

# Deaf-Blind Perspectives

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## A Report on Deaf-Blind Technical Assistance Collaboration

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**R**estructuring, reorganizing, resizing—all are current buzz words of business and industry. The increasingly competitive environment of our emerging global economy drives many organizations toward organizational change. This momentum behind change in private business and industry is beginning to spread to public entities, as exemplified by movements such as Re-Inventing Government, America 2000, and Health Care Reform.

There are, however, differences that surface when comparing change in the private and public sectors. Business and industry can affect the supply and demand of a product or service by manipulating the micro economies associated with that product or service. Education and other human service organizations, on the other hand, strive to meet the multifaceted needs of their constituents, but have little control over the variables that influence the availability and quality of resources. For example, the number of constituents eligible for services and the responsibilities of many public agencies have steadily increased, but increases in funding have not kept pace.

The Services for Children with Deaf-Blindness Program, which currently funds 46 single state and 3 multistate deaf-blind projects, is not immune to this dilemma. The number of children, birth to age 21, identified as being deaf-blind has grown from less than 2500 at the program's inception in 1975, to over 8400 children reported in the most recent census (Baldwin, 1994). We have also seen more children with complex etiologies and/or severe medical needs being identified, due in part to modern technology's role in the survival of medically fragile newborns.

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Because of the implementation of Part H Programs (for children birth through 2) across an increasing number of states, greater numbers of children with disabilities, including those who are deaf-blind, are becoming eligible for state-mandated services. Within states that have implemented a Part H program, Federal Regulations 307.11(a) and (b) clearly state that the state or multistate deaf-blind project is not permitted to provide these direct services. However, according to Federal Regulation 307.11(c), the project must take an active role in coordinating services for these children with other state agencies. This often requires the state or multistate deaf-blind project to provide technical assistance services to a large number of agencies so they may provide direct services to these children.

The challenges become even more significant when viewed in light of the funding of the Services for Children with Deaf-Blindness Program. There have been no increases in funding in the past several years, even though all the variables discussed above have greatly affected the quantity and quality of expected services. The projects are being asked to do more for a greater number of children with no additional funding.

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Combine this with the staggering cost of inflation over the last 20 years, and the result is an urgent need to do things differently.

Clearly, if the expectations for state or multistate projects have changed, then the strategies to meet these expectations must also change. This article will define collaboration as a strategy to meet changed needs and will provide examples of how several state and multistate deaf-blind projects have used collaboration with other agencies for the development, enhancement, and the delivery of services. These efforts have involved multiple agencies within a single state, consortiums consisting of other state or multistate deaf-blind projects, and other combinations of technical assistance providers.

## Understanding Collaboration

Successful collaboration requires mutual understanding and respect for each collaborator's work and is driven by the common needs and goals of the collaborators. Agencies within a state who provide services for children who are deaf-blind and their families and service providers (e.g., state and local education agencies, the Services for Children who are Deaf-Blind Project, HeadStart, Department of Health, Coordinated System for Personnel Development) have several inherent commonalities: constituency; state legislation, administrative procedures, and budgets; and participation in a common system (or lack of system) for coordinated service delivery. Such commonalities provide a forum for mutual understanding among intrastate collaborators.

The state or multistate deaf-blind projects also share characteristics that ensure collaborative success. For example, all of the projects are guided by the

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**“The projects are being asked to do more . . . with no additional funding. . . . the result is an urgent need to do things differently.”**

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same federal rules and regulations, providing a common understanding of what must be done. Common needs have been consistently and clearly identified among state or multistate project directors. And, most important, the projects share a common goal: to provide the best possible services to children, families, service providers, and others who have direct contact with children who are deaf-blind.

Collaborative technical assistance activities are as varied as the needs that drive them. Table 1 illustrates five levels of collaboration and the conditions that must be present for success (Western Regional Resource Center, 1991).

Table 1: *Levels of Collaboration*

Level Of Collaboration	In Order To Succeed
<b>Information Sharing (<i>agreeing to keep agencies informed</i>):</b> making sure that collaborating agencies know one another's plans and anything else that might affect their (shared) work.	Those involved must consider the information needs of their collaborators.
<b>Calendar Coordination (<i>agreeing to not trip over other agencies</i>):</b> making sure that the calendars of all collaborators are organized well enough to avoid conflicting schedules.	Collaborators must be willing to constrain calendars and arrange timelines to fit with those of other agencies.
<b>Events Coordination (<i>agreeing to do things at the same time, or in logical sequence</i>):</b> arranging independent events (not necessarily related to the collaborators) at the same time/location, or in logical sequence (immediately following), so that there is some benefit in time, travel, or other event-related savings.	Those involved in the collaboration must set joint calendars; coplan events that are compatible; focus on more or less the same target audience.
<b>Activities Collaboration (<i>agreeing on what to do and doing it together</i>):</b> cosponsoring activities in which collaborators have codependent roles (e.g., sharing parts of a single conference agenda, sending related service personnel to the same location at the same time to facilitate training).	The cosponsored activities must be directed toward reaching compatible goals of the collaborators involved.
<b>Strategy Collaboration (<i>agreeing on what to do, how to do it, and what the long-range outcomes should be</i>):</b> cosponsoring a series of activities in which collaborators agree on a set of outcomes and actions as part of a long-range plan to promote systems change.	Goals and outcomes must be shared and all must agree on the strategy or series of steps to be taken to reach the goal. This employs collaboration for long-range strategic planning for change.

Clearly, collaboration can take many forms. Systems as they evolve, may move through all the levels or focus on activities within only one or two of the described levels. Collaboration becomes easier as trust grows and mutual respect deepens. The first few levels of collaboration can help build trust. Relatively small endeavors, such as sharing pertinent information in a timely, consistent manner, create win-win situations for the collaborators. As the complexity of the issues increases, (i.e., moving through the levels of collaboration toward strategy collaboration), a collaborative relationships becomes more complex. Trusting relationships become imperative. The foundation of a trusting relationship is believing that the other person and the agency he or she represents (a) has the integrity to meet commitments and keep promises; (b) will sometimes lead and not always follow; (c) has sensitivity to other people's needs and interests; and (d) will be open and honest while keeping others informed about actions and intentions.

### Using Collaboration

As a way of maximizing effectiveness, many state or multistate deaf-blind projects have already participated in one or more levels of collaboration. Table 2 provides examples of recent collaborative activities between states or multistate deaf-blind projects and other organizations. Some efforts are ongoing; others have already taken place or are in the planning stage. By reorganizing, encouraging, and through the mutually reinforcing outcomes of collaboration, future opportunities for collaboration in the Services for Children with Deaf-Blindness Programs are enhanced.

