real life. Gradually, the teacher adds her part and together they move gradually away from the concrete reality into the world of fantasy in which accompanying language plays an in-

creasingly important role. It is very important to note that Russian deaf-blind education has a strong social component. Its purpose is to have a group of students participate in the activities, asking one another about the experience his or her playmate has gone through. Eventually, the conversation is put into words, picture books (embossed), or in large print and these products are put on display in a central location, preferably a library so that other students can read the stories of their peers.

## Social Relationships

Deaf-blind education in the Netherlands has always had a strong emphasis on the development of social relationships. Conversation, the major principle of working with deaf-blind children, was stressed from the beginning. Social relationships are an integral part of conversations between communication partners. However, in some instances, despite intervention by the teacher or caregiver, the child might be unable to play his or her conversational role. In order to prevent the fragile relationship from going astray, the educator might be forced to prompt the child with an object indicating that he or she wants the child to participate in an activity. This may lead to a one-sided, teacher-oriented approach that may be socially undesirable, but necessary. Sometimes this situation arises because the educator lacks the skill to engage the child in meaningful communication and then overlooks the child's communicative intents for the sake of her own dominance. The theory itself, however, is not responsible for such poor implementation.

Over the years, we have become very aware that it takes good on-the-job supervision and carefully planned training to develop true conversational skills in educators. Present research should be continued to develop teacher training and corresponding parent programs to address this need.

## Questions Remain

While parts of our original theories have evolved over time, it can be stated that a number of principles of deaf-blind education developed in Europe still hold and are even stronger as many have received support from developments in the scientific field of early childhood and early language development. Far from anecdotal are the comments of teachers of the deaf-blind all over the world who have put our ideas into practice: "It really worked!" There are, however, a few points that continue to need evaluation:

- The role of sign language in deaf-blind education
- The role of the parents in the decision-making process
- The role of inclusion.

## The Role of Sign Language

In early educational programming, the development of "private signs" created by a child was encouraged. This might be a simple hand movement to indicate a wish to switch on the fan or a finger movement to express the desire to continue playing the drums. It was stated as early as 1967 by Van Dijk that the private signs that the child developed himself could be expanded to signed Dutch (Van Beek system). He supported the idea of replacing the signs with fingerspelling or even speech using the Tadoma method. Fingerspelling was encouraged because at that time it was felt to be superior to signing. These views have changed dramatically. It is understood now that sign language is a true, and very effective, language for deaf persons and probably for individuals who are deaf-blind. It was decided fairly recently that the use of sign language for deaf-blind children should be considered as a real option. When the child has sufficient vision, signing can be presented visually, and in cases of blindness or decreased visual capacity (e.g., in persons with Usher Syndrome), tactual signing should be offered at a fairly early age since the earlier this language is used, the better the person's command of sign language will be.

## The Role of Parents

In discussions of which language code to use or whether or not to send children to residential settings, the role of parents in some European countries has lagged behind British, Scandinavian or United States counterparts. In these countries, parents have shared in IEP (Individual Education Program) meetings and have had a decisive voice in educational programming for quite some time. In the United States, parents and their young children who are deaf-blind begin receiving assistance and early intervention as soon as the disability is identified. When the children are old enough for preschool, parents have already gained a great deal of knowledge about the needs of their children and have much to offer as educational decisions are made. Although times are rapidly changing in Europe, too little attention has been given to parents who do not want to send their children away and

prefer to educate them with necessary help at home and in their neighborhood school.

## The Role of Inclusion

Increasingly, parents want their children educated in the regular classroom with nondisabled peers. The idea of including children with the most severe disabilities in regular education classes is a topic of hot debate in the United States. Is it really effective? Can we really require that a regular education teacher develop the skills to successfully interact with, and teach, children with all different types of disabilities? It is too simple to reject the inclusion movement as a nonrealistic dream. There is ample research showing that simply through observation of their nondisabled peers, children with disabilities can learn social, play, and communication skills. In the coming period, this issue should be looked upon seriously and not rejected out of hand. Types of supports needed by children who are deaf-blind to ensure that learning is enhanced in regular classrooms must continue to be researched as to their efficacy and when and how they should be used. Such supports might include the intervenor system as was developed in Canada and technological advances such as augmentative communication devices and devices for individuals with low vision.

In the early days of deaf-blind education in Europe, as well as in the United States, strong emphasis was placed upon the distinction between educable and trainable children. In the Individuals with Disabilities Education Act (IDEA) in the United States, this distinction is no longer mentioned. All children regardless of their mental and/or physical impairments including combined sensory loss must receive adequate services. The system of consultation is widespread in the United States and a deaf-blind consultant assesses the child and contributes to the IEP and subsequent intervention plans regardless of the level of the child's functioning.

