

Simple Lives, Rich Gifts, Caring Communities

by David O. Jenkins

On the Assumption that People Should be Independent

For more than thirty years after she was abandoned by her parents, Flora lived in a large institution for the "mentally insane." Her life there was defined by bureaucratic relationships, locked wards, verbal and physical abuse, no creative work, no contact with "the outside world," no interaction with her family, no concern for her spiritual or emotional well being.

Near her fortieth birthday, Flora was invited to live with a newly formed community of mentally handicapped people and their assistants, a community named L'Arche. L'Arche (meaning "the ark") offered Flora the opportunity to live in personal relationships not characterized by staff-patient roles. For the first time in her life Flora was encouraged to use her gifts and skills in creative work. She was reunited with family members willing to face her again. She had a home once more.

It was in this friendly setting that Flora developed many of the virtues needed for living in community. Because of her patience, her trustworthiness, her honesty, her gentle and kind way with others, Flora became the "matriarch" of this community. She patiently welcomed new members into the traditions and routines of the house. She taught new people the skills in the L'Arche workshop as they learned to weave, sculpt, garden or do carpentry. Flora modelled the virtues of friendship and hospitality for members of the community, she was perhaps the one most at home in this way of life.

Several years ago, a team of professionals visited this L'Arche house and, in reviewing Flora's development, found her to be well-suited for more "independ-

ent" living. She had acquired the practical skills necessary for living on her own. The professionals recommended that Flora have her own apartment and find work outside the L'Arche workshop. They claimed that a "normal job environment" would expose her to non-handicapped people and provide her a greater income and more independence.

Flora now lives alone in a large apartment complex. Her neighbors never visit, though she is seen periodically by a social worker. She pays all her own bills,

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buys her own groceries, prepares and eats her meals alone, takes public transportation to and from her job as any other independent working adult would do. Flora is now markedly "independent."

My purpose in relating this story is to challenge some of the key assumptions buried in the now fashionable ideal of "independence" for handicapped people. If what we currently mean by "independent living" is the isolation which characterizes Flora's new life, and if her "autonomy" is a prized value of Western civilization, then clearly something has gone wrong.

In 1986 the United States Congress passed the "Education of the Handicapped Act" [Public Law 99-457] saying "there is an urgent and substantial need . . . to minimize the likelihood of institutionalization of handicapped individuals and maximize the potential for their independent living in society." This suggests that as a society we are interested in enabling handicapped people to become more independent. Nothing wrong here, especially when we consider

historically how we in Western culture have treated the handicapped, how people with disabilities have been institutionalized so as to keep them dependent on hospital professionals and on the state.

Society often tries to provide "helpful" professional services for newborns, children, and adults who are developmentally delayed, but without explicitly knowing why. To ask this question, of ourselves and especially of our caregivers, is to expose the incoherent and often troubling lack of moral reasoning behind such helpful proposals.

Yet this legislation assumes there is some moral consensus about the goodness of being an independent individual when, in fact, there may not be. For instance, if independence is seen as *the* overarching good, then any handicap will be viewed as an obstacle to maximum autonomy; every handicap will be labelled as something bad, something wrong, a condition to be overcome or avoided. Hence we have the common practice of amniocentesis and widespread cultural support for abortion of a handicapped fetus. A handicapped fetus, born and grown into adulthood, might never be "independent" of his or her parents and thus be viewed as an albatross, an unbearable burden on the family and on tax-paying citizens. Can we imagine a community in which independence is not *the* good, not a predominant goal, where a child's handicap would not be experienced as a burden? What kind of people do we need to be to experience a handicapped child as a gift?

