

# **THE CHANGING VIEW TOWARD PERSONS WITH DOWN SYNDROME**

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**(Chapter 10: Attitudes, Acceptance and Awareness in NEW PERSPECTIVES ON DOWN SYNDROME. Edited by Siegfried Pueschel, Carol Tingey, John Rynders, Allen Crocker and Diane Crutcher. Baltimore: Paul Brookes Publishing Company, 1987)**

Not long ago, the author's family nagged him for ignoring stop signs when he drove the car. Later, they warned him of approaching stop signs, and once or twice, with soft voices, they suggested a visit to the optometrist. Patriarchal power and pride was used to resist them – until the state driver's license examiner told him to get glasses or stop driving.

Of course, the ultimatum upset the author, until he put on his new prescription lenses. Then he saw stop signs three blocks away. The author peered into what used to be a distant blur and saw people – male and female people – and saw leaves on trees and flower petals and blades of grass in such vivid color and detail that his world view became happier and safer. Of course, it does not take an Einstein to know that the rest of the world was happier and safer, too.

Not long ago, most citizens thought that persons with Down syndrome should be out of sight and out of mind, away from the mainstream of society. Then came organizations like the Association for Retarded Citizens or the United States (ARC-US) and the National Down Syndrome Congress (NDSC), who began fashioning corrective lenses that help everyone see persons with Down syndrome more clearly than ever before. The following is a journalistic attempt to trace the progress of this effort toward attitudinal change.

## **A NEW VIEW IN THE MAKING**

Consider some “headlines” taken from newsclips and the author's interview notes. (The real names of the persons in the stories have replaced the nouns and pronouns that usually appear in actual headlines.)

NATIONAL POSTER FEATURES MATT STARR BAR MITZVAH (National Organization on Disability, 1984)

JASON KINGSLEY STARS IN *FALL GUY* (UPI, 1984)

JOE CONNORS SERVES AS CONGRESSIONAL PAGE (Chafee, 1985)

RON SCHULTZ DROWNS TRYING TO SAVE FRIED (Perske, 1980)

*QUINCY* EPISODE FEATURES DAVID MACFARLAND (National Broadcasting Corporation, 1982)

DAVID DAWSON CO-AUTHORS BOOK (Edwards & Dawson, 1983)

BLOOD BANK APPROVES JOE MAYER AS DONOR (Steward, 1979)

KEVIN LEE WRESTLES FOR GLENBARD HIGH (Perske, personal observation, 1982)

ROBERT MISSING DIES PULLING BROTHER FROM BURNING HOUSE (Perske, 1981, p.49)

PAUL WILKE DRUMMER FOR WARRN HIGH (Association for Retarded Citizens – Minnesota, 1984)

DARSI HILTY GETS REGULAR DIPLOMA AT COLUMBIA HIGH (O'Callahan, 1982)

TINA DIRKSEN PLAYS “ANNIE” AT NEWTON SOUTH HIGH (Association for Retarded Citizens Massachusetts, 1982)  
 TIM FREDERICKS MAKES LITTLE LEAGUE (Fredericks & Fredericks, 1980)  
 TOM HOULIHAN LONG-DISTANCE CALLS OLD FRIENDS AT CHRISTMAS (Perske, personal Observation, 1984)  
 AL QUACKENBOSS EQUIPMENT MANAGER MILAN HIGH WRESTLING TEAM (Perske, 1985a)  
 MITCHELL LEVITZ CREATES OWN MIRACLE AT BAR MITZVAH Walden, 1984)  
 BENGT OLSON OPERATES STAMPING PRESS FOR VOLVO (Perske, personal observation, 19690)

Like most headlines, these focus on celebrities and heroes in the movement, and fail to feature rank-and-file people who live in ordinary houses on ordinary streets and attend classes or work in the community. They fail to mention those persons with serious impairment who also have achieved higher rungs on their own developmental ladders, achievements that may be just as dramatic to them, their families, and friends. And sadly, they fail to highlight heroic families who keep struggling to care for and train their children, even though their children suffer from degenerative conditions.

Even so, the headlines give a hint that a new view, a clearer, richer view, of persons with Down syndrome is now possible. Such stories would not have been considered authentic in 1968.

