

## Programmatic Considerations Taken into Account when Developing Educational Programs for Persons with Congenital Rubella Syndrome

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After 51 years of work in the field of disability services I have made several findings that have enlightened me and guided me in my work. These findings did not come from my own wisdom; they emerged as I began to understand the real problems and not just the symptoms of the problems.

I have begun to realize that it is the system that is disabled, not the person. Somehow that was intuited 39 years ago when I received my first referral of a person with Congenital Rubella Syndrome. My teacher was Dr. Natalie Barraga at the University of Texas at Austin where I was working on my doctoral degree. I was working as the psychologist for the Austin Cerebral Palsy Center. A local military installation referred a child with Congenital Rubella Syndrome, deafness, blindness, and delayed cognitive development. I asked Dr. Barraga what I was to do with this referral. She looked over the top rim of her glasses (which was a clear sign that a student was in trouble) and said, "Well, you are going to teach him." Just like all of you at this symposium I was suddenly in the business of providing services to persons who are deaf-blind as a result of Congenital Rubella Syndrome. Luckily I could combine my training in vision with Dr. Barraga with my training in Child Development with Dr. Phyllis Richards and my training in Health Impairment with Dr. William G. Wolfe. Three years later the Callier Center for Communication Disorders sent Dr. Doin Hicks to Austin to interview me about a new grant Callier had received to develop educational programs in 5 states for persons who were deaf-blind.

One of my first actions at Callier was to conduct a survey of persons working for agencies that could be providing services to persons who were deaf-blind. The survey results indicated that local staffs were very willing to work with the person who was deaf-blind, but it was not the policy of the agency to do so. When I followed up with the supervisors and commissioners of these agencies, they said that the budget did not allow them to serve persons who were deaf-blind. This finding led me to my first insight:

- The budget drove the service delivery system, not the needs of the client

It seemed easy to say, "We don't have the budget" to do something rather than admit that they did not intend to do something. This cycle of the budget driving services proved hard to break and it is still with us.

We have the knowledge to teach the person who is deaf-blind. We have individuals who are willing to teach and provide services to persons who are deaf-blind. But there is a cycle of budget-driven denial by agencies of expanding services that leads to continuing what is rather than consider what could be. The program at Callier was really about system change, not pioneering educational services. The system was the barrier to educating persons who are deaf-blind at the local level.

It was then that a second finding came into focus:

- If you can teach a person who is deaf-blind then you can teach any person regardless of their disabilities.

If a person who was deaf-blind were allowed the opportunity to be in educational programs, then there really was not anyone who could not benefit from education. These were powerful thoughts in the 1960s. These were days before the Pennsylvania Association for Retarded Citizens (PARC) v. Lancaster case that determined that if you live in a school district you have a right to education in that school district. This was before the Penhurst case in Alabama that said that if you have a person with disabilities in your services, that person has a right to treatment. This was 6 years before federal law 94-142 (the precursor to I.D.E.A. in the United States) was passed. At that time, Texas had recognized 4 students who were deaf-blind. Two attended the New York Institute for the Blind in Queens and two of the students attended the Helen Keller School in Talladega, Alabama. All 4 students had some form of Usher.

I was impressed with the children who were deaf-blind as the result of CRS. They had such amazing patience teaching the staff and me how to educate them. Remember I had been working with children who had cerebral palsy. The children with CRS were so much more motor-driven than my previous clients. The students with CRS had unbelievable motivation to seek light sources, to exert their total energy to get sensory input, and to repeat comforting patterns to themselves. With the students who had CRS I saw children who would crawl, roll, and walk, a whole new world for me as an educator. I saw intelligence in the children who were deaf-blind as the result of CRS.

I could show baseline and learning profiles that indicated progress in the children who were deaf-blind as the result of CRS. The system did not seem interested in seeing the results. The system's cycle seemed to be about maintaining the status quo. There seemed to be a threat to the formal system. This threat seemed to be that if you opened the door of opportunities you would be overwhelmed.

I certainly can relate to that as illustrated by the "sedate meeting" I held at Callier in 1969. It has envisioned a small meeting of key representatives from key agencies across the 5 state region. What I found came to me in a blurring trauma. Box lunches were ordered from Neiman-Marcus (a very Dallas thing) and an orderly meeting was planned for 25 individuals. Instead of the 25 individuals I planned to have attend, 250 individuals showed up from all over Arkansas, Oklahoma, Texas, Louisiana, and New Mexico.