The Amish are a good example of the kind of community whose life together stands in sharp contrast to the wider culture in the United States. The Amish believe that a baby is a gift from God to the entire community, not merely an extension of the parents. Thus **all** children, handicapped or not, are celebrated as joys. There is no recorded incident of an Amish family institutionalizing a family member for any reason, whether that be an elderly person no longer able to be in-

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dependent or a handicapped child unable to become autonomous. Every aspect of community life highlights the central role of the family and the community itself. By contrast to public schools which train children to function as individuals who must search for some community in which to live, Amish culture sustains a common life in which church, home, and school cooperatively support children so they will be able to

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find their place in the community. (Hostetler 1971) For this reason, brothers and sisters will often be in the same classroom even if they are years apart. This enables the older ones to help the younger ones learn well. Older siblings are expected to model the virtues of Christian life for their younger siblings. Even playtime is an opportunity for group play, rather than individual play. Youngsters are encouraged to include shy or lonely children and not shun those who might be different.

Regarding the presence of developmentally delayed children in the schools, the Amish believe that because an individual's talents are God-given, no one should be praised for being a quick learner nor condemned for being a slow learner. Teachers and children accept intellectual differences without saying that cognitive ability makes one a better person. Intellectual differences are neither concealed nor minimized, and although slow learning makes for added difficulties, it is nothing to be ashamed of. (Hostetler 1971) The Amish ideal of raising virtuous rather than independent children is also expressed in most of the Native American tribes. An old Hopi saying sums it up: "One need not be ashamed of being poor or being slow, so long as you are good to others."

As we learn from our friend Flora, "independence" is not a benign value. We should be prepared to challenge the exalted status of "autonomy" when it encourages the transitory, uprooted, isolated, self-sufficient, competitive character of our culture. These are hallmarks of modern Western life, yet there are Jews, Christians, Hindus, Native Americans, and others who believe this striving for independence and in-

dividualism needs to be confronted.

Assumptions About Professionals

Our society makes certain assumptions about professionals who work with developmentally delayed people. By and large, most of us believe that (1) professionals are **objective** in recommending services; (2) professionals know best what services to recommend; (3) professionals are the best advocates for people with disabilities. Each assumption has moral implications.

Alongside each assumption about professionals exists a converse assumption about parents: (1) parents will be **subjective** in caring for their children, allowing the details of their backgrounds to bias decision making; (2) parents are unaware of available professional services and are naive about how to choose well among existing services; (3) parents often hesitate in seeking help for their children because they are skeptical about professional intervention and are not sufficiently aggressive advocates for their handicapped children.

In her well-documented book *Families Against Society*, Rosalyn Darling offers story after story of parents challenging the biased attitudes of professionals. Darling's research indicates that many parents believe that the medical care their children receive is not only inadequate but also dehumanizing. Physicians too often advise parents to institutionalize their handicapped child or criticize parents who decide to keep their child at home. Parents report being made to feel unwelcome in the doctor's office, as though their child were an embarrassment. Darling's interviews illustrate how almost all doctors dislike caring for children who are handicapped or retarded. There seems to be a striking discord between the attitudes of pediatricians and the values of parents of handicapped children.

Because no human being can be free from his or her own fears and loves, social background, religious heritage or cultural outlook, we cannot assume that professionals will offer us "objective" counsel. Professionals are no less or more "objective" in their outlook on life than are parents. And this is not a bad thing. Accordingly, to present only negative accounts of physicians is to distort the picture. For the total picture also includes physicians who are compassionate, understanding, tender, and self-sacrificing. The point is not that all professionals are biased for or against anyone or anything, it's just that no human being can ever act in a value-free way, whatever one's profession or position. Everyone caring for a handicapped

child approaches decision making from a "subjective" point of view. Realizing this can encourage parents not to be shy about their own lives and values.

From this perspective, we can suggest that many voices are relevant to decision making for handicapped children. Perhaps the key here is not to rely exclusively on any single opinion, no matter how "professional." For instance, should representatives from the family's religious community be involved? Wouldn't it be appropriate for a rabbi, priest or pastor to offer assistance for the child's development? After all, isn't the child's moral development worthy of attention? And what about handicapped people who might speak personally about particular treatments or therapies?

