

The Medical Safeguards Project: Standing By the Most Vulnerable

submission to the Canadian *Parliamentary Committee on Palliative and Compassionate Care* by Jo Massarelli and Marc Tumeinski of The SRV Implementation Project (www.srvip.org)
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Abstract

We live in a culture that increasingly devalues the lives of vulnerable people, of those impaired in mind or body, whether from birth, by illness or accident, or due to aging. The very structures and institutions of our culture are similarly tainted by such patterns of societal devaluation. Medicine is no exception. Hospitals and health care programs intended to heal are all too often likely to cause harm to societally devalued patients, unintentionally or even with the best of intentions. When a societally devalued patient's life is seen as being of lesser value, contemporary medicine to an increasing extent seeks to end suffering by ending the patient's life. Those most in need are most at risk, paradoxically from those who are supposed to cure the sick.

We can and should respond to this crisis for our vulnerable citizens. The understanding, commitment to and application of time-tested advocacy principles and tactics can improve health care outcomes for individuals, save lives, and potentially contribute to an overall improvement in systemic health care in the long run. The ongoing experience of the *Medical Safeguards Project* over the past 15 years has been that a fairly moderately-funded, regional, independent 'medical safeguarding' program is relevant, effective and viable, and most importantly can make a positive difference in the lives of vulnerable people. Independent clinicians, doctors and nurses, trained and supported in advocacy, can help safeguard quality medical services for devalued people and can save lives. Our expectation is that such a program could be replicated in other locales.

Introduction: Heightened Vulnerability of Hospital Patients

Across North American culture, people with significant physical and/or intellectual impairments are highly vulnerable to being perceived and treated negatively by those around them and by their society.¹ In a culture that so highly values health, strength, intelligence and freedom, those who are sick, weak, impaired or dependent challenge the foundational values of that culture. This is a sad reality of human social life, but what makes it even more devastating is that the pervasive societal devaluation of children and adults with physical and intellectual impairments is apt to degrade even the most noble and well-intentioned of human services. Medicine would certainly fall into this category. As well-trained and highly-principled as medical personnel commonly are, they are not exempt from reflecting the stereotypes and blind spots of the culture in which they live.² Though medical staff are most likely unconscious of such negative treatment, this is in a certain sense not important to the patient who is at risk. Taken to the extreme, the societally devalued person's life may even be shortened by absence of quality medical care or by medical interventions which hasten death. Such heightened vulnerability of societally devalued people plays out particularly in hospitals but even generally in other types of medical care. Rather than resting assured in the healing care of the medical system, societally devalued people often (a) receive a lesser quality of care than typical people and (b) have to be concerned about others taking steps which can shorten their lives prematurely, though it may be

¹ Wolfensberger, Wolf. *A Brief Introduction to Social Role Valorization: A High-order Concept for Addressing the Plight of Societally Devalued People, and for Structuring Human Services*, 3rd (revised) ed. Syracuse, NY: Training Institute for Human Service Planning, Leadership and Change Agency (Syracuse University), 1998 (reprinted 2004).

² Patient characteristics negatively stereotyped by doctors. J. M. Najman, D. Klein and C. Munro. [Social Science & Medicine Volume 16, Issue 20](#), 1982, Pages 1781-1789.

extremely difficult to see these dangers through the cloud of technical-medical-legal jargon and procedures.

Recent studies have shown that all people should be cautious when they enter the hospital for treatment.³ Medical and medication errors, both of which can have life-threatening and health-impairing effects, are pervasive in today's world of increasingly complex hospital medicine. However, when a person is also societally devalued, the risk of harm is multiplied.⁴ Societally devalued people are highly vulnerable to not receiving a typical quality of medical care, despite the good intentions, high principles and intricate quality control systems in place in medicine. We understand that this is not an easy topic to face and that many will deny its reality. Yet our experience witnessing and resisting such trends compels us to share what we have seen and learned, for the sake of vulnerable people, and to call others to join together to stand up on behalf of the vulnerable.

For the past 15 years, the *Medical Safeguards Project*, a state-funded human service project in Massachusetts (US), has striven to address the heightened vulnerability of devalued people in medical settings within a particular geographic locale and population (see Appendices A and B for vignettes about the work of the *Project*). In this written testimony, we will describe (a) the concept of medical safeguarding; (b) who requires medical safeguarding; (c) the structure of the *Medical Safeguards Project*; and (d) recommendations for setting up similar projects in other locales.

³ <http://www8.nationalacademies.org/onpinews/newsitem.aspx?recordid=11623>; <http://www.nap.edu/openbook.php?isbn=0309068371>.

⁴ Societal devaluation describes the negative perception and subsequent negative treatment of certain individuals and groups of people who are seen as representing the opposite of what a culture highly values, e.g., sick people and the value of health; those with intellectual impairment and the value of intelligence; poor people and the value of wealth; physically impaired people and the value of independence; elders and the value of competent youth; etc.

What Drives Medical Safeguarding?

Medical Safeguarding is a concept that must be deeply rooted in positive values. It hinges on the belief in the intrinsic dignity and worth of all people irrespective of impairment, and the understanding that all should have access to the most excellent standards of health care. In many cases, this is not likely to happen for societally devalued individuals with significant impairments **without** strong advocacy and active follow-up and support.

Relevant and effective medical safeguarding requires a conscious mindset which involves:

- appreciating the vulnerability of patients, particularly patients who have an impairment and/or who are societally devalued;
- knowing what can and will go wrong in medical settings;
- having strategies to employ for:
 - * preventing harm from occurring,
 - * mitigating harm that has been done, and
 - * protecting against future harm;
- reflecting on and learning from safeguarding tasks, activities and processes; and
- interpreting medical safeguarding to relevant others.

Who Most Needs Medical Safeguarding?