*(continued on next page)*

**Table 2: Examples of Collaboration**

Note. From, Western Regional Resource Center. (1991). *Proposal for a grant to operate a regional resource center to serve Region VI.* (CFDA No. 84.028). Eugene, OR: Author. Reprinted with permission.

<b>Collaborative Partners</b>	<b>Need Identified</b>	<b>Collaborative Action</b>	<b>Level Of Collaboration</b> <i>(from Table 1)</i>
District of Columbia Maryland Virginia	Ongoing training opportunities for family members and professionals	Maryland sponsoring a parent retreat. Virginia hosting a summer institute; parents and professionals from DC invited to both; DC assisting financially; DC will host future activities for three states	Events Coordination
Indiana Illinois Blumberg Cntr for Studies in Spec Ed Project ENABLER	Information regarding infants and the development of vision	Support for writing of booklet titled "Helping Young Children with Visual Impairments Make Use of Their Vision"	Activity Collaboration
14 states in TRACES Western Region	Literature describing deaf-blind project and common behaviors of children who are deaf-blind	Developed "unified" awareness level brochure to be customized for use by all state projects in the region	Activity Collaboration
Arkansas Texas Five state agencies	Build instate expertise in area of effective practices for individuals who are deaf-blind	Planned and sponsored a conference to train family members and service providers from Texas, Arkansas, Oklahoma, Louisiana	Activity Collaboration
West Virginia North Carolina TRACES	Functional hearing and vision assessment processes and materials	North Carolina shared process and materials for vision assessment; states jointly developed process and materials for hearing assessment	Strategy Collaboration
Illinois Two state agencies American Foundation for the Blind HKNC TRACES	1. Training for professionals on early intervention strategies  2. Statewide parent organization	Sponsored workshop to train professionals and develop goals and action plans for parent organization	Strategy Collaboration
Utah Nine state agencies TRACES	A coordinated system for delivery of all services within the state for persons who are deaf-blind	Regularly scheduled meetings to develop a fully coordinated service delivery system with a single point of entry	Strategy Collaboration
Delaware Five state agencies TRACES	System for delivery of special education services for individuals who live in nursing homes and have complex health care needs	Process developed and implemented with four children for the delivery of special education services in local school district instead of in nursing home setting	Strategy Collaboration

Collaborative Partners	Need Identified	Collaborative Action	Level Of Collaboration <i>(from Table 1)</i>
14 states in TRACES Western Region NEC*TAS Western Regional Resource Center California State University-Northridge California Part H coordinator California Part B coordinator	1. Understanding Parts B and H  2. Knowledge of available state, regional, and national resource providers for early childhood services  3. Comprehensive, effective early childhood services delivery system	Two-day meeting held to: (a) discuss resources, (b) identify methods for collaborating with other providers including those not in special education (i.e., other state agencies, medical facilities, preschools), (c) identify components of a comprehensive, effective program for early childhood services	Strategy Collaboration

### Benefiting From Collaboration

Numerous benefits result from the collaborative process. First, creativity flourishes when the talents, abilities, and resources of the participants are combined. Creativity not only strengthens the current methods used for providing services, but can lead to the development of new, innovative ideas. Second, as time and money resources become more scarce, collaboration enhances the resources available to any one project. Third, collaborative efforts help build a social support network that has benefits reaching far beyond the workplace and helps maintain personal and professional vitality. And finally, collaboration has been proven to be far more effective than competitive or individual endeavors. In a review of 122 empirical studies conducted by a group of University of Minnesota researchers 60% of the studies found that collaboration promoted higher achievement than competition did. Ninety-five percent of the studies found higher achievement through collaboration than through individual effort (Kouzes & Posner, 1987).

Groups working together and pooling resources can achieve much for children and families. Collaboration provides opportunities for extraordinary results.

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## Rabbits and Retards

Joyce Ford  
Parent

My 13-year-old daughter, Sarah, is an animal lover. At age two, she adopted her first kitten—a kitten that was destined to wear lacy bonnets and ride in a pink plastic baby buggy. Apparently, neither of them knew that this wasn't typical animal behavior for they both accepted it as a routine part of each day. She was heartbroken at age 4 when roaming neighborhood dogs attacked and killed Tooie early one cold spring morning.

Like many other parents, we immediately began searching for a new pet to help ease her pain. We tried many: two more kittens within the first year, a turquoise parakeet a few years later, a puppy the following Christmas, and a couple of hamsters. Our house was beginning to resemble a zoo, as we didn't seem to have enough sense to eliminate previous pets before adding another one. Sarah loved them all. Still, I did not see the bonding and devotion that had once existed when she was a toddler.

When Sarah was 11 we acquired two adult rabbits from my nephew. It sounded like a good idea. It wasn't. The rabbits were virtually wild and would growl and bite her each time she attempted to care for them. We soon had to find new homes for them. I was convinced that this would be the end of the rabbit business, but it wasn't. Sarah begged for another one. She wanted a little one that she could raise herself.

That Christmas, Santa felt the need to bring Sarah a baby bunny, and for the first time since she was little, I saw the essence of pure love and devotion pour out from within her. She and the bunny shared a special bond.

As time passed, more rabbits were added. We began building cages to house the pedigreed collection and Sarah was spending considerable time with them. Breeding soon took place, and eventually she had her own crop of bunnies to sell for Easter. It was delightful.

In April of 1994, Sarah entered two of her rabbits in a formal competition. This was a new experience for our entire family. It was also one of the few times, other than Christmas mornings, that I could recall Sarah being happy to be up so early. We loaded the whole family into the car along with our thermoses of coffee and hot chocolate and left the house early that Saturday morning for the half-hour drive to a small town west of us. It was a gray drizzly morning, but our spirits were high as we headed off on this new adventure.

I have never seen so many rabbits in one place. Big ones, little ones, wooly ones, and velvet ones. Each of them were accompanied by their loving owners—some adults, some children. There was a great deal of commotion as everyone prepared for the show. Rabbit paraphernalia filled the large room. I decided to escape the confusion by taking Riley for a walk.

We paused outside of the building to put Riley's jacket hood on. It was here that we met Everett, a blonde fifth grader who stared at Riley as he jumped excitedly in the light rain. I said hello and smiled at him. Everett took this friendly gesture as an invitation to talk.

"The kids at my school would call him a retard," he began. "I know they would."

I was surprised by his openness. His words stung me, still I was willing to continue the conversation.

"I think that's sad," I replied, "because Riley really likes school and he especially likes kids. I think that friends are really important to him." I paused as I tied the cord of Riley's hood and tightened the zipper closer to his chin. "Sometimes people are afraid of things they don't know about," I added. "Are you ever like that?"

Everett immediately assured me that, as an 11-year-old, he wasn't afraid of anything.

