



NEWSLETTER  
WINTER 2003

INDEPENDENTLY MERGING  
PARENT ASSOCIATIONS  
OF CALIFORNIA

*Together for Deaf and Hard of Hearing Kids*

**1-877-322-7299**

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IMPACT Newsletter  
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## CONFERENCE '04 ON THE WAY!



Santa Clara, CA – Get your calendars ready! We have the scoop on the 2004 Cal-Ed / IMPACT joint conference! Our annual event for families and educators will be held from March 5th - 7th at the Marriott Hotel in beautiful Santa Clara, CA. This year's theme is "Creating the Bridge Between Ability and Achievement", and our keynote speaker will be Dr. Ellen Schneiderman of California State University, Northridge. As always, we'll be offering a comprehensive Children's Program so that parents can attend conference events and workshops without worrying *too* much about the little ones. A site visit is planned in San Jose; registration fees vary depending on how many persons are attending and your membership status with Cal-Ed and/or IMPACT. Registration packets are in the mail now, and we will follow up with a complete conference extravaganza in the next edition of this newsletter. In the meantime, feel free to pick up the registration packet and other conference materials at [www.deafkids.org](http://www.deafkids.org).

# IMPACT BOARD

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E-mail addresses for board members can be found at:

**WWW.DEAFKIDS.ORG**

## *What is IMPACT?*

IMPACT is an organization of parents, teachers and professionals serving deaf and hard of hearing children. Our organization was established in 1986 with 12 parents and has a current membership of over 400. We are supported and encouraged by a host of organizations serving the deaf community. IMPACT's purpose is to meet the needs of the parents we serve.

## *IMPACT Mission Statement*

We as parents, members and professionals of the deaf and hard of hearing community are rising up as a single voice. Regardless of communication modalities, we stand united in the task of getting the very best for our children. We will take no less than quality education for our children, support and early intervention for our families, information and education for our parents.

## *Support IMPACT*

IMPACT needs your support to continue advocating on behalf of you and your deaf or hard of hearing child. We currently offer four levels of membership. For as little as \$30 a year, you can support our efforts and qualify for a registration discount at our annual Cal-Ed/IMPACT conference. All members of IMPACT also receive a copy of the IMPACT newsletter mailed directly to their homes.

If you would like to learn more about IMPACT or need this organization's assistance in any matter related to your child's education, please feel free to contact us at 1-877-322-7299 or visit [www.deafkids.org](http://www.deafkids.org).



## IMPACT BOARD SPEAKS OUT (CONT.)

population, the need for the current regulations might be reduced.

Accordingly, we submit the following specific comments regarding the proposed regulations:

1. The underlying premise of the regulations as they relate to excluding deaf and hard of hearing students with other “disabling” conditions requires significant additional work. We note the use of key “triggering” terms in the regulations which are vague, and while they give the State Schools great flexibility in who they admit, they will likely deny many students the right to access those Schools based on unjustifiably vague terminology.

2. Specifically we note the following in the proposed regulations:

A. “CSD cannot serve students with the following characteristics when accommodation of a student’s disability would constitute an undue burden and/or fundamentally alter the nature of the CSD’s program.”

The terms “undue burden and/or fundamentally alter” are vague and provide no direction as to what constitutes such a situation. How is an “undue burden” defined and proved? What constitutes a “fundamental alteration?” While the need for such regulations may be justified, they require significant clarification; otherwise CSD can virtually reject any student who may not fit the precise profile desired by CSD.

B. The proposed regulations then proceed to list 3 categories of students who would create such an “undue burden.” The most troubling is (b) which excludes “deaf students whose primary, ongoing educational needs are related to emotional, behavioral, physical and/or cognitive deficit.”

This sub-category does not provide detail or direction regarding what is meant by “primary.” How does one determine what is the primary need? And even if that is possible, how does one weigh one need against another? IDEA requires that all needs be provided for, not just the ‘primary’ need.

If a child is profoundly deaf and is in a wheelchair (“primary” needs are related to “physical deficit”), and except for her physical limitations can function effectively linguistically and academically at CSD, she can nonetheless be excluded based on this language.

C. Given the vagueness of the terms described above, the burden on the individual student to justify placement at CSD becomes insurmountable, a burden that should not rest with the student but instead with the LEAs and the State Schools. Such a burden is fundamentally unfair to these children and their parents seeking placement in a least restrictive environment.