### **A SAMPLING OF AN OLDER VIEW**

In April, 1968, *The Atlantic Monthly* published “the Right to Die,” an article by *New York Post* journalist Bernard Bard and Joseph Fletcher, a professor at Episcopal Theological School in Cambridge, Massachusetts. Bard, upon learning that his newborn son, Philip, had Down syndrome, sent the child to a “sanitarium” in Westchester County to die, which the infant did on the eighth day of his life. Bard’s article provided a step-by-step account of the birth and death of his son:

1. Bard stated that he himself had not seen anything wrong or repulsive about Philip, but that Dr. F., the physician, had provided numerous details about people with Down syndrome, all of them negative (p. 59).
2. Dr. F. described the sanitarium that was willing to accept Philip as one that “contains no oxygen, gives no inoculations, does no operations, and administers no ‘miracle’ drugs” (p. 61).
3. The sanitarium’s administrator, Dr. K., was described as a “specialist in mental retardation for thirty years” who had examined every child with Down syndrome in Westchester Country. He ran the sanitarium as a “hobby” (p.61).
4. Dr. K.’s view of parents: “Some parents regularly visit their children here. They waste their lives trying to expunge a feeling of guilt that should not be there, instead of devoting themselves to their normal children” (pp. 61-62).
5. Dr. K. claimed support from the local clergy: “There are churches on all sides of me. Every one of these ministers agrees with me that it would not be moral, or serving God’s will to prolong these lives” (p. 61).

On Philip’s eighth day, he was placed in the sanitarium. A few hours later, the infant died of “heart failure and jaundice.” Fletcher, who later became professor of Medical Ethics at the University of Virginia School of Medicine, supported the actions of Bard, Dr. F., and Dr. K.:

Bernard Bard is a loving man. He is not a vitalist, which is the label philosophers attach to those who make an idol of life. . . . [He stated that physicians in obstetric situations often refrain from respirating newborn infants with Down syndrome.] Our statute and common law, that is our official morality, is thoroughly idolatrous and vitalistic . . . People in the Bards’ situation have no

reason to feel guilty about putting Down's syndrome baby away, whether it's "put away" in the sense of hidden in a sanitarium or in a more responsible lethal sense. It is sad, yes. Dreadful. But it carries no guilt. True guilt arises only from an offense against a person, and *a Down's is not a person* [italics added]. Bard & Fletcher, 1968, pp. 62-64).

If this event had happened today, the NDSC, the ARC-US, The Association for Persons with Severe Handicaps (TASH), and other associations for persons with disabilities would have raised loud concerns. But that was 1968, and only a few isolated voices, like Gunnar Dybwad's (1970) spoke out against this clinically perfumed homicide. No organized movement made a formal protest.

And yet, veteran workers and volunteers cannot be too smug about this neglect. For example, the author worked in an institution for people with developmental disabilities at the time *The Atlantic Monthly* article appeared and many of his colleagues were on the fence regarding it. Many felt that John Langdon Down (1866) was correct when he described people with Down syndrome as "reversions to a primitive racial type."

In the author's opinion, professional libraries in 1968 contained bleak textbooks on "mongolism," pages filled with gloomy words, stomach-turning photographs, and a depressing "course of illness," predicting that most would die before age 10. Many professionals saw persons with Down syndrome as "no-program" people; the author recalls how an educator was laughed off an institution's grounds for trying to convince staff members that these persons could learn to read and write.

But that was 1968, and the views of that day differ from what many people now believe about persons with Down syndrome. This leads one to believe that a perceptual revolution has begun.

## **ISSUES INVOLVED IN PERCEPTUAL REVOLUTIONS**

Changes in attitude happen slowly, It is much more comfortable to continue seeing familiar things. In a psychological experiment that deserves to be far better known outside the field, Jerome Bruner and Leo Postman (1949) placed average citizens before an apparatus that flashed playing cards before their eyes. The people were merely asked to identify the cards. Then, strange cards were introduced in the exposures (e.g., a red six of spades or a black four of hearts). Thomas Kuhn, in *The Structure of Scientific Revolutions* (1970, pp. 62-63) described the results:

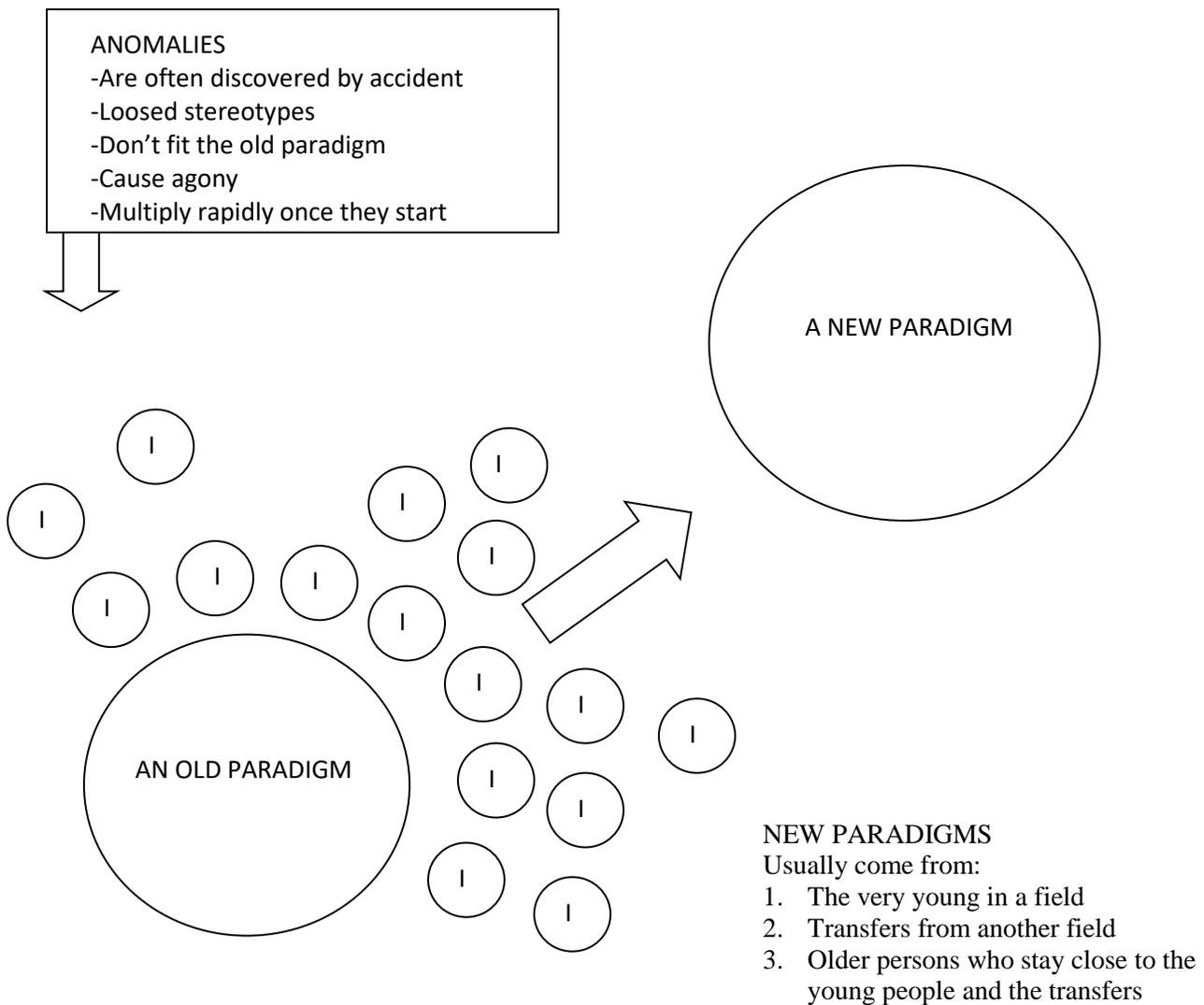
1. People had a terrible time recognizing unfamiliar cards.
2. People usually failed to recognize unfamiliar cards even when the cards were exposed 4 times longer than the recognizable exposure rate of regular cards.
3. Even though people were told that the unfamiliar cards were in the sequence, they still became confused and uncomfortable. One person's recorded response: "I can't make the suit out, whatever it is . . . . I don't know what color it is now or whether it's a spade or a heart . . . . I'm not even sure now what a spade looks like . . . . My God!"

Kuhn used this and other experiments to show how even brilliant scientists have resisted new views that challenge old ones. He described in elaborate detail the agony people went through before they accepted the fact that the world is round, not flat; that the earth is not the center of the universe; that electricity is not a liquid; that X-rays are real. His findings:

1. Perceptual revolutions take place after massive numbers of anomalous happenings and facts are discovered that cannot be explained by an old paradigm.

2. The anomalies are often discovered by accident. They are upsetting and painful, and they loosen stereotypes. Once they start appearing, they often keep multiplying until they force the discovery of a new paradigm.
3. New paradigms usually come through the work of two classes of people; the very young and people coming into a field fresh from another. (The point may be stretched, showing that veterans in the field can help with breakthroughs by staying close to the “youngsters” and the “transfers.”)
4. A new paradigm emerges, the textbooks on the issues must be rewritten.

Kuhn’s ideas about perceptual revolutions may provide some basic principles for changing attitudes toward people with Down syndrome. (See Figure 1 for a visual representation of the model.)



AS A NEW PARADIGM EMERGES,  
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Figure 1. A visual representation of Kuhn's (1970) model.

**KEY EVENTS IN THE PERCEPTUAL REVOLUTION TOWARD PERSONS WITH DOWN SYNDROME**

Although there are many other anomalous events, the following were key to the perceptual revolution toward persons with Down syndrome.

