

A GUIDELINE ON PROTECTING THE HEALTH AND LIVES OF PATIENTS IN HOSPITALS, ESPECIALLY IF THE PATIENT IS A MEMBER OF A SOCIETALLY DEVALUED CLASS, 2nd rev. ed. By WOLF WOLFENBERGER. Training Institute for Human Service Planning, Leadership & Change Agency, Syracuse, NY, 2005.

Reviewed by Norberto Alvarez, M.D.

THIS 100 page monograph started as a 22 page appendix in *The New Genocide of Handicapped and Afflicted People*, written in 1987 by Dr. Wolf Wolfensberger, one of the leading thinkers in the field of mental retardation. Presently Dr. Wolfensberger is Professor Emeritus at Syracuse University (US), School of Education. Much of Dr. Wolfensberger's work, which spans several decades, has been concentrated in the evaluation of the provision of human services to people considered vulnerable or less valued by certain societal standards. His work has been focused on, but not limited to, the protection and enhancement of the social value of people with mental retardation. Dr. Wolfensberger in 1983 formulated the concept of Social Role Valorization (SRV), an analysis of human relationships and human services, the basic premise of which is very simple (Wolfensberger, 1998; Race, 1999; Osburn, 2006). There are roles in society that have positive value while other roles have no value or have negative value. Whoever gets into valued roles will have more access to the good things that society has to offer, for example, respect, dignity, being accepted by the rest of society, and material well being, among others (Wolfensberger, Thomas & Caruso, 1996). Those cast into social roles that have no value or negative value are at a high risk of being subjected to a pattern of negative experiences (for example being perceived as deviant, being rejected, being considered a burden to society, being the object of abuse, and even being 'made dead'), besides not having access to the good things in life.

The introductory chapter defines this monograph as "a set of guidelines that can be given to a prospective hospital patient, and/or to the person's family, friends and allies, especially where the patient is a member of a group or a class that is societally disadvantaged, or generally held in low esteem" (p. 2). Even though the guidelines are based on the above mentioned SRV approach, the reader will not find in this book a detailed description of the theoretical basis of SRV theory. This will be found in other books written by Dr. Wolfensberger, or other professionals associated with his work, that are mentioned in the references at the end of the Guideline.

THIS MONOGRAPH is mostly the practical application of what the analysis of hospital care, under the scrutiny of the SRV principles, teaches regarding the deficits of the care provided, especially to devalued people, and how to avoid or at least to minimize these deficits. However the concepts of SRV, as expected, are present in the different sections of the book. For example in the section about "Enhancing and Monitoring the Quality of Medical/ Nursing Care," one of the issues addressed has to do with "imaging" the "look" of the patient. The reality of imagery is one of the themes of great relevance in understanding and applying SRV. The way people see you affects the way they value you. Improving the appearance (via shaving, grooming, washing, providing good clothing) of the patient makes the patient more valued in the eyes of the attending personnel. "Humanizing" the relationship between care providers and the patient by describing his/her interests, achievements and skills; keeping pictures of the patient when he/she was in good health; seeing that the patient receives get well cards, flowers and the like would result in a positive impression. Such efforts help support hospital patients to be in valued roles.

I STRONGLY AGREE with the statement under the "General Considerations" section that

“The single most effective strategy for protecting the health and well-being of a hospitalized person is to have at the patient’s bedside at all times a competent and vigilant person who is committed to the defense of that patient’s welfare and life” (p. 18). As a Medical Director of an institution for persons with developmental disabilities, I can testify to the importance of having a person at the bedside during the entire length of the hospitalization. The book is also very useful and explicit in the characteristics, training and role of these advocates/protectors. This is an important and very useful contribution. The book provides guidelines that cover from what to do before the patient is admitted to the hospital to how to prepare for the discharge from the hospital and the return of the patient to his/her home. These sections, presented under “Measures to Prepare a Patient for Hospitalization or Visits to an Emergency Service” and especially the guidelines presented as “Suggested Guidelines for Carrying Out the Functions of Advocates/Protectors” are very detailed and are worth reading by those who care for individuals that need hospital care.

It would be too long to comment about each particular section, however it is worth expanding the discussion of some of them. While not against the use of mind drugs or restraints, the section on “Monitoring the Prescription (Mind) Drugging of the Patient” alerts advocates about the premature and inappropriate use of these procedures, a real risk, especially for people with developmental disabilities. The section “Special Considerations When the Patient Appears to be Nearing Death, or is Interpreted as Dying or as Lacking ‘Quality of Life’” addresses issues that have received a lot of attention by Dr. Wolfensberger and his associates (Wolfensberger, 1994; Wolfensberger, 2005). The perception that persons with disabilities have a “quality of life” that is poor to start with, and is much poorer when they are sick, might lead to early implementation of “Do Not Resuscitate” orders that could result in early discontinuance of treatments, which could then

hasten death. For example, the discontinuance of nourishment or liquids which the Guideline presents as “being justifiable in only extremely few cases: (a) when the provision... is itself very harmful, and maybe even hastens death; and (b) when it is intolerably invasive or torturous to the patient” (p. 73). Probably the statement “When in doubt, opt for treatment and life” (p. 75) in this section is a short and concise summary of the philosophy underlining the efforts of SRV advocates in this area.

At the very beginning of the book (p. 3), the author states, and I agree, that “Hospitals are very dangerous places for ill people,” and this dangerousness is one of the main reasons that motivated the writing of the Guideline. However, hospitals are an important component in the provision of health care, and in the “Conclusion” (p. 101), the author makes sure that the reader is not left with “the impression that hospitals are poorly run. In fact, given what hospitals are up against these days, it is an amazing feat of organizational skill that they work at all, and accomplish as much as they do.”

I FOUND these guidelines very useful. They are written in a way that is very simple to understand, there is an order in the presentation, and each section can be read independently. Persons responsible for the care of people that require (frequent) hospitalizations, independently of the presence of developmental disabilities or not, will find these guidelines extremely helpful.

SRV conclusions are scientifically based. However, many of the statements in this book are based on vignettes and single case examples, which I think are good to document and dramatize the points, but usually isolated cases do not make good science. In other instances, studies are mentioned but are not included in the references. Some statements are outdated, for example, it is very unusual these days to have four to twelve persons in a hospital room or to have secret DNR orders. Probably these

are remnants of old editions of the Guideline that will be updated in the future.

In summary this monograph presents good advice that, when followed, will result in improved medical care for people that are devalued under present societal standards. It would be good reading for among others administrators as well as health professionals.

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