D. In addition we question whether these regulations are consistent with the requirements under IDEA and Cal. Ed. Code Sec. 56000. Even if clear parameters and specific definitions are established, there may be no justification for the distinction between a child who is deaf and who may have other conditions or characteristics. Parents feel that their child will be discriminated against.

We urge the Department to:

1. Postpone implementation of these regulations, pending a more thorough debate and consideration of the issues discussed here today. Work together with the Deaf Multi-handicap workgroup now in progress at the Department trying to address the issues facing deaf and hard of hearing students with special needs. As mentioned, this is a complex issue and this workgroup has members from across the state and from a variety of placement options, including CSD.

2. Address the question, unanswered by the proposed regulations: how will deaf and hard of hearing students with disabilities, particularly those with severe disabilities, be served and how will their unique communication and language needs be provided for? We suggest that the Department to go back and review Deaf and Hard of Hearing Task Force Report from 1999. This is important work that had specific recommendations to regionalize programs for deaf and hard of hearing students in the state that is not yet completed. It called for the state special schools to expand their roles in collaboration with county offices in regionalized programs. We look to the State Schools to be taking a leadership role in this area.

3. Consider that if these regulations are promulgated and if the state does not implement the recommendations made by two different state task forces on the needs of deaf, multi-disabled children, both the state and CSD will face on-going conflict and the likelihood of more due process and even legal action.

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*The needs of deaf and hard of hearing children have been historically misunderstood. IMPACT is troubled that the very institution most able to take a leadership role in the education of all deaf and hard of hearing children is in a position of trying to exclude many of those same children. It is unfortunate that this debate is taking place at all. The State Schools have been and should continue to be a marvelous treasure to the state, to the LEAs, and to the many children they serve.*

*Nancy Eddy      John Allmann      Sandy Harvey  
President      Past President      Parent Advisor*

The following letter was written by Jon Levy, an IMPACT board member, in response to the proposed regulations:

*I have had the opportunity to read the proposed State Schools admission criteria and it disturbs me greatly. On one hand the California Dept. of Education (CDE) currently sponsors the Deaf multi-handicapped Workgroup which has been working for over a year on a written report much like the Task Force Project. This Project is chaired by CDE Deaf Consultant Nancy Sager and includes 4 members of the IMPACT Board, including myself. Although we have not completed the project and are looking at several draft reports, the workgroup conclusions are fairly solid. This CDE Project mirrors the Task Force Report in concluding that there must be a joint effort which includes districts, SELPAs,*

*and our State Schools for the Deaf with interagency cooperation in a regionalized effort to tackle the educational issues related to this important multi-handicapped population.*

*I was floored to learn that the same CDE office is also sponsoring the Proposed Rulemaking for Admission Criteria for the State Schools. This attempt to change the Education Code appears to be exclusionary and discriminatory to those Deaf multi-handicapped students and their parents who wish to explore all of their educational placement options. Although the bill rarely mentions multi-handicapped or special needs students, it is obvious that they are not welcome if they don't work well in groups, have a poor attention span, or don't have good expressive or receptive ASL skills. This is the definition of a multi-handicapped Deaf young person. In addition, this Rulemaking allows the State Schools to come out and visit a student and decide at that time if they "fit" in to their guidelines. The IEP team set by federal law should be the determining factor as to individual educational placement decisions. In my opinion, the Admission Criteria is a huge step backwards in the effort to get all state agencies to work cooperatively to serve the multi-handicapped Deaf students in our state.*

*Jon Levy, Principal D/HH  
Orange County Department of Education*

We hope to carry a response to these concerns in the next issue of the IMPACT newsletter.

## UNIQUE COMMUNICATION NEEDS: OUR BABIES AND THE IFSP

*By Sandy Harvey  
IMPACT Board Member, Parent Links Coordinator, Parent*

*"Communication is at the heart of everything human beings do; it defines and gives meaning to our emotions, beliefs, hopes, creativity, and life experiences. Without communication, a child is lost. The effective development, understanding, and expression of language are fundamental to any educational experience and are particularly crucial for deaf and hard-of-hearing children." - Report of the California Deaf and Hard of Hearing Task Force*

Information is power. To become informed about your child is to take the first step along the road of effective advocacy. As we begin our journey into the world of hearing loss, we are often not aware of our rights under state and federal law. Families with infants and toddlers fall under the mandates of Part C of the federal law known as the Individuals with Disabilities Education Act (IDEA).

