Coping with disabled child

When the improbable happens

Pregnant women expect their child to be as healthy, bright and handsome as the healthiest, brightest, handsomest child around.

No one imagines a child with an IQ of 30, a child who can't speak, a child who will never be able to care for him or herself.

So what happens to a family when a child with a severe disability is born?

The question was posed by social worker Martha Dickerson to an audience in a colloquium on the contemporary family at Eastern Michigan University. Mrs. Dickerson is associated with the Institute for the Study of Mental Retardation and Related Disabilities at the University of Michigan.

She and her husband have two children and are also foster parents to four retarded teenage boys. In addition, she is a consultant and therapist for disabled people and their families.

The effect of developmental disability on the family is tremendous, Mrs. Dickerson testified. "They had a dream child, and the dream died. They have to deal with it as though it was a death, except that there is nobody to inter and the mourning work is never done," she said.

In coping with the shock of learning their child is disabled, families go through the same stages Dr. Elizabeth Kubler-Ross described in "On Death and Dying." Like a person dealing with death, the first reaction families experience is instant denial. Mrs. Dickerson explained that good things do come out of this denial period. "We mobilize our forces and move to solve our problem," she said.

The next stage these families pass through is extreme anger, the thought "Why did it happen to me?" Ready to blame anybody for their child's disability, parents often accuse the doctor and other medical personnel of incompetence. Or they blame themselves, thinking that they are being punished for some grave sin.

Having passed through this phase, families frequently try bargaining with God for a miracle. Joining organizations that promote the welfare of the retarded can be one way of saying, "I'm going to do something so big and so good, it will change things for my child."

The next change, Mrs. Dickerson related, is depression. As the family gradually realized that the situation will not change, they typically become sad and withdrawn. Frequently, a lack of care of one's self and a disregard for one's responsibilities accompany depression. Despite outward appearances, Mrs. Dickerson called this a "very healing time."

Finally, families accept the condition of the disabled child. "We pick up the pieces, and go on," Mrs. Dickerson said. "We grow from it. It becomes an OK part of our life."

The difference between accepting death and accepting disability, he asserted, lies in the life of the family after acceptance. After the mourning over a death is done, the family continues its own life. But families with mentally disabled children face a further problem. "You put away the dream child, but you still have the responsibility for the real child," she said.

Mrs. Dickerson believes families experience four "plateaus of pain" and must pass through each of the above stages again at each plateau. The first comes when the family first receives the diagnostic statement of their child's disability, the news that their child won't be like other children. Many parents accept this news courageously, she admitted, but their courage often wavers as they meet new crises.

The family reaches a second plateau with the realization that "their child is not going to have access to the American system the same way all the rest of us did," Mrs. Dickerson noted. Special education, for all its advances, is different from mainstream U.S. educaton, Mrs. Dickerson said, adding that she has yet to hear of a parent who is delighted to have his or her child in a program for mentally disabled people. But even this difficult stage is handled well by many families.

The "killer" plateau, in which "families are thrown into a tailspin," according to Mrs. Dickerson, occurs when the family realizes that their child is a sexual person, with all the sexual curiosity, interests and desires of other people, but without all the ability to learn the responsibilities of sex.

Another dream or expectation is destroyed at the fourth plateau. Parents look forward to concentrated parenting for a few years, with a gradual decrease in responsibility and the eventual move into the doting grandparent role after their children reach maturity. With developmentally disabled children, however, the future often looks far different. "These children are not going to grow up and go away," Mrs. Dickerson pointed out, "and the parent realizes 'I'm not going to be able to retire from parenting.' "

Mrs. Dickerson urged families to "make maximum use of support systems—to seek help from occupational and physical therapists, psychologists, medical personnel, educators, social workers and community agencies."

Club Circuit

SENIOR CITIZEN DROP IN CENTER is open Mondays and Wednesdays for bridge and pinochle games from 10 a.m. to 2 p.m. The center is in the Masonic Temple on Grand River and Farmington Road.

Guests may bring a sandwich for lunch. Beverage is furnished.