Who requires medical safeguarding and who can most benefit? All patients and sick people, but particularly those who are also vulnerable due to intellectual impairment. Several signposts help to identify the most vulnerable, at-risk individuals:

- low or marginal social status, i.e., societal devaluation in response to physical and/or intellectual impairment;
- someone that few or no people know very well (e.g., perhaps the person has little or no family contact, few long-term staff who know the person, and so on);
- those who frequently receive medical care from an emergency room or emergency services;
- frequent hospitalizations;
- a chronic medical issue or condition (e.g., diabetes, thyroid disorders, cardiac issues, etc.);
- receiving multiple drugs from one or more prescribing physicians;
- prescribed one or more psychotropic drugs.

Overview of *The Medical Safeguards Project*

The *Medical Safeguards Project* in southeastern Massachusetts (US) has two major components:

- health care enhancement, and
- safeguarding and advocacy

Health Care Enhancement

The health enhancement component is oriented to complementing and assisting, as necessary, primary health care providers in delivering optimal care for service recipients of the Department of Developmental Services who are living in southeastern Massachusetts. In the first few years, *Medical Safeguards Project* staff focused particularly on (a) working to ensure higher quality clinical care for service recipients and (b) identifying good general practitioners in the

community. Over time, another priority focus developed; namely, to get a good handle on the often multiple drugs (including psychotropic) which most patients were prescribed.

Assisting primary care physicians and other health care providers means:

- preparing accurate, complete and up-to-date medical information for a consultation;
- interpreting and explaining the presentation of symptoms, including by providing a past medical history;
- discussing diagnoses and treatment plans;
- offering access to medical specialists;
- assuring medical follow-ups with concerned parties;
- monitoring the results of the treatment plan, as well as being in contact on an as-needed basis with families, agency staff and the primary care providers;
- home visits for assessment and follow-up;
- support and advocacy during hospitalizations;
- development of health-care plans and emergency protocols for people with complex health care needs; and
- training for the person served, family, friends, guardians, and human service staff on specific health issues.

Medical Safeguards Project staff have been able to demonstrate conclusively to other clinicians how fairly typical treatments (e.g., dialysis, chemotherapy, radiation, transplants) can and should become normative for people with significant intellectual impairments. Such demonstrations have been eye-opening for many clinicians and have helped to challenge previously-held

stereotypes. This important lesson can be broadened to include normative access to typical medical treatment for people of **all** types of societally devalued status, e.g., low social status associated with mental disorder, aging or poverty.

Safeguarding and Advocacy

The safeguarding and advocacy component of the *Medical Safeguards Project* focuses on assuring that service recipients of the Department of Developmental Services living in southeastern Massachusetts have prepared and competent family, friends and advocates in their lives, and/or an active and competent guardian who will defend their access to treatment. Our objective is for societally devalued people to receive the same level of excellent care and support as the most socially valued persons in their community. Further advocacy efforts center on:

- ensuring proper supports during any hospitalization (see Appendices C through E);
- training families and residential agency staff on safeguarding-related issues;
- reviewing medications and monitoring for potential problems; and
- insuring that no inappropriate ‘Do Not Resuscitate’ or withholding/withdrawing treatment orders are put into place.

Conclusion: What Can Be Done?

The project described above is a ‘portable’ model that in our estimation can be replicated elsewhere, taking into account relevant local needs and conditions, as well as specific vulnerabilities related to different impairments and devaluing conditions. Given what we know about the heightened vulnerability of societally devalued people within medical contexts, we

believe that this is a widespread problem, not limited to southeastern Massachusetts or the United States. In light of the role of this *Parliamentary Committee on Palliative and Compassionate Care*, we strongly recommend further study of this critical situation, specifically in regards to Canadian society and medical services, and the subsequent creation and support of local independent medical safeguarding projects in different locales and provinces.

To start similar local projects in other locales, we recommend the following preliminary next steps. [Costs for the initial planning stages would be relatively minimal (e.g., meeting space, travel, printing, coordination time, etc.); start-up, operation and evaluation of local safeguarding projects would each require fairly moderate ongoing funding.]

1. In this testimony, we have identified key parties who are interested in and/or have a stake in medical services to vulnerable, societally devalued people (including devalued people themselves, family, friends, advocates, clinicians, policy- and decision-makers). We recommend that representatives from these parties be invited to come together for a multi-day initial meeting in a central location following the release of the Committee's report. The intent of this initial meeting would be to capitalize on the momentum of the Committee's work and to plan next steps together. This process would include discussions with clinical, administrative and other staff from the *Medical Safeguards Project*, to draw from their expertise and experiences.
2. Policies and intentions alone are not enough of a protection; people in clinical and advocacy roles with the right mindset and training are also needed. Part of the work of

this initial meeting would be to plan opportunities for education, training, consciousness-raising and facilitated reflection on the relevant issues, such as the reality of heightened vulnerability, hospital-specific dangers for devalued people, the necessity of relevant and coherent safeguarding principles, etc. The key parties and stakeholders identified above would be the intended audience for these educational opportunities.

In any coordinated safeguards effort, clinical expertise is necessary but not sufficient:

‘safeguarders’ also need to embrace the necessary positive values and to understand the principles of advocacy. Along with the gravity of the vulnerability of societally devalued people, this gap in knowledge speaks to the imperative for education and reflection on the necessity for and practice of medical safeguarding. Based on our long experience with the *Medical Safeguards Project*, our training initiative (www.srvip.org), in collaboration with Canadian partners, is in a good position to help facilitate such training and consciousness-raising (e.g., see Appendices F and G). We already have connections with a number of Canadian stakeholders whom we could turn to in this effort.

3. MPs and other key players will be encouraged to begin local facilitated planning sessions, with an eye toward the creation of independent, local medical safeguarding projects. This would also entail drawing on existing networks and local allies. The *Medical Safeguards Project* in Massachusetts, for example, began looking for staff by tapping into the personal and professional networks of the original project planners.

At this stage, specific efforts at seeking out of start-up and sustaining funding for these local projects will also be necessary.

4. Along with clinical, advocacy and funding development, efforts at self-organization (developing a board, policies, staffing, etc.) for local projects would be necessary.

5. In our experience, the principles of medical safeguarding will be fairly universal while local needs and situations will vary. One of the keys to ongoing relevance and to sustainability is outside evaluation of local projects. This can help to ensure adherence to principles, connectivity among local projects doing similar work, the relevance and effectiveness of project practices, etc. Parliament can play an important role in initiating and sustaining such independent evaluation.

