

# **Aging and Self-Determination**

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**Immersion: Learning about Self-Determination**

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## I. Introduction

Last week I was in the company of three great system reform lawyers---Morris Dees, head trial lawyer for the Southern Poverty Law Center, Steve Gold, counsel for Disabled in Action and Adapt, and Michael Churchill, Executive Director of the Public Interest Law Center of Philadelphia. They have been at the forefront of the great advances in justice of the last 30 years: changes that made effective the civil rights legislation for people of color, changes that virtually eliminated institutionalization of people with developmental disabilities, changes that have opened up transportation, housing, streets and sidewalks, and employment opportunities for people with disabilities of all types. They are among the great warriors for civil justice.

They shared a common guiding belief: above all, focus on the big issue, the big idea. Don't lose sight of the fundamental injustice we seek to overturn, or the nature of the fundamental rights we seek to vindicate.

Don't be deterred by patchwork fixup solutions or arguments that real justice is impossible to attain, or that remedies will be too expensive, or just can't be done. Those are the arguments that lead to the fictions of "separate but equal" schools, fixed up institutions for people with mental retardation or mental illness, or loading dock entrances for people using wheelchairs.

And those are the arguments and obstacles to changing the culture of care for the chronically ill and chronically disabled elderly of America. It is sum of their vision, their message, that I want to bring here today.

Focus on the big issue, the big idea. Don't lose sight of the fundamental injustice we seek to overturn, or the nature of the fundamental rights we seek to vindicate.

## II. The Big idea: The Right to Flourish

Too many of America's seriously chronically ill and chronically disabled are victims of beliefs and public and private policies which consign them to life in long term care institutions---almost two million elderly people with disabilities will go to bed tonight in America's long term care facilities. These especially are among those our society regards as different.

Our society continues to regard people who are different whether by virtue of color, race, gender, old age or young age, physical disability or cognitive disability as somehow less than whole, less worthy, less deserving of respect, less capable, and in constant need of protection and paternalistic assistance to manage their daily lives.

That those beliefs and policies consign them to long term care institutions is unjust. That all people, young, old, black, brown, or any color, whether physically or cognitively disabled, whether feeble or not have a right to flourish is the justice we pursue.

Self-determination rejects this dominant cultural assumption, that old age in America, when accompanied by disability or physical or mental decline is pathological loss and diminution of worth.

Instead, we posit that all people who are elderly, are worthy of respect in the full meaning of the word, and have the capacity and right to flourish, irrespective of the nature or degree of disability.

The right to flourish in old age means concretely that individuals who age with disabilities are entitled to profound respect based on the principles of self-determination. These principles need to guide public policy, private insurance, and the interface with services

Vindicating the right to flourish will not be achieved simply because we have articulated the right. Perhaps our most difficult obstacle lies in the beliefs of too many elderly persons. Too many have succumbed to the notion that disability in old age automatically signals an end to participation, an end to contributing to family, neighborhood, church and other association. Too many have bought into the notion that disability in old age means that one is less than a full member of the community, however community may be defined.

This phenomenon is not unique to the aging population. There is a long history of buying into "lessness" by those least favored as members of American society. Women, people of color, the mentally ill, the developmentally disabled have fallen victim to the mystique. The mystique somehow persisted. It survived a great civil war, it endured so-called protective legislation, and it defied the women's suffrage amendment, civil rights acts, Americans with Disabilities Act, and the Older Americans Act.

Too many people of color, some in high places, too many women, too many disabled people and certainly too many elderly---and indeed, those who love and care about them have believed that they *were* inferior, that they could not do what others could, that they were not entitled to respect, and, in fact, do not respect themselves.

Major assaults to overcome the mystique have been made among people of color, women, and young people with cognitive or physical disabilities.

The mystique continues to persist among older people with disabilities.

Perhaps the best description of the phenomenon came in Betty Friedan's *The Feminine Mystique*.

