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Disincentives to Independent Living

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**Abstract:** Incentives motivate and reward people for certain behaviors. Disincentives, obviously, deter and negatively reinforce or punish people for certain behaviors. Our social structure is replete with both incentives and disincentives to shape and maintain those behaviors that are valued. Many incentives and disincentives are covert, some are overt, but subtle, and others are clearly communicated. These incentives and disincentives are both psychosocial (manifested in attitudes and social behaviors) and established elements of public policy (manifested in laws and judicial decisions). The disabled population in this country has experienced in the Independent Living Movement a new awareness of these incentives and disincentives. This awareness has focused primarily on the disincentives, with growing concern for the social and economic consequences associated with them. Irving K. Zola suggests in this paper that some of the basic disincentives come from the rehabilitation world itself — the one group that should be most sensitive to what will act as an incentive or a disincentive. The “rehabilitation world” is generally viewed from a global perspective without reference to specific agencies or organizations and, thus, speaks to us all. This paper was the basis for Dr. Zola’s address in the closing session of the National Conference on Independent Living, “. . . With Independence and Justice for All,” in Kansas City, Missouri, November 11—13, 1981. The presentation presented both a personal and professional perspective and struck a responsive chord with the conference participants. At the time of this publication, Irving Kenneth Zola was a professor and Chair of the Department of Sociology, Brandeis University, Waltham, Massachusetts, and affiliated with the Boston Self-Help Center, Brookline, Massachusetts.

*Editor’s Note:*

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## **Introduction**

In recent years we have heard a great deal about disincentives (Berkowitz, 1978). This has called attention to features in our rehabilitation approach that work to the disadvantage of our clients. It is an important move both politically and socially. It shifts significantly our analysis onto the very system that is supposed to serve that client. Historically such a shift follows a pattern. In the late 1950s and early 1960s there was a similar refocusing in the study of a wide range of social problems (Becker, 1963, 1964; Schur, 1965). Then, too, questions were raised about the role of treatment systems in maintaining, if not creating, the very problems they were supposed to solve. It is, at the very least, “a tribute” to the strength of the medical model that it has taken nearly two decades for this critical approach to filter first into the field of medicine (Illich, 1976; Illich, Zola, McKnight, Caplan, & Shaiken, 1977) and then into rehabilitation (DeJong, 1979).

The resistance to such refocusing goes deep. The first attempts to assure physical accessibility to those with handicaps are particularly illustrative. Though financial issues were often paramount in the retrofit of existing facilities, it became clear that where new buildings were concerned, financial and architectural issues were but a smokescreen. I remember attending an architectural class where a student objected to the ramping of a facility on aesthetic grounds. When a consumer-participant in the class objected, the student argued that this was a matter better left to experts. So, too, have I far too often heard consumers’ objections to their treatment brushed aside as being a “technical” problem and, as such, better left to the technical experts.

In the rest of this paper I want to trace out the implications and thus the disincentives that come about when we neglect the consumers’ input into “technical problems.”

### **Independence — Whose View?**

Independence and self-reliance are very strongly held American values. American dependence on foreign energy sources need only be mentioned and the public rises in indignation. The striving for independence is a similar hallmark of the rehabilitation literature. But as unreal as complete independence is in the field of energy, so, too, it is in the life of many with a disability. The key seems to be who is defining what is independence.

In my personal life space, the issue has most clearly surfaced in regard to wheelchair use. Most people with mobility problems have had to face the increased physical difficulty in doing things which once were easy. We have had to overcome much reluctance, fear, and even pain to use our muscles while our arms, legs, and even heads rebelled. And once we could reach certain physical goals — take those steps, climb those stairs, scale that hill — we were told explicitly that we must always do them in order to maintain our strength and independence.

In my own case, I was always told to push myself to the maximum of my physical capability. Yet I was never given any advice as to what to do when my capability had reached its limits. For me this meant traveling just like everyone else. I would park my car where they parked and walk the full distance to wherever it was that I wanted to go—even in winter on icy sidewalks.

No matter that it took me five times as long to get there or that I slipped along the way, or that I arrived at my destination exhausted. The important thing was that I got there under my own steam — physically independent and mainstreamed. But the price I paid was a high one. After awhile, fewer and fewer people wished to walk at my pace. Thus, either through my embarrassment or theirs, I eventually went earlier or alone, or not at all.