One critical lesson demonstrated by the *Medical Safeguards Project* is how much the project staff have learned over time, gaining greater understanding as they actually engaged in safeguarding, protection and advocacy efforts. This is a deepening process, not a static one. We anticipate that this would be the case elsewhere as well. We therefore encourage those exploring these ideas to take the time to carefully reflect and plan, but also not to be overwhelmed by the potential barriers to implementation. The health and lives of those at risk deserve no less.

Contact

Jo Massarelli and Marc Tumeinski, SRVIP, 74 Elm Street, Worcester, MA 01609 US.
info@srvip.org

Other Resources

- Medical Safeguards Project; <http://medicalsafeguarding.org/>
- SRV Implementation Project; www.srvip.org
- Wolfensberger, Wolf. *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. Training Institute for Human Service Planning, Leadership & Change Agency, Syracuse, NY, 2005.
- Euthanasia Prevention Coalition; <http://www.epcc.ca/>
- Secondhand Smoke blog by Wesley Smith; <http://www.firstthings.com/blogs/secondhandsmoke/>
- Not Dead Yet News and Commentary; <http://notdeadyetnewscommentary.blogspot.com/>

Appendices

Appendix A: Safeguarding Vignette

Owen was a 78-year-old man admitted from a nursing home to a local hospital for treatment of aspiration pneumonia. Once quite active in his town, a hard worker and a Little League baseball coach, Owen had a stroke when he was 75. Unable to swallow or walk, he spoke with some difficulty and had use of his right arm and hand. He had a gastric feeding tube (G-tube).

On the day of his admission to the hospital for pneumonia, Owen's case manager visited him. He was alert, as well as quite hungry and thirsty. Why? Because his G-tube had been clamped, and a decision had been made to withhold further nutrition and hydration—food and water—and not to treat the pneumonia. Plans to transfer him back to the nursing home were in motion, where if nothing changed he would have died a slow death.

The physician contacted Owen's nephew, his legal guardian, describing Owen as a non-verbal bed patient who had frequent aspiration pneumonias from reflux of G-tube feedings. The doctor said that further G-tube feedings would kill him. Owen's nephew sadly agreed that his uncle had "suffered enough" and that "his time had come." Rightly alarmed, the service coordinator contacted a *Medical Safeguards Project* nurse practitioner, who immediately went to the hospital to assess Owen's condition. After speaking with his physician, who stated a refusal to "go against the wishes of family," our nurse practitioner contacted an attorney from the (then) Massachusetts Department of Mental Retardation.

Within three hours, the attorney had obtained a court order for temporary resumption of G-tube feedings as well as treatment of the pneumonia. Treatment was resumed after the *Medical Safeguards Project* nurse practitioner presented the court order to Owen's physician. Subsequent

investigation by the court found that Owen had not been treated for aspiration pneumonia for over a year, and so his active treatment status was reinstated permanently.

The *Medical Safeguards Project* nurse visited Owen the following day, and found him singing one old song after another in a wonderful booming voice. His roommate at the hospital was an elderly man who was dying, surrounded by his family. The family sang along with Owen through their tears. Owen enjoyed two more years of life, beating anyone who dared play cards with him, and singing and enjoying all kinds of music. His nephew would visit, grateful for the happy outcome.

This experience illustrates several safeguarding lessons. Owen was highly vulnerable, due to his medical condition but more significantly to his socially devalued status, as a man who was elderly, physically impaired, and had an intellectual impairment. Owen's condition was treatable, a reality unfortunately covered over with misleading language. Quite upset, the service coordinator knew who to call for help. The nurse practitioner had access to important resources, including a lawyer. The language used by the physician—such as “already suffered enough”—was a red flag to our medical safeguarding staff. Communication between the doctor and family, as too often happens, was carried out over the phone, without personal contact, and without other concerned individuals included in the conversation.

Appendix B: Safeguarding Vignette

Our project staff often encounter reluctance on the part of medical providers to treat people with intellectual impairments. Much of what we do focuses on getting people to see our patients as deserving the same good medical care as those without disabilities.

Christine is a 64 year old woman who lived most of her life at home with her parents. When her parents died in 1996, she moved to live with another family in a supportive setting. She has early Parkinson's disease in addition to an intellectual disability. As her Parkinson's disease progressed, Christine began to have falls. One of these resulted in an ankle fracture. She was hospitalized, and was also found to have pneumonia. The physician contacted her guardian prior to treating either condition, and asked: "Should we treat Christine or let her go?" Christine's guardian, who was also her cousin, was puzzled by the question, and replied: "Of course you should treat, why wouldn't you?" Christine was treated.

Despite good medical care prior to this illness, the hospital ignored other conditions Christine was currently being treated for. Her care became fragmented, and this problem persisted into her convalescence. The worried guardian spoke to a nurse practitioner from the *Medical Safeguards Project* and enlisted her help.

It became clear to the nurse practitioner that oversight, coordination and advocacy were needed. After her hospitalization, Christine went back to live with the same family after several months. She had several life-threatening crises over the next few years. Those crises including conditions that needed vigilant tracking and a keen eye for preventative care. It became obvious over time to the *Medical Safeguards Project's* nurse practitioner that Christine was too medically

vulnerable to remain living with that same family, for a variety of reasons. Christine was helped to move into a more supportive situation where she now receives the care that she needs.

Christine is happy and healthy, enjoying life, and looking forward to the future.

The nurse practitioner from the *Medical Safeguards Project* clarified health problems and treatment measures, coordinated care with medical providers, supplied information during crises, and advocated for treatment and support. At several junctures, she supported the guardian to convince medical providers that aggressive care for Christine was warranted.

Appendix C: Book Review

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 Wolfensberger. 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.

References

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Wolfensberger, W. (1994). Let's hang up "quality of life" as a hopeless term. In Goode, D. (Ed.), *Quality of life for persons with disabilities: International perspectives and issues*. Cambridge, MA: Brookline Books, 285-321.