By now Riley had discovered Everett's presence and was busy trying to identify who this person was. He was feeling his hair, face, shoulders, and arm. I intervened when Everett appeared uncomfortable as Riley reached for his throat. I briefly explained Riley's disabilities and told him that Riley was touching his throat in order to feel him talk. I demonstrated this with Riley's hand on my throat. Everett still appeared nervous.

"Well," I said, "Riley and I were just going to take a little walk. Maybe we'll see you later." It seemed like a graceful way to let Everett off the hook. We turned away and began walking toward a second-hand shop I had spotted on the way into town. I knew it wouldn't be open that early, but I wanted to browse through the windows. Besides, it was pleasant outside in spite of the light rain and Riley was enjoying the walk as well. We stopped at an intersection a block away. I glanced behind me. There, a half-dozen steps behind, stood Everett.

"Would you like to walk with us?" I asked. He eagerly ran to Riley's side. I asked if his parents knew where he was. He told me a short walk would be okay with his dad. And so we continued on our journey, introducing ourselves, discussing our interest in rabbits, and talking with greater ease about being blind and deaf. I taught him sighted guide technique. He showed me what he could remember of the manual alphabet he had learned in Boy Scouts. He asked a lot of questions. I answered each of them. Eventually we decided that it was time to return to the show.

Riley and Everett walked and jumped together on the way back. They discovered a couple of mud puddles to stomp in. They held hands. They felt each other's throats and laughed at the vibrations of their voices. I smiled as I watched them together. It was I who now walked a half-dozen steps behind the two of them—by their choice.

They also chose to spend much of the day together. Everett patiently and carefully showed Riley each of the three hundred or so rabbits on exhibit. They ate donuts together. They checked out the guinea pigs. They shared hot chocolate. Everett taught Riley how to eat "Now-n-Later's," a gooey, chewy candy in a tattered wrapper that had obviously been stuffed into his pocket for some time. They were inseparable.

At the end of the day Everett told me he thought that Riley should be in 4-H. He had decided that Riley could raise rabbits by touch and I agreed with his thinking. He said he wished Riley lived in

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**"The kids at my school would call him a retard," he began. "I know they would."**

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his town so that they could be in a 4-H Club together. He said he would like that.

Sarah brought home three blue ribbons that night. She was beaming with pride. Her efforts had served her well.

There is something to be said for persistence. I was reminded of that by Sarah, two small boys, and a conversation about rabbits and retards.

*\* For those readers who prefer to digest the author's points in a more traditional format, the author has graciously provided such a draft which Deaf-Blind Perspectives would be pleased to furnish upon request. —ED.*

## Communication and Language Acquisition: To Teach or Not To Teach\*

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One of the most important, and often difficult, instruction areas for students who are deaf-blind is communication. Over the years our approach to teaching communication may have changed but our intent remains the same: to teach students the skills necessary for effective interaction with others in their lives. The following article examines some of the history of communication instruction of students with disabilities, including students who are deaf-blind.—ED.

### The Beginning

Once upon a time there was a Training Maiden who was responsible for assessing and teaching language to students who had disabilities. The King decreed that this training should be conducted in a quiet turret room, high in the castle. In this manner, training would be held without other distractions. In those days "functionality" was not yet invented. The Training Maiden carefully selected stimuli that would be consistently presented. She knew the specific response that was being targeted, the conditions under which this response would occur, and the object/activity that would be used to elicit this response. Correct responses, incorrect responses, and approximations were recorded and analyzed so modifications could be made. In this manner, the students could be more successful in learning some aspect of language. This process was called the acquisition phase and, at that time, it was disputed by few persons in the Kingdom.

### New Developments

As this type of training continued, there were some new developments in the Kingdom. It was noted that the students were using few of their newly learned responses outside the quiet, turret room. Only the Training Maiden could get the students to talk or use their signs. Only the Court Jester could get the students to play and laugh. Only the Knights could get the students to work. The world outside that turret room was a whole different world, a real world. There were many different objects, activities, and persons involved in the affairs of the castle and kingdom. Many of these persons did not know about the magical techniques that could be used to get the students to state their wants and needs and make choices. Members of the Round Table determined that the acquisition phase was not the only phase of training. Behold, there was generalization and maintenance of training as well. From that day forward, training changed. And that was good. Change was necessary if things were to progress in the Kingdom. Merlin had a vision that these students could be even more successful if *their* perspective was considered. He decreed that all persons should look more closely at the students' worlds and what might be important to them.

### The Kingdom Gets Involved

More and more students with severe disabilities, including students who were deaf-blind, were seen in the Kingdom. The educational job became too much for the Training Maiden alone, and rightfully so. No one person in the Kingdom was wise enough to answer all the questions that arose. It was decided that every person who had any kind of a relationship with the students would share the responsibility of increasing their communication skills. Members of the Round Table declared that it was not enough to focus only on "how the students communicated." From that day forward each person also had to look at "why the students communicated." They had to realize that they had to be more sensitive to each student and that there were, in truth, many ways in which a student could communicate. Behold, a facial gesture, a slight movement, a vocalization—without being a word—could communicate something, sometimes, at least to someone who was special in the life of that student. It was determined that all the "natural" happenings in the students' Kingdom held potential for many opportunities to communicate. And this was true. And the Members thought that in this way everyone would live happily ever after. Different procedures were developed and evaluated to show that the natural Kingdom could present many opportunities for development of communication, participation, and relationships (Goetz, Gee, & Sailor, 1985;

Halle, 1982; Hart, 1985). And many students flourished under these new rules.

### Concerns in the Kingdom

As there was less strife with other Kingdoms, life within and outside the castle became more active. Knights, Knaves, Ladies, Jesters, and Serfs all had a role in keeping the Kingdom safe and productive. But as life went on, it was noted that the Kingdom in its natural state was not always as good as it could be, especially for students who were deaf-blind. The King and Queen concurred that *all persons*, regardless of rank of nobility or serf, should have a voice in the affairs of the Kingdom. The Queen became especially concerned that this was not the case for many students who did not have the advantage of communicating at a distance. Thus, her findings were posted on the castle wall:

**First:** Many communication attempts made by the students have not been responded to. And for students with multiple disabilities, very few opportunities for communication have been made available (Houghton, Bronicki & Guess, 1987). Over the years as students with more severe disabilities reached adulthood, their communication attempts diminished, possibly in relation to the diminished opportunities for communication or the noncontingent consequences for their communication efforts (Calculator, 1988). For many of these students, instruction became passive rather than active, with persons acting on, rather than with, the students (Downing, 1988). Persons in many of the environments stimulated the students rather than targeting specific outcomes that would lead to an increase in effective communication and greater participation in the Kingdom.

