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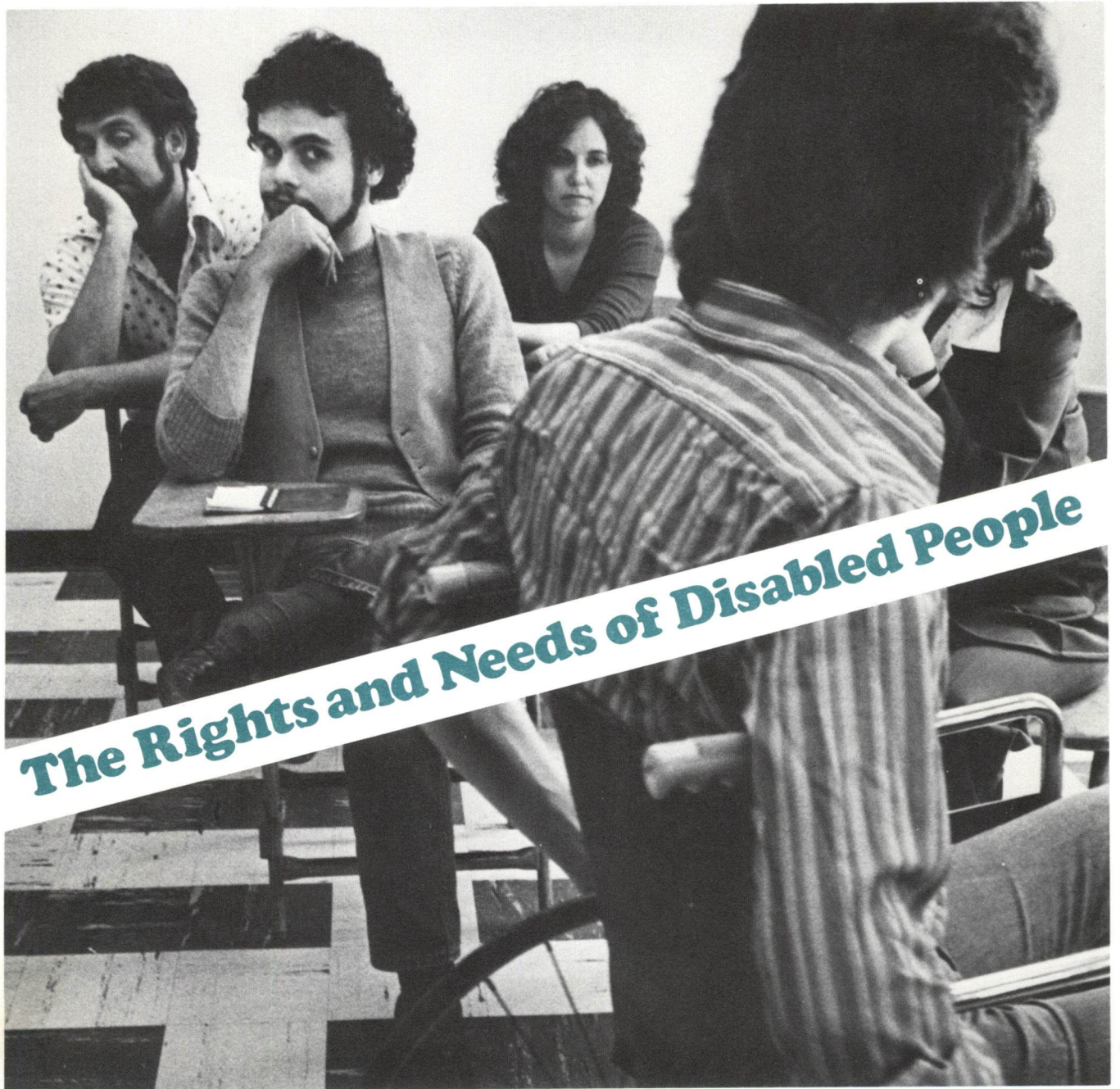
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JOURNAL OF CURRENT SOCIAL  
**ISSUES**

# Looks Can Kill!



**The Rights and Needs of Disabled People**

# LOOKS CAN KILL: The Rights and Needs of Disabled People

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Address editorial correspondence to Paul H. Sherry, 287 Park Avenue South, New York, NY 10010.  
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# Editorial: Take Care

A short time ago I took a cab to the Dayton Airport from the Bergamo Retreat Center in Dayton, Ohio. The cab ride took about thirty minutes so the cabbie and I had time to talk at some length. In the course of the conversation, he told me that he and his wife were about to leave for a convention for the deaf in Rochester, New York. His wife is a deaf mute, and about ten years ago the two of them were instrumental in helping build an organization for the deaf. They have been attending the organization's conventions on an annual basis since then, and were looking forward eagerly to this convention-vacation.

The cabbie was in a talkative mood and began to tell me about his wife and family. They were married seventeen years ago and have three children—a sixteen-year-old son interested in animal husbandry who already has highly developed veterinary skills; a rebellious thirteen-year-old son who is in danger of failing this year in school; and a nine-year-old daughter who is everything her father ever hoped she would be. He sounded like a typically concerned father.

The cabbie was especially eager to talk about his wife. When he first met her, she was insecure and withdrawn, but no more. He told me, with great pride, that he "had been good for her." He drew her out of her shell, gave her a sense of her many abilities, helped her over a period of five years to learn to lip read, and in general helped her see that her disability need not prohibit a fulfilling life. He spoke most, however, about how much his wife means to him. Enthusiastically, he told of her position in a local Dayton bank operating a machine which few others in the area have mastered. She runs the household "like clockwork," cares deeply for their chil-

dren, and is a loving and supportive wife. Their work together in the association for the deaf is drawing them ever more-closely together, and is a source of great satisfaction. The cabbie's words were reassuring in a period when so many couples are struggling to hold their marriage together.

I relate this brief conversation because it helps illustrate many of the themes addressed in this edition of ISSUES:

—The disabled, like all of us, are unique children of God whose lives are in many ways very different and in other ways are quite the same;

—The disabled, like all of us, have individual needs which can be met if we reach out in loving care;

—The disabled, like all of us, have a remarkable God-given potential which can be released for fulfillment and service;

—The disabled, like all of us, need to love and be loved if we are to live.

This ISSUES illustrates these themes. The issue does not over-romanticize; rather, it tries to speak candidly about the difficult and oppressive situations in which disabled people often find themselves. But neither does the issue wallow in despair. Rather it points to ways by which a disabled person can be a full and contributing member of society so that all our lives can be enriched.

When the cabbie dropped me off at the airport, he told me to "take care." That's good advice for all of us as we seek to minister to each other—take care.

PHS

## ON READER'S RESPONSE

With the next ISSUES, Summer '79, we would like to start a Reader's Response section, perhaps a page or two of your reflections or opinions—expert or otherwise—about what we print. We say Reader's Response because we want this to be more than a letters-to-the-editor column: we want it to be your response to each other.

The topics we address affect us all, and, while each edition of ISSUES touches upon a new theme, these are not mutually exclusive nor are they without mutual cause and concern. Reader's Response is your chance to speak your mind or heart while enhancing the continuity of our investigations together.

As a reader of ISSUES, you have thoughts, feelings, anecdotes, experiences, or advice about what you read in these pages. We encourage you to send them, bearing in mind that space is limited. Send whatever you deem appropriate to: Reader's Response, Journal of Current Social Issues, Room 710, 287 Park Avenue South, New York, NY 10010.

One other thing. This ISSUES is printed with justified type. This means we get more words to the printed page without sacrificing the openness of our graphics. This change follows two others within the last year: a new logo last spring, and a smaller typeface last summer. We hope you agree these changes improve the quality of this journal.

JF

# Looks Can Kill

## Robert E. Neale

How do I put my arm around the shoulder of a colleague who has no arms? How do I embrace an acquaintance whose body is encased in a wheelchair? And how do I clasp the hands of my friend who uses crutches, holding one of them with a misshapen appendage? From a distance. I do not touch them. I look at them. And they look at me. One of them has spoken about it. Ron Whyte's credo, "I Believe," tells me:

*You can get Muscular Dystrophy from a toilet seat.*

*Paraplegics are contagious.*

*Cancer can be transmitted by sex.*

*Never touch a dead person—Death is catching.*

*Good people die young.*

*Looks can kill.*

*I am looking at you.*

This is absurd. But it is easier to look at my friend's poem than at him. I see whimsey, anger, and, most of all, these graceful words that clash so with his physical appearance. The poem is a window more tolerable than the eye. "Looks can kill." This is the last of his list of superstitions. We are prepared to dismiss it along with the others, but are unable. He is looking at me, at all of us, in this poem. If we can return his gaze, we glimpse something we do not care to see directly. Loneliness. The credo is: "I Believe I'm Lonely." This is illicit communication. Muscular Dystrophy, paraplegia, cancer, and death are infectious because loneliness is. The looks of loneliness can kill. We cannot look into the eyes of the disabled because we know that to see their loneliness is to uncover our own. How difficult it is when they insist upon looking at us. How understandable it is that we do our best to teach them to avert their gaze or close their eyes. But "superstition" prevails. Even the blind can look at us. No inoculation is possible. Loneliness is catching.

It is our inclination to affirm: "There is only one suffering—that is to be alone." Hell is neither other people nor the self, but disconnections between self and other. The infant cries when she cannot see her mother and Jesus cried when he could not see his Father. And the disabled—the 35 to 45 million people in our country who are physically disabled, deaf or have hearing impairments, blind or are visually impaired, mentally disabled, institutionalized, or homebound—cry out also as the invisible who cannot see or be seen. For all of us, full vulnerability is the remembrance, experience, and anticipation of loneliness. The one human suffering is to be alone and the one human cry, "Why hast thou forsaken me?"

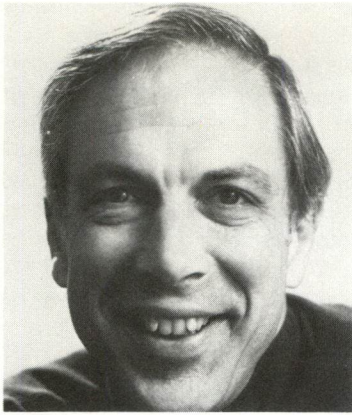
But this is not so. Our inclination is devious and our conclusion erroneous. Loneliness is not the only suffering, not the worst suffering, and not even an entirely negative experience. When the condition of loneliness is so fostered and yet equally concealed, as it is in our society, it becomes inflated and all the more difficult to understand. Loneliness is not the only suffering. It is a discrete psychic state which does not replace such sufferings as anxiety or depression. And there are social conditions of poverty, class and racial discrimination that are sufferings in their own right. To consider loneliness as the only suffering is flight from the complexity of suffering. Nor is loneliness the worst suffering. Consider the infant who no longer cries out, but has succumbed to the silence of apathy. She is beyond loneliness in the worse condition of despair. What if Jesus had not cried out to his Father, but become dumb in spirit? It is at least possible to wonder if the resurrection would have occurred. Living beyond loneliness is the suffering involved in forfeiting humanity. Finally, it cannot even be claimed that loneliness is only a

negative experience. It is a movement away from despair and toward hope in relationship. The rage of "Looks can kill./I am looking at you" is energy directed outward for the sake of connection. It is an affirmation of what must come to pass between human beings. Loneliness is not the only suffering, not the worst suffering, and it can be redemptive suffering.

The intent of this essay is to explore loneliness as catching. The occasion is the lack of relationship between the disabled and the able. The theme is that loneliness is a condition of separation and search which leads to companionship, and that getting caught by it is a valuable experience. The goal is such companionship between the able and disabled. There are looks of loneliness that can kill. These must be. To be so eyed is to have our own loneliness uncovered and our willful blindness destroyed. But there are also looks that kill loneliness. These too must be.

What is this condition that is so contagious? It is hard to say. It is hard because thinking about it recalls the experience and we would prefer not to. We are apt to consider the experience as baffling, terrifying, and alien, as what occurs when we are not really ourselves. Perhaps the poem, "I Believe," is wise in being so indirect about it. Others have been more direct. Speaking of an old man living in isolation on a winter night, Robert Frost records: "A light he was to no one but himself." Quite different from this quiet chill is the fiery anguish of the Psalmist:

*Those who see me in the street  
Hurry past me,  
I am forgotten, as good as dead in  
their hearts,  
Something discarded. (Psalm 31)*



Robert E. Neale is Professor of Psychiatry and Religion at Union Theological Seminary where his teaching includes aging and religious symbolism. He has written extensively in the area of death and dying and is presently writing on the subject of loneliness and companionship.

And those poets who are quite without capacity to protect themselves may be even more direct. Here is the question of a schizophrenic:

*And is there anyone at all?  
And is  
There anyone at all?  
I am knocking at the oaken door  
And will it open  
Never now no more?  
I am calling, calling to you—  
Don't you hear?  
And is there anyone  
Near?*

*And does this empty silence have to  
be?  
And is there no-one there at all  
To answer me?*

*I do not know the road—  
I fear to fall.  
And is there anyone  
At all?*

To read this poem aloud—to use one's own voice in asking, "And is there anyone at all?"—is to hear the ensuing silence. This we cannot bear. So we retreat from the expression of mood to consider more abstractly the dynamics of loneliness.

Perhaps the initial awareness we have when lonely means just that something is wrong is the awareness of absence. And this sense of absence is usually, but not always, social in nature, a reference to absence of relationship to one or more human beings. Typically, we are aware that this is the result of a change—loss of relationship. Continuity of social support has been broken. What is important is not the absolute level of social support, but its continuity. Those who experience the death of a spouse or a divorce may be more lonely than either the married or the single.

One can be isolated without being desolated. However, we may experience isolation for a long time without being very aware of it. When awareness occurs, loneliness may flood into consciousness even though social support has been continuous at its low level over a long period. Therefore, it is either an exterior or an interior change that causes awareness of an absence. What is loneliness? It is the recognition of separation.

Loneliness is more than this. The psychiatrist, Harry Stack Sullivan, defined it as "the exceedingly unpleasant and driving experience connected with inadequate discharge of the need for human intimacy." The absence is noted, but the stress of the definition is on need and drive. The point is that this awareness of absence fosters a restless drive for restoration or replacement. Sullivan's definition has the merit of pointing out that loneliness is not a passive and static condition, but a most active one. It is a searching for relationship, an attempt to right the wrong of absence. Sooner or later, loneliness may be replaced by apathy. One gives up the search. When this happens, the individual is isolated, but not lonely. Loneliness includes hope. The last lines of Siegfried Sassoon's "Alone" express this:

*Alone. . . . The word is life endured  
and known.  
It is the stillness where our spirits  
walk  
And all but inmost faith is  
overthrown.*

The experience is pervasive here. The poet's whole life is perceived as lonely. Even so, "inmost faith" remains. This hope is the source of the action to restore relationship. Without it, there is

the non-action of apathy. With hope, the search continues. What is loneliness? It is the experience of searching.

Loneliness is a dynamic state with two aspects, each of which must be present for it to occur: recognition of separateness and the attempt to overcome it. Without the recognition of separateness, it is clear that loneliness does not occur. But the recognition may not lead to loneliness when the individual either experiences separation affirmatively or despairingly. Therefore, loneliness is a dynamic state. Neither a wallowing in despair nor an exultation in victory, it is a full engagement in the battle to participate. It may end in pseudo victories or in apathetic withdrawal, but while loneliness exists, the individual is devoted to a life and death cause with maximum use of human powers. And since loneliness is a common, daily experience, the battle is a continual aspect of human life. It is a dynamic that is related to much of our daily activity. All of our behavior is overdetermined, has many causes and serves many functions, fundamental ones being elimination of loneliness and pursuit of participation. What is loneliness? It is full engagement in the battle to participate. To be lonely is to be between denial and despair in precarious, but realistic, hope for relationship.

This basic definition of loneliness can be expanded in many ways, three of which will be summarized here: the causes of loneliness, the objects of loneliness, and the need for balance between separation and search. A review of these concerns will remind us of the complexity of a phenomenon that we are all too prone to simplify in our eagerness to flee it.

The mood of loneliness is one, but it can be the consequence of different causes and experienced at different levels. The first level is *primary loneliness*. This is a discovery of the human condition as being such that one is always separate as well as participant. Such loneliness is an inevitable and necessary aspect of human existence. It is not dependent necessarily upon the loss of a relationship, but on our capacity to perceive the self as separate. However natural, this is not an awareness we tend to seek and cherish. The second level is the *loneliness of social discontinuity*. This is the common understanding of loneliness as being due to actual losses of objects and persons. Such disruptions are natural and inevitable, however disturbing. The loneliness is pervasive, but also occasional and capable of being overcome.

The third level is *problematic loneliness*. This refers to causes of loneliness that are unnecessary, although common, in the self or society. Some individuals and some societies are loneliness-prone. Individuals may be afflicted with such physical appearance or early formation of personality that others are led to keep their distance by means of ridicule or ostracism. Of course, problems of the self are partially created, and certainly matched, by problems in society. The loneliness-prone individual is never the only cause of the loneliness. It requires two or more human beings with one or more *in absentia*. There are societies and groups within societies that are destructive of the loneliness-prone because of the high degree of social discontinuity present. Class and racial divisions, breakup of family and community life, mobility, and the conditions of rapid cultural change—all are characteristics that suggest a loneliness-prone society. When both society and individuals are prone, unnecessary loneliness becomes common.

The fourth level is that of *faulty response to loneliness*. This is the situation in which the already lonely compound the problem by their responses. It involves pampering oneself, disparaging others, opting for casual sex, keeping busy, and all other such arrangements we devise which both ward off the awareness of loneliness and excuse it. Rather than resolve or diminish, they actually increase loneliness. This brief review suggests that there can be a danger in acknowledging only one cause. To dwell only on primary loneliness is to avoid the role played by one's

own personality and one's own society in fostering unnecessary suffering. Those who focus only on the unnecessary levels of loneliness can be prone to the temptation to abolish all such suffering. The four levels remind us that we can neither deny nor despair over loneliness but must fight the battle even though the war is unending.

Loneliness also has different objects. We can become lonely with regard to almost anyone or any thing. As the levels of loneliness refer to the depth of it, so the objects of loneliness refer to the breadth. These are five possible types of relationship. The first two are those we commonly think of with regard to loneliness—the *individual* and the *group*. We are aware of the driving restlessness and yearning search for relationship when continuity with either of these relationships has been broken. Being without an individual gives rise to pervasive apprehensiveness over a world and self that are perceived as barren and hollow. Being without a group relationship fosters boredom, aimlessness, and a sense of being on the margin of social life. The end of a marriage, by death or divorce, may give rise to both objects of loneliness. Either of the two disruptions may be the most significant. In a society which stresses the one-to-one relationship so strongly, we are inclined to play down and then be surprised by the power of a social network. Both objects for relationship are essential and neither is a substitute for the other.

The third object for relationship is the *material world*. Our need and our creativeness in fulfilling it are obvious. Houses, neighborhoods, pets, plants, automobiles, the toys of all generations—these are objects from which we can become separated and for which we will search. We are all collectors. Such materialism is profoundly human. We have bodies in space and so must connect ourselves to it by means of objects. The material world is never to be a substitute for the world of a person or people, but regarded as a companion in its own right. The fourth object for relationship is *history*. Because we can recall the past and anticipate the future, to not have a relationship to time is to experience oneself as disconnected and lonely. We remain lonely, not knowing who we are and what we are worth, until we find and make friends with our beginnings and endings. To lose the loneliness is to discover relationship with the generations.

Finally, the fifth object for loneliness and relationship is the *world as a whole*. There is a world loneliness that occurs even when we may have relationships with some of its parts. Life as a whole can appear so foreign as to engender an indefinable restlessness. The question, as Chesterton noted, is "How can we contrive to be at once astonished at the world and yet at home in it?" As "strangers in a strange land," we become pilgrims in search of the world as companion. This is the avowed business of formal religion, but the loneliness may occur in anyone who is moved to wonder about the whole. This brief review can remind us of the danger of assuming we know what any concrete instance of loneliness is about. It may pertain to any one or more of the possible relationships. And the discovery of one kind of relationship will offer little comfort about, and fail to substitute for, the other kinds being sought. The fundamental reminder is that our need to be so firmly embedded in existence renders us prone to a great variety of separations and searches. Our loneliness can be of unimaginable breadth. The unending battle we must fight is waged on a variety of fields.

Finally, in amplifying the basic definition of loneliness, we consider the issue of balance between separation and search. Our experience of loneliness includes both poles, but we tend to verge more on the side of one or the other. To function with balance is to avoid both denial and despair and to achieve realistic hope. Unbalanced loneliness diminishes the latter and increases the denial and despair. One whose loneliness is most characterized by recognition of separation is not realistic about the possibilities of searching. The separation is inflated. This is natural at the time of discovery of the separation, but continued inflation indicates unreality about the relationship. The most obvious example is the abnormal grief of the bereaved which typically indicates difficulties in the relationship prior to the death which are masked by idealization.

In a similar way, imbalance on the side of search raises the question about how much genuine hope exists. Human beings, like other animals, can be so shocked that they are immobilized. But often they are shocked simply into random activity. In the immediate aftermath of a severe separation such as the death of a loved one, there is often a

great deal of busyness, a "bustle in the house," that reflects both a need to keep oneself occupied in order to ignore what happened and also a need to randomly search in a panic for relationship. The searching is manic, a defense against unbearable threat. It may express more the need for hope than actual hope itself. As one can "protest too much," so can one search too much. As a focus on separation can be, paradoxically, a despairing denial of separation, so a focus on search can be a despairing denial of search. Neither is realistic and hopeful.

However, we should be careful not to focus on realistic hope in such a way as to ignore or disparage denial and despair. Such an attitude would be neither realistic nor hopeful. There are times when absence of denial and despair would be most suspicious. These are fundamental human reactions that are legitimate means for protection and survival. They have negative effects, but these can be worth the positive effect of enabling the person to endure until such time as other means of coping can be instituted. One does not counsel a bereaved wife of two days that she will find another husband. The denial and despair need to be. But they need not be everlasting. To understand and sympathize with the fact that they can be does not lead one to conclude that they inevitably and interminably must be. Chronic denial and despair, regardless of the situations that have prompted them, are indications that the causes and worlds of loneliness have not been sufficiently explored. Denial and despair are human, but so also is the attempt to overcome them. This is to assert that the individual is naturally moved toward a loneliness in which separation and search are balanced. And to apply this dynamic of balance to the depth dimension of different causes and the breadth dimension of different objects adds another complexity to any exploration of a specific experience of loneliness.

This summary of a definition of loneliness, its causes, its objects, and the necessity of balance between separation and search, is intended to underscore the richness of the loneliness experience. In so exploring, we have fled the mood of loneliness, but have prevented flight to a simplistic understanding of the condition that is equally dangerous. The summary is heuristic, based, not so much on research or even informal experience, as on a need to provide ways of thinking about loneli-

ness. The ideas are means of ordering chaos, but also of bringing to mind aspects of this chaos that have been forgotten or concealed. However toneless in the face of the experience itself, they may help recall and fix the richness of being lonely. It is an awesome richness, equally frightening and exhilarating. Looks of loneliness kill what needs to be killed—the perception of loneliness as only frightening. And looks of loneliness revive what needs to be revived—the exhilaration of loneliness and the wonder of companionship.

Ron Whyte's credo, "I Believe," communicates a loneliness that is catching. It does so just barely because it is almost entirely a "circus" poem. The circus is a setting for display of beautiful bodies and graceful movement. It is where we parade human form in the guise of gods and goddesses, and where we tumble like agile monkeys and fly like winged birds. This circus is our reminder of bodily perfection. There are two exceptions. In the side show, we see the freaks displaying their imperfections with serious and solemn factuality. In the main tent, we see the clowns using their imperfections with awkward self-regalement. By the former, we are amazed; by the latter, amused. In neither case, are we and the disabled engaged. The freaks and clowns serve only to emphasize the main show of bodily perfection. Their looks do not kill for we do not see each other. The poem, "I Believe," has much of the freak and clown in it, but the last lines, "Looks can kill./I am looking at you," are powerful precisely because they leave the setting of the circus. And when the disabled join the mainstream of life, their looks can kill. We see their loneliness and catch it. My friend looks at us again in two poems:

*Glad to Meet Your Measurements*

*Whenever you meet  
a new person,  
either a girl or a boy,  
you immediately measure  
the distance from the bottom  
of their ass,  
up to their shoulders,  
and see how your torsos compare  
in size,  
just in case you'll ever end up in bed  
together.  
It doesn't matter  
how long their legs are:  
just the length of their torso.  
It is a great comfort*

*to find people with the right  
torso length.  
When you have  
artificial legs  
you think about  
things like that.*

*Love Song*

*Hold my hand  
if you dare to.  
Do not hold my right hand  
which at first glance  
looks to be like your own hand,  
with fingers/fingers four and thumb.  
Rather, grasp and hold  
my left hand,  
that thick thing  
that bends at the wrist  
into one long finger and  
what is the other shape,  
a thumb?  
or is it, perhaps,  
stunted fingers grown  
together beneath a single  
finger-nail?  
Hold my left hand,  
hold my right hand.  
I promise  
I too shall hold your hands with mine  
as best as I am able.*

There is still a little of the circus in these poems (and let us hope there always will be some reminder of the freak and clown realities), but they have moved largely into the mainstream of our lives. To read them aloud—to use one's own voice in saying, "When you have/artificial legs/you think about/things like that" and "I too shall hold your hands with mine/as best as I am able"—is to hear the ensuing silence. It is his voice, but it becomes our own as well. The sexual intimacy of torsos and the warm friendship of holding hands—these are images which reveal to us the separation and search in which we are all caught. His loneliness is contagious. He believes he is lonely and so do we. It is a credo we have in common.

There are dangers that can occur in the process of getting caught by loneliness when the disabled and able look at each other. They are numerous. First, there is the danger of assuming that loneliness *per se* can be permanently eradicated. It cannot, as examination of the various causes reveals. Second, there is the accompanying danger of assuming that nothing can be done about it. Something can, as some of the causes are not inevitable. Third, there is a danger of assuming that either the disabled or the

able are more lonely than the other. This is doubtful because both the causes and worlds of loneliness are many. This danger may involve a kind of bizarre romanticism or equally bizarre disparagement of the other. Both society and the individual may foster loneliness by their behavior. The complicity is universal. Neither the able nor disabled are without the blemish of self-imposed distance from the other.

Fourth, there is the danger of assuming that absence, or elimination, of loneliness in one world lessens or removes loneliness in another world. A disabled person's attachment to crutch or wheelchair, however meaningful, substitutes for no other world of relationship, nor would such attachment to the world of history or to the world as a whole. Equally, it is the case that relationship with an intimate lover is not a substitute or relationship with a network of friends. We suffer loneliness when either is lacking. Neither the able nor the disabled can write off the other by means of the assurance that they have one world of human relationship.

Fifth, and finally, the great danger for all lies in assuming that loneliness is either negative or positive, either separation or search. Some of the able may need an existential pratfall to discover their separation and some of the disabled may need an existential kick in the pants to discover their search. Catching loneliness should remove all these assumptions of distance. They reflect the circus mentality wherein all participants, performers and spectators alike, grandstand as freaks and divinities rather than meet as human beings.

The dangers that can occur in the process of getting caught by loneliness are matched by possibilities. Ron Whyte's three poems are contained in his essay on disability, "New Forms of Grace." (*Issues*, Vol. 15 No. 3, Fall, 1978.) He concludes: "I believe there is only one grace, but that grace has many forms." Just so. He is one form and I am another. All of us make many forms, old and new. But the grace is one. We experience it as companionship. The dictionary defines a companion as follows:

*One who accompanies or is in company with another for a longer or shorter period, either from choice or casually; one much in the company of another or others; an associate; comrade.*

This is the first definition given, but the term can also mean a person who is employed to live or travel with another, a member of an order of knighthood, or simply one of a pair or set of like or matched objects. Synonyms of companion are fellow, mate, and compeer. Further, the term, "companion," is assumed to be the most general one for a person who is in another's company. An "associate" suggests habitual fellowship, usually on terms of equality. And "friend" tends to signify a closer and more intimate relationship. "Comrade" refers to an association in which there is a common calling or pursuit or community of interest, as in "comrade in arms." So we can conclude that a "companion" must be defined very imprecisely as one who is in the company of another. This is valuable because it fosters understanding of its breadth and depth of meaning.

Companionship has breadth. The term allows us to speak of lovers, friends, and members of interest groups as companions all, regardless of the differences between these relationships. Companionship is what they all have in common. Whereas we could not so easily subsume all our human relationships under the common understandings of love or friendship, and because of our special meanings for these latter kinds of relationship, we do not use them easily in reference to our material, historical worlds, let alone the world as a whole. What we do seek in all worlds of relationship is companionship. The term is useful because of its breadth.

But companionship also has the possibility of depth. The term comes from the Latin, being comprised of *com* (together) and *panis* (bread). The sharing of food is one of the most fundamental human activities, both an act for survival and an ultimate religious act in most, if not all, traditions. Like sexual intercourse and only a few other actions, it is rich with associations and meanings at every level of individual and social and religious existence. We do break bread with lovers, families, friends, associates, and even with strangers and enemies. The breadth of being a companion remains. But in the breaking of bread together, we act at the deepest levels of our lives. So what is most broad in meaning can also be the most deep, even deeper than friendship or love as usually defined. The very flexibility of our use of the term, "companion," is a sign of its depth as well as of its breadth of meaning.

Loneliness is catching. But the contagion is a fever which heals by engendering companionship. We need not circuses, but bread. The disabled are looking at us and we are to look at them. To do so is to leave the circus together. Such companionship will not eliminate all our loneliness. We will dine together, but only while traveling. Such movement always entails change in relationship. Both parties will flee back to the circus and loneliness will reoccur. Moreover, both parties will fight for growth, and such changes in relationship will create new loneliness. As loneliness does not and should not end, so companionship is not and should not become secure. The grace of companionship is like the wind in that it cannot be caught and controlled in the paper bag of our desire for status. We cannot catch it, but we can be caught by it. The poet looks at us, saying, "I am lonely and could be your companion." Can we look at him and those he speaks for, saying, "We too are lonely and could be your companions"? How will I greet Ron Whyte the next time he and I see each other? How will you greet the disabled when they and you see each other? And how will they greet us? If we have been caught by loneliness, we will attend to the matter. ■

# We Have Come to Understand

## Jerome J. Hevey

Our beautiful daughter, Myrle, has Parkinson's disease. Parkinsonism results in damage to the nerve cells controlling function. It is sometimes called Paralysis Agitans. Tremor and shaking accompany it. It is also characterized by a shuffling gait, stooped posture, a fixture of facial muscles—usually referred to as "Parkinson's Mask"—and progressive rigidity of muscles. The disease is progressive although there are plateaus. Quite recently, remarkable response has been noted in some patients to L-Dopa,—the so-called "miracle drug."

The diagnosis in Myrle's case was not made until the age of twelve when she weighed forty-three pounds, was unable to swallow or speak, and had both hips dislocated. Since that time she has been on large doses of Artane, Valium and Benedryl daily, and since 1972 when the medical people felt the L-Dopa was safe enough to try on her, she has been on that medication, in addition to the others, with dramatic effect.

Our family experience began with an undiagnosed illness when Myrle was eighteen months. We shall never know the exact etiology of her problem and there are many question marks. She had strep throat and a temperature of 106 degrees when she was taken to the hospital where she had one seizure. The high sustained temperature is a symptom of Viral Encephalitis, and yet, at the time, we were told all tests proved she did not have it. Years later, when a famous Johns Hopkins Medical Center pediatrician diagnosed the Parkinsonism, he said, "She *must* have had Encephalitis." We shall never know.