Who assesses "family strengths" and on what grounds? Some professionals argue that poverty is a weakness, others do not. Some might claim that a traditional Navajo family life — especially if examined through the eyes of a white, middle-class, "enlightened," professional perspective — could not strengthen a child, but instead block his or her development into an independent individual. Interestingly, "individual" doesn't even exist as a word in Navajo culture; being a member of the tribe is critical to one's identity.

How should we map a child's psychosocial development? Any assessment will inescapably reflect the values of the person doing the evaluation, and different people will "see" the child in discrepant ways. Can you imagine a team of traditional orthodox Catholics evaluating a family of Hasidic Jews?

Who decides what are "appropriate" diagnostic instruments for measuring developmental delays? If cognitive

In Judaism and Christianity, children do not belong to their parents as a piece of property, they are a gift from God to the community of faith.

development is not a central goal in a particular community, as with Amish or Navajo culture, how will a handicapped child be described to his parents, and what kind of services will be recommended? Who can capably determine the needs of child and family? Won't needs vary according to community? That is, different communities will assess the needs of a handicapped child and

arrive at divergent judgments about what is best for him or her. A specific community's understanding of human needs — physical or emotional or social — will not be universally shared with that of other communities.

We must see to it that professional intervention, especially at such an early stage in the child's life and at such a vulnerable time in the family's story, is not a powerful form of professional dominance. We should not assume that professionals will offer us the most objective evaluation of our child or the most objective evaluation of the services our child needs. Likewise, we must be clear about the parents' role and the role of the particular community in which parents and child live.

Is it always true that professionals know best what services to provide, or that they are the best advocates for children with special needs? For example, let's say an occupational therapist sits on the team of evaluators. He or she will presumably be able to help us identify jobs that might one day be open to our child, and to work with him or her over the years to develop appropriate employment skills. Yet if one were to ask about the purpose or meaning or value of our work, one would quickly discover that we have no coherent cultural account for **why** people work. Is it simply to survive, to pay the bills? If so, then many handicapped people could make more money collecting government welfare checks than working at minimum wage (or even less) in a sheltered workshop. Do we work as an expression of our basic need to be creative? Do we work as a service to our fellow human beings, as a good for our society? The point is that simply consulting an occupational specialist doesn't necessarily help us understand why we should work at all, what kind of job is truly suited to the kind of person we are or the kind of community in which we live. It is not a coincidence, for example, that the Amish have occupations related to the land. Agrarian communities are rooted in Amish theology. Nor is it just an idiosyncrasy that some professions are prohibited by some communities. These basic values are philosophically prior to any conversation with a professional therapist.

From time to time we hear about cases where the state initiates legal proceedings to compel parents to provide medical care for their children. The belief is that the state, through its professionals, must coerce parents into providing adequate services. Yet this is not an accurate picture. It is important to

emphasize that most parents have experienced disappointment or frustration in their attempts at finding competent state resources. Handicapped children teach their parents what special services they need; parents turn to the state for these services, often creating them when they do not exist.

A fine example of parental activism is the Association of Retarded Citizens. Local chapters of the A.R.C. are often responsible for special education classes in public schools, they initiate respite care programs for families and sponsor early childhood day care. The A.R.C. organized the first residential homes for previously institutionalized handicapped adults. Local chapters (all volunteer, by the way) have created and funded a position for someone who places handicapped people in community jobs. Significantly, the A.R.C. seeks to raise the awareness of churches and synagogues to the spiritual needs of mentally retard-

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ed people. Parents and other volunteers are the chief lobbyists in Congress and state legislatures. They have created summer camps, dance and art classes, plus the Special Olympics. History tells us that were it not for parents and families there would likely be little or no professional involvement with handicapped people at all. The family and the community in which the child is raised must remain central to the process of evaluating and providing professional services.