**Second:** Many teachers did not understand the progressive nature of communication and language and thus, unknowingly, simply nurtured affective states of behavior (Stillman, 1992).

**Third:** In fact, many students who were deaf-blind were not acquiring higher forms or more effective communication. It was difficult for anyone in the Kingdom, except Merlin, to learn any new skill when only 5–10 opportunities a day were available to learn the skill. Thus, it was noted that even the Knights who repeatedly practiced hitting a target on a tree were more successful in hunting and in battle than those Knights who only shot their arrows in battle. Often those nonpracticing Knights did not return from battle. However, the practicing Knights who never had an opportunity to hunt or to go into battle soon became bored and lazy.

In summary, the King and Members of the Round Table agreed that the effectiveness of teaching communication and language in highly structured contexts with systematic teaching procedures had been adequately demonstrated (Guess, Keogh, & Sailor, 1978). Whereas the acquisition of communication and language based on direct instruction in 1:1 or small group formats had been effective with many types of students, the corresponding use of the targeted skills in more natural environments had often been disappointing (Halle, 1988; Reichle & Keogh, 1985; Warren & Rogers-Warren, 1980).

### Solutions

Thus, in the years that passed, it was determined that generalization was only “real” if some behavior or skill had first been “acquired.” The elders determined that possibly some of the new ways were indeed working for some students, but not with others. That somehow, in all the years of “individualization,” they had missed looking closely at the individual student. They had not truly looked carefully to see what was working for some students and not for others—and why. A Round Table summit was called to determine the knowns and unknowns so that the Members could report back to the King and Queen.

**The Knowns.** A Subcommittee of the Round Table reviewed the massive literature and found some interesting findings. The need to utilize *both* direct instruction and the natural environment for those students who infrequently initiated communication and language had been proposed in the past (Keogh & Reichle, 1982; Holvoet, Guess, Mulligan, & Brown, 1980; MacDonald & Horstmeier, 1978) but many teachers of students who were deaf-blind and severely disabled seemed to have forgotten this. Perchance, they thought words such as, *enhancing*, *facilitating*, and *promoting*, would make the student’s communication such. Thus, the Members considered the knowns:

1. **Engagement:** Those students, who were learning to communicate more effectively in their natural environment by using new forms, new uses of communication, and communicating about more things to more people, demonstrated high rates of engagement with their physical and social environment (Halle, 1988; Hart & Rogers-Warren, 1978). Many of these students had vision and hearing abilities so they had the advantage of learning language at a distance. Thus, they could learn incidentally.
2. **Motivation:** Activities that afford opportunities for communication must also be motivating to the student. That does not mean that activities that are moti-

vating will naturally contain frequent opportunities for communication. For example, work experiences may be very motivating and yet few opportunities for communicating wants and needs may be available. Or, gesturing "finished" may only be reinforcing if it is followed by a cool drink.

3. Repetition: Activities that have frequent cycles of repetitions also present more opportunities to teach communication than those activities in which a skill is not repeated. Activities for younger children are often more repetitive than age-appropriate activities for older students.

**The Unknowns.** The Members of the Round Table reviewed the report of the Subcommittee and announced that there remained a number of unanswered questions.

1. Why do there remain so many students who are deaf-blind, with other disabilities, who do not make better progress in communicating?
2. Are the teachers no longer being taught by Merlin to conduct direct instruction or to determine when it is necessary and for which students?
3. Are the magicians the only ones able to use procedures in the natural environments?
4. Do the magicians have to develop new ways of teaching the teachers?
5. Do teachers, who conduct direct instruction, provide more opportunities in the natural environment than teachers who do not conduct direct instruction? Are they then, perchance, more responsive to the students' forms and functions of communication?

### Summation

The Members of the Round Table reported to the King: Perchance, we need to look again at direct instruction.

*The End* 

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## Deaf-Blind Perspectives To Be Or Not To Be A Journal

Bud Fredericks  
Executive Editor

**T**his is the fourth issue of *Deaf-Blind Perspectives*. When we started this publication we had the goal of creating a forum for parents and professionals to share ideas, opinions, and research. Because of the heterogeneity of people who are deaf-blind, we anticipated we might generate some debate. To some extent we have succeeded. We are receiving

some articles of opinion and a few containing research, but to date, we have generated little debate.

We have also established journal-like standards for the publication. Each submission is reviewed by at least three readers who do not know the identity of the author(s). This explains why some of you may have been asked to revise your writing or may have had your article rejected.

We have established these rigid publication standards because we are considering converting this newsletter to a journal. As we consider this, we appreciate any input that you, the readers of *Deaf-Blind Perspectives*, may have.

Some of the concerns that enter into our deliberations for conversion to a journal are the following:

- Are the readers interested in a journal?
- Can we generate a sufficient number of articles to maintain the publication of a journal?
- Are readers willing to pay a nominal fee for a journal? (The journal would be published at cost.)

If we were to convert *Deaf-Blind Perspectives* to a journal, we anticipate that it would

- Maintain rigid standards for publication and continue the practice of having submitted articles reviewed by a jury of peers.
- Have no established philosophical orientation and would entertain articles with differing views.
- Accept for publication an eclectic array of writings—research articles, conceptual pieces, and submissions—that present practices and opinions from parents and providers.

We recognize that this latter characteristic would cause our journal to differ from many existing research journals. We maintain that such a feature is necessary if we are to retain the ability to represent the wide diversity of views that are present.

We are struggling with this decision regarding conversion of this newsletter to a journal. We seek your opinions about such a change.

Please contact us at:

*Deaf-Blind Perspectives*  
345 N. Monmouth Ave.  
Monmouth, OR 97361

ph: (503) 838-8401  
TTY: (503) 838-8821  
fax: (503) 838-8150  
dbp@wou.edu.

## Recreation and Leisure\*

Lauren Lieberman  
Doctoral Student  
Oregon State University

**P**eople join recreational groups for many reasons—for fun, exercise, and meeting others. They look forward to Tuesday bowling, Saturday hikes, Sunday book discussions. Best of all, when people take time off from everyday responsibilities, they return to them later, refreshed. In a way, recreation re-CREATES us.

People who are deaf-blind and have cognitive disabilities enjoy recreational activities just as you and I do. To combat the isolation and lack of independence that often result from their disabilities, they NEED them even more than we do.

### Start with the Individual

#### What is he or she interested in?

- What types of recreation has he or she participated in previously?
- What are this person's favorite activities?
- With whom does he or she prefer to spend leisure time?
- At what time of day is recreation most enjoyable for this person?

People who are deaf-blind are as diverse in their interests as everyone else. Check the list below for some ideas. Remember, this list is only a start.

