

# Deaf-Blind Perspectives

Volume 1, Issue 1

Fall 1993

## Why Deaf-Blind Perspectives?

by  
Bud Fredericks  
Research Professor, Teaching Research

**F**or more than 20 years the staff at Teaching Research have been involved with matters related to people who are deaf-blind. We provided technical assistance to the Northwest Regional Deaf-Blind Center, directed a number of demonstration projects funded by the federal government, and for the past few years provided technical assistance to the states and regions through TRACES. We conducted, together with the federal government, the National Symposium on Children and Youth Who Are Deaf-Blind. We have most recently formed a consortium with the American Association of the Deaf-Blind, the American Foundation for the Blind, Helen Keller National Center, and Perkins School for the Blind to establish DB-LINK, the National Information Clearinghouse On Children Who Are Deaf-Blind.

During all these activities we published newsletters, reports, made presentations, wrote chapters for books, and in general, tried to promulgate information. The National Deaf-Blind Bulletin Board of SpecialNet was established recently and is being managed by Teaching Research and the California Deaf-Blind Program.

Despite the amount of information being promulgated through these channels, we recognized that there were many issues, problems, concerns and different opinions about matters that affected those who are deaf-blind and their families which were not being adequately discussed in the existing printed periodicals. That such issues existed and needed a medium through which they could be comprehensively aired was amply demonstrated by the papers presented at the Hilton-Perkins National Conference and through the National Symposium on Children and Youth Who Are Deaf-Blind, sponsored by the federal government. We examined existing newsletters to determine whether any met the need that we perceived. We found them all to be quite parochial in their subject matter. For instance, the TRACES newsletter focused only on children and youth who are deaf-blind (birth to 21 years). The Helen Keller TAC newsletter targeted the transition years. We concluded that there was a need for a publication, such as Deaf-Blind Perspectives, that would span the entire age range from birth to senior citizen, and consider the heterogeneity of people who are deaf-blind, to include discussions about those who are deaf-blind and cognitively able and those who are deaf-blind and cognitively disabled.

We recognized that what we were considering had characteristics that were more journal-like than a newsletter. However, the effort and resources to undertake a journal publication at this time were not available, nor did we wish to ask readers to pay for the publication.

In order to finance Deaf-Blind Perspectives we decided to combine the resources of three entities: (a) Teaching Research currently publishes an eclectic newsletter that focuses on projects that Teaching Research staff are conducting. These range from early childhood special education programs to residential facilities for adults with disabilities who have severe behavior problems. Teaching Research agreed to contribute the resources of that newsletter to Deaf-Blind Perspectives. (b) In addition, TRACES agreed to contribute the resources it had for the publication of its newsletter with the understanding that a section of Deaf-Blind Perspectives would be devoted to TRACES matters. (c) DB-LINK agreed to the same arrangement. Thus the TRACES Newsletter will no longer be published as a separate entity nor will DB-LINK

### In This Issue

<b>Why <u>Deaf-Blind Perspectives</u>?</b>	
Bud Fredericks .....	1
<b>Rationale For Editorial Policy On Terminology</b>	
John W. Reiman .....	2
<b>Doors</b>	
Joyce Ford .....	4
<b>Teaching Students Who Are Deaf-blind and Cognitively Disabled To Effectively Communicate Choices During Mealtime</b>	
Carole R. Gothelf .....	6
<b>The National Information Clearinghouse On Children Who Are Deaf-Blind</b>	
Bruce Bull.....	9
<b>Regional News</b> .....	11
<b>For Your Library</b> .....	14
<b>Calendar of Events</b> .....	15

commence promulgating their own newsletter. In addition, Teaching Research will, during the next couple of years, cease the publication of its newsletter.

What type of articles do we foresee being published in Deaf-Blind Perspectives? We want the newsletter to focus on pertinent issues regarding people who are deaf-blind and those involved with them. An article that discusses the discrepancies between services available for adults who are cognitively able and those who are cognitively disabled might be appropriate. For instance, we know from previous discussions with adults who are deaf-blind that a disturbing issue is the availability of transportation to those who are deaf-blind and cognitively disabled whereas comparable transportation services are not available for those who are deaf-blind and cognitively able.