Wolfensberger, W. (1998). *A brief introduction to Social Role Valorization: A high-order concept for addressing the plight of societally devalued people, and for structuring human*

services (3rd ed.). Syracuse, NY: Training Institute for Human Service Planning, Leadership & Change Agency (Syracuse University).

Wolfensberger, W. (2005). *The new genocide of handicapped and afflicted people* (3rd rev. ed.). Syracuse, NY: Training Institute for Human Service Planning, Leadership & Change Agency (Syracuse University).

Wolfensberger, W., Thomas, S., & Caruso, G. (1996). Some of the universal “good things of life” which the implementation of Social Role Valorization can be expected to make more accessible to devalued people. *SRV/VRS: The International Social Role Valorization Journal/La revue internationale de la Valorisation des rôles sociaux*, 2(2), 12-14.

Norberto Alvarez, M.D. is the medical director for Wrentham Developmental Center in Wrentham, Massachusetts, USA.

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Appendix D: Table of Contents from *A Guideline on Protecting the Health and Lives of Patients in Hospitals, Especially If the Patient Is a Member of a Socially Devalued Class*, 2nd ed.

- The History of this Monograph
- Introduction
- Dangers to Patient Health in Contemporary Hospital Settings
- Special Dangers to Socially Devalued Classes
- Conceptualizing the Functions of Advocates/Protectors
- Measures to Protect People in Hospitals
 - * General Considerations
 - * Measures to Prepare a Patient for Hospitalization or Visits to an Emergency Service
 - * Advantages and Disadvantages of Different Rooms in a Hospital
 - * Suggested Guidelines for Carrying Out the Functions of Advocates/Protectors
 - * Preparing for Hospital Discharge
 - * Measures to Increase the Effectiveness of an Advocate/Protector
 - * The Advantages and Disadvantages of Having Prominent People as Advocates
 - * An Issue of Discretion
 - * Recruiting Sufficient Advocates/Protectors, and Setting Up Shifts and Logistics
- Conclusion
- References

Appendix E

Workshop Description

Protecting the Health & Lives of Hospital Patients Especially Those Who Are Societally Devalued

This workshop is based on the work of Dr. W. Wolfensberger of the Syracuse University Training Institute, as well as the practical experiences of clinicians, family members, and advocates. Dr. Wolfensberger is considered to be one of the most influential thinkers of the century on disability and social devaluation. The workshop explores the unpleasant and paradoxical reality that anyone who is hospitalized is exposed to grave dangers which jeopardize that person's health and safety, sometimes to the point of making the person dead. This is a reality for all ill people in the hospital, including valued citizens, but is especially ominous for people who are members of a socially disadvantaged class, such as the elderly and the impaired. The workshop will offer practical information and examples on necessary guidelines and measures for protecting people in the hospital.

Format: This workshop is presented in lecture style, using overheads, with opportunity for participant questions, comments and general discussion. A panel will present in the afternoon. The panel consists of individuals whose personal life experiences and roles as family members, (former) patients, medical professionals, advocates, and service workers, have direct relevance to the issues.

What participants will learn:

- The general perils of hospitalization for all people.
- Additional perils that threaten devalued people.
- Measures to take to defend the well-being and lives of hospitalized people.
- The reality, causes and wounding impacts of societal devaluation, and related mind-sets.
- Opportunities for additional learning related to this critical issue.

Workshop materials: Each participant will receive the monograph *A Guideline on Protecting the Health & Lives of Patients in Hospitals* as well as valuable handouts.

Who should attend:

- Families who have children, parents or other relatives with medical needs;
- Impaired people and other citizens who are socially disenfranchised, and their families, friends and advocates;
- Human service and medical staff.

Presenters:

- **Joe Osburn, Director of The Safeguards Initiative, Bardstown KY**
Joe Osburn has worked in human services since 1964, in a variety of direct service, administrative and consultative positions, primarily with poor families and families with impaired children. Since 1974, his work has focused particularly on the dissemination and application of normalization/Social Role Valorization (SRV) as a major safeguard in the lives of socially vulnerable people. He directs the Safeguards Initiative, a non-profit SRV-based project established in 1991. His main activities include planning and conducting SRV and related training; coordinating and leading comprehensive in-depth evaluations of service quality of human service programs, agencies, and service systems; writing; and other related SRV-based projects. He regularly provides support to a few small communal organizations that practice hospitality, life-sharing or other forms of solidarity with socially vulnerable families and individuals.
- **Jo Massarelli, Director of the SRV Implementation Project, Worcester MA**
Jo Massarelli is Director of the SRV Implementation Project based in Massachusetts (USA). She divides her time between teaching Social Role Valorization theory, PASSING workshops and related topics; and working to effect positive change for individuals with impairments and elders. Ms. Massarelli is a consultant to the Medical Safeguards Project, an effort of physicians and nurses who seek to protect the lives of impaired people in medical settings. She has a particular interest in advocacy in hospitals. She and her colleagues teach workshops on defending vulnerable people in hospitals and on medical decision-making. She and her husband Marc Tumeinski are members of a community responding to the needs of homeless people in downtown Worcester, Massachusetts, where they live.

**To Schedule This Workshop
Or For More Information,
Please Contact:**

Jo Massarelli at *The SRV Implementation Project*
74 Elm Street
Worcester, MA 01609 USA
508 752 3670
jo@srvip.org
www.srvip.org

This workshop could save a life or limb!