#### Fitness Activities

aerobics	running
swimming	cross-country skiing
walking	weight lifting
track and field	gymnastics
wrestling	bicycling (stationary/tandem)

#### Outdoor Activities

fishing	camping
hiking	canoeing
kayaking	horseback riding
sledding	rowing

#### Home Activities

cooking	gardening
needlepoint	knitting
arts and crafts	listening to music

#### Table Games

card games	bingo
dominoes	board games (chess, checkers, etc.)

#### Community Activities

bowling	ice skating
roller skating	dances (folk/social)
martial arts	diving

#### Sports Activities<sup>1</sup>

\* This article is available as a fact sheet from DB-LINK. To request your copy(ies), refer to the contact information at the end of this article.—ED.

USABA	Special Olympics
AAAD	community leagues
school sports	goal ball (individuals with hearing)

### What Activities are Age-Appropriate?

Age-appropriate activities are those activities normally found in the individual's culture and geographic location that are geared to the individual's chronological age.

Observe other people of the same chronological age to determine what activities are appropriate. Some examples of age-appropriate activities enjoyed by teenagers in our culture are bowling, dancing, swimming, and video games. Activities which are not appropriate for this age are duck-duck-goose, riding children's tricycles, or interacting with preschool toys. Many children who are deaf-blind will choose an inappropriate activity. Our goal is to broaden their experience and move them on to choices that are appropriate.

### What is Safe?

If the individual is engaging in a new fitness program, the physician should be informed. If there is a heart condition, a potential for retinal detachment, tubes in the ears, or a shunt, the physician will then inform the staff or parents of any cautions that must be taken. But remember, almost any activity can be adapted for individual needs.

### What is Available?

Find out what recreational activities are available at the person's home and school. Consult with the following groups to see what is available in the community.

- YMCAs/YWCAs
- church leagues/synagogue leagues
- community leagues
- college- or university-affiliated programs
- local deaf clubs
- local associations for the blind

### Research the Communication Patterns

It is important to determine each person's communication patterns and needs. For example, he or she may use augmentative communication devices such as schedule boxes and communication boards that use symbols, pictures, objects, and/or words. Since each person will have developed unique ways of using these, you will benefit from all the information you can gather. This can be as easy as looking in the files or getting the information from previous teachers, residential personnel, parents, siblings, or peers. You'll soon find that each person is unique.

*1 Work with clubs and organizations for those who are deaf to encourage individuals who are deaf-blind to participate in social activities to reduce isolation.*

## Develop a Plan

Once the above steps have been taken, you can develop a recreation plan. This plan should include short- and long-term objectives that have been developed, if possible, by a team consisting of the individual, the family, and the staff. Remember that the overall goal is to find an activity that will be fun and will provide relaxation. Be sure to set the stage for successful recreation.

## Maintain Interest

### Establish a Time Period

Establish a period of time that is appropriate for trying out a new activity. At the end of the period, let each person evaluate the pleasure derived from the activity. He or she can then decide whether or not to continue. Use of a time period helps prevent feelings of failure; it also ensures that enough time is given to the activity to provide adequate information for making a good decision. For example: 17-year-old Robert chooses Tae Kwon Do in the community club. The parents suggest a 6-week session to determine if he enjoys the activity. At the end of the 6 weeks, Robert may choose to continue, or he may end the session and choose another activity.

### Select the Proper Time of day for the Activity

Try to schedule the recreational activity for the time it is most needed to meet individual needs. For example: Amy is a 14-year-old who is in an educational setting. She is faster than her peers at getting dressed in the morning. As a result, Amy has 20-25 minutes every morning when she has nothing planned, and there are not enough staff to direct her play or an activity. She used to engage in self-abuse and became intensely agitated. When the recreation specialist noted that Amy loves to ride the stationary bike, the bike was made easily accessible to her. Now, every morning, Amy gets on the bike and rides for 20-25 minutes. She does not become agitated, and her self-abusive behavior has decreased.

### Modify the Activity When Necessary

Most recreational activities were developed with hearing and sighted people in mind. In many cases, an adaptation that is relatively minor can make these activities enjoyable and safe for those who are deaf-blind. For example, the children in Shannon's Girl Scout troop go roller skating every week. Shannon, like many young individuals who are deaf-blind, has difficulty keeping her balance. By using a skate aid device, Shannon can safely participate in roller skating.

Ask each person if he or she prefers the help of a guide or assistance from peers. However, be aware that some persons may prefer activities that promote personal independence.

### Discover the Best Ways to Teach

The following teaching strategies will help each individual succeed and make the learning process more effective.

#### Orient the Individual to the Playing Area

Give each person the opportunity to explore and become familiar with the equipment involved, other persons in the room, and the physical site. The absence of reliable visual and auditory input makes this a time-consuming process, but it is essential.

#### Explain

Select language (oral, sign, or augmentative systems) appropriate to the pupil's functioning level and communicate the key points of the skill.

#### Demonstrate

This is a practical teaching strategy only for persons with usable vision.

#### Use Braille or Feeling and Imitation

In this method, the individual who is deaf-blind feels the instructor execute the skill or activity being taught. The skill must be carefully analyzed by the demonstrator prior to the instruction in order for the demonstration to be effective.

#### Use Physical Guidance/Hand Over Hand

Place the student's body and/or limb(s) into the appropriate position and help him or her perform the desired movements at the preferred speed. Physical guidance can range from total physical assistance to a gentle touch that prompts him or her to complete a task.

#### Enable Choice Making

Many people who are deaf-blind go through their days with someone else making decisions for them. When they get involved in recreational activities, they must use choice-making skills. Begin with simple choices. First, offer two activities and allow him or her to choose the order in which they will be done. Next, give a choice of two or three activities and let him or her choose which one to perform. As each person increases in ability to make choices, remove prompting and allow more independence in decision making.

#### Use Additional Strategies

Begin with the amount of assistance that will ensure desired performance and success.

Combine teaching techniques to ensure the individual is learning as much as possible. For example, Eddie is 16 and learning the game of T-ball. He is deaf and has some residual vision. When standing at bat in the game, Eddie needs to be reminded of which way to stand and when to bat the ball. The instructor models which way to stand, signs "hit the ball," and taps Eddie on the elbow. Eddie then bats the ball off the "T." In this case, both explanation and physical guidance techniques are used.

Be aware of the individual's responses. Try to minimize assistance as soon as you feel the individual is learning the skill in the appropriate manner.

Provide immediate and accurate feedback so that he or she can make necessary adjustments before the next attempt (McInnes & Treffry, 1993).

Allow each person to practice the skill in an environment that is as normal as possible. This will allow the transfer of skills to occur much more easily.

Be patient. Progress may be slow due to learning the new skill as well as learning a new terminology to go with it.