Other articles might examine inclusion. We certainly have heard many opinions about inclusion and its merits and faults over the past few years. Articles representing the spectrum of opinions would be welcome. The

### ***Deaf-Blind Perspectives***

Volume 1, Issue 1  
Fall 1993

#### ***Executive Editor***

Bud Fredericks  
Teaching Research

#### ***Managing Editor***

Bruce Bull  
Teaching Research

#### ***Consulting Editors***

Janice Adams  
Deaf-Blind Consultant

Bruce A. Dalke  
Teaching Research

Joyce Ford  
Parent

Marilyn Gense  
Oregon School for the Blind

Jay Gense  
Mid Oregon Regional Program

Karen Goehl  
Indiana Deaf-Blind Project

Richelle Hammett  
University of Maryland

Barbara A. B. McLetchie  
Boston College

Kathy McNulty  
Helen Keller National Center

John W. Reiman  
Teaching Research

Marianne Riggio  
Perkins School for the Blind

Submit manuscripts or  
inquiries to:

Deaf-Blind Perspectives  
Teaching Research Division  
345 N. Monmouth Ave.  
Monmouth, OR 97361  
(503) 838-8403  
TTY (503) 838-8821  
fax (503) 838-8150.

range of subject matter of articles is endless - early intervention, transition, communication techniques, syndrome characteristics, parental concerns, etc. are all appropriate. We encourage controversy and discussion and will at times invite articles that will represent opposing views on topics. We want the newsletter to be perceived as a forum for ideas and discussion.

We encourage persons who are deaf-blind, parents of persons who are deaf-blind, and professionals to submit articles to Deaf-Blind Perspectives. The articles will be reviewed by a panel of editors and will be either accepted as is, accepted with suggested revisions, or rejected, based on the reviews of the editors. Quality will be the criterion for acceptance. Ideological positions will not be grounds for nonacceptance.

We believe that by presenting the diverse opinions that exist among those who are deaf-blind, their parents, and the professionals who are involved with them we shall begin to accept the differences that exist within the field and perhaps reconcile some of those differences. Thereby, we might help to build a discipline that is united in purpose and yet retains its diversity.

We look forward to publishing this newsletter. We wish it to be of high quality and welcome your suggestions and criticisms. Kudos are appreciated at any time.

## **Rationale For Editorial Policy On Terminology**

by

John W. Reiman

Associate Research Professor, Teaching Research

**T**he promotion of choice, inclusion, and self-determination for people who are disabled requires something from everyone. For those who write on matters related to such persons, the requirement is accuracy and precision.

Imprecise linguistic descriptions of people who are deaf-blind pervade contemporary literature. Do constructs from the vernacular of professionals like "dual sensory-impairment", "with deaf-blindness", and "the deaf-blind" serve the best interest of the people they attempt to describe? To dispute the use of such terminology is not to be pedantic and nitpicky, but to express concern about a real problem. In the paragraphs that follow, I will (a) provide examples of questionable terms and phrases, (b) comment on their possible negative effects, and (c) present an editorial policy for Deaf-Blind Perspectives that will invite greater precision in language used to characterize this population.

## Examples of Imprecise Terminology

The terminology in question assumes three primary forms. First, is the medical-model-inspired **pathologizing** variety with its deficit-based watchword, “impairment.” “Dual sensory-impaired students”, “hearing- and vision-impaired students”, “sensory-impaired students”, and a host of related descriptions of human beings that champion what is absent about a person and fail to describe what is present—such terms simply alert us to something about a person being wrong. Person-first language (e.g., “students with dual sensory impairments”) is purported to address this problem by emphasizing the person first rather than the disability. Placing the person first, however, doesn’t erase the negative associations invited by “impairment”—a term out of favor in most other areas of special education and rehabilitation.

A variant on the pathologizing theme is the now popular “with deaf-blindness” (e.g., students with deaf-blindness). The “-ness” is a suffix that forms abstract nouns denoting quality and state (Random House Webster’s College Dictionary - 1993). Is an abstract noun adequate for defining the population of people who are deaf-blind? Unfortunately, the abstraction’s lack of precision invites creative connotations—the notion of affliction in this case. Combined hearing and vision loss are made to seem like an infirmity or ailment that someone ends up “with.” Adversity, distress, hardship, and tribulation are implied. Understandably, some people who are deaf-blind hold contempt for this construct. Escaping disability-related stigma spawned by professionals’ use of “with deaf-blindness” terminology, must be an additional and unwelcomed challenge.