At the time of its onset, Myrle's problem was diagnosed as Cerebral Palsy. When we left her in the hospital crib that December 8th, it was the last time for many years that we saw her sitting up

alone. When she was released, she was unable to function as she had before. She had little balance and would fall over easily. She could not creep for a long while. There was tremor in her arms. She could not walk or sit up without assistance. She had no problems speaking nor did she show any intellectual damage, although as the years went on it became evident that she had conceptual difficulties. She could remember telephone numbers, addresses and post office boxes we hadn't used for years, but she could not multiply or divide, and she lost her sense of distance and direction.

The illness at eighteen months started a pilgrimage from one famous diagnostician to another, a seemingly never-ending search for the answer to "What is wrong with our child?" The very first answer we had was "an undiagnosed case of polio." This well-known doctor packed her into a brace which effective-

ly immobilized her. Several months later when, dissatisfied with this procedure, we were referred to one of the world's best known physicians in New York City, he took one look at her and said, "Take off that goddamn brace and throw it away." Our association with this world-renowned temple of rehabilitation, where it was assumed that she had Cerebral Palsy, continued for eight months until brain surgery was recommended. However, three other neurologists disagreed, and the surgery was never performed.

To encapsulate a twelve-year story of progressive difficulty and damage, Myrle's situation grew worse year by year. With Cerebral Palsy the initial damage, no matter what its etiology, is done and then you work with what you have. You retrain and rebuild and rehabilitate. But as parents we could tell that Myrle's problem was not Cerebral Palsy. Yet, whenever we suggested that



Jerome J. Hevey is ordained in the United Church of Christ, and is minister of the First Congregational Church of Manchester, Vermont.

there might be another diagnosis, we were looked upon by the medical profession as presumptuous idiots. I frequently paid a week's salary and traveled several hundred miles to have some prima donna of the medical profession take a fifteen minute look at my child (incidentally, after waiting hours after the appointed, overbooked time), and tell me the same diagnosis, saying that he, having seen her for that brief time, could tell better than we, who lived with her night and day, what her problem was. Who were we to disagree with some of the best medical minds on the entire eastern seaboard! So let us admit to a love-hate relationship with the medical profession. We learned years later that each doctor, so impressed by the name and reputation of the colleague who had confirmed the previous diagnosis, just went along with it.

In December, 1963 the situation was its blackest. By a strange and provident circumstance, a young intern friend of ours came to see us and discovered for himself the serious and hopeless nature of the problem. He said he didn't know the answer but he would find it. Myrle, dying slowly of malnutrition, was given three months to live. Our intern friend led us to a doctor at Johns Hopkins who took one look at her and said, "That's Parkinson's." Within two weeks of taking anti-Parkinson medication, we noticed a difference. In a year Myrle was a new person. We have Myrle's progress on film.

That was not the end of her problems, however. Several procedures had been done for Cerebral Palsy which were contraindicated for Parkinsonism. The damage had to be dealt with. This meant surgery, hospitalization, therapy, special schooling and a host of inciden-

tal problems. Each surgery held as its aftermath—as did each minor illness such as the twenty-four-hour virus—a trauma which quickly became life-threatening. Anxiety was our daily companion for twenty-three years, and this did not cease once Myrle was hospitalized because we tended to believe that no one could care for Myrle as well as we could. We had to learn to overcome that feeling.

To date Myrle is in the twenty-third hospital she has been in in her twenty-seven years. In some of them she has been physically and mentally abused; in others deeply loved and cared for creatively. Her life has been saved. Yet, more than once, she nearly lost it because the medical or nursing profession refused to listen to her parents.

Now what are the feelings with which parents deal during these crises? First of all and primarily, there is frustration—economic, emotional, physical, spiritual, philosophical and psychological. We learned early on that if we knew what we were dealing with, we could deal with it. But the unknown we cannot deal with. We have made a pact with the marvelous doctors at The Medical Center Hospital of Vermont, who have been dealing with my wife's cancer for seven years, that we know exactly what they know. We believe the truth can be dealt with by the patient and the patient's family. We learned that there is only one way to deal with frustration and that is to accept and adjust. A psychiatrist friend of mine helped me deal with my frustration and anger. When I used to see my neighbor walk hand in hand down the street with his little girl, I had to go into the house with clenched fists. There was so much repressed anger inside of me that I actually had a brief blackout once in the middle of my pastoral prayer. Only my wife and my secretary perceived that it was a longer than usual pause, but I was persuaded to get help while I could ask for it. My psychiatrist friend helped me realize that the two best words in mental health are *accept* and *adjust*.

Once in Philadelphia we went for eight months without more than twenty continuous minutes of sleep. Day and night looked the same to me. Myrle cried all the time. Dorothy cried. I cried. Finally, we contemplated suicide. It seemed the only way out of the hopeless morass. Death was preferable to life. There was one deterrent—our wonderful, blond-haired, blue-eyed boy, eight years

younger than Myrle. So we persevered through the black tunnel, not seeing any light, turned away from hospitals because Myrle was custodial, and turned away from custodial hospitals because she was not mentally retarded.

Now, years later, I have come to understand the medical profession better. We have met some men and women whose skill, compassion, common sense and godliness amaze us. However, I am still angry at the clinics and physicians' offices which overbook, to say nothing of overcharge. We once arrived at a famous Boston orthopedic physician's office fifteen minutes early for a nine a.m. appointment and waited until late afternoon to get in. It cost me more than a week's salary plus one whole day of work to cross his threshold, and he had not even the courtesy to apologize for our waiting, and became impatient when Myrle, having endured through the day, was testy and irritable. For a long time, I actually thought doctors took courses in how to be discourteous, and quite soon doctors and hospitals lost their sacrosanct atmosphere and demeanor for me. The Medical Center Hospital at UVM has shown me quite the opposite. Myrle was an outpatient of the Rehab Unit there for nine years, and our relationship has been one of constant and deepening mutual trust and cooperation.

Occasionally my anger got the best of me. I realized I was jeopardizing Myrle's care and treatment by venting my anger on those providing her health care and therapy, but when they insisted on misunderstanding, I boiled over. One of those incidents occurred in Philadelphia when a therapist, who enjoyed the reputation of being "the best in the business," kept Myrle lying on a mat, face down, from nine in the morning until three in the afternoon, without either lunch or respite, in an attempt to get Myrle to raise her head. The therapist insisted Myrle was lazy. We knew she wasn't but how could we persuade the therapist? With Parkinson's, Myrle could perform certain functions at one time, and an hour or two later be utterly unable to repeat that function. This happened particularly with feeding. In the morning after a night's rest, she might be able to feed herself at breakfast, but not so at lunch or dinner. Some nursing staffs refused to accept this as a fact, even after the Parkinson's was diagnosed.

When Myrle was finally carried into the house from the hospital van after all those hours on the mat, her face puffy, she was still crying and at the same time laughing with the joy of accomplishment. She asked over and over again, "Are you proud of me, Father?" Whenever she was able to accomplish anything, this seemed to be her goal—to make us proud of her. In response to this, we always said we were proud *for* her, because we did not want her ever to feel that because she could not accomplish something physically she did not meet our expectations.

I was so furious at that therapist that the next morning I rushed to the clinic and confronted her with what I believe was her inhumanity. I told her I would much rather live with a physical handicap than an emotional wreck which she was well on her way to developing. Her response was a cold, professional smile and a reminder that "If you don't like the treatment we prescribe, you are free at any time to take your daughter elsewhere." She also patronizingly observed that I must have felt much better to have gotten my anger off my chest.

Another problem which parents of handicappers face—at least we did—is constant economic disaster. We have always been in debt. We still are. You cannot save money when you are buying braces, wheelchairs, casts, paying for appointments or the cost of travel and accommodations to and from appointments. By the time Myrle was twelve, we had paid over \$15,000 on her medical expenses alone. If anybody wants to talk with me about national health insurance, they will know instantly which side I am on. We waged battles with insurance companies for years, yet never dared be without coverage. In one year alone—1968 when she had hip surgery and several months of hospitalization and round-the-clock, constant duty nurses—my medical expenses over and beyond what the insurance companies paid were \$5,000.

And that brings up the matter of employment. Do you know that some churches do not want handicapped children in the pastor's household? Four large, sophisticated, suburban and wealthy parishes did not want a minister with a damaged child—even one as charming and bright as ours. And some of them are not too kind about how they break the news of their rejection. One large Baptist church in a Boston suburb

told us quite frankly they didn't want their minister's wife tied down by a damaged child. That was in the year that Dorothy had been soprano soloist in the Chancel Choir, taught Sunday School, served in the Women's Fellowship, and by actual account (for the benefit of the IRS) entertained over five hundred people in our spacious parsonage.

Now what about the attitudes of relatives, friends, and colleagues? Well, in the first place, let's be frank about it: nobody knows what you are going through unless and until they have been through it themselves. Often they refuse to understand; more often, they cannot. Parents of handicappers wear out. We have seen thirty-five-year-old fathers with white hair and younger mothers committed to psychiatric institutions simply because they could not deal with the frustrations, the anger and the daily problems. Some relatives just cry. They are not much help. Some use the "if-I-don't-see-it, it-won't-be-there" approach. They just stay away. The situation makes them uncomfortable, and who wants to be confronted constantly by a moribund, hopeless situation. Who wants to try to deal with a child who can't speak and can't swallow and who is screaming with the pain of undiagnosed dislocated hips?

The relatives and friends I wanted to throttle—and sometimes did—were those who patted her on the head and assured her that when she grew up she would be able to walk and dance and do anything she wanted to. I had to restrain the urge to kill. False hope is a terrible enemy. One has to constantly and consistently deal with the bald truth. So after they would leave or get thrown out, we would try to repair the damage.

And then there are the clergy, God bless them! Most clergy simply do not know how to handle the problem of suffering, and the answer to that is quite simple. They are just like anybody else; they haven't the life-equipment or the existential encounters to enable them to understand. Our problem was unique: to whom does the pastor go when he or she needs a pastor? And particularly important, to whom does the pastor's spouse go? Her husband is not her pastor. He can counsel a whole parish of people, but he cannot counsel his wife. We had our share of the clergy who came and knelt by the wheelchair

or the bed in the hospital, placed their hands on her head (she couldn't fight back you understand), and pray that God would make her walk. To this day, Myrle is uncomfortable when a clergyman asks her if she wants him to pray with her, and as for the laying on of hands, better forget it. She might bite you.

The most disheartening experience I had with a colleague was on Christmas Day in 1962. Myrle had just emerged from a body cast accompanying an Abductor Tenotomy—a procedure used for Cerebral Palsy and almost fatal for her. On Christmas Day in the morning she was wracked from head to toe by muscle spasms. We finally had to admit her to the hospital from which she had recently been released. It was a dreadful experience—finding some place to deposit Tommy with his new toys, getting Myrle re-encased in concrete, and securing private duty nurses around the clock on a holiday since the floor nursing staff could not cope with her complicated problems. After depositing her in the room, I left Dorothy to go through the interminable admission procedure. I encountered a fellow clergyman in the elevator. I thought my heartbreak, anxiety and pain were written all over my face and, answering his question, told him I had admitted my daughter. His response was immediately to tell me about some big shot denominational executive he had been able to secure for a special service he was having. Some clergy, you see, just cannot or will not deal with another's crisis. It is far too threatening. He was far different from the Vermont clergyman who, unannounced and unbidden, quietly walked into the room as our daughter, years later, was going into surgery to have one of the offending hips removed. He said nothing, but put his arms around us both and stayed with us all day long.

Schooling for Myrle was always a special problem. We moved to our last three churches because of her physical problems, and to the last two churches so that she could have the advantage of special schooling. The suburban Boston church we had was nearby the Children's Hospital so their well-known rehabilitation people could oversee her care. She was also admitted to a C.P. nursery school the hospital operated in Wellesley. She went there three days a week for \$7 a day. My weekly salary was \$72. It was twenty-one miles each trip,

twice a day, three days a week. Later, when she outgrew that institution where she learned to read before she was four years old, we enrolled her in the unappealingly named Industrial School for Crippled Children in Boston. It was a school with, believe it or not, no staff psychologist or counsellor of any kind either for parents or children, and a superintendent who had formerly been the head of a correctional institution, whose discipline methods had not changed when he transferred jobs.

Our problems became insurmountable, and we finally were able to enroll Myrle in one of the only two public school classrooms then in operation for crippled children in the whole state of Massachusetts. Here, in this classroom, we encountered a sheer genius by the name of Mrs. Hale. Her influence on Myrle and on us was inestimable. But it cost us \$5 a day five days a week to employ a driver to take her the fifteen miles twice a day. Even that was worth it, but of course added to the never-ending increase of debt.

Some years later, we moved to Philadelphia so that Myrle could attend the famous Widener School for Crippled Children—a truly unique school and at that time one of only two such schools in the nation. If her physical problems hadn't become so much worse during those years, her schooling would have progressed under the magnificent talents of the incredible staff. But she was in and out of hospitals so much and, when in school, suffering so greatly, she gained little formal training. There was also severe and marked disagreement among the experts as to the degree of her mental ability. Depending on the testers, Myrle has tested all the way up and down the scale, and our experience with testers in general has been an extremely sad and bewildering one. Most people almost instinctively equate physical disability with mental retardation. Just notice the number of people who raise their voices when speaking to someone who cannot talk or who has a speech impairment. Several doctors, nurses and therapists frequently talked right over Myrle's head—making her a rag, a bone and a hank of hair—when she could easily have answered their questions and sometimes, to their amazement, actually did.

When we moved to our beloved community of Manchester almost fourteen years ago, the church and the neighbor-

hood opened its arms to us and to Myrle. The school did everything it could to include her in its programs. One teacher, herself handicapped, asked to have Myrle, sight unseen, because she felt she could understand and help her—which she did, abundantly. Years later when, because of the pain, Myrle had to leave high school, this same teacher became Myrle's home teacher for some years. Vermont's law is—or at least was at that time—that a child must be educated until he or she is eighteen or a legal adult. Thus a teacher is provided in the home. Unfortunately, if a child has spent much time in and out of hospitals or is too sick to study, by the time the child is a chronological adult his or her education may still be very incomplete. Education ought to continue until it is completed if that is possible.

Finally, the time came when Myrle, at a particularly low ebb physically, was placed on the miracle drug, Larodopa. Nobody knows what effect lifetime usage of this drug will have, but to date there have been no ill effects. In one month Larodopa changed Myrle from a completely helpless individual unable to hold her head up, feed herself, control her saliva, or in fact do anything for herself, to an almost completely independent person. That was when the hospital staff initiated the subject of institutionalization on the basis of the fact that parents wear out and Myrle needed independence. Myrle felt she should make the decision before there was a crisis and the decision would then not be hers to make. However, on one point she was adamant: she would not consider a nursing home where most patients were geriatric. We and the staff agreed, and providentially we found our salvation in what we think is a truly unique institution exhibiting the finest comprehensive health care services for the chronically ill we have ever seen—in fact the only one of its kind we have seen. We know of only one other, and that is in the Midwest.

In order to enter this hospital, which is in New Britain, Connecticut, Myrle had to become a ward of the state. The alternative was \$23,000 per year out of our own pocket. The wondrous procedure of dealing with the welfare system and its bureaucracy then began. Nothing availed, even though we carefully proceeded up the bureaucratic ladder beginning with the local case worker on up to the Commissioner of Welfare and

then the Governor. Such buck-passing you never saw. We had learned that you have to fight for your rights. Appeals to compassion or even common sense are useless and unavailing. But when we finally spoke to a member of the staff of our Congressman, within three days all the red tape disappeared. She was miraculously on the waiting list. After that it was a wait of thirteen months before the call came.

Finally the day came—July 23, 1973. It was indeed a turning point in the life of our whole family. The first week was sheer hell for all of us. We allowed her unlimited use of the telephone and she called us every day. She cried every day and so did we. But, every day she said she loved it. She has been saying that ever since, and today has achieved a degree of independence and personal fulfillment which would never have been possible otherwise. Her leaving the home and our care produced another adjustment—that of her parents to unlimited access to one another, free from the burden of her care, something we had not known for most of our married life. It also had an effect on her younger brother with whom we were able to spend more time and energy than ever before.

Institutionalization is not always the answer, but it is sometimes the only answer, and happily in this case it was Myrle's decision and not ours. In this respect, we have often had to deal with the guilt parents feel about institutionalizing a child. In this brief time we could not possibly tell you what we have learned from all of this incredible experience. But one thing I know: as a minister, when I go into a home where there is pain, suffering and desperate trouble, I know what people are going through and they know that I know.

Our church families have always been, almost without exception, as supportive as they could be. But church members, like anybody else, need education in how to help parents of a handicapper. We have been the recipients of unlimited thoughtfulness and kindnesses. However, what we needed most was respite care. We need to teach our people how to overcome their fear of dealing with handicappers—the marble speech, the spastic movements, the vacant expression, the grotesque appearance or contorted motions. We need to learn that love is the same in everyone,

whether handicapped or not, and that the need for acceptance and the fear of rejection is there. "I am a person," the handicapper is saying. We need to listen to that and to hear it.

Today the move—and I think for the most part, it is a good one—is to keep disabled persons in their homes and communities as much as possible. But if that is to be done, not only must accessibility to public buildings become a reality—that is a large, obvious priority—but also those responsible for primary care must have respite and support. One mother and one father, to say nothing of the single parent, cannot take the place of an entire institutional staff. But with assistance from the community of faith—the church—as well as the secular community, it can be done. Dorothy and I have often found the secular community more responsive to our needs than the church.

Now Dorothy and I are still dealing, after all these years, with certain guilt feelings. We remember occasions when we were harsh with Myrle, unduly and unjustly. We feel there were times when our anger and frustration were vented on her. We also remember times when her innate sense of humor was able to divert an unhealthy situation. During those terrible eight months in Philadelphia when we were having to shift her position every fifteen or twenty minutes, adjust pillows and so forth, and when she could not tell us what was comfortable and what was not, I once took her by the shoulders and shouted, "Speak! Speak!" She managed to say "Arf!" and reminded me thereby that I was not, after all, dealing with a dog.

Our friends and relatives, as well as many of the professionals we have dealt with, feel that Myrle is exceptionally selfless, and cannot understand why she is never sorry for herself. We tried never to let her be the center of attraction. We learned early on that a handicapped person can become a tyrant in a very short time. Handicapped persons tend to be manipulative, and Myrle had her share of this. But we began to understand that if your whole life is totally dependent upon others, and your security is determined by others, to say nothing of your survival, then it is perfectly natural to be manipulative.

In terms of Myrle's brother, we retain guilt feelings and regret constantly that we were not able to spend more time with him in his formative years. We simply did not have the emotional or physical energy, and he was an undemanding child. A psychiatrist warned us that the effect of Myrle's handicap upon him would manifest itself in some deleterious manner at some point. We have not seen this. He was an under-achiever and, until recently, lacked academic motivation while being capable of superior performance, a fact brought out by testing. We realize that this places him among the majority of nineteen-year-olds these days, but we still feel that if we had read to him and played with him and worked with him as much as we did Myrle, he would have performed better academically.

We have taught both our children that we are born into families because it is God's plan that we take care of one another. Tom realizes that some day he will be almost totally responsible for his sister and her care. Everyone in an institution needs an advocate, and there are certain decisions with which she will always need help, especially those having to do with finances. Already, she has learned to turn to him for brotherly advice and he has met the challenge in what we think is a mature and responsible manner. If and when he marries, his wife will need also to realize that she is marrying into this responsibility. Handicappism affects every single person in a family; no one can escape or deny it.

Spiritually, as well as in many other ways, Dorothy and I are better persons for having met the challenge of handicappism. Having faced death prepares one to face life. Similarly, learning to face life and the thousand daily battles which a handicapped person and his or her family have to face enables one to face death. We have learned that death is not the worst thing that can happen to one we love. We have also learned that there are immeasurable gifts which reward those who are a part of the handicapper's support system. Once we watched Myrle peel an orange for her father. It took her twenty minutes, but the joy of accomplishment was worth everything. We have a picture of her taking her first bite of food after months of being unable to feed herself. That smile, which we captured on film, is, again, worth a lifetime of effort.

Love, courage, perseverance—all the fruits of the spirit—can accomplish what medicine, science and technology cannot possibly do alone. And at the risk of being "preachy," let me suggest that we have learned that suffering increases one's capacity for joy. The woodcarver must take a knife to the wood to create an Amati or a Stradivarius. The potter must fire the vessel in the clay before a vase can emerge. The deeper the cup of sorrow, the more joy it can also retain. It is no accident that the Psalmist says, "A broken and contrite heart thou wilt not despise." Who else but God can use a broken thing? Can a broken cane or a broken crutch or a broken glass be patched and used? No, but a heart that is broken God can use, and by it strengthen other hearts. "A bruised reed he will not despise."

Finally, let me share with you this prayer which was one of our standbys along the way. It is yellowed with age and dog-eared with use.

*I do not know what tomorrow will bring forth,  
But I will not lose courage.  
I did not know yesterday what today might produce,  
And here I am unscathed.  
Tomorrow may be no worse than today,  
Therefore I will trust tomorrow  
For it, too, is in thy hands, O God.*

We have learned that the worth of the worthless is that they have made us worthy; the help of the helpless is that they have made us at times a little lower than the angels; the use of the useless is that they have forced us to find within ourselves the good we weren't sure was there. ■

# Access

# William Sloane Coffin, Jr.

*The following sermon was preached by Dr. Coffin on October 22, 1978.*

Today is the first day in what is being announced as the "first annual human rights week for persons with disabilities." In large part the organizing work has been done by Riverside's *Mainsteam*, a group headed by that indefatigable modern missionary, Betty Knapp, whose wheelchair figuratively and, perhaps, literally has covered more ground than the feet of ten able bodied persons.

If we measure progress by how far we have come there is cause for rejoicing. In the United States today deaf people are far better off than they were in 1817 when the first school for the deaf opened in Hartford, Connecticut. The same can be said of the blind, since 1832, when the Perkins Institute for the Blind opened in Boston; and even the emotionally disturbed are better cared for in our public institutions today than they were in 1854 when President Franklin Pierce vetoed the first bill to provide federal funding for mental hospitals. Science and medicine have wrought wonders for the disabled, and thanks to their own inspired protests, landmark legislation on accessibility has just now been passed by HEW and the Congress, although the struggle for compliance and implementation has only just begun.

But how are we to measure progress: by how far we have come, or by how far we might be if only we cared more?

Imagine yourself for a moment in a wheelchair trying to get up the steps of a subway station; or trying to go down the steps; or into a bus anywhere; or into the balcony of a theatre for a play; or a classroom on the second floor of

almost any public school. For that matter, imagine yourself in a wheelchair trying to get into most churches. And I blush myself to realize that I have arrived Sunday after Sunday at the front door of Riverside and have never noticed, until Betty told me, that we don't even have a sign for disabled tourists indicating that accessibility is on the Claremont Avenue side.

Or, imagine yourself a blind person in the elevator of an office building, trying to find the right button to push; or, once you emerge on the right floor, trying to find the right office door, when the doors are shut and none, as in the elevator, have numbers that are raised so a blind person could feel them.

And how many movie theatres provide hearing aids for the hard of hearing? On and on we could go listing obstacles that wittingly or unwittingly, have been placed in the path of what now amounts to thirty-six million American citizens, who to some degree are physically or emotionally disabled. And, by the way, what about our little people? What about the thousands of children in this city who live in high-rise apartments who are simply too short to reach the elevator button that will carry them to their homes?

Christians in particular will have much to think about—and do—this week, especially as we remember how much time our Lord spent trying to relieve the suffering of the lame, the blind, and the emotionally disturbed.

It all boils down to how we view one another. Why else would physical access to so many places be denied so large a minority of our citizens if not that they have been denied access to the

hearts of the able-bodied majority? And I can't help thinking that the button panels in our elevators would be further down if we sought to support our children more, and to dominate them less. (It helps to remember that children are loaned treasures. They belong to God before they belong to their parents.)

Let me tell you a story about John Silber, the current president of Boston University, who is a short man from Texas and, as if that weren't bad enough, his right arm is only a withered stump. Years ago I knew Silber as an instructor of Philosophy competing fiercely with another instructor, Chet Lieb, for that first rung on the ladder leading to academic success. Silber in particular was aggressive, and to the point that one day Lieb couldn't take him any longer. "Silber," he said, "I'm inviting you outside."

"What," said Silber, "You'd fight a man with only one arm?"

"For a man with only one arm you've got too big a mouth. Come on, let's go."

Telling me the story, Silber ended it, "You know, if I had had two arms, I would have embraced him. He treated me as a human being, not as an aberration."

People in wheelchairs will tell you they are smiled at more than anyone else, that even their dumbest opinions meet nodding agreement on the part of people who don't believe a single word of what they are saying. Blind people who work in offices will tell you they always receive the loudest "hello" in the morning, until they remind people that there is nothing wrong with their ears.



William Sloane Coffin, Jr. is Senior Minister at the Riverside Church, New York, New York.

Why can't people be just different—not different up, or different down? Why can't the disabled be just folks, natural and normal, with specific limitations?

I think I know the answer. When I was a college undergraduate I found myself one sunny morning in lower Manhattan where a bunch of Bowery winos were slumped up against the wall enjoying the sunshine. They looked up at me, but I had trouble looking down at them because that is exactly what I was doing in more ways than one. For their looks said to me, "You think you are pretty smart with your college education, don't you." And, I had to admit, "Yes, I think I am pretty smart." Their looks said to me, "You think you are hot stuff because you are young and healthy while we are old and beat up, don't you?" And I had to admit to the truth of that, too. Those winos, having given up their responsibilities, had also given up their pretensions. But I had about ten pretensions for every responsibility.

The poor unmask the pretensions of the rich—that their money somehow makes them superior. The old unmask the pretensions of youth—that their youth somehow makes them superior. And youth unmasks the pretensions of the middle aged—that somehow middle age makes them superior. The uneducated unmask the pretensions of the college crowd, and the disabled the pretensions of the able-bodied. The poor, the elderly, the uneducated, the disabled—they threaten the status quo of all pretentious people who are seeking status elsewhere than in the sight of God. Ah, if only we could stop judging ourselves in relationship to each other and start judging ourselves and others in relationship to God! Then we would

be of one heart and soul, united in one Lord whose love is not blind but visionary, and perceives behind the wheelchair, behind the braces, the leather, the dog, human beings created in the image of God.

And of course, the disabled have to view the able in the same light, which may be even harder. I love the words from the 37th Psalm, because they obviously come from such a struggle against bitterness.

*Fret not yourself because of the wicked,  
Be not envious of wrongdoers . . .  
Trust in the Lord, and do good;  
So you will dwell in the land, and  
enjoy security.*

It must have cost the psalmist a lot to say that.

To live from morning to evening the bitterness of one's grievances is no way to live. "To pity oneself," wrote Weatherhead, "is the most weakening of all emotions," and all of us have had experience with that. "Jealousy," wrote Cervantes, "sees with opera glasses, making little things big, dwarfs into giants, suspicions into truths." None of us are victims only of others, never of ourselves. And grievances beget grievances. If ever the wolf is to lie down with the lamb it won't come about because of the grievances of the lambs. It will come about because all see, with St. Paul, that "none is righteous, no, not one," and that all are redeemed by the love of God, made members one of another in one sacred family.

So during this week let us remember the size of our true family, and how we have rent its fabric by denying rights to the

disabled among us. Spiritually speaking, none of us are that able, are we? We all need access, most of all to each other's heart. Maybe that's a right too. In any case we shouldn't be loathe to grant such access when we remember how accessible God has made his own heart to all of us. ■

# Who Are the Handicapped... Are Not We All?

## Frank Bowe

Suddenly, a "new minority" has emerged before us, monopolizing media and public-policy attention, demanding of each of us that we re-examine some of our most cherished beliefs about ourselves and the way we treat our fellow citizens. America's thirty-six million disabled men, women, and children constitute our nation's largest "open" minority, a group anyone may join at any time. For disability respects no race, sex, social class, religion, or geographical boundaries. By the year 2000, in fact, it is believed that there will be one chronically ill, disabled, or over sixty-five person for every able-bodied citizen.

Every American, then, is or may become disabled. This is one part of what I mean when I say that we are all actual or potential members of this new minority. But I must extend this thought further. One American household in twelve has a member who is disabled. Of those families who are on welfare, fully twenty percent are there because the head of the household is disabled. A member of a lower-class family is twice as likely to become disabled in any given year as is a member of a middle-class family. More than sixty percent of all poor families having at least a husband and a wife at home include a disabled adult. Half of the seven million disabled children now in school are believed to come from poor, inner-city families. Looking at employment patterns, we find that a majority of working-age, non-institutionalized adults who are disabled are not working, with most not even being in the labor force because they have given up looking for jobs. Among the severely disabled, the proportion is one in ten. About twenty five percent of all persons not in the labor force are disabled; almost the same figure holds for those in the labor force but unemployed.

What all of this means is simple: America itself is handicapped because we handicap disabled people. That is, we as a country suffer because we are not removing the barriers that confront disabled persons. We as a people are poorer, and becoming more impoverished annually, because we fail to recognize barriers when we see them, neglect to remove obstacles when we can, and ignore opportunities to spare ourselves a similar fate should we at some time in the future become disabled ourselves.

We are, then, handicapped by our own ignorance and inertia. This is the second sense in which I am using the term. Consider, if you will, what handicapping America means for each of us. The economic costs surely are lower and less devastating than are the human costs, but at least we can quantify and understand them. Let us, for a moment, look at the economics of disability.

The United States Congress in 1977 passed amendments to the Social Security Act increasing the taxes each worker pays to the government by a very substantial amount. Why were these taxes increased so greatly? If we examine the Congressional reports and budget analyses, we find that the primary cause was the rapidly growing expense of the disability insurance program administered by the Social Security Administration (SSA). The figures computed by SSA and presented to the Congress at that time were shocking:

\$1 out of every \$13 in the Fiscal Year 1980 budget is for disability programming.

Five million persons are now on disability insurance.

Three out of every ten men now entering the work force may end up on disability insurance.

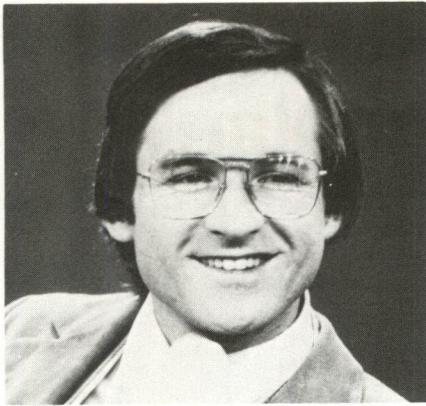
Two million people are on income maintenance owing to disability.

One out of every twenty civil cases filed in federal courts involves disability.

The costs for social security disability programming in 1980 alone are estimated to be \$40 billion.

Fortunately, by early 1979, SSA realized that the numbers of persons applying for benefits was declining sharply, having reached a plateau shortly after the costs just cited were computed and then declining to 1972 levels. This realization by itself was sufficient reason to impel the Congress to consider cutting back the just-enacted social security tax increases. In fact, when the news broke, the *Washington Post* considered it so important that it displayed a front-page screamer headline and story, with continuation on the second page, something it does very rarely. The impact of disability on the 1977 tax increase, and the expected impact in 1979 and 1980, are indicative of the very major role disability now plays in our lives.