Within 2 working days of the time your infant is identified (by an audiologist) as a deaf or hard-of-hearing child, your child's

*(continued on next page)*



*Sandy Harvey, left, with her son Daniel*



## UNIQUE COMMUNICATION NEEDS: OUR BABIES AND THE IFSP (CONT.)

information will be referred to the appropriate public local education agency (LEA) or regional center agency. Within 45 days of this referral, you should expect that a) an evaluation and an assessment will have been completed, and that b) an Individualized Family Services Plan (IFSP) will have been developed. The IFSP is a written record of services that the LEA or regional center must provide to meet a child's early intervention needs.

One of the challenges we face in California is lack of expertise from service providers and early interventionists. The system was not designed for deaf and hard of hearing babies, and services have not addressed the *unique* communication needs that our children bring to the system. For instance, you may be referred to a speech/language therapist whose background is in helping toddlers who have oral motor problems...but who may have never actually worked with a deaf child before. We cannot identify a baby's hearing loss at birth, only to neglect his/her need for *unique*, intensive language and communication services!

In 1994, the Joint Committee of the American Speech-Language-Hearing Association (ASHA) and the Council on Education of the Deaf recognized that "children who are deaf or hard-of-hearing and their families/caregivers constitute a unique group whose needs differ from those of other families". This uniqueness can be attributed, in large part, to the fact that our children lack full access to communication. This alone supports the need for specialized training for the professionals who work with our children. These professionals must be knowledgeable about the unique characteristics of infants and toddlers who are deaf or hard of hearing -- and the unique characteristics of their families, as well.

Your IFSP needs to look at the unique communication needs of your child. You will want to ensure that the service coordinator who is assigned to your child has an understanding of deaf or hard of hearing issues. Also, history has taught us that infants who are deaf or hard of hearing and who also have additional special needs are harmed when there is no attention to their communication and language development. You may want to include on the IFSP the need for unbiased information on communication choices, too. The federal law (Part C of IDEA) says, "The IFSP must include the name of the service coordinator from the profession most immediately relevant to the child's or family's needs, who will be responsible for the implementation of the IFSP and coordination with other agencies and persons."-Sec. 303.344(g) (1).

In California, *Programs for Deaf and Hard of Hearing Students: Guidelines for Quality Standards*, Standard #7 states "The assessment of infants and toddlers suspected of having a hearing loss is conducted by qualified personnel knowledgeable about deafness. The assessment includes evaluation of cognitive development, physical and motor development, communication development, social/emotional development, and adaptive development." As a parent, it is reasonable to advocate for a professional to work with your child (and your family) who has the experience, certification and educational background to meet your infant's unique communication needs. Parent involvement and advocacy is very important. You are not responsible, however, for carrying out the IFSP outcomes/objectives. That is the responsibility of the Early Intervention system.

Parents must lead the way when it comes to ensuring that the people in your child's world have the expertise to address his or her *unique* language/communication needs. Since the establishment of the newborn hearing screening program, there has been an influx of infants and toddlers with hearing loss into our early intervention system. In some areas of California the system is overwhelmed. As parents, and as partners in the Early Intervention system, we must advocate that our children's unique language/

*(continued on back page)*

*The feeling of being connected or linked may be one of life's sweetest moments – when someone understands you, really understands you, because they have "been there"*

*If you would like to be a volunteer Link (resource, friend, seasoned parent) for a family just finding out that their baby is deaf or hard of hearing, please fill out the attached form and return it to :*

**PARENTLINKS**  
**4708 Roseville Rd. Suite 112**  
**North Highlands, CA 95660**

*Additional information about Key Parent Links will be sent to you.*

*Name:*

*Address:*

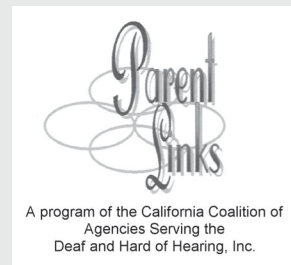
*Phone:*

*E-Mail:*

*Age of your deaf/hard of hearing child:*

*School/Program your child attends:*

*Program funded by The California Endowment*



# A MOTHER REFLECTS ON THE EARLY YEARS

by Denise Spaeth

IMPACT Board Member, Mother

My name is Denise Spaeth. I am, first and foremost, Jayne and Cody's Mom. Jayne is my 12-year-old deaf daughter, and Cody is my 8-year-old hearing daughter. When I was young, I never thought about who I was in connection to someone else. Life has taught me that it is not just my relational connection that makes me a mother, but my relational commitment. I feel very certain that if both my daughters had been hearing, I would have missed out on a substantial part of this journey called motherhood.

