

## My Experience: The Parent of a Child Living With Autism

**Olansky 1962 and Jacques 2003 stated ‘The permanent, day-to-day dependence of the child, the interminable frustrations resulting from the child’s relative changelessness, the unaesthetic quality of mental defectiveness, the deep symbolism buried in the process of giving birth to a defective child, all these join together to produce the parent’s chronic sorrow’ The birth of a child with a disability is sometimes seen as a situation without hope of resolution or adaptation.**

My son Kofi will be 8 years old this month of October, 2008. First let me say he is my blessing from God, my soul, my heart and I love him with a fierceness that is unexplainable.

People often believe that because I am a teacher of children with special needs that I have some really effective way to handle my son’s autism. I am able to look at him in a more realistic and clinical fashion. But I also ache as his mother when there seems no solution to a problem. I am no different, but the same as any parent in these shoes. I have been through the grieving stage, denial, anger and depression and all the pain and suffering, anxiety and sleeplessness .These may lessen but they never totally leave me.

Autism has its text book definition but to parents it can be just plain rotten luck. Why my son or daughter? Autism is the most devastating developmental disability there is. Why us? Our children are seldom in wheel chairs or deformed. They look normal and are usually quite beautiful to look at. Kofi’s nicknames at nursery were “The Prince” or “Mr. Handsome” and so our children are very attractive to look at, and here in lies the dilemma. What you see is not what you get.

My particular situation is a bittersweet one. To me autism can feel like a gift as well as a curse. At these times I turn to God because there must be a reason that my son is living with autism in Barbados in 2008.

I completed the first leg of my university education by submitting a thesis on the coping skills of relatives and parents who live with persons on the spectrum. My position as a teacher of special needs for 13 years and parent of a son with autism affected that project in relation to what I perceived to be the lack of attention paid to research involving disabilities in Barbados. Unfortunately in every area involving persons with special-needs the word '**lack**' is a popular and much used one.

I live with a child who lacks reasoning and understanding of many basic concepts, and who is unable to fully communicate his needs clearly. Kofi is also unable to answer necessary questions beginning with what, where, how, and when. The words I use every day are stressful, hopeless, unmanageable, anxious, obstinate, aggressive, frustrating, exhausting, unbearable, heart-wrenching, depressing and painful. It would be very easy to say that **I can not cope**. Just like the negatives there are positives and these vary from child to child and family to family. My son is also happy, quite a comedian, social, friendly, loving, caring, intelligent, displays empathy, a joy to know, fun, sharing, very affectionate, helpful and independent, talented, curious and aware of the world he is in. He is almost like any other child except that he lives with autism.

Parents and family members of persons with autism are aware of the high levels of stress involved. These stress levels are frequent and a regular part of the **twenty four hour management** of children and persons with autism. The misunderstandings and confusion due to

behavioural problems generally caused by the inability to communicate can be extremely taxing and nerve wracking on the body and mind of both parent and child.

It is almost impossible to imagine how parents must feel when faced with a child who may be dependent on them for life, and unable to fulfill the parents' dream of a normal, productive young man or woman.

These children have urgent needs, specifically the need to have somewhere to live safely when we are dead. The psychiatric hospital is not it. Our children are not crazy, but the world can be a crazy place for them.

Families need education and informational services, diagnostic and other resources and research must be done. We need cradle to grave services for our children; we need nursery and preschool care, decent free secondary education, vocational programmes and adult care. We need to actively lobby or protest for the acquisition of needed resources, primarily diagnostic, respite care, and assisted living facilities and teacher training. Community education about disabilities, parenting classes for those with disabled children and regular workshops will help to decrease the lack of control and helplessness that parents in Barbados obviously feel.

I do not need to wonder how long my child will be at home after leaving primary school or wonder where he will go. Kofi is completely innocent and ripe for those who will take advantage of a child that can not say where he has been or what has happened to him. This fear is unimaginable and I put him and all these children in Gods hands. I fear dying before him, and I often ask God to help every one of us with this fear.

Parents need a sense of mastery and control because they are surrounded by stigma within a society that lacks education. Stigma is a result of social attitudes about negative impact of disabilities and about the worthlessness of persons with disabilities (Goffman 1963). For this reason it is important to continue research into positive contributions of persons with intellectual disabilities to their families and to society, and into ways to educate them and their families. **Ignorance is extremely costly to persons who are different.**

I will not nor am I prepared to stand by and watch as Kofi suffers because persons are blind to his potential or the contribution he can make, or blind to his human rights. God created Kofi and eternal salvation awaits the parent who will love, protect and care for a child far less than perfect in society's eyes, the type of child that most persons would rather not have. Well, I have him, God gave him to me, and he is my gift. Kofi is my chance for God to say "well done Gillian." Kofi is here to save me, not the other way around.

**Written by Gillian Cadogan**