Why are the costs of disability programming so high? To answer this question we must consider some rather dry statistics. In the United States today, we are spending \$20 on dependency among disabled people in medical, income-maintenance, and insurance costs, for every \$1 we spend on making these people independent. Thus, while we are averaging \$40 billion annually in federal entitlement and other payments to people who are disabled, our investment in programs such as special education and rehabilitation that help these



Frank Bowe is director of the American Coalition of Citizens with Disabilities. An internationally respected authority on disability, he is author of *Handicapping America* and *Rehabilitating America*, both published by Harper and Row.

people to get off the social security rolls is a pitiful \$2 billion. These figures reveal our expectations of disabled people. We think that they are dependent people who must be helped, rather than people whose potential can and should be developed. We consider them disabled, rather than capable; unable rather than able; dependent rather than independent.

Because we think this way, we segregate disabled people apart from the rest of us. We place them in far-away institutions, in basements and attics, in back rooms, rather than investing in their potential and doing all we can to ensure them full access to the assistance they need in order to realize the goals they aspire to and can reach. That is, we handicap them more than we rehabilitate them. And the tragedy is that, by doing this, we hurt both these people and ourselves. For disabled people, these attitudes mean that even a chance at equality is denied; for those who are currently able-bodied, it means that increasing proportions of our paychecks are being taken from us. And the situation for both groups worsens each year.

What can we do to turn the tide? First, we can make a solid investment in our disabled citizens. We can increase substantially our spending on education and rehabilitation, betting on these people, as it were, and believing that with training and opportunities they can become prepared to work and support themselves. Second, we can remove barriers in our communities: barriers to transportation, housing, education, employment. Third, we can re-examine our own life patterns, recognizing that disability may be in our own futures unless we exercise care in preventive medicine, safe driving, and good nutrition.

Fourth, we can attack the causes of disability through medical and social research, realizing that poverty is as much a "cause" of disability as is multiple sclerosis. Fifth, we can do whatever it is we as individual citizens can do to make our communities "open" to all their residents, welcoming those who may be disabled into our theatres, restaurants, schools, and churches.

Designing for access makes sense. It helps all of us. More than that, it makes not just cents but dollars. For every dollar we invest in helping disabled people become more independent, we can expect more than \$10 returned in income taxes paid by these people to the U. S. Treasury, \$3 spent by these people in our local industries and stores, and, what perhaps is most meaningful to many of us, \$2 removed from our taxes.

Disabled people need not be handicapped. Nor need the rest of our citizens. We can rehabilitate not only disabled people, but America itself.

We must make the decision, or it will be made for us. I can see two possible futures, one if we invest in disabled people and one if we do not. The Supreme Court in its recent *Papachristou* decision articulated the former more clearly than I can. If we develop the potential of disabled people as fully as we are able, these people will enjoy, "Independence and self-confidence, the feeling of creativity . . . lives of high spirits rather than hushed, suffocating silence." And Langston Hughes told us what will occur if we do not. "See what happens to a raisin in the sun, and a dream deferred too long." ■

# Toward Independence

# Deborah Kaplan

In a world that seems to be constantly changing, disabled people are taking advantage of these changes. We are actively organizing to work for our own new causes. Following the example of racial minorities, ethnic groups, and women, we now perceive our greatest needs to be increased civil rights and independence rather than increased charitable benefits and dependence. The issue truly is one of independence. Disabled people are questioning old values and stereotypes which portray us as people who need others to take care of us.

We are working for an environment in which we will be our own caretakers and seen as valued, contributing members of society. We are constantly learning about ourselves as we join broad coalitions of groups representing a multitude of very different disabilities, and we are constantly reminded that our limitations are not necessarily inherent but are often created by ourselves and others. The purpose of this article is to examine the goals and objectives that disabled people are advocating and to further examine the role of the federal government, and other governmental units, in furthering these goals. This article is based on several years' experience and observation as a disabled person and a member of the disabled community.

Above all, disabled people are demanding to be treated with dignity; we do not want pitiful stares or charitable and patronizing treatment. This can create confusion for those who have been trained to recognize the differences and inabilities of disabled people rather than the common bond of human experience. Many people, when confronted with this issue, insist on pointing out that a disabled person is, by definition, a person who cannot do something whether it be walking, seeing, hearing

or learning. However, there is more to it than that. A person with a temporary disability, for instance, a sprained ankle, is treated qualitatively differently from a person with the same permanent functional disability—a club foot. Disabled people have been limited by others' attitudes about them for too long, and they are demanding to be treated, if not seen, as equals with respect and dignity. It may be interesting to analyze and discuss the causes of negative attitudes towards disabled people, but disabled people would rather see positive changes in behavior first and discussion later. Too often discussion is a substitute for change.

Self-reliance to the maximum extent possible, coupled with ever-expanding expectations, is another major objective of disabled people. Of course, there must be a concomitant recognition of the fact that in some circumstances disabled people need accommodations in order to be self-reliant. Accommodations can take many forms: adaptive equipment, environmental design changes, or restructuring and redesigning systems of operation so the disabled person can fit in. Making use of equipment, whether it is a wheelchair, a hearing aid, or another device, is now being viewed as a means to achieve self-reliance, as opposed to the old-fashioned view that such use is a form of giving up or becoming dependent. Changing the environment, by building ramps or placing Braille markers by elevator buttons, is also a means of allowing a disabled person more self-reliance. And, equally important, entire systems of education, employment, and recreation need to retain a certain amount of flexibility so that a disabled person can participate or compete equally. This could be done through the elimination of unfair testing procedures, by modifying schedules, and by re-

arranging job duties and descriptions.

Almost everyone is familiar with the theory of self-fulfilling prophecies: if failure is expected, it is more likely to occur than if success is expected. Disabled people have learned that this is especially true when applied to their own capabilities and expectations. Therefore, we have come to see that we should rarely allow ourselves or others to totally close any door to us. Disabled people can do and are doing many surprising things, especially when accommodations are made and provided. For example, blind people are successfully attending law school and becoming lawyers; wheelchair racers are entering marathons and coming in first, before all others, the able-bodied included.

Disabled people do not want to be excluded from participating or competing in any activity solely because of their disabilities. Of course, in some instances a person's disability is so closely related to the qualifications for participation that there is no feasible way to include the disabled person. The crucial issue to be resolved is whether there is an accommodation that can be made to allow for inclusion. It is important to recognize that accommodations are already being made for many people. A blind person cannot drive a car or a bus. But there are hundreds of thousands, if not millions, of us who are able to drive when we wear glasses but are actually forbidden to do so without them.

Negative assumptions are constantly being made about the abilities of disabled people. In many instances, these assumptions become the basis for excluding disabled people from participation in a broad range of activities ranging from social events to education or employment. Disabled people are de-

Deborah Kaplan is director of the Disability Rights Center in Washington, D.C., and staff attorney for the Public Interest Law Center in Philadelphia, Pennsylvania.

manding that these assumptions be identified and challenged. A disabled individual, like any other person, should be considered or evaluated on the basis of his or her experience, skills, knowledge, and other qualifications. However, disabled people tend to be judged as a class even though this treatment is particularly inappropriate for disabled people. Stereotyped as we are, we are more diverse than any other group. Disabled people come from every race, culture, age, sex, and background. We have as much experience, talent, skill, education, and perspective as any other class of people. Yet disabled people are commonly expected to be passive, less intelligent, submissive, asexual, lonely, and perhaps bitter underneath a superficially cheery exterior.

Despite the stereotypes, disabled people are as diverse as the entire culture. And it must be pointed out that sharing the same disability does not make people alike. Almost every disabled person has either suspected or else known that someone else is expecting him or her to be just like the other deaf person, blind person, paraplegic, or other disability type that the non-disabled person has known. Unfortunately, disabled people are not readily prone to such an easy comparison. Very often, two people may be categorized as having the same disability, but the disability affects the functioning of those people in very different ways. For instance, one paraplegic wheelchair-rider may be able to feel and wiggle his toes while another may not. When all other dimensions of a person besides function are considered, it becomes even clearer that there are countless factors that contribute to making all paraplegics, or any other group, very different from one another.

Our society has had a long tradition of keeping disabled people separate, creating separate schools, institutions, workshops, living facilities, and other arrangements. Disabled people want to change that tradition, with a few exceptions, and we have been successful recently in convincing both state and federal legislatures to mandate such a change. The basic reason for this goal is that no matter how well-designed or high quality the separate programs or services may be, serious damage is done to the disabled person's self-esteem and ability to relate to others. In addition, most segregated programs tend to take on a protective attitude towards the disabled people they serve, thereby limiting the possibility that the disabled person will be able to learn and grow by tackling difficult or new experiences. Another related common characteristic of segregated facilities is that the staffs tend to foster low expectations for the disabled they serve. And the low expectations become self-fulfilling prophecies, again limiting the disabled person's opportunities to expand personally or professionally by accomplishing new goals even while making mistakes.

A basic tenet that has been developed in civil rights law is that separate is not equal. There is a stigma of inferiority attached to separate treatment, especially when the target group is one that has historically been seen as inferior. Disabled people strongly believe that the only way to break down negative attitudes and stereotypes is to end the standard practice of segregating disabled people. Again, the concept of providing accommodations is central to this objective. Certainly there will be circumstances for which special services or programs for disabled people only may be necessary. For instance,

many leaders of the deaf community strongly assert that deaf students need to be educated in a separate environment because of the significant communication problems that a deaf student would encounter in a regular school, surrounded by teachers and students who didn't know how to communicate by sign language. A key factor of this example, however, is that the community of deaf people is the proponent of this particular method of serving deaf students. This is a crucial point: the disabled community involved with the issue should have a large say in deciding whether integration or segregation is the best policy, over and above the service providers, the local authorities, or the general community. After all, they will have to live with the effects of such a policy directly, and perhaps for their entire lives.

What is the role of the federal government and the local community? To be able to answer this question, it is necessary to understand what has been the role of the federal government and the local community. A large function of the government has been to provide disabled people with maintenance benefits such as Social Security Disability Insurance, Supplemental Security Income, or Veterans Administration Disability Benefits. The major assumption upon which these programs were established, especially those emanating from the Social Security Administration, is that disabled people are not capable of contributing in a meaningful way either to society or toward supporting themselves, and therefore the government needs to give them support payments or take care of them. Numerous state and local programs provide similar benefits, seemingly based upon the same demeaning assumptions.

This is not to say that countless disabled people are not in need of some sort of support benefits, either for a protracted period of time or for a short duration. However, simply doling out benefits primarily because of a person's status as a disabled person results in social stereotyping. Disabled people have for too long been labelled "invalids," resulting in their social invalidation.

The other major focus of the federal and state governments has been in providing vocational rehabilitation services to disabled people through a federally funded state agency. This program is based on a very different and more worthy assumption: that with training and assistance some disabled people can re-enter, or enter for the first time, the labor market and find successful employment. This program traditionally has not served those with severe disabilities, and although the Rehabilitation Act of 1973 mandated that states give high priority to serving severely disabled individuals, there are indications that this mandate is not yet fully implemented. At least in some states, a high proportion of state rehabilitation clients merely need dental work or have other relatively minor physical or mental limitations.

To the disabled community, these two major focuses of federal and state governments need to change. More emphasis needs to be placed on providing programs and services that will lead to self-sufficiency and independence. One new program that is more in line with these goals is the Independent Living Services Program established in Title VII of the Rehabilitation Amendments of 1978. This program would enable states to provide direct services to severely disabled individuals who need them in order to function independently in the community and, possibly, to eventually pursue a vocational goal. The program also enables states to give grants to nonprofit organizations, with substantial numbers of disabled people running them, to provide independent living services ranging from peer counseling, rehabilitation and physical services, to finding home-care attendants or engaging in advocacy.

The attractiveness of the Independent Living Services Program is that it never assumes a person's limits, but presumes that severely disabled people have great potential, with appropriate

community services, to take charge of their own lives and become independent. There is never an assumption that all disabled people will be able to engage in full-time work, but the assumption that they can never do so is also absent.

Clearly, this is the model approach that most disabled people, individually and organizationally, support. We believe that this country's resources will be more prudently spent on such a model. It doesn't make sense to put money and other resources into programs that perpetuate dependence, which is the effect of many present systems. Too often a severely disabled person will gratefully receive a combination of benefits such as Supplemental Security Income (from Social Security), Medicaid, and Social Service attendant care, only to discover that taking on any form of regular, minimally substantial employment disqualifies them from receiving any benefits at all. Presently, a disabled person could earn as little as \$300 a month and be taken off all benefits even though \$300 could never begin to pay for rent, food, clothing, medical expenses, transportation, and attendant care. The result of these systematic work disincentives is that many severely disabled people don't even think about working. It's too much of a risk, especially when it may be impossible to receive benefits again if a job doesn't work out.

It is important for local and national policy makers to understand that disabled people do not want to be locked out of jobs, education, and other social opportunities. Programs which tend to do so should be re-examined to determine how they can be changed to encourage disabled people to gain control over their own lives. Programs which are not traditionally targeted for disabled people also need to be re-examined to determine how they can be altered to allow the participation of disabled people. Job development programs, educational enrichment programs, and others similarly structured to enhance the opportunities of disadvantaged groups should be modified to include opportunities for disabled participants.

A central issue which runs throughout careful consideration of this issue is control: control over one's own life and control over vital programs affecting disabled people either as a group or as

part of society. For too long, others have been making the decisions and molding the lives of disabled people. What we are saying now is that we want to make our own decisions and control our own lives. Of course we don't expect to avoid making mistakes, but we would like to have the right to do so and to learn from them. Other people seem to have been faring well under such a system. Once we have some control, we look forward to working as equal partners with our families, friends and communities in striving toward our goals. Together we can create a society that does not exclude disabled people but that expects active participation and will provide support for the concepts of independence and self-determination. ■

# Baybie

It was the summer of 1948, and the Reverend Baybie Hoover and her close friend, Virginia Brown, were broke in New York, two frightened young women from the farmlands of Kansas who were working their way across the country to attend a convention in Baltimore.

Doing the only thing they knew to do, they slowly walked up Broadway, singing gospel hymns and holding out a tin cup for people to put coins in. Near 46th Street, they were stopped by a policeman. Explaining that they were new in town, Baybie told the officer they were just trying to raise some money to cover their expenses. "Well, if this makes you happy, go ahead and do it," said the officer. "I don't even see you."

Baybie Hoover laughed. "Well, officer, we don't see you either."

The two women, blind since birth and friends since they first met in the Kansas School for the Blind in 1928, had come to New York that summer almost by accident. As the first two members of the Kansas chapter of the National Federation for the Blind, they had decided to attend the federation's national convention in Baltimore. They also thought it would be a good time to visit their favorite radio program, "Let's Pretend," in New York. "We didn't realize how far Baltimore was from New York," recalled Baybie. "We thought it was only about seventy-five miles. We had no Braille maps or anything in those days. We just thought they were both in the East." After months of planning, and with tickets to "Let's Pretend" in their pockets, they set out for New York.

By bus and train, they hit the big cities—St. Louis to Chicago to New York—collecting money in the streets by entertaining people with their songs.

"In those days we didn't have enough money to travel to the conventions and buy decent clothes, too," said Baybie. "So we were shunned at the federation conventions by the people who had partial sight. Also, we would run out of money and we would have to work on the street. The federation didn't like it. They finally said the Kansas organization wasn't big enough and that we weren't members anymore." It marked their last convention, but it was not the last of their streetwork.

To Baybie and Virginia streetwork is a way of life. For thirty-three years it has brought them the pleasure of meeting people face to face as well as extra money to supplement small relief checks—checks which have often been cut off because of the women's street jobs. But mainly, pitching—as they refer to their work on the street—has brought them an independence they failed to get from working in blind workshops in Kansas and New York. The income from their pitching also helped them establish New York's first church for the blind—the Radio Gospel Church—in 1964, and for the last three years has provided them with their own radio show, a fifteen-minute Friday morning program over WHBI-FM.

"Streetwork turned my life around," said Baybie, a sixty-two-year-old ordained minister who permanently settled in New York in 1954. "I love to sing to the people. I love to have people come up and talk to me. I feel like I'm performing. Like I'm making my little contribution."

Making her contribution was not easy. For years, the established agencies for the blind tried to stop her streetwork. "At first, they tried to shame me out of it," she recalled. "When they saw that

# Martha Sandlin

Martha Sandlin is an independent filmmaker working in New York, New York. She is a graduate of New York University's Graduate Institute of Film and Television.

wouldn't work, they tried to psychologize me out of it. When I was in group therapy, they got the other blind people to try and talk me out of it. They would say that I was putting the blind back centuries when I worked on the streets. They said that if I worked in the street, people would associate all blind people with the cup and beggars. I said I am not a beggar. If you see a sighted person on the street with a cup or something to take in the money, you would say they are street singers or street entertainers or minstrels. I said I am a gospel street singer and I am proud of it."

It is not as if Baybie hasn't tried to get a real job. She welcomes hard work. She sold doormats house to house in Wichita to earn money to go to Bible college. While attending Kletzing College in University Park, Iowa, she earned her keep by washing dishes and peeling potatoes. In 1943 at the age of twenty-seven, she landed her first and only salaried position. That was in the blind workshop in Wichita where she rolled newspapers for \$1.00 a day. "Sighted people would have turned up their noses and spit at it. It was filthy work. But I absolutely loved it." Still, the job didn't last.

During World War II, she applied for work at the Boeing Aircraft Plant in Wichita and made it past three desks before being told that she had to have a recommendation from an agency for the blind. The local agency, however, said it could only put her on a waiting list. "I have been waiting every since," she recalled thirty-seven years later.

In 1970, Baybie joined a rehabilitation program in New York and learned to type at the rate of 120 words per minute. She says, "Myself and one other student were the fastest ones in the

class. He was in his twenties and got a good job. Somehow or other I didn't make it. I went to job interview after job interview. Every time I'd leave a place they'd say, 'Well you've really got the brains,' and after that they stopped."

Of the nation's 1.7 million blind people, according to the American Federation for the Blind, only about 200,000—or twelve percent—are employed. Among these are about 6,000 who work at so-called sheltered workshops operated by private agencies which, by law, are permitted to pay less than the federal minimum wage which rose from \$2.65 to \$2.90 an hour on January 1. Most workshop jobs involve the making of mops, brooms, brushes, sheets, towels and other materials primarily sold to government agencies. Baybie and other blind persons who have tried to break away from the workshop system to obtain regular jobs say they have encountered discrimination. Early in life, Baybie chose the street as her workplace.

Baybie's mother died when Baybie was eighteen months old. She was sent to the Missouri School for the Blind when she was four years old, and has been on and off some form of public assistance since the age of twenty-one. In 1938, her first assistance was \$15 a month for care which the state paid a farm couple in Burden, Kansas. In return, Baybie did their housework. The next year, a caseworker sent her to Miltonvale, Kansas where she attended Wesleyan Methodist College. Her tuition was paid by the

state. In 1940, she was assigned to the Cowley County Poor Farm near Winfield, Kansas. She received her first welfare check in her own name in 1941. Throughout these years in Kansas, Baybie's name was carried in the public listings in local newspapers as a welfare recipient. By law, the amount of money she received was also printed. Several times through the years, she was taken off welfare because of her streetwork.

"I was really raised by the blind system," Baybie said of her early years of being cared for by a society that put blind adults on so-called poor farms along with the elderly and the mentally retarded. "I am a product of that society. And just as normal children rebel to pull away from their parents, I had my little rebellions against the system. And I'm still having them."

One of her rebellions involved her name. Baybie actually was born Nadine Hoover on November 15, 1916 in Puxico, Missouri. But she always hated the name, thinking it sounded too harsh. She felt that "Baby"—a name she had never been called—was more endearing and had an affectionate sound. At age fifty-five, she adopted the name "Baby". The name wasn't a big hit with everyone.

A sighted friend told her, "Don't you think it's preposterous for the world to call a big person like you Baby? Isn't it stretching their imagination a little bit? You're not a baby; you can't even possi-

bly be pictured as a baby." A counselor at the Lighthouse for the Blind, who was trying to help her to get a job, said, "Don't you think it's undignified to sign your name Baby?" A Lighthouse teacher, in trying to persuade her that Nadine was an appropriate name, told her that Nadine was a Russian name meaning hope. "I said, yeah, that's great. But I am getting tired of just hoping. I said it can't be Nadine, it has to be Baby. Baby is the fulfillment of my hope." Finally, as a compromise, she changed the spelling to BAYBIE, and told the world, "I'm a lady named Baybie." Baybie Hoover said the name gave her a new life. "It means young, powerful, loved, approved of . . . that's all the things Baybie means to me. And all the things Nadine needed and never did get."

Another rebellion involves pitching, much to the dismay of the agencies for the blind and to the bureaucrats in charge of public assistance for the poor. "If you're on relief you're not supposed to have any pleasure," said Baybie. "You're supposed to be grateful, and I guess you're lucky you're eating. But the restaurant allowance I get isn't enough to eat on in New York with inflation and all. I have to supplement my check, and at that I can only afford one good meal a day. It's pretty awful because they won't give you enough to live, but if they see you in the street they click their tongues at you in a most superior way. I don't ask anymore of life than just to be left alone in the street. Just let me sing my songs and give my little performances and make people happy."

Baybie has learned all the tricks of the trade since the days she began her streetwork in 1945 with a fundamentalist preacher in Wichita. Instead of shuffling along the street, against the pedestrian traffic, as she and Virginia did on their first day in New York in 1948, Baybie now sits in one spot—at a different location around the city each day—and faces her public head on. "I learned to follow the sound of voices and turn my face right towards them," she said. "If you don't look them in the face, nobody pays attention to you. They don't mean to be hateful or mean, but when the sighted don't see you, they don't hear you and just pass you by."

She also has a practiced act. "I can sing four hours straight and not sing the same song twice. My songs come from all over the country. Some are folk-gospel, but the majority are the real old





when I get up there I won't need it. But when I'm down here I need it . . . for food, taxis and warm clothes."

In addition to her streetwork, Baybie gets much pleasure from her church work. Using money earned in the street, Baybie and Virginia set up a church for the blind fourteen years ago in a run-down building they rented on 48th Street between 8th and 9th avenues. The church was later moved to Gates Avenue in Brooklyn and is now located at 57 East Third Street in Manhattan's Lower East Side. "If we ever get money enough, we're going to have Braille song books. And we would like to have our scripture in Braille too, so the congregation could follow along."

Baybie began her ministry at the age of twenty-four on a poor farm in Kansas. "I would read the Bible to different ones,



and I just felt the Lord was telling me to go to the different rooms and preach and to read and help them." In 1941, she was ordained to preach by the Church of the Nazarene in Udall, Kansas. But her theology is what she calls a "Baybie denomination." "It is based on my own beliefs mixed with the different places I've attended. It's got some Baptist, some Nazarene and some Methodist. Mostly, we just want to make people feel at home and love one another and follow the Golden Rule. It is especially for the blind people. It's a place where they can come and not feel left out."

Baybie's services—in which Virginia plays the accordion—include a lot of audience participation. Different blind members sing solos. They trade stories about events of the week. Afterwards, they get together over coffee. There is

much laughter. The blind don't always feel comfortable at the churches for the sighted. Virginia recalled one experience she had at a regular church. "After the evening service, a lady told me, 'You can't go out there in the dark. Now you sit down and we will get you a cab.' I tried to explain that the blind know how to take care of themselves, but she didn't listen."

"They look at us as though we're some kind of burden," Baybie added. "They either feel overly responsible or else they just ignore us completely. At times the sighted get in the way of the blind."

Being blind has its hardships. But Baybie believes it also has certain advantages. "We can stick our Braille books under the cover and read in the dark," laughed Baybie. "And if the power fails, we don't go to pieces. We are in a way less dependent on modern conveniences because we don't need light." Their blindness also has given Baybie and Virginia a vivid imagination. As kids, they used to imagine someday being discovered by a talent scout and becoming famous.

Their relocation to New York has helped them realize part of that dream. Several years ago a folk singer heard Baybie and Virginia singing on the streets and was instrumental in having a record made of them singing their favorite gospel songs. And now they have become the subjects of a documentary film, "A Lady Named Baybie", which is scheduled for release this spring. While they have a full appreciation of sound—they listen to the radio and records by the hour—neither can visualize or understand film.



hymns from the Methodist churches, the Baptist churches, the different ones we attended in the Midwest. I know I've had people come up to me and say, 'Oh, my mother used to sing that hymn. I haven't heard that hymn for years.' Every day I work I start with 'What a Friend We Have in Jesus,' then I go through the friendship songs. I always have the order kind of planned out in my mind before I get to my spot because otherwise I would be thinking what will I do next, and that wastes time. I mean this is my job. I am giving people the best I got. I'm not just sitting there putting in time with a cup. Then I have songs about the cross and then I go to the assurance songs like 'Blessed Assurance.' Then I have 'How Jesus Leads Me' and the leading songs. Then come the songs of praise. Then the heaven songs like 'In the Sweet Bye and Bye' and 'How Beautiful Heaven Must Be.' One of the Heaven songs is always last."

She loves the praise she often gets for her singing and the words of people who miss her when she doesn't show up on one of her locations. "They couldn't pay me enough to keep me from singing to my dear beloved New York," she said. "It's never just the money. It's the rhythm of the song, the beat of the cup. It's being out among the people and performing and having people come by and speak to me."

Baybie admits that the money helps too, especially now that she is older and has to rely on taxis because of arthritis. She recalled how one man, looking at her cup of coins, once told her, "You know kid, you can't take it with you," to which she replied, "Yes, that's true. In the first place, I haven't got very much. But



"Films are completely foreign to me," said Baybie. "I've been to a few and I didn't really understand much because they change the screen so quickly. Really, when I think of film I think of a bunch of slick plastic stuff. But I think that it's great to make a film for the sighted world. I have been so overlooked all my life, and I would like for the film to help us human beings to be more alive to the world and more aware of each other."

"To me, a film is just a noun," added Virginia. "I don't know what it's shaped like because I have never seen one. I think it's like Bette Davis in "Dark Victory" or Barbara Stanwyck in "Stella Dallas." I don't know what the screen's like. I don't know why they have to have the



projector in the back of the room and the screen up front. You see, all these things are just a big mystery to me."

Michael Rehack, who appears in the film

as a member of The Radio Gospel Church, says, "I lost my sight when I was twelve so I have seen movies. I think Baybie is a good subject for a film. The blind people's story hasn't really been told. Most of the blind films are made by the agencies, and naturally they show only the good parts—like rehabilitation. But Baybie's story could tell the public the true meaning of what it is to be blind and how it is to live as a blind person. Also I think it's good to let blind people like Baybie speak for themselves."

"A Lady Named Baybie" is an hour-long documentary film funded by the National Endowment for the Arts, The Joint Foundation—Woman's Support, and the United Methodist Church. It's the



story of a woman—Baybie Hoover—who fights to get her independence by finding alternatives to the lifestyle dictated by a sighted world. It's a film that Baybie and other blind persons can only listen to.

After a recent screening, Baybie said, "You know, I've never gotten a look at myself with a mirror or anything, so when I heard just a little bit of the film I was enthralled. I actually forgot it was me. I just hope and pray that what the sighted world sees is favorable because I tell it like it really is." ■

# Into the Workplace

Ever since the lepers were expelled from camp in biblical times, the disabled have been a segregated and stigmatized minority that the social, cultural and economic fabric of society has systematically excluded from active participation. For the millennia they have been kept in the back room, hidden in the closet or in the institution. Locked away, they were all but invisible, and easily ignored. Now the situation is changed.

It would be nice to believe that increased sensitivity and humanity on the part of Americans has caused this redirection of attention, but this is not, unfortunately, the explanation. Antibiotics have increased the number of disabled persons who survive their disease or illness process, and psychotropic drugs have increased the number of disabled people who can manage outside institutions. Modern medicine, therefore, has multiplied the numbers of the disabled in our communities. Armed with a new militant definition of their civil rights, and strengthened by their numbers, the handicapped have demanded equality of opportunity. More than any other issue, employment has been their target.

Although work may be differentially experienced and valued by people of various socio-economic groups and occupations, the majority of us prefer to work rather than to experience unemployment. Freud said that the ability to work and to love were the two hallmarks of adulthood. It is not surprising therefore, that many observers have confirmed that self-image and self-esteem seem to be bound up with one's work; with the place where one develops a sense of mastery.

The status others assign us is also a function of our work. Who has not entered a room of strangers and been asked, "What do you do?" The exchange of this information permits the basis for understanding and interaction: "I am a carpenter" (meaning a skilled and highly paid craftsman), or "a nurse" (translated as a caring individual), or "a sanitation worker" (highly paid and relabeled from "garbageman" to gain a higher status and self image), or "I don't work, I'm just a housewife" (as if the day in and day out effort to maintain a home and raise a family is less valued because it is unpaid). In effect, we know men and women by the work they do.

Work is also an organizing activity for daily life. To go to work each day is to have something to do rather than to have to create daily some way to spend one's time. It is at work that we experience many of our social interactions and participate in group activities. The most significant contribution of work, however, is probably that it supplies us with our financial support. Indeed, we often mark the passage of youngsters into adulthood at the time they begin to work and become self-supporting. The financial remuneration from work helps determine the style in which we live, our neighborhood of residence, the people with whom we have contact, the way we spend our leisure, and countless other aspects of our existence.

While it is true that for some people work is drudgery, and that many would change their work or improve their working conditions if they could, most would agree with Albert Camus that,

# Sheila H. Akabas

"Without work, all life goes rotten." Work provides income, status, prestige, an organizing activity, and the social interaction without which we would have little sense of ourselves and less to convey to others about us. Work may not be Paradise, but neither is being without a job. The disabled fervently wish to be included in the ranks of the employed.

Although in his historic book, *The Other America*, Michael Harrington did not focus on the disabled when he called attention to poverty in our society, he might well have. Poverty in this group is excessive, running twice as high as for Americans generally. Estimates of the number of disabled persons vary widely, but there are approximately twelve million Americans sufficiently disabled to experience some discrimination in the workplace. They include those with hidden disabilities like heart disease and cancer, and those whose physical condition is readily apparent like amputees and quadriplegics. They include those with stabilized congenital disabilities like deafness and those with progressive degenerative diseases like multiple sclerosis. They include those for whom there is considerable community sympathy like blind people and those who are severely stigmatized like people with a history of emotional illness.

Whatever their disability, the disabled include people who are severely discriminated against in the labor market. Their earnings are excessively low. In 1971, the median income for the disabled was \$4,380 while the comparable figure for able-bodied Americans was \$10,678. Severely disabled college graduates that year earned, on the average, less than non-disabled elementary school graduates. Over 25% of



Sheila Akabas is associate professor at the Columbia School of Social Work and director of the Industrial Social Welfare Center, New York, New York.

all disabled persons fall below the poverty line compared with less than 12% of the non-disabled. Problems for the disabled are compounded because they comprise a higher proportion of other discriminated categories than their distribution in the total population. They are more often black, aging, women or poorly educated. Some handicapped people, because they have long been denied access to mainstream activities and education, have no marketable skills.

Work for the disabled is often a negative experience. They tend to be the last hired and the first fired. They experience more frequent work interruptions, and when there is an excess of labor, the disabled are not hired at all. They tend to be underemployed or employed part-time, although they are available for more demanding jobs or full-time work. Their earnings are less than any other group, and their pension expectations are likewise the most limited. They are truly America's poverty population.

Equal opportunity in employment is a route out of poverty; a feasible goal for millions of disabled barred only by environmental and attitudinal barriers. Employment for the handicapped is surrounded by confusion, myths and misconceptions. Claims that insurance costs go up when the handicapped are hired have been disproved by documented studies. Insurance rates are based on experience, and in safety, absenteeism and second injury the handicapped have built up an admirable record according to such varied sources as Du Pont, Insurance Company of North America, and International Business Machines Corporation. Even with the common fringe benefit of health insurance, group policies are provided without regard to the physical condition of those covered, and the

handicapped worker usually gets lost in the group experience. We should note that many of the handicapped have stabilized conditions—deafness, blindness, loss of limb—which should not negatively affect their utilization of medical care in any event.