One mother observed that "our society is not geared for the retarded. We used to send them all away and now we don't know what to do with them" (Darling 1979) In an inhospitable society, parents realize that they must take responsibility for establishing services appropriate for their children. Parents learn from their handicapped child what it means to be a parent. Parents challenge sentimental attitudes by demanding that their children be treated with respect. Interestingly, it is often the case that lower-income and less-educated parents become the most effective advocates for their children, as they have

the most experience in dealing with unresponsive bureaucracies. (Hauerwas 1986)

Professionals frequently assert god-like expertise when it comes to administering services. Common to a hospital setting, for instance, is the attitude of the nursing staff. "Pediatric nurses often become very protective of their patients. They begin to feel and act as if no one, including the child's mother, can care for the child as well as they can; in fact, the others interfere with proper care." (Bluebond-Langner 1978)

Yet as "unprofessional" as it sounds, we must learn to trust parents' judgment. It is not easy for parents to learn to trust themselves, especially when a whole team of professionals intervenes at the first weeks of the child's life. The parents have no time in which to experience the child's ways or their own emerging love for the child before a team of strangers imposes directives for "appropriate" care. They have barely welcomed this life as child before the experts have redescribed it as "patient" or "client." It is crucial for professionals to learn to see the child as the parents do. It is morally important for society to see the newborn as the parents do, and later to see this teenager as his parents and siblings and friends do, not as "abnormal" or "deformed" or cognitively impaired or even physically disabled. Rather we must begin to see this one as "Nick" or "Katherine" or "Jean," as child, as gift, as friend, as brother, as carpenter, as fellow human. This language does not come easily to professionals who have a diagnosis ready, so we must listen attentively to parents and friends.

This is one reason why the evaluation team ought to include handicapped adults. Their presence would encourage the experts to be cautious about potentially dehumanizing labels and descriptions. To have a cross-section of professionals is not sufficient. The child's well-being can be best protected if parents, handicapped people, and community folks all have a voice in decision making.

Do We Know What it Means to Parent a Handicapped Child?

There are actually three assumptions in this question: (1) that we know what a handicap is; (2) that we know what a child is; (3) that we know what a parent does. All three claims are moral ones, as we shall see.

To assert that something is a handicap or disability is to make several claims. That some disabilities are disabling for one culture but not for another (for example, a low IQ would never be counted

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as a disability in many cultures), reflects values held by the society which is doing the labeling. In the United States for instance, we hear many professionals refer to a family's economic poverty as a disability for their children. The point may be sharpened when one understands Mother Theresa's claim that our nation is the poorest on earth and that American children suffer from spiritual disability. So, **who** it is doing the labeling is a critical moral question.

For instance, in a culture that emphasizes physical prowess or athletic talent, handicapped children might be made to feel inadequate or incomplete. In a society like ours where physical perfection is a tacit ideal, handicapped children might experience an impoverished sense of self. A disabled youngster will likely find it impossible to be satisfied with his or her body when social messages celebrate vigorous physique and fine-tuned coordination. Indeed, one study suggests that when parents deflect attention away from physical attractiveness or athletic ability, children enjoy better self-esteem and parents can maintain optimistic attitudes toward their child's disability. (Darling 1979)

There is also ample evidence that mental retardation is a social construct. Social pressures and cultural factors make a decisive impact on how we name and understand disability. (Gliedman and Roth 1980) We have a tendency to see handicapped people as permanently disfigured, or to assume that the disability tells us everything significant or interesting about a person. Stanley Hauerwas argues that we need "discriminating forms of judgment that denote those aspects of life and activities where the category of retardation simply is irrelevant." But as Hauerwas notes, we do not have sufficiently precise or flexible ways of seeing, hence "retardation too often becomes a self-fulfilling prophecy that unfortunately is perpetuated by the very theories and people who want to 'help' the retarded." (Hauerwas 1986)

This self-fulfilling aspect of stigma brings us back to a previous point about the roles of parents and professionals. What happens to a child once the label "handicapped" is attached to him or her? From early in life the child understands him or herself as abnormal, as someone who is developmentally delayed or physically disabled. This "looking glass theory" of labeling is important, especially since parents can help the child nurture an affirmative self-concept. There is real danger when professionals label children as handicapped, inferior, marked or separated, since they

will begin to see themselves in that light and act accordingly. The key question is, "How early in their lives do we want this to happen?"