Decrease physical involvement cues to cues that are natural or typical to initiate desired performance. For example, in a dance unit, start with hand-over-hand assistance (unless he or she has enough ability to start with a less intrusive cue) and work toward a touch cue to initiate desired movement.

Be sure hearing aids and glasses are on and functioning (unless, of course, you are in the pool).

Be sure to select leisure activities that are chronologically age appropriate and also are utilized by the general population (Hamre-Nietupski, Nietupski, Sandvig, Sandvig, & Ayres, 1984).

Consider featuring individuals who are deaf-blind who have special recreational talents on local news shows to raise public awareness.

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**For copies or information, contact DB-LINK.**

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*DB-LINK (The National Information Clearinghouse on Children Who Are Deaf-Blind) is funded through Cooperative Agreement No. HO25U20001 by the U.S. Department of Education, OSERS, Special Education Programs. The opinions and policies expressed by DB-LINK do not necessarily reflect those of the U.S. Department of Education.*

## For Your Library

### ***Ain't Misbehavin': Strategies for Improving the Lives of Students who are Deaf-Blind and Present Challenging Behavior***

*by Outreach Department of Texas School for the Blind and Visually Impaired. Austin: 1993*

*This video tape offers practical strategies for proactively avoiding interactions which challenge relationships. It is valuable to families, educators, educational support staff, in-home and residential support providers, friends and community members, and anyone else who regularly interacts with a child who is deaf-blind. The crucial links between behavior and the issues of communication, control, and quality of life are examined. A copy of the script accompanies the video and is available in braille upon request. Length: 16 minutes, cost: none send a blank VHS tape (30 minutes minimum) and request this title.*

**To order contact:**

Outreach Department  
Texas School for the Blind and Visually Impaired  
1100 West 45th Street  
Austin, TX 78756  
ph: (512) 454-8631

### **Request for Assistance**

The 307.11 Project staff of Arizona, Utah, Colorado, and New Mexico are gathering information on working with families of cultural diversity. The three areas of interest include the following:

- information about sensory impairment that is presented in a language other than English
- information on how to work with families from different cultures
- information about the state of national resources on multicultural education for families with children who are disabled

If you have any information you would like to share, please send it to:

Tanni Anthony  
Colorado Dept. of Education  
201 E. Colfax Ave  
Denver, CO 80203

ph: (303) 866-6681  
fax: (303) 866-6811

### **Thank You!**

The editors of *Deaf-Blind Perspectives* would like to extend a special **thank you** to the following individuals who have donated their time to review all of the manuscripts submitted to *Deaf-Blind Perspectives* for possible publication in Volume 1, Issues 1-3.

- |                |                   |
|----------------|-------------------|
| Harry Anderson | Barbara McLetchie |
| Bruce Bull     | Kathy McNulty     |
| Bruce Dalke    | John Reiman       |
| Joyce Ford     | Marianne Riggio   |
| Bud Fredericks | Art Roehrig       |
| Jay Gense      |                   |

### NFADB Membership Drive Join the National Family Association for Deaf-Blind

NFADB has been established to address the needs of families of people who are deaf-blind. If you would like to join this national non-profit organization, please complete and return this coupon.

**Regular Memberships:** any person who is deaf-blind, the parent, guardian, adult sibling, or other individual having a similarly close interpersonal relationship with a person who is deaf-blind.

**Regular - One Year \$15**

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**Lifetime \$100**

**Associate Memberships:** individuals interested in supporting the mission and purpose of the Association.

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**Contributing Sponsors** are those involved by reason of monetary or other gifts of value to the Association.

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How old is the person who is deaf-blind? \_\_\_\_\_ Their relationship to you is \_\_\_\_\_

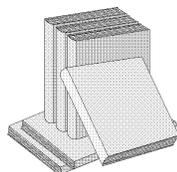
What is the cause of this person's deaf-blindness? \_\_\_\_\_

Please return with check payable to NFADB to:

**NFADB  
111 Middle Neck Rd  
Sands Point, NY 11050-1299**



ph: (800) 255-0411 ext 275  
TDD: (516) 944-8637  
fax: (516) 944-7302



## For Your Rolodex

### **Collaboration Among Parents and Health Professionals (CAPP)**

*CAPP is a parent-run resource system for children with special health needs and their families. The purpose of the project is to develop a parent organized, nationally coordinated system that will maintain and strengthen parent and family involvement in health care. The project is built upon the recognition that understanding the needs of families is central to achieving this nation's agenda for family-centered, community based, coordinated care. CAPP provides written materials, training packages, workshops, and presentations for families and professionals.*

**Contact:**

CAPP  
95 Berkeley Street., Suite 104  
Boston, MA 02116  
ph: (617) 482-2915  
(800) 331-0688

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### **Sibling Support Project**

*The goal of the Sibling Support Project is to facilitate the creation of statewide systems of peer support and education programs for brothers and sisters of children with special needs. This is accomplished by providing training, providing demonstration and technical assistance to projects and agencies, disseminating written materials and presentations, and developing and refining products related to peer support and education programs.*

**Contact:**

Sibling Support Project  
Children's Hospital and Medical Center  
4800 Sand Point Way NE  
Seattle, WA 98105  
ph: (206) 368-4911

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### **National Center on Educational Restructuring and Inclusion (NCERI)**

*NCERI is concerned with inclusion of students with disabilities in the context of broad educational restructuring. Toward this goal, NCERI addresses issues of national and local policy; disseminates information about programs, practices, evaluation, and funding; provides training and technical assistance to school districts and state departments of education; builds a network of inclusion districts; identifies individuals with expertise in inclusion and conducts research.*

**Contact:**

NCERI

Graduate School and University  
Center City University of New York  
33 West 42 Street.  
New York, NY 10036-8009  
ph: (212) 642-2656

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### **Parent Advocacy Coalition for Educational Rights (PACER)**

*PACER is an educational advocacy organization providing parent education and training to help parents understand the special laws and information on how to obtain special education school programs for their children and young adults. PACER offers workshops and programs on a variety of topics as well as inservice training, interpreter services, computer resource center, transition planning, newsletters, booklets, videos, and other materials*

**Contact:**

PACER  
4826 Chicago Avenue South  
Minneapolis, MN 55417-1055  
ph./fax: (612) 827-2966  
(800) 53PACER (Minnesota only)  
TTY: (612) 827-3065

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# Traces

## Regional Reports

### KANSAS

*A series of three staff development training sessions are being sponsored in a collaborative effort by personnel from four projects. Those projects are the Kansas Services for Students with Dual Sensory Impairments Project, HKNC-TAC Project, TRACES Project, and the Kansas Dual Sensory Impairment Pilot Project: Promoting Access for Children with Exceptionalities. Each session is designed to build on the information provided in previous training sessions, but participants may elect to attend one, two, or all three of the sessions. Follow-up technical assistance from the Kansas Deaf-Blind Project is provided for those participants who complete all three sessions.*