Appendix F: SRV Implementation Project workshop list

- The Human Service Recipient: Understanding & Addressing Vulnerability
 - BASIC level workshop: Insight Into The Lives Of People With Impairments (half day)
 - INTERMEDIATE level workshop: Understanding The Societal Context: What People With Impairments Are Up Against (one day)
 - LEADERSHIP level workshop: Providing Relevant & Effective Service To People With Impairments: An Introduction To Social Role Valorization (SRV) (four day)
 - PRACTICUM experience: Facilitated Visit & Analysis Of Two Human Service Programs: Application Of SRV Through The PASSING Tool (prerequisite -- SRV workshop) (five and 1/2 days)

- Protecting The Health & Lives Of Hospital Patients, Especially Those Who Are Devalued (one day)

PART II: Crafting The Protective Mindset for Medical Decision-Makers (one day)

- Medical Decision Making (one day)

- In Sickness & In Health: The Service Worker's Role (one day)

- Tube-feeding At Thirty-thousand Feet: De-mystifying Assisted Nutrition/Hydration & Other Life-Enhancing Decisions (half day)

- The Tension Between Personal Autonomy & Community Living: An Examination Of The Rights Issue (one day)

- Longing & Belonging: Understanding Relationship Needs (three-part series)

- Structuring Positive Personal Social Integration & Valued Social Participation (one day)

- Getting To Know You: Building Identification With A Person With Impairments (half day)

- The War On The Poor: Exploring The Link Between Poverty & Vulnerability (half day)

- The Price Of Economic Inequality: How Poverty Endangers The Health Of Poor People (half day)

- The Spend-Down Syndrome: The Creation of Poverty & Its Negative Impact On The Lives Of Human Service Recipients (half day)

- The Importance Of People With Impairments Having Valued Roles In Society (half day)

- Crafting Valued Roles For One Person (half day)
- On Being A Neighbor: Supporting The Valued Role Of Neighbor (half day)
- On Being A Worker: Supporting The Valued Role Of Worker (half day)
- On Being A Housemate: Supporting The Valued Role Of Housemate (half day)
- Problem Solving From A Social Role Valorization Perspective (one day)
- Idealizing Home In Residential Service (half day)
- Strangers in the House: The Dilemma of Living with In-Home Services (one day)
- Issues Of Power & Control That Lead To Violence In Human Services (half OR one day)
- Exploring Fundamental Issues Associated With Human Service Restraint Use (one day)
- Embracing a Personalist Response within Impersonal Service and Social Structure (half day)
- Called To Serve: Being In Service To Another Person (one day or three-part series)
- The Human Service Worker As Social Justice Activist (half day)
- Frailty In Old Age: Understanding Vulnerability (one day)
- Recognizing & Countering Stereotypes About People With Impairments (one day)
- Writing to Learn and Learning to Write within a Human Service Context (one day)
- Getting it Right: Improving Decision-Making Processes in Nursing Services to People with Impairments (one day)

Appendix G: Description of ‘Life Threatening Public Policy’ series facilitated by *The SRV Implementation Project*

Public policy that threatens the lives of people with disabilities is not a new or even a modern concept. However, the *legitimization* of policies and methods that end up killing people in today’s world is unprecedented. We hope that our series will generate a nucleus of people who will be able to recognize public policy which threatens the lives of people with disabilities and who will be prepared to challenge such policy.

The series will heighten understanding of the vulnerability of people with disabilities to life threatening public policy and will invite participants to respond to this crisis. This series is intended to help identify and promote values and ideas that are crucial to the overall well-being of people with disabilities, challenge values that pose a threat to the well-being of people with disabilities, and provide thoughtful examination of matters of value. Series topics include:

- A Lesson From History: The German Euthanasia Program and its Echoes in Our Own Day
- Societal Devaluation and the “Killing Thought”
- Common Wounding Life Experiences of Human Service Recipients and How They Contribute to Their Deaths
- Protecting the Lives of Hospital Patients
- Understanding Vital Organ Donation
- An Exploration of Some Fundamental Issues of Restraint as a Human Service Technique
- Quality Of Life and Medical Deathmaking
- Euthanasia and Assisted Suicide
- Relevant, Adaptive and Constructive Responses

Appendix H: Book Review

Rethinking palliative care: A Social Role Valorisation approach. By Paul Sinclair. The Policy Press, U. of Bristol, UK, 246 pages, 2007.

Reviewed by Harry van Bommel

It is not often one can say it has been a real treat reading a book on dying, death, and loss. Paul Sinclair's book, *Rethinking Palliative Care: A Social Role Valorisation Approach*, was a treat for me because it finally analyzed palliative care using the detailed framework of Social Role Valorization principles (Osburn, 2006; Race, 1999; Wolfensberger, 1998). Although the book is highly critical, justifiably so, of the hospice palliative care movement in Australia, the UK, and the US, Sinclair does more than just highlight faults. He goes further to provide real examples of what can be done differently to enhance this movement.

Sinclair begins with the argument "that palliative care does not deliver on its aims of valuing people who are dying and making death and dying a natural part of life" (p. 1). He proves his assertion through a rigorous academic analysis of current and historical data. His assertion will be considered 'fighting words' within the palliative care movement that often feels it is above reproach because its intentions are so clearly good. Sinclair points out that he is not critical of individuals within the movement but that, systemically and unconsciously, most of us are blind to the deadly effects of our beliefs and behaviours.

Sinclair has a Ph.D. from the Palliative Care Unit in the School of Public Health, Faculty of Health Sciences, at La Trobe University in Melbourne, Australia. He has worked with people who have an intellectual disability (during which time he learned about Social Role Valorization principles) and people with chronic or terminal illnesses. He is a social worker, palliative care instructor, and writer in the fields of palliative care as well as Social Role Valorization (SRV).

Sinclair wrote this book because he felt that palliative care philosophy and programs were not sufficiently examined to understand how good intentions can often lead to institutionalization of people who are dying, rather than providing them the home care they so often request and deserve. He was heartened by the fact that within the intellectual disability field, over 30 years of SRV training and advocacy have led to most institutions closing, with positive results for most people. Although imperfect, having people live in their own homes with sufficient supports has led to often surprising (for people outside SRV training) results.

Sinclair divides his book into three parts: (1) the palliative care paradigm; (2) palliative care and social devaluation; and (3) reconceptualising palliative care and death.

For those new to the field of palliative care, palliative care is a philosophy of care that tries to meet people's physical, emotional, and spiritual needs, using modern medicine to deal with pain and symptom management, and a religious ethos to underscore its emotional and spiritual supports. Its modern roots lie in England at St. Christopher's Hospice started by Dr. Cicely Saunders in the mid-1960s. She was originally a nurse and was horrified by the treatment afforded dying patients. She became a social worker and later a physician in order to make systemic changes to how people lived before they died. She proved to the world that people need

not suffer needless pain or debilitating symptoms. Her model was an institutional one with a community outreach, based upon a strong Christian faith that you take people as they are and treat them well.