In a society which expects everyone to work, we are not without some history of concern for work opportunities for the disabled. Disabled veterans were the impetus behind Congressional action in 1920 which provided vocational training, counseling, prostheses and job placement for some of the physically handicapped. Over the years amendments increased the disabilities covered and expanded the types of services available to the rehabilitation candidate. But no federal law specifically prohibited discrimination against the disabled until the passage of Title V of the Vocational Rehabilitation Act of 1973. With its regulations and subsequent amendments, it covers all those who have a physical or mental impairment which substantially limits one or more major life activities. It also covers those who have a record of such impairment or are perceived as having such impairment.

All governmental jurisdictions, federal grantees, and contractors of the United States Government are covered by provisions which require affirmative action to recruit, hire, maintain and promote "qualified handicapped persons" who can perform the "essential functions of the job." Further, employers are required to make "reasonable accommodation" to such people as long as it does not constitute "undue hardship." Disabled people who feel they have been discriminated against may file a complaint with the United States Department of Labor which is empowered

to hear and adjudicate such situations. In many states the disabled receive comparable protection from local human rights legislation.

The elimination of discriminatory behavior is only one dimension of a total program to increase the employment of the disabled. A prescription designed to achieve improved work opportunities for the disabled would also include full employment legislation for the economy, and sheltered workshops or enclave work opportunities in sufficient quantity to accommodate all those who cannot perform adequately in fully competitive employment. It would require the removal of architectural barriers so that no workplace is off limits. (State Vocational Rehabilitation agencies will often cover accommodation expenses for a particular disabled worker, and tax abatements help businesses defray other costs resulting from barrier removal.) It would provide national health insurance so that employers would not use the cost of insurance as an excuse for inaction, and so that disabled people would not be penalized with loss of their essential health-care coverage if they returned to work. (This would eliminate the present "Catch 22" disincentives to employment experienced by many of the disabled.)

In addition to improving entry into the workplace, there is a need to be more concerned about those already there. We need to pay more attention to how work can be dangerous to health as it has been for workers around asbestos and chemicals so that we reduce work related disabilities. Further, for employees who become disabled or who experience deteriorating physical or mental health during employment, maintenance on the job is of foremost impor-

tance. Often in danger of slipping out of the workforce, they may need special help. Since such disabled incumbents understand their job and have performed satisfactorily in the past, employers may be willing to assist in their maintenance. Affirmative Action legislation provides an additional impetus to those employers to seek ways of retaining such workers who include:

- those whose disabilities worsen, causing them to be unable to continue at their prior work,
- those whose disability is stable but whose job changes, causing them to be unable to perform their work, and
- those who develop new disabilities which change their ability to work.

Evidence suggests that it is possible for an employer to develop a policy which responds to the job needs of these groups.

In the total quest for jobs for the disabled, unions have taken an important role. By pressing for goals of full employment, they have, in effect, spoken for all the disadvantaged including the handicapped. They have also supported national health insurance, and in their own collective bargaining arrangements have encouraged the maintenance on the job of their handicapped members. Finally, they have involved themselves in national and local efforts concerned with employment of the disabled.

Implementation of any social program requires monitoring and enforcement efforts. It also requires the commitment and good will of the population since the "police" cannot be everywhere all the time. All studies show that the best way to find a job is through family and friends. More people use this source

successfully than any other. That means that employment of the disabled is everyone's business and responsibility. Each of us is aware of a job opening, and each of us knows a disabled person who may be looking for a job, may be searching for a better job, or may know another disabled person who is looking for a job. Each of us can serve as a connecting link—the bridge between the disabled and their job opportunities.

Success in providing employment opportunities and job maintenance for the disabled has multiple payoffs. People begin to support themselves rather than having to depend on the largess of an unwilling society (if Proposition 13 is to be believed). Easier access through swinging doors is symbolic of a workplace which cares; one which has begun to be concerned about the human being each worker is. And there is an important trickle effect as well. Inevitably, the world improves for everyone as consideration for the disabled permeates our society. The millions of baby-carriage-pushing parents are only one group that has benefited from the curb cuts demanded by the disabled.

Most of the credit for the movement towards independent living and equal economic opportunity for the disabled must go to the handicapped themselves. In demanding their civil rights they have helped the nation improve the quality of work and the quality of life for us all. ■

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# John's Story

# Murnan T. Ogburn

It took John Van Deusen seven years to find his first job; yet only two months after he began working last year at age thirty-nine he was picked by the Columbia, South Carolina, Mayor's Committee on the Employment of the Handicapped as "Handicapped Employee of the Year." Now he has just been named as "Handicapped South Carolinian of the Year" by the Governor's Committee on the Employment of the Handicapped. (Editor's note: this in 1978.)

"We nominated John for the award for the same reasons we hired him," says Gordon Fearing, assistant vice-president of personnel and training at Blue Cross and Blue Shield of South Carolina. "His intelligence, his uncanny ability to adapt to any situation and his tremendous drive to succeed make him an asset to our company. Despite years of being regarded as unemployable he never gave up. John deserves any recognition he gets."

A native of Rhinebeck, New York, Van Deusen began looking for work in 1969 after graduating from Columbia's Lutheran Theological Southern Seminary with a master's degree in theology. His first five years of job hunting were in the Washington, D.C., area, where his family lived for thirty years before moving to Columbia in 1975.

"When John was nine years old he began complaining of weakness in his right leg. By his mid-teens he was unable to walk, feed himself or put on his own clothes," says Ruth Van Deusen, John's small, white-haired mother. "It was several years before his illness was diagnosed as dystonia, a rare neuromuscular disorder of the central nervous system that makes muscles spastic and uncontrollable."

Unable to attend regular public school beyond sixth grade, Van Deusen managed to continue his education through homebound instruction. "John got as far as starting the eleventh grade even though by that time he was twisted as a pretzel," says his mother, who, along with his father, sister, nephew and his fiancée (now his wife), sat at the table of honor while Van Deusen walked the short distance to receive the award from Mayor John Campbell at the luncheon last May.

"When he was about eighteen we heard of a doctor who was doing brain surgery for diseases similar to John's, so we went to see him," explains Mrs. Van Deusen. "But the surgery was still experimental. Patients could and did die from it."

After he and his family learned all they could about the surgery and its results, the Van Deusen family discussed the possibility of such an operation. But it was John Van Deusen himself who made the decision to go ahead with it. Over a period of six months, beginning in 1956, he had three operations at St. Barnabas Hospital in New York City. He was twenty years old and had been an invalid for eleven years; for many of those years he had been confined to his bed.

The first surgery stopped his illness from doing further damage to his already contorted muscles. The next two operations "produced remarkable improvement of the disabling symptoms," according to Van Deusen.

"Although I still had to use a wheelchair and hadn't finished high school, my condition improved so much that within six months of the third operation I took a battery of psychological, aptitude and achievement tests to see if I could function in college," he recalls.

His father, Dr. Robert E. Van Deusen, headed the Lutheran Council in the USA's Washington Office for Governmental Affairs for many years. Now retired, he recalls how John was accepted at Gustavus Adolphus College in St. Peter, Minnesota. "It was 1,200 miles away from home," he says, "but Gustavus Adolphus was one of the few colleges at that time to accept students who hadn't finished high school."

After graduating from college in 1961 with a Bachelor of Arts degree in psychology, Van Deusen returned to St. Barnabas for more brain surgery before looking for a job. The operation had been perfected in the five years since he had had the first three operations. "We hoped his muscles would be easier to control," explains his father. But a second tragedy struck.

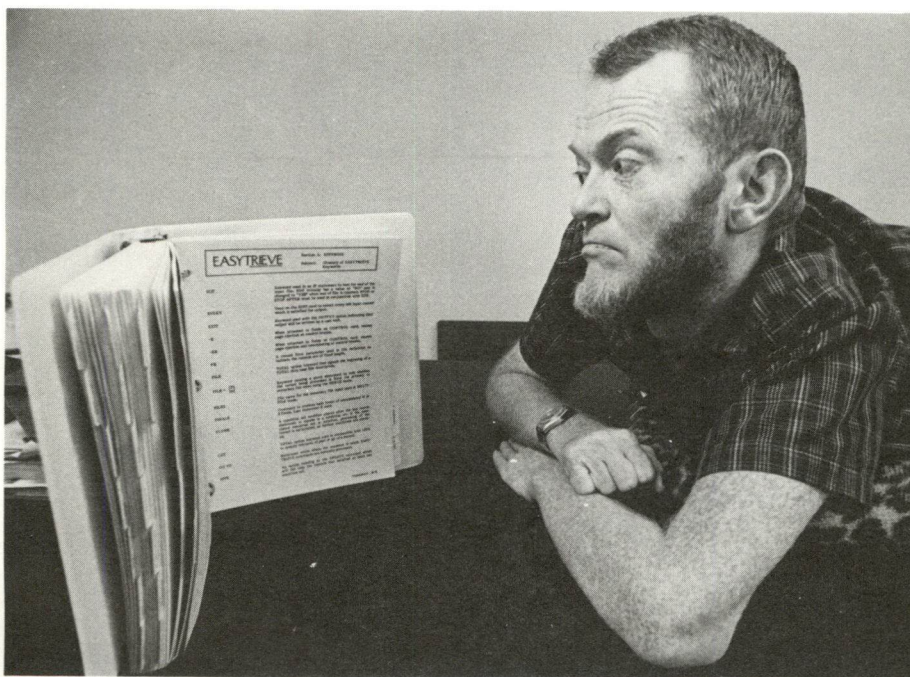
At age twenty-five he couldn't talk. The new surgery had given him slightly more mobility, but it had affected the control of his throat muscles, producing spasms that make it almost impossible for him to speak.

"Most of all I miss being able to hold a verbal conversation with John," says his mother. "He was such fun to talk to. Through all his years of being sick he had never lost his sense of humor."

With the help of physical therapy Van Deusen has since learned to speak a few words at a time. But most of his "talking" is done by note writing and sign language. And he has become an accomplished typist.

He indicates that at times the loss of his voice is more frustrating than his years of being physically helpless and totally dependent on others for all of his needs.

Murnan T. Ogburn is a manager in the Underwriting Department of Blue Cross and Blue Shield of South Carolina, and a free lance writer.



Even though the symptoms of dystonia had advanced no further since the five brain surgeries, his muscles had been affected for so many years that they were still considerably contorted. Coupled with his silence, it was improbable he would find work, so in 1963, at age twenty-seven, Van Deusen was admitted to the Albert Einstein Hospital in New York City for orthopedic surgery.

"The doctors actually spliced the muscles in his foot, side and neck to make them longer," recalls his father, "just as a telephone wire is spliced."

Van Deusen can now walk unaided for short distances and by using a motorized wheelchair is "completely independent" in caring for himself. His physical condition has improved to the extent that he is taking driving lessons arranged for by Susan Gottshall, his counselor at the Columbia office of the South Carolina Department of Vocational Rehabilitation.

"She has devoted much time and effort over the past two years trying to help me find a job. Many would have been inclined to give up on me but her encouragement and persistence were finally successful," wrote Van Deusen in response to his award.

Van Deusen first arrived in Columbia in 1965 when he entered the Lutheran Theological Seminary after his series of orthopedic operations. He specialized in pastoral counseling and graduated in 1969 with a master's degree. He hoped this education would equip him to counsel deaf people; before he began his theological studies he took an evening course in language at Gallaudet College near his home in Washington, D.C.



"John had us understanding sign language about two weeks after he came to work with us," says Viki Lee, a co-worker of Van Deusen's in Blue Cross and Blue Shield's underwriting department.

"John is very witty and was fun to work with," says Lee. "He works in another department now, but when we hear this wheelchair coming we all look at each other and smile because we really look forward to a visit with him."

Van Deusen began working part-time at Blue Cross and Blue Shield a year ago. Because he can't sit for longer periods of time his "desk" is a six-foot-long couch.

The sight of Van Deusen with his bright red hair and beard, lying on his stomach on a bright orange couch using a typewriter that sits on a wooden chair in front of the couch was at first startling to other employees because it was so unexpected. But now it's only visitors to his area who do a double-take. "When John flashes that infectious grin you immediately smile back. We seldom thought about the unusualness of the scene," says Viki Lee.

Because of his interest in computer technology Van Deusen took a computer programming aptitude test shortly after he began work. He made the only perfect score ever made at Blue Cross

and Blue Shield of South Carolina on that particular test. That and his attention to detail prompted Linda Hair, director of a newly formed utilization review department to offer him the full-time job of research coordinator in April, only seven weeks after he began as a part-time employee. "John's job is to extract complicated medical data from our computer and analyze it," says Hair.

"No 'thank you' would be complete without mentioning my employer," Van Deusen wrote in his acceptance speech of last year's award by the Mayor's Committee on Employment of the Handicapped. "From my very first day there I have been amazed at the lack of attitudinal barriers at Blue Cross.

"Other employers would do well to consider their example. If enough employers did, the Mayor's Committee would find themselves with nothing to do.

"I don't really feel deserving of this award. There are many handicapped men and women who have struggled to overcome obstacles far more difficult than those I have faced. Every single one of them deserves this recognition. I would rather consider this as being for all of them. I feel privileged to accept this award on their behalf."

Van Deusen credits his family with his basic sense of security. He wrote, "If a

handicapped individual is not loved and accepted as he is, he cannot learn to accept himself and come to terms with his own handicap. Until he does that, he can't develop the fighting spirit to overcome obstacles and take his rightful place in society. The love and understanding and acceptance of my parents and family enabled me to accept myself as I am and to realize that understanding and helping other people is far more rewarding than personal gain or accomplishments."

A new degree of acceptance and understanding came as Van Deusen and Linda Pohland fell in love and were married in May, giving John's story, as well as Linda's, a happy ending . . . or rather, another beginning. ■

*The preceding article is reprinted with permission from the Greensburg Tribune-Review Focus, February 11, 1979. "We've Got a Lot of Living to Do," copyright 1978 by Murnan T. Ogburn.*

# We Have a Lot of Living to Do

## Murnan T. Ogburn

In five years Linda Van Deusen learned to walk, talk, brush her teeth, bathe, feed and dress herself; she completed her elementary and high school education, passed the college entrance exams, found a job, was promoted twice and got married.

During those same years, between the ages of eighteen and twenty-five, she spent almost a year in the hospital, where she had brain surgery twice and a total hip replacement. Prior to age eighteen, Linda spent eleven wasted years in various institutions for the emotionally disturbed. And before that, between ages three and seven, she had been in and out of hospitals in futile attempts by her parents to have her illness diagnosed.

"All the while the doctors kept telling me and my parents that I was mentally ill, I tried to hold on to the reality that I wasn't. And after eighteen years, a doctor finally asked *me* if I thought my problems were emotional," explains Linda.

"I was afraid to say no because I might be kidding myself, but I knew if I didn't I wouldn't have a chance in the world."

On the strength of Linda's answer and his own feelings about her, Dr. R. Norton Hall, a neurosurgeon practicing in Greensburg, made the telephone call that changed Linda's life. He called the Johns Hopkins University Medical School in Baltimore, Md., and asked that she be considered for evaluation of a possible neurologic illness. Linda was admitted to Johns Hopkins on May 23, 1973.

On May 24, her illness was diagnosed as dystonia musculorum deformans, a rare neuromuscular disorder of the cen-

tral nervous system that makes muscles spastic and uncontrollable. Her husband John is also a dystonia victim.

When Linda was three-and-a-half years old she began limping and falling; she started walking tip-toed. By age four she was wearing short leg braces to stretch her heel cords, which seemed to be too short. But braces didn't help.

"Everything kept getting worse," says Linda. "My falls were frequent and my hands started to shake."

At age five she was put in a wheelchair because she couldn't walk at all without falling. Prior to this she had attended a church kindergarten, but when it was time for her to start first grade "my father said he and the teachers didn't think I could go to public school so he found a school I could go to," Linda recalls. The school was Coulter Avenue School for the handicapped.

"I prefer to think of it as a school for slow learners, rather than for the handicapped," says Linda. "Coulter Avenue struck me as a nursery school. We had play time and took naps. We also had physical therapy. I didn't learn much except how to scribble. I couldn't write because my hands shook too much. I stayed at that school for almost three years."

Linda's father had taught her and her brother, Brian, and sister, Janice, to read before they started school. "His sisters were teachers and he believed in education. He brought me books the whole time I was in those hospitals," she says. "That's one of the reasons I was able to learn so quickly when I was eighteen."

During the ages of three and seven Linda's parents, Mr. and Mrs. August Pohland, took her to Children's Hospital in Pittsburgh, and to Shriners Hospital in Philadelphia. She had already been to numerous doctors in the area around her home in Latrobe, where she was born on Sept. 7, 1954. In March 1963, at age eight, Linda reentered Children's Hospital in Pittsburgh, this time for psychotherapy.

"No one could find anything physically wrong with me," she recalls, "so they decided I had an emotional problem. I was supposed to stay there for three months but I was there for eleven months. Then they moved me to the Home for Crippled Children in Pittsburgh. I stayed there for two years."

For one whole day during her last admission at Children's Hospital, Linda could walk without falling.

"This often happens with people who have dystonia," says Ruth Van Deusen, Linda's mother-in-law. Mrs. Van Deusen has become something of an expert on dystonia after thirty-one years involvement with it—her son, Linda's husband, was nine-years-old when he first developed symptoms of the insidious disease.

"We'll never forget the day John woke up and it was as though he had never been sick. But the next day his muscles were uncontrollable again. The same thing happened to Linda."

"I could do everything. It was marvelous," Linda says. "But it only lasted for one day, which reinforced the psychiatric diagnosis of hysterical conversion reaction."

Nancy Pohland, Linda's mother, had a cerebral thrombosis five days after Linda was born. For several years, Mrs. Pohland was extremely ill from the effects of the stroke, so the new baby stayed with both sets of grandparents, leaving home and returning depending on the state of her mother's health.

Linda's brother Brian, five years her senior, had perthes of the left leg and spent a great deal of time in traction. He has since recovered, but Linda's earliest memories of Brian include a limp and a brace.

"After I started limping and falling and none of the doctors could find anything wrong with me, they thought I wanted attention, especially my mother's, and was copying Brian," Linda says.

Soon after entering the crippled children's home her vision blurred and she lost her voice. "I couldn't talk above a whisper. No one would talk to me because they thought it was hysteria and that I could talk if I wanted to."

During her two-year stay at the crippled children's home, Linda's muscles became increasingly spastic and she almost quit trying to talk. Her left arm and right leg and hip became stiff and almost unbendable. Her neck muscles also distended, thrusting her neck and head backward so that the top of her head hit the back of her chair. She sat in a chair all day "trying not to fall out

because I knew how hard it would be for me to get up off the floor."

Linda's attempts to convince people she was in agony trying to sit were useless. "The doctors thought I could sit, talk and feed myself if I really tried to overcome my hysterical reaction, so everyone else thought I was acting that way on purpose, too," she says.

At age eleven Linda was too old to remain at the Home for Crippled Children. "I wasn't getting any better, the insurance had run out long before, and my mother wasn't physically able to take care of me," she explains.

Linda was moved to Western State School and Hospital for emotionally disturbed and retarded children in Cansburg, where she stayed until she was sixteen. All attempts to continue her schooling were stopped. During her eleven months at Children's Hospital and her two years at the Home for Crippled Children in Pittsburgh, she had managed to finish third grade, but her inability to talk or write brought the end of her education.

"But my daddy never stopped bringing me books and I had a little radio. I listened to the radio all the time and I learned words and what they meant. I knew what was going on in the world, like who was president," Linda says.

"I couldn't talk but I understood everything. If people had tried to listen to my whisper they would have known that. But they thought I could talk if I wanted to so they wouldn't listen."

After two years at Western State it was discovered her right hip was dislocated; she was sent back to Children's Hospital for three weeks where her hip was set. After returning to Western State, she was spread-eagled in a cast from her waist down for six weeks.

"While I was in the cast they put me in a ward for the retarded rather than back in the ward for emotionally disturbed children. When I got out of the cast I went back to the emotionally disturbed ward, but my hip got dislocated again the next year, when I was fourteen," Linda recalls. She was taken back to Children's Hospital in Pittsburgh, this time for hip surgery and more time in "that awful cast. Oh, how I itched!"

To protect her from an emotionally disturbed child who repeatedly pushed Linda out of her wheelchair or pushed the chair over with Linda in it, hospital personnel put her in a room by herself. It had a dutch-door, the top of which was kept open. It didn't have a bed—just a mattress on the floor.

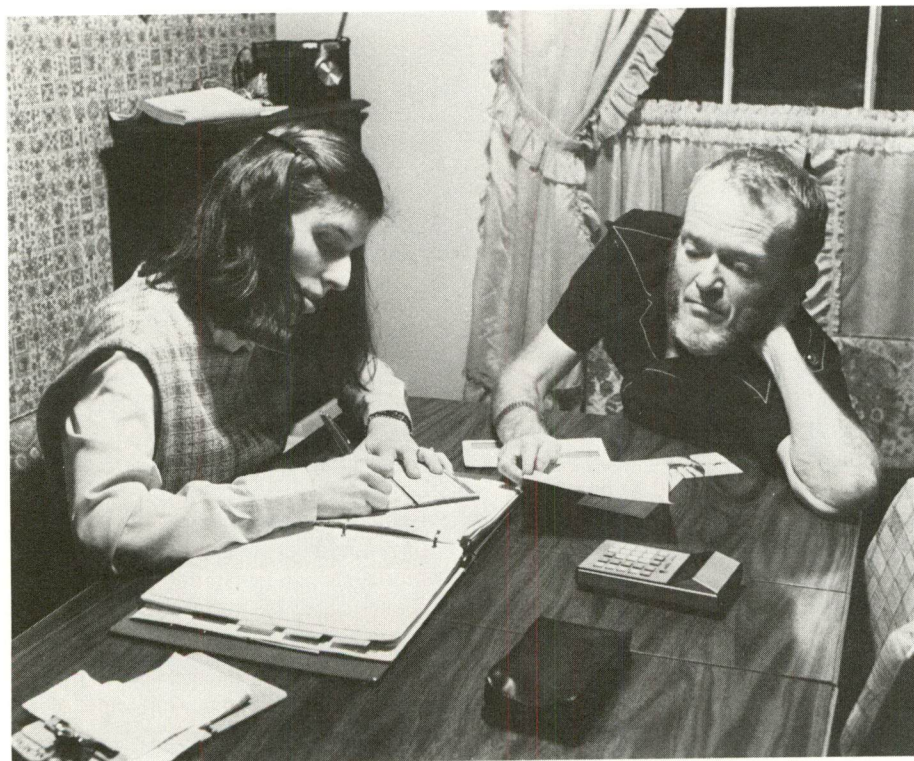
"I could get off the mattress, but I just couldn't get back on, even that close to the floor. So I stayed on that mattress for five months unless someone took me off it and put me back," she says. "To occupy my time I read and re-read my books and listened to my radio."

After five years at Western State School and Hospital, Linda was transferred, in 1971, to Torrance State Hospital in Torrance. She stayed there, with no hope of ever leaving, until her fateful visit with Dr. Hall.

She was sixteen when she entered Torrance and had been in three hospitals in nine years, never having the option of returning to her home she had left for what was supposed to be a three-month stay at Children's Hospital when she was eight years old.

"By the time I went to Torrance I was wise to the fact that if people realized I could do anything at all for myself they wouldn't help me," Linda says with a chuckle.

"You see, when I first woke up in the morning my muscles were fairly relaxed



and I could move them a little. Sometimes I could even feed myself after a fashion. But as the day progressed they got more and more spastic until finally I was helpless again.

"For a whole month I didn't do anything, until they found me out. But it was a great month. It was the first time in years that I got every meal every day. Because of my psychiatric diagnosis it was assumed I only fed myself breakfast if I liked the nurses, so sometimes I didn't get any breakfast or other meals if the nurses didn't have time or didn't want to feed me.

"I would have loved to feed myself every meal," Linda says indignantly. "I was *always* hungry. That's why I eat so much, now. But I'm lucky; I don't gain weight."

Linda is a petite 5-2¼, with shoulder-length brown hair, wise brown eyes and a crooked grin. She describes herself as "bossy because I've lived my whole life in five years and I get impatient for things to happen."

John Van Deusen, her husband, indicates with a solemn look in his usually merry blue eyes that he prefers "strong-willed" to "bossy."

When Linda was fifteen and a patient at Western State School and Hospital, her mother, Nancy, was in a serious automobile accident. Three years later she still had recurring headaches related to her auto injuries. During an appointment with neurologist Hall to discuss those headaches, Mrs. Pohland mentioned her daughter Linda to him. After asking some questions about Linda and looking at her picture, Dr. Hall asked Mrs. Pohland to bring Linda to his office.

"It was quite a production getting me anywhere," says Linda. "I couldn't sit in a car and I kept sliding off the back seat. One wheel of my wheelchair kept falling off even though my grandfather kept fixing it. But we finally got to Dr. Hall's office—only he wasn't there. He had been called away on an emergency.

"We waited all afternoon but he didn't come back, so my parents took me back to the hospital. About a month later he called my mother to say he still wanted to see me; we went through the whole business all over again and this time he was there. And that's when he

asked me if I thought I was mentally ill and when I said no he called Johns Hopkins with me right there in his office, listening to the conversation."

Six months later, on May 11, 1973, after more medical records had been lost in the mail and were recopied and re-mailed to Johns Hopkins, and after the admitting committee at Johns Hopkins evaluated the records, Linda was discharged from Torrance State Hospital. She was allowed to leave on the provision that she would re-admit herself if nothing physically wrong was found in Baltimore.

"My parents had to sign me out because I had been a child when I was admitted, but if I came back I would be an adult and would have to sign myself in," Linda says with a trace of sarcasm.

Within twenty-four hours of her admission the doctors diagnosed her illness as dystonia musculorum deformans, a disease so rare it remains unrecognized and untreated in most people. Following the diagnosis, her first month at Johns Hopkins was spent weaning her off of the psychiatric medicines she had been given for years. Then she was given new medication to see what effects it would have on her condition.

At the end of the month, on a Monday, Linda was given 250 mgs. of L-Dopa, a medicine that usually helps dystonia patients. On that same day her muscles began to relax. Each day there was more improvement.

Every Monday and Thursday the amount of L-Dopa Linda took was increased by 250 mgs. And every time it was increased she learned a new skill—how to sit up, move her arms and legs, feed herself, bathe, brush her teeth, and how to talk again in a normal voice.

"I remember the first time I could talk loud enough to use the telephone. I called my parents and my father answered. I said, 'Hi, Daddy.'"

"Who is this?"

"This is Linda."

"Who is this? It can't be Linda. My daughter Linda can't talk."

"I was so excited I handed the telephone to the nurse and she told my daddy it really was me. My parents got

there the next day—and it's a long trip—just to be able to see me talk," recalls Linda with a catch in her voice.

Gradually Linda learned to walk with the help of four-pronged quad canes, although she had great difficulty because of her right hip, which had never healed properly after being dislocated twice.

Her daily dosage of L-Dopa eventually reached 3,250 mgs., but it soon became evident that she couldn't tolerate that level and it was decreased. With each decrease she began to lose her painfully developed skills. There was an alternative to the massive dosage of L-Dopa, but it was an extremely dangerous alternative.

"They explained all the risks of brain surgery to me: how I could go blind, be paralyzed, lose my voice, or die," says Linda. "But I said if I could be like everyone else, if I even had a chance to be like people who aren't handicapped, then I would have the surgery."

"They also told me that before the surgery could be done I would have to completely stop taking my medicine. That meant I would be helpless again. I was scared to be like that all over again, but I knew it wouldn't be forever if the surgery worked."

It took three weeks to decrease the L-Dopa until Linda wasn't taking it at all. At the end of that time she was in the same condition she had been in when she entered Johns Hopkins four months earlier. She was absolutely helpless. Then, in October 1973, she had the first of two brain surgeries.

"They shaved off all my hair. I hadn't realized they were going to shave it all off," Linda exclaims.

The surgery on the right side of her brain lasted four hours, during which Linda was awake so she could move her arm and leg as requested by the doctors.

"I didn't really believe I was moving them all by myself, even when I did it. But right after the surgery I could move my left arm and leg fairly well," she says. "I could sit up pretty well, too."

She couldn't get out of bed because her right side was still spastic and would be until the surgery on the left side of her brain. "I picked the right side of my

brain to be done first because the left side of my body hurt the most."

In November 1973, the surgery was performed on the left side of Linda's brain. "I was immediately able to function as I had with the largest dosage of L-Dopa, only better, and I didn't have to take all the medicine. I still take a small amount of it daily because it makes my muscles work even better."

On December 22, 1973, Linda was discharged from Johns Hopkins with no question of having to sign herself back into Torrance State Hospital. She would never have to go back there, again.

She did return to Johns Hopkins, however. Eight months after leaving the first time she returned for a total hip replacement. "I was admitted on Sunday, had surgery on Tuesday, sat in a chair on Friday and was walking the next Monday," Linda recalls. "Oh, the surgery hurt, but not more than I could tolerate and not more than my hip hurt with every move I made before it was replaced."

After leaving Johns Hopkins, the Pennsylvania Department of Vocational Rehabilitation in Johnstown arranged for her to attend business school.

"I finished business school but still couldn't find a job. Everywhere I went, people said I needed a high school diploma," says Linda. "I did volunteer work in a hospital, but I was twenty-one years old and had never been to high school. If it hadn't been for John I might never have gotten my diploma."

Linda met John, also a dystonia victim, in New York at a conference for dystonia patients, and they fell in love.

John and his parents, Dr. and Mrs. Robert E. Van Deusen, met Linda in New York City at the second International Conference on Dystonia held in May 1975. Ten dystonia patients, among them John and Linda, attended the conference along with doctors from all over the world. As head of dystonia research at the National Institutes of Health in Washington, D.C. and a consultant to Johns Hopkins, Dr. Roswell Eldridge knew Linda and the Van Deusen family. It was he who introduced them.

"Dr. Eldridge knew Linda had come by herself to the conference from Pennsylvania. He didn't want her to be alone so he asked us to look after her," recalls Dr. Van Deusen, who retired in January 1978, as associate pastor of the Ebenezer Lutheran Church in Columbia, S.C. Prior to moving with his family to Columbia in July 1975, Dr. Van Deusen headed the Lutheran Council in the USA's Washington, D.C. Office for Governmental Affairs.

"John and I stayed up and talked until midnight," Linda says. "We had so many things in common, like brain surgery. We exchanged addresses and I got my first letter from him in August of 1975, after they moved."

Linda and John corresponded regularly and through her letters he learned how much Linda, then twenty years old, wanted to earn a high school diploma. He sent her an application for the Wil Lou Gray Opportunity School in Columbia, where students are able to live on campus while attending classes. Two weeks before registration on May 31, 1976, she was notified of her acceptance.

Linda graduated from the Opportunity School at the end of April 1977, after seven months of classes that began in September 1976. When she entered the school she was at a fourth grade math, eighth grade reading and tenth grade English level; these levels were established by academic tests she took during June 1976, during her first month at school. She spent July taking tests and working with her counselor, Carl Murphy, at the Columbia office of the S.C. Department of Vocational Rehabilitation. School was closed in August.