In my professional life I repeated this sequence. Arriving at Brandeis with my freshly minted Ph.D., I was greeted by a colleague who gushed about my new office. “It has a beautiful view,” he said, pointing to the third floor window. “Can you make it up there all right?” “Of course,” I nearly shouted. No matter that it would take me fifteen extra minutes to reach my destination or that some colleagues might have thought me inhospitable when I did not regularly drop in on their offices one or two flights below. Such notions of independence thus meant that until my late thirties I omitted many activities that required considerable walking or where my slowness impeded the progress. Specifically, I stopped going on tours, visiting museums, attending large public events, and going with colleagues for a quick lunch or coffee break. I occasionally mentioned this to my varying orthopedists and prosthetists. They, in turn, only shook their heads in sad acknowledgement. None of them ever suggested that I use a wheelchair! This only a change in consciousness permitted. And then very reluctantly and only in the last eight years! In fact, it is only within the last four years that I have permitted myself the luxury of regularly using wheelchairs in airports.

My point is that in living in accord with someone else’s definition of physical independence, I for far too long, contributed to the demise of my own social and psychological independence.

The dilemma becomes even clearer with people who only use wheelchairs, particularly those who are forced to use physical means to propel themselves when electronic means are unavailable. I would argue that there are few physical circumstances of which I am aware where the increased physical independence is worth the decreased social and psychological independence. In the rare situation where the physical exercise is essential, I am sure other forms can be created. And where, in the rarer circumstances, a substitute cannot be created, why then not have at least two wheelchairs — one electric and one hand — propelled?

As you can see, I’m concerned with whose values define “independence.” In my more cynical moments, it seems a matter of whom we are dependent on. There seems to be a great fuss about paying for our dependence on personal care attendants, about letting the client control the money, and about the fact that fees may range from \$3 to \$10. But

there seems little argument about our costly dependence on kidney dialysis machines. Could this, I occasionally ask myself, be in any way related to the fact that such dialysis treatments are medically dominated, technologically fascinating and profit-making? Efforts to make us independent of this are greatly resisted. Thus, attempts at self- and home- dialysis seem to vary more by geographic location than physical condition, ranging from under 15% in the Northeast to over 50% in the Northwest (Kolata, 1980a, 1980b).

The Independent Living Movement crystallizes very well with this issue. Its very philosophy proclaims a new notion of independence. Independence, we claim, is not measured by the mundane physical tasks we can do but by the personal and economic decisions we can make. It is not the quantity of tasks we can perform without assistance but the quality of life we can live with help (DeJong, 1979). To retain the old physicalist criteria of independence can only ironically contribute to the very isolation and dependence we clearly seek to avoid.

### **Assessment — A Question of Premature Closure**

Sometimes operating assumptions are not so visible as in ideas about independence. Sometimes they are buried in more pragmatic matters such as the way rehabilitation programs assess an individual's physical and mental capabilities. That such assessments may be unduly influenced by historical and cultural considerations was illustrated to me by an experience I had when living at Het Dorp (Zola, 1982). If you are unfamiliar with this place, let it suffice to say it is a village in the Netherlands, created specifically to house people with severe physical involvements. People lived there because there were no community alternatives and because no further rehabilitation was possible.

While the village did have medical services, there was no formal rehabilitation program. And yet, during my stay a few people "improved" sufficiently to leave the village. While some critics have attributed this to a faulty selection policy, I do not think it was so simple. For many residents, uninhibited by external standards and timetables, were simply able to experiment with new ways of doing things with no cost to themselves. They were able to fail — and when they did, they would try again. And some did until they eventually "succeeded." One implication of this observation is that many programs not only give up too early in the rehabilitation process but also have no systematic way of assessing our long-term progress and capability. In fact, most of us with disabilities are never given the chance to learn about new devices.

Here, again, it is easy to be very concrete. For I am an excellent example — a well-educated, rather informed individual, with good health insurance, interested in prevention, a staff member of several local hospitals, and a friend and colleague of many eminent physicians. It has been thirty years since my polio and twenty-six since my accident — both incidents that left me with considerable rightside weakness. I thus wear a long leg brace, a back support, limp and use a cane. And yet I have never, in the over twenty-five years since my rehabilitation was "completed," been called in by any of my

orthopedists or prosthetists for a check-up or to discuss new ways I could do things or new devices I could use. I do not mean, of course, that I have not seen these people but rather that I only did so when something was awry and then, quite naturally, we all focused on the trouble. Anything new that I do or use today I learn from friends or journals. Now some might argue that that is the American way. I would argue that it is haphazard rehabilitation — a consigning of me and many like me to the “we have done all we could” category. I am not claiming callousness. I am claiming that there exists a system built on certain assumptions that prevents the rehabilitation world from ever really knowing if it has done all it can.