In some European countries, deaf-blind children in institutions for the mentally handicapped receive very inadequate services. Fortunately, it can be said that this is changing rapidly. However, some countries have been slow to admit that the quality of life of children with severe mental disabilities in combination with sensory impairments can be improved significantly with proper intervention. If outcomes for children with such impairments are to improve, government agencies and educational decision makers must be made aware of the right of all persons to the highest possible quality of life and what must be provided in order for them to achieve such a life.

## Summary

Through the collaboration and sharing of knowledge of many countries, successful methodologies to teach individuals who are deaf-blind have increased rapidly since the time of the Rubella outbreak. This knowledge has successfully been disseminated to many educators around the world. Such collaboration must stay alive as we address new challenges with a low-incidence and ever-changing population who have demonstrated over and over to us that they can learn when given proper intervention.

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A bibliography of Dr. van Dijk's publications is available from DB-LINK. Call (800) 438-9376.

## Ways to Incorporate Physical Fitness Into the Lives of Individuals Who are Deaf-Blind

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**P**hysical activity is an essential component of a healthy lifestyle. The following anecdote illustrates some of the difficulties that may occur in individuals who have not had an opportunity to develop physical fitness through regular exercise or activity:

Juan, a 17-year-old boy who became deaf and blind from Usher Syndrome, has been placed through vocational training as a horticulture assistant for a mall. His commute to work consists of walking a half mile to the bus stop, a 30-minute bus ride and a five-block walk to the mall. His responsibilities at work include planting, weeding, watering, and repotting. Whereas most 17-year-olds could handle this easily, Juan is often too fatigued to complete his work. Physical fitness is limiting him, not only at work, but in all aspects of his life. He could benefit socially and physically by increasing his current physical activity level.

### Justification for Physical Activity

Physical activity is defined as any bodily movement produced by skeletal muscle, resulting in substantial increase over resting energy expenditure (Bouchard & Shephard, 1994). Increased physical activity can decrease the chances of dying from heart disease, plus the risk of developing diabetes, high blood pressure, dangerous cholesterol levels, and high stress levels (Surgeon General, 1996). Furthermore, the social and psychological benefits of increased physical activity are tremendous. According to Blessing, McCrimmon, Stovall, and Williford (1993), a regular program of aerobic exercise can improve cardiovascular function and body composition. Many individuals involved in daily exercise report better ability to sleep, improved self-esteem, increased stamina, and decreased stress levels leading to a better attitude about life. Many practitioners also find that when their students are involved in daily physical activity, negative behaviors, as well

as self-injurious or self-destructive behaviors, decrease.

Research indicates that children who are blind tend to have more body fat, and less cardiovascular endurance, muscular strength, and muscular endurance than their sighted peers (Lieberman & Carron, 1998; Winnick & Short, 1985). Winnick (1985) has also determined that children who are blind are behind in activities such as throwing, catching, balancing, striking, and body and spatial awareness. Researchers attribute these various delays not to genetic limitations of performance, but rather to over-protection and discouraging attitudes on the part of the parents or teachers (Nixon, 1988; Winnick, 1985). To date, research on the fitness and motor ability of individuals who are deaf-blind is limited, yet one can logically conclude that children who are deaf-blind, due to their additional communication and mobility needs, will exhibit the same or more severe characteristics.

It is imperative to encourage individuals who are deaf-blind to participate in physical activity in school and in their recreational time. The physical, social, and psychological benefits of physical activity will increase the likelihood of independence and improve the quality of life for these children.

### Fitness Activities

A complete medical examination is recommended prior to beginning a fitness program. Clearance should be granted by an ophthalmologist for activities involving physical exertion if there is a history of detached retina, retinal bleeding, and other tenuous eye conditions. Once medical clearance is obtained, a fitness assessment should be conducted by a certified person such as a health/fitness instructor, exercise specialist, health or physical education teacher, fitness director, exercise test technologist, or personal trainer to determine a starting reference point. Once the preliminary examinations and assessments are completed, an exercise program should be created to include a warm-up phase, an exercise phase, and a cool-down phase. The warm-up and cool-down phases should have a duration of approximately 10 to 15 minutes and should consist of low-intensity cardiovascular exercise (walking, cycling, aerobics, stretching, etc.). It is essential that the individual choose an exercise activity that he or she enjoys.

Many individuals may not at first like the feeling of discomfort that comes with extended periods of physical activity such as bicycling or running; therefore, short distances and times are recommended. It

is important to set challenging, yet attainable, goals with each person.

