

# The SRV JOURNAL

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June 2006 • Volume I • Number I

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### **Re-Thinking Respite** *by John Armstrong & Lynda Shevellar*

**Some Helpful Points to Keep in Mind in the Presence of  
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# The SRV JOURNAL

## Editorial Board:

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## Statement of Purpose:

We believe that Social Role Valorization (SRV), when well applied, has the potential to help societally devalued people to gain greater access to the good things of life, and to be spared at least some of the negative effects of social devaluation.

Toward this end, the purposes of this journal include: 1) disseminating information about SRV; 2) informing readers of the relevance of SRV in addressing the devaluation of people in society generally and in human services particularly; and 3) fostering, extending and deepening dialogue about, and understanding of, SRV. We see this journal as a helpful addition to the international SRV training culture.

We hope that the information provided in this journal will help family, friends, advocates, direct care workers, managers, trainers, and others in relationship with, or serving formally or informally upon, devalued people to provide more valued life conditions as well as more relevant and coherent service.

We believe that interested persons and 'servers' can do this primarily by helping devalued people to attain and maintain valued social roles. We believe that over the long run, such efforts will improve the life situations overall of vulnerable people, increasing their access to the good things of life. We sincerely hope that this journal will contribute to such efforts.

The SRV Journal is published under the auspices of the SRV Implementation Project (SRVIP). The mission of the SRVIP is to: confront social devaluation in all its forms, including the deathmaking of vulnerable people; support positive action consistent with Social Role Valorization; and promote the work of the formulator of SRV, Dr. Wolf Wolfensberger of the Syracuse University Training Institute for Human Service Planning, Leadership & Change Agency.

## Editorial Policy:

We believe that informed and open discussions of SRV, and even constructive debates about it, help to promote its dissemination, relevance and application. Therefore, we encourage people with a range of experience with SRV to submit items for consideration of publication. We hope that those with much experience in teaching or implementing SRV, as well as those who are just beginning to learn about it, will contribute to the Journal.

We encourage readers and writers in a variety of roles and from a variety of human service backgrounds to subscribe and to contribute. We do expect that writers who submit items will have at least a basic understanding of SRV, gained for example by attendance at a multi-day SRV workshop, by studying relevant resources, or both.

We are particularly interested in receiving submissions from family members, friends and servers of devalued people who are trying to put the ideas of SRV into practice, even if they do not consider themselves 'writers.' Members of our editorial boards will be available to help contributors with articles accepted for publication. The journal will also have an academic peer review section for those who are interested.

## Information for Submissions:

We welcome well-reasoned and clearly-written submissions in English. The language used in submitted items should be clear and descriptive. We encourage the use of ordinary grammar and vocabulary that a typical reader would understand. The *Publication Manual of the American Psychological Association* is one good and easily available general style guide. Academic authors should follow the standards of their field.

Submissions are reviewed by members of the editorial board, the associate editorial board, or both. Submissions may be made on paper, or electronically with an e-mail attachment, to the address below.

Examples of submission topics include but are not limited to: SRV as relevant to a wide variety of human services; descriptions and analyses of social devaluation and wounding; descriptions and analyses of the impact(s) of valued social roles; illustrations of particular SRV themes; research into and development of the theory of SRV and its particular themes; critique of SRV; analysis of new developments from an SRV perspective; success stories, as well as struggles and lessons learned, in trying to implement SRV; interviews; reflection and opinion pieces; news analyses from an SRV perspective; book or movie reviews and notices from an SRV perspective.

## Annual subscription rates in USD (as of January 2006) - two issues per year

	Individual	Organization	Family/Student
US/Canada	\$40	\$80	\$25
AU/NZ/Europe	\$45	\$85	\$30

## Dear reader,

WELCOME TO THIS FIRST EDITION of *The SRV Journal*. We are quite pleased to offer what we believe is an important resource for the dissemination of Social Role Valorization (SRV). We have started this journal because we believe that SRV, when well applied, has great potential to help societally devalued people to gain greater access to the good things of life, and to be spared at least some of the negative effects of social devaluation. This potential has been actualized within different service fields across the globe. Toward this end, the purposes of this journal include: 1) disseminating information about SRV; 2) informing readers of the relevance of SRV in addressing the devaluation of people in society generally and in human services particularly; and 3) fostering, extending and deepening dialogue about, and understanding of, SRV.

THIS ISSUE has a range of relevant and timely articles concerning issues of SRV theory, implementation and training. We welcome all of our contributors to this first issue -- some with decades of experience with SRV; others who are relatively new to the ideas. They are writing from their perspectives as trainers, consultants, human service system and agency workers, friends and family members of devalued people. Our editors and contributors are from the US, Canada, the UK, New Zealand and Australia. We are also pleased to have a column of SRV news and reviews from Wolf Wolfensberger, the founder of SRV. His column will be a regular feature.

We encourage and welcome your letters and submissions of manuscripts for possible publication in this journal. We believe that informed and open discussions of SRV, and even constructive debates about it, can only help to promote its dissemination, relevance and appli-

cation. Therefore, we encourage people with a range of experience with SRV to submit items for consideration of publication. As this is a new journal, we are open to trying new formats and ideas. If you have any suggestions, please feel free to send them to us at the address below.

I WISH TO THANK Raymond Lemay, founding editor and manager of *SRV/VRS: The International Social Role Valorization Journal/La revue internationale de la Valorisation des rôles sociaux* (another journal about SRV), for his years of effort at publishing that journal (now discontinued), as well as for his encouragement and support of this new journal. We are also pleased that Raymond will continue to write for *The SRV Journal*.

I would like to thank all those who have encouraged and supported our efforts to begin this journal, particularly the members of the editorial boards, as well as the members and correspondents of the North American SRV Training, Safeguarding & Development Council. I would also like to particularly thank Shriver Clinical Services (Massachusetts, USA) for their financial support of this issue.