### **Safety — At What Price?**

With such global considerations as a context, I want to examine the effect of similar assumptions on the direct application of rehabilitation technology. An issue of great concern in the design of activities as well as devices for those with handicaps is safety — the protection of the individual from unnecessary harm. While the wish to protect vulnerable people from danger is a worthy goal, it is often achieved at too great a cost. Loring Mandel wrote of this in a play, “Do Not Go Gently Into This Good Night” (Mandel, 1967). Melvyn Douglas portrayed a retired cabinetmaker that, for “his own good”, was placed in a nursing home. His breaking- point occurred when the staff refused to allow him to use the available woodworking machinery because it was too dangerous. He rebelled. He claimed that he had the right as a human being to run the risk of injuring or losing his finger. Since they disagreed, he quit the home. Most of us are not so fortunate. We do not have the power to quit. The authorities will not let us leave. And we have no place to go.

This is seen most dramatically in regard to people with mental handicaps — those labeled “retarded.” The tone was set early in this century:

“. . .self control and independent life are not for mental defectives, either in their own best interests, or in the best interests of the family, the community, and the nation. Common sense forbids it. In the nature of things it cannot be. Mental defectives may be nearly or quite self-supporting; they can never be self-controlling or self-directing except in a childish way, and they can never be the masters of their own fate except at the cost of disaster and ruin to themselves and to others — disaster that affects future generations as well as the present generation, the homes and the nation concerned. Mental defectives are permanent children . . .” (MacMurchy, 1917, p. 89).

It took over sixty years to begin to undo this perspective — to question what in this statement was social fact and what was self-fulfilling prophecy. Though many had speculated about what over-protection might do to such children (Levy, 1943), it was not until the early 70s that someone gave empirical truth to this fear.

In a study of mildly retarded children, the investigators reported that the more over-protective and controlling the mother was, the more likely was the child to

oftentimes intellectually have a decrease in I.Q. score and physically to experience poorer muscle coordination (Sharlin & Polansky, 1972). In short, many became “permanent children” when they need not have.

There is a body of psychological literature that claims that risk-taking is essential to the growth and development of all individuals (Viscott, 1977). Robert Perske summed it up best when he concluded:

“The world in which we live is not always safe, secure and predictable. It does not always say ‘please’ or ‘excuse me.’ Everyday there is a possibility of being thrown up against a situation where we may have to risk everything, even our lives. This is the REAL world. We must work to develop every human resource within us in order to prepare for these days. To deny any retarded person his fair share of risk experiences is to further cripple him for healthy living.” (Perske, 1972, p. 26).

I spent a day recently with a paraplegic who races auto cars and sometime before that with a quadriplegic who was learning how to ski. Both of these are activities I would not have engaged in BEFORE I got polio! Without trying for a moment to denigrate the achievement and courage involved in their doing this, what else I think they are doing is putting some risk back into their lives where so much has been denied them. Hoping there are no police safety officials reading this paper, I realize my risk defiance comes from a continual neglect of seat belts and an almost congenital inability to keep to the 55-mile-per-hour speed limit. Given that I travel a lot, I think I am on the way to collecting a speeding ticket in every state.

In short, if society does not let us have normal risk in our lives, many of us will go to extreme lengths to establish it. Thus, to design an environment or device to prevent any kind of risk may go too far. It may not produce a real life but a mirage of one. There is human dignity in risk. There can be dehumanizing indignity in safety.

### **Doing Too Much Too Technically**

Technology can also do too much for those of us with disabilities. The machines technology creates may achieve such completeness that they rob us of our integrity by making us feel useless. There is an example of this in a very different area but it has relevance here. Many years ago when the “convenience food” business was in its most expansive phase, the manufacturers discovered that where cake mixes were concerned, they had gone too far. Early in their marketing all the ingredients were included. All one needed to do was to add water, stir and then bake — the same formula that worked so successfully with soups. But there was customer resistance and sales faltered. They soon realized that cake making contained some important elements that differed from soup preparation. Baking had more intimate connotations — it had associations with being “fresh” and even “special.” As a result, the manufacturers quickly altered their strategy. They not only instructed the customer to add fresh eggs but on the sides of the box they

gave hints on how to improve the recipe — how to make it more special, more one's own.