For more information on basic fitness principles for individuals with sensory impairments see Lieberman (1996) in the Winter issue of *Deaf-Blind Perspectives*. The following are successfully tested strategies to adapt fitness activities for individuals who are deaf-blind. Remember that activities should be chosen based on the individual's strengths and weaknesses. In addition, these activities need be adapted to each person to increase the chances of reaching his or her potential.

## Bicycling

- **Independently:** Individuals who have some usable vision may be able to ride a bicycle independently in a quiet park or around a track. Going with sighted companions will help ensure safety.
- **Tandem bicycles:** Tandem bikes allow the sighted participant to peddle in the front of the bike while the participant who is deaf-blind peddles in the back. The person in front is responsible for steering and stopping. Tandem bikes can be purchased through most bicycle stores and range from \$400 to \$2,000. To find riding partners, contact your local bicycling club, university, or deaf club. Develop specific signals for turning, stopping, or emergencies.
- **Surrey or duo bikes:** These bikes enable the participants to ride side by side, making conversation easier. The sighted participant is responsible for steering and stopping. A local bike store can usually supply a catalogue for these bikes.
- **Stationary bicycles:** Anyone who has some functional use of the legs can use one of these. Many stationary bikes will log the distance traveled and amount of time ridden. They can be purchased for \$100 to \$1,000 in most sporting goods stores.
- **Bicycle stand:** Bicycle stands can turn an ordinary 10-speed into a stationary bike. These work like stationary bicycles and can be purchased for under \$100 from any sporting goods stores.

## Jogging

- **Sighted guide:** The runner grasps the guide's elbow, shoulder, or hand depending upon what is most comfortable for the runner and guide.

- **Tether:** The runner and guide grasp a tether which is a short string, towel, or shoelace. This allows the runner full range of motion of the arms, while remaining in close proximity to the sighted runner.
- **Sound source:** The guide rings bells or shakes a noisemaker for the runner to hear while they run side-by-side. This works best in areas with limited background noise and for runners with enough residual hearing.
- **Guidewire:** This allows the runner to run independently. A guidewire, set up permanently or temporarily, is a rope or wire pulled tightly across a gymnasium or track. The runner holds onto a sliding device such as a rope loop, metal ring, or metal handle, which prevents rope burn and allows for optimal performance.
- **Sound source from a distance:** The runner runs to a sound source such as a clap or a bell. This can be done as a one-time sprint or continued for a distance run.
- **Sighted guide shirt:** The runner with partial vision runs behind a guide with an easily recognizable shirt. This must be done in relatively uncrowded areas.
- **Independently around a track:** Runners with low vision can follow white lines on a dark track when the track is relatively empty.
- **Treadmill:** Running on a treadmill provides a controlled and safe environment. Treadmills, which can be purchased at most sporting good stores, cost anywhere from \$200 to \$1,000. The best treadmill will include a safety feature for quick stops. Many come with timers or mileage readers.
- **Wheelchair racing:** An individual in a chair can use any of the above adaptations if necessary and appropriate around a track, through the neighborhood, or on a paved path with assistance.

## Circuit Training

The safest way to train for muscular strength and endurance is with a circuit of stationary machines. The machines may consist of bench press or leg flexion-extension machines, a sit-up board, or a universal machine. The following strategies will help ensure success:

- **Enough time:** Allow time for tactile and/or visual exploration when introducing an individual to a machine.
- **Demonstration:** The instructor should demonstrate the movement and link the movement to language, including the name of the exercise and muscle involved.
- **Option to perform:** The individual is encouraged to try everything, yet it is important that they understand that they can decline.

The following adaptations may be made:

- **Pictorials/braille instructions:** Allow time for the person to look at performance pictorials and/or the opportunity to read about it.
- **Visual or tactual perimeter:** For safety, mark the perimeter of the exercise machines with rope or contrasting colored tape on the floor.
- **Adaptations to equipment:** Use large print, Hi-Mark and braille to mark on/off switches. Vibrating timers can be worn around the neck or in the pocket.
- **Number stations:** Use large print, Hi-Mark, and braille to mark each piece of equipment with a designated number. A rope, tape, or tactile guide can lead from one piece of equipment to the next one.