***Parents organized*** Around 1950, mothers and fathers of persons with disabilities, confused by professional advice of the day that clashed with the dictates of their hearts, and feeling extremely alone with the problem, began searching for other families in the same situation. Some even advertised in newspapers. When they got together, they shared in one another's suffering for a time. Then, drawing strength from their togetherness, they rolled up their sleeves and developed the first community services. At first, professionals, observing these homespun little organizations in action, shook their heads in dismay. The author recalls how the clinical wisdom of that day tagged parents as traumatized, agitated, and helpless when it came to doing anything creative for their own child, and many professionals predicted that these parents' actions could only make things worse.

***Local parent groups began to charter national organizations*** Lobbying and public attitude change efforts were initiated around 1953. Outstanding national organization newspapers described new perceptions and attracted new members to the organization. Many professionals joined the National Association for Retarded Children (now the ARC-US) for the remarkably informative *Children Limited*, a newspaper edited by veteran newspaperman Eric Sandahl. Now, many professionals join the NDSC to receive *Down Syndrome News*.

***Jerome Lejeune and the 47<sup>th</sup> Chromosome*** In 1959, Lejeune discovered the 47<sup>th</sup> chromosome. By 1968, researchers in some institutions began recording systematic arrays of chromosomes in single cells (karyotypes) from residents with Down syndrome. At the time, it didn't seem like a very big deal to most professionals. But those attending the annual meeting of the NDSC in San Antonio in 1984, could not help but notice how parents surrounded keynote speaker Lejeune, thanked him, shook his hand, and hugged him.

***The President's Panel*** In 1961, President Kennedy called for a national plan regarding mental retardation. His stirring message of October 11, coupled with his appointment of the President's Panel on Mental Retardation, led to the drafting of "A National Action to Combat Mental Retardation" in 1962 (PCMR, 1977).

***Nigel Hunt*** In 1967, *The World of Nigel Hunt* was published. Although many leaders in the field saw persons with Down syndrome as being unable to read or write, this young man with Down syndrome nevertheless wrote a pithy, humorous story about high points in his life.

***Who Shall Survive*** A film about infant death, entitled *Who Shall Survive*, was shown in 1971, in the Eisenhower Theatre in the John F. Kennedy Center for the Performing Arts, in Washington, D.C. It was the first time the theatre was used. Sargent Shriver, representing the Kennedy Foundation, paused during his opening remarks while technicians pulled a small cannon onto the stage. They exploded a blank charge while other technicians, stationed throughout the theatre, took acoustical readings, since that was the first time that the new theatre had been filled with people (Menolascino & Perske, 1972).

The leaders in mental retardation from all over the world experienced a second cannon shot. They watched a 25-minute documentary showing how a newborn infant with Down syndrome and an intestinal blockage had been moved to a corner in the nursery of Johns Hopkins University Hospital, and was starved to death. Using the actual doctors and medical personnel involved, but with actors playing the real-life parents, the film traced the grisly, 15-day, step-by-step developments from birth until death. Unlike the 1968 Westchester County incident, a furor was raised. But even then, the reactions were not as intense as those surrounding later infant starvations.

***Right to Education*** In 1972, a Pennsylvania right to education case ruled that every child has the right to appropriate education. A panel of three judges made the decree in the case between the Pennsylvania ARC and the Commonwealth of Pennsylvania. One more precedent was set that slowly began to revise an older view toward all people with developmental disabilities (Perske & Smith, 1977).

***National Down Syndrome Congress*** In 1973, the NDSC was formed. This organizations developed a sharper, more intense focus on issues surrounding the situation of Down syndrome. The organization further refined the advocacy begun by the National Association for Retarded Children in the 50s and 60s.

***PL 94-142*** In 1975, the Education for All handicapped Children Act (PL 94-142) called for a “full service” public school education. This mandate may have increased the interaction between special and regular education, and it set the stage for face-to-face activities between students with disabilities and regular students.

***Child’s Rights versus Parent’s Rights*** When Phillip Becker’s parents fought successfully in a California court, in 1980 to block lifesaving surgery for their 13-year-old son, dooming him to a slow and painful premature death, the rights of the child against the parents became an issue. And even though the Supreme Court refused to hear an appeal, letting the law stand, legal pressures continued until Phillip was awarded to the custody of foster parents. Recent reports have shown a young man, once destined to die, living a healthy, happy life. His current development has outstripped the earlier expectations of physicians who testified on behalf of his natural parent (Melberg, 1984).

***Baby Doe*** At first, it appeared to be just another quiet refusal to repair an easily corrected obstruction in the esophagus of a newborn infant with Down syndrome. It took place in 1982, in Bloomington, Indiana, with the Indiana Supreme Court saying that a starvation death was legal. But this time, people *moved*. Volunteer organizations began drafting petitions for the U.S. Supreme Court, and people willing to adopt the infant rushed to the scene. Unfortunately, the infant died before any further legal action could be taken.