AGAIN, WELCOME TO THIS JOURNAL, and we hope that you find it thought-provoking and relevant.

Regards,

*Marc Tumeinski, Editor*

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# An Overview of Social Role Valorization Theory

Joe Osburn

EDITOR'S NOTE: *The following is an updated version of an article originally published in The International SRV Journal in 1998 (Osburn, J. (1998). An Overview of Social Role Valorization Theory. SRV/VRS: The International Social Role Valorization Journal/La revue internationale de la Valorisation des roles sociaux, 3(1), 7-12). I asked the author to revise his original article to incorporate significant developments in SRV made by Wolfensberger since 1998. We are particularly pleased to offer this revised article in our first issue, as a clear overview of what this Journal is all about.*

“SOCIAL ROLE VALORIZATION” (SRV) is the name given to a concept for transacting human relationships and human service, formulated in 1983 by Wolf Wolfensberger, Ph.D., as the successor to his earlier formulation of the principle of normalization (Lemay, 1995; Wolfensberger, 1972; Wolfensberger, 1983). His most recent definition of Social Role Valorization is: *“The application of empirical knowledge to the shaping of the current or potential social roles of a party (i.e., person, group, or class) -- primarily by means of enhancement of the party's competencies & image -- so that these are, as much as possible, positively valued in the eyes of the perceivers”* (Wolfensberger & Thomas, 2005).

THE BASIC PREMISE of SRV is that people are much more likely to experience the “good

things in life” (Wolfensberger, Thomas, & Caruso, 1996) if they hold valued social roles than if they do not. Therefore, the major goal of SRV is to create or support socially valued roles for people in their society, because if a person holds valued social roles, that person is highly likely to receive from society those good things in life that are available to that society, and that can be conveyed by it, or at least the opportunities for obtaining these. In other words, all sorts of good things that other people are able to convey are almost automatically apt to be accorded to a person who holds societally valued roles, at least within the resources and norms of his/her society.

There exists a high degree of consensus about what the good things in life are (Wolfensberger, et al., 1996). To mention only a few major examples, they include being accorded dignity, respect, acceptance; a sense of belonging; an education, and the development and exercise of one's capacities; a voice in the affairs of one's community and society; opportunities to participate; a decent material standard of living; an at least normative place to live; and opportunities for work and self-support.

SRV is especially relevant to two classes of people in society: those who are already societally devalued, and those who are at heightened risk of becoming devalued. In fact, SRV is primarily a response to the historically universal phenomenon of social devaluation, and especially societal devaluation. In any society,

there are groups and classes who are at value risk or already devalued in and by their society or some of its subsystems. (For instance, in North America, it has been estimated that from one-fourth to one-third of the population exists in a devalued state because of impairment, age, poverty or other characteristics that are devalued in society.) Devalued individuals, groups, and classes are far more likely than other members of society to be treated badly, and to be subjected to a systematic -- and possibly life-long -- pattern of such negative experiences as the following.

1. Being perceived and interpreted as "deviant," due to their negatively-valued difference. The latter could consist of physical or functional impairments, low competence, a particular ethnic identity, certain behaviors or associations, skin color, and many others.

2. Being rejected by community, society, and even family and services.

3. Being cast into negative social roles, some of which can be severely negative, such as "subhuman," "menace," and "burden on society."

4. Being put and kept at a social or physical distance, the latter most commonly by segregation.

5. Having negative images (including language) attached to them.

6. Being the object of abuse, violence, and brutalization, and even being made dead.

THE REALITY that not all people are positively valued in their society makes SRV so important (Kendrick, 1994). It can help not only to prevent bad things from happening to socially vulnerable or devalued people, but can also increase the likelihood that they will experience the good things in life. Unfortunately, the good things in life are usually not accorded to people who are devalued in society. For

them, many or most good things are beyond reach, denied, withheld, or at least harder to attain. Instead, what might be called "the bad things in life" are imposed upon them, such as the six experiences listed above. This is why having at least some valued social roles is so important. A person who fills valued social roles is likely to be treated much better than if he or she did not have these, or than other people who have the same devalued characteristics, but do not have equally valued social roles. There are several important reasons why this is so. One is that such a person is more likely to also have valued and competent allies or defenders who can mitigate the impacts of devaluation or protect the person from these. Also, when a person holds valued social roles, attributes of theirs that might otherwise be viewed negatively are much more apt to be put up with, or overlooked, or "dismissed" as relatively unimportant.

IT IS ROLE-VALORIZING to enhance the perceived value of the social roles of a person, a group, or an entire class of people, and doing so is thus called social role valorization. There are two major broad strategies for pursuing this goal for (devalued) people: (1) enhancement of people's social image in the eyes of others, and (2) enhancement of their competencies, in the widest sense of the term. Image and competency form a feedback loop that can be negative or positive. That is, a person who is competency-impaired is highly at risk of suffering image-impairment; a person who is impaired in image is apt to be responded to by others in ways that delimit or reduce or even prevent the person's competency. But both processes work equally in the reverse direction. That is, a person whose social image is positive is apt to be provided with experiences, expectancies, and other life conditions which are likely to in-

crease, or give scope to, his/her competencies; and a person who displays competencies is also apt to be imaged positively.

Role-valorizing actions in the image-enhancement or competency-enhancement domains can be carried out on four distinct levels and sectors of social organization.

1. The individual;
2. The individual's primary social systems, such as the family;
3. The intermediate level social systems of

an individual or group, such as the neighborhood, community, and services the person receives;

4. The larger society of the individual or group, including the entire service system.

Combining these different dimensions and levels yields a 2x4 matrix for classifying the major implications of SRV, as shown in Table 1 (adapted from Thomas, 1999).