## Aerobics

The term aerobics means literally “with oxygen” or the “steady state transport of oxygen to the working muscles” (Shephard, 1990, p. 5). Thus, aerobics involves sustained physical activity to a point at which the body is utilizing oxygen or reaching 60%-80% of maximum heart rate over a period of time. To determine an individual’s working heart rate, subtract his or her age from 220, then multiply that number by .60, .70, or .80 depending upon how hard he or she wants to work (American College of Sports Medicine, 1991). For example, Nancy, who is 32 wants to work at 60% of her maximum heart rate. She would calculate  $220 - 32 = 188 \times .60 = 112.8$ . This means that Nancy’s working heart rate would be 110-120 beats per minute. To see if Nancy is working up to this level, she would sustain an activity such as aerobic dancing, cycling, or jogging in place for 5-10 minutes. While continuing this activity, she would take her pulse for 6 seconds, then add a 0 to her pulse score and compare that to 120. If her 6-second pulse was 14, that translates to 140 heartbeats per minute and she should slow down a little. A pulse count of 10 translates to 100 beats per minute and

she needs to step up the pace a little to maintain her desired heart rate. The working heart rate should be sustained for over 15 minutes, and preferably 30 minutes. It’s important to start out slowly. Some examples of aerobic activities include the following:

- **Step aerobics:** This is sustained stepping on and off a 4-, 6-, or 8-inch platform at varying tempos and in different directions. This type of activity is adaptable to any level of ability. If an individual cannot step onto a platform, he or she can do the same activities without it.
- **Low-impact aerobics:** This is sustained activity keeping one foot on the ground at all times. This includes marching with high knees, kicks to the front, bringing knee up and clapping under leg, marching in place and bringing arms up and down, toe touches to the front, right, and left, or just walking briskly around the room. As long as the individual is moving and keeping his or her heart rate up, this activity can be executed successfully by anyone who is ambulatory.
- **High impact aerobics:** This is sustained activity with both feet leaving the floor at some point during the movement. This includes jumping jacks, kicks to the front, jogging in place, bringing knee up and clapping under leg with a jump with the other leg, pendulum leg swings out to the sides, side jumps and front jumps in alternating directions. Doing these for any length of time requires good physical condition.
- **Wheelchair aerobics:** While sitting in a wheelchair, the individual moves his or her arms up in the air, out to the sides, punches down, or twists at the hips for eight counts or more to elevate the heart rate. If possible, the individual can move his or her legs at the same time.
- **Physical assistance and/or brailleing** (Lieberman & Cowart, 1996): When the individual does not have enough vision and/or hearing to understand the details of a movement, the instructor can simplify all the moves to one touch cue or a sign cue that the participant will understand. For example, if the instructor wants the participant to march in place, the instructor would make the sign for soldier or tap the individual’s knee to signal marching. Since this has been previously explained, the participant will know what to do until a new cue is given. Routines that are consistent in their content will allow the instructor to gradually fade out cues and will lead to more independence.



- Others: Any activity that raises the heart rate for a sustained period of time is considered an aerobic activity. Cycling, running, swimming, or walking can also accomplish this.

All these activities can be enjoyed with or without music. It is much easier to practice them without music first, then add that variable later.

## Aquatics

Swimming is one of the best activities for individuals who are deaf-blind. There are few barriers, and the swimmer can move freely without worrying too much about obstacles. Water can aid in range of motion, balance, stability, locomotion, and socialization. Adaptations for aquatics include the following:

- Flotation devices: A variety of flotation devices is available, and an individual can still receive an aerobic workout while using a flotation device. Kickboards are especially helpful since the board hits the side of the pool before your head does!
- Trailing: Use the wall and lane lines as guides for lap swimming the length of the pool.
- Counter devices: Use flip cards, counters, or rings to assist in understanding of distance traveled or number of laps.
- Hand-over-hand teaching and braille: for beginners (Lieberman & Cowart, 1996).
- Tread water: As an alternative to swimming laps, treading water provides a good aerobic workout.

## Dance

Dancing gives an opportunity for free movement and exercise as well as a chance to be involved in a crowd, bumping bodies, moving, holding hands, and socializing (Smith, 1994). Pay attention to the following:

- Decibels: Play music very loud and turn up the bass. Be sure to inform those with hearing aids before you turn the music up so they can adjust the setting if necessary.
- Beats of music: Strobe lights can reflect the beat of the music or participants can hold a balloon which will pick up the vibrations from the music (Smith, 1994).

- Wooden floor: Dancing on a wooden floor produces vibrations and tactile cues.
- Peer tutors: Peer tutors can model and give physical assistance (Houston-Wilson, Lieberman, Horton, & Kasser, 1997; Lieberman & Cowart, 1996).

Deaf peer tutors are also excellent role models!