HADASSAH, Metropolitan-Detroit Chapter, will give its "Jerusalem Fashion Show" at 12:45 p.m. Tuesday, Jan. 30, in Congregation Shaarey Zedek in Southfield.

Admission is by an $8 donation to "Emphasis on Youth Education."

The clothes featured in the show have been made by the senior fashion design class of Hadassah Selisberg Comprehensive High School, which was founded by Henrietta Szold, who also founded Hadassah. The school's objective is to help girls from oriental backgrounds fit into a modern society.

Some of the fabric for the clothes was woven in the school. Most of the clothes are accessorized with delicate embroidery, beadwork, and applique.

The fashions range from ethnic vests to eyelet nightgowns.

Commentator for the afternoon will be Marilyn Turner.

Mrs. Harold Provizer of Farmington Hills is chairwoman of the day. Mrs. Oscar Kramer of Southfield is Hadassah chapter president.

RENAISSANCE SINGLES meet for a "Super Gong Show," at 8 p.m. Wednesday, Jan. 31, in Berkley American Legion Hall, 2079 Twelve Mile.

Cash prizes will be awarded to the local talent. Judges will be selected from the audience.

All sessions of the club wind up with dancing. Music will be furnished this week by DJ Bob Cox.

Admission is $3.50, at the door. There is a cash bar.

AMERICAN WOMEN IN RADIO AND TELEVISION meet for a 7 p.m. dinner Wednesday, Jan. 31, in Southfield's Holiday Inn, 26555 Telegraph.

The program, conducted by a panel, is called Continuity and Broadcast Standards. Panel members are Helen Skinner, continuity director at WMJC HND; Andrea Fresard, assistant continuity director at WJR Radio; and Jerry Lesz, broadcast standards and practices manager at WJBK-TV.

Cost to members is $9.50 or $10 to nonmembers. Reservations are taken by calling Agnes Kerekes, CKLW Radio, 963-1567.

Balloon Day requests still being answered

Letters from far away places are still being received by members of Hope Lutheran Church in response to the congregation's "Balloon Day."

Hundreds of colored balloons filled the skies in the Farmington Road and Twelve Mile area last August on the opening day of the church's Vacation Bible School.

The released balloons each carried a message asking the person finding the balloon to write a note telling where the balloon was found.

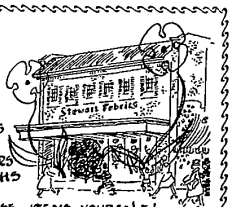
One letter began "Greetings from New England." Jack Stillings had found a balloon from the Farmington Hills church in Corinth-Vershire, Vermont, near the New Hampshire state line.

The Gunn children, from St. Thomas, Ontario, Canada, found a balloon in the woods alongside a creek which flows through their farm. St. Thomas is south of London, Ontario, almost directly across Lake Erie from Cleveland, Ohio.

Laurie Osborne found a red balloon while hunting in Darien State Park, Darien, N.Y.

The Vacation Bible School staff promised a small gift to the party whose balloon was found the farthest away, but with letters still coming in, they are still not sure who that will be.

MORE "BLOOMIN" IDEAS FOR HOME DECOR



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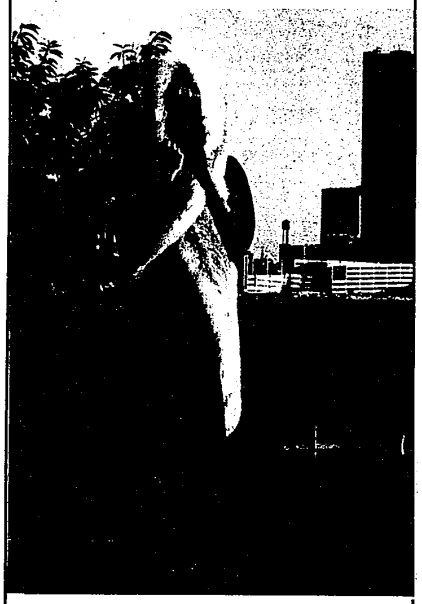

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