

Dr. Jan van Dijk

Introduction by Maurice Belote

Education Specialist, California Deaf-Blind Services

Professor Dr. Jan van Dijk, of the Sint-Michielsgestel Institute in The Netherlands, is one of the world's leading experts in the education and development of children who are deaf-blind. Dr. van Dijk's research has focused on many areas, including language and communication, attachment theory, stereotypical behavior, atypical development of hearing and vision, Congenital Rubella Syndrome, and rare genetic disorders. In the mid-1960's, Dr. van Dijk developed the theoretical base for the pre-language movement based program, which included the practice of co-active movement as one component of the program. His curricular approach focused on the functional learning environment-an integrated approach utilizing natural environments, contexts, and activities throughout the child's daily program.

While his theories and teachings have evolved over the past thirty years, his approach to language development and communication systems continues to serve as the foundation of educational programs for most children with deaf-blindness in the United States. Many of the techniques and strategies, such as reference and experience books, object communication, calendar boxes and tangible symbol systems are based on the early work of Dr. van Dijk and his associates. Dr. van Dijk, after three decades of scientific and practical work, has arrived at a personal conclusion, stated here in his own words: "The multi-sensory impaired person is a unique human being with a unique line of development which is more dependent on the professional's willingness to accept this and act accordingly than any other group of disabled persons." The April 1995 conference featuring Dr. van Dijk was conducted jointly by California Deaf-Blind Services and Project NEEDS. Project NEEDS was created as one of six California Regionalization Pilot Projects, and is operated by the San Diego City School District. The conference marked Dr. van Dijk's first speaking engagement in California, and was attended by over 300 family members and educators throughout North America.

The following statements are excerpts from professionals who attended the conference:

Marilyn Stack, Educational Specialist
Deaf-Blind, Anchorage, Alaska

Having worked in the special education field of deaf-blindness for eight years with children from birth to 21 years in the State of Alaska, I was familiar with the work and writings of Dr. van Dijk. He has an excellent teaching/ presentation style and is a very endearing man.

Dr. van Dijk covered many different points but I would like to discuss two: (1) attachment theory; and (2) sensory deprivation in an individual as it relates to exemplary teaching qualities and assessment of an individual with deaf-blindness.

He feels that developing a close attachment early in life with a “significant other” is extremely important. It is the basis for communication and the development of a rapport between the child and the “significant other”. In most cases this “significant other” is a child’s mother but could be a teacher, father or caregiver. I heard Dr. van Dijk saying that it is important for teachers to develop a close attachment to their deaf-blind students because it will open the doors to communication. I strongly agree.

Dr. van Dijk discussed the early maternal bonding theory. This is critical throughout life because if the child feels secure they will explore the world and establish secure emotional bonds with others. The children who do not develop this bonding have trouble throughout life with attachments (trust) and exploration of the world. Their mental health is compromised.

It is most important that a deaf-blind child develop a positive sense of attachment. With a deaf-blind child this attachment occurs through the skin and touch. Sensory deprivation can complicate this process. Basic needs involving touch such as holding, moving, touching and bathing were given as examples of how this attachment occurs. Communication follows once the child’s basic needs are met. Dr. van Dijk believes in the person before the disability.

A good teacher who has “it” will be able to develop an attachment with the deaf-blind child and play a central role in that child’s life. The good teacher who has “it” will:

- * continually assess the student
- * determine the student’s best learning mode
- * work as a team member using specialists for their ideas but allowing the student to do for self
- * be a “lazy teacher” (do not do for the student, avoid learned helplessness)
- * sense the child’s rhythm
- * build the child’s curiosity
- * provide choices
- * present things which are age appropriate but not above the student’s functioning level
- * teach at the most opportune times.

Van Dijk’s major points on assessment of learning style were that you must let the child show you how they learn best. Much of this can be done through some simple observation. His other suggestion in assessment of learning style was to simply ask the mother!

Mary Maussang, Special Education Teacher
Kroc Middle School, San Diego, California

Dr. van Dijk was articulate and enjoyable to hear. Although a lot of the material was familiar to me, it was refreshing to have it brought together and reviewed.