## Summary

The benefits of physical activity have been well documented, yet many children who are deaf-blind are excluded from participation. Even when included, success or failure depends upon the attitude of the physical educator, teacher, parent, support staff, and the individual him/herself (Downs & Williams, 1994; Rizzo & Kirkendall, 1995). It is hoped that the above suggestions will foster creative ways to adapt attitudes, equipment, and the environment so the person who is deaf-blind may achieve his or her highest possible level of physical fitness. This will in turn lead to greater independence—the key to good job performance and a better quality of life.

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## Benjamin's Bar Mitzvah

Nancy Sall

St. Luke's - Roosevelt Hospital Center

Harvey H. Mar, Ph.D.

St. Luke's - Roosevelt Hospital Center

With:

Carole Devon, Parent

Laurie Roth, Teacher

*"My grandpa Ben truly believed that each child had something to teach us, a message that would help explain why we are here. Today, my grandfather would be very proud of me." (Excerpt taken from the dedication of Benjamin's prayer book.)*

**O**n March 23, 1996, at the age of 13, Benjamin was called to the Torah. A handsome boy with blond hair, he stood at the *bima* (platform) in a black tux-

edo, accompanied by eight friends, his parents, his teacher, the rabbi, and the cantor. Among the 300 people assembled in the sanctuary were Benjamin's relatives, schoolmates, teachers, neighbors, and special guests. After three years of hard work, Benjamin was finally to become a Bar Mitzvah. Bar Mitzvah literally means a boy who fulfills the commandments. It is a rite of passage into adulthood, a celebration that a young man can now participate in the rituals that represent full membership in the Jewish community. On this day, a boy reads the blessings over the Torah for the first time in the Hebrew language.

But Benjamin is a child with multiple disabilities. He has been diagnosed with cerebral palsy, severe mental retardation, hearing loss, and cortical blindness, which refers to difficulty making sense of visual images. Benjamin is not able to speak, but communicates with gestures and vocalizations. He walks with a slow and unsteady gait, often swaying from side to side. He needs constant help and attention for day-to-day routines, like dressing or getting something to eat. Benjamin is usually affectionate and calm, but when he becomes frustrated or upset, he might scream, hit himself, or bite his hands. How, then, could Benjamin be expected to study Hebrew? Recite the prayers? Know the meaning of Jewish rituals?

For Benjamin's mother, Carole Devon, a Bar Mitzvah meant more than the ability to prepare for the ceremony: "There is something about a boy having a Bar Mitzvah that transcends going to synagogue. I had thought it meant Hebrew School for three years—read, write, and study. But then I read that if a child could smile at his mother or touch the hand of his father, he was following the commandment honoring his mother and father. He therefore knew a sense of God, and was entitled to a Bar Mitzvah."

The acceptance. Carole, who is Jewish and whose husband David is Christian, set out to speak with the principal of the religious school of one of New York's more liberal synagogues, Stephen Wise Synagogue. The principal suggested that she present her request to the synagogue's Religious School Committee. She explained to the committee how much easier and comfortable it would be, for her as a mother, for Benjamin to stay within a segregated environment because of the nurturing and protection it would offer him. But that wouldn't necessarily be better for Benjamin. She argued that children like Benjamin needed the chance—and the support—to become contributing members of society by being with members of their own communities. About this experience, Carole remarked, "This was the most courageous thing I have done in my life, to put

Benjamin and myself on the line.” The committee members voted unanimously to accept Benjamin into the Sunday School.

Now the real worry was to begin. Carole, herself, could not picture how Benjamin might be accommodated. How would the teacher handle this? How could Benjamin participate in lessons? What would happen the first time Benjamin screamed and hit himself? What would the other children think? Carole knew that she would need help. The assistant principal of Benjamin’s special education school introduced her to two teachers, Tom and Laurie, who were committed to “inclusion,” the belief that individuals with disabilities should be fully integrated with nondisabled people in their schools and communities.

Tom agreed to meet with Benjamin’s classmates and their parents a week before Benjamin was to begin. During that meeting, he described Benjamin’s physical appearance, his way of communicating, behaviors they might observe, and his interests. He was prepared to address their anxiety about how Benjamin’s presence might interfere with the children’s study but instead, they talked about Benjamin’s abilities more than his disabilities.

Laurie volunteered to attend Sunday School with Benjamin. She would involve him in activities, adapt materials, and attend to his personal needs. What began as a simple act of goodwill turned into a promise to her grandmother that she would see Benjamin through to his Bar Mitzvah. Over the course of three years, her role would evolve from that of Benjamin’s personal teacher to that of classroom facilitator.