Most of the registrants were parents. It was a mad house. Out-of-state people wanted to know when classrooms would be set up in their neighborhood. People wanted to enroll a child who was deaf-blind in the Callier program the next day. Within months 600 referrals had been received at the Callier Center requesting services for persons who were deaf-blind. I thought the program would be for 4 students. Out of that meeting and the subsequent referrals, a third finding emerged:

- Parents are the key to services

State agencies were not the source for service development. The federal government was not prepared for the number of students identified. Local school districts were not interested. It was the parents who were the key to service for persons who were deaf-blind. If you want to make a soup you must start with a broth and parents are the broth. Schools may be the vessels, but parents make it happen.

I found that another dodge was that the formal system cut services into artificial ranges such as age levels, functioning levels, IQ, SQ, and DQ levels, budgetary constraints, or vocational potential for employment. This allowed for short-term commitment rather than buying into the reality that services were life-long.

After that original meeting at Callier in 1969, I quickly asked the funding agency in Washington if I could change the name to the South Central Center for Persons Who Are Deaf-Blind and THEIR FAMILIES. By receiving permission to include parents as direct participants, I set about to try to understand parents, the stresses of having a child who was deaf-blind, and how to use every available resource. There is a 30 year longitudinal study on my web site, [www.winfssi.com](http://www.winfssi.com) that details how to go about understanding the parents of persons with complex disabilities. Parent training and empowerment are vital to developing educational programs.

The fourth finding was realized when I tried to repeat my work as a psychologist and find ways to assess the 600 plus children who had been referred to the Callier Center. I sometimes call this part of my presentations the "Confessions of a Binet Jockey." I had been trained to take my little testing kits (which included the Stanford-Binet test), go down the hall and administer the protocol in a standard manner. Well, the children with Congenital Rubella Syndrome were not impressed with my training. I was lucky if the child with CRS did not try to eat the testing materials. Standardized testing did not work. That is when I ran stumbled into the 4<sup>th</sup> finding:

- Standardized tests are based upon a deficit model to predict outcome and to tell what the person cannot do.

I needed to show what a person could do. An abilities model was needed. This assessment model needed to allow for description, not prediction. Two sources guided me in trying to find a way to assess children with CRS (and probably to save face that all my training in testing was really beneficial to ME!). Of course one was that wonderful genius Jan Van Dijk of St. Michelgestel in the Netherlands. He and Van Uden had presented a

film at the world congress on deaf-blind that I ordered. The film was in Dutch and I do not speak Dutch but the logic of the presentation was so clear, so solid, that it became the base for training all personnel including parents about how to look at a person who is deaf-blind. The second influence came from Wepman, Jones, and Van Pelt. They had written an article about the "Organization of the Central Nervous System." This greatly influenced how I looked at students. The Wepman model helped me adjust my perspective of how to observe behavior. Using these resources it was possible to establish classrooms at the Callier Center that I believe were the first community-based day educational programs for persons who were deaf-blind in the United States. These two resources led to the development of 78 local day programs in the region over the next 3 years.

As a result of these sources I started working on the Callier-Azusa Scale with the staff at Callier and the personnel from the East San Gabriel Valley program in Los Angeles, California. Staff, parents, therapists, and others worked to describe behavior. The work of Jean Piaget served as the guiding approach...remember it was Piaget who said, "...it is the stage, not the age." By using Piaget, I was able to move away from standardized measures that showed deficits in intelligence, development, social maturity, and academic achievement. It allowed for the processes of behavior to be observed over a period of time. Unfortunately I lost control of the Callier-Azusa Scale but it worked well and continues to be a major source for observing persons with Congenital Rubella Syndrome. As far as I know, the Callier-Azusa Scale was the first research-based measure that was developed specifically for persons with Congenital Rubella Syndrome. The Callier-Azusa covers the period of time that Piaget called the Sensory-Motor Period and the Pre-Operational Period. This approach works up to the end of the Pre-Operational Period and then we needed something else to assess persons with Congenital Rubella Syndrome. That is when I worked with another team to develop the Functional Skills Screening Inventory (FSSI). The FSSI is a functional assessment that may be used from 7 years of age to 80 years of age. It was based upon persons with Congenital Rubella Syndrome but has proven to apply to persons who are deaf-blind from other etiologies, deaf-multihandicapped, blind-multihandicapped, autistic, traumatic brain injury, cerebral palsy or who have complex combinations of disabilities that impede use of usual tests. The FSSI, which has been on the market since 1984, has a wide application to all disabilities because it uses the person being assessed as both subject and control through an ipsilateral assessment approach.