Having “it” was emphasized. I have seen teachers who make little progress with students because they are not in tune with what is really happening. They often look at what the student is doing wrong instead of looking at what they could be doing differently. The teacher needs to assess where the child’s starting point is, start there and then continue taking cues from the child. Routines must be established with realistic objectives and goals. We, as teachers, must also remember to stay back and let the student do as much as possible on his own. We need to look for each student’s best learning avenue. After a bond and trust are developed the student will be ready to explore. Once routines are established the student learns to anticipate and will begin to do things on his own. A team approach is very important when assessing and working with students with special needs. Professionals and parents must work together. How professionals and parents interpret what the child is trying to say is critical and we must react appropriately remembering that all behavior is meaningful. We need to be responsive yet demanding. It becomes a very frustrating situation for parent, child and teacher when true communication is not established.

Jane Montgomery, Special Education Preschool Teacher
San Bernardino County Superintendent of Schools

Dr. van Dijk discussed the importance of being aware of where the child’s vision and hearing problems are located (in the eye, in the brain, inner ear, etc.). This will help decide how to assess and what measures to use for assessment. It is very important to find the best environment for these children both for assessment and placement. The multi-disciplinary team should take into consideration all these things to make the best placement.

Dr. van Dijk also talked of “learned helplessness” Some teachers and parents give so much help that the child finally concludes “I cannot do it.” It is very important to give the deaf-blind child the opportunity to make decisions. Dr. van Dijk called this approach “hands-on, hands-off.”

One of the most important things Dr. van Dijk talked about was making memory books or boxes for the deaf-blind child. This helps to improve their memories of events that have taken place in their lives. It helps to organize their world. The Doctor noted that deaf people organize their visual world in sequential order; therefore a memory book or box should be put together in a somewhat sequential order. Another idea of Dr. van Dijk’s was to not be too structured in working with the deaf-blind. Be open to change. Have a wild card ready in the event that what you are doing isn’t working. Don’t be stuck and not able to change your plans if those plans are not working that day.

Dr. van Dijk gave us a list of some of his assessment tools; i.e.: sing, talk, sign, move and breath with the child. He suggested blowing your breath on the child’s body and find out when

the response is positive. (Try not to startle the child.) Interpret the child's behavior and be responsive to it. Most important in communication with a deaf-blind child is that you want them to experience success!!

Antoinette (Toni) Anderson
Itinerant Teacher Visually Impaired San Bernardino
County Superintendent of Schools

Individuals who are deaf-blind are born into a world in which they do not have the senses to properly interpret and relate. It is essential, then, that they are surrounded by a team of well-informed caregivers who can properly understand their attempts to communicate and help them feel successful when they try to interact with their surroundings and the people in it.

There are 80 syndromes that cause deaf-blindness. Often not only do these syndromes cause visual and auditory deficits but they also are frequently compounded by physical and mental impairments as well. However it is vital that those who evaluate the mental levels of deaf-blind children keep an open mind and realize that the severe sensory deprivation that these children face must be counteracted with sensory-motor experiences before any final conclusions are drawn. This is a process that could take many years. It is particularly important that parents get help in the first three years of a child's life so that an emotional bond can be established. Without this bond it is difficult to motivate the child to reach out and interact with the physical and social world around him.

Connie Johnson, Butte County
"Early Start" Infant Toddler Home Teacher

I found the van Dijk Conference affirming, thought provoking and energizing. Dr. van Dijk's emphasis on establishing a relationship with the student first felt "right" both professionally and emotionally. Taking the time to build trust is such a crucial element when interacting with any human being, especially children with sensory impairments. Dr. van Dijk took the time to watch, observe, examine and let them be themselves, to reach out and to search. He started his children on their road to independence (even though they had handicaps that ordinarily would make them very dependent) and allowed them to move out into the world giving them the tools they needed to interact successfully with their environment.