"We were out of town for two weeks in August, so we arranged for Linda to stay with our friends Nancy and Mel Amundson," says Dr. Van Deusen. Mel, pastor of Redeemer Lutheran Church in Columbia, served as a groomsman and Nancy was a bridesmaid at John and Linda's wedding at Ebenezer Lutheran Church on May 28, 1978.

"I took the GED (general education diploma) test on April 23 and then spent one of the longest weeks I can remember waiting to see if I had passed," Linda says. She had already taken and passed college entrance exams a few months before taking the GED.

"You know, I never expected I'd be able to do any of these things," says Linda. "I thought I would die in one of those state hospitals."

Linda wears a brace on her left foot and ankle, the results of the foot being broken "sometime when I was little, but nobody knew it." She uses a wheelchair when she's in crowds or has a fairly long distance to go. She limps a little and her hip tires easily.

But Linda Van Deusen sees only good things in store for herself and her husband, just as good things have happened over the past few years. Even with a master's degree it took John seven years to find his first job; yet only two months after he began working, at age thirty-nine, he was picked as Handicapped Employee of the Year by the Columbia Mayor's Committee in March 1977. He was also chosen as the 1978 Handicapped South Carolinian of the Year.

Linda was second runner-up in the 1977 Miss South Carolina Wheelchair pageant. Carl Murphy, her counselor at Vocational Rehabilitation, received the 1978 counselor and case of the year awarded for the Columbia area due to Linda's phenomenal progress.

Linda and John both work at Blue Cross and Blue Shield of South Carolina, in Columbia, where John's sister Betty is also employed.

Linda's parents, who attend Trinity Lutheran Church in Latrobe, and her brother and sister all attended the Van Deusen's May 28 wedding held in Columbia—a wedding after which the bride and groom both walked down the aisle, a major accomplishment considering John has difficulty walking more than a few feet at any one time.

"I may get around to having the surgery on my foot some day," Linda muses, "but probably not soon. John and I have so many things to do together."

"We have a lot of living to do." ■

*The preceding article is reprinted with permission from the Greensburg Tribune-Review Focus, February 11, 1979. "John's Story," copyright 1978 by Murnan T. Ogburn.*

# We Are All Special People

# Sondra Diamond

*The following is a revision of a speech Sondra Diamond originally made to a group of medical professionals.*

If little else is accomplished as a result of our interaction, it is my greatest hope that you will be more comfortable with your feelings concerning disabled individuals so that you may see us as total human beings with all the potentials and feelings of the non-disabled.

My expertise is comprised of two components. The first is my personal neurotic bias. The second is that a greater part of my life is taken up running barefoot through the psyches of the physically disabled.

Each time I have an illness, unrelated to my disability, which warrants hospitalization, my doctor will go to great lengths to treat me at home. He knows that ignorance of and insensitivity to my physical disability will make a hospital stay a traumatic ordeal. In the June issue of *Nursing '75*, I wrote an article about one of my hospital ordeals typifying my experiences.

The nurse's aide wheeled me into my hospital room. Even though I'm thirty-three years old and a counselor in private practice, I still have the same fears and apprehensions about hospitals that every prospective patient has. But no one seems to notice or care—RN's, LPN's, even interns.

As soon as the aide had gotten me into my room, she ordered me to get undressed and get into bed, and immediately left.

When she came back ten minutes later and found that I hadn't obeyed her, she shook her head at me as if I were a naughty child and said, "I'm going to have to get the head nurse," leaving the

room for the second time without giving me the opportunity to explain that I am unable to undress myself.

A few minutes later, the head nurse marched into the room with the aide and a male orderly covering her flanks. She took one look at me and said, "I understand you're being uncooperative. Why haven't you followed orders?" I tried to explain, but she ignored me.

After the aide undressed me and prepared me for bed, the orderly, with the poise of a longshoreman, loaded me onto the bed, folded my wheelchair and stashed it in a corner. That's like putting a patient, who can walk, into bed, taking off his or her legs, and stashing *them* in a corner. My wheelchair *is* my legs. As they were leaving, I heard the head nurse say, "How'd I get stuck with her?"

By this time, my nervousness began to affect my bladder. I pressed the button to call the nurse. Twenty minutes later a nurse's aide came in. Once understanding that I needed a bedpan, she placed it at the foot of the bed, well out of my reach, and hurried out. On returning some time later, and finding the bedpan unused, she placed it back into the night stand, and left.

At this point, I was reduced to tears, again experiencing the realization that the people in whose hands my fate rests lack the training and perception to be able to identify a physical disability. If they do recognize a disability, the gap in their knowledge and experience precludes them from understanding the extent to which it affects the functioning of the disabled individual, or how to deal with it. In their frantic attempt to cope, nurses say, "People like you should have a private duty nurse." Resi-

dents get hung up on the fact that I'm shaking, and want to either tie me down or sedate me.

Routine workups become bizarre happenings. X-rays are a case in point. Despite my protests to the contrary, and my ignored attempts to explain that I am unable to hold still long enough to be x-rayed, I was hauled off to the x-ray department by two orderlies. After positioning me on the x-ray table, the technician instructed me to lie perfectly still. I told her that this was impossible because I have cerebral palsy. My comment was ignored, and she left the room to take the first of many sets of x-rays. After the first set of x-rays was developed, the technician returned and told me that a second set would have to be taken because the first was unreadable. This time, she had commandeered two gorilla-type orderlies who were instructed to hold me down. I drew in a breath and tried again. I said, "Because of my disability, the more you try to restrain me, the more I shake." For the third attempt, I was secured firmly to the x-ray table by 2' wide adhesive tape. For the fourth attempt, the x-ray technician instructed the previously described strong-arm men to straighten out my legs.

That really terrified me. I tried to control my anger and fear of pain, and managed to yell, "You can't straighten my legs, they're permanently bent by contractures. If you try to straighten them, it will really hurt me!"

Although I was the victim, and in need of comfort, my three assailants busied themselves bestowing words of sympathy on one another, assuring each other that they were doing the best that they could, and faulting me for their inability to successfully complete their task. After an hour and a half of painful, useless activity, I was taken back to my room.



Sondra Diamond has been in private practice as a counselor for the past nine years. She also lectures widely throughout the United States and Canada, and is currently a consultant at the Matheny School for Handicapped Children in Peapack, New Jersey. Ms. Diamond has been physically disabled since birth as a result of cerebral palsy.

The quality and quantity of medical care, be it in a hospital or elsewhere, is controlled by doctors. Administrative bureaucracy aside, it is the physicians' instructions that control how a patient will be treated. In order for professionals in the medical field, or professionals in any field for that matter, to work with the physically disabled, you must be armed with two bodies of knowledge: an insight into your own feelings about the physically disabled, and a store of information concerning physically disabling conditions and the effects of and adjustments to those conditions. The accumulation of the second body of knowledge is predicated on the first for, although gaining insights is a subjective process, it enables us to fully understand the didactics and allows us to implement it.

The area of your education that has been most neglected concerns subjective feelings that confront you when you meet disabled people. There are no textbooks you can turn to for help in this area. What then can be done? Examine your feelings. Examine them in terms of what you were taught about the disabled while you were growing up. You were probably taught not to look at the disabled and told not to stare. Yet you were freely permitted to look at other people. Examine your feelings about the disabled in terms of your own fears, self-doubts, and your own self-concepts about your body image. It is too easy to project how you think you might feel if you were physically disabled. Being disabled is not the same as thinking about what it would be like if you were disabled.

Many of you look at a person in a wheelchair and feel that you couldn't live a life like that. If you see a person on crutches struggling to climb a flight of stairs, you may think to yourself, "I wouldn't have

the emotional strength to deal with such obstacles." If you see a blind person walking down the street, you may think to yourself, "I couldn't go through life like that." If your personality is one that is highly motivated, an added disability will not change your personality. If you are a person of great patience, a disability will not change that facet of your personality. One deals with a disability via a personality. A disability does not dictate a personality.

Aside from the programming you received as children, some of your negative feelings concerning the disabled may be based on the cosmesis of the disability in that facial grimaces, twisted arms and legs, severe facial or bodily deformities elicit strong negative feelings in some people. Before we can acknowledge that there is a personality behind what we see, we must be honest with ourselves and acknowledge that we don't like what we see.

You are human beings! In working with the disabled you must acknowledge your feelings—the negative ones as well as the positive ones. Face these feelings and deal with them! Let us not think, "I shouldn't feel this way." We do! Therefore, as adults confronted with the problems native to the disabled, we operate with a set of long forgotten unconscious feelings. That this is true, even of the curriculum developers in medical schools, is borne out of the fact that courses on the problems of the physically disabled are not taught. One barely learns to identify a disability, let alone what the accompanying problems and unique needs are.

As children, you were segregated from the disabled in the educational system due to the fact that disabled children went to special schools—an isolation which harmed the disabled children as

well as yourselves. Social segregation further separated you from the disabled through architectural and attitudinal barriers.

The mass media perpetuate your distorted myths about the disabled. Ad campaigns to solicit funds communicate their message through adorable, crippled children or bedridden elderly women. Television dramas depict us in two polarized ways: either we are superheroes, like Ironsides, or pathetic invalids. The greatest exposure that disabled people have in the media, especially in television, is through telethons. Children on crutches are paraded past cameras to evoke the proverbial lump in the throat. If disabled adults are shown, which is seldom, they are treated patronizingly and condescendingly rather than as individuals who have overcome their disability.

Perhaps, in helping you acknowledge your feelings, we should take a closer look at how I feel about being disabled. What is it like to be disabled? It's happy, it's sad, it's exciting, it's frustrating. It's probably just like being non-disabled. You worry about the future. You revel in the joys of the present. You wonder what will become of you when your parents are no longer around to help you with your special needs. You want to go places and do things just like everyone else. You have the same sexual drives, the same hopes and dreams for marriage and a family, the same aspirations for a successful life as everyone else does.

I have never felt that it was intrinsically a burden to be disabled. It has always seemed to me that society, in its lack of accommodation, made it a burden to be disabled. I recall as a child not feeling particularly different from other children. I was aware that I could not do the

same things that they could, but I did not feel badly about this. This was largely due to the fact that I have very supportive parents. No matter what battles I had to fight in the outside world, I always knew that I could come home and be reassured by my parents that the fight was worth it.

Being disabled is also a puzzling experience because people don't react to you the way you feel inside. People look at you and assume that you are retarded or incompetent or a pitiful sight. And you don't feel retarded, incompetent or pitiful.

There is a great emphasis placed on physical competency, so when you are confronted with an individual who can't toilet or dress him or herself, there is a tendency to treat this person as if he or she were also emotionally and intellectually helpless. The two do not go hand-in-hand. Yes, it is true that I cannot take myself to the bathroom or dress myself, but I can speak to you about my feelings, I can carry on a full professional life as a counselor, and I can lead a rich social life.

It is also important for you to know that there are moments when a great deal of self-pity washes over a disabled person. These feelings are born out of the conflicts that we experience as a result of what we want to do, what we are capable of doing, and what we are permitted to do. But I have found self-pity quite productive. Self-pity, rather than a negative feeling, is a positive motivating force which creates an inner-strength which helps me to continue to strive forward.

To complete the picture of how it feels to be disabled, I would like to share an experience with you that will illustrate how, as a patient or a client, my feelings have been dealt with. When I was thirteen years old and still getting physical therapy, I was assigned to a male physical therapist. I found this to be a highly sexually stimulating experience—not particularly enjoyable, for it was hard for me to keep my mind on physical therapy. I asked the chief physical therapist who was a female if I could have a female physical therapist. She asked me why, and I, feeling very embarrassed at thirteen, tried to explain. I was not given permission to change therapists. This is a clear example of how the feelings of the disabled are not perceived.

If we clearly understand the feelings of the disabled and our feelings about the disabled, then we can begin to effectively relate to the disabled.

Those of you who work with the disabled, must know fundamental symptoms, characteristics, and prognoses about each individual disability such as cerebral palsy or multiple sclerosis. However, each individual with said disability adapts in a unique way to his or her disability. Therefore, it is necessary when examining or treating a disabled person to fully understand the way a person has adapted to his or her disability. This is a tall order. For example, you may feel that injected medicine is less painful in the buttocks rather than the arm. But, for a person who must sit in a wheelchair for at least 16 hours a day, he or she would prefer to have that injection in the arm. In the longrun, in this individual's case, this would be less painful. To further exemplify, oral medication for disabled people poses individual problems. There may be difficulty in swallowing, tight throat muscles or a sensitive gag reflex, requiring understanding. In some cases, liquid medication may be best; in others, a tablet that can be crushed and mixed with a substance such as apple sauce may be more effective.

In my case, I have had to learn that taking a mouthful of water first and then having someone place a pill in my mouth and swallowing both at the same time is the most effective method. It causes the least problems and discomfort.

A disability cannot be cured! Some of the symptoms can be alleviated and adapted to, but it is permanent. Because you cannot cure it, you may feel frustrated and turn away from it, forgetting that there is a whole person behind the disability. This often leads to less than complete medical care. If a severely disabled person becomes critically ill, doctors frequently feel that it is pointless to use all resources on behalf of the patient, their feeling being—"Why bother? Their life will be meaningless anyway." This viewpoint is primarily due to lack of information about how well this person has adapted to his or her disability, lack of information about rehabilitative techniques, adaptive techniques, and availability and use of assistive devices once the critical period of illness has passed. When an able-bodied person acquires a disability through a trauma, such as an accident

or a stroke, often for the same reasons that complete medical care is withheld from the disabled, it is withheld from these patients as well.

One time I was hospitalized with third degree burns over sixty percent of my body. It took weeks of pleading and urging by myself and my family members before the attending physicians would do more than maintenance medical care. The medical staff felt that the severity of my disability precluded the necessity for grafting or similar restorative procedures. My parents showed the doctors photographs of me swimming and others of me playing the piano. Despite the protests to the contrary, I was left to remain in the same position as when I was admitted to the hospital, a fetal position which I assumed immediately after the accident which caused the burns. I explained that my disability would be worsened if I were not given passive exercises and helped to assume a more normal position. Their attention to the immediate medical problem overshadowed any possible foresight of future consequences.

Before the accident, through intensive habilitation, I had become one hundred percent independent in my daily living skills. It took two years of work in a rehabilitation hospital to regain less than fifty percent self-sufficiency, the level at which I presently function.

If we approach each disabled person as an individual, are there rules of thumb or general principles we can talk about and learn? Yes, and one of the first is that a physical disability is not an illness. To view it as such does a great disservice to the disabled. For it says, "You are sick; therefore, our expectations of you are low. We do not expect you to study, work, or enjoy life." This, in turn, reinforces an individual to see him or herself as ill—to have low expectations of him or herself. Although a disability may have been caused by an illness, such as a stroke or poliomyelitis, once the individual has recovered from the precipitating illness, we must relate to and treat him or her as disabled and no longer ill.

Another basic principle to keep in mind is that the disabled are experts on their own bodies. Because our lives are modified as a result of our physical limitations, and could be further modified if we are not mindful of good health, we

are keenly aware of our body and its function—to a greater degree than the able-bodied. We must know to which illnesses we are susceptible, how we can avoid them and how we can take care of ourselves in the event of their onset. If the nature of our disabilities necessitates the taking of regular medication, we must be thoroughly familiar with it. If you are confronted with an individual who has been disabled for a period of time, it is important for you to utilize the understanding and knowledge that he or she has of him or herself. If you are treating a disabled child or an individual who has recently become disabled, it is incumbent upon you to teach these people to assume the responsibility of maintaining good health through awareness of and techniques to deal with the problem areas of their disability.

The disabled know that they are more susceptible to certain conditions such as respiratory problems, decubed or pressure sores, urinary, bladder and kidney problems, low appetite and muscle contractures due to sedentariness and less mobility. It is equally important for all members of the medical profession to know these. Because we understand the possibility of these complications, we avoid extended periods of immobility in bed which is the primary villain in causing these complications. The medical profession must keep this in mind before too hurriedly prescribing bed-rest following a surgical procedure. You may think that if a urinary tract infection develops all that needs to be done is to prescribe a sulfa drug and the intake of large amounts of fluids. For the disabled, this is a serious problem, for the task of going to the bathroom is a difficult one for many of us. Psychologically, a confining illness will cause a greater feeling of depression for the disabled than for the able-bodied, for the illness magnifies the limitations that the already existing disability presents.

A third principle to keep in mind is that a large part of an individual's adjustment to a disability is the way his or her environment is modified. We can be rehabilitated, but if our home and the things we use in it are not accessible, our adjustment is incomplete. Pluck us from our environment and deposit us into a hospital which lacks accessibility, and then you reduce us to a frustrated state. The strangeness of a hospital environment is, at best, a difficult one; for the disabled it is devastating.

One of the ways to make this a less traumatic experience is to have disabled individuals, when admitted into a hospital, bring as many assistive and self-help devices as are normally used. A second solution is to make sure that the hospital is a barrier-free environment—with accessible bathrooms, light switches, elevator buttons and other such hardware at arm level so that they can be fully utilized.

There are community-based agencies that work with the disabled like the United Cerebral Palsy Association, the Easter Seal Society, or the Multiple Sclerosis Society. Most of these agencies have nursing consultants who would be happy to provide on-the-spot training when a physically disabled person is admitted to a hospital. The information and help that these agencies are prepared to provide makes a hospital stay for a disabled person much smoother. And further, they can provide the nursing staff and technicians with techniques on how to best care for the disabled individual. Beyond this on-the-spot training, they also, by invitation, conduct training courses in hospitals for members of the staff who deal directly with the patient.

Potential psychological counselors must understand that the physically disabled experience the same psychological problems as the able-bodied. We are also faced with the unique psychological problems arising from dealing with and adjusting to a disability. These unique problems are myriad: the deprivation of the universal need for "private space" (the unseen boundary around our body which we do not want invaded by touch or look unless we give our tacit approval), the recurrent periods of self-pity that are born out of the conflicts that we experience as a result of what we want to do, what we are capable of doing, and what we are permitted to do; and the distorted self-image which arises out of the conflict between the way a disabled person sees him or herself, and the way others relate to us.

Potential sexual counselors must examine their own attitudes concerning the importance of sex in the lives of the physically disabled and the way in which your attitudes coincide with reality. People, and members of the medical profession not excluded, seem to feel falsely that the less a disabled person knows

about sex, the less likely it is that he or she will be sexually irresponsible. And further, doesn't the disabled person have enough trouble learning how to read or eat? Why worry about sex? A disabled person has the same physical and emotional needs as everyone else. We experience the same anxieties during adolescence as a result of the need for sex role identification and control of sex impulses. A disabled person has the same need for affection and the same hope for marriage and a family.

Sexual counseling must be non-directive in helping the individual explore his or her feelings, but it also must be directive in that concrete information must be disseminated. Let us put aside our hang-ups and deal with what the disabled need to learn: 1) positioning that will circumvent problems within the disability—problems such as paralysis, contractions of the legs, and bowel and bladder control problems; 2) alternate techniques to sexual intercourse, helping to overcome limitations intrinsic in the disability; 3) birth control techniques; 4) child bearing.

There are unique and different problems for each disabled individual in bearing and raising children. Depending on the type or severity of the disability, the solution to these problems depends heavily on the individual's capabilities. There may be a need for an assistive device for one new mother. Another may need to learn a unique diapering technique, and a third may require something altogether different.

In summation, I have spoken about the physically disabled on a feeling level as well as a pragmatic level. The most important point that I would like you to remember is that the disabled are not abnormal—we are different. We are as different as each of you are from each other. Our eye colors are different, our hopes are different, our emotional levels are different. As different as each of yours are. We do not see an inferiority in being disabled; rather, we are different. ■

# Still a Woman, Still a Man

*All of the quotes in this article are from interviews with disabled people.*

It is paradoxical that disabled people have a great deal to teach the rest of us about sexuality. As an able-bodied culture, we have overtly and covertly denied the sexuality of physically and sensorially handicapped people. In an effort to protect them from the pain and frustration of sexual involvements, we have encouraged them to think of themselves as asexual or incapable of sexual expression. The comments of disabled people reflect this attitude.

*It's like you lose your womanliness when you become disabled. Someone said to me, You were such a beautiful woman. People seemed to think—and I believed—that no one would ever want to be close to me again.*

*I used to think I could never have sex. I was twenty-three when I found out differently. I always thought you had to be able to walk to have sex.*

In the face of this process, disabled people continue to involve themselves in sexual relationships and sometimes come closer to realizing intimacy than the nondisabled majority. Just as people who have been enslaved can speak knowingly of freedom, so disabled people who have been "desexualized" may offer a profound lesson about the dimensions of human sexuality.

There are many reasons why we have found it necessary to deny sexuality in those who are disabled. Perhaps the foremost reason is our own ignorance and fear about disability and its impact on sexual function. If we think sex requires physical agility, sensation, health, stamina and certain desirability criteria, then it may indeed be difficult

to imagine a disabled person as a sexual person. A typical spinal cord injured man is unable to move his legs, occasionally has erections but cannot ejaculate, and generally looks different from other men. A blind woman does not use typical facial language and may ambulate with less grace as she explores obstacles in her path. Because most of us have had so few opportunities to know disabled people, our curiosity and apprehension about them is overwhelming. We fantasize what it must be like to be in their bodies and assume, "No one could ever be attracted to me if I looked like that." In defending ourselves, we set them apart by declaring them non-sexual. The real tragedy occurs when disabled people start internalizing their non-sexual label and behaving accordingly. A vicious cycle begins.

*I used to have what I thought was a pretty neat body before the fire. But now when I go to a store, I come out tremendously depressed because there's clothes and dresses that I want to buy. But if I wore them, the sight of my scars would shock everybody. I'm very conscious of not what I want anymore, but the way I'm going to affect somebody else. I've had too many people say to me too many things.*

Unlike a temporary weight gain or broken limb, this physical reality is permanent and a constant reminder that they will never look or function like other people.

It seems that we continue to have exaggerated fears about the less physically perfect members of society reproducing, and prejudiciously believe that "cripples will breed cripples." This again is born of an ignorance which

# Jane Bogle and Susan Shaul

does not allow discrimination between those disabilities which are genetically transmitted and those which are not.

*Even after being told I had broken my back in a car accident, one girl I was dating actually told me she thought I shouldn't have children because, "Kids should be able to run." When I finally figured out her logic—or lack of it!—I was amazed. I couldn't believe it.*

This then becomes additional reason to believe that disabled people really should not be engaging in sexual activity. The facts are that most disabilities are not hereditary and that more and more disabled people are choosing to have children and are making fine parents.

Despite these obstacles, many disabled people come to understand that disability does not preclude attractiveness, and that sexual desirability is not inextricably linked to a standard of physical beauty. Herein lies a lesson for the rest of us: a person's sexuality and sexual attractiveness need not be dependent on how he or she looks or how functional his or her body might be.

*Right after my stroke I was—quote—crippled. Then I discovered I was still a woman. I knew I had things to offer other than a limp, a brace, and a sore arm. I've become more aware of the beauty within myself and in relating to others.*

Often such self-acceptance is nurtured by a partner's acceptance:

*When we're making love and I see her hands on my body—on the parts of me I can't feel anymore—it somehow*

Jane Bogle has a Masters in Public Affairs from the University of Washington and is a consultant and trainer specializing in management. Jane has been disabled from infancy with scoliosis and partial paralysis.

Susan Shaul is a doctoral student in educational psychology at the University of Washington, and a consultant and trainer in women's health care and health education issues.

*makes me whole again. If she can still love me, I suppose I can slowly learn to care about myself again.*

This different awareness of what makes a person attractive is a powerful insight as it elevates loving to where it should be: an acceptance of the way a person is, regardless of looks or abilities. This acceptance is a natural and essential component of love and sexuality.

Even if we acknowledge disabled people as fully participating sexual people, our curiosity remains. We wonder, "How does a man who cannot ejaculate have sex?" "What sexual positions work for people who are paralyzed?" "Do you have more sensation if you can't see?" It is true that disability can have a significant effect on sexual function. For instance, people who have sustained spinal cord injuries may have lost all genital sensation. Spasticity associated with cerebral palsy may make intercourse impossible. People who have rheumatoid arthritis may experience extreme pain with movement. Because these and many other physical limitations may preclude traditional penile-vaginal, male-superior intercourse, disabled people have been forced to explore a much fuller spectrum of sexual options and awareness than most of us ever consider.

*Sometimes we just lie in bed. Maybe I'll rub his back, maybe he'll rub mine. Then maybe we'll kiss for a while or just lie there and talk. Somehow it all seems sexual. It seems like we're making love the whole time, even though we don't happen to have intercourse in a traditional sense. The way we are together is just tremendously satisfying.*

This couple is somewhat unusual in their physical inability to have intercourse, but their interaction illustrates very well that sexual expression can be quiet caressing as well as acrobatic multi-orgasms. It is this breadth of sexual experience which is important for all people, disabled or not.

*Before my accident, we had sex quickly in what I suppose you'd call a "traditional way." There wasn't much to it for me. Strangely enough, now it's so much better. We need to take more time with each other, experiment, talk more.*

When considering the physiological impact of disability, it is also interesting to note that the sexual implications seem to reflect the different sexual roles and expectations we have of men and women in general. For example, virtually all professional attention, until recently, has focused on the physically disabled male, in view of the fact that he seems to be faced with a greater sex role discontinuity than disabled women. He may have difficulty maintaining erections and ejaculating, his physical strength and agility has been impaired, his earning capacity may be compromised, and, in short, he may no longer be able to fulfill the traditional role expectations we have for men in our culture.

Disabled women, on the other hand, are usually able to fulfill a traditional sex role of wife and mother. In order to be a satisfactory sexual partner, they need only to "just lie there" to achieve the passive role stereotypically ascribed to women. Disability does not usually affect fertility, so disabled women can also continue to fill the motherhood role. Thus, our assumption is that the sexual implications of disability for

women are negligible. Because of this belief, there has been virtually no professional consideration of her sexual needs or problems beyond her ability to be a satisfactory and fertile partner.

On the surface, therefore, disability does imply greater disparity with the male sex role than the female role. However, a closer look reveals that the sexual impact for women is also significant. Consider the following. Statistics indicate the divorce rate for disabled women is higher than for disabled men, suggesting that disability is not so readily integrated into the traditional wife and mother role. Many congenitally disabled women report that their parents programmed them to be "super career women" in the belief that they would never be considered marriage material. And in a culture which evaluates women more stringently than men in terms of their physical appearance, disabled women are at an even greater disadvantage.

However, living well with a disability involves some transcendence of the traditional male and female role to a more comfortable (and perhaps more androgynous) role which accommodates the realities of disability.

*I think as a woman you're not aggressive in a sexual relationship to start with and you wait for the man to make all the moves. But if you're handicapped, I think you have to overcome that. You have to be the aggressive one. It's your satisfaction as well as the other person's that's important, so I say, go after it. There are men out there who can be very sensitive to a disabled woman. In fact there are some who can gain a better perspective on themselves by being able to have a sexual relationship with a disabled woman. It just takes a little guts to try at first.*

Disabled women may not compete well in the beauty market, but may have a strength and independence that is decidedly feminine and attractive. Disabled men may indeed be more physically dependent, but still masculine and valuable as human beings. Often, the relationships of disabled people demonstrate a unique kind of symbiosis.

*Like most other couples, we do things for one another. My husband (who has multiple sclerosis) needs help transferring, or reaching something, and he can't help with much stuff around the house. And that is an inconvenience. But he has more time now to help me with my studies and is the best friend any person could ever hope for. I may be silly, but to me that's worth a lot.*

Too often, we have assumed that disabled people are much more dependent than people who do not live with disability. Dependency implies childishness and, certainly, children or those persons we have to take physical care of are not considered sexual. If an individual needs help transferring in or out of his chair, we ironically label that person as more dependent than someone who is emotionally dependent and unable to make a simple decision about what to do tomorrow. Interestingly, we associate the negative aspects of dependence with physical rather than emotional dependence, which is where the emphasis more appropriately belongs.

Disability does demand cooperation. If arthritis affects a woman's hands, her partner may need to insert a diaphragm or check for IUD strings. If either partner is hearing-impaired, they may need to develop manual or tactile signs for "a little lower, please." One man, paralyzed at age thirty from back surgery said,

*Everyone has to learn what they can do and what they can't do. And then work with what they've got. In a couple, at least one of you has to keep trying when the other is ready to give up.*

Communication is therefore essential, too, about what he or she can feel or do.

*I have very patchy sensation from my accident. Once I can remember we were making love and I knew his hand was on my body, but I couldn't feel it. I reached for his hand and suddenly*

*when I found it I was crying. I cried and cried. I wanted so much to be able to feel him all over, like before. But since then I've had some testing to help us learn what I can feel and where, and that's helped our love-making tremendously. And we talk—both of us—about what feels good.*

For people whose disability affects elimination processes by virtue of paralysis or surgery, it is essential to attain some degree of self-acceptance before expecting others to do so. Many have tremendous difficulty, but some develop a realistic, natural attitude towards their bodies' functioning and are able to communicate with others about it in a straightforward way.

*At first, I thought I would literally die when a partner needed to see my catheter. I was convinced he would just take off or I'd say something stupid or he would lose his erection or something. And the first few times were miserable, with all the worrying. But now, I warn him before we ever get into the bedroom, tell him what it will look like, what usually happens, everything. Then there's no surprises. Though I must admit that sometimes I just get a feel about someone—that he can handle it—and I'm almost always right.*

In the midst of this inconvenience and awkwardness is a reminder for the rest of us that sexuality is a natural bodily process, and needs to be integrated into our lives as such.

In conclusion, it can be seen that in many ways and for long periods of time disabled people have been denied sexual expression and have too often considered themselves asexual. Still, in the face of this, they may epitomize the real struggles society faces regarding sexuality today. Do people need to be beautiful to be loving? Is sexuality a story-book scene or a natural expression of two people caring sincerely about one another? Do sexual acrobatics mean more than simple strokes of affection? The degree to which we, as a society, exclude disabled people from having sexual thoughts and actions is the degree to which we clutch a restricted concept of sexuality and reproduction. That conceptualization hurts all of us because it leaves us vulnerable to aging, surgery, and other always unpredictable acts of fate. One woman summed it up:

*In a way, I suppose, I'm lucky. I know that my partner loves me just the way I am, with leaky catheter and bum legs. It took a long time to believe that, but now I do. But I can tell from talking to people who aren't disabled that they are never sure just what might come along that will make them less "marketable." It seems a shame to me that people would think their beauty has so much to do with how they look. ■*

# Centers for Independent Living

## Gini Laurie

Housing for the disabled cannot be dealt with separately from the problems that face the rest of the community. As for everyone, a solution to housing problems requires a broad attack on a variety of social injustices. Housing for the disabled includes the total environment and the whole spectrum of problems of education, training, employment, transportation, home services, recreation, and architectural and attitudinal barriers.

The total environment—psychological and physical—must be made hospitable to those with problems of mobility, of hearing, of sight, of retardation, and of aging. Awareness of the problems of accessibility must become an essential part of the education of architects, urban planners, builders, and real estate personnel.

There is no wholesale solution to the housing problems of any individual. As do all people, disabled individuals need individual solutions. The basic needs of all are the same: to love and be loved, to be useful, to feel fulfilled as a person, to have a valued niche in life, and to be a participating member of a community.

Of first importance is the right to freedom of choice to live as normal a life as possible within the community, either through one's own impetus or with the supportive services of appropriate independent living and other community programs. Disabled individuals must have opportunities to make mistakes and to take risks. They must be able to progress, as gradually as do their peers, from family homes through a series of apartments and houses or farms. They must be able to choose life-styles to match each stage of progress and development.

