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ABSTRACT

The mother of a 16-year-old daughter with autism offers a parental perspective on coping with a child's disability. The paper emphasizes that through direct interaction with the child and the child's teacher and through taking an active role in the child's activities and achievements, the child's potential can be discovered and the child can be motivated to achieve it. The development of communication skills in the 16-year-old girl, through use of such techniques as "reverse echolalia" and having family members join in with her during her self-stimulatory acts, is described. The parents' role in educating and sensitizing the public, school personnel, and physicians about the needs of children with disabilities is also discussed. (JDD)

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MAXIMIZING POTENTIAL: THE PARENTS' ROLE

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Abstract

This article presents the importance of coping with a child's disability from a parental perspective. A major emphasis is placed upon motivating and discovering the child's potential. These goals are reached through the parent's direct interaction with the child and the teacher. Maximizing the child's potential includes taking an active role in the child's activities and achievements. This can be done by assisting him/her to assimilate into society and encouraging his/her language development. A note book of the child's progress is especially helpful. Finally, it is the parents responsibility to educate and sensitize the public about the needs of children with disabilities. School age children, physicians, and the general public should be educated about the abilities and needs of this population. This knowledge could be helpful to all who are involved with children who have disabilities.

PERSONAL STATEMENT

Aside from my involvement with the Center for the Study of Handicapped Children and Youth, I am also an employee of Howard University, in the Center for Academic Reinforcement where I serve as Administrative Assistant. I am the mother of a child with special needs because of a disability called "Autism." I also have a normal child. Both children live with my husband and me, and we are a very close family. I am happy to share with you today my views of the "special" parents' role in maximizing the potential of their children. Personally, I feel that it is primarily the parents' responsibility to do so, but I also realize that it is not an easy task.

Introductory Statement:

First, I want to express how utterly necessary it is for parents to accept that a child born with, or who later acquires a disability, is DIFFERENT. If we can do this we have surmounted the first, and the greatest hurdle (Beste, 1986; Bonnett, 1986).

Secondly, DISCOVER this different human being. By this, I mean, try to learn something about the way this person thinks, rather than impose your ideas and values. Not even normal children react positively to the "teeth-pulling" method. They withdraw. Your special child may withdraw completely, or mirror your chaotic emotions, or react obliviously with little interest in the environment.

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You cannot effectively motivate a child to reach his or her fullest potential unless you do these two things first. In short, accept the difference and discover the child. Without these basic elements, you're working from an artificial basis bound for failure. Who suffers? Both parents and child suffer.

Some of us might think we are being noble, investing in persons with special needs, but in truth, we need them to invest in us. We need them to reach out to us in whatever way possible before we can really help. How? How do we do this? My son said it best. He told me that parents need to be "A lighthouse in the fog." "A thick branch over the quicksand." We must pull from ourselves our strongest talents, and sell our children an appealing image; a secure image; a rock. Make them want to invest in us and buy into us; show them there is something outside of themselves to latch onto; let them know that they are our most important commodities. This spells LOVE, and CARING in capital letters, and children, special or not, recognize and understand it. I know from personal experience that they will invest in it, and can be motivated to do things that some think should be impossible.

The Parent

As a parent, I have found it necessary to STOP, LOOK and LISTEN. It is part of discovering the child. STOP thinking about learning, playing, working, communicating and other social functions in a conventional way. LOOK at the child's behavior in an analytical way, but do not try to make judgements about it. Get guidance from school or other professionals if necessary, but also use that special parent's intuition born in each of us. LISTEN to everything the child says or does not say (Smith, 1980).

There is so much involved in "maximizing" the potential of a child with special needs. For example, a parent must learn when not to say NO to such a child. You might say NO to a normal child who yells in a grocery store, but when your special child yells out APPLE for the first time--even in a crowded store, you DO NOT SAY NO! You clap your hands! The light bulb just turned on for that child, and he is reaching out to you--the "lighthouse in the fog"--for acceptance.

Aside from direct interaction with the child, a parent can help maximize a child's potential through parent/teacher interaction. Keep a tab on what's going on at school. The child could be a completely different person there, or may be having difficulties that even the teaching staff do not understand. Make sure the teaching staff receives information about the child's behavior at home. For instance, I have been told repeatedly over the years that my daughter cannot initiate conversation. In fact, she never stops talking at home, and even insists on having her time to talk about subjects she emphatically states are important for me to listen to. I tape some of these conversations and send them to school. The school also provides a notebook which we use daily to record home and school events and behavior. A notebook can also serve as a good chronicle of a child's progress.

Public Awareness

Public awareness, or the lack of it, is one of the most inhibiting factors in maximizing the potential of our special children. Some people seem to feel that anyone who is different is crazy. Some outwardly display their fear, their disgust, or wonderment as to why such people should be in public places. I call it the "Them and Us Syndrome." The only ones who seem to be purely receptive are the little children. But even they lose this quality when they grow up. The onus is on parents, in whatever small way possible, to educate the public. We owe it not only to our children, but to society. Anyone, everyone has the potential to become a person with special needs. It is possible that a family member, or friend, or co-worker, will be a special needs person in each of our lives. Why the "Them and Us?" "Them" could become "Us" at any given moment in time.

Some special parents get very angry when people ask questions about or stare at their children. An appeal is needed to help parents realize that these people are victims of a society that is ignorant about handicapping conditions and how families are affected. Some of these questions and stares really deserve a response, because the people truly want to understand, but may not know how to tactfully present themselves. You will readily know the ones who do not deserve a response. Conferences like this one are excellent vehicles for educating the public one-on-one. It is very important and nothing can take the place of it. Sensitivity and sensibility are two concepts that the general public could develop.

