

Perspectives

The “Big Bang” Theory and Down Syndrome

Robert Perske

I am convinced that some of the most joyful, life-changing conventions in our field are those that focus on families with children who have Down syndrome. Whole families come. Some appear with babes in arms. Clinicians named Pueschel, Crocker, Kumin, Falvey, Rosenberg, and many others hold impromptu clinics in halls, lobbies, and special session rooms. It all goes so well because these parents hunger to learn everything they can about their own child with this disability.

There are sharing sessions galore for moms, dads, brothers, sisters, and grandparents. There are even sessions for persons with this disability who help one another to speak for themselves. Then come the banquets and the laughter; the awards and the cheering; and the dances, where all are dressed in their very best clothes. Many leave exhausted from these carnivals of hope, education, and comradeship, but they leave knowing that they are part of a powerful, expansive movement.

One cannot help but wonder whether some earlier “big bangs” in history gave rise to such an expansive movement. I say yes. I can pinpoint at least two such explosions. These explosions were heart-ripping. Even so, the way the folks in this field gathered around these wounds and worked for healing was fantastic.

Washington, DC, The John F. Kennedy Center for the Performing Arts, October 16, 1971

People from all over the world arrived for the International Symposium on Human Rights, Retardation and Research. The Eisenhower Theater was packed with persons eagerly waiting for the opening plenary to begin. When it did, a film was shown that shook many in the audience right down to their socks.

The film was entitled, “Who Should Survive?” It focused on a real newborn baby boy in the maternity ward of Johns Hopkins hospital. The child was born with Down syndrome and an intestinal

blockage. The latter could be corrected with a fairly simple operation. So the physician asked the parents for permission to operate. The parents refused. They said that it would be unfair to their other two so-called “normal” children to be brought up with a “mongoloid” sibling. The infant was moved to a corner in the hospital nursery, and a sign was hung on the crib that said, “Nothing by mouth.”

From time to time the father telephoned to ask, “How are things going?” The film showed the anguish on the faces of the caring staff. The senior pediatric resident in charge of the infant’s care stated: “I tried not to look at the baby and when I did, I didn’t want to touch it.” Later, he said, “It took 15 days for the baby to become dehydrated enough to die. That was an awfully long time.”

After the film, six famous experts representing key legal, moral, ethical, social, public policy, and mental retardation aspects gathered in a circle on the stage. They faced each other and discussed the film. At first, the circle widened as each expert tried to define the situation in his or her own professional language. Then they drew closer, trying to speak a common human language about a neglected, dying baby. When the closeness became too painful, one of them would “blow it” by making an asinine remark. For example, during one moment of such closeness, a physician blurted out, “What about the war in Vietnam?” The audience clapped in a mindless, impulsive way.

I did not sleep that night. Instead, I tried to analyze my own feelings about that horrifying situation and put them into a poem. That poem follows this article.

During the next 3 years, the unrest and agitation among families of children with Down syndrome was so palpable that they approached leaders of the Arc of the United States (Then known as the National Association for Retarded Children—NARC) and asked to be given a large meeting room at the 1974 NARC convention in Milwaukee. The request was granted. So, under the wings of The Arc of the United States, the National Down Syn-

drome Congress began to take shape. They gathered strength and became more alert in case another tragedy like the death in Johns-Hopkins took place. Sure enough, it came.

Bloomington, Indiana, Bloomington Hospital, April 9, 1982

“Infant Doe,” a baby boy with Down syndrome, was born with an esophageal atresia, the separation of the esophagus from the stomach. Again, doing the life-saving surgery was no problem. Again, parents refused to permit the operation. Again, an infant was shoved into a corner and starved to death.

This time, however, the shock and disorganization surrounding the issue was less pronounced. Numerous families contacted the hospital begging for permission to adopt the baby. Persons who had children with the syndrome made heart-warming statements about them. National syndicated columnist George Will spoke out on the issue:

Jonathan Will, 10, fourth grader and Orioles fan (and the best Wiffle-ball hitter in Southern Maryland), has Down syndrome. He does not “suffer from” Down syndrome. He suffers from nothing, except anxiety about the Oriole’s lousy start.