Housing for the disabled is not a program that can be solved by building a building to solve problems that can be solved only by services. A totally accessible building without attendant care is useless to a person who is severely disabled, and liberating to those who are less disabled only if there are solutions to the other problems of information, adaptations, income, employment, and transportation.

The basic requirement of an existing building is that it have an accessible entrance and that there be sufficient space to be able to move freely through the principal rooms and the kitchen and bathroom. Thereafter, each person can make individual adaptations.

Beware the edifice complex! Many well-meaning individuals and groups have become victims of the build-a-building approach to housing, and have built large, segregated facilities. Some became victims because they knew of a severely disabled person in a nursing home. Others were parents of disabled children who wanted a building waiting as insurance for "when-and-if-we-die." Most of them have been strong-minded disabled individuals who were institutionalized or over-protected by their parents, and who dreamed of a large, segregated facility because they were cocoon-minded and unaware of the possibility of integrated, independent living.

Segregated, special buildings put too much emphasis on heights of toilets and kitchen counters, and too little on human differences, potential, adaptability, and motivation. They inhibit normal movement from one location to another. They make it more difficult to convince the general public that people

who are disabled are people too, and that they can blend into existing facilities in the community.

Segregated, special buildings serve too few people and are too costly. A Michigan university made a comparative study of the costs of special facilities and of independent living within the community. The study estimated that for the cost of an eight-unit apartment especially for the disabled, eighty disabled individuals could have apartments and homes adapted so that they could live independently. Other studies estimate that when the costs of home services are balanced against nursing home costs, four severely disabled persons can live at home for the cost of maintaining one in a nursing home.

The unnormal grouping of people with physical disabilities in segregated, special buildings creates mini-institutions. Group living is extremely difficult for people with nothing in common except the dubious bonds of physical disability and low income.

Group homes the size of a large family, with a parent-image housekeeper, are proving successful steps to independent living for those who are mentally retarded. However, they are not as feasible for adults with physical disabilities. The parented, cosseted, protected environment results in immaturity and the deprivation of individuality. Group living swallows the individual. Disagreements lead to the formation of cliques and the establishment of a pecking order. Rules and regulations promote a false sense of security. Even group apartments within the community should be limited to clusters of three or four to minimize the abrasions and smothering effects of group living.



Gini Laurie has been volunteering with disabled people for thirty years. She is editor/publisher of an international journal, *Rehabilitation Gazette*, and author of *Housing and Home Services for the Disabled*.

The Swedish Fokus Society pioneered a system of delivering services to individuals in special apartments. The program was created in 1964 by Dr. Sven-Olof Brattgård, a paraplegic. The organization arranged for 260 accessible and adapted apartments to be interspersed within newly built government housing in thirteen cities, and set up a system of services in each city to bring in whatever attendant care or other services might be needed by each disabled individual. The total cost of a Fokus apartment—including rent and service—is about half the cost of care in a long-term clinic and two-thirds of the care in a nursing home.

Presently, groups of disabled persons and related service agencies in the United States are developing systems of using existing apartments, along with individual adaptations and services through their umbrella organizations, that have even greater potential for truly independent living. In addition to the obvious benefits of integration within the community and the freedom of choice of location, programs based on the use of existing apartments have the advantage of being able to expand or contract to fit current needs. A further advantage is that the strict licensing procedures and zoning that inhibit group living arrangements are avoided by having apartments rented by disabled individuals.

Many variations of combining apartments and services are being tried by groups of physically disabled individuals and by voluntary organizations representing the developmentally disabled.

The most uniquely American, and the world's most exciting development in the area of home services and adjust-

ment to life in the community, is the program of centers for independent living.

The most effective centers follow the general pattern of the original model, the Center for Independent Living in Berkeley, California, which was started in 1972. The center was founded by and is staffed by blind, deaf, and wheelchair individuals. It is funded by HEW, the State of California, and private foundations. The center's services cover every facet of independent living. It is a powerful source of information and strength through peer models. It has effected an accessible environment through curb cuts, furnishes transportation through vans with lifts, operates a wheelchair repair and maintenance shop, maintains a registry of attendants, and assists in their training. It keeps files of accessible apartments and advises on means of adapting them. It offers peer counseling and rights counseling, acts as a referral service to service agencies, and trains rehabilitation counselors to cope with the problems of severely disabled persons.

Presently, there is a tendency to confuse segregated, residential facilities with the service programs, run by disabled persons, that fulfill the true concept of centers for independent living. Although an individual may indeed live relatively more independently in a residential facility than in a nursing home, if it is a residential or a segregated facility, it is not an independent living center. This confusion is typified by the list, "Independent Living for Handicapped Individuals: Sources of Information," which is available from Clearinghouse on the Handicapped, Office for Handicapped Individuals, Department of Health, Education, and Welfare, Washington, DC 20201. The list includes some of the

most flagrant examples of ghettoized facilities. It also includes most of the true centers for independent living which are rapidly spreading around the country. So, it is well worth studying.

Centers for independent living have been largely financed by State-Federal Innovation and Expansion (I&E) vocational rehabilitation grants, and Community Development Block grants. This will be changed drastically if there is sufficient funding for Public Law 95-602, the Rehabilitation Comprehensive Services and Developmental Disabilities Act of 1978, which was signed by the President on November 6, 1978. For the first time in federal legislation, except for pilot or demonstration projects, there is a mandate in this act for the provision of independent living services for disabled individuals who have no immediate potential for a vocational goal. This program of comprehensive services will be based upon the cooperation of HEW and HUD. HUD has had an Office of Independent Living for the Disabled since 1977; HEW is in the process of establishing a parallel office.

Attendant care is the keystone of independent living for individuals who are so severely disabled that they require assistance with the basic activities of daily living. Many of these individuals, after being dressed and fed in the morning, can live and work independently until the noon and evening meals, and the undressing routine of evening. Consequently, they can manage with part-time help or help that is on call.

With boundless ingenuity, many individuals who are severely disabled manage to be self-supporting and live independently in the community. They have



adapted their homes or apartments to their individual needs and found attendants from newspaper ads, school bulletin boards, or one of the new centers for independent living. Their attendants include students, housewives, mildly retarded persons, persons released from mental hospitals, aliens, and persons with minor disabilities. For most people, several attendants are more satisfactory than one, particularly if there is a combination of family, neighbors, and paid live-in attendants. Most importantly, they want to hire, train, and fire their own attendants.

Funding and payments for attendant care vary widely from state to state. California has an excellent system which may allow more than \$600 per month. New York State may allow up to \$20 a day. Oklahoma uses Medicaid for a program of attendant care. Massachusetts is pioneering a system of personal care assistance under Title XX which is based on actual income on a sliding scale to eliminate the disincentives inherent in most other state plans.

Integrated housing in the community, with a proportion of accessible housing at all price levels, will not be achieved until existing building codes are enforced and until every state has an effective state building code. Three

states—North Carolina, Illinois, and Washington—which have outstanding codes, have published illustrated guides that may serve as models.

The following priorities of the American Association on Mental Deficiency (AAMD) are useful guidelines to the integration of both physically disabled and mentally retarded persons in their communities. In the summer of 1977, AAMD sent a letter to the governors of all states asking for a moratorium on residential and service space in segregated settings of more than 16 human beings. It also resolved that:

*the following priorities should be used and that each should be exhausted before the next alternative is considered: 1. Support, don't supplant, the family in their natural home. 2. Use individual foster parent or existing family alternative nearest the natural home, not group living. 3. Lease or rent living arrangements, don't buy. 4. Buy existing dwellings, don't build. 5. Build typical, not specialized. 6. Build special in the center of the population, not isolated.*

To solve the housing problems of physically disabled individuals through services and universal accessibility, consider the following suggestions:

- Start with a program of supportive services directed by disabled individuals.
- Don't start by planning a specialized, segregated building.
- Don't expect any program or project to be THE solution for everyone.
- Use as a model the Center for Independent Living in Berkeley, California.
- Assist individuals to live in existing apartments with their own live-in attendants.
- Start by placing one or two individuals and use them as role models for further successes.
- If there is any grouping, limit it to three or four individuals, with shared attendants.
- Concentrate on influencing the design, legislation, and attitudes of the future so that more and more people can live as they choose.
- Concentrate on helping the most people, with the least money, to live the most normally, with the most freedom of choice.

In conclusion, the problems of housing and supportive services for disabled individuals will be solved when it is as feasible to live in the community in integrated housing as it is to merely exist in a nursing home, when vocational rehabilitation agencies assume responsibility for attendants and independent living, when disabled individuals are automatically involved in the solutions, and when disabled individuals can move as freely as the rest of the population and choose where and how they wish to live. ■

# A Checklist of Accessibility Design Factors

The checklist below was developed by the Iowa chapter of the AIA for use in community surveys to determine if public buildings are accessible to and usable by the handicapped. It is also useful for the architect who wants to check a design project to see if he or she can answer "yes" to the questions, thus helping make a barrier-free environment a reality.

## Parking Lots.

1. Are accessible spaces approximate to the facility?
  - a) Are they identified as reserved for use by individuals with physical disabilities?
2. Are there parking spaces open on one side, allowing room (12 feet minimum width) for individuals in wheelchairs or on braces and crutches to get in or out onto a level surface?
3. Is it unnecessary for individuals in wheelchairs or those using braces and crutches to wheel or walk behind parked cars?
4. Is distribution of spaces for use by the disabled in accordance with the frequency and persistency of parking needs?

## Walks.

1. Are public walks at least 48 inches wide? Is the gradient not greater than 5 percent?
2. Are walks of a continuing common surface not interrupted by steps or abrupt changes in level?
3. Wherever they cross other walks, driveways or parking lots, do walks blend to a common level?
4. Do walks have a level platform at the top of which is (a) at least 5x5 feet if a door swings out onto the platform or toward the walk, or (b) 3x5 feet if door does not swing onto the platform?
5. Does the platform extend at least 1 foot beyond each side of the doorway?

## Ramps.

1. Do ramps have a slope no greater than 1 foot rise in 12 feet?
2. Do ramps have handrails on at least one side?
  - a) Are they 32 inches in height measured from the surfaces of the ramp?
  - b) Are the surfaces smooth?
  - c) Do they extend 1 foot beyond the top and bottom of the ramp?
3. Do ramps have a surface that is nonslip?
  - a) Do platforms comply with questions 4 and 5 under "Walks"?
4. Do ramps have at least 6 feet of straight clearance at the bottom?
5. Do ramps have level platforms at 30-foot intervals for purposes of rest and safety, and wherever they turn?

## Entrances/Exits.

1. Is at least one primary entrance to each building usable by individuals in wheelchairs? (It is preferable that all or most entrances and exits should be accessible to, and usable by, individuals in wheelchairs or who have physical disability.)
2. Is at least one entrance usable by individuals in wheelchairs on a level that would make the elevators accessible?

## Doors and Doorways.

1. Do doors have a clear opening of no less than 32 inches when open?
  - a) Are they operable by a single effort? (Note: Two-leaf doors are not usable by those with disabilities unless they operate by single effort, or unless one of the two leaves meets the 32-inch width.)
2. Are the doors operable with pressure or strength which could reasonably be expected from disabled persons?
3. Is the floor on the inside and outside of each doorway level for a distance of 5 feet from the door in the direction the door swings?
  - a) Does it extend 1 foot beyond each side of the door?

4. Are sharp inclines and abrupt changes in level avoided at doorsills?
5. Do door closers allow the use of doors by physically disabled persons?

## Stairs and Steps.

1. Do steps avoid abrupt nosing?
2. Do stairs have handrails 32 inches high as measured from the tread at the face of the riser?
3. Do stairs have at least one handrail that extends at least 18 inches beyond the top and bottom step?
4. Do steps have risers 7 inches or less?

## Floors.

1. Do floors have a nonslip surface?
2. Are floors on each story at a common level or connected by a ramp?

## Rest Rooms.

1. Is there an appropriate number of toilet rooms for each sex?
  - a) Are they accessible to physically handicapped persons?
  - b) Are they usable by physically handicapped persons?
2. Do toilet rooms have turning space 60x60 inches to allow traffic of individuals in wheelchairs?
3. Do toilet rooms have at least one toilet stall that:
  - a) is three feet wide?
  - b) is at least 4 feet by 8 inches (preferably 5 feet) deep?
  - c) has a door that is 32 inches wide and swings out?
  - d) has grab bars on each side, 33 inches high and parallel to the floor, 1½ inches in diameter, with 1½ inches clearance between rail and wall, fastened securely to the wall at the ends and center?
  - e) has a width of at least 48 inches between the wall and the front of the stall entrance?
  - f) has water closet with seat 20 inches from the floor?

4. Do toilet rooms have lavatories with narrow aprons, which when mounted at standard height are usable by individuals in wheelchairs?
5. Are drain pipes and hot water pipes covered or insulated?
6. Are some mirrors and shelves at a height as low as possible and no higher than 40 inches above the floor?
7. Do toilet rooms for men have wall-mounted urinals with the opening of the basin 19 inches from the floor, or have floor-mounted urinals that are level with the main floor of the toilet room?
8. Do toilet rooms have towel racks mounted no higher than 40 inches from the floor?
  - a) Are towel dispensers mounted no higher than 40 inches from floor?
  - b) Are other dispensers mounted no higher than 40 inches from floor?
  - c) Are disposal units mounted no higher than 40 inches from floor?
9. Are racks, dispensers and disposal units located to the side of the lavatory rather than directly above?

#### **Water Fountains.**

1. Is there an appropriate number of water fountains?
  - a) Are they accessible to physically handicapped people?
  - b) Are they usable by the handicapped?
2. Do water fountains or coolers have up-front spouts and controls?
3. Are they hand-operated?
4. If coolers are wall-mounted, are they hand-operated with basins 36 inches or less from the floor?
5. If there are floor-mounted fountains, are spouts no higher than 30 inches?
6. Are the fountains accessible to people in wheelchairs?

#### **Public Telephones.**

1. Is there an appropriate number of public telephones accessible to physically handicapped persons?
2. Is height of dial from floor 48 inches or less?
3. Is coin slot located 48 inches or less from the floor?
4. Are there telephones equipped for persons with hearing disabilities? Are they identified as such?

#### **Elevators.**

1. If more than a one-story building, are elevators available to the handicapped?
  - a) Are they usable by the physically handicapped?
2. Are all of the controls 48 inches or less from the floor?
3. Are the buttons labeled with raised (or indented) letters beside them?

4. Are they easy to push or touch-sensitive?
5. Is the cab at least 5x5 feet?

#### **Controls.**

1. Are switches and controls for light, heat, ventilation, windows, draperies, fire alarms and all similar controls of frequent or essential use within reach of individuals in wheelchairs?

#### **Identification.**

1. Are raised (or recessed) letters or numbers used to identify rooms or offices?
2. Is identification placed on the wall, to the right or left of the door?
  - a) Is it at a height between 4 feet by 6 inches and 5 feet by 6 inches, measured from the floor?
3. Are doors not intended for normal use, which might prove dangerous if a blind person were to exit or enter by them, made quickly identifiable to the touch by knurls on the door handle or knob?

#### **Warning Signals.**

1. Are audible warning signals accompanied by simultaneous visual signals for the benefit of those with hearing or sight disabilities?

#### **Hazards.**

1. When access holes or panels are open and in use, or when an open excavation exists on a site, when it is approximate to normal pedestrian traffic, are barriers placed on all open sides at least 8 feet from the hazard, and warning devices installed?
2. Are there no low-hanging door closers that remain within the opening of a doorway, or that protrude hazardously into regular corridors or traffic ways?
3. Are there no low-hanging signs, ceiling lights, fixtures or similar objects that protrude into regular corridors or traffic ways? (A minimum height of 7 feet measured from floor is recommended.)
4. Is lighting on ramps adequate?
5. Are exit signs easily identifiable to all disabled persons? ■

*The preceding article is reprinted from the American Institute of Architects Journal, March 1975.*

# Moving Into the World

## Lee W. Tyler

*About two years since leisure afforded opportunity and duty prompted me to visit several prisons and almshouses in the vicinity of this metropolis, I found, near Boston, in the jails and asylums for the poor, a numerous class brought into unsuitable connection with criminals and the general mass of paupers. I refer to idiots and insane persons, dwelling in circumstances not only adverse to their own physical and moral improvement, but productive of extreme disadvantages to all other persons brought into association with them. I applied myself diligently to trace the causes of these evils, and sought to apply remedies. As one obstacle was surmounted, fresh difficulties appeared. Every new investigation has given depth to the conviction that it is only by decided, prompt, and vigorous legislation the evils to which I refer, and which I shall proceed more fully to illustrate, can be remedied.*

(Dorothea Lynde Dix, to the Massachusetts legislature, January, 1843.)

The quality of care for developmentally disabled individuals (traditionally referred to as mentally retarded) in the United States has improved considerably since Dorothea Dix reported to the Massachusetts Legislature 136 years ago. But there remain today in every state of the union, haunting echoes of conditions she found so wretched in the jails and almshouses she visited.

People who are developmentally disabled comprise approximately three percent of the population of the United States. This encompasses nearly six million people nationwide.

Since the 1800's institutionalization has been a major source of residential placement for people who are developmentally disabled in the United States. Historically, the treatment of the mentally handicapped has been in response to feelings that they are a "deviant" population.

In ancient Greece and Rome, the mentally handicapped were treated as objects of scorn and persecution. There was no role for the handicapped or deformed in Plato's *Republic*, and in ancient Rome it is alleged that children who were blind or deaf or mentally dull were thrown into the Tiber River by their parents to relieve themselves of the burden of support.

The dawn of Christianity brought pity for the retarded. Biblical scholars refer to the charge of St. Paul to "comfort the feeble-minded." However, such philanthropy as may have been awakened by the early Church again subsided into indifference during the Dark Ages.

The mentally retarded served as fools or jesters in medieval times or were regarded as *les enfants du Bon Dieu*, wandering about the streets of Europe, unmolested. Similar regard for the retarded was found in the Orient, among the American Indians, and in the writings of Confucius, Zoroaster, and the Koran. However, there is little evidence, if any, that they were regarded by physicians as part of their medical responsibility, and no attempts were made to educate them.

The growth of individualism during the Reformation may have had positive repercussions for the mentally retarded with the demands for the end of feudal bondage and relief from human suffering in general. However, superstition

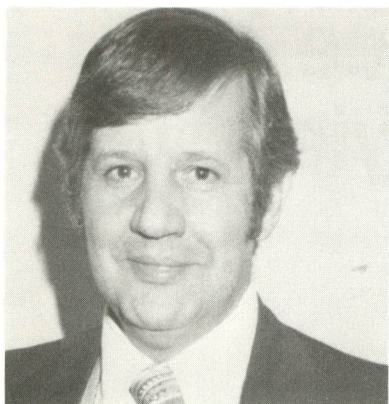
still flourished; both Luther and Calvin denounced the retarded as "filled with Satan."

In early New England, the Puritans looked with suspicion on any deviation from behavioral norms, and irregular conduct was often explained in terms of evil supernatural powers such as witchcraft. There is reason to believe that retarded or disordered persons were tortured, hanged, and burned on this suspicion. With that beginning in the "new world," it is small wonder that Dorothea Dix found the developmentally disabled amongst the insane, the criminal, and the poor some 200 years later.

The first institutions for the retarded in North America were built (circa 1850 - 1870) in a period of optimism regarding mental retardation as well as education of the deaf and blind, and many facilities for those groups were erected during that time. The later disillusionment about retardation was also not isolated, but part of the more generalized aversion toward, and virtual persecution of, deviancies. Isolated and segregated farm colonies were a logical development in the history of residential institutions of many types.

During the period from 1890 - 1925 an incredible variety of deviancies were believed to be associated with retardation. Indeed, the following some thought caused by retardation: illness, physical impediments; poverty; vagrancy; unemployment; alcoholism; sex offenses of various types including prostitution and illegitimacy; crime; mental illness; and epilepsy. All these were called the "degeneracies."

The placement of retarded into institutions, while begun in good faith as a means to care for their needs, soon



Lee W. Tyler is an ordained minister of the United Church of Christ and administrator of Evangelical Child Care Center, Detroit, Michigan, a residential facility for mentally retarded children and adults.

became a movement to keep the retarded and other "deviants" away from society, as a means of protecting society.

Not until the 1950's did significant change begin with the development of groups of parents of retarded children organized as associations. The National Association for Retarded Children was chartered in 1950, and spearheaded a movement across the country that was to revolutionize the delivery of services to retarded people.

The impact of that movement now known as Association for Retarded Citizens is still being felt in improved educational programs (and in the initiation of education programs), provision of medical care where little was known or available, state and federal funding for care and maintenance, and the development of the community placement movement. In Michigan, it is this latest movement which affected the ministry of the Evangelical Children's Home.

Community placement as an operating concept began in Michigan in the early sixties and continues today. This involves returning many people to the community who have previously been institutionalized. An example of what this involves is apparent by what happened to the population of state institutions in Michigan for the mentally ill and mentally retarded. In 1960 the population of these state institutions was 30,320. By 1975 the population was 11,540, a decrease of sixty-two percent. Community reaction to placement was and is varied. Today institutional populations for people who are mentally retarded in Michigan are still decreasing.

While community placement is the goal for the Department of Mental Health, a local association for retarded citizens

has filed a law suit against one of the state institutions charging abuse and neglect of retarded residents there. The Circuit Court judge has ruled that the state institution must decrease the population in the institution even more, and at the same time increase the staff in the institution and improve the quality of care.

It is within this historical perspective and present climate that the Evangelical Children's Home carries on its ministry to forty-eight developmentally disabled young people.

The Evangelical Homes of Michigan, a non-profit corporation, was established in 1879 for the expressed purpose of caring for orphans. Through its one hundred years of history and service it has held to that original goal, has grown in size, expanded services, and improved the quality of care.

Presently, services are provided in facilities located in northwest Detroit and in Saline, about 50 miles west of Detroit. Licensed as a home for the aged, a skilled nursing home, and a child care institution, they provide care and service to approximately 575 children and elderly.

The Homes are governed by a twenty-eight-member Board of Directors which determines policy and provides oversight for the operation. It enjoys a supportive relationship with congregations of the United Church of Christ throughout Michigan.

In 1971 the Board of Directors decided the need for an orphanage-type ministry was declining, and at the same time the need for community placement for developmentally disabled children was increasing. And so forty-eight residents of a state institution were transferred to

the Evangelical Children's Home in late December, 1971.

The new ministry was an experimental one. For the first time "trainable mentally impaired" children were being placed as a group in the community. The so-called "trainable child" is one whose I.Q. is in the 30 - 50 range. It has been believed (and for many still is) that this range of functioning enables children to be trained but never educated—able to master academic subjects.

Almost half the children that came in that week following Christmas were diagnosed as having Down's Syndrome. These are the youngsters who are visibly different because they have a smaller head, almond shaped eyes, shorter extremities, a fissured tongue or some other abnormality. The balance of the children were disabled due to a variety of causes—injuries at birth, brain damage, cerebral palsy, epilepsy, and several unknown causes. Most of the children had been in an institution since birth. Doctors then and now often recommend to parents of retarded children that such a placement is the only wise alternative.

Parent involvement was and is as diverse as the causes. Many families maintain close and regular contact with their child. Others, never. Twelve of the children have no contact with their families, or their family is unknown. For those children the Evangelical Home is their family. Some families struggle painfully with the feelings of guilt and anxiety caused by societal attitudes which maintain that children are born retarded because of some "sin" committed by the parents or grandparents. The attitudes of the past do not change easily.



The Evangelical Home staff was faced with the monumental task of creating a new living environment, indeed a new world environment, for the children who had lived in the steel and tile sanitized wards of institutions. On arrival most of the children ignored the comfortable furnishings of the cottage and moved robot-like to the closest wall to sit on the floor and rock as they had so often in the overcrowded institution.

The tasks were monumental—to teach the use of normal home furnishings, the skills of feeding oneself, dressing and grooming, and participating fully in the day-to-day life of the cottage.

The split-level cottages which were to become home for the children were built in 1957. They are spacious (4,000 square feet) and designed in a way that communicates a feeling of openness from the kitchen through the dining and living area which includes a two-way fireplace between it and the lounge. Five bedrooms provide adequate space for each child to establish his or her living area, complete with closet, dresser, and a place to display personal

possessions. A recreation room in the lower level provides space for more active expressions of life such as folk and circle games, dancing, and a myriad of table games including Ping-Pong and pool. Each cottage is home for twelve. The four cottages are located on an eighteen-acre campus in a residential neighborhood of tree-lined streets in Detroit.

The purpose of the program is to provide a learning experience which will prepare the young people for adult life in the community at a level of functioning as normal as the culture of which they are a part. In some instances, they will need some level of supervision and direction throughout life. But the development of adequate self-care, social, academic, and work skills will make daily living a much more satisfying experience.

Through the efforts of many concerned groups, Michigan has a mandatory special education law which requires the state to provide educational programs to all people through age 25 or until they receive a diploma. Youngsters from the

Evangelical Home attend school daily in one of four different educational programs operated by the Detroit Public Schools or the Wayne County Intermediate School District. Those in the work-skills centers are learning skills which will prepare them to work either in a sheltered workshop or in competitive employment in the community. The two Children's Home social workers maintain constant contact with the schools to assure that the youngsters are receiving the best educational experience possible.

Special services including medical, dental, speaking, hearing, and psychological are provided within the community, another means of familiarizing the young people with the world of which they are a part. A visit to the doctor's office is met with many different feelings of anticipation and reluctance.

Cottage staff (child care workers) are responsible for daily program activities. They plan with the social workers and the activities director a healthy variety of activities designed to meet training needs. Trips are planned. One or two

children go with a staff person to purchase clothes, supplies, or to experience eating out in a restaurant. Such trips are designed to give each child individual attention. There are times when a larger group may go to a movie, a museum, a park, or the circus, but the goal is to seek and plan experiences which require independent functioning as much as possible.

While this program of community orientation and mobility training is underway, there are a variety of activities unfolding daily back "home." A music teacher helps the children express themselves through singing or the playing of a rhythm instrument, even an autoharp or piano. There are a dozen who labor faithfully to express themselves more and more through guitar. A physical education program is available through the use of a neighborhood school gym. This is especially helpful during the cold Michigan winters. A Boy Scout troop was started during the past year, and fifteen of the young males are part of this new and exciting experience. A woodworking shop provides additional opportunities to master new skills through the manipulation of hands and tools.

Opportunities are sought to challenge the individual in a variety of activities. Last winter two young men participated in the Midwest Regional Winter Olympics at Schuss Mountain in northern Michigan. The pride and joy expressed by each of them as they displayed their gold medals (one for speed skating and the other for figure skating) communicated to all who saw and heard that they were proud of their achievement. Preparation for the summer Special Olympics are underway to provide similar achievement opportunities for more of the young people.

The program is funded through the County Community Mental Health Board which provides for a combination of federal, state and county funds to be channeled into one agency. It has been funded in this manner since the beginning of the program. But the involvement of area churches, especially United Church of Christ congregations, makes possible additional resources which enrich the program beyond what the tax dollars can provide. This one-hundred-year tradition of support from the churches assures that the ministry will continue, and that it will be a ministry of caring and concern for the whole person.

Since coming to the Home in 1971, many of the young people have reached and passed the age of 18 when they should be moving to an adult home facility. The Evangelical Home plans to develop and operate adult homes in the community with an average of six persons in each home. While working out the funding to assure continued care for the current residents and new children currently in state institutions, an even greater problem must be overcome—community resistance.

From the beginning of the community placement movement there has been community opposition to having group homes in residential neighborhoods. In suburban communities throughout metropolitan Detroit, a variety of groups have voiced their opposition through legal suits, vocal harassment, and threats to recall city officials who do not oppose homes for retarded persons. Some efforts have been quite effective; others have served only to slow the process and discourage other groups who might consider providing similar services.

The Evangelical Home is in a position where local congregations can and will work to shepherd a group home for retarded citizens. That will happen because of the long-term joint ministry that has served to make it "A Hundred Years A Home."

Other communities across the country do not have that history, but do have the same need. The timing is crucial to bring the community placement movement to fruition. If community opposition is not offset by churches involved in community acceptance there is the threat that state departments of mental health will return to the practice of caring for developmentally disabled individuals in large institutions. For the congregation that wishes to express its concern, but does not know how to proceed, a contact with a local association for retarded citizens will open the door to a variety of options for service.

Congregations have an opportunity to break the historical patterns of suspicion, ignorance, and fear about the developmentally disabled who have been placed in institutions "out of society" so society can be "safe." Today the demand is that we reach out and create an open society in which all of God's children can share life together. ■

The following agencies related to the Council for Health and Welfare Services of the United Church of Christ offer services to developmentally disabled persons.

Emmaus Homes, Inc., Rt. 2, Box 132, Marthasville, MO 63357. The Rev. James E. Rinne, Superintendent. Residential facility for handicapped adults offering rehabilitation and training services.

Emmaus Enterprises, R.R. 2, Box 185, Marthasville, MO 63357. Harold F. Habecost, Manager. Sheltered workshop offering rehabilitation and training services plus remunerative employment for handicapped adults.

Emmaus Homes, Inc., P.O. Box 220, 2200 Randolph Street, St. Charles, Mo. 63301. Rev. Rudolf S. Allrich, Superintendent. Residential facility for handicapped adults offering rehabilitation and training services.

Evangelical Child Care Center, (Evangelical Homes of Michigan), 6700 W. Outer Drive, Detroit, MI 48235. Rev. Ernest R. Klaudt, Executive Director; Rev. Lee W. Tyler, A.C.S.W., Administrator. Residential facility for handicapped children and adults offering rehabilitation and training services.

Hope Homes, Inc., P.O. Box 355, Kent, OH 44240. Dominic J. Gambone, Jr., Administrator. Residential group homes for handicapped adults.

The Ridge, 825 Magnolia Avenue, Corona, CA 91720. Mrs. Jean W. Powers, Administrator. Residential group homes for handicapped children and adults offering rehabilitation and training services.

Additional information regarding these agencies and their programs may be obtained by writing to them directly or to the Council for Health and Welfare Services, United Church of Christ, 287 Park Avenue South, New York, New York 10010, Rev. J. Robert Achtermann, Executive Secretary.

# Susan and Terry

Susan Gulick is twenty years old, likes to color and hook rugs, and gushes at much of what she comes in contact with. The day we met she had stayed out of school and had paid special attention to her hair. It was one of those very early, warm spring days when the newly returned sun squeezes sloth out of the brown grass. We were introduced on a path surrounded by that brown grass in the middle of the four cottages of Evangelical Home—Hope, Faith, Charity and Zoar they are named. Susan took my hand as we met. I said I was glad to meet her. She said I was nice. She didn't let go of my hand. I talked with her counselor, the director of the home, and a woman who worked in her cottage. We talked of schedules, programs, times and places. Susan didn't let go of my hand. I was embarrassed and patronizing. Here I was standing with all these adults, trying to get some work done, and this woman wouldn't let go of my hand. I felt awkward. Susan didn't. She was glad to see me.

Terry Garrison is eighteen. At school he is learning building maintenance along with reading skills. As a way of absorbing and thinking he repeats most of what is said to him. For our meeting Terry wore a nice three-piece suit. After our interview I asked Terry if he would mind wearing his school clothes while I photographed him. He invited me to his room and forgot I was there as he changed. Terry has a bit of trouble walking. Several years ago there was a 50-50 chance he would never walk again. Changing from his suit to his school clothes was not a simple task. But it was one Terry did with care, completely oblivious to a camera carrying stranger. In the end I was self-

# Doug Magee

Doug Magee is a free lance writer and photographer living in New York, New York.