The first year. To any parent, a child’s first day of school is a time of anxiety. For Carole and David, it was no different. What made Carole apprehensive was how the other children would respond to Benjamin. In fact, her initial fears were legitimate. On their first day together, all of the children stared at Benjamin. For no apparent reason Benjamin had a tantrum. He yelled, smashed himself against the desk, and threw himself back toward the floor. Laurie took Benjamin out of the room so he could calm down. When they returned, the children in the class asked, “Is he okay?” “What’s wrong?” “Did I do something to upset him?” Laurie explained this was Benjamin’s way of communicating that something bothered him, that maybe he was bored, nervous, or

hungry. The children were scared and concerned, and they didn’t quite know how to respond to him. So they stayed away from him.

Over the next two weeks there was little change. When his classmates did interact with him, they took on a role that was closer to a care provider than a peer, and they typically spoke to Benjamin as if he were a baby. There was also a physical distance between Benjamin and the other children. His classmates did not want to sit near him or touch him. They would be out the door and down the hall before Benjamin even stood up from his desk. When they moved from the classroom to the sanctuary, the children would run up or down the five flights of stairs and leave Benjamin behind to take the elevator alone with the teacher.

Things changed around the fourth week. One boy, Zach, had been observing Benjamin, quietly showing interest from a distance. During a class break, he began to ask Laurie about Benjamin. He asked if Benjamin could read, if he liked music, if he could

feed himself, and if he could go to the bathroom by himself. Everyone in the class stopped to listen. Of all of the children, Zach bonded most quickly with Benjamin. He began talking to Benjamin. He sat next to him in class. He seemed comfortable with Benjamin.

Over the next several weeks, there were gradual but noticeable changes in the way the children interacted with Benjamin. As they arrived in school, they would approach Benjamin to say hello. They volunteered to help him walk to the sanctuary where services were held. They got Benjamin to participate in folk dances during music time.

Initially, Laurie and Benjamin sat together in the back of the classroom and did parallel activities while the other children did their work. If the children were studying from their textbooks, Laurie might read aloud to Benjamin or help him do an art activity related to the lesson. By this time, the other children began offering ideas of how to include Benjamin. One boy suggested that he, rather than Laurie, read aloud to Benjamin. One of the girls wanted to make a collage with Benjamin to depict a religious passage from the text.

Not every child, however, would come to accept Benjamin. As the year progressed, one boy became increasingly disturbed by Benjamin’s presence. He



would call Benjamin names and offer negative remarks about him to his peers. Before year's end, the boy withdrew from Sunday School. But at the last session before summer vacation, all of the children went up to Benjamin. They told him they would miss him.

A circle of friends. In the fall, Benjamin and his classmates had a new teacher. Zach, Benjamin's closest friend in Sunday School, had left the temple. Yet, the children picked up right where they had left off. They came in on the first day and asked to see Benjamin's pictures from summer vacation. When Benjamin yelled or hit himself, the children explained to the new teacher that Benjamin was tired, maybe bored. Early on, it was evident that Benjamin was accepted and embraced by his peers.

Carole was delighted. "Truthfully, it's worked out beautifully. Last Sunday they wanted to go up on the roof because the weather was nice. The teacher said, 'Well, we have a lot of things to go over.' And Benjamin let out a little, you know—one of his things—and all the kids said, 'See, Benjamin doesn't want to study. He wants to go on the roof.' And that's what they did. They all went to the roof."

By then, Benjamin was learning to use an electronic communication device called the Speakeasy. The Speakeasy can record and store in its memory several different messages. Each message can be played out loud by pressing a different switch or key. When Benjamin first brought the Speakeasy to Sunday School, it was only programmed to say "Yes" and "No." Carole recalled, "A couple of the children in the Sunday School class came up and said they thought this was very unfair, that Benjamin had things he wanted to say, and that he shouldn't always be required to be answering 'Yes' and 'No' and 'I don't know.' So the twelve children—and there was a big battle between gender because at first they wanted boys' voices for the Speakeasy because he is a boy, but the girls were having none of that—so everyone programmed in what they thought Benjamin wanted to say. We let them make it up as long as it was relevant to Benjamin, such as 'I want to go out and play.' Some of the boys got together laughing. They had to program something his mother was not allowed to hear. One was 'I have to take a whiz,' which I guess is 12-year-old vernacular for 'I have to go to the bathroom.'

This was very important to them. Kids actually programmed in what they knew another 12-year-old would want to say."

Interactions between Benjamin and his friends were frequent now that a barrier to communication was removed. The children would sit close to Benjamin to ask him questions and wait for his responses. They would touch him on the shoulder to prompt him to use the Speakeasy, or bring his hand to the switch so that he could make a comment or request. It was as if the Speakeasy provided Benjamin and his peers with a common means of expression.