Even after the infant’s death, the interest continued. Letter-writing campaigns and newspaper editorials abounded, and even president Reagan made what some view as one of his quickest, strongest, unilateral moves yet, when he threatened to withdraw federal funds from any hospital that ever did anything like that again. Baby Doe’s death became something that was far from quiet.

## **SENSING THE DEPTHE OF THE PERCEPTUAL REVOLUTION**

How far has the movement come since *The Atlantic Monthly* article in 1968? Consider the following fact.

Within the movement's organizations and networks, the dignity, value, and rights of persons with Down syndrome have soared. A few workers and volunteers still hold to an older view, but they are usually removed from current hands-on technology and advocacy efforts.

With ordinary citizens, the perceptual revolution may not have come as far as those in the field think. Everyone does not understand yet. However, enough new information has been introduced to make the average citizen take a second look.

Many physicians have become kinder and more understanding toward persons with Down syndrome. But the "Dr. K.s" are still present in the world, ever ready to give bleak prognoses about persons with an extra chromosome. One can see a hopeful trend in the number of physicians who have become active members of organizations such as the ARC-US and the NDSC. But physicians who refuse to accept a higher valuing of these persons remain, in the author's view, the movement's largest problem. Without sympathetic, understanding physicians, the going, especially for "new" families, will always be tough.

Judging from the recent spate of news articles about persons with Down syndrome, many reporters have become health catalysts for this perceptual revolution. Some have become so caught up with what they observed in a family, a group home, a classroom, or a workshop, that they took copious notes and wrote long, spirited success stories. The only problem is that editors often cut the stories from, for instance, 50 column inches to 11, or they choose not to print them. (Editors know that success do not sell newspapers as well as troubles do.) Even so, editors can be counted on to run hundreds of stories they would not have touched in 1968.

## **CURRENT EFFORTS THAT CAN HELP**

Although it may not have been the primary goal, almost every effort on behalf of persons with Down syndrome also helps change public attitudes – legislative efforts, parent activities, technical breakthroughs, supported employment programs, generic recreation programs, and many others. Since 1968, ordinary citizens have observed the enthusiastic actions of many parents, professions, and volunteers in community settings and many in the community now show an increased kindness and respect toward persons with Down syndrome. Even the gracious little things, like the way courageous parents take their children to public activities and send holiday greeting cards with pictures of their children with Down syndrome, have helped to make it more "in," more right, and somehow more godly to relate to people with disabilities than ever before.

***Good Working Relations with the Media*** Some organizations, even formal networks, now nurture individualized relationships with reporters who produce helpful pieces on behalf of persons with disabilities. Some organizations have been uncanny about making a reporter feel as if he or she had won a Pulitzer Prize for a story that helped the cause.

***Leadership and Candor of Public Figures*** Writer Emily Kingsly helps work people with disabilities into *Sesame Street*, *Quincy* and *Fall Guy* used actors with Down syndrome through the influence of writer-producer Low Shaw. Syndicated columnist George Will produces penetrating commentaries when crucial situations like the Baby Doe and Phillip Becker cases hit the national press. The U.S. Office of Special Education and Rehabilitative Services moves forward as a no-nonsense, leading-edge organization under the leadership of Madeleine Will. Senator Lowell Weicker fights vigorously for

legislation on behalf of persons with disabilities. Senator Hubert Humphrey openly discussed his grandchild with Down syndrome. Well-known people now seem more comfortable disclosing facts about their parent-age of children with Down syndrome than they did at the time Dale Evans (1953) wrote about her daughter. And this situation doesn't apply only to Down syndrome. The disclosure by present John F. Kennedy of his sister's mental retardation helped change public attitude.

***Creative Contact with Physicians*** The problem with physicians looms so large that massive campaigns will need to be planned on many levels at the same time. Even so, one should never underestimate the power some parents have had in converting their own family physicians to more positive attitudes toward persons with Down syndrome. Of course, some parents failed and had to change doctors. But even so, something may have been gained in the trying. NDSC might consider a parent-training seminar in which successful parents describe the steps they took to change the attitudes of their physicians. Physicians can now earn continuing education credit for participation in conferences about Down syndrome (e.g., the first annual conference on research and practice in Down syndrome, NDSC & Utah State University, June, 1985).

***Community and Family Living Amendments*** The movement began as Senate Bill 2053 in 1984. In 1985, it became S.B. 873, with 9 co-sponsors; House Bill 2902 emerged as a companion bill – with 77 co-sponsors. If it fails, advocates will see that it reappears in another form until a federal law is voted that supports persons with disabilities in the community, and their families as well. When that happens, attitudes of the average citizen will be affected, just like they were when the Education for All handicapped Children Act (Public law 84-142) became a law.