*The first session was July 25-29, 1994, in Topeka, Kansas. The institute activities were facilitated by Terry Rafalowski-Welch and guest speakers included Pam Cress, Program Coordinator of a special project to prepare personnel to provide vision screening and evaluation services to children from birth to three years of age; Joan Houghton, Program Associate from HKNC-TAC; John Mascia, Coordinator of Audiological Services at HKNC; and Sally Roberts, Assistant Professor at Kansas University and Project Director of a project to prepare educational interpreters for the deaf. Topics in this one-week institute include basic anatomy of the auditory and visual systems; as well as interpretation of the results from both medical, functional, hearing, and vision evaluations for the purpose of designing instruction. Additional topics included consideration of sensory impairments in the design of community-based instruction, as well as the impact of dual sensory losses on planning, implementing and evaluating instructional programs.*

*The second in a series of sessions will occur in the fall with a focus on communication intervention. The third session will occur in the winter with a focus on orientation and mobility intervention for individuals who are deaf blind.*

**For additional information contact:**

Julie Mohesky-Darby  
Kansas D/B Project  
(913) 296-3953

Cheryl Kennedy  
TRACES Project  
Northeast Regional Co-ordinator  
(412) 648-7176

### ARKANSAS

*In 1992 a need was identified for training service providers and families in the area of functional assessment of vision and hearing and subsequent adaptation of materials and activities for children who are deaf-blind. This need was met through group instruction and on-site consultation which focused on two students who are deaf-blind in the Little Rock Public Schools.*

*In September, 1993, while implementing the consultants' recommendations, it was noted that there was also a need for training service providers and families in effective practices for communication and orientation and mobility for these students. Therefore, during the 1993-1994 school year technical assistance was provided by two consultants with expertise in these areas. As before, there was on-site consultation with child-specific recommendations for three identified students. Large group instruction on these topics was provided at the statewide conference, Special Show, in July, 1994.*

*Although only three students received hands-on technical assistance, the techniques and strategies suggested will be applicable to many other students with sensory impairments and multiple disabilities.*

*In addition, the 307.11 coordinator is working to develop these classrooms as implementation sites which can then be used when other local education agencies in Arkansas want to replicate the effective practices demonstrated here.*

**For additional information contact:**

Teresa Coonts  
Project Coordinator  
(501) 682-4222.

### CALIFORNIA

*Parents and teachers in California are getting "Just the Facts!" and smiling about it. Specialists with California Deaf-Blind Services (CDBS) have developed over 20 fact sheets for teachers, families, and others who work with individuals who are deaf-blind. The fact sheets are single-topic information pages that are written to be easily understood. They are designed for the beginning professional and others who may not have extensive background or training in this area. In cooperation with TRACES and states in the Western Region, fact sheets have been developed to address medical issues, light sensitivity, basic interaction and communication, ideas for recreation and leisure, and many more topics. New fact sheets are developed based on requests from families and teachers.*

The fact sheets have recently been translated into Spanish, allowing many more families to increase their effectiveness and involvement in planning and supporting the educational programs for their children. TRACES is assisting CDBS in translating the fact sheets into several Southeast Asian languages and other Pacific Rim languages. Fact sheets in these languages will be available beginning early in 1995. The fact sheets will also be supported with multimedia. CDBS and TRACES are developing several video tapes that will graphically illustrate and enlarge the information available in the written pages. The fact sheets in English have been made available on SpecialNet on the National Deaf-Blind Bulletin Board and are included in the DB-LINK collection. Additional fact sheets will be disseminated as they become available.

**For additional information contact:**

Steve Johnson  
 CDBS  
 California Department of Education  
 515 L Street, Room 270  
 Sacramento, CA 95814  
 (916) 327-3502  
 SpecialNet: CA.SE. Johnson

**INDIANA**

Six teachers of students who are deaf-blind have recently completed their fourth and final summer institute leading to their designation as mentor teachers. These mentors support other Indiana teachers in the implementation of educational best practices for students who are deaf-blind.

Summer Institute IV was conducted July 11-15, 1994 at Indiana State University. Topics for the week included housing options and community supports for young adults in Indiana who are deaf-blind, parent perspectives on educational planning for their child, resources available through state agency programs for children and youth who are deaf-blind, assistive technology and augmentative communication strategies, and a session on meeting the visual needs of students who are deaf-blind.

The mentor teachers left the summer institute with technical assistance responsibilities for the upcoming school year. Action plans were developed by each mentor. Follow-up support will be provided by the Indiana 307.11 project coordinator. The mentor teachers will also attend a weekend retreat in September, 1994. The topics for this retreat are the use of creative problem-solving strategies and how to recruit and train the next cohort of mentor teachers.

**For additional information contact:**

**VIRGINIA**

Karen Goehl  
 Indiana Deaf-Blind  
 Project  
 (812) 237-2830

Margie Briley  
 Regional Coordinator  
 TRACES  
 (412) 648-1424

The Virginia 307.11 Project has just completed its first Summer Institute for parents, service personnel and teachers of children who are deaf-blind. Presenters and guests from around the United States and Canada were given an overall view of children who are deaf-blind, from the perspectives of community members, the family, and education personnel.

Many of the participants came to the institute as part of an educational team, others made additional contacts with other teachers from their area, and all gathered information on team building. These teams and individual teachers will incorporate the action plans developed in the Summer Institute into the new school year. Participants will also encourage parents to be more involved in the educational decisions as part of the educational team. Better interaction of school, home, and community—with the child at the center—is the goal of this and future summer institutes.

**For additional information contact:**

Toni Waylor-Bowen  
 Southeast Regional Coordinator  
 TRACES Project  
 (404) 651-4089

*TRACES (Teaching Research Assistance to Children Experiencing Sensory Impairments) is funded through Cooperative Agreement No. HO25C30001 by the U.S. Department of Special Education, OSERS, Special Education Programs. The opinions and policies expressed by TRACES do not necessarily reflect those of the U.S. Department of Education.*

## Sorting Out the Challenges of Fatherhood: Vision and Reality

Robert W. Moore  
Parent

This article shares the perspective of one father of a child who is deaf-blind. The editors of *Deaf-Blind Perspectives* would like to invite other parents to share their views.—Ed.

**B**eing a father is one of life's great challenges. This is true regardless of the circumstances in which a man takes on that role. One problem I have faced as the father of a child who is deaf-blind and has other disabilities is sorting out which parts of my experience are regular father-role challenges and which result from an extra increment of challenge due to my son's serious, multiple disabilities. Here is what I have come to think as I sort out my own experience. Other fathers will no doubt have different interpretations of their experiences which are equally legitimate. Perhaps some of what follows is relevant to the experiences of mothers as well, but I'll let women speak for themselves and interpret their own experiences.