Because Jayne was born deaf, she required a different approach to parenting. It's as simple as that. So, with a few years under my belt, I'd like to share with you some of the things I did in the early years that have paid off big time. Jayne's only "difference" is her deafness; she does not have additional handicaps or learning disabilities to further complicate our struggle. For this, I am very grateful, and I hope you will be mindful of this fact as you relate my experiences to your journey.

First, I had Jayne hooked up with an infant preschool program by the time she was 18 months old, and we had three family members attending school with her on a daily basis. Why, you may ask? To help us know intimately what was being taught, and to take that and use it ourselves in our own time with Jayne. The preschool teachers and aides were our daily sign dictionaries and models. I piggybacked on their teaching. If the color that month was green, I pointed out every green thing we ran across or drove by in the car. I adapted a mini "calendar time" idea. I would point to the right box on the calendar and sing (yes, sing!) and sign, "Tuesday is preschool, lunchtime, and nap. Then you will play and I'll pick you up." When the teacher asked what today was, it wasn't long before Jayne would sign the first sign in my song. It was that simple to give her a leg up in class.

To improve my signing skills, I made small agreements with myself. I would pick one word to teach Jayne. One time, I picked "hole". We went on a walk to the park and I pointed out all the holes along the way. Just one week later, she showed me a hole of her own. How awesome that was! I can still recall the thrill. That was my word — my teaching and mine alone. I decided to ask one new question a day. "Do you want the blue shirt or the white shirt?" When she reached for her choice, I modeled her answer: "You like the blue shirt." I took sign classes, community classes, classes offered by the school, community college classes -- whatever fit our family schedule. But I always made sign class a priority. Over the years, I've had to take occasional breaks from class, which is okay -- but I'm still not where I'd like to be as a signer, so I continue taking sign classes!

I made a pact with myself never to back out of the driveway or parking stall without first telling Jayne where we were going. I read the sign dictionary, one letter at a time, one letter each night. In the early years, it was the SEE sign dictionary. Now, I will look up signs in three different dictionaries. (My two favorite dictionaries these days are the Random House/Webster's American Sign Language Dictionary and the Picture Plus Dictionary; but I still consult my dog-eared, yellow SEE sign Dictionary. I highly recommend the Picture Plus Dictionary to all parents with young children). My willingness to do that engendered in me what I hope will be a lifelong love of sign language and how it relates to English.

If I hadn't had to wait with visually baited breath for Jayne to use each new sign, I would have soon taken for granted the human ability to manipulate and acquire language. If I hadn't specifically targeted new words/signs I wanted to see Jayne learn during the preschool years, I would have discounted my importance to Jayne's education. If I had not challenged myself to learn more sign language and gain comfort in using it, I would have never witnessed the impact that discussing daily happenings and upcoming events with my daughter, in front of a calendar, would have on her life. This simple activity gave her a structure upon which she could hang everything that was happening in her life, and because of it, she was able to experience a measure of personal, emotional and physical control over her world. So, for my daughter's deafness, I will forever be grateful.

*This is the first in a two part offering; in our next newsletter look for "A Mother Goes to Middle School".*

## BABIES (CONTINUED FROM PAGE 6)

communication needs be treated as critical to their development. Communication is the key to our children's future!



*The Parent Links program is generously funded by The California Endowment. The program provides links to services, programs, information and parent-to-parent support for families with infants and toddlers, birth to age three throughout the state. For further information, call toll free at (877) 322-7299 and press option 4#.*

### What to look for in an Early Intervention program

- Experience in serving deaf or hard of hearing children
- Methods of assessment specially designed for deaf or hard of hearing children
- Respect of family choice in communication methods/language
- Qualified/certified staff
- Specific curriculum for deaf or hard of hearing children
- All direct staff uses language/communication methods of child
- Service coordinator knowledgeable in deafness/hearing loss
- Family training in chosen language/communication method
- Ability to provide needed assistive listening devices
- Ability to offer group support for parents
- Communication accessibility for deaf/hard of hearing parents
- Opportunity for parent interaction with deaf or hard of hearing adults
- Knowledge of local, state and national resources
- Lending library with information about deafness/hearing loss

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