I believe a similar phenomenon is occurring with device use. I have noticed that many disabled persons have invented an addition to their appliance or altered its use to suit their purposes. For years I thought this was merely our way of correcting the faults of our prostheses. But now I think something more is at stake. For fifteen years, my own leg brace has not fit properly. No matter what they do, there seems to be one place where within twenty-four hours a pressure sore will be produced. It is, however, a problem that I have solved by creating a special patch that I place over the spot every day. It is clear I have a certain pride in solving something the professionals could not. But I have also done something else. I have made the brace more a part of me because I have given it my own unique stamp. Now again, I am not arguing that the rehabilitation world should stop inventing devices that we need, particularly when we ask for them. But, rather, that whatever the device, it need not do everything. It may even be worthwhile to encourage us to create things that not only serve us better but make it more our own.

There are other even more subtle ways in which the use of technology has gone and is going too far — where our very integrity is at stake. There is very little understanding of what happens when bodily parts and functions are replaced by equipment. It is not an unmixed blessing. It has been found in regard to transplants and skin grafts that the physiological body rejects parts that it feels are alien. So, too, the psychosocial person rejects parts that he or she feels are alien. No one who thinks of himself as independent wants to use even a cane or crutches. And when he does, he often tries to avoid it in public or simply gets angry, as Barry Goldwater did in his 1980 speech before the Republican National Convention. The problems escalate the closer the appliance gets to the human body. Thus it is not at all clear what it means to have as part of one's daily routine the putting on of braces and the strapping on of prosthetic limbs. The adjustment may become more serious — if not psychosis producing — when we become internally attached and thus dependent on machines, from the insertion of pacemakers to the attachment of the kidney dialysis machine.

A warning note on this issue was sounded nearly thirty years ago when Francis MacGregor studied the effects of plastic surgery on people with major facial disfigurements. Unprepared for what the new "me" would like, there was, instead of relief and gratitude, profound feelings of distrust, anger, depression and even suicide (MacGregor, 1951). I am not, of course, arguing for the elimination of all such mechanical aids but merely that those who use them may neither be as proud nor as grateful as the inventors think they should be. For these appliances alter a sense of self so profoundly as to make the now livable life not worth living.

There may be a similar problem in the over-technicalization of "care" such as in the invention of robots or the training of chimpanzees to service, dress and feed quadriplegics. While it might well be cute when one's favorite pet brings in the newspaper or, in rare instances, one's slippers, it is less cute when these involve more intimate tasks. I realize that part of the appeal of machines and animals is because of the

intimacy, which it may be perceived easier to share. But there may be a long-term loss of this short-term gain. I did not accidentally use the term “care” when I introduced this thought. According to Webster’s dictionary “care” involves:

“painstaking or watchful attention; regard coming from desire or esteem; a person that is an object of attention, anxiety or solicitude.”

My point is a simple one — that care, as in the terms “medical care” or “personal care” is not merely a technical task. On the contrary, it involves quite personal aspects. To thus objectify this care into a technical service, to replace the human element with a mechanical or animal one, can only lead to the further objectification of the individual receiving that service. Moreover, when the technical side of care becomes so prominent that it becomes the same as care itself, then we have a situation ripe for ethical tragedy. In the fall of 1981, three Boston physicians were convicted of rape. While out on appeal, one of the doctors got a job in another state. He was able to do so on the basis of the recommendations of other physicians, including superiors, who later claimed that these other matters (i.e., the rapes he had committed) did not affect his practice or good technical medicine (Diamont, 1981)!

Of course, much of the traditional caregiving has also produced problems. Any time that it is patronizing or infantilizing, it cannot be a good thing. But as bad as such qualities are, they are at least human ones. They reinforce the humanness of the individuals involved. To be handled by a machine or animal, where once I was handled by a person, can only be invalidating of me as a person.

### **In Conclusion**

My conclusions are straightforward. We must expand the notion of independence from physical achievements to sociopsychological decision-making. Independent living must include not only the quantity of physical tasks we can do but the quality of life we can lead. Our notion of human integrity must take account of the notion of taking risks. Rehabilitation personnel must change their model of service from doing something to someone to planning and creating services with someone. In short, unless the rehabilitation world frees itself from some of its culture-bound and time-limited standards and philosophy, we may one day find ourselves in the position of Walt Kelly’s Pogo who once exclaimed in despair, “We have met the enemy and he is us.”

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