So, too, did Benjamin's participation in religious studies increase. During the first year, he was literally a figure on the perimeter. When the class performed a Bible story, Benjamin's role was to stand on the side and hold up cards with the written text of the skit. By their third year together, his classmates created parts for Benjamin. For instance, knowing that Benjamin liked to bang things, his classmates brought a chair to the front of the room, gave him a gavel, and made him the judge. Whenever he banged on the desk, one of his classmates yelled, "Order in the court!" Benjamin also participated in



religious services and presentations to the congregation. The children would record portions of a certain prayer into his Speakeasy and Benjamin would press a switch to recite the prayer.

An unexpected problem developed the last year which seemed sure to jeopardize Benjamin's Bar Mitzvah, as well as his friendships. The class was switched from Sunday morning to Tuesday evening. Benjamin had a hard time staying awake. He would fall into a deep sleep and have tantrums when he was roused. One time he accidentally hit his teacher when she tried to wake him up. His agitation was beginning to disrupt the students' ability to concentrate on their work. Both Carole and David worried that Benjamin would have to withdraw from the program.

Laurie approached the children and told them she needed their help. She asked the children for their ideas, and eventually, they came up with a solution. Benjamin would practice his Bar Mitzvah routine in the sanctuary with Laurie for a portion of classtime. Benjamin and his classmates would still see each

other every week before and after the lessons. Every two or three weeks Benjamin would return to the class for the entire evening. The children would all perform a skit about the passages they had studied in his absence. His classmates would create a role for Benjamin so that he could participate in the play as well.

The ceremony. “For his Bar Mitzvah,” Carole recalls, “Benjamin’s classmates all volunteered to participate. And believe me, it has to come from love because no one wants to learn Hebrew to speak in front of 300 people, let alone do it a second time.”

As part of the Bar Mitzvah ceremony, Benjamin would have to recite several prayers. Benjamin’s classmates decided that they would all help him with his readings. Each classmate would select one of the prayers, and record part of it onto Benjamin’s Speakeasy. During the ceremony, each child in turn would accompany Benjamin to the pulpit. The child would assist Benjamin to activate the Speakeasy, and the passage would be played over loudspeakers. The classmate would then chant the remaining segment of the prayer that he or she had previously recorded.

From beginning to end, the planning and rehearsal of Benjamin’s Bar Mitzvah took seven months. Benjamin and his classmates, Laurie, the rabbi and the cantor, rehearsed the ceremony step by step. They repeated the songs and blessings until they felt that Benjamin was familiar with them. They programmed the Speakeasy, figured out where to place it on the *bima*, and decided on how to cue Benjamin to press the switch at the right time. They thought about what they would do in case Benjamin got tired or frustrated.

On the day of Benjamin’s Bar Mitzvah there was much spirit and joy in the synagogue. Somehow having learned of Benjamin’s special ceremony, a local television station dispatched a news team to cover the event, adding to the excitement. The Mayor of New York City also made an appearance to honor the boy whose acts of faith were about to be celebrated.

As the music began, Benjamin was led by his classmates to his place on the *bima*. The rabbi made welcoming remarks, and talked about the symbols of the ceremony. He called on Benjamin’s grandmother and two aunts to say the first *aliyah*, or blessing, over the Torah, and Benjamin’s three cousins,

Sabrina, Sasha, and Samara to recite the second blessing. Benjamin was called to make the third *aliyah*. He arose with the help of his classmate, Jesse, and walked to the pulpit. The blessing was recited perfectly, and one could hear the collective sigh of Benjamin’s classmates. Then, one by one, they helped Benjamin chant the blessings, as they had so carefully practiced, with confidence and pride. Benjamin handled it like the young man he had just become. There were no tantrums, yelling, or hitting, as some feared.

After the religious service, a celebration took place in the synagogue’s large reception room. Balloons, music, and laughter filled the room. Benjamin’s classmates swarmed around him. They held his hand, patted his back, talked with him, and danced with him. Watching the children interact with Benjamin on this day, no one would have known that the initial weeks of his involvement in Sunday School were so tense and difficult. In a special prayer book for the occasion was a letter from Benjamin to his classmates:

You accepted me as a friend and classmate. You always looked at what I could do — not what I could not do. You always let me be who I am. I have never spent time with typical children before this experience. If all children are like you, then children like me really do have a chance at life.