Once educational services were freed from the constraints of what the person could not do when compared to some reference group (IQ, DQ, SQ, etc.), it was possible to join with the person being assessed. Once this was recognized it was possible to let the person being assessed take you where the person wanted to go. Teaching the person who is deaf-blind requires learning to read that person and to shape that person's behaviors and motivations into socially appropriate behaviors. That, to me, is what all education should be about. But with the student who is deaf-blind it is central to making any progress. I learned at the University of Kansas the "dead-man's rule" that said that extinguishing behaviors is not productive, no behavior means you are out of business. So learning to pinpoint a behavior and shape into the desired socially appropriate behavior becomes the

base for educating persons with disabilities. Fitting them into Van Dijk's logic within the framework of Wepman, Jones, and Van Pelt became the guiding structure for educational programming in local day-programs for persons who were deaf-blind. Carmella Ficociello put all of this into an organized format called Process Teaching. It basically voiced, "If the process is in place, teaching the skill is a piece of cake."

Every person learns. It is our challenge to find out how that person learns. It has been estimated that 80% of what you and I know comes from us just being there. By watching someone else you and I tend to learn. This is called incidental learning. Just being there allows us to learn. We are beginning to understand this phenomenon with the recent research on the "mirror neuron system" of the brain. Daniel Glaser of University College London is doing interesting research in mapping the mirror neuron system. Shenk et al of the Center for Brain and Cognition at UC San Diego have tracked the mirror neuron system in persons with autism to show that this seems to be a basic flaw in the brain of persons with autism.

The person with CRS (and most persons with deaf-blindness) must have directed learning, meaning that they do not always benefit from just being there, just watching what someone else does; they must experience the stimuli directly and organize the stimuli internally themselves, not through the observation of others. Persons with CRS will tell you that they need directed learning if you will let them. The key is to have the patience to allow the person with CRS to learn at their rate and in their own way. In the 1960s we learned not to start at the cognitive level (of the Wepman model). We learned to use Van Dijk's motor-base of learning and the subsequent development of language from the motor level to the cognitive level. That is so commonly accepted today that it seems that this approach has always been there. Not so. I still work with school districts in Texas and the Southwest U.S. where they want to start with "fish, ball, and shoe" speech training on the first day. Old habits are hard to break, whether it is a person who is deaf-blind or those who provide services to them. I learned not to be a Binet Jockey but it was painful....

Programmatic considerations that must be taken into account when developing educational programs for persons with CRS starts with system change, within our self and within the formal system of service delivery. Keeping services flowing was again a system issue that impeded transitions to new services. Lack of adequate case management from the formal system required an informal system to be developed. This informal system uses parents and family members as critical resources in system change. Thus, parent training and support is a necessity when developing educational programming. Teaching the person who is deaf-blind could be done effectively with existing knowledge. Finding people who wanted to provide services to persons was easy. The difficult part is getting decision makers to see the 5<sup>th</sup> finding:

- It is not a question of whether funds will be spent on services to a person who is deaf-blind, it is a question of how money will be spent on providing services to persons who are deaf-blind.

Currently the state agency in Texas in charge of mental retardation services admits that it costs between \$70,000 to \$80,000 per person to keep an individual with mental retardation in a residential institution. I wish I had \$70,000 per student who was deaf-blind to apply to their educational program.

So, if this is the Last Hurrah of Ed Hammer (or maybe the next-to-next-to last...) then what have I learned about educational programming for persons with complex disabilities? I have reviewed findings that unfolded over time to help me realize exactly what business I was trying to conduct. From this I started as a joke to talk about "Hammer's Laws of Learning." These have mellowed over time to become points to consider when developing educational programs for persons with CRS. I present them to you (with tongue in cheek) and encourage you to address the implications of these:

### Hammer's Laws of Learning

#1: The more complex the disabilities the longer the assessment period.