Reflecting on this, wasn't van Dijk just treating his students the way we ourselves would like to be treated? Wouldn't we all like to have someone walking with us as a partner, as we discover new things about the world and our place in it, sharing new insights? Someone to be there to support and encourage, not do for us, when we hit the rocky places in life? Wouldn't we all like someone to share the joy of our discoveries? I believe that we need to take more time to find out who each student is as an individual. Dr. van Dijk challenged me to look at students who are considered "behavior problems" and "tactually defensive" from another perspective. Perhaps we need to enable these students to interact more positively with others and their environment by establishing a trusting relationship with them; and then giving them the tools and techniques to reach out more independently.

I was fascinated by van Dijk's use of "conducted learning." In this approach, one adult (or conductor) interacts with the child consistently. Professional input about the child and ideas for appropriate activities and materials all go through the "conductor" who has primary responsibility for the child. This allows all of the child's "therapies" to be integrated into a whole approach. Instead of a segmented schedule of seemingly unconnected events, elements of the program are combined into a cohesive whole. As the child moves through the day, physical, communication, vision, hearing and academic goals are worked on concurrently.

What I took away from van Dijk was that at the core of any partnership is a good relationship. It is that bond that allows both parties to grow and learn.

The Latest Research Findings

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Dear Readers of reSources,

During the last year, I was invited to come to your country several times to give talks on the assessment and education of persons with multi-sensory impairments. I was always so thrilled with the enthusiasm of my audience. I returned home from the workshops, which I conducted in Utah for the Utah Project for Children with Dual Sensory Impairments and for Project Needs in San Diego, with more than 100 questions I was unable to answer during the workshops.

When the editor of this magazine requested that I write a short article on the new developments in the field of multi-sensory impairments, I thought it would be a good idea to relate some of the questions I received with some of the intervention experiments I have carried out with my students. In this way, I hope to kill two birds with one stone as you say it. I have requested that Cathy Nelson from the Utah Project for Children with Dual Sensory Impairments in Salt Lake City, coauthor this article with me in order to tailor the information to the American reader. If you want further information, please feel free to write me.

There is a growing awareness that the quality of life of persons with severe or profound disabilities can be improved by teaching skills which allow for participation in activities with a minimum of staff supervision and/or interference (Lancioni et. al, 1995). At the same time there is a trend to provide stimulation to a child with physical and/or sensory impairments as early as possible to take advantage of the plasticity of the central nervous system (Trevorphen 1993). As these two trends have come to the forefront the need for parents and other professionals to learn

and receive technical assistance on intervention programs and strategies which have been proven to be effective has also become apparent. People involved with a child who is deaf-blind or has severe or profound disabilities are often eager to grasp at every new idea they come across. While it is important to be willing to accept change and innovation it must also be recognized that often strategies are advocated which lack an empirical underpinning.

As part of the masters program in Special Education at Catholic University Nijmegen (The Netherlands) students carry out an intervention study using the scientific method of single subject design (Barlow & Hersen, 1984) under the supervision of the first author (J. van Dijk). In the last two years a number of studies have been completed which might be of interest to those involved in the lives of children and adults with sensory impairments. Two studies were carried out to evaluate the effect of Lilli Nielsen's Little Room (LR) on exploratory behavior (Bedhaf, 1994) and on vocalization (Peters, 1995) of young children with profound visual disabilities. Two students (Bastings and van Gool, 1994) replicated the research carried out by Leguire, Fellows, Bier, Bremer and Fillman (1992) in stimulating the use of residual vision in children with cortical visual impairment. Zijlstra (1995) measured the effect of a self-monitoring and supervision program in relation to attention to a simulated traffic situation. The subjects of this study were persons with Usher Syndrome, Type I with cochlear implants.

The Little Room

The idea of the Little Room or LR was conceived and developed by the Danish psychologist Lilli Nielsen. It is a small playhouse designed to give the child with visual impairments an opportunity to learn about space and reach for objects in order to stimulate sensory integration and object permanence. The LR has the shape of a cubicle (cubiform) with one open side. The other three sides are covered with different textures which give the child different kinds of tactual information. The ceiling is made of Plexiglas, from which tactile, visual, and auditorially attractive objects are suspended.