Now, nearly six months since the Bar Mitzvah, Carole had hoped that Benjamin and his friends would maintain contact. But they have seen each other only once or twice since last March. Carole knows she must take up the challenge again so Benjamin can have opportunities to be with peers and maybe make some new friends. She also knows that it will be difficult to find community programs that will readily accept Benjamin. “I want for my child the same thing that everybody wants for their children, which is to help them be the best they can with what they have been given. I don’t know if that means keeping them segregated or not keeping them segregated, but I know the more normalized I can make his existence, the better it’s going to be for Benjamin later on.”

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Benjamin with New York Mayor, Rudolph Giuliani



## IDEA 1997 - Product Updates

**I**n the last issue of *Deaf-Blind Perspectives*, Fall 1997, DB-LINK contributed a list of articles and materials pertinent to the reauthorization of the new Individuals with Disabilities Education Act Amendments of 1997. We are just beginning to see the new wave of materials designed to inform school districts, teachers and parents about the new provisions and legal requirements of this act. Following are two titles recently added to the DB-LINK shelves.

**The Individuals with Disabilities Education Act Amendments of 1997: Curriculum**, Office of Special Education Programs U.S. Department of Education, 1997, Washington, D.C.

This two volume set is a cooperative publication between Office of Special Education Programs (OSEP), the National Information Center for Children and Youth with Disabilities (NICHCY), and the Federal Resource Center for Special Education (FRC). The curriculum is designed as training materials for parents, administrators, teachers and advocates. The Curriculum includes more than 500 pages of background information, resources, handouts and training scripts on the law. Pertinent sections cover Appropriate Evaluation, IEPs, LRE and Parent & Student Participation. Information is presented employing a variety of strategies consistent throughout the chapters, and includes an accompanying set of 145 overhead transparencies. The cost of the two volume set is \$175.00 and is available from NICHCY. Contact NICHCY for more information at (800) 695-0285.

**1997 IDEA Amendments: An Overview of Key Changes**, LRP Publications, 1997, Horsham, PA.

This recent LRP publication summarizes important changes in the new law. Summaries and assessments of the changes are written by nationally known experts in the field. A good reference for translating the law into language that is accurate and accessible. Available from LRP Publications for \$14.85. Contact LRP at (215) 784-0860.

## The Canadian Deafblind and Rubella Association (CDBRA) Announces Conference

### The 6th Canadian Conference On Deafblindness

Hosted by The Ontario Chapter of CDBRA

**Theme:** "Let's Celebrate Our Harmony Together"

**Dates:** August 12-15, 1998

**Location:** Delta Meadowvale Resort and Conference Centre  
Mississauga, Ontario Canada (Part of the Greater Toronto Area)

*Save with early registration by May 31, 1998*

**W**ith harmony as the theme, this conference will focus on the cooperation of consumers, families, professionals, organizations, and governments to ensure that persons who are deafblind achieve the best possible quality of life. Topics that will be specifically addressed in relation to the theme will include: Deafblindness, Intervention, Communication, Education, Medical Issues, and Independence/Advocacy.

**For further information please contact:**

CDBRA Ontario Chapter  
350 Brant Ave  
Brantford, Ontario  
Canada N3T3J9

Ph: (519) 754-4394  
Fax: (519) 754-0397

**You are welcome to copy articles from *Deaf-Blind Perspectives*.**

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## The American Association of the Deaf-Blind Announces National Convention

June 13-19, 1998

**T**he American Association of the Deaf-Blind (AADB), originally established in the late 1930s, is a not-for-profit consumer organization, committed to promoting awareness about deaf-blind people, and to working towards ensuring educational and employment opportunities, high standards of living, and equal access for all Deaf-Blind Americans. The central focus and purpose of AADB is its national convention.

**When:** June 13-19, 1998

**Where:** Central Connecticut State University  
New Britain, Connecticut

The theme is “**Deaf-Blind Connection: Expanding Opportunities.**” For information, contact:

Elaine Ducharme, Convention Chairperson

TTY: (860) 379-0193 (please type slowly to give her time to read braille connected to TTY)

Tom Peters, Co-chairperson

TTY: (860) 621-6610

Fax: (860) 621-7291

funnytom@megahits.com

**We need volunteers for general conference assistance, relief worker, and as support service providers for deaf-blind persons.**

Contact

Susan Sjolholm

TTY: (860) 379-0193

110104.2207@compuserve.com

AADB also publishes a quarterly newsletter, *The Deaf-Blind American*. For more information about AADB, or the newsletter, contact:

AADB

814 Thayer Ave, Ste. 302

Silver Spring, MD 20910

TTY: (301) 588-6545

Fax: (301) 588-8705

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