When Cherry told me she was pregnant, it pleased and excited me. We were ending a decade as married students and we were in our early thirties. The time to start our family had arrived. It made me proud when it appeared we had gotten a "hit" on our first try at pregnancy. I embraced my new role as father-to-be with joy and expectation.

From the moment I knew I was going to be a father, I began creating a vision of my child. I built that vision with personal experience, memories, and cultural resources, ideas and images about "childkind." As the pregnancy progressed, we undertook our household preparations, Lamaze training, and social celebrations. I became more committed to my vision. I even learned through ultrasound about 2 months before delivery that I could expect a son.

I believe this vision-making process is a normal part of taking on the role of a father. As with most visions, however, mine was idealized, oversimplified, and unrealistic. That was okay, though. There would be time enough to bring my vision into conformity with reality as my son grew. I expected adolescence would be the time of the greatest challenge as my son created his own adult identity, separate from the one his mother and I had supplied for him. I would have to face the fact that my son would grow into a person with a mixture of strengths and weaknesses, that he would become more complex and more real than the

vision I had constructed of him. I was prepared to work through adolescent conflict when it came in a decade or so. I expected to move beyond it into a lifetime of satisfaction as my son's adult friend.

Lew was born in the late summer of 1981 after a seemingly normal pregnancy, labor, and delivery. It wasn't until he was 5 months old that the evidence of problems was too strong to deny. After 2 more months, filled with a multitude of medical tests and consultations, we learned that Lew had suffered a brain injury of unknown origin. He had a seizure disorder and cerebral palsy. In the next few years other diagnoses were added, including functional deaf-blindness and severe mental retardation. Despite his assets (he is a handsome child with a sweet disposition), Lew faced lifelong dependence and on-going developmental and medical challenges.

Before Lew was 6 months old, I began to grieve for the loss of my vision of him. I believe some of my grief was much like that to which every father is vulnerable as his child moves away from that early parental vision into adulthood. There were some important differences for me, however. Perhaps

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**"From the moment I knew I was going to be a father, I began creating a vision of my child."**

---

other fathers of children with disabilities or special health needs have experienced some of these differences as well.

The first difference was that I experienced the loss of my vision for my son much earlier than I expected, earlier than normal, I believe. I imagined that adolescence would be the climax of my confrontation with the fact that my vision was inadequate to explain the reality that my son would become. It was painful for me to take up this developmental challenge in my own life more than a decade before I expected it.

The second difference was that I experienced the whole loss of my vision in a very short span of time. Rather than a gradual, part-by-part giving up of my vision, it quickly became clear that the whole of my vision was inappropriate to the reality that was Lew's life. I couldn't revise my vision gradually with incremental adjustments, or give it up a little bit at a time. It all went at once.

The third difference was the depth to which my vision of my son was shown to be wrong. I was prepared to see Lew grow up to be different from me. For example, I value academic life, but I was willing for him to be an average student. Graduate school, or even college, though desirable from my point of view, would be up to him. I was not prepared to face the reality that he will never read, write, or speak. My vision had what I thought was a generous latitude within which he would make choices that expressed his own gifts and interests. I didn't allow room in my vision, however, for what I now expect

will be his total lifelong dependence on others for feeding, dressing, moving, toileting, and deciding.

The fourth difference is in the additional tasks imposed on both Cherry and me by Lew's disabilities. Implementing therapy programs at home, being partners with professionals in planning care and education, dealing with the financing of needed services, advocating for better practices, policies, and laws, and participating in training and support activities are some of the tasks that have made the substance of fathering different for me.

I have found the sadness or grief over the lost vision of my son to be deeply and persistently painful, perhaps an instance of chronic sorrow which has been described by Olshansky (1962) and others. I've worked at revising my vision to consider the impact of my son's disabilities on his life chances. This revisioning has been difficult in part because I started from a poorly informed understanding about the lives of people with disabilities. I had few memories or experiences with which to build that new vision. The culture of segregation and denial which hides people with disabilities from sight gave me few cultural resources to use and even fewer that were hopeful or uplifting. I found myself hungering for stories, for information I could use to construct a hopeful, positive new vision of my son's life.

Until now, 12 years later, I've not been very successful. Many of the success stories told at conferences and training events don't apply to my son. Some are like miracle stories upon which it seems unrealistic to rely. I've become wary of professional fads upon which some people build their careers which don't have much impact on people like my son. Trust, and trustworthiness, is in short supply. The fragmented vision which persists in my imagination is not particularly positive nor hopeful, at least compared to the espoused values and aspirations that I hear from some professionals who try to help Lew.

I've tried to find generalizations about fatherhood to attain a better understanding of my own experience of fathering. For example, I believe it is common for fathers to eventually see their children grow into people who are different from the oversimplified, idealized, and unrealistic vision that they began constructing before they were born. I think this is a normal, natural part of the life cycle for men who take on the father role. When severe illness or disability challenges their children, however, the way they experience this process may accelerate. It may become more comprehensive and of greater degree than many men are prepared to adapt to with a feeling of

success. In addition to grief, I find that I personally also experience a deep sense of failure in my role as a father.

Though many people are ready to discuss grief with me, I find few who will legitimate, affirm, and help me work through my feeling of failure. Some fathers of children with disabilities may not interpret their experience as failure. Others, however, have acknowledged that the idea has the ring of truth for them. Most commonly, when I bring up the topic, people will deny the legitimacy of my feeling with contradictory words meant to be supportive ("Oh, you haven't failed, you're a wonderful father," or some similar denial). Thus a painful, sometimes debilitating aspect of my own emotional life remains mostly private and unshared. I suspect this matter of failure is acute for many fathers of children with disabilities because of the way men are socialized in our society. Perhaps most people find it easier to deal with a man's feelings of grief, or even guilt, than with his feelings of failure. I believe that reticence in facing, legitimizing, and sharing feelings of failure de-

values fathers. It is part of a social control system that can reduce their power and feelings of self-worth. This, at least, has been part of the experience that I have had as the father of a child with severe disabilities.

Fathers of children with disabilities face huge challenges in the performance of their roles. I'm sure that not all of them interpret their experience in the same way. Some of these challenges are faced by all fathers, while extra challenges derive from their children's disabilities. Sorting out the regular from the special challenges has been important to me as I try to be a better a father to Lew.

Bob Moore lives in Lexington, Kentucky. He is married to Cherry Winkle Moore and they have two sons, Jay age 11 years, and Lew, now 12 years, who resides at the Home of the Innocents in Louisville, Kentucky.

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**"I have found the sadness or grief over the lost vision of my son to be deeply and persistently painful. . . ."**

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