**Table 1: Social Role Valorization Action Implications**

		<b>Primarily to Enhance Social Images</b>	<b>Primarily to Enhance Personal Competencies</b>
<b>Level of Action</b>	<b>Individual Person</b>	Arranging Physical & Social Conditions for a Specific Individual That are Likely to Enhance Positive Perceptions of That Individual by Others	Arranging Physical & Social Conditions for a Specific Person That are Likely to Enhance the Competencies of That Individual
	<b>Primary Social Systems</b>	Arranging Physical & Social Conditions in a Primary Social System That are Likely to Enhance Positive Perceptions of a Person in & via This System	Arranging Physical & Social Conditions of a Person's Social System That are Likely to Enhance That Person's Competencies
	<b>Intermediate &amp; Secondary Social Systems</b>	Arranging Physical & Social Conditions in Secondary Social Systems That are Likely to Enhance Positive Perceptions -- in & via Those Systems -- of People in Them, & of Others like Them	Arranging Physical & Social Conditions in Secondary Social Systems That are Likely to Enhance the Competencies of People in Them
	<b>Entire Society of an Individual, Group, or Class of People</b>	Arranging Physical & Social Conditions Throughout Society That are Likely to Enhance Positive Perceptions of Classes	Arranging Physical & Social Conditions Throughout Society That are Likely to Enhance the Competencies of Classes of People

FOR THOSE who wish to improve the situation of devalued people, SRV constitutes a high-level and systematic framework to guide their actions. In other words, it provides a coherent overall conceptual foundation for addressing the plight of individuals, groups, or classes of devalued people. Within this overall framework, SRV points to comprehensive service principles, from which are derived major service strategies, from which, in turn, flow innumerable specific practical action measures. These principles, strategies, and action measures are relevant in both formal and informal service contexts, and are thoroughly spelled-out in the SRV literature. In fact, SRV is one of the most fully articulated broad service schemas in existence. For example, within each of the eight boxes in Table 1, innumerable more specific role-valORIZING actions can be imagined, and indeed, a great many have been explicitly identified (Thomas, 1999). Even in just the few words of the short definition of SRV (stated above), there is incorporated an enormous amount of explanatory power and implied actions which can give people much food for thought in their whole approach to serving others. If implemented, SRV can lead to a genuine address of the needs of the people served, and thus to a great increase in service quality and effectiveness.

SRV IS A SOCIAL SCIENCE CONCEPT and is thus in the empirical realm. It rests on a solid foundation of well-established social science theory, research, and empiricism within fields such as sociology, psychology, and education and pedagogy, drawing upon multiple bodies of inquiry, such as role theory, learning theory, the function and power of social imagery, mind-sets and expectancies, group dynamics, the social and psychological processes involved in unconsciousness, the sociology of deviancy,

and so forth. SRV weaves this body of knowledge into an overarching, systematic, and unified schema.

SRV is not a value system or ideology, nor does it prescribe or dictate value decisions. Decisions about whether to implement SRV measures for any person or group, and to what extent, are ultimately determined by people's higher-order (and not necessarily conscious) values which transcend SRV and come from other sources, such as their personal upbringing, family influences, political and economic ideas, worldviews, and explicit religions. What people do in their relationships and services, or in response to the needs of the people they serve, or for that matter in any other endeavors, depends greatly on their values, assumptions, and beliefs, including those they hold about SRV itself. However, SRV makes a big point of how positive personal and cultural values can be powerfully brought to bear if one wishes to pursue valued social roles for people. For example, in most western cultures, the Judeo-Christian value system and liberal democratic tradition are espoused and widely assented to, even if rarely actualized in full. SRV can recruit such deeply embedded cultural values and traditions on behalf of people who might otherwise be devalued and even dehumanized. Every society has values that can be thusly recruited to craft positive roles for people (Wolfensberger, 1972, 1998).

As a social science schema, SRV is descriptive rather than prescriptive. That is, SRV can describe certain realities (e.g., social devaluation), and can say what are the likely outcomes of doing or not doing certain things in regard to those realities, in what has come to be called the "if this...then that" formulation of SRV (Wolfensberger, 1995a). For example, SRV points out that if parents do things that help others to have a positive view of their child and



that help the child acquire skills needed to participate positively in the community, then it is more likely that the child will be well-integrated into the community. If one does not emphasize the adult status of mentally retarded adults, and/or does not avoid things which reinforce their role stereotype as "eternal children" (such as referring to adults as children, engaging adults in children's activities, and so on), then one is likely to perpetuate the common negative stereotype that mentally retarded adults really are overgrown children, with all the negative consequences that attend this stereotype. So, these are things that SRV can tell one. However, once people learn SRV, they themselves have to determine what they think about it, whether they believe in its power, whether they want to apply it in valorizing the roles of a person or class, and to what extent -- if at all -- they even want to valorize other people's roles. For example, while SRV brings out the high importance of valued social roles, whether one decides to actually provide positive roles to people, or even believes that a specific person, group, or class deserves valued social roles, depends on one's personal value system, which as noted, has to come from somewhere other than SRV.