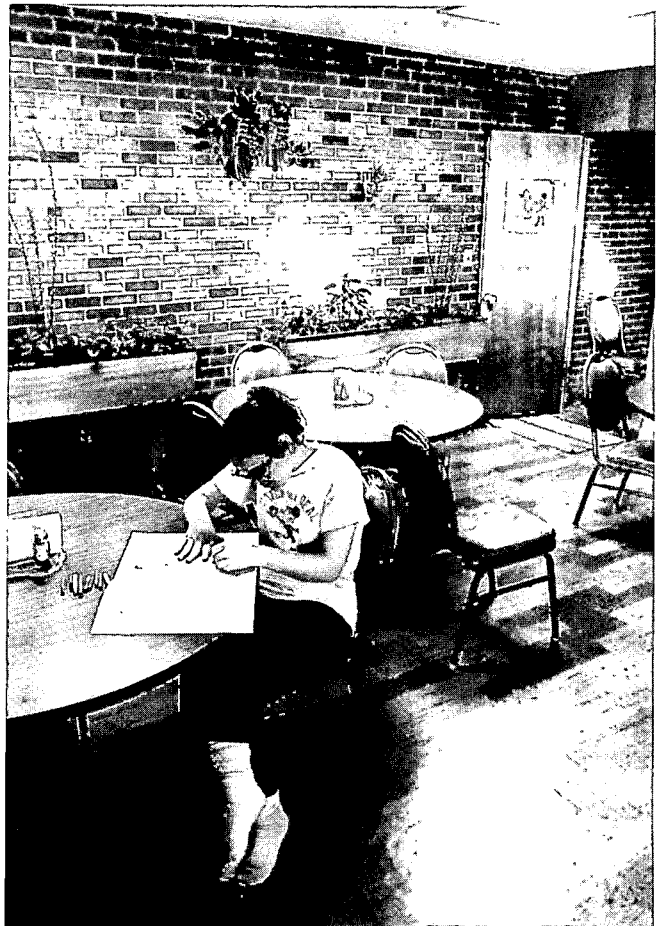


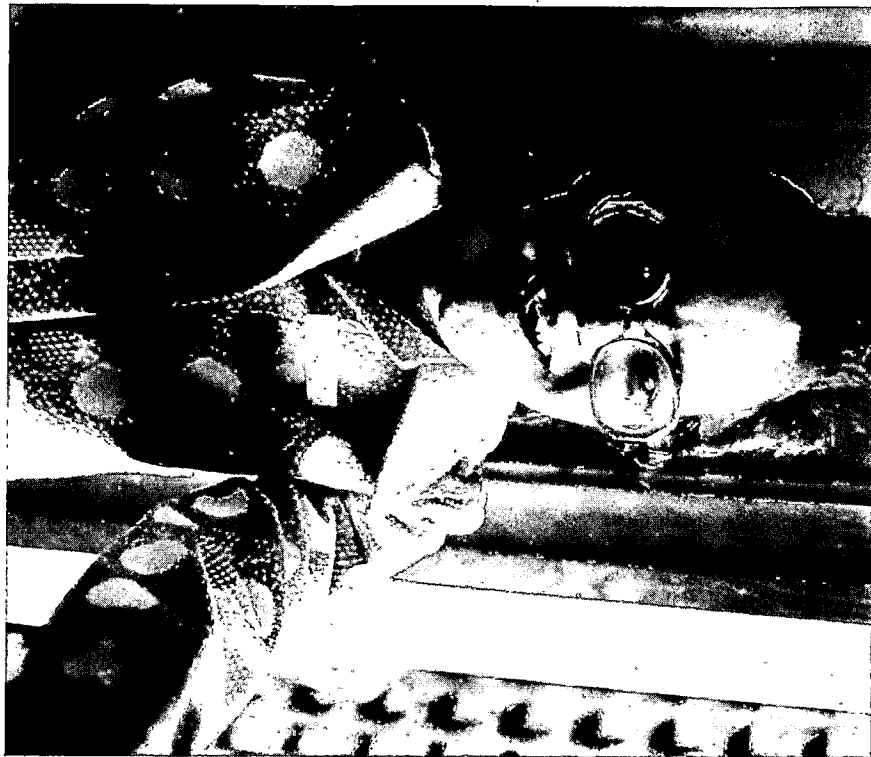
conscious to the point of distraction. I was not worried about intruding. I was aware that I could never be as relaxed with anyone as Terry was with me.

Having met Terry and Susan I sat down with them, turned on my tape recorder and began an "interview." It didn't work. I didn't know the language. Terry and Susan understood each other, and I came to understand the speech patterns foreign to my ears. But I was, finally, lacking. I didn't know the questions.

So I made out as best I could on a verbal level, and Susan would take my hand and Terry would forget I was there. And I photographed.

The world of the developmentally disabled is foreign to most of us. We translate their language loosely and functionally. We are trying to use our words to understand their reality like colonists come to instruct the natives. They are disabled so we think them less than we—missing something. We have not learned the value of really understanding their language—not just translating it.







# The Wholeness of the Family of God

## Harold H. Wilke

A special junction in history has come to pass. An emerging minority called "the handicapped" is now raising before our entire society, including the religious community, its own statement of identity and its sense of rightful appropriation of opportunity of achievement. Our secular society is responding with legislation, regulations, voluntary agency action, and publicity.

But what of the churches and synagogues? Some of us are "running scared" lest we fail at this critical juncture of expressed need on the part of the alienated and handicapped. Let us recapture our charter in the religious community! From the beginnings our Scriptures have affirmed the value of each individual in the sight of God, and this ages-old teaching must constantly be renewed.

At this point, let us note some of the facets of this new presence, this new minority, and our relationship to it. We must describe again who they are. They are the physically disabled. They are the retarded. They are the persons with grave emotional problems. Many of them seem just like the rest of us, but the physically disabled, of course, carry their difference from us in that outer hulk, the shell, the body. They walk with a crutch; they have to arrive in a wheelchair; they walk very slowly up the steps, pausing for breath at the third and the sixth: their amputation is at least partially overcome with some prosthetic device like a steel hook.

We know that these people are different. But quite often we take the difference to be negative, and think that somehow they are totally different from us. Ironically, do we remember that even the eyeglasses we wear are medically called prosthetic appliances? And false teeth as well! But when the pros-

thetic device is attached to the arm or leg, somehow that seems to make the person almost totally different. In our minds we know that this is not the case, and in our understanding of the faith we do indeed come to the recognition that there are angels all about us, and we may indeed entertain them unawares.

There is now a unique opportunity for the church as a whole to respond to persons with handicaps. Their number is legion. With so many of them—more than a tenth of our population in the United States—we can assume that something like a tenth of our congregation's membership would be these disabled and handicapped persons. Yet our experience is that there are very few of them. What is the reason for this? The answer leaps to us at once, and we realize that so many of these persons feel so unwanted that they simply stay away from public gatherings, even from church, and they are therefore the ones who are, "out of sight" and also "out of mind." We don't think about them because they are not around us or within our immediate fellowship to any considerable extent.

The time is ripe now for the church to take the lead in helping the whole community facilitate the coming together—the integration—of all such persons within the body of the community. And we start with the church. Better yet, we start individually with ourselves. We start with me.

A person's ability to see him or herself—the individual's personal grappling with living—is critical in our lives. "I accept the universe," said an early American philosopher, to which an English compatriot responded, "Gad, she'd better, it's there!" Not only this universe about us, but myself within it.

How can I see that self at all, much less "to see it steadily and to see it whole"? Acceptance of others is intertwined with acceptance of oneself. Therefore, fear of accepting others can be overcome through my own self-acceptance.

In being honest with myself, I really do look at this fear for what it is. I do not try to squelch it or pay no attention to it in other ways. I recognize and deal with it. I leave it to my consciousness and attempt to look at it as openly and clearly as possible. As I look at myself, I see the other fears and anxieties intertwined with this one, and I recognize a whole new series of tasks on which I must work.

Counting their number and defining their situation is not simple. Many handicaps are hidden, having to do with a weak heart, a tendency to break bones, or other forms of the human condition which are genuinely difficult for the person but which do not actually show on the outside. These "hidden" handicaps are many and varied, and millions of persons suffer—usually silently—within those bonds.

Another group of handicaps may seem to be invisible, but then will suddenly show up in very embarrassing ways difficult to understand. Narcolepsy is a case in point. A handsome young man has a distinguished air about him. Yet he has gone through a dozen jobs in a dozen years. His wife, a nurse, supports the family because soon after he had a job, he fell asleep at some critical point to the discomfiture and anger of his colleagues or bosses. He can't help it. He may fall asleep at any moment and he has no control over it at all. Medicine helps, but for this particular person—and there are many like him—a hidden handicap suddenly becomes extremely visible, and embarrassing both for him and the others.



Harold H. Wilke teaches at Union Theological Seminary and directs the Healing Community project. He has served as United Church of Christ pastor, armed forces chaplain, and director of the National UCC Agency for Ministry. Mr. Wilke is totally independent in daily living, even with the physical impairment of armlessness. His book, *Creating the Caring Congregation*, will be published this year by Abingdon.

Another handicap which seems to be invisible becomes suddenly apparent when we attempt to converse with a deaf person. Our responses are sometimes ludicrous. Rather than enunciating more clearly so that our lips can be read—difficult at best and impossible the way so many of us slur our speech and mumble our words—we talk much more loudly, trying to force the individual to hear what we have to say. When other people begin to look, we blush, and we move away.

Many blind persons carry a walking cane to warn of obstacles, steps or curbs. Still we don't know how to help, or even if help is needed. We may too often attempt to guide by pulling rather than by simply giving our elbow for the blind person to hold.

Then there is the individual in the wheelchair. She or he is very likely to be a young and handsome person, because spinal cord injury seems to especially hit the sports-minded, the virile drivers of a high speed car or a motorcycle. Or the "wheeler" may be past middle age, confined to wheels by an attack or chronic illness of advancing years. Their numbers are increasing. Medical advances have now made it possible for the great majority of persons with severe spinal cord injury to continue a useful life. This is a far cry from what happened in the period of the First World War and following, when most such people died within a few months or a few years of the injury. Now, because of medical science breakthroughs, the span of life may be quite considerable.

Responding to a person in a wheelchair means that I am standing up and looking down on this individual, which causes certain constraints within myself. Usually, it is difficult for us to bend

down on one knee so that we're at the same height. The constraint therefore continues in the wheeler and in us. Further, the question arises how we may help, especially if there are steps to be climbed, as with entrances to churches. We don't know if we ought specifically to ask or whether to chatter about the weather.

The response of the church to these people has in the past been a noble ministry of concern, expressed primarily in a mission to them. As "specialized ministries," the United Church of Christ and other groups reach out to specific groups of impaired, especially to the deaf or the blind. Such ministries stem sometimes from the national denominational offices. More often they have come out of diocesan or synodical responses, which then have spread to other areas of the church. The usual target groups for such ministries have been persons representing very specific difficulties, such as the deaf or the blind. Within a local area, numbers of churches will tacitly accept an ecumenical answer by simply pointing out that "signing" for the deaf is carried on at one or more specific churches in the city, and deaf members in a church where such signing is not practiced are, in effect, invited to the church where it is, even though that church may be of another denomination.

The church has created institutions for the care of persons with disabilities so serious as to make it painful and difficult for them to live in society. In the U.S.A. it has been thought proper for the church to institutionalize them. In many cases the church has turned over to secular society the keeping of such institutions. Several of our denominations have been leaders in this work which is motivated by humanitarian concern and, often, is necessary, al-

though institutionalization is not always the best solution. The church in Germany helped to create there and through churches in this country the idea that institutions can best take care of alienated people.

Such institutional care is "big business" in the churches in the U.S.A. and in West Germany. It continues also in the German Democratic Republic where, of eight rehabilitation centers for sick and disabled, four are run by the church. In the U.S.A., directors and chaplains of the institutions for orphans, elderly, handicapped, retarded, and others meet annually in a week-long symposium, sharing concerns and problems. There are a thousand chaplains of institutions, most selected within the context of rigorous training standards of clinical pastoral education.

Many millions of dollars are provided by the churches in a noble attempt to care for persons of special need. Within the structures of the church, agencies are developed to respond to institutional need, recognizing the facets of church institutional life and secular institutional life. They attempt to bring the experience and ideals of the church into the secular institutions. Thus, most of the major denominations have councils for health and welfare, designed not only to work with the health and welfare institutions operated by or related to the denomination, but also to relate the denomination to the varied secular institutional responses, and thus to keep open the lines of communication between religious motivation and secular response to need.

At top hierarchical levels, both denominationally and ecumenically, the churches have expressed concern for the disabled. The Louvain Conference held by the World Council of Churches

in 1971 clearly placed on the agenda of world Christianity the matter of the church's ministry for persons with handicaps. At Nairobi in 1975 the W.C.C. not only included this matter on the agenda again, but in putting emphasis on "ministry for and with" fostered a far more accurate theological understanding of that ministry, and placed it squarely at the heart of the gospel. The words that the Nairobi assembly spoke are these:

*The Church's unity includes both the 'disabled' and 'the able.' A church which seeks to be truly united within itself and to move toward unity with others must be open to all; yet able-bodied church members, both by their attitudes and emphasis on activism, marginalize and often exclude those with mental or physical disabilities.*

But there are dark sides to this picture also. My blind friend speaks bitterly of the many "church people" who say to him, "If your faith in Jesus were strong enough, you could overcome your blindness." While you and I cringe at hearing this response, many Christians cringe daily in having such judgmental words spoken directly to them.

"What have you done for me recently?" is a nettlesome phrase, reminding the church always to be there. This challenge is taken up by organized groups of persons with handicaps, in some cases ignoring the church, and, in other cases, directly challenging religious institutions.

The White House Conference on the handicapped, with eight hundred delegates comprised of disabled people, parents of the disabled, and professionals and providers from every state and territory of the United States, presented this challenge directly. "We deplore . . . we challenge . . . we demand . . ." Augmented by over a thousand additional concerned persons, almost all handicapped, the group met at the invitation of the President of the United States to assess the entire spectrum of concern for the handicapped. A clear call to the churches set these (and more) tasks:

- Integrate persons with handicaps into active participation.
- Aggressively recruit persons with handicaps into the leadership (clergy, church committees, parish councils, etc.).

—Initiate programs aimed at overcoming attitudinal barriers.

—Promote quality of life for handicapped people.

—Continue to extend the community of God to those who cannot be mainstreamed or deinstitutionalized.

—Be it further resolved that all organizations (secular as well as religious) of, for and working with persons with disabilities shall insure their fundamental Human Right to express and to benefit from a religious dimension to their lives.

Perhaps worse than attack is being ignored. Such is the case where a congregation's members may say, "Oh, but we have no handicapped persons in our membership," illustrating precisely the result of a policy of excluding such persons, of keeping in front of the church the five steps—or even one—that say to the person in the wheelchair, "We are not interested in your worshiping with us." Of course, the handicapped go farther down the street to those places which more openly accept them!

The disparity between public buildings—forced by legislation to be accessible—and the buildings of private organizations such as the churches is an implicit form of this attack. When the church should be leading society as a whole, it follows reluctantly behind.

The marked difference between those churches which have torn down architectural and attitudinal barriers and the many others which are self-protective, may mount further the attack on persons with handicaps.

The negative reaction we must realize is deep-rooted, found in basic psychic responses and reflected in the Scriptures. It applies most especially to leadership in the church. In the church today, Orthodox and Catholic, there are clear statements of doctrine opposing ministry by persons with physical disabilities, and what is *de jure* in these two churches is *de facto* in Protestantism. The Catholic canon law doctrine expressing this understanding is called *admiratio populi*, the discomfort or distraction within members of the congregation caused by that public figure whose outward appearance would distract the congregation.

For the priestly life, the primary concerns center around a doctrine or role widely accepted within Protestant as well as Catholic circles, that the priest is "a man for others," the "one for others." This role "before the congregation" is visible in the administering of the sacraments, preaching the word, and being of service to other human beings within and without the congregation. This public nature of priestly expression, for the Catholic Church of recent years as well as for the Levitical priest three thousand years ago, recognizes the admixture of the various elements of response within a public to the person acting for them.

The psychological base of the doctrine of *admiratio populi* must be dealt with. There is no question that since we are all symbols to one another, the person with a severe and immediately recognized disability carried a symbolic value highly charged and mostly negative. The doctrine recognizes this reality, and as such makes the presence of such a disability a consideration for disqualification to the priesthood.

Attitudes in society change, and if a major segment of society can respond more positively than negatively to an open physical disability, so then the canon law of *admiratio populi* would also change, reflecting the more acceptable attitude. Since the law concerns the distraction or discomfort rather than a specific disability or stigma, such change towards acceptance would be quite in line with the pragmatic approach in the Pentateuch statements which allow for the continued activity by the priest if the congregation has "grown used" to the blemish he exhibits. This acceptive attitude is one of the two primary resources for change within the church. More sociological than theological in nature, it nonetheless can truly mirror a change within society at large.

The second, and more important, hope is in the theological dimension: the Messianic feast vision of Jesus, and the "strength in weakness" statements of Paul are cornerstones for the doctrine that within the very nature of the church itself, weakness is present that God may be glorified.

The parable of the banquet in Luke 14 recounts the invitation to the great dinner, and the excuses the invitees gave: "I just look at my newly bought piece of land, or examine my five yoke of oxen."

Angered, the host demands, "Hurry out into the streets and squares of the city, and bring the poor, the maimed, the blind, and the lame in here" (Good-speed and Smith, verse 21). The peroration of the householder at the end of the chapter, and the introductory conversation of Jesus and the Pharisees prior to Jesus' description of the great banquet, are interrelated: "For I tell you that none of those men who were invited shall have any of my dinner" (verse 24). The phrases prior to the description of the great banquet include, "For everyone who exalts himself shall be humbled, but the man who humbles himself will be exalted" (verse 11). Finally, "Do not invite your friends or your rich neighbors or your relatives, for then they will invite you in return and you will be repaid. But when you give an entertainment, invite people who are poor, maimed, lame, or blind. Then you will be blessed, because they cannot repay you: for you will be repaid at the resurrection of the upright" (verses 12, 13, 14).

The Kingdom of God is not complete without the poor and the maimed! And each member thereof is not complete, nor has hope of salvation, save that the lame and blind are included.

A new "church struggle" is before us: to change the concept of "ministry to" to that of "ministry with." That struggle expresses itself sharply by church resolutions, by action groups, and by changing directions in national church bodies.

The World Council of Churches stated the new approach most clearly in a document created in April, 1978 by a special working group:

*But the church must go beyond the institutional response and move to a dramatic affirmation of congregational acceptance of the handicapped within the mainstream of congregational life.*

The United Church of Christ is in the forefront of denominations accepting a "ministry with" understanding. At the General Synod of 1977 in Washington, D.C.—significantly, on Independence Day!—it adopted a statement of liberation for the handicapped. The United Presbyterian Church in the U.S.A. acted a week before, in Philadelphia, calling their statement, "That All May Enter." The Southern Baptists were next, then

the Roman Catholics in November, 1978. The United Methodist Church has been working on a statement for several years.

But in the front lines of this battle, within any congregation, is the question how are they to begin the task of bridging the barriers? Here are some suggestions. All are important. The congregation may begin with any one and go on to the others. None may be passed over.

Pervasive and continuing theological dialogue within the churches will help to relate biblical understanding about persons with handicaps to the current scene. Invidious conclusions from some of the biblical insights must be faced squarely. Do we correctly say that people born with disabilities reflect the sins of their parents even to this fourth generation? It staggers the imagination to think of thousands of congregations engaged in biblical study on God's gracious promise to provide wholeness for everyone!

Worship must reflect the biblical insight, and specifically lift up in prayer and litany and sermon the plight of the disabled individual, the relationship of that individual's situation to all of the rest of us, and the meaning of the spiritual and personal handicaps which all of us share.

Astute political action will carry the concern of the church into the public arena, and help to inform that struggle.

A vivid example was the months-long struggle for advocacy for disabled in attempting to press the United States Secretary for Health, Education and Welfare into signing regulations for the Congressional act on the handicapped. The church had at least a small part in that effort. In one specific area, San Francisco, the church moved in to support the handicapped advocates in the person of Dr. Norman Leach, staff director of the Healing Community in the San Francisco office. Utilizing the national resources of the Healing Community and winning approval from various levels of denominational and inter-church bodies in California, a united front of the Community was presented to the government. That demonstration was a significant factor, along with others, in helping the government see the validity of the concern and finally to sign the regulations.

"Consciousness-raising" is the device used so effectively by women in the church, and is now another step for the concern of church and handicapped. From the building of ramps and the discussions of attitudinal barriers, from an awareness-day program of members placing themselves in wheelchairs and under blindfolds to the study of community resources for handicapped, the church helps to raise the consciousness of its membership.

The Healing Community is a national project in the U.S.A. designed to raise this awareness. Directed toward church and synagogue, the Healing Community advocates the cause of physically disabled and other handicapped persons, and helps to facilitate the integration of handicapped and alienated persons into the mainstream of society.

The action-research program has created models of ministry within congregations in four major U.S. cities, pointing the way for close to one hundred million potential volunteers to respond to the national policy of deinstitutionalization—taking people out of the institutions and back into society.

Creating the caring society, building the healing community, organizing the caring community—however one names the goal, the ultimate objective here is to help the church reclaim its original charter of total concern for the lost, demonstrating that underneath are everlasting arms. We shelter each other, and God all!

Theological education is another "next step." Institutions of higher education—seminaries and theological schools—must educate the next generation of ministers, priests and rabbis to become aware of and expert in ministry with people who have physical and emotional disabilities. Prestigious Union Theological Seminary in New York City is the very first to institute such a course, and this writer notes, from personal involvement with a dozen other theological schools and the American Association of Theological Schools, that this concern is slowly rising in the purview of seminary officials.

Overcoming architectural and attitudinal barriers is a basic step. In many hundreds of local churches a minister or a lay leader has raised the question of why a disabled member of the congre-

gation has to go elsewhere. "Of course we must make it possible for her (or him) to attend here," they say, and then they intentionally work at overcoming two kinds of barriers—architectural and attitudinal.

The architectural barrier is to be found in all too many places. A 1975 survey in a major city by the former director of the St. Louis unit of the Healing Community project, O. Walter Wagner, indicated that only one percent of St. Louis buildings were accessible to persons in wheelchairs. Now more and more churches are building ramps and designing new structures, or renovating old ones, so that persons with crutches or wheelchairs, persons who have suffered coronaries, and others can enter easily.

Attitudinal barriers are more difficult. Certainly the first step is that of making the church building accessible so that the congregation no longer says in effect, "We don't want you here." But once means of easy access have been created, the response of the church membership to persons of special need requires intentional action on the part of individuals, supportive statements from the pulpit, and a deeper understanding of biblical acceptance of all of God's children.

Leaders in this "church struggle" need a battle cry, and such a clarion call is in the motto "For Gheel and St. Dymphna!", deriving from the story of the early Christian martyr, princess Dymphna, slain in 500 AD in Gheel (Belgium) by her father, an Irish king. Paradoxically, there developed out of this murder a hopeful tradition: people understood the act of the king as obviously that of a mad person and came to believe, as a somewhat illogical corollary, that his daughter had a special healing quality for the mentally ill. People started coming to Gheel from all over Europe, the numbers swelling through the centuries, and, finally, in 1245 Princess Dymphna was canonized by the church.

The remarkable thing—that which speaks to us across the years—is that all the people who came to be cured stayed in the homes of the parish and the homes of the people in the community, and the visits lasted from a month to a year or more. No institutions were built and no huge dormitories prepared.

The homes of church people were opened to the sick who came. In fact, the only change that has come about in this whole expression of acceptance is that about one hundred years ago, the Belgian government began reimbursing the people of Gheel for extra costs in room and board for their suffering guests.

Perhaps the concept of Gheel and St. Dymphna may help us most in the matter of acceptance. Gheel expressed that acceptance by offering to these seekers for cure of their mental illnesses, hospitality within their own homes. Gheel represents a kind of community of acceptance which most of us have experienced at one time or another in our lives. You have felt it on occasions when you were accepted as a person just as you are, when you felt the "attributed wholeness" that society can and does give. We must extend to the person with a disability that supportive community of acceptance which can in turn receive and learn from such an individual. ■

# A Testimony to Strength: An Interview with Curtis Brewer

*The following is an edited transcript of a taped radio interview conducted by Paul H. Sherry with Curtis R. Brewer.*

**Sherry:** We have rearranged our studio today to accommodate our guest and friend, Curtis Brewer. Curtis is paralyzed from the neck down. To get around he drives a wheelchair that weighs about 200 pounds. He moves it with an apparatus he can touch with his tongue which makes the chair maneuver wherever he wants it to. Carl Martial, one of his attendants, is here to help him since Curtis can do nothing more himself. Since his paralysis twenty-five years ago, Curtis Brewer has married, raised a son, finished a college degree, completed a Masters degree in Public Administration, served as a private ombudsman, and then at forty-five years old, enrolled in law school. Four years later, he graduated and now he heads his own law firm in New York City, handling special legal problems of the disabled. Curtis Brewer, some twenty years ago, you became quadriplegic. What exactly is a quadriplegic?

**Brewer:** A quadriplegic is a person who is disabled because he or she has no use of the arms and the legs.

**Sherry:** What does that mean in terms of your own life?

**Brewer:** It means that I am totally dependent as far as scratching my head or putting a book in front of me or turning a page, and for the most part, moving from one place to the other.

**Sherry:** You were not at all disabled before you became a quadriplegic? It was a total change in your life situation?

**Brewer:** A total change at the age of twenty-nine.

**Sherry:** What were your feelings when you became gradually aware that you were not going to become better, and that you were going to have to adjust to being a quadriplegic?

**Brewer:** That's interesting. When I first had the symptoms while working at the Post Office and going to school, I didn't think that this was something that would be more than temporary.

**Sherry:** It came on gradually, then, Curtis?

**Brewer:** It came on gradually over a period of about two months. When I went into the hospital, I was walking on my tiptoes, painfully.

**Sherry:** In the hospital, a doctor took care of you, and you thought that you would work it through?

**Brewer:** That is exactly what I felt, yes. Then on that fateful day, April the first, 1955, while in the hospital, I tried to transfer from one chair to another, and fell flat on my face. And I wept. I could not fathom what was going on, and I really became frightened then. Then as the succeeding weeks passed, my breathing became affected, and they decided that they would have to do an exploratory operation in the upper part of my spine to determine what the cause was. By this time I could not move anything from the neck down.

**Sherry:** Well, then, you stayed in the hospital and, as I remember the story, you still were not convinced that you could not really be rehabilitated and you checked out of the hospital and you went into physical therapy. Is that correct?

**Brewer:** No, not quite correct. I still am not convinced today that I can't walk, even though there is much evidence, I suppose, to indicate that I will not walk again. Perhaps one just has to have hope. Hope because one doesn't like to live a life of total dependency on another or others. My wife, who has done a beautiful job in trying to maintain herself and me all these years, has resigned herself to the conclusion that I will not walk again.

**Sherry:** But you are still not convinced?

**Brewer:** That is right. You see, I still have full sensation. All that is knocked out is my motor.

**Sherry:** You could feel, then, if I would touch your leg. You can fully feel that.

**Brewer:** Absolutely.

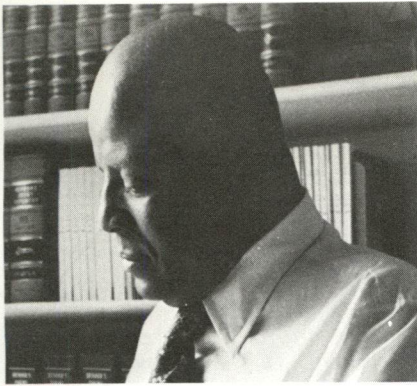
**Sherry:** Were you married when you became a quadriplegic?

**Brewer:** No.

**Sherry:** You became married after that time. Was that a tough decision to make?

**Brewer:** No, from my point of view, it was a very practical decision to make. It was a decision made in the true Horatio Alger tradition—that you will conquer, separate yourself from the daily stream and re-enter in a more powerful way.

**Sherry:** You are a very interesting man because of the strength of your personality, and one really can't meet you, Curtis, without being aware that you are really a very strong personality. Has your personality changed at all since you became a quadriplegic or have you always been a man with self-assurance?



Curtis R. Brewer is an attorney in private practice in New York, New York, handling the special legal problems of the disabled; and is also director of *Untapped Resources*, a comprehensive, free legal service for the physically or orthopedically disabled.

*Brewer:* I guess I have always been a person who was eager to get from point 1 to point 2.

*Sherry:* What has that meant in terms of how you have dealt with becoming a quadriplegic? Has it been helpful to you, or has it been frustrating for you to have such drives and yet have to adjust those drives to this condition?

*Brewer:* No, Paul. Bear in mind that all the time that I have been disabled, I have had a tremendous amount of help from my wife and friends and attendants and the young man who came in with me today. People like this have always attempted to relate to me and not only to the disability. And this was true in school, it was true in social relationships, in many, many ways. So I found no problem.

*Sherry:* Was that difficult for you—to learn to depend on other people?

*Brewer:* No, I don't think so because you know, I grew up kind of a frustrated and lonely and searching human being. Now when people relate to me, we just keep on searching for our common interests.

*Sherry:* Tell us, what does a typical day look like for you? I am sure that you have things to deal with in your life that I don't even think about. What is a typical day for you?

*Brewer:* Well, let's start at twelve midnight. I might sleep three or four hours. Then I will probably awaken and ask my wife to jot some notes down.

*Sherry:* In the middle of the night you do this?

*Brewer:* I'm afraid so. And she will jot the notes down, and I will go back to sleep. Then when my assistant comes in the morning at seven, he lifts me, and he washes and shaves me and gets me into the wheelchair and into the office which adjoins my bedroom. And the secretary will come in and start the day, or one of my associates will come in and we will discuss a case, and make phone calls. You know, whatever has to be done to get through that day—maybe dealing with a case, or cases, and correspondence. Or it may be that there will be some things to do in terms of keeping the house which I might want to do.

*Sherry:* You do things around the house then?

*Brewer:* Yes, my wife goes out to work. She prefers to do her own thing.

*Sherry:* You mentioned cases that you deal with day by day. You are an attorney, you have begun an organization which has become nationally known now. It is called Untapped Resources, Inc. Tell us exactly what Untapped Resources is.

*Brewer:* Untapped Resources is a comprehensive, free legal service for the physically or orthopedically disabled. It was developed out of the idea that there is legislation specifically aimed for protective rights of the disabled. If they are abused, we would step in, if we are asked, on behalf of the individual. We are not an advocacy-oriented organization in the sense that we deal with big issues. We deal with very small, individual issues—a wrinkle in the total fabric of the abuse.

*Sherry:* I want to get to some of those specific cases in a few moments. But tell us a bit more about the legislation. This is federal legislation, is it not?

*Brewer:* Federal and state. It has been passed for years. What is occurring to me is the Rehabilitation Act of 1973 which has been hailed as the first civil rights statute for the disabled. It seeks to establish legal rights for the disabled in the areas of health care, education, and employment, as well as the crumbling of architectural barriers.

*Sherry:* But what are some of the specifics of the legislation?

*Brewer:* One of the major thrusts of the legislation is to provide funding on a federal and state basis for disabled persons, particularly severely disabled persons, to work toward a vocational objective that will enable them to be reasonably independent.

*Sherry:* So that the government owes it to that person, is that essentially it?