A second form of questionable terminology is the **objectifying** variety. “Educators should prepare deaf-blind for...” and “...when the deaf-blind use interpreters” are two examples. Both completely omit the person reference making the human and the disability one and the same. Ironically, there is a twist to this one. On one hand, when hearing/sighted professionals in education and other fields use such language to describe children who are deaf-blind, charges of objectification and paternalism may be leveled. On the other hand, when numerous adults who are deaf-blind (many of whom belong to the American Association of the Deaf-Blind) refer to themselves or to each other, the same terminology deemed as objectifying above, becomes the opposite—validating and affirming. In this context, as a mark of respect and affirmation for community, linguistic, and cultural integrity, usages like “the deaf-blind are...,” “some

deaf-blind feel...,” and “when Deaf-Blind want...” (note upper-case usage) are the norm.

Terminology of the **overgeneralizing** variety is the third form in question. To say that people who are deaf-blind uniformly think, feel, need, or want almost anything universally, is to discount the heterogeneity and enormous differences that characterize this population. These differences are pronounced in the multiplicity of gifts they contribute to the world, as well as the differences in their needs.. The de facto claim, for example, that “clients who are deaf-blind present with serious communication deficits” (drawn from a counseling context) is fallacious. Can an eighteen year-old Gallaudet University student who is deaf-blind (Ushers Type I) and, using interpreters, maintaining a 3.5 GPA, be viewed as having “serious communication deficits?” **Which** people

who are deaf-blind is the question always begging an answer.

In short, the use of pathologizing, objectifying, and overgeneralizing terminology may compromise accuracy in describing people who are deaf-blind, and may erroneously homogenize such peoples’ dissimilar characteristics and needs.

## Possible Negative Effects of Such Terminology

Two possible effects come immediately to mind stemming from use of the terminology described above.

First, is it possible that professionals’ use of the aforementioned terminology may lend fuel to others’ inaccurate portrayals of people who are deaf-blind? A recent telemarketing campaign by a company contracted to raise funds for an agency related to people who are deaf-blind included the following among its categories for sponsorship:

- “Power of Communication” sponsors... who “open up the worlds of hearing and sight for persons who are deaf-blind.”
- “Lift the Darkness” sponsors... who “help the curtains of communication be opened and the darkness lifted by the rays of awareness.”

Tugging at the heartstrings of potential contributors with misleading images of “worlds being opened” and “curtains lifted” does little to contribute to general understanding of people who are deaf-blind. Isn’t it incumbent on us as professionals to forego pathologizing, objectifying, and overgeneralizing terminology in the interest of encouraging realistic and accurate portrayals? Mightn’t our inaccurate terminology lend tacit

support to the sale of images as above by modeling imprecision as acceptable?

A second negative effect of the foregoing terminology may be directly experienced by people who are deaf-blind. Amidst deficit-based characterizations across a wide range of print media, what amount of such negativity is directly experienced by the person who is deaf-blind? Imagine one's experience of being labeled in terms limited to what about one was weakened, damaged, injured, or deficient. Whether it be directly through auditorally, visually or tactually received information, or indirectly through the reflected pathos of mass culture, isn't it likely that such terminology does a disservice to the very people it seeks to describe?

As a hearing/sighted person, it would be presumptuous to assume I understood the magnitude of such terminology's negative impact. People who are deaf-blind are presumably affected in untold ways beyond those suggested above.

### **An Editorial Policy Inviting Greater Precision**

Given the above, it shall be the editorial policy of Deaf-Blind Perspectives to require that manuscripts define in no uncertain terms, the population being referenced. The responsibility for defining which subset of people who are deaf-blind each article is referencing, shall remain with the writer (and editors), not the reader. Deaf-Blind Perspectives will edit submissions to reflect person-first language (e.g., "... who are deaf-blind") except in such cases where community, linguistic, or cultural integrity are being cited (e.g., American Association of the Deaf-Blind).