THE IDEAS BEHIND SRV first began to be generated by the work that was being conducted by Wolfensberger and his associates at the Training Institute for Human Service Planning, Leadership and Change Agency, which he directs at Syracuse University. One major source of these ideas was an on-going effort on the part of Wolfensberger to continually explore, advance, and refine the principle of normalization -- an effort that began almost as soon as normalization first appeared on the scene. For example, since normalization was first explicitly formulated in 1969, several

books, numerous articles, chapters, and other publications (several hundred altogether) on the topic have been written and disseminated (see, for example, St-Denis & Flynn, 1999). And it was Wolfensberger, more than anyone else, whose writings successively clarified and helped to increase comprehension of the meaning and application of normalization. This process involved a concerted effort on his part to systematically incorporate into teaching and training materials the deepening understanding achieved in the course of: (a) thinking, writing, and teaching about normalization over the years; (b) its increasing incorporation into actual human service practice; and (c) numerous normalization-based service assessments, mostly using the PASS tool (Wolfensberger & Glenn, 1973, 1975, reprinted in 1978). There were also continuous attempts, again mostly on Wolfensberger's part, to deal with frequent misconceptions and even "perversions" of the concept of normalization (see Wolfensberger, 1980), often due to the ease with which the term "normalization" itself could be (and was) misconstrued or misapplied.

This stream of concentrated development resulted in an evolution in thinking which brought about the conceptual transition from normalization to Social Role Valorization. Not surprisingly, the main substance of the concept of SRV began to evolve before the concept itself was defined, and before a new term was coined to describe it. For instance, Wolfensberger's last published formulation of the principle of normalization defined it as, "as much as possible, the use of culturally valued means in order to enable, establish and/or maintain valued social roles for people" (Wolfensberger & Tullman, 1982), thus foreshadowing both the new concept and the new term Social Role Valorization. This article was the first publication that articulated the insight that valued so-

cial roles for people at risk of social devaluation were -- even more than merely culturally normative conditions -- the real key to the good things of life for them. This represented such an advance that it was clearly a higher conceptualization than the earlier formulation of normalization. Thus, SRV definitely amounts to far more than a renaming or rewording of the normalization principle; rather, it constitutes a major conceptual breakthrough based on the double insight that (a) people with valued social roles will tend to be accorded desirable things, at least within the resources and norms of their society, and (b) the two major means to the creation, support, and defense of valued social roles are to enhance both a person's image and competency.

Another big boost to the conceptualization of Social Role Valorization was the work being done by Wolfensberger, and his Training Institute associate, Susan Thomas, over a three to four year period on a human service evaluation tool called PASSING (Wolfensberger & Thomas, 1983), which stands for "Program Analysis of Service Systems' Implementation of Normalization Goals." One could say that this first published edition of PASSING (i.e., the second edition) was ahead of its time in at least one sense: it spelled out the major action implications of the new concept of SRV in much more detail than in any other previous publication, and did so even before a term had been coined to name the new concept. PASSING thus incorporates mostly SRV concepts while still using the earlier normalization language. Happily, this anachronism is corrected in the anticipated third revised edition (Wolfensberger & Thomas, in press) which uses SRV terminology exclusively. The development of PASS-

ING contributed much to the insight that actions to achieve the ultimate as well as intermediate goals and processes of SRV can all be classified as dealing with either image and/or competency enhancement.

In order to help communicate new concepts, new terms are often needed. The selection of the term "Social Role Valorization" was quite deliberate (see, for example, Wolfensberger, 1983, 1984, 1985, and 1991a). Not only does it overcome many of the historical and other problems that had always plagued the term "normalization," but it is based on two additional discoveries that are highly relevant to the essence of its meaning (Wolfensberger, 1985).

1. In modern French human service contexts, people had begun to use the word *valorisation* in order to signify the attachment of value to people. In Canadian French specifically, the term *valorisation sociale* had been used in teaching the normalization principle since ca. 1980 (Wolfensberger, 1991b).

2. In both French and English, the term valorization has its root in the Latin word *valere*, which means to value or accord worth. Relatedly, the word "valorization" has, or elicits, very strong positive connotations that clearly correspond to the concept it is meant to convey.

In combination, the above discoveries suggested that in English "Social Role Valorization," and in French *La Valorisation des Roles Sociaux* (Wolfensberger, 1991b), would be eminently suitable terms for the new concept, both having positive connotations, while being unfamiliar enough not to evoke wrong ideas. The French term brings out even better than the English the fact that people hold multiple roles, and that more than one can be valorized.

**Table 2: Sequence of Topics for a Leadership-Oriented Introductory Social Role Valorization (SRV) Workshop**

**PART 1: INTRODUCTORY ORIENTATION**

- a. How the Workshop Will be Conducted
- b. Introduction to the Workshop Topic, Including a Brief Preliminary Sketch of SRV
- c. Orientation to Some Concepts Crucial to the Workshop

**PART 2: SOCIAL EVALUATION, DEVALUATION & ITS IMPACT**

- a. Basic Facts About Human Evaluation, & Social Devaluation Specifically
- b. The Devalued Classes in Contemporary Western Societies
- c. The Expressions of Social Devaluation: The Most Common Wounds of Devalued People
- d. The Common Effects on Devalued People of Being Systematically Wounded
- e. Conclusion to the Material on Wounds

**PART 3: A MORE DETAILED INTRODUCTION TO SRV**

- a. The Rationale Behind SRV
- b. Some Facts About Social Role Theory That Are Easily Understood & Crucial to SRV
- c. A More Global Overview Sketch of Social Role Valorization (SRV)
  - c1. Some Broad Facts About SRV
  - c2. Making Distinctions Between Empirical Versus Nonempirical Propositions
  - c3. Concluding Clarifications