Chantal van Bedaf (1994) used an alternating condition design (Kratochwill, 1978) to measure the quality and quantity of exploratory behavior of subjects in a LR and in an alternate "frame" condition. The frame, or LR control, was only the metal frame of the LR from which the objects were suspended. The three side walls and ceiling were not used in this condition. The subjects were 4.2, 4.4 and 5.5 years of age. All had severe mental, physical and visual impairments. During the baseline period of four weeks, each child was placed 16 times for 20 minutes in the open frame. The intervention period was eight weeks. Three times a week the subjects were placed in the LR and once a week in the open frame. All sessions were videotaped. At random, the tapes were scored (event scoring) by two observers. Intervention agreement ranged from 61 to 69%. The results of the experiment confirmed Nielsen's claim that the LR does enhance exploratory behavior.

Ingrid Peters (1995) used the same research design to test the hypothesis that manipulating objects in a Little Room (LR) encourages the child to produce vocalizations and babbling sounds. According to the hypothesis the LR condition (e.g. echo) facilitates the comparison of the sounds produced by the objects with the child's own voice. Speech is enhanced as

vocalizations become more differentiated (Nielsen, 1994). Peters again used the control “frame”. The three subjects were 4.2, 4.4, and 5.5 years of age with severe visual, cognitive, and physical disabilities. The baseline condition “frame” was measured 16 times during four weeks. The intervention period was eight weeks with the child in the LR a total of 24 times for 20 minutes each and in the frame eight times. All sessions were videotaped and scored by two independent observers using a specially designed computer program. Results showed that the vocalizations of two subjects did not differ in the frame or LR conditions. One subject produced fewer vocalizations in the LR than in the open frame. The variety of sounds were not different in two subjects when the experimental conditions were compared. One subject clearly produced more complex sounds in the LR. This experiment failed to support Nielsen’s assumption that the LR condition facilitates vocalizations and differentiated use of voice. There are several possible reasons for the negative outcome of this experiment. The intervention time may have been too short, or the children’s physical conditions may have prevented a referred use of their voices. From an acoustical point of view, the LR may need to be better prepared to obtain the results Nielsen mentions. As an intervention strategy for children with multiple disabilities, the LR appears to be useful for stimulating active manipulation without the intervention of an adult. This is a significant outcome when one considers the learned helplessness so often exhibited by this group of children. Our small scale experiments did demonstrate that children with multiple disabilities do need a prolonged period of exposure in the LR before the activities learned can be generalized to other settings.

Visual Stimulation

In 1992, Leguire et. al. published a paper demonstrating the afferent (nerve pathway bringing vision from the eye to the brain) visual system of young children with visual training. Leguire and his colleagues from Columbus Children’s Hospital collected data on 25 children with severe neurological and visual impairments (mean age 72 months). Fourteen subjects with similar conditions were used as a control group with another 50 non-disabled children also used as controls. The stimuli material were 222 specially designed slides on which simple black and white patterns were represented. These slides were presented twice a day to the child, five days a week for a full year. Visual Evoked Responses (VER) measurements were taken at regular intervals. Bayley scales were used to follow the mental development of the subjects. During the experimental period it became apparent that the VER’s of the children in the experimental group improved in contrast with the control group of children with disabilities. It also was shown that motor skills of the experimental group did not level off as was the case in the non-experimental group. This study is rather interesting because with solid physiological and psychological instruments. The effect of a stimulation program was clearly demonstrated. An advantage of this program is that no adult intervention is necessary apart from switching on the projector.

This program was replicated and expanded by two doctorate candidates, Ilona van Gool and Marielle Bastings, using the technique of multiple baseline across subjects. They used seven subjects who had severe visual impairments of neurological origin (CVI) who had a mean age of 1.4 years. Three of seven subjects were randomly assigned to a group which received the stimulation program. The control group received a broad nonspecific stimulation program which is normally carried out by Clinical Services for Visually Impaired Children. In order to

test the effects of the program on visual acuity, the Teller Acuity Cards (TAC) procedure was administered by an optician who was not informed of the subjects' group assignments. Visual behavior was recorded by direct observation and mental development was measured by the Bayley Developmental Scales. The administrator of these instruments also did not know of the group assignments. The total length of the intervention program was 18 weeks.