***State Zoning Laws*** Few people would want to live next door to a fraternity house, a large rooming house, or a larger-than-family-size home for persons with disabilities, not even if it was a federally approved intermediate care facility. No matter how much they like the people, their larger number could overwhelm neighbors and keep them at a distance. That is why many state zoning laws mandate that small group homes with six or less persons with disabilities be treated as single-family dwelling; in doing so, they have set the stage for healthy neighborhood relations.

***Adoption Networks*** Janet Marchese, the wife of a New York City policeman, who has been featured on network news programs and in magazine articles (see the May, 1983 issue of *McCalls*), runs a volunteer adoption program from the kitchen table of her White Plains home. She has successfully placed for adoption over 600 newborn infants with Down syndrome. The NDSC also maintains a list of people waiting to adopt infants with Down syndrome. Activities like this cannot help but influence many average citizens.

***Children's Peer-Group Education*** More and more students with disabilities are attending special education classes in their own neighborhood public schools. As that happens, more regular students will rub elbows with them in tutorial, advocacy, and guided-friendship programs being developed by forward-thinking educators. Brown (1979) pointed out that the future doctors, police officers, teachers, ministers – even the future parents of children with Down syndrome – are in the schools now. And the earlier people can understand and feel relaxed with persons with disabilities, the better. Someday, it may be proven that much of the jeering and derision that used to be hurled at children with disabilities really steamed from a lack of involvement with such children at an early age.

***Natural Reinforcement programs for Good Neighborly Acts*** Eight years ago, Gunnar Dybwad stated that more neighbors are for persons with disabilities than against them. These words were taken to heart during a series of national assignments conducted by the author. Over time, 158 neighbors were interviewed who lived near 87 well-run family-scale residences, each housing six or less persons with disabilities. The findings can hardly be considered scientific since a journalist's senses were used, rating

each interview tape in one of three ways, friendly, indifferent, and hostile. Twenty-nine percent were warmly involved with their neighbors with disabilities, 62% were indifferent, and only 9% were hostile (Perske, 1980, 1985b). Admittedly, most of those neighbors lived close to homes that leaders in the field claimed to be the best in their state. But the number of interviews with good neighbors moved the author to produce a novel, *Show Me No Mercy* (Perske, 1984), in an attempt to dramatize how valuable good neighbors could be to the Banks family and no Ben, their 16-year-old with Down syndrome.

This leads one to wonder if perhaps so much time and energy have gone to dealing with the loud neighborhood opposition, that the quieter, more caring neighbors have received little recognition and reinforcement. For example, staff writer Joseph Grace, in the March 19, 1985 issue of the *Bucks County Courier-Times*, reported that of 55 group homes in Bucks County, Pennsylvania, only 4 received neighborhood opposition (unfortunately, they received most of the press coverage, too).

Since educators are now quick to believe that unreinforced good behavior in students can fade, could that apply to neighbors, too? The day has come when new-breed professionals and volunteers will develop schemes for catching neighbors in the act of doing good to people with disabilities, then reinforcing them so naturally, that the good neighbors will feel valued and their gracious acts will continue (Perske, 1985b).

***Persons with Disabilities in Advertising*** “I am writing to you . . . about a matter of conscience . . . but, even more to the point, a matter of just plain good business sense” wrote Emily Kingsley of Chappaqua, New York, in one of her mailings to the nation’s top advertisers (personal communication, 1985). “In America, where advertising has always been so responsive to demographic needs and to the pressures of various minority groups, it is surprising to me that the advertising industry continues to ignore the group which is acknowledged to be “the *Largest Minority*” – that of the physically and mentally handicapped.” Kingsley set the figure at 37 million, then added the spouses, the children, the extended families, and the concerned friends, to help corporate heads see a glaring chasm in their advertisement campaigns.

She cited another survey she carried out with parents of persons with disabilities: “*Every single letter tells me that people would buy the product whether they need it or not.*” Her plea was so detailed and convincing, that executives have discussed the situation with her over the telephone. As efforts like these take place, the day will come when persons with Down syndrome will be seen doing ordinary things in the media, like appearing with other individuals in a Coca Cola ad, or sitting with other passengers in an Eastern Airlines Whisper jet.

***Neighborhood Support Plans*** The Children’s Clinic and Preschool, in Seattle, Washington, developed a 6-month project in which 16 families were given a budget of \$200 per month, to be used for payments to relatives, friends, and neighbors for support services they rendered. With this money, the families managed to recruit 84 persons who helped with in-home training, respite care, babysitting, transportation, mending clothes, and the building of special equipment (Moore, Hamerlynck, Barsh, Spieker, & Jones, 1982). Six months later, when the payments ceased, 64% of the helpers continued their duties as volunteers. Although the program was designed to purchase added family support, the attitude change of some outsiders came as a happy surprise.