He is doing nicely, thank you. But he is bound to have quite enough problems dealing with society—receiving rights, let alone empathy. He can do without people like Infant Doe’s parents, and courts like Indiana’s asserting by their actions the principle that people like him are less than fully human. On the evidence, Down syndrome citizens have little to learn about being human from the people responsible for the death of Infant Doe.

This time, movements on behalf of persons with Down syndrome “pulled out the stops.” They filled the media with positive letters to the editors. They approached legislators. They reached the ears of President Ronald Reagan, who was shaken by the news. He discussed the issue in depth with Surgeon General C. Everett Koop. Since then, a cascade of legislative acts and judicial judgments has protected citizens with Down syndrome as never before.

I also experienced shock waves coming from this perplexing issue. In response, I spent time talking to families with children who had Down syndrome. I even stayed overnight with some. Consequently, in 1984 I wrote the novel *Show Me No Mercy*, with all of the characters in it being fashioned after real people. Even so, the solution to the Bloomington explosion came long before the book came off the presses.

American Journal of Obstetrics and Gynecology, March 2005

A study in this journal may fuel another explosion regarding the life and death of infants with Down syndrome—or it may not. The *Harvard University Gazette* billed the study as “the largest and most comprehensive study on prenatally diagnosed Down syndrome to date.” It “estimates” an abortion rate of 80% to 90% when prenatal screening reveals the possibility for the condition.

Interestingly, there are now three national agencies standing ready to respond: National Down Syndrome Congress, National Association on Down Syndrome, and National Down Syndrome Society. I do not know how this came to be, but I do know that many parents and professionals hold memberships in all three. From them a chorus of early responses can now be heard:

- Most expectant mothers only learn about the painful side of such a birth from clinicians.
- Many admitted that they felt pressure from physicians to terminate the birth.
- Almost never did they receive the latest information on Down syndrome.
- Almost never did they receive information about organizations for persons with Down syndrome.
- Some of the prenatal Down syndrome testing is wrong 20 to 40% of the time.
- Most young expectant mothers carry such hope and joy regarding the baby within them that they refuse all offers of prenatal testing.
- One organization claims that these children bring more love in the world.

Of course, obstetricians are more prone to talk about “perfect births.” We would not go to one who did not possess this high goal.

Even so, everybody longs for Superbaby, but nobody gets one. Many times those who become the greatest among us, do so out of personal needs to compensate for limits in their lives; and their success is often an utter surprise to their parents—mothers and fathers who felt that *this one* was too sickly, slow, nervous, loud, erratic, or strange.

Reference

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Words for a Child With Down Syndrome

(Written on the sleepless night after watching the documentary, "Who Should Survive," in Washington, DC, October 16, 1971)

Robert Perske

We didn't want you,
Helpless child of fifteen days.
You were in the way,
So we shoved you into a corner
 And let you starve to death.

No one wanted you,
Helpless child of fifteen days.
Not your parents,
 Nor those who speak for God,
 Nor the "helping" professionals,
 Nor men using their wits to uphold justice.

Why didn't we want you,
Helpless child of fifteen days?

Would you have stood in the way of our mad chase
 After the ideal family?
 (Which none of us will ever achieve.)

Would we trip over you as we raise higher
 The GNP as our Holy Grail?
 (We must be "Number One" you know.)

Is it because we have never learned
 To live graciously with our failures?
 (Failure is such a hard thing to face.)

Is it because your less-than-perfect presence
 Reminds us of our drives to "be something."
 (We never want to be "a nothing.")

You bothered us,
Helpless child of fifteen days.

We had to reject you
Because you made too obvious something in our-
 selves . . .
 That we just didn't want to face.