**PART 4: TEN THEMES OF GREAT RELEVANCE TO UNDERSTANDING & APPLYING SRV**

- a. Introduction to the Ten Themes
- b. The Dynamics of UNCONSCIOUSNESS, Particularly About Deviancy-Making, & the Unrecognized Aspects & Functions of Human Services
- c. The CONSERVATISM COROLLARY of SRV, i.e., the Importance of Employing the Most Valued Options, & Positive Compensation for Disadvantage
- d. The Importance of INTERPERSONAL IDENTIFICATION
- e. The Power of MIND-SETS & EXPECTANCIES
- f. The Realities of IMAGERY, Image Transfer, Generalization, & Enhancement
- g. The Concept of Service MODEL COHERENCY, With Its Requirements of RELEVANCE & POTENCY
- h. The Importance of PERSONAL COMPETENCY ENHANCEMENT & THE DEVELOPMENTAL MODEL
- i. The Pedagogic Power of IMITATION, Via Modeling & Interpersonal Identification
- j. The Relevance of ROLE EXPECTANCIES & ROLE CIRCULARITY to Deviancy-Making & Deviancy-Unmaking
- k. SOCIAL INTEGRATION & VALUED SOCIETAL PARTICIPATION of Devalued People in Valued Society
- l. Grouping & Association Issues That Derive From Combinations of Themes
- m. Conclusion to, & Relationship Among, All the Themes

**PART 5: IMPLEMENTATION, ELABORATIONS, CLARIFICATIONS & CONCLUSION**

- a. Some Further Issues of SRV Implementation or Practice
- b. The Benefits of SRV
- c. Brief Review of the Limitations of, & Constraints on, SRV
- d. A Brief Note on the Limitations of This Workshop
- e. Ways to Learn More About SRV
- f. Conclusion & Adjourment

Finally, another advantage of the switch from normalization to SRV is that because Social Role Valorization is an uncommon term, people are more likely to listen to definitions and explanations of it rather than attaching their own preconceived notions to it, as they had tended to do with the word "normalization."

SRV IS BEING DISSEMINATED across the world. For example, in the English language, both the overarching SRV schema and its major elements have been described in an original introductory monograph (Wolfensberger, 1992), which was later revised into a 139-page edition (Wolfensberger, 1998) that now serves together with the PASSING manual (Wolfensberger & Thomas, 1983; revision in press) as the main current SRV texts. Other prominent SRV-related texts in English are the published proceedings of the 1994 International SRV conference held in Ottawa (Flynn & Lemay, 1999), with many chapters that reflect recent perspectives on SRV, and two books published in England (Race, 1999, 2003). There is also a massive set of (unpublished) teaching materials used in SRV training by qualified trainers (Wolfensberger & Thomas, 2005). The multitude of SRV action implications to human services and human service workers are thoroughly spelled out in SRV and PASSING training workshops, both of which are intensive teaching events, conducted in a variety of formats, of anywhere from one to seven days in length. Table 2 provides a list of topics covered in the most recent version of introductory SRV training workshops.

To date, most SRV and/or PASSING training events have been conducted in English, with several variations in terms of length (i.e., anywhere from half a day to five days duration), processes, and depth and quantity of content.

There have also been a significant number of SRV/PASSING training events in French, conducted mainly by francophone trainers, again in different versions. In addition to English and French, such training has also been conducted in Spanish, Dutch, Welsh, Icelandic, Norwegian, and possibly other languages, typically with the aid of interpreters.

Both the English SRV (Wolfensberger, 1991a) and PASSING (Wolfensberger & Thomas, 1983) texts have been translated into French (Wolfensberger, 1991b; Wolfensberger & Thomas, 1988), and the SRV monograph into Italian (Wolfensberger, 1991c) and Japanese (Wolfensberger, 1995b), and is in the process of being retranslated into German.

Another obvious vehicle for dissemination (in English) of general SRV related information and news is *The SRV Journal*. On the internet, there are several websites devoted to SRV matters, including one called Social Role Valorization at <<http://www.socialrolevalorization.com/>>. There are also several groups in various countries that have formed around SRV; while these range from formal to informal and have slightly different purposes and processes, they tend to be composed of people well-versed in SRV development, dissemination, and/or application. Perhaps the two most prominent of these are the (North American) SRV Development, Training, and Safeguarding Council, comprised of members from both Canada and the United States of America, and the Australian SRV Group. The membership of both of these groups includes representatives of smaller more localized groups in various parts of their respective countries.

Information on the most recent SRV-related developments, and/or SRV training events, can be requested from the above-mentioned Training Institute for Human Service Planning, Leadership and Change Agency (800 South Wilbur

Avenue, Suite 3B1 Syracuse, New York 13204, USA; 315/473-2978; fax: 315/473-2963).