***Efficient Media Monitoring*** Media persons now learn the hard way that demeaning statements about persons with disabilities can unleash a deluge of protests on an editor’s or program director’s desk. Those who organize on behalf of persons with disabilities are becoming keener and quicker about such monitoring. An article in the April 3, 1985 issue of *USA Today* serves as an example. In a featured interview, Jeff Lyon, the author of *Playing God in the Nursery*, approved of the death of Baby Doe in Bloomington, Indiana. He did not approve of the starvation method, but he upheld the parents’ belief that

the child was better off dead. His facts were pessimistic and he turned a blind side to the whole movement on behalf of persons with disabilities.

Before the sun had set, calls and telegrams reached the news room in Arlington, Virginia. NDSC, ARC-US, TASH, The Center on Human Policy, and others put organized protest efforts into motion and demanded a chance to present the other side of the story. Two days later, the editors had promised at least one such feature. One editor state unofficially that no other article had evoked so many letters, telegrams, and telephone calls. A one-half page article by NDSC's executive director, Dian Crutcher, appeared in the April 25, 1985 issue of *US Today*.

***Parallel Attitude Change Campaigns*** In the case of the aforementioned *USA Today* issue, many organizations moved on the editorial offices, each in their own way. Power would have been lost if all efforts had been centralized into a single push. And yet, when ships in a convoy move in different directions, there can be disastrous effects. Not so in this case. Valuable interchanges of information took place between organizations, showing that the more public attitude change efforts there are, moving in the same direction, using their own resources and channels, the better it will be.

***Fresh Perspectives from Self-Advocates*** In 1983, six Californians with developmental disabilities, one with Down syndrome, traveled throughout the state gathering the views of other persons with developmental disabilities on the services they received. With one advisor, a recorder/editor, and financing by the State Developmental Disabilities Council, they traveled 1,500 miles in California, talked to 150 people with disabilities, and recorded 70 hours of audio tapes. By oral training, not reading, they became expert on the Lanterman Developmental Disabilities Service Act, California's fill of rights and service delivery law. Anyone reading their report, *Surviving the System: Mental Retardation and the Retarding Environment (People First of California, 1984)*, will sense a fresh viewpoint emerging. Some points raised:

- “The Lanterman Act pushes for development . . . but the system pushes back” (p.9).
- Some persons with disabilities talked about being treated as if they were only commodities, only things Worth money to others (p.8).
- Questions were raised about being a Boy Scout at age 35 (pp. 14,31).
- Some persons with disabilities discussed how case managers told them they weren't ready to leave a residence when they knew they were being held back because of the money they brought into the service system (p.56).
- Some spoke about how they hated going bowling and to movies in large groups (p.14).
- Some felt successful services are rare because success is not rewarded (p. 58).
- The task force members felt that every service provider should have a course in the Lanterman Act (p.33).
- Some talked about workshops that made them more retarded (p. 32).
- Some hoped they would never have to work on another wind chime (p. 66).
- Some made it plain that they should be seen as “primary consumers” (p. 7).
- Others did indeed see themselves as “system survivors in retarding environments,” as the title on the report implied (p. 7)

The report, with its pithy and candid statements, has, according to the California Council on Developmental Disabilities, become one of the most widely read documents they have produced. It has been in demand throughout the nation and has undergone multiple reprinting.

Now that self-advocates are being heard, they will be introducing perspectives that would have been totally ignored in 1968. For example: New Jersey, New York, Pennsylvania, and Connecticut held a combined self-advocate and professional retreat (InterServ, 1986) in which persons with disabilities were

paired with high-ranking officials and professionals. They lived together (two people in each room) and attended sessions together. InterServ intended to show how face-to-face relationships can foster healthy attitude changes, more efficiently than mere didactic sessions could ever do.

***A Concern for all Persons with Disabilities*** To deal only with public attitude change toward persons with Down syndrome tends to be awkward. For example, in the aforementioned *USE Today* article, Jeff Lyon (1985) opened his article by singling out persons with Down syndrome in alluding to persons with all kinds of disabilities. The public can be expected to generalize like this, too. Therefore, when it comes to changing attitudes, there is a strong need for groups advocating for persons with specific disabilities to pull for one another.

## SUMMARY

The events highlighted in this chapter hint that there is a difference between the way persons with Down syndrome were viewed in 1968 and the way they are seen today. There has been an explosion of happenings leading to improved attitudes, acceptance, and awareness. A perceptual revolution has been taking place, but it is far from finished. Some individuals still cling to an older view based on misunderstanding, confusion, fear, and false assumptions about persons with Down syndrome. And such persons who fight to exclude individuals with disabilities from their circle of acceptance can cause disastrous setbacks.