At the end of the program, one subject in the experimental group demonstrated a gain in visual acuity from 3.36 cyc/deg to 6.5 cyc/deg. Another subject showed a rather spectacular gain in visual acuity but improvement had already begun during the baseline period (0.22 and 1.22 cyc/deg to 6.50 cyc/deg at the end of the program). In the two other subjects no response could be recorded by using TAC. The same can be reported by 2 children from the non-experimental group. One subject in this group did respond, but no improvement could be observed. It is interesting to note that there was a clear improvement in the mental development of the experimental children (0.3 years) while the non-experimental group gained 0.1 year. The observation of visual behavior revealed that three subjects of the experimental group improved considerably in the area of visual attention. Parents reported better eye contact in one child from the experimental group and better attention to books and TV in another child. One parent was disappointed when the experiment concluded because while their child was watching the slides they felt free for one half hour.

The conclusion drawn from this experiment is that for some children with Cortical Visual Impairment and severe disabilities the introduction program as developed by Leguire et. al. should be considered. The results appear to be promising and both children and parents enjoyed it. One of the authors (J. van Dijk) uses the Columbus Slides as an assessment technique in his Center. By projecting the slides and making observations of the child the type of visual pattern (black-white stripes, chessboard patterns, geometric forms, line drawings or human faces) which interests the child most can be detected. This information can be very useful in designing an intervention program. Simulated Traffic Situation and Usher Syndrome Another interesting experiment was carried out by Rita Zijlstra (1995). From the experiences of our Orientation and Mobility (O&M) instructors we learned that clients with Usher Syndrome, Type 1 who had received a Cochlear Implant (CI) were unable to assimilate the newly regained auditory information into their mobility skills. They became anxious when they perceived noises because they were unable to identify them. A program was devised to train these persons to discriminate sounds which are important to travel (e.g., cars, motorbikes, police cars sirens, and drilling) and those which can be safely ignored (e.g., airplane noise, church bells and barking of dogs. Three subjects were selected with a mean age of 28 years. Two persons were implanted with Nucleus 22 and one with a one electrode system (3M Vienna). Two of the participants had been wearing the CI for more than three years, while one subject had only one year of experience with his CI. A course was set in a park close to a main road and a service road. This situation provided natural background noises. Five loud speakers were placed on the course itself. These were connected with two cassette recorders which played two different noises in random order.

A multiple probe, multiple intervention design across subjects was chosen in order to detect the functional relationship between training and the correct changes in mobility behavior. Recording was done by two observers. Baseline measurements took four, five and seven weeks;

the training 13 weeks. The subjects were asked to record what sounds they had discriminated and whether they had initiated search behavior (self-monitoring procedure). The results revealed that two subjects improved considerably in their ability to discriminate sounds in traffic. One subject's behavior did not improve. Positive training results were maintained during follow-up. Discussion: It is, of course, impossible to generalize these results to other persons with Usher Syndrome, Type 1. Clinical observation taught us that, after training, two clients were much more relaxed and confident. It can be assumed that this has a positive effect of O&M skills in natural traffic situations. Because of the positive feedback we received from the subjects we have decided to preserve the training course and include it in an O&M program for blind as well as deaf-blind clients.

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What's a Calendar Box?

Pam Schachter, Educational Specialist
California Deaf-Blind Services

As I listened to Dr. Van Dijk's presentation and watched the accompanying videos I noted the frequent use of "calendar boxes" by his students who are deaf-blind. Listening to chitchat during the breaks, I heard many participants in the conference express interest in the use of calendar boxes as a communication tool. Calendar boxes help a person who is deaf-blind anticipate what activity is going to happen next by sequentially organizing object cues that represent the day's activities. Calendar boxes can be used at home and school, by families and teachers. Communicating with a child who is deaf-blind may seem highly technical and complex. The purpose of this article is to show you how easily you can get start. Gather together the objects that the child is using for communication. If you are just getting started with object communication it is important to select object cues very carefully. The object should be an item that will be as easy as possible for the child to associate with the activity, by sight, sound or touch. Consider how it feels, looks and sounds to do the activity from the child's perspective, not yours. Put on a blindfold and hold the object. What does it tell you?