#### Implications:

1. There needs to be entry-level efforts that are diagnostically teaching the new student. These can lead to greater understanding of the learning style of the student with CRS. Unfortunately, too many programs go through elaborate intake and assessments that seem to have nothing to do with "what do we do on Monday morning." Then we place the student where we were going to place him/her anyway. Why not teach diagnostically and then ask referral questions of others to answer specific issues in the IEP process? If instruction is to be based upon the needs of the learner, why is assessment not based on answering the needs of the learner?
2. Why not recognize that providers need time to learn about the student before starting in with canned or mechanical programs. Lock-step learning is futile for persons with complex disabilities.
3. All assessments must direct program services toward inclusion of the learner with persons who are not disabled. The goals of all education must be to prepare the learner 1) to live in the community, and 2) to occupy time in a productive manner. This cannot be done in isolation. The person with disabilities must be free to be with others who can learn to support, tolerate, and accept differences.
4. What do you consider implications? Please list:

#2: It is more important to describe behavior than it is to predict outcome?

Implications:

1. 2005 represents the 100<sup>th</sup> anniversary of the use of intelligence tests. These tests were developed to predict outcome. They are based on a deficit model. Ask service providers how useful tests that predict are. Yet these are conducted to qualify a person for services and to establish an Individualized Education Plan.
2. Documentation is a mental health issue for staff. If you provide education to a person who is deaf-blind you must establish a baseline of current behaviors because you will forget the small steps that the student makes. This means you document to provide feedback about progress. No one else will give you that feedback. You must take it upon yourself to show what has happened. This is descriptive data, not for protection or compliance.
3. What are your reactions to this statement? Please list:

#3: Let the learner take you where the learner wants to go. In the process of following the learner, you guide and shape learning to the content you want.

Implications:

1. Teachers have an underlying fear that someone will come by when they are teaching and find the teacher "doing nothing." It is all right to observe the learner. It is necessary to observe the person in exploration, problem solving, recreation, and interpersonal interaction. Joining means being "with" the person, not feeling that you must be in charge and always in control.
2. It is critical to establish a relationship before trying to instruct.
3. What are your reactions to "joining" with the learner? Please list:

#4: General Education addresses content (3<sup>rd</sup> grade, Algebra II, English IV, physical education, etc.) while Special Education addresses the needs of the learner.

Implications:

1. This seems to be the basis of great misunderstanding about why there are special education services in the schools. Special education is not a separate or parallel educational system. Special education is a support service to maintain the learner in General Education.
2. This means that the learner is maintained in the General Education curriculum. But what if the General Education teacher does not have the knowledge and time to work with the learner with disabilities? Then the Special Education teaching staff goes into the General Education classroom (before placement is even attempted) and works with the teacher to define exactly what type of support is needed. Notice the phrase, "going INTO the General Education classroom."
3. What are your reactions to the relationship between support services and curriculum content? Two decades ago I wrote a paper, *Learner Standards for Students with Disabilities*, that details how to support the learner with disabilities in the General Education program. What I observe in the relationship between Special Education and General Education is that it seems to be just another slice of service delivery that is not coordinated, it not wanted (mainly by General Education), and does not fit into a proactive agenda but is done to make sure the "folders are in compliance."
4. What are your impressions? Please list:

#5 The goal of all education must be to teach the learner to 1) live in the community as a productive citizen, and 2) occupy their time in a productive manner.

Implications:

1. There seems to be a problem of "goal/means displacement", meaning that the goal of education seems to have been overtaken by the means. So many schools are more concerned about having their folders in order, their documentation correct, or that their procedures do not affect their funding that they forget what they are trying to do.
2. Persons with CRS, deaf-blindness, or other complex problems do learn. The problem seems to be to understand exactly how they learn. Learning will happen; the challenge is to make sure it is the learning you want to be learned. Once a person with CRS learns something, it sticks with them.
3. What are your thoughts about the goals of education? Please list:

#6: Persons with disabilities have a longer "growing season".

Implications:

1. This is a corollary to the above statement. Murdina Desmond, M.D. reported her findings about Congenital Rubella Syndrome in 1985. This pioneering study concluded that the central nervous system of persons with CRS continues to mature and myelinate into the third decade of life. Yet the system has not taken into account that it may be that persons with CRS need educational experiences and learning opportunities into their 30's.
2. It is our responsibility to keep the doors open for persons with CRS to have new experiences, to repeat interesting activities, to structure the intake of information. Being locked into age-related services is probably the most serious offense that happens to persons with CRS. That is not to say that it is appropriate for a twenty-year old who is severely developmentally delayed to play with Fisher Price toys for three year olds. Services need to be based on the individual's needs, stage of development, and what is appropriate for his or her age.
3. What have been your experiences in the learning of persons with CRS who are past the age of 22 years? Please list:

#7: Reading should be taught to everyone, because you can see words four to ten times faster than you can listen to them.