She, and every other advocate for those perceived as different from the dominant majority---non-disabled white men---have posited self-respect as the essential precursor to the application of the ethical principle of Respect for Persons to those regarded as inferior.

Thus, an underlying goal is acceptance and advocacy for the ethical postulate that *each of us, irrespective of age, ability, intelligence, physical prowess, beauty, wealth or poverty* is entitled to respect that grants life with dignity.

Self-determination embodies the principles that underlie this principle of justice.

That's the big idea I want to talk about today. That's the idea we want to promote and translate into cultural and policy change.

### III. Characterizing the Problem, Finding the Numbers, Defining the Goals

What is the nature of the issue? Why does it seem to be so difficult a problem, particularly when there is virtually universal agreement among elderly people that they don't want to be cared for in long term care facilities, they want to stay in the community, they regard nursing homes as a bad end.

1. The most recent statistics on Long Term Care Facilities (LTCFs) indicate that there are 1.8 million LTCF beds available with national utilization at about 84 % or roughly 1.5 million LTCF beds occupied on any given night by Long Term Care Patients (LTCs). This is undoubtedly a conservative estimate which does not include some number of residents of Assisted Living Facilities with physical and/or cognitive disabilities. Nor does it include the elderly folks with DD or mental illness in facilities for people with DD or mental illness.
2. Each person in a long term care facility is so located for a reason. Each encountered a RISK that could not be dealt with by the resources available at the time the RISK was faced.
3. Some number of those in long term care facilities are there for good and sufficient reasons, e.g. complex medical and nursing support, hospice care not possible in the available residential home, rehabilitation and convalescence. Others are there by default, e.g. unavailable appropriate housing, no family or other person to compensate for ADL deficits, no family or person to organize and manage daily life chores (different from ADLs), unavailability of existing low- and high-tech assistive devices and home modifications, and lack of financial capability to correct for the "default".

4. Not all persons with chronic illness or chronic disability are in LTCFs. In fact, there are as many such persons with chronic illness/chronic disability (CICD) living in the community *not* in LTCFs as there are in LTCFs. Furthermore, they are substantially the same in terms of CICD as those in LTCFs. Those in the community have managed, well or poorly, to avoid residential long term care. Some are worse off and some are better off.
5. Those in long term care facilities vary as to projected length of stay, projected course of CICD, reason for being in a facility, nature and degree of disability, "connectedness to family/community", financial status, and other salient characteristics.
6. Succeeding cohorts of the very old (e.g. 85+) are expected to differ from their predecessors in significant ways, i.e. SES characteristics, home ownership, asset accumulation (including inchoate estates), "medical smarts", "connectedness", health and disability status, health coverage through the lifetime, access to quality health care, etc. These differences may be expected to have both positive and negative effects on the demand for residential long term care.
7. A reasonable goal, given that elderly people hate the idea of ending life in a nursing home, and given that there are alternative ways of dealing with the RISKS that lead to use of LTCFs, and given that some placements may be appropriate, is to reduce utilization of nursing home beds by half over the next 10 years while enhancing the quality of life for elderly people with CICD.
8. Achieving the goals, i.e. the necessarily *joint* goals of enhancing the quality of life *and* reduction of LTCF utilization is not a simple linear process of shifting resources from in-patient care to community-based care. It involves shifts in the social psychology which drives our collective view of "successful aging"<sup>1</sup>. It involves our systems of assessing health and disability status and methods of delivering the wide range of compensatory services to CICDs. It involves significant shifts and adoption of insurance notions of protecting against risks in the most humane, decent, ethical and economic ways (i.e. spreading risk over large populations and over time). All of this requires constant focus on the big idea---self determination of, by and for the elderly with disabilities.

Undertaking this requires the following:

- Qualitative and quantitative fact gathering regarding the assertions set out above.
- Planing a deliberate strategy to accelerate the shift in views of "successful aging".
- Exploration of current Long Term Care Insurance provisions including both private and public provisions (Medicare, Medicaid, VA, Merchant Marine) to explore what works, how it works, what is used, not used, etc. in terms of contribution to the goals of enhanced quality of life and bed utilization.