This realization raises the issue of how society expects the family and handicapped child to deal with the stigma. Society holds ambiguous attitudes toward and expectations for the handicapped. "The handicapped are expected to 'adjust' to and 'accept' their handicaps and at the same time to 'deny' them by acting as 'normal' as possible. The handicapped are expected to work, but the physical accommodations at most jobs are not suitable. The mother is told to treat her handicapped child as 'a normal child,' but the child is denied access to normal schools and other facilities. The disabled are thus stigmatized because they are not normal but, at the same time, they are denied the opportunities to be normal by the society which stigmatizes them." (Darling 1979)

Studies of how children are socialized help focus the varying notions of childhood itself. Interestingly, the child's own understanding of childhood is almost always overlooked. Most studies point out that in the United States children are usually defined in terms of what they will become. "Childhood is viewed in terms of its bearing of future activities and status. Adults hold up a pre-existing image to children, and measure them according to that standard" (Bluebond-Langner 1978) In our culture, children are trained and molded for their futures. They are creatures to be prepared for an occupation. In raising their child, parents respond to social expectations and to a hypothetical image of what the child must become if he or she is to live successfully in a changing, unpredictable world.

Contrast this view of the child with that of any particular community and we will see a lack of consensus about what we mean by children. Look, for instance, at the liturgical claims about children expressed in the rituals of infant baptism in Christianity and circumcision in Judaism. Both liturgies claim that the child is a gift, but a gift not to the parents alone. Children do not belong to their parents as a piece of property, they are a gift from God to the community of faith. At the deepest level, children belong to God and are "on loan" to their families and to their covenant communities. These families and communities are therefore responsible for raising the child in such a way that the child will eventually understand and welcome his or her identity as a child of God and fellow member in this community of faith.

Congregational participation in the liturgies of baptism, circumcision, and bar mitzvah indicates that from the community's perspective, **all parents need help in raising their children. Parents were never intended to raise their children alone.** Even though many people no longer practice these rituals, there exist flourishing communities who model faithful witness to this profound theology of the child.

If we believe that parents are the primary care givers — but not the only care givers — we can keep in mind one of the primary goods of society: shared skills and mutual service. Although parents are primarily responsible for the care of their children, no parents are expected to raise their children alone. We will provide good education and health care for each other's children. There are people whose unique skills can tap the giftedness of my children in ways I cannot.

So a critical question arises: "How can the state best enable parents to parent well, not usurping the parents' role or calling, not overpowering the parents with expertise, not replacing the parents' values with its own?" Professionals should envision their task as empowering parents to discover their own gifts for parenting. In this light, professionals can helpfully challenge assumptions parents might have about their own children, especially regarding their children's limitations and capabilities.

Of course there will be occasion for state intervention against parents; every case of child abuse reminds us of this. Let us not presume that just because two people are biologically capable of producing a child that they are able to fulfill the moral task of parenting. But to intervene against parents of handicapped children we must first know what good parenting of the mentally handicapped looks like. It is not clear that we do.

If we discover what good parenting of handicapped children looks like, it is because we have watched handicapped children teaching their parents what this means. As Hauerwas has rightly stated, "... through their children parents of retarded children are trained to be parents in a manner that illuminates what it means morally to be a parent for anyone." For "most of us learn what it means to be a parent from our children. Their needs teach us our responsibilities. . . . For parenting is not a 'natural' role, but involves skills that can be acquired only by learning them from others. . . . The only justification for looking at parents of retarded children is that they are taught their responsibilities

more quickly and more intensely than most of us. They learn from the beginning that our children have a claim on us even though they do not turn out to be what we expected. Normal children, of course, also always turn out to be quite different than we expected, but we are not made so intensely aware of the implications of that fact in those cases" (Hauerwas 1986)

Implicit in this paper is the belief that there is no universal ethic we can rightly apply to help us sort out the problems highlighted. I would argue that there is no such thing as "ethics," especially in the United States. Rather there are Amish ethics, Hopi ethics, Jewish ethics, Black pentecostal ethics, maybe even something that looks like modern American professional ethics. Consequently, decision making for our handicapped neighbors will reflect the unique characteristics of communities across this country. And well it should. Pivotal notions such as "autonomy" or "handicap" or "family" will be interpreted in thousands of different ways by thousands of different communities.