## References

- Flynn, R.J., & Lemay, R. (Eds.) (1999). *A quarter-century of Normalization and Social Role Valorization: Evolution and impact*. Ottawa: University of Ottawa Press.
- Kendrick, M. (1994). Some reasons why Social Role Valorization is important. *SRV/VRS: The International Social Role Valorization Journal/La Revue Internationale de la Valorisation des Roles Sociaux*, 1(1), 14-18.
- Lemay, R. (1995). Social Role Valorization and the principle of Normalization as guides for social contexts and human services for people at risk of societal devaluation. In Dell Orto, A. E. & Maraneli, R. P., *Encyclopedia of disability and rehabilitation*. New York: McMillan, 515-521.
- Race, D. (1999). *Social Role Valorization & the English experience*. London: Whiting & Birch Ltd.
- Race, D. (2003). *Leadership and change in human services: Selected readings from Wolf Wolfensberger*. New York & London: Routledge.
- St-Denis, C., & Flynn, R.J. (1999). A comprehensive bibliography on Normalization, Social Role Valorization, PASS, and PASSING, 1969 - 1999. In Flynn, R.J., & Lemay, R. (Eds.) (1999). *A quarter-century of Normalization and Social Role Valorization: Evolution and impact*. Ottawa: University of Ottawa Press, 507-547.
- Thomas, S. (1999). Historical background and evolution of Normalization-related and Social Role Valorization-related training. In Flynn, R.J., & Lemay, R. (Eds.), *A quarter-century of Normalization and Social Role Valorization: Evolution and impact*. Ottawa: University of Ottawa Press, 353-374.
- Wolfensberger, W. (1972). *The principle of Normalization in human services*. Toronto: National Institute on Mental Retardation.
- Wolfensberger, W. (1980). The definition of Normalization: Update, problems, disagreements, and misunderstandings. In Flynn, R.J., & Nitsch, K.E. (Eds.), *Normalization, social integration, and community services*. Baltimore, MD: University Park Press, 71-115.
- Wolfensberger, W. (1983). Social Role Valorization: A proposed new term for the principle of Normalization. *Mental Retardation*, 21(6), 234-239.
- Wolfensberger, W. (1984). A reconceptualization of Normalization as Social Role Valorization. *Mental Retardation (Canada)*, 34(7), 22-26.
- Wolfensberger, W. (1985). Social Role Valorization: A new insight, and a new term, for Normalization. *Australian Association for the Mentally Retarded Journal*, 9(1), 4-11.
- Wolfensberger, W. (1991a). *A brief introduction to Social Role Valorization as a high-order concept for structuring human services*. Syracuse, NY: Training Institute for Human Service Planning, Leadership and Change Agency (Syracuse University).
- Wolfensberger, W. (1991b). *La valorisation des roles sociaux: Introduction a un concept reference pour l'organisation des services*. (A. Dupont, V. Keller-Revaz, J. P. Nicoletti, & L. Vaney, Trans.) Geneve, Switzerland: Editions des Deux Continents.
- Wolfensberger, W. (1991c). *La Valorizzazione del ruolo sociale: Una breve introduzione al concetto di valorizzazione del ruolo sociale inteso come concetto prioritario per la strutturazione dei servizi alle persone* (M. Costantino & A. Domina, Trans.). Geneve, Switzerland: Editions des Deux Continents.
- Wolfensberger, W. (1992). *A brief introduction to Social Role Valorization as a high-order concept for structuring human services*. (2nd (rev.) ed.). Syracuse, NY: Training Institute for Human Service Planning, Leadership and Change Agency (Syracuse University).
- Wolfensberger, W. (1995a). An "If this, then that" formulation of decisions related to Social Role Valorization as a better way of interpreting it to people. *Mental Retardation*, 33(3), 163-169.
- Wolfensberger, W. (1995b). *A brief introduction to Social Role Valorization: A high order concept for addressing the plight of societally devalued people, and for structuring human services*. (Japanese trans. by Y. Tomiyasu). Tokyo, Japan: K.K. Gakusha. (Based on a revised and enlarged version of: Wolfensberger, W. (1992). *A brief introduction to Social Role Valorization as a high-order concept for structuring human services*. (2nd (rev.) ed.). Syracuse, NY: Syracuse University Training Institute for Human Service Planning, Leadership, & Change Agency.
- Wolfensberger, W. (1996). Reply to John O'Brien's "Nobody outruns the trickster: A brief note on the meaning of the word 'valorization.'" *SRV/VRS: The In-*

*ternational Social Role Valorization Journal/La revue internationale de la Valorisation des roles sociaux*, 2(1), 16-20.

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 and Change Agency (Syracuse University).

Wolfensberger, W. (1999). Concluding reflections and a look ahead into the future for Normalization and Social Role Valorization. In R. J. Flynn & R. Lemay (Eds.), *A quarter-century of Normalization and Social Role Valorization: Evolution and impact*. University of Ottawa Press, 489-504.

Wolfensberger, W., & Glenn, L. (1973). *Program analysis of service systems (PASS): A method for the quantitative evaluation of human services. Handbook. Field Manual*. (2nd ed.) Toronto: National Institute on Mental Retardation.

Wolfensberger, W., & Glenn, L. (1975, reprinted 1978). *Program Analysis of Service Systems (PASS): A method for the quantitative evaluation of human services: (3rd ed.)*. Handbook. Field Manual. Toronto: National Institute on Mental Retardation.

Wolfensberger, W., & Thomas, S. (1983). *PASSING (Program analysis of service systems' implementation of Normalization goals): Normalization criteria and ratings manual* (2nd ed.). Toronto: National Institute on Mental Retardation.

Wolfensberger, W., & Thomas, S. (1988). *PASSING (Programme d'analyse des systemes de services applica-*

*tion des buts de la valorisation des roles sociaux): Manuel des criteres et des mesures de la valorisation des roles sociaux*. (2ieme ed.). (M. Roberge, trans.; J. Pelletier, Adap.) Toronto: l'Institut G. Allan Roeher & Les Communications Opell.

Wolfensberger, W., & Thomas, S. (2005). *Introductory Social Role Valorization workshop training package*. Syracuse, NY: Training Institute for Human Service Planning, Leadership and Change Agency (Syracuse University).

Wolfensberger, W., & Thomas, S. (in press). *PASSING: A tool for analyzing service quality according to Social Role Valorization criteria. Ratings manual*. Syracuse, NY: Training Institute for Human Service Planning, Leadership and 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 Roles Sociaux*, 2(2), 12-14.

Wolfensberger, W., & Tullman, S. (1982). A brief overview of the principle of Normalization. *Rehabilitation Psychology*, 27(3), 131-145. Opell.

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**The citation for this article is:**

Osburn, J. (2006). An overview of Social Role Valorization theory. *The SRV Journal*, 1(1), 4-13.

# Re-Thinking Respite

John Armstrong & Lynda Shevellar

EDITOR'S NOTE: *Within this article, the authors have at our request interspersed comments pointing out connections of their topic with SRV. Those interspersed comments are printed in a different font so that they can be easily recognized.*

Social Role Valorization provides a framework for upgrading the social status of people at risk of devaluation and even those already devalued. This article examines one particular service model – the traditional respite service model – to assess the ways the potential for valued roles is facilitated or impeded, and what steps might be taken to increase the chances that children especially, but also their parents, might receive the benefits that valued social roles may bring.