In his book, Sinclair argues strongly that this view is insufficient to combat the social devaluation that exists for most dying people, and especially those who are already devalued for other reasons, such as if they are old, poor, chronically ill, without family, or without gratitude for the care they receive.

Palliative care is at the bottom of the health care hierarchy. People who are dying are not valued as patients or as a population deserving of a lot of health care dollars. As Sinclair writes: “For palliative care, seeking credibility, authority and status including recognition within the medical mainstream, the institutional model is the established means to achieve these ends” (p. 47).

Part 2 highlights how SRV applies to palliative care. Unlike the deinstitutionalization of people with intellectual disabilities, Sinclair believes that the palliative care movement can move toward a model of excellent care at home because most people already live at home. They are not living in hospitals but rather will likely end up there, unless the movement begins to value home care more than it does at present.

After defining SRV for readers new to the concept and providing them with examples of its success, he goes on to explain its particular relevance to palliative care. The key to understanding the results sought after is to understand that “it is vastly more important to stop harm being done to devalued people than it is to try to achieve any sort of generalized positive benefit for people in general” (p. 104). In other words, only when we recognize the unconscious and conscious

devaluation we impose on other people, and which may be imposed upon us, can we truly provide the supports that people request before they die.

Using the culturally valued analogue (Wolfensberger & Thomas, 2007, pp. 30–31) and Wolfensberger’s ten core themes of SRV (Wolfensberger, 1998, pp. 103–127), Sinclair highlights their applicability to palliative care. He then presents the four key principles of SRV that provide objectives of the kind of approaches one should take in developing palliative care systems. The four are: (1) identification of unconscious devaluation from imported models; (2) social integration; (3) image enhancement.

One quote summarizes the inconsistencies of the movement that wants to institutionalize people who are dying: “One’s ordinary life is worthy of imitation on a grand scale, [i.e., making the institution homey] but not worthy of preservation” (p. 129).

Sinclair offers the following model, consistent with SRV values, that would provide people with the palliative care services they request:

1. No institutional care—if it can be done in an institution (hospital, long-term care facility, hospice), it can be done better at home. You can bring a hospital to a home, he argues, but you cannot bring a home to a hospital or hospice.
2. Dispersed services, so that no one agency concentrates all the care provisions needed in home care.
3. Separation of case management (often by people other than nurses or by a team with a nurse and social worker/spiritual leader) from direct care.

He concludes his book with a new conceptualization of dying, death, and loss. He compares the typical model of seeing everyone as equal and good at the end of life with his ‘three faces of death.’ The first face is a natural death; a non-discriminatory, without-malice dying. The second face speaks to the vulnerability that comes from being treated or cared for by others who unconsciously devalue some of their patients. If someone is poor or ungrateful or addicted to drugs or alcohol, their lives are at jeopardy by mostly unconscious behaviours of their carers. The third face relates to the conscious harm inflicted on patients by others, whether through actual killing or withholding of necessary treatments or through purposeful neglect. This last face, Sinclair refers to as having evil, conscious deathmaking results (Wolfensberger, 2005).

In this conceptualization, Sinclair hopes to bring conscious thoughtfulness to the palliative care movement, so that people can identify their own beliefs and behaviours that are harmful or deadly to their patients.

Sinclair provides us with an enormous task—to bring SRV concepts and principles to the day-to-day practices within the palliative care movement. The movement will not be receptive to this task, just as the leaders within the intellectual disability movement were not eager to accept it. It would mean: (1) accepting they have done harm; (2) changing their models and, perhaps, losing what little credibility they have within the health care system; (3) giving up control, hard-fought for resources, and their small to large ‘empires;’ and (4) learning something new, outside their field, that only highlights their errors.

I agree that the hospice palliative care movement, of which I have been a part from a patient and family perspective for nearly 30 years, is failing. Its intentions are admirable but its

unconscious assumptions are harming people, as are its acceptance of an institutional model in many parts of the world. Typically, where poverty prevents institutional care, SRV principles have a better chance of filling the philosophic void of how to provide excellent home care.

Sinclair's conclusion is correct: "palliative care does not deliver on its aims of valuing people who are dying and making death and dying a natural part of life" (p. 1). It does not have as far to go as the deinstitutionalization of people with intellectual disabilities, but it also does not have a strong and large community voice to demand the changes necessary. Sinclair's book is unlikely to be read by many in the field, even though everyone should read it—and more than once. The 'pill' is too hard to swallow by a movement that already feels under-appreciated and under-funded.

People within the SRV movement, however, do have valued voices within their communities. They have an understanding of what is necessary, what is possible, and how it can be accomplished. If they have the energy to recruit new members and energy to their ranks, they can accomplish for palliative care what they are achieving in their own work and families. The readers of this Journal and participants within communities who understand SRV principles are the real audience for this book. I will promote it within the palliative care movement; but it will be you who actually make the changes happen with your own communities around the globe.

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Harry van Bommel is the author of 30 books, including ten in the field of palliative care. More information on his work can be found at <http://www.legacies.ca/>

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Appendix I: Book Excerpt

Enhancing the Hospitalized Child's Social Standing

by Joe Osburn and Jo Massarelli

*(Originally published as Chapter 13 (pp. 224-231) in: Hildebrand, Adam. **Stories of Vigilant Courage: Families Protecting the Lives of Their Children with Complex Medical Needs Through Faith, Hope, and Love.** New York: iUniverse, Inc., 2008.)*

If any lesson has come through with unmistakable velocity in this chronicle of parental faith, hope, and love, it is the rockbottom certainty of mothers and fathers that they must never leave their child alone in the hospital: never. We can but join our voice to theirs in echoing this unanimous conviction. Such presence is the ultimate protective measure, at least on a human level.