If you need a cue to tell a child that she will be placed in her wheelchair, look at her when she is in her chair and observe where her hands typically rest. Does her face generally touch

something? A piece of fabric or metal that feels the same will likely be a meaningful cue for the student. A dollhouse wheelchair, while a very concrete symbol for us, will not look or feel at all like her wheelchair to the student.

Some activities are not practical to represent with the most significant feature; for instance, using water to represent bath time. You may need to add an object to the routine to help you choose an object cue. Consider using a favorite bath toy or adding scented soap that the child can use during each bath. Keep in mind that your object cues may be lost, thrown in the trash or otherwise destroyed. Make sure you choose something you can easily replace! Try to choose objects that are small enough for a child to hold in one hand, but not so small that they are easily lost or swallowed.

When a child is using more than one object cue, calendar boxes will help to organize and sequence the day's activities. Even just 2 different objects can be organized to help the child know what is going to happen next. Dr. Van Dijk's students had wooden boxes with many compartments mounted to the wall. This style of box may work for some students but is not practical for all situations.

Plastic containers or shoeboxes that are glued in place or tied together will work just as well. Any containers that you have in the classroom or at home can be used. Consider the physical abilities and needs of your child when choosing materials. A child who uses materials forcefully might do well with sturdy plastic containers, while a child with limited range of motion may be able to grasp an object out of a very shallow container. Consider the color of the containers and choose a color to contrast with the object cues for students with some usable vision. Choose another container for a "finished box". This is where the child will place an object when the activity it represents is completed.

In a classroom the calendar boxes may be placed near the entrance to the classroom or in the area where the day's schedule is posted. Place the student's calendar box in a location where he can most readily use it. At home, families will need to determine a central location that is convenient and accessible to the child. In my house there is a shelf in the kitchen where phone messages, milk money and homework are kept. It is the place that everyone checks as they come and go from the house. Identifying that kind of place in a student's home may tell you where to place her calendar boxes. Infants and young children may need their calendar boxes on the floor or a low shelf where they can easily reach them.

There is no magical moment when you and your child are ready to begin. As soon as you have gathered the materials, leap right in. Guide the child to the boxes and assist him to reach in, touch, look at and examine the object. Mouthing it is fine, too, if this is not a behavior you are trying to stop. Give the child enough time to thoroughly examine the object. Tell him, with a few words or signs or both, what is about to happen. Take the object with you to the place or activity it represents. When the activity is completed, return to the calendar boxes and help the child place the object in the "finished box." Say or sign "finished" or "all done." Completing the cycle of getting out an object and then putting it in the "finished box" is really critical. Many children with deaf-blindness have no concept of the beginning or end of objects or activities.

With limited sight and hearing, everything just appears, almost magically, and disappears the same way. Consistent use of calendar boxes assists children to anticipate what is going to happen next and to understand that events have a start and a finish. These are important concepts to develop; they provide the child with a wonderful sense of control over his environment. Of course, these techniques will not always work so easily in your home or classroom as I have described above. Your child may throw the objects, tear them or scream when you help him to reach into the box. You may need to choose more indestructible objects, or move more slowly in asking the child to hold or reach. You may need to choose objects that are not overstimulating to children with tactile defensiveness. Don't give up because it seems that you are doing all the work and the child is passively receiving your input. It may take many months or even years of consistently telling the child what is about to happen before you see a noticeable response. Think of it as "listening" time taking in what you are "saying." All children deserve to be told what is happening to them in a way that they can understand, even if they don't tell us anything back. Add more objects and boxes when the need arises and you feel that the child can handle more demands and input. It is better to have only a few objects that are used consistently than many that have no real meaning for the child.