*“Families with a child who has a disability or chronic illness know the commitment and intensity of care necessary for their children. The level of dedication and care becomes part of daily life, part of the family routine, but this same commitment can make stress routine too... It is obvious to anyone who has lived this life that respite care becomes a vital service – a necessity, not a luxury”* (National Information Center for Children and Youth with Disabilities, 1996).

## The “Need” for Respite Care

THE “NEED” for respite care is generally uncontested. Respite is commonly regarded as a necessity and indeed is often described as a “right.” This paper seeks to explore the Respite Service Model as being one of *the* most dominant and expanding service models available to children and families. In this exploration, we are not seeking to critique specific respite services, nor to question the very genuine struggle that families experience, as articulated in the above quote. Rather we seek to explore the assumptions underpinning the model that such service responses rest upon. Whilst our analysis is drawn from working with and evaluating respite services in Australia, we suspect that these trends are consistent amongst other Western countries. Researchers note that there is an increasing demand for even greater levels of respite care to be provided by governments around the world (Pearson & Moore, 2001). With increasing demand comes increasing expectations. This paper asks whether it is possible for the respite model to bring the benefits that most of us have to come to expect from it. Moreover, could it be possible that the respite model exacerbates the very problems it is designed to remedy, for the parents as well as their son or daughter?

“RESPITE” IS A TERM that at first seems clear but has a number of subtle meanings. It

shifts from respite as use of time, to respite as a geographical location. The Respite Review Report defines respite as a “desired outcome of an intervention” and “a description of those alternative care arrangements that are funded and provided as one way to produce the desired outcome for carers” (Australia’s Commonwealth Department of Health & Family Services, 1996, p. 40). Pearson and Moore (2001) see it as simultaneously meeting two policy goals: to provide support to carers; and to prevent or delay admission to residential care. At a more practical level, Ingram (n.d.) suggests that “respite” refers to short term, temporary care provided to people with disabilities to provide relief to families from the daily routine of caregiving. Referring to it as “the gift of time,” she suggests that one of the important purposes of the respite model is to give family members time and to temporarily relieve the stress they may experience while providing extra care for a son or daughter with a disability. Respite services also operate within the aged care arena, providing similar assistance to people who care for their parents, or spouses. Ingram also supports the notion that this “relief” helps prevent abuse and neglect, and supports family unity.

The features of such services vary enormously; however the dominant versions at present include day centres, overnight care for an extended period of time, or occasionally in-home assistance (which may also include shorter outings). The shared feature is a response to the question, “Who takes care of the caregivers?” (National Information Center for Children and Youth with Disabilities, 1996).

PEOPLE IMMERSSED IN A CULTURE tend towards uncritically embracing that culture. It is not surprising to find some families who become enveloped in a human service system simultaneously growing more isolated from the

wider culture. Such families will “need” and seek more of those things that the human service system has to provide. This need arises from many reasons that include:

- few service arrangements that really advance people's circumstances;
- a poor array of service options - especially for adults with disabilities;
- respite being a familiar and historically valid response;
- a school system that most often poorly prepares children for adulthood, and adult and work roles;
- “post school options” for adults that provide few real community roles, skills or associations;
- political imperatives that encourage the development of particular solutions to community issues but which unintentionally lock devalued people out of valued roles and into negative or devalued roles;
- economic imperatives that encourage congregate models of care;
- low expectations for disabled adults generally; and
- in the face of such systemic inadequacies, a call to provide more respite to alleviate the “needs” of families.

Certainly, the severe nature of many family circumstances exacerbated by systemic dysfunctionality leads parents to reach out for what is often the only presented “solution;” namely, respite. Families with members who have disabilities experience the absence of appropriate financial, emotional, physical and social supports. These difficulties are heightened as parents become older. For example, Queensland Parents of People with a Disability (QPPD, 1989) reveals the following comments by parents:

- “He goes to the nursing home in the next



town for a holiday. That's very expensive and hardly a holiday;"

- "No one will take her for respite because of her special diet;"
- "I can never do anything spontaneous. Any respite has to be planned weeks ahead;"
- "All I have for respite now is a trip to the local hospital for a couple of weeks;" and
- "It's so undignified asking for help. I virtually had to slash my wrists and drop blood all over their desks before the administration would give me respite."

It is assumed that a break will deliver much needed rest and refreshment, especially in the presence of an incoherent service system, that the parents will have become strengthened and ready to take on the challenges of the returning family member. However, evidence suggests that rather than strengthen parents, it may actually reinforce the necessity for such periods of respite at increasing intervals and duration.<sup>1</sup> McNally, Ben-Shlomo and Newman (1999) reported "29 studies from which there was little evidence that respite intervention has either a consistent or enduring benefit on carers' well being" (cited by Pearson & Moore, 2001, p.12). Like an addictive drug, respite is both an expression of things not being quite right while also being the panacea for it.

Many parents and people with disabilities are highly conscious of the limitations of the respite model, but struggle with the lack of alternatives, or the lack of flexibility in how funding might be used. The prospect of placing a family member with strangers, or being placed in particular environments, creates a dilemma, and even dread:

- "I don't like the idea of a respite care bed in their house with a different person coming to stay every week. That's not a normal home life!" (QPPD, 1989, p. 61).

- "I have respite in (a nursing home). I dread it every year. It's like doing a term in prison" (QPPD, 1989, p. 61).

### Implications of the Respite Model

IF THE RESPITE MODEL was actually renewing, it should enable parents to *better* deal with the support issues of their son or daughter. Instead what it typically reinforces is how much families "need more respite," in an ever increasing cycle of escalating "need." Why is this the case? Why do parents who receive respite need even more? Why can it still end with permanent residential care, as is evident from anecdotal experience (which respite is supposed to prevent or delay), for a son or daughter? And most importantly, is there any other way around this? Setting aside the issue of "rights to respite" and other entitlement perspectives, let us look at what respite is commonly like.