*Brewer:* Guarantees of support, through State offices of vocational rehabilitation. Then of course, there is the Architectural Barriers Act of 1968. Then of course, there are the pieces of legislation dealing with housing, health care, like Medicaid-Medicare, or social security. In fact, in 1967 about \$35 billion was spent on medical, social security supports for the disabled. Those figures were worked up by reputable Rutgers University. \$35 billion. That is a lot of money. And the sense of that is that I am not sure that we are entirely concerned about really mainstreaming the disabled as much as we are about taking care of them.

*Sherry:* That is an interesting point that you are making. In a sense, we are more concerned about putting the disabled off in a corner and taking care of them, rather than finding out ways by which the disabled can be contributing more fully to the society. And that is still the case, you think?

*Brewer:* Absolutely.

*Sherry:* Why is that? Why are we so fearful of the disabled? Is it because we are afraid that we might become disabled, and we don't want to face that reality?

*Brewer:* Yes, that is one of the reasons. Another reason is that there is a problem in communication. You have said that you had a certain reaction, upon first meeting me, and it was a positive one. But you might meet another dis-

abled person you might not have a positive attitude with, and that is part of a mix between two personalities. Now "handicap" is not the term that I would use. I think that we are disabled, and we are sometimes handicapped by our disability, you see.

*Sherry:* Some are disabled and some were disabled sometimes, that is a very fine distinction.

*Brewer:* I wouldn't think that Governor George Wallace is handicapped. He is just disabled. That is the kind of thing that I mean.

*Sherry:* You made an interesting point a few moments ago when you said that legislation which goes back for many years, specifically prohibits the construction of buildings, which deny access to disabled people. Federal buildings. Why is it that all around me I continue to see buildings which really do not have access to people of particular disabilities. Why is that the case if we have legislation prohibiting it?

*Brewer:* I don't know if those buildings are subject to the law. Many times I can't get someplace. If I want to get to church on Sunday, I can't worship in church because I can't get into the building.

*Sherry:* That's right, and many sanctuaries are on the second floor and the only way up is by those stairs.

*Brewer:* There is a law here in New York, Article 15 of the Executive Law, which prohibits such types of architectural barriers. We are trying a case under it now. (Editor's note: The case was won on August 15, 1978.)

*Sherry:* Tell us, Curtis, some specific cases that you have been involved in which really illustrate very dramatically the kinds of problems that face the disabled.

*Brewer:* There is an agency in this state, The Office of Vocational Rehabilitation, with which we have several cases pending. One in particular involves a young woman, a quadriplegic, who had gone through the OVR sponsored training program, had gone to work, and could not with her salary keep a Medicaid attendant. She was told that if she wanted to keep that Medicaid attendant, she'd better go back on welfare. (Editor's note: These cases have been successfully closed.)

*Sherry:* A doctor told her this?

*Brewer:* No, this was a social service worker. And it was the Social Services Department. She needed an attendant because, as I said, she was a quadriplegic, and she had gone through four years of training to get this job. The job paid about \$9000 a year, and an attendant would cost about that much. They would not permit her to have an attendant unless she paid all of the costs. Consequently, putting her through the training program was a move of stupidity.

*Sherry:* And a waste of the taxpayers' money.

*Brewer:* Right. Absolutely a waste. However, there was then and there is now, provision in the law where she could have gotten the attendant, and kept her job had she had proper representation. We did step into the case. We did exercise that section of the law which would permit her to work, under certain conditions, in a training program, maintain her attendant and keep on being mainstreamed. (Editor's note: Court action is pending.)

*Sherry:* What you are saying is that in many cases the legislation is there. It is just that many disabled people don't have access to the legal representation necessary to enforce the law.

*Brewer:* That is why Untapped Resources was formed.

*Sherry:* You are the only law firm of that sort?

*Brewer:* Yes, we are. Now, in health care, we recently concluded a rather serious problem involving the well known Institute of Rehabilitation Medicine. There was a denial of the attendant services to this quadriplegic living in that facility on the physician's theory that to bring him to reality he needed to deny him the use of an attendant. Then there was the question about his emotional capability. I want to emphasize one thing—we seek for negotiation of the problem first. We are less interested in going into court and beating the drums than we are in resolving the problem by talking to the appropriate people.

*Sherry:* And most cases would be solved this way?

*Brewer:* I firmly believe that, yes. We did it. We brought in a psychiatrist with impeccable credentials to evaluate this situation. The Institute was still unwilling to go along and newspapers got involved, and then they went along. We have had another situation where there was an architectural barrier, where this man, in order to get to work, had to have some means to park his car and then be able to get over to that car. We went through a government agency which was involved and spoke with one of the executive people there, and they helped us resolve the problem without going into court. We didn't have to go into court to test the law. In employment, it is the same kind of problem, where there have been attempts to dismiss disabled persons because somebody feels that this person is not going to be able to do the job. We have stepped in knowing that they can do the job. It is because of the capability that the person has demonstrated.

*Sherry:* Curtis, if someone had a particular problem they needed assistance with, should they write you for that, or are there other ways? Would you be willing to receive letters from people who are looking for particular answers?

*Brewer:* We will take any letters, and answer them. If we can't help them, we will find the means to refer them to the appropriate place.

*Sherry:* As you look at your own life now, for the next ten or fifteen years, what will be the strongest directions that you expect to take? How are you going to spend the next ten years of your life.

*Brewer:* Practicing law. Starting to walk. I hope to argue the first case before the United States Supreme Court on the architectural barriers throughout the land.

*Sherry:* Mr. Brewer once wrote the following about a woman who had written of her own son's paralysis. I want to repeat them because I think that they say a great deal about Curtis Brewer. He said that, "perhaps more than most, you know something about the meaning of disability. While it can be a searing experience for each and every person who confronts it, it can also be one of life's events which calls for the nobility of spirit and imagination which transcends ordinary human perception." Curtis Brewer's life is a testimony, I think, to that statement. ■

# Learning is a Partnership

## Jane Weil

Usually when we talk or read about the mainstreaming of handicapped children we have school-aged children in mind. Recent federal legislation (P.L. 94-142, the Education for All Handicapped Children Act) has mandated educational services for all children no matter how severe their handicap. This law has been likened, in its educational and social implications, to the civil rights legislation of the 1960's. The handicapped have been a minority who have been denied full access to the mainstream of life. The prejudices which affect the handicapped may be somewhat different in nature than those which have affected other minorities, but they have nevertheless caused most handicapped people to live as second class citizens.

As with other civil rights struggles, there is every reason to suppose that this one, too, will be of long duration. There are economic issues to be reckoned with such as the implementation of public transportation services for the physically handicapped. In these days of inflation and the faltering dollar we are already seeing the retrenchment of support for social services and programs.

One of the social institutions which has the greatest influence (whether positive, negative or somewhere in between) is the school. Schools are particularly affected by P.L. 94-142. The law mandates reimbursements from the federal level to the state and from the state to local school districts for handicapped children who are served. This is positive in that it assigns funds to pay for the increased costs which local school districts must bear. However, as with any changes in social policies there are problems to be overcome and it will take considerable time and effort to overcome many of them.

One problem is the public versus the "special" school. A large number of the handicapped who have received education in this country have received it in a school where specially trained staff and special equipment or materials have been available. Some parents, understandably, are very afraid that their handicapped children may not receive such good services through the public schools. The advantages of mainstreaming may not sound like advantages to parents who fear rejection and ridicule of their child. Until integration of the handicapped has become more widespread there will be instances of rejection, and one can understand some of the parental reluctance to mainstreaming. However, in the long-term mainstreaming will be the answer to this problem. Full integration of the handicapped will come through mainstreaming and for many children this will begin with the educational process.

Other long-range problems are the training and re-training of staff to work with the handicapped, and the bringing together of the educational, medical, social and psychological expertise necessary for the development of a complete program for the particular child.

I attended a workshop recently where a first-grade teacher appeared to have a very positive attitude toward mainstreaming and toward having two or three special-needs children in her classroom. However, she was extremely frustrated in her attempts to implement an educational program because the children had to leave the room so often for services from specialists. Many specialists (therapists of various types or persons with backgrounds in working with the emotionally disturbed) are unaccustomed to working in school settings. They may have gained most of their training in hospitals or other insti-

tutional settings. Bringing together this background with that of the public school educator and hoping to create a "team" takes more than a little understanding and good will on the part of each team member.

P.L. 94-142 requires the development of an individual education plan (an IEP) for every handicapped child. The parents are to be a part of the team which develops the plan. Parents can, and hopefully will, play an important role in helping an interdisciplinary team work well together. After all, they and their child are the ones most directly affected by the team's efforts. However, it is very easy for a team of "specialists" to intimidate and overwhelm even the most aggressive and articulate of parents. Parents will need many kinds of support as the mainstreaming process continues.

I continue to advocate smaller class size as a way to improve educational opportunities for *all* children. It is unlikely that this will happen given the current social and political climate. Nevertheless, I tend to support most teachers who feel they could accomplish much more if they had fewer students.

Another social institution which has a profound influence on children is the family. Despite the many changes which have occurred in this century, every child is born into some type of family structure. Most children continue to be raised within some type of family structure. For a handicapped child what happens during these early formative years will have as much influence as what happens after the beginning of formal education. P.L. 94-142 does not affect handicapped children during their earliest development. It is the family that has the greatest influence during these



Jane Weil is director of the Washington County Children's Program, Machias, Maine, a home-based program for young people with a wide variety of special needs.

years before school. The mainstreaming process can begin during infancy and proceed through the toddler and preschool years depending upon the attitudes of parents and other family members.

The Washington County Children's Program in Washington County, Maine, has been designed to work with families who have a young handicapped or developmentally delayed child. For the most part the children are under five years of age and are not yet attending public school. The remainder of my comments are based on experience with this program.

Education and mainstreaming for most handicapped children begin where they do for all children—within the family. This may be the traditional nuclear family; a single-parent family; the extended family; or a commune. Whatever the setting, it is within this context that the handicapped child begins to learn and begins to be integrated.

Washington County uses the commonality of the "family" as its point of departure. Our reasoning is that if a child can learn basic skills within the family setting and within the normalcy of the home environment, then the beginnings of both the educational and mainstreaming processes have been laid. This sounds like a logical place to begin and we believe it is. But there are problems to meet and work on. Chief among these are the fears and lack of knowledge which families may have.

Family members are the young child's first and most important teachers. This is true for all children whether they are handicapped or not. In almost all cases children will be raised by the parent or parents to whom they are born. Circumstances may not be ideal in such critical areas as parenting abilities or financial

resources. However, our staff (called home teachers) sees their job as helping parents of handicapped and delayed children become the best possible resources they can be for their child.

Building the partnership between the home teacher and the family takes place in the family's natural setting—the home. Because Washington County is very rural and covers a large geographic area, the program was designed originally to be "home-based" rather than center-based. However, there are now strong philosophical reasons for going to the home which have come to supercede the original, practical reasons.

As a guest in the home, the home teacher can develop a trusting relationship with the family over time. She can become familiar with the individual assets and constraints that a particular family can bring to their child's program. She can get a better and quicker



knowledge of the family's value system and methods of childrearing. She can better understand both the benefits and complications attached to siblings or other adults who may live in the home.

Parents are brought into the assessment process and into the development of an individual program (the IEP) for their child. These are carried on during home visits. Subsequent visits, which are weekly, bi-monthly, or monthly depending on the child's needs, are opportunities for the home teacher to teach the parents new activities in relation to the child's program. The home teachers feel they are achieving greater success when parents increasingly assume more responsibility for developing their child's program. Ideally, the child will make social, emotional, physical and educational progress within its natural setting—the family.

However, when the child reaches two and a half or three years of age, it is important that the handicapped child has opportunities to be mainstreamed into a wider circle. Play groups, nursery schools, preschools or partial day care can be very useful. The lack of adequate resources should be of concern in every neighborhood in the country. Exposure to a positive, high quality preschool experience for the handicapped or delayed child will make mainstreaming much easier when the child enters public school.

Mainstreaming, then, is a process which is not connected only to educational institutions. The goal is to develop a society in which handicapped persons can be "mainstreamed" in every aspect of their lives: their work, their recreation, even their travel. The years of formal education are extremely important in the sense that they can lay the groundwork for much that will follow.

However, the earliest formative years are the ones which lay the groundwork for all that follows. It is during these years that concepts of self, the most basic skills, and abilities to make meaningful human attachments are developed. Parents and the family can play the most important role in these developments. As they expose and make the child aware of the extended family—family friends, the neighborhood and the larger community—they are beginning the important mainstreaming process, which with full public support will become a lifelong process for the handicapped person. ■

# Lights of My Life

# Joann Jones

A profoundly retarded ten-year-old boy in a neighboring city died a few months ago. His life had been a daily struggle just to stay alive. His mother had devoted those same ten years of her life to his needs. She had been actively involved in his daily therapy. Literally hundreds of friends, relatives and strangers had, at one time or another during those ten years, made sacrifices of their own in his behalf. Scotty had never spoken a word of thanks. He never walked. He wasn't even potty trained. Someone had to feed him at every meal and carry him wherever he went. His prognosis had not been good from the day he was born. His bouts with pneumonia and frequent *grand mal* seizures throughout those ten years finally took the last of his meager strength.

The church funeral was packed with family, friends and those who only knew Scotty because they cared. It might seem that his life had carried little meaning and had offered little to others in return for their investment of time and energy. Why then were there few dry eyes among them when they sang "You Light Up My Life"?

As the mother of two children like Scotty, I know why! I learned why over a period of years and after seemingly endless tears of disappointment. Joey is twelve now and Jessica is six. They will never walk alone due to cerebral palsy, and it is doubtful if either of them will ever be totally potty trained. Both are diagnosed as mentally retarded to varying degrees. They are totally dependent on others for their most basic needs. Joey has never spoken, but Jessica is never quiet. What they have to offer others may seem to the casual observer to be very insignificant. It is really quite the opposite! Let me share a few of their blessings with you.

Joey was born to us after we had adopted five children. We had been married thirteen years when I first became pregnant, and the advent of his birth seemed like a miracle to all of us. We spent those first few weeks after his birth in sheer ecstasy, not noticing his slow progress. Then the fateful day arrived. The doctor informed us rather bluntly, and without preparation, that Joey had cerebral palsy. We were told there was nothing we could do for him but just "wait and see." Knowledge of the accompanying mental retardation was gained from reading the sign on the door of the evaluation clinic a few weeks later. The initial shock and disbelief was followed by despair and hopelessness. The futility of all our hopes and dreams for him made us mourn as though he had died. There were times when we hated God for having allowed this to happen, but He gave us the strength to meet the challenges of those next few months and years.

Joey's needs were our responsibility, regardless of how unprepared we were to meet them. Society imposes upon us all the ever-present demand to be productive members. Not only did we feel accountable for ourselves in this regard but also for Joey. He needed intensive therapy, lots of stimulation and constant motivation. He was going to need to go to school as other children did. Many of these things were not available to him in our community. The determination to provide them took us, as parents, on a long and strenuous journey.

When Joey was just eleven months old, and after extensive evaluations and testing, we began a program of home therapy prescribed by the Philadelphia Institutes in Pennsylvania. It required an intensive eight hour workday and the recruitment of dozens of volunteers.

This was carried out in our home seven days a week, fifty-two weeks a year for the next three years. During that time, two daughters were born to us who were both very beautiful and very normal. After three years of home therapy, Joey was able to sit alone and could creep on hands and knees. His chin bore the scars of numerous falls, the price he had paid for that meager achievement. The vigorous demands of such a daily schedule also drained our physical and emotional energies.

As Joey neared school age, he did not begin to measure up to the basic qualifications of any existing school in our community. During these years we had become acquainted with other parents whose children had the same needs. The logical solution was to create a school for them. This meant locating a facility to house the school, staffing it, and identifying a means of funding. There were presentations to the Governor's Task Force on Mental Retardation and numerous grant applications to write. The state officials had to identify the total county need before a recommendation for funding could be made. Out of necessity, we became self-educated in the newly phrased area called "developmental disabilities." Each time a door was closed for any reason, it seemed that two more opened. On February 1, 1971, the Preble County Developmental Training Center opened with an enrollment of ten children including Joey. It was the first such school in the State of Ohio, and it set a precedent for other counties to follow. The profoundly retarded and multi-handicapped need not meet any minimal requirements to attend this school five days a week, twelve months a year. It had already been determined that these particular children experience too much regres-

Joann Jones is a homemaker and mother who, along with her husband Lewis, has cared for a family of 17 natural-born, adopted and foster children.

sion during long periods of inactivity during vacations. Because of Joey other children were going to school for the first time and many parents were thankful.

The following February, just a year later, Jessica was born. Once again we enjoyed the first few weeks in relative confidence that she was just as beautiful as her sisters and just as normal. There had been some concern during this pregnancy because of my age, and I had gone to Cleveland for an amniocentesis earlier. The results had been rather unusual, prompting some concern on the part of the physicians who said there was sufficient evidence to terminate the pregnancy if we desired. These fears had all been put aside after Jessica was born. Then, a few weeks later, we noticed some of the same characteristics Joey had exhibited at that same age. This time it was necessary for us to convince the doctor of a problem. He thought we were overly concerned from our experience with Joey. Extensive tests and evaluations were initiated, and six months later Jessica was enrolled in the Developmental Training Center with her brother Joey.

Giving birth to a second child with almost identical problems is not all that rare. However, this fact does not help the parents deal with the trauma all over again. Friends of the family who had been so helpful throughout the first experience were now having their own reservations about dealing with us and our situation. We felt as though we were being blamed for having done this to society. There had been some who had been so reassuring during the pregnancy itself, almost to the point of guaranteeing us a normal child, who now were unable to confront us in our despair. In many ways, we had a more difficult time in working through this second tragedy

than we had the first. Much of the grieving process was confined to the immediate family, and only the knowledge gained from the first experience and God's unending love carried us through. As time passed and friends gained assurance of our having worked through the situation, we once again enjoyed their loving support.

Joey and Jessica are both attractive children in appearance. Seated at the kitchen table with the braced legs and atrophied muscles hidden from view, they could pass for normal children to the casual observer. The children smile readily and radiate a genuine love for those around them. Joey, being a typical boy at heart, loves to tease, and Jessica, the con artist at heart, can usually get him into trouble. Their pleasures in life are usually satisfied by a trip to the nearest McDonald's or a new Sesame Street record. Compared to the demands of five teenagers in the family, these pleasures seem quite simple. The gratitude they show for even such small pleasures instills within me a deep sense of humility.

Shortly after Jessica's third birthday, our lives were blessed with another daughter as beautiful and just as normal as any child can possibly be as the youngest of ten children! We have learned to enjoy her normalcy in a way that is only possible by the parents of a handicapped child. Our gratitude and thankfulness of heart are so enhanced by our experiences in which Joey and Jessica play a major part, that this child could literally have lived on love.

The patience required to care for two severely handicapped children did not come naturally to me as a parent. It was a gradual learning experience which

took place over the years, but which is now an ever-present compliment to the growing needs of all our children. Friends and volunteers share the same testimony: these children "light up their lives." They make others more conscious of their own blessings. They instill patience, and they love genuinely without reservation.

Our community has experienced a tremendous growth in public awareness of the needs of children like Joey and Jessica. Within a few years, programs have been initiated and have expanded to serve hundreds of people of all ages. During the expansion of one aspect of service, a residential home, we toured our state's largest institution for the mentally retarded. A small, thin boy stood forlornly in a ward of older men. The tour guide explained the need for foster homes and stated that Keith could leave if there were a foster home for him. A few weeks later, and after much red tape, our's was licensed as a foster home. Keith joined our family as our first foster child. Since then five more have joined us.

This has been a new learning experience for us as parents of our own retarded children. It has made us thankful that, due to circumstances God has allowed, we have been able to keep Joey and Jessica at home with us. We have shared other parents' grief as they humbly ask us to care for their child. We hear with sympathetic ears the insurmountable obstacles they have confronted due to circumstances in their home. We share their frustrations, their tears, and most of all their love for their child. We marveled at Keith's progress when he was transferred from a school for the trainable mentally retarded to a classroom in public school. Gratitude to



God comes from the depths of our hearts each day that He allows us the opportunity to serve Him in this way.

Parents don't ever come to a full understanding of *why* when it comes to dealing with the problems of a severely handicapped child. As the child grows, the problems grow, and there are frequent relapses in the emotional strength of the family. It was during one of these times recently that I expressed my regrets to my husband. I was in the process of feeling sorry for myself and for these children who's potential in life will always be so limited. After some serious thought, he responded to my feelings by reflecting on Joey's attitude toward himself. In essence, he said, "I can't feel sorry for someone who feels so good about himself." Joey does feel good about himself and he feels good about those around him. What greater influence could one person have on the life of another than to reflect a positive attitude. In essence, to light up their life.

Raising a family of ten children and adding the individual handicaps of six foster children has been a real challenge. We have had firsthand experience with the physical barriers to crutches and wheel chairs our everyday world presents. We are also aware of the great emotional barriers of those who either don't understand or are unwilling to accept these children as members of society. As each of our older children matures and leaves our

home, we become more and more aware of the lifetime responsibility that is vested in us with regard to the lives of Joey and Jessica. We deal with our feelings on a day to day basis with the mutual support of family and friends. Their love and understanding have helped to heal the wounds of disappointment throughout the years.

We often wonder about the unspoken feelings of our normal children in relation to having experienced such a unique home environment. Our impression is that it has helped to mold characters that are prepared to deal with disappointments and challenges in their own lives. It has certainly given them the basis for a broader understanding and concern for others who are less fortunate. Each of them has donated many hours of volunteer work during the summer months at the school Joey and Jessica attend. They frequently use the subject of mental retardation or cerebral palsy for school papers and have actually taken the children to school with them occasionally. Their arguments are centered around who gets to push the wheel chairs. Our oldest daughter has chosen to be a houseparent at a resident home for adult mentally retarded clients in a neighboring county. These are an indication to us that they have worked through their own feelings and have dealt with them in a very satisfactory manner. Our eight-year-old daughter has already given thought to the possibility that she too

might have a son or daughter like Joey or Jessica. Her solution? She said she would bring it home for us to care for!

I will always regret that Joey and Jessica are this way, just as I regret any imperfection in our lives. But Jesus had His own way of perfecting each of us, through His love by His grace. I don't blame God for these imperfections. He only allowed them to happen and He gave each of us the strength and courage to deal with them. Through them we have learned a much greater dimension of love than would otherwise have been possible. Joey and Jessica have enriched our lives and the lives of countless others, just by their existence. They do light up our lives, just as they light up the lives of those they come in contact with each day. The greatest compliment either of them can pay us is for them to continue to feel good about themselves because this reflects our attitude toward them. ■

# Resources

## Books, Articles, and Pamphlets Concerning the Retarded

*A New Day for the Retarded*, a series of articles published by the *Other Side*, August, 1977, issue

Public Affairs Pamphlets available from: 381 Park Avenue South, New York, New York 10016

No. 288, *How Retarded Children Can Be Helped*

No. 349, *The Retarded Child Gets Ready for School*

Perske, Robert, *New Directions for Parents of Persons who are Retarded*, Abingdon Press, Nashville, Tennessee, 1973

Perske, Robert, *The Pastoral Care and Counseling of Families of the Mentally Retarded*, National Association of Retarded Citizens, P.O. Box 6109, Avenue E East, Arlington, Texas 76011

*Ministry With Persons Who Are Retarded*, Fortress Press, 2900 Queen Lane, Philadelphia, Pennsylvania 19129, 1976 (copyright).

A comprehensive portfolio of materials for leaders and committees in parishes.

*Adventures in Christian Living and Learning*, Cooperative Publication Association, P.O. Box 179, St. Louis, MO 63166. Two part series of curriculum resources for use with trainable retarded children and youth. Ages 6-10; 11-15; 16-21

*Exploring Life Series*, Cooperative Publication Association, P.O. Box 179, St. Louis, MO 63166. For use with persons who are mildly retarded (educable) or have other learning difficulties. Ages: 7-12; 13-16; 17-25.

*Resources for Ministry with Adults who are Retarded*, and Selected Resources on Human Sexuality and the Mentally Retarded. Administrative programming materials for use with ministry with retarded adults. Copyright 1976. Contact: Director of Special Learning Needs, Education for Christian Life and Mission, 475 Riverside Drive, New York, New York 10027

The President's Committee on Mental Retardation

Washington, D.C. 20201  
Order from: Supt. of Documents, U.S. Government Printing Office  
Washington, D.C. 20201

*Mental Retardation: Century of Decision* (Stock No. 040-000-0034306)

Report to the President makes recommendations for next 25 years concerning: prevention, humane services, full citizenship for retarded persons, etc.

*The Church's Ministry to the Mentally Retarded Adult* written by Charles M. Palmer, D.D. (Vice President—Services to the Mentally Retarded). Prepared under the direction of Nancy Wahonick (Director of Communication, The National Benevolent Association)

## Books, Articles and Pamphlets Concerning Physical and Emotional Disabilities

*A Kit: Christian Education and the Hearing Impaired Adult and the Hearing Impaired Adolescent*

*Education for Christian Life and Mission, Room 708*

475 Riverside Drive, New York, New York 10027

## Public Affairs Pamphlets

No. 479, *Helping the Child Who Cannot Hear*; No. 504, *Helping My Handicapped Teenager Mature*; and No. 352, *Serious Mental Illness in Children* available from 381 Park Avenue South, New York, NY 10016.

*Resources for the Christian Education of Persons with Special Learning Needs*. Contact: ECLM/DEM/NCC, 475 Riverside Drive, New York, New York 10027

Includes general, mentally retarded, emotionally disturbed, visually impaired, physically and socially handicapped.

*The Church and Persons with Visual Handicaps*

Contact: Director Special Learning Needs, Room 706

475 Riverside Drive, New York, New York 10027

Schoonover, Melvin (Rev.) *Letters to Polly*, Eerdmans, 1974

Wilke, Harold. *Strengthen With Might*, Westminster Press, Philadelphia, Pennsylvania, 1952.

"The Church and Persons with Handicaps" No. 11gs-1

Order from: 297 Park Avenue South, New York, NY 10010 (Office for Church in Society).

*Pastoral Care with Handicapped Persons*, Fortress Press, Philadelphia, 1978

Bowe, Frank, *Handicapping America: Barriers to Disabled People*, Harper & Row, 1978.

Bowe, Frank, "Looking Beyond the Disabilities" *Worklife*, May, 1977, pg. 13-15

*A Handbook of the Legal Rights of Handicapped People*, President's Committee on Employment of the Handicapped, Washington, D.C. 20210

*Selected Federal Publications Concerning the Handicapped*, compiled by U.S. DHEW and the Welfare Office of Human Development Services, Office for Handicapped Individuals, Washington, D.C. Annotated Listing of federal publications pertaining to handicapped persons.

*The Disability Handbook*, ed. Golden-son, McGraw-Hill, 1977.

Gollay, E. and Bennet, H., *The College Guide for Students with Disabilities*, ABT Associates, Cambridge, MA, 1976

Laurie, G. *Housing and Home Services for the Disabled*. Harper & Row, New York, 1977.

Lenihan, J. "Disabled Americans: A History," *Performance*, Nov.-Dec. 1976-Jan. 1977—whole.

#### Books for Children

Fassler, Joan, *One Little Girl*, Human Sciences Press, 72 5th Avenue, New York, New York 10011

Gold, Phyllis, *Please Don't Say Hello*, Human Sciences Press, New York, New York; story about autistic children.

Levine, Edna S., *Lisa and Her Soundless World*, story about a deaf child

Wennerstrom, Genia, *Pooka: The Penthouse Cat*, Ives Washburn, Inc., New York, New York, story about a cat with osteo genesis imperfecta—also a human disease.

For further information, contact: Board for Homeland Ministries, Div. H&W 287 Park Avenue South New York, New York 10010

#### Audio-Visual

*Like Other People*, 16 mm. color 36 minutes, \$37.50.

For information contact: Perennial Education, Inc., P.O. Box 236 1825 Willow Road, Northfield, Illinois 60093

Deals with sexual, emotional, and social needs of mentally ill.

*Right to Be*, 20 minutes, 16 mm. color sound film.

For information contact: The National Benevolent Association, 115 North Jefferson Street, St. Louis, Missouri.

Deals with sexual myths about retarded. Intended for use of professional, paraprofessionals, and parents' groups.

*"I am Not What You See: Sondra Diamond Overcomes Cerebral Palsy."* For information write: Filmmakers Library, Inc., 290 West End Ave., New York, New York 10023. Rental fee \$40.00

This is a filmed interview in which Sondra Diamond tells of her feelings concerning the attitude of society toward disabled people.

*National Catalog of Films in Special Education*, compiled by the staff of the New York State Education Department Learning Resource Center, Albany, NY. An annotated listing of films in the area of special education.

*What Can One Church Do?* Rental fee \$5.00. Filmstrip includes script and study guide. Sponsored by U.C.C. Advisory Committee on the Church and the Handicapped. For information write: BHM, 287 Park Avenue South, New York, New York 10010

*Who Are the Debotts and Where Did They Get 19 Kids?*, 1978

For information write: Film Feedback, Communication Commission, National Council of Churches, Box 500, Manhattanville Station, New York, New York 10027

This academy award winning film tells the story of a family who adopted 19 handicapped children.

*What Do You Do When You See a Blind Person?* For information write: American Foundation for the Blind, Inc., 15 West 16 Street, New York, New York 10011. Offers guidance on how to interact with people who are blind.

*Sight for a Lifetime* available from: Society for the Prevention of Blindness, 75 Madison Avenue, New York, New York 10016

*The Triumph of Christy Brown*. 60 minutes black and white, rent \$15.25 Indiana University, 1970. Film describes life of Christy Brown, author and painter who has cerebral palsy.

*Helen Keller*. Biography of Helen Keller. Association Sterling Films, Inc. 1966. Film is the story of Helen Keller including footage of events in her life.

*Beyond Science*, 15 minutes black and white, free loan for educational purposes, Gallaudet College. Shows what life is like for the students at Gallaudet College (a college for deaf students) in Washington, D.C.

*Leo Beuerman*. 1969. Centran Films, 1621 West 9 Street, Lawrence, Kansas 66044.

Life story of a man who has multiple handicaps including deafness. 13 minutes. Color rental \$19.00. Available from public libraries.

*A Walk in Another Pair of Shoes*. Filmstrip, cassette recording. Available from California Association for Neurologically Handicapped Children, P.O. Box 4088, Los Angeles, California. Rental fee \$3.25 plus postage.

Designed to explain the problems of a neurologically handicapped child to other children.

*It's Their World, Too*. 20 minutes. 1976 Available from: Presidents' Committee on Mental Retardation. Director of Communications, Washington, D.C. 20201. Presents the stories of three people from across the country who are described in the report. *Mental Retardation: Century of Decision* Presented by President's Committee on Mental Retardation.

*Handicappism*. Slide show. Deals with prejudice, stereotyping and discrimination practiced against disabled persons. Available from: Human Policy Press, P.O. Box 127, University Station, Syracuse, New York 13210 ■

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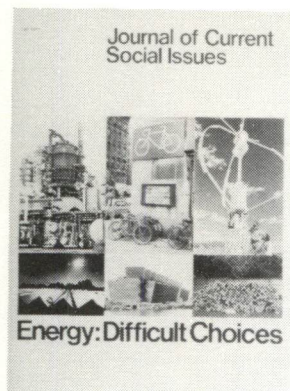
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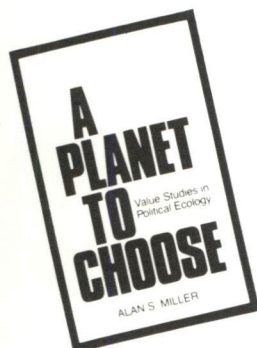
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