That modern hospitals in North America are dangerous places for all patients is by now pretty much an undisputed fact, one amply demonstrated by the accounts of family lives in this book. Similar accounts of the perils of hospitalization appear almost daily in newspapers, journals, magazines, books, television, and other contemporary media. However, what may be less well known is that the dangers of hospitalization do not fall randomly across the spectrum of patients. Rather certain kinds of hospital patients are far more imperiled than others. The most endangered patients are those whom society perceives as having low or no “quality of life” due to physical and mental impairment or other devalued conditions. Few hospital patients are thus more imperiled than seriously and multiply handicapped children—people whom many medical practitioners (and others as well) see as better off dead and even as not fully human, and whose actions or inaction in the hospital can so easily and quickly result in their actually being “made

dead.” Hence, we think that the constant presence of someone committed to being a vigilant defender is an absolutely essential safeguard for these children. We refer to that person as a “protector,” and, as we shall elaborate further, there may be more than one of them.

Thankfully, many such children have parents who not only fill this protector role on their behalf but, in fact, dedicate their lives to it, as we have just read wonderful examples of. However, not all such children are so fortunate as to have such or an parents in their lives, and they therefore need as much or more dedicated protection by at least one loving competent adult who may not be that child’s parent but who is fully committed to doing everything in her or his power to see to it that this child lives and thrives. For example, we read earlier of the citizen advocate who was recruited to protect and advocate for the newborn Keiki. She is a perfect example of a child’s life being protected and preserved by someone who is not the child’s parent.

Whoever the protector is, parent or otherwise, that person will need some assistance from others willing to also take on that role or at least parts of it. Therefore, there may be multiple protectors, and this is especially important if the hospital stay is lengthy. What distinguishes a protector from a visitor or a friendly supporter is his or her mindset. A protector must appreciate what the perils are for the hospital patient, and how vulnerable that particular patient is to them. Further the protector must be willing and able to engage in protective measures. Some of these measures are further discussed next in this chapter, and many more are elaborated in Wolfensberger's excellent book, *A Guideline on Protecting the Health and Lives of Patients in Hospitals, Especially if the Patient is a Member of a Societally Devalued Class* and the accompanying and similarly entitled workshop taught by the authors of this chapter.

Having established the physical presence of one or more adult protectors in the hospital as an irreducible need, we come to the question of what ought they do while there in that hospital room being present to the child they are pledged to protect. This book is already loaded with important ideas along this line. Here in this brief chapter, we want to elaborate on one of the other main strategies employed by most of the parents in these stories, sometimes on an intuitive basis. It is a very powerful protective measure that must not be underestimated or overlooked by parents/protectors.

Simply stated, the strategy is to DO EVERYTHING WE CAN TO PUT GOOD THINGS INTO THE MINDS OF HOSPITAL PERSONNEL ABOUT OUR CHILD.

Why? Because one thing we know for certain about human beings is that what they have in their minds about other people has everything to do with how they think, feel, and act about those other people.

One enormous implication of this reality is to enhance our child's social standing in the eyes of others. What we mean by this is to “humanize” the child by helping others see him in their minds as an intrinsically valuable human being. There are certain things that we know work extremely well in accomplishing this. Some of these things were noted only in passing earlier in this book; others were not mentioned. And so, we will now elaborate a bit more on this strategy of enhancement of a hospitalized child's social standing.

To begin with, if anyone questions whether this strategy is worth the effort, he or she should contemplate several crucial points. One is the dark but starkly simple fact that handicapped children live in a constant state of “heightened vulnerability,” meaning among other things that the likelihood that they will be devalued, rejected, seen as unduly burdensome worthless

subhuman creatures is so high and so constant that the risk that others will wish them dead and actually work toward that end is incalculably higher than for ordinary children. Another dark fact to contemplate is that such children will almost automatically consciously or unconsciously be accorded lower status in the hospital, and perhaps very low status indeed, by some. On the brighter side, we see the importance of a child's having a good social standing in the eyes of medical personnel from the actual experiences of parents in this book whose children's deaths were prevented and their lives preserved by just one doctor or nurse who came to see their child as a fellow human being. And further, by the example of their actions and efforts on the child's behalf, these same doctors and nurses witnessed to the truth of the inestimable worth, dignity, and value of all human life. They taught this perception powerfully to others, including others whose minds were previously benighted by the prevailing "quality of life" mentality. What could be a more potent safeguard to a hospitalized child than adults who value his life as a unique and precious human being? Yes, it is worth the effort, and the good thing about it is that really not all that much effort is required.

Secondly, the need to protect and elevate the child's social standing in the eyes of others derives in large part from the very nature of contemporary hi-tech hospital medicine which, in contrast to earlier times, is prone to reduce the social status of a person—even a valued person—to that of sick patient, and to overlook the patient's sense of dignity and self-worth. Whether intended or not, this can be degrading as well as dangerous. In other words, even if a child were surrounded in the hospital by medical personnel who truly saw and valued him as a unique human being, these same personnel may nevertheless, in their minds, still cast that child into the role of "sick patient," "diseased organism," or even "dying and hopeless creature."

Also, people are at great risk of being defined not by their personhood, but exclusively and totally by their illness or condition:

- “the A-line” in neonatal intensive care
- “the transplant kid on 6-east”
- “the liver in room 402”

Many parents and children end up demoralized and even depressed by this loss of status. For people who started out at a disadvantage due to being socially devalued, and who may not have much status to begin with, being perceived as “less than” can have even more dire consequences, as we mentioned. Therefore, it is important to uphold their status and dignity as much as possible.

As a general guideline, we suggest the following specific ways to enhance the perceived importance and value of a hospitalized child in the eyes of hospital personnel.

First of all, it is very important to personalize and even humanize the relationship of hospital workers with the child. “Humanizing” the child will have a thoroughgoing affect on the quality of care he receives from medical staff. This means to help hospital personnel see the child fully as a person, and a valued one at that, and as a unique individual, rather than as an object or in some other stereotyped way. This is important to do anytime, but it is especially essential to do when the patient is at such high risk of social devaluation, and even more so when that patient’s

circumstances increase the likelihood of his/her being perceived as an object instead of as a person. If hospital personnel identify with the child as more like themselves than not, the quality of medical care will be better than if the patient is perceived as "other than human," or as "subhuman."