Implications:

1. Why is this in a listing of learning related to persons with CRS? Because the person with CRS often does have tactile and residual vision to see signs, symbols, and colors. This is a pivotal area in teaching the person with CRS. They learn that symbols have meaning and that they can convey that meaning by various modalities. This is the heart of Van Dijk's system. Our work must be to facilitate language using symbol systems. Thus, "reading" may be recognizing that Coca Cola signs mean "sweet drink" or that the golden arches mean "tasty food", but learning to use symbols to organize and codify is a great challenge to those of us who observe and teach persons with CRS.
2. The deep structure of language is based upon the premise "If a person does not have language, the brain will create one." Using Van Dijk's progression helps the person with CRS move through the progression of direct experience, paired with actual items, paired with drawings of the same items, paired with symbols and drawings, that leads to codifying the experience.

3. Use of print or graphics allows us to "bind time" meaning that what was experienced in the past can be preserved and used in the present and future. Persons with CRS need to be able to organize temporally as well as spatially.
4. This delicious topic could take a lifetime to explore. What are your reactions?

#8: Learning begins at the brainstem level, not the language level.

Implications:

1. Learning seems to be based upon simultaneous and sequential processing of information stimuli. This means that we must understand how the person with CRS recruits information (mouthing, looking, feeling, how else?).
2. After recruitment of information, there must be some way to store what has been experienced. Three major memory systems are involved: Short-term memory, long-term memory, and proprioceptive memory. For persons with CRS, the problem seems to be in short-term memory. Short-term memory seems to be concerned with recruitment of information and holding it in memory until it can be accommodated to what is already experienced. Thus experiencing information is key to entering it into proprioceptive memory or long-term memory. Piaget, Van Dijk, Steiner, and Montessori understood the need to explore and experience before codifying can take place.
3. What are your thoughts about where to start learning activities?

#9: To teach, you must first connect with the context of the learner (stress levels, current crises, readiness to participate, energy level, previous experiences). We must explore the environments of the learner as well as the opportunity to occupy space and time in a productive manner for that learner. Contextual Assessment is just as important as Abilities Assessment.

1. Learning for persons with CRS needs to be in the actual setting in which they will use the skills or information they learn. The context in which a learner is experiencing information reinforces the use of that information in that context.
2. What contexts are involved? The home or living setting where the person will use the learned behavior; the work place or training sites where the person will be expected to use the skills – All of these places are where

learning must take place. We need to assess those contexts to see what the learner wants and needs to know to be effective in them. An example is, if you want a person to be able to work a cash register, go to the real cash register to teach that person.

3. List the contexts where you believe learners need to focus their learning.

#10: All behavior is communication. It is our problem that we do not know how to understand the communicative behaviors of others.

Implications:

1. Teach the person with CRS by extending the existing behavior into socially appropriate behavior. Know and understand that the behaviors of the person with CRS are powerful attempts to communicate.
2. Research indicates that there are 6 levels of awareness that may be observed. Level 4 is designated the place where learning may occur. This same research talks about cues that communicate: approach cues, avoidance cues, and potent withdrawal cues. Use this information to understand what the person is "saying" with their behavioral reactions to the context and the lesson.
3. What do you think about understanding that behavior is the base of communication?

Back in my youth, there was a prodigious philosopher named Pogo who gave us the dictum "...we have met the enemy and it is us..." I can conclude that the main issue when developing the first community-based day programs for persons who were deaf-blind due to CRS was to ask: How willing am I to let go of my perspective in order to understand the person with CRS? It really starts with each of us. When we get past that fact, there really are few limitations.

In conclusion then, my travels over the past 51 years have taught me that:

1. The service delivery system is driven by money, not by the needs of the people it is supposed to serve.
2. Persons who are deaf-blind from CRS can learn, and it is the responsibility of the system and the teacher to figure out how to teach them.
3. Parents are the key to obtaining services for children who are deaf-blind/
4. Standardized tests (that tell you what a person cannot do) are not appropriate assessment tools for persons who are deaf-blind.
5. Persons with CRS learn best from direct learning that begins with joining with the learner.
6. If things are not going well, see if the system is disabled, not the person.