And yet, the time may be right to apply Thomas Kuhn's ultimate questions, testing whether this perceptual revolution is successful: Has this movement progress to the point where *the textbooks are being rewritten*? The author of this chapter believe it has.

## REFERENCES

- Association for Retarded Citizens – Massachusetts, (1982, May). Tina Dirksen plays “Annie” at Newton South High School. *The ARC of Tomorrow* (annual convention program).
- Association for Retarded Citizens – Minnesota, (1984, Summer). Paul Wilke drummer for Warren High, *Focus*.
- Bard, B., & Fletcher, J. (1968). The right to die, *The Atlantic Monthly*, 3, 59-64.
- Brown, L. (1979). Education for living. In R. Perske (Ed.), *the child with retardation today – The adult of tomorrow* (pp. 16-18). Arlington, TX: Association for Retarded Citizens of the United States.
- Bruner, J., & Postman, L. (1945). On the perception of incongruity: A paradigm, *Journal of Personality*, 17, 206-223.
- Chafee, J. (1985, June), *Joe Connors serves as page in Congress* [a press release]. Washington: Senate Office Building.
- Crutcher, D. (1985, April 25). (Inquiry). *USA Today*.
- Down, J. (1866), Observations on an ethnic classification of idiots, *Report on Observations: London Hospital*, 3, 259-262.
- Dybwad, G. (1970). Treatment of the mentally retarded – A cross-national view. In H.C. Haywood (Ed.), *Social-cultural aspects of mental retardation*. New York: Appleton-Century-Crofts.
- Edwards, J., & Dawson, D. (1983). *My friend David*. Portland, OR: Ednick Communications.
- Evans, D. (1953). *Angel unaware*. Los Angeles: Fleming H. Revell.
- Fredericks, H.D., & Fredericks, D. (1980, June). Batter up: Baseball for children with disabilities. *Exceptional Parent*, p. 29.
- Hunt, N. (1967). *The world of Nigel Hunt*. New York: Garrett Publications
- InterServ. (1986). *How we lived and grew together*. New York: Author.
- Kuhn, T. (1970). *The structure of scientific revolutions* (2<sup>nd</sup> ed.). Chicago: University of Chicago Press.
- Lyon, J. (1985, April 3). *USA Today*.
- Lyon, J. (1985). *Playing God in the nursery*. New York, Norton.
- Melberg, K. (1984, February). Whatever happened to Phillip Becker? *Dialect*.

- Menolascino, F. & Perske, R. (1972, March). Afterthoughts on "Who Shall Survive." *Mental Retardation News*.
- Moore, J. , Hamerlynck, L., Barsh, E., Spieker, S., & Jones, R. (1982) *Extending family resources: Project of national significance*, Washington, DC: Administration on Developmental Disabilities.
- National Broadcasting Corporation. (1982, February). "*Quincy*" episode features David MacFarlane. New York: Author.
- National Organization on Disability. (1984, September). [ the press release on Matt Starr]. Washington: Author.
- O'Callahan, P. (1982, June 3). Darsi Hilty gets regular diploma at Columbia High, *Tri-City Herald* (Paso, WA)
- Pennsylvania Association for Retarded Citizens v. Commonwealth of Pennsylvania, Civil Action No. 71-42 (1971).
- People First of California. (1984). *Surviving in the system: Mental retardation and the retarding environment*. Sacramento: State Council on Developmental Disabilities.
- Perske, R. (1980). *New life in the neighborhood*. Nashville: Abingdon Press.
- Perske, R. (1981). *Hope for the families*. Nashville: Abingdon Press.
- Perske, R. (1984). *Show me no mercy*. Nashville: Abingdon Press.
- Perske, R. (1985a, February) Writing a first novel. *The Writer*, pp. 33-34.
- Perske, R. (1985b). A second look at neighbors. *TASH Newsletter*, 11, 2.
- Perske, R., & Smith, J. (Eds.). (1977). *Beyond the ordinary: The preparation of professionals to educate severely and profoundly handicapped persons* (p. 3). Seattle: American Association for the Education of the Severely/Profoundly Handicapped.
- President's Committee on Mental Retardation. (1977). *Mental Retardation: Past and Present* (pp. 105-106.3), Washington, DE: Author.
- Stewart, R. (1979, August 16). Blood bank approves Joe Mayer as donor. *The Providence Journal* (Providence, RI).
- UPI. (1984, December 16). Jason Kingsley stars in "Fall Guy." *The Nashville Tennessean*.
- Walden, G. (1984, April 14). Mitchell Levitz creates his own miracle. *Westchester Count Reporter Dispatch* (White Plains, NY).