Since handicapping conditions are so prevalent in our world, it is recommended that such conditions be defined at the grade-school level (Scheifer and Klein, 1986). These children have the first encounters with special needs children, and should have the opportunity to understand how "they" fit into society with "us." Many of these children are the siblings of special needs children and have to live with the stigma imposed by the community. No one should think that because a person is in a wheelchair that the person cannot talk--but some do. Everyone should know how loving a Downs Syndrome child can be--but many do not. Everyone should understand basic facts about retardation--but they really don't.

Many physicians are not prepared to assist parents in this regard. My daughter's first pediatrician was not. When I asked questions, he wanted to know if we were having marital problems. I have heard similar accounts from a number of other parents. Many teachers do not read background information about special children, and may be ignorant as to how to help them without parent intervention (Wing, 1985; Scheifer and Klein, 1986). We, all of us, are just recently learning. What makes us think our professionals came up differently. They are just learning also, and unless they have special needs children themselves, we parents know a bit more about the basic concerns involved.

My Child

Finally, I want to tell a little bit about my personal situation. As I mentioned, I am the mother of a special needs child. My daughter is autistic--residual type. She started out being diagnosed as simply autistic when she was around three years old. She did not display human warmth, had no eye-contact, displayed ritualistic behavior such as rocking, finger flexing, handshaking, headshaking, belching noises, and a number of other such repetitive self-stimulatory acts over the years--one immediately following the other. She also would not communicate. I say "would not" because it was apparent that she had the capability but would not use it. She looked at our dog, and talked to him in what seemed to me a normal way. She looked at herself in mirrors and smiled and made faces. But with us it was like she was deaf and blind. She had perfect diction and repeated in echolalia style everything said to her, verbatim. She did not respond to pain, odors, and loud noises. However, there were certain noises that did bother her like the shaking of liquids and

crying babies. When she heard these, she could be upset for two hours or more. She used the toilet for the first time when she was four years old.

My daughter is now sixteen years old. She talks, reads, writes, is good academically in school--though not up to grade level. She retains information, practices excellent personal hygiene without my assistance, and is gradually integrating her ways of doing things in a normal way. These behaviors are consistent with those identified by Brutton (*cf.*, Brutton, et al., 1973). She is still very concrete in her thinking and somewhat bizarre in her habits, but assimilating into everyday life.

Our outlook for the future? I have no reason to believe that my daughter will not go on to higher education some day. She will have her first real job during the summer through the Mayor's Summer Youth Program.

How did we accomplish this? Basically by doing the same things described previously. Of course, each child will bring with him different qualities, and variations in methods (Wing, 1985).

My daughter would not come to us so we went to her. We got to know her, and to interact with her. I began doing what she did, whether it was to rock back and forth, scream or handshake. These were her first social interactions, and she began to RESPOND by REJECTING me. LISTEN TO THE MAGIC! She rejected me. That was a wonderful and appropriate response. My whole family joined in this concept, and over the years we have conquered each one of her self-stimulatory acts. For the first time in her life, I have not noticed a self-stimulatory sound or movement for several months.

If you have seen the movie "Son Rise" you saw a glimpse of what happened in my household. When I saw that movie I cried because it was the same approach I had used with my daughter. The only thing I did not like about that movie was that someone could get the impression that wealth is needed in order to work like that with a child. Both parents in the movie left work and stayed home for a year, I believe working around the clock with their child--rocking, twirling, or whatever he did. How many could afford to stop working? Well, my daughter is living proof that the same thing can be done in normal everyday activities--at home, in the car, walking along, everywhere. Amazing, our interaction was the very thing that made my daughter abandon each of these bizarre acts. She was desperately seeking to be alone--to do something that only she could do. I hope she has given up.

Language developed very similarly. I noticed that there was a pattern--a thin ribbon strung through everything that said "Reverse Me." My daughter started out with echolalia. She said her first sentence before she was a year old which was : "See the little flowers." I did not realize that she was echoing what she had heard me say the day before. I also didn't realize later on that she was attempting to reverse the echolalia. (Wing, 1985)

The day I realized that she wanted me to repeat--verbatim--everything she said, or seemed to ask, was the first day that she went to the bathroom with no prompting. She had said, "You go to bathroom." She was so emphatic that I had to look. She was almost bent over. My light bulb went on. For the first time I realized she wanted me to repeat what she said. She went. She went by herself. From that moment, I was echolalic (reverse echolalia, if that is a word). She told me what to say to her, what to ask her, how to play with her--everything. I used that medium to teach her proper behavior, vocabulary, social skills, and to discover her, the person. Soon I was able to get her to turn it around and initiate what she wanted to say or do without going through me. If I had only learned to STOP, LOOK AND LISTEN much earlier, she certainly would have been toilet trained before she was four years old (Wing, 1985).

How do we maximize potential? Since each special child is different from one another, there is no cut and dry method. In my opinion the mold is created by the child. There need only be receptive family members and teachers, and if one can access this mold--discover the real person in this child, then it can be used for retraining, and helping the child to reach his or her full potential. The poem below summarizes some of my feelings and thoughts regarding this.

THE INTRUDER

by SHIRLEY POINDEXTER DYER

A Child
A strange child,
In a world all her own, but
Which she did not make,

She rocked,
And she twirled,
She screamed in her room,
But She did not awake.

Dare I preside
In those unmindful eyes
And try to be a friend?

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The end result
Would no doubt tell
Whether bending her will
Would make her well.

So I rocked with her
And twirled with her
And I too
Screamed in her room.

She tended not my eye,
And she did not like my play;
She turned from me in silence,
But I saw it this way:

By her attempt to exclude
My efforts to intrude,
The first contact was made,
Meaning she was now awake.

The end result
Was a great beginning
For a "special" girl
In a "special world."

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