One adult person we know is very severely impaired and undergoes frequent hospitalizations because of her condition and the medical care she requires. She is so acutely aware of how important this protective measure is that she has written up a little statement about herself that she posts in her hospital room above her bed for medical staff to read. Here it is.

PERCEPTIONS

The Assumption

She has spent all her life in institutions. Never read a book or wrote a letter. Never went to a movie. Never had a job. The nursing home sent her here because she got sick. We'll do our best to patch her up because we believe that every life is important no matter how miserable. If she recovers, we'll send her back to the nursing home, where she'll live out the rest of her useless days. Then she'll die.

The Truth

She grew up in a family that loved her. Her parents thought of her as having much potential. College was always assumed, and she graduated with honors. Now nationally recognized, she writes books and articles, counsels individuals and groups, and travels over a large area to share her knowledge. Always popular, she surrounds herself with wonderful people whose commitment sustains her through the hard times. She lives on her own, in a home that belongs to her. She plans to get married. Life is good.

When a person speaks for herself,
the assumption pulsates loudly, while the truth only whispers.

Care enough to learn the truth.

Then dare to pass it on!

Even though the woman who wrote this is an adult, and a very intelligent, competent one at that, her statement is still very instructive for us, and one can easily envision parents developing similarly eloquent and positive statements to post in their own child's hospital room. Their faith, hope, and love will give them the words.

In fact, many children who end up in the hospital a lot could do this for themselves or at least play a major role in producing such a statement. There are also many other types of fairly simple, but important and effective, actions that you as parents/protectors can take to help humanize a hospitalized child for medical staff. For example, you can ...

- “force” the physician to talk to your child in the bed, rather than only to you or other adults at the bedside;
- use your child’s name often in the hearing of hospital personnel;
- share your child’s modes of communication with hospital personnel, especially if your child doesn’t speak; for example, “Doctor, when she squints her eyes like that, she is saying...”;
- say to the doctor or nurse, “Jason (your child, the patient) has something he wants to tell you”;
- ask the doctor or nurse to talk to your child before they leave from the room;
- shed light on your child’s valued roles, what he is good at, enjoys, the contributions she has made, and so on, for example, by talking about these things with the nurses and doctors;
- tell complimentary stories about your child;
- describe how much she means to you; and
- have about the room photos, both of your child looking good and doing interesting things, and with you and the rest of your family.

One group of people helped a woman who had no family to literally write a book about her life that featured many highlights and enhancing visual images of her, both by herself and with friends, and even one picture of her having an audience with the Pope! Her book was kept prominently on her bedside table whenever she was hospitalized. It was bound and had a beautiful photograph of her on the cover under her name. Each time she was hospitalized, her book went with her; several nurses and doctors took the time to sit down at her bedside and look through the book. This always had a positive impact on the way she was treated in the hospital, on the quality of care she received, and thus obviously also on her health and well being. In other words, **her book put good things about her into other people's minds.**

Another important idea is to do as much as we can to enhance the child's personal appearance. It is a simple fact of human nature that we judge other people by how they look. We may not like this. We may feel that it shouldn't be that way. But it is that way, for all of us: me, you, your child, doctors, and nurses. This is particularly true of the first impressions we form of others, which are heavily influenced by their appearance and other personal characteristics. We can't help doing this really; it is the way we are made, and it actually plays some very useful functions. People can overcome their initial negative judgment of others (that they may have made on the basis of their appearance), but that takes conscious effort and will on their part. Knowing all this gives you a very useful direction for improving the chances that others will perceive and relate to your child more positively. People's appearance can be improved in hundreds of ways, literally from their head to their toes. And most of these are simple and easy to do. For example, this can be done quite simply by replacing or supplementing or disguising their hospital garb with better fitting and better looking clothes from home; or making sure the child's

hair is clean and nicely combed, and so on. Not only appearances, but smells, too, are also important in creating impressions, and therefore use of things like deodorants, perfumes, lotions, mouthwash, tooth brushing, etc. can also be quite enhancing in this regard. Just keep in mind that everyone can be helped to make a better personal appearance—even our own children who are always utterly beautiful in our own eyes—and that this is a simple but very important—even potentially life-saving—thing to pay attention to.

Another effective means to help elevate your child's status in the eyes of hospital personnel is to have other obviously competent allies stand by your child, both literally and figuratively, alongside you. Having such people bedside, especially if they are valued citizens, will serve the function of raising the child's status by demonstrating the fact that he and his parents have committed allies at their sides. It communicates to others that there are other people besides you who care a great deal about your child and are very concerned about the care he receives. One reason this idea is effective has to do with another of those simple and well-known facts of human nature: we strongly tend to judge others by the company they keep. How often have we heard this, and how well do we know it is true! Since we know this, we can use it to build an element of protection for the hospitalized child. Other friends and family members can be enlisted.

Obviously much of what we have described in this chapter has to do with the ideal. We mention this because there are obvious limitations regarding what one parent or family or even community can do. But even in an ideal way, despite excellent protective measures employed by excellent protectors, sometimes the results are still hard to bear. So, if a patient does not get better; if a patient actually gets sicker, or even dies, that does not mean that one is a failure as a

protector. Nor does it mean that one's protection was in vain. Being present with the patient, talking, praying, giving comfort and solace, taking bodily care of the patient (washing, grooming, dressing, helping him eat), interceding with doctors, nurses, and others on the patient's behalf, looking out for the patient's interests, reducing his stress, bringing as much comfort and calm as possible, helping him stay connected to his world and life and people outside the hospital, showing in your words and deeds how much you value this person, how important his safety and well-being and comfort are to you—all of these things are great goods that you have brought to the patient's life, and the good of these things is not negated by the patient's sickness or even death, if that should come to pass.

And, lastly on this point, it is important to remember that even limited, less-than-ideal protection, carried out by fallible ordinary human beings like you and me can be *great*. It can make all the difference in the patient's hospital experience. It can make the patient less worried and less afraid. It can buffer the patient from intended or unintended slights by hospital personnel. It can prevent the patient's accidental death. It can make the patient more comfortable. It can seal your relationship with the patient. And, it can, indeed, save the patient's life.