Development of this policy is motivated by the editors' wish to promote respectful relationships between people that honor and embrace individual differences. In the event a writer feels limited by such constraints, we welcome the opportunity for dialogue.

## **Doors**

by  
Joyce Ford

**T**eaching skills to my son who is deaf-blind has often meant dissecting activities into tiny increments. To drink from a cup begins with locating it, grasping it, lifting it...and ten steps later taking a sip. Setting it down right-side up is another skill. Someone appropriately named it backwards chaining; the learning of a skill by chaining the sequence together backwards from the completion to the beginning.

So it was when it came to doors, except that the variety became greater. There are doors with door-knobs, and some with push-bars. There are sliding doors, folding doors, cabinet doors, car doors, and automatic doors in some places. Southwestern Idaho doesn't have many revolving doors...so I put that one aside for later. I focused on the plentiful assortment of doors that Riley encountered daily.

To fully consider the use of doors, I knew that our support services at McKinley Elementary School would be involved as they had been in other activities. Physical therapy would be concerned with Riley's upper body strength. Some doors are quite heavy. The therapist would plan exercises to develop those muscles. Occupational therapy would be troubled with the twisting wrist movement necessary for doorknobs, a motion quite unnatural for Riley. Speech therapy would emphasize signing words such as open, close, inside and outside into Riley's hands. The orientation and mobility instructor would worry about doors that others might dangerously open in Riley's path. Riley would need to be better with his cane. The Special Ed teacher would discuss data: 80% success on 50% of trials with 25% accuracy...a goal would be developed for Riley's Individual Education Plan.

In March of 1992, Riley left the McKinley Special Ed classroom and moved into a regular third grade classroom. Riley is the only deaf-blind student in our school district and one of the first students with severe disabilities to be included full time in a regular education classroom. He was now one of twenty-two third-graders, and the only one who didn't do doors. Fortunately, he was in the company of twenty-one eager 8-year-olds who were more than willing to overlook that. In their eyes, Riley could do lots of other things with them...eat lunch, play at recess, art, P.E., music, and library...all of which they felt were much more important than doors.

The following September the McKinley third-graders moved on to fourth grade, but it was without Riley. As a team, we had decided that Riley needed a full year of regular third grade before moving on. He started this new school year

























I enjoyed this issue of Deaf-Blind Perspectives but I am not on your mailing list. Please send future issues to the address below.

I've moved! Please send future issues of Deaf-Blind Perspectives to my current address.

I'm buried in interesting publications! Please remove my name from your mailing list.

Name: \_\_\_\_\_

Agency: \_\_\_\_\_

Street: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_

**Mark appropriate categories (3 max.)**

- |   |   |
|---|---|
| <input type="checkbox"/> Person or parent of person with disabilities       | <input type="checkbox"/> Regular educator (non Spec.-Ed.) |
| <input type="checkbox"/> Special educator (e.g., teacher, aide)             | <input type="checkbox"/> Therapist (e.g., OT/PT/speech)   |
| <input type="checkbox"/> Administrator, Dept. of Ed. employee               | <input type="checkbox"/> Teacher trainer                  |
| <input type="checkbox"/> Service provider (e.g., social worker, group home) | <input type="checkbox"/> Government personnel             |
| <input type="checkbox"/> Technical assistance provider                      | <input type="checkbox"/> Other _____                      |
| <input type="checkbox"/> Higher educator teacher/researcher                 |   |

**Please mail this coupon to: Deaf-Blind Perspectives  
! Teaching Research Division ! Western Oregon  
State College ! 345 N. Monmouth Ave. !  
Monmouth, OR 97361 ! or call (503) 838-8885, TTY**

Deaf-Blind Perspectives is also available in grade 2 braille, large print or on

---

Deaf-Blind Perspectives is published quarterly by the Teaching Research Division of Western Oregon State College. Information contained within the newsletter does not necessarily reflect the position of the Teaching Research Division.

---

---

***Deaf-Blind Perspectives***  
**Teaching Research Division**  
**Western Oregon State College**  
**345 N. Monmouth Ave.**  
**Monmouth, OR 97361**

---

Non-Profit Organization  
U.S. Postage  
**PAID**  
Permit No. 12

---

*Forwarding & Return Postage Guaranteed,  
Address Correction Requested*