- Manpower implications of the massive shift in LTC methodology implicit in the goals.
- Economic implications and projections of alternative courses of action to achieve the goals.
- Exploration of legal and ethical strategies to achieve the goals.

#### IV. The Right to Flourish---Changing the Culture

That's an ambitious agenda, to say the least. We will be stuck with tinkering and fix-up if we don't recognize the fundamental task---Changing the culture. Difficult? Certainly! Impossible? No!

We already have some wonderful examples of how cultural change about self-determination have played out in practice: the ways and means of hospice care, the best relationships implicit in self-determination programs for the developmentally disabled, the support amenities provided in Independent Living programs for severely physically disabled . . . and in each of these, the dying, the developmentally disabled, the people with severe disabilities have all proceeded with the personal belief in their worth and their capacities to enjoy their unique status as human beings, entitled to respect for themselves, by themselves, and by others.

These examples encourage us, even as we understand we have just begun. But we have a long way to go in extending the principles to the world of old age---the world we all aspire to, and which too many elderly look down upon.

The elderly persist in the endemic belief that old age brings inevitable decline in worth as biological decline imposes limitations on activity and capacity.

The generally held standard of "successful old age" is to stay middle aged forever. What Max Lerner wrote in his 1957 commentary, *America as a Civilization*, is, unhappily still true today: " (Americans) treat the aged like the fag end of what was once good material . . . the nicest thing you can say to an older American is that he doesn't look his age or act his age, as though it were the most damning thing in the world to grow old."

The result for the elderly with disabilities has been to consign them to "colonies", to places where their rights to be kept alive, be given medical care, kept warm, fed, clean and medicated will be vindicated. Indeed, we have financed, built, and maintained some 23,000 such "colonies" with 1.8 million beds which are regulated to assure safety, cleanliness, and life.

This "solution" to biological decline has nothing to do with how the elderly perceive it. The elderly abhor the thought of ending their days in a nursing home. And yet they acquiesce in the "solution". Worse yet, there is little outcry from the traditional self-proclaimed advocates for the elderly to undertake the system reform, the massive change in prejudicial attitudes about the worth of the elderly with

disabilities, and the insistence upon the systematic attack on the Elderly Mystique that holds the aged in its thrall that disability in old age is an unmitigated disaster which precludes joy, enthusiasm, engagement, or significant power to control one's fate.

Self-determination rejects that conventional wisdom.

Self-determination requires virtual elimination of the nursing home solution.

Self determination sets a path and a direction for the exercise of power and control over one's fate in old age, irrespective of disability, gender, color, intellect, or wealth.

Self determination sets out the principles of Freedom, Support, Authority, Control, and Confirmation as the underpinnings of specific targeted programs, populations, and methods.

This is the Big Idea.

Self-determination requires changes in cultural assumptions about the nature and meaning of Old Age in America, system reform in how individuals, communities, states, and the federal establishment address disability in old age, and systematic improvements in the economics of late life for the individual.

Some initiatives have a long-term nature to them, just as initiatives in altering our American world-view of race, gender, and disability among the young do. Others are addressed by specific, legislative or private market changes and/or demonstrations. And still others may take the form of educating and informing those who care for or who determine "programs" how such programs must be changed to conform to ethical principles of Respect for Persons, Justice, and Beneficence/Non-maleficence, and the principles of Self-determination.

The initiatives may take the form of broad-based efforts aimed at changing community values or the neatly prescribed elements of a measurable demonstration of new ways of doing things. Others may require changes in educational curricula. Most will require a range of forums for discussion and exchange. And, in all likelihood, overarching efforts at dissemination and involvement of those who are old, those approaching old age, and those who care about the elderly.