What might stand as a moral binder for us are the lives of the parents. "I think what we must do is let the witness of such parents guide our way, as they stand as a beacon to remind us what it means to be a parent no matter what our child may be like" (Hauerwas 1986) In letting these faithful parents stand as witnesses for us, we must surely learn what it means to be human.

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Kaleidoscope: 10 Years

A Review Essay by Mary Johnson

it's not the crutches we decry it's the need to move forward

Nikki Giovanni

Kaleidoscope, which calls itself an "international magazine of literature, fine arts, and disability" is celebrating its tenth anniversary. The fact that a literary magazine focusing on the disability experience has been publishing continuously for ten years should remind us that the experience of disability is not a barrier to creativity. Indeed, much of our art and literature has been born in the disability experience itself.

Why *Kaleidoscope*? Why 1980? In the first pages of this "look back" issue, we meet staff members who reminisce about the magazine's origins and its growth; they comment on mundane problems such as funding, staff roles, and office space. Yet I was looking for the answer to a more basic question: Why a literary magazine with disability as a theme?

In retrospect it seems that 1980 was a pivotal year in the disability movement, though few of us may have recognized it at the time. *Kaleidoscope* published its first issue. The Disability Rights Education and Defense Fund was founded. More than any other group nationwide, DREDF has championed disability rights legal action. DREDF staff successfully advocated Congressional passage of the 1990 "Americans with Disabilities Act," and in the early 1980s they organized the nationwide lobbying effort that saved the rules implementing Section 504 of the "Rehabilitation Act" and the "Education of All Handicapped Children Act." And in 1980 *The Disability Rag* published its first issue.

Now all three of us have reached the decade point. For *Kaleidoscope*, the passage of time signals a steady growth in literary work that focuses on the experience of disability as a valid springboard for creativity, rather than as mere

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metaphor for something tragic, which is how disability has typically been treated.

In his essay "En-Abled Poetry," Joseph L. Baird discusses the change that has occurred:

Suffused as the subject of physical impairment has become (certainly in Western culture) with emotions of supersentimentality, self-pity, and sympathy, it is scarcely to be wondered at that such a theme has been branded as *verboden* by the canons of good taste. Yet one cannot help wondering whether this attitude does not speak to some deficiency in our own sensibilities. For the theme, in and of itself, is no less 'poetic' than the other frailties of the human condition...

Has the disability movement given us permission to write about disability "as though it mattered?" I can only guess. But, as Baird notes,

Almost totally unknown to the general public, a rather substantial body of poetry devoted to this theme has been quietly growing up over the past few years. Published in local anthologies, daily newspapers or magazines... these poems have gone largely unremarked. And yet in their simple, sparse delineation of tangled, complex feelings, and their penetrating glance at humanity from a startling, oblique angle, they have earned the attention of a far wider audience.

Although he doesn't mention it, Baird introduced a wider audience to this poetry in his anthology (co-edited with Deborah S. Workman), *Toward Solomon's Mountain: The Experience of Disability in Poetry* (Temple University Press, 1986), which showed that an "aesthetics of disability" is indeed emerging. This creative outburst, not only in poetry but also in fiction, theater, and dance, has stimulated *Kaleidoscope* and kept it publishing for ten years.

Kaleidoscope has published some of the finest writing born of the experience of disability. Poetry, fiction, and criticism have all been published in its pages, as have profiles of visual artists, musicians, and actors.

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