SRV helps in distinguishing between what a need is versus how to meet it. It is a common error to confuse these two aspects and can cloud one's thinking about how to best meet someone's needs, if you have *already* determined how it should be met. For example, no one needs 'respite' – not even parents. What they may need is rest, recovery, re-energising, and inspiration. They may also need a way of hanging onto their valued roles and to remain part of a wider community. If we define their needs as the service, i.e., 'respite,' we have already closed off the possibility of exploring other things that would really meet these needs.

The respite model physically and/or socially separates one party out for the benefit of another. In other words, the primary recipient of respite – the family<sup>2</sup> – receives an *indirect* service; the secondary recipient – the son or daughter – receives a *direct* service. By removing the person or exchanging the “care giver,” the primary purpose of respite has been attained. Nothing more need be expected – except more of it! The interests of the primary recipient party (the family) have been served. What happens to the person once they are removed is *not* the essential or primary concern. The focus is on the removal and/or separation of one party to affect a “break” for another.

Another important SRV related construct is whether a service is *relevant* to the person(s) being served. Relevance requires that there is a precise match between what a person needs and what they get. This of course assumes that the service recipients’ needs have been correctly appraised, how urgent or exaggerated those needs are, and what response is suitable or relevant. If a service is irrelevant, then the person’s needs will be exacerbated to some extent, even to the point that the service becomes damaging because of the mismatch between what they need, and what they receive. This article is looking here at the potential of such a mismatch in a respite care context and what that might produce.

Consequently, respite becomes a passive service form. By passive, we mean a service response that is at the same time concerned about time (away from the family), but also not concerned about time (how the time of the removed person is occupied). This is because the respite model, even when it is regularly and repeatedly provided, is often an immediate

short-term response to a longer-term difficulty within a family, but which does not address that difficulty. Thus, not only is respite passive, it is a short-term remedy applied repeatedly – sometimes for a very long time, even decades – with little or no remediating effect on the family structure. In short, it is a solution that does not actually address the fundamental problem.

Passivity is further demonstrated when sons and daughters receive activities, outings, trips to places like shopping malls, movies, television, picnics and the like, or confinement in facilities which of themselves *appear* benign enough but are largely irrelevant and wasteful to an adult future, and especially so because it is endlessly repeated. The other people in the respite program which one does this with, who may be *very* diverse in age, ability and compatibility, can reduce even further the potential of doing something for the service clients that contributes to a beneficial future.

The respite model also raises problems in relation to its purview. Our assumption is that services should be developing competencies – assisting people to learn and grow.

Most competency or ‘function contingent’ roles (e.g., cook, mechanic, economist, homeowner, etc.) require competencies to perform them. Thus a major SRV-related strategy – also in common with many other approaches – is the developmental growth orientation a service will require if it is to successfully facilitate people’s development into valued social roles.

However, if the respite model is utilised, the opportunity for developing competencies is reduced because the influence on a person’s life *appears* to be so small. Yet the cumulative effect of years of non-growth-oriented respite is

devastating.

If the culturally valued analogue (CVA) for respite is one of "holiday," it may be argued that respite provides "rest and relaxation" to people with disabilities, in much the same way as people without disabilities look forward to holiday time.

The *Culturally Valued Analogue* (CVA) comes up a lot in SRV because it relates to the way a service effort would operate if it was provided to valued people. Such a handy construct provides insight into how those types of needs would typically be met, how growth would be facilitated, and how images about people would be enhanced. In other words, the CVA is a handy benchmark for a service to compare its activities against, and to ask whether one is doing anything that violates the CVA, and what might be done about it. Violation of a CVA runs the risk of failing to meet people's needs, looking strange against the wider culture, and therefore damaging the image of service recipients. Violating the CVA (as in a prominent example like an institution) can also lead staff to think that strange practices are warranted and can overlook or excuse how bizarre things may have become (cf. Wolfensberger & Thomas, 1983, pp. 16-17).

Within this CVA a reduced purview may therefore be appropriate. There are however a number of important considerations. *Firstly*, rest and relaxation are appreciated in contrast to a hectic and demanding life. For many people with disabilities the dilemma is more one of a lack of busyness and the need for meaningful activity rather than a need for yet more rest. *Secondly*, such an approach denies the multitude of forms that a holiday can take. For

many people recreation may also take the form of learning ("Let's travel overseas"), pursuing interests ("I want to get to the artist's retreat this year"), setting goals ("At last I can repaint the kitchen") and taking on new roles ("I can't wait to become a gym-member again"). For some people, holidays actually require a greater expenditure of energy and provide a rich range of experiences and roles. For people with disabilities experiencing the respite model, particularly centre-based respite, there is often simply the continuation of the role of client and the opportunity to continue doing little within a new location. Judith McGill asserts that given the isolation and lack of community integration for many people with disabilities, and the importance of developing strong identities, there is a compelling need for more active, person-centred, community-based recreation, rather than yet more passive leisure time (Hutchinson & McGill, 1998; McGill, 1996).

### **A Change in the Nature of the Parent/Child Relationship**

RESPITE CAN START for one reason but continue for another. Parents normatively become more exhausted the more isolated they are. But desperation and competition for scarce support can draw a parent into a cycle of exaggerating demand where their "needs" for respite have to escalate. Sometimes collective action by parents also reinforces this claim by interpreting the need for respite as a "Right."<sup>3</sup> This is further reinforced by a broader societal trend (at least within Australia) to present oneself as pathetic as possible in order to be "eligible" for a particular service or payment. In our experience, this arrangement can foster and promote an unhelpful role dynamic.

SRV utilises what is known (from social

science) about how valued and