All of these elements require the collection of data which informs the promotion and measurement of self-determination belief and programming. Most difficult of all, is the requirement that we relinquish traditional measures of cost effectiveness and achievement of traditional *legal* objectives (safety, warmth, clothing, paper compliance), while at the same time we begin to find measures of respect, particularly for those who have lost or may never have had the ability to articulate in conventional speech their preferences, desires, likes and dislikes.

There is no priority suggested here other than the articulation of goals and objectives, the dissemination of a point of view, the further development of strategic plans, inquiries and demonstrations, and the initiation of dissemination. Indeed, all *may* proceed simultaneously, or in some pragmatic step by step sequence.

Specifically, we target the following:

- First, a reversal of the current default system which holds that the nursing home, the long term care facility is the default option against which community based service is measured---in cost, feasibility, and outcomes. Rather, the community based option is the default against which the institutional option must be measured. (This opens the debate over whether and how we press forward on the so-called 1115 and Social Security Waivers).
- Massive reduction in the use of long term care facility placement as the solution to disability in old age, and concurrent system reform of public and private arrangements for providing supportive services for the elderly disabled who require such.
- Initiation of demonstrations with the private long term care insurance industry to favor in-home care for chronic illness and disability, place control of service with the person with the disability and/or his family, next best friends, and those who care about him.
- Initiation of analysis and demonstrations of protective services both within and without the judicial system to assess new ways of providing needed protection within the "softer" parameters of self-determination, avoiding excessive intrusion on preference and choice-making, and honoring known likes and dislikes.
- Development of a research agenda which better measures needs, desires, and outcomes of service programs. This requires at the outset an assessment of existing literature bearing on self-determination for the elderly, collection of existing data on disability among the elderly and the programs addressing such, and the framing of research questions which bear on the issue. The range suggested is vast, extending from the projected changes in mortality and morbidity experience of old age, longitudinal studies in health, wealth, attitudes, and other matters, economics of disability in old age, manpower implications, and research into existing and changing ethical standards.
- Development of a dissemination strategy which better enlists the elderly, those who care about them, service providers, and third party payers. This involves identifying existing structures which may or may not be useful, initiating efforts to enlist existing movements whose goals are congruent with self-determination in aging, and development of techniques which include both conventional and internet methodologies.

## V. Conclusions

First, we must recognize that the self-determination movement must include the fastest growing group of people with disabilities in America---the people over 80 who encounter late life disability.

Second, we must be explicit in rejecting the dominant cultural assumption that old age in America, when accompanied by disability or physical or mental decline is pathological loss and diminution of worth.

Third, we posit that all disabled, and particularly the elderly, are worthy of respect in the full meaning of the word, and have the capacity and right to flourish, irrespective of the nature or degree of disability.

The right to flourish in old age means concretely that individuals who age with disabilities be accorded a new found and profound respect based on principles of self-determination: Freedom, Support, Authority, Responsibility, and Confirmation. These principles need to guide public policy and private insurance, create consonance between the two, and support the liberation of older individuals with disabilities within our communities, our homes, our places of worship, culture and play.

These Principles are those which now underlie all self determination programs and approaches. They are operationalized in close personal relationships, private enterprise and commercial behaviors, traditional and non-traditional not-for-profit activities, and public programs.

And finally, reinforced by the successes of self-determination implemented within the developmental disabilities and independent living movement people with disabilities, we reaffirm our conviction about the rightness of self-determination, we recognize the injustice of the institutional response to the needs and desires of older people with disabilities, we now dedicate our attention and energies to the "Big Idea" of Self-determination and Aging.

<sup>1</sup>"Successful aging" is itself a term which suggests that the inability to participate fully in family, neighborhood, community, or other activities represents "failure", i.e. a "blame the victim" orientation. We do not use the terminology of success/failure to describe childhood, adolescence, young adulthood or middle age. Its absurdity becomes apparent if we do---"he really failed childhood, had a so-so adolescence, a moderately successful young adulthood and middle age, but then he really failed old age---and we had so hoped it would be successful."