You will know that the objects are gaining meaning by closely watching the child's behavior. A smile when feeling the object, a relaxing of muscle tone, a purposeful reach toward the box, a look toward the place or activity to be done, approaching the boxes and searching for the object- these are just a few of the possible behaviors that will tell you that a connection is being made.

Object communication and calendar boxes can be powerful communication tools for a child with deaf-blindness. They may also be a new and confusing method of communication for a teacher, parent or therapist. Don't hesitate to call California Deaf-Blind Services to request assistance to develop a communication system that is uniquely suited to your child.

Some Gems of Wisdom

Bil Aulenbach, Family Specialist
California Deaf-Blind Services

About the same time that Dr. Jan van Dijk was starting his career as a medical doctor in the Netherlands working with children who were deaf and blind, my wife was giving birth to our second child (Heidi) at Memorial Hospital on the island of Maui. Immediately we knew that Heidi had problems but did not understand to what extent or how to deal with them. In retrospect I wish Dr. van Dijk had been there. We would have done things differently.

Thirty years later, as I was sitting in a room listening to the good doctor sharing his wisdom, I could not help but reflect on some of the little gems of wisdom he would share with the 300 attendees. As a parent who was constantly grasping for answers in raising a daughter who is deaf-blind (with other issues) I heard him say some things that really hit home. Let me share some of them.

The first gem: "You, as parents, are ultimately responsible for your child who is deaf-blind." There is no question about it - our children with special needs are a handful. Secretly most of

us wish that we could take a magic pill and everything would be fine. But we know that is not going to happen. As parents we must take full responsibility for our child. We need to oversee what happens on a daily basis and plan for their future. No one else can do it. Along the way we shall probably meet a few professionals who seem to know what they are doing; but don't count on finding many who really understand a child with dual sensory impairments. My wife and I received some terrible advice from doctors who did not understand our kind of child. Early in the game we learned to "interview" doctors concerning their experience in working with a Heidi. We rejected many primarily because they were not willing to learn along with us.

A pearl: Mom! Dad! You must advocate for your child in a positive, creative fashion. Use the ideas of professionals to help the two of you formulate your action plan but don't delegate, or abdicate, your responsibility to anyone else.

Next gem: Dr. van Dijk directly and indirectly stressed the importance of obtaining the best for our children with dual sensory impairments. So many times society is willing to give our children only second (or lower) best. Most of the world has no idea how a child who is deaf-blind functions but is willing to make decisions based on that knowledge. We can't settle for second best. Our children have enough issues. Consequently, at times we need to be confrontational, demanding, assertive in expecting the best. For many, this is uncomfortable behavior but we parents must learn how to do it. Sometimes the best means that we have to move to a better school, city, state because what is around us isn't very good. We moved two times to obtain the best education for our Heidi. Once from Maui to Oahu and the second time from Hawaii to Santa Ana, California. Those moves paid big dividends.

A pearl: We must use the law (which we did not have 30 years ago) that says our children will have the best. Settle for nothing less.

Final gem: "Parents have a tremendous challenge." I suspect none of us need to be reminded about this. But notice that Dr. van Dijk said "challenge" not burden, handicap or any of those other negative words. Our Heidi was a challenge - lots of them. We had no idea what the future had in store for her or us. We did have a general idea what the future held for her younger and older sister. But Heidi was different! Instead of crawling she scooted on her back staring at bright lights. She made high pitched noises that would often start our basset howling. She loved to "play" in the middle of the night; especially during the full moon. She would "rock" on her bed for hours. Coming into puberty she started having grand mal seizures. On and on. In retrospect I must admit that as time went on either the challenges became less traumatic or we became better at meeting them. Whatever it was, thirty years later my wife and I can look back and say Heidi was a tremendous challenge but by working together with a multitude of professionals we did a heck of a job.

A pearl: Our children who are deaf-blind are a challenge, but there is an array of professionals, agencies, and support groups who can assist us as we encounter each new challenge. Use them. Dr. van Dijk dropped many more gems of wisdom but I selected these because they were so important to us as we raised our daughter with multiple handicaps. We hope that maybe they will give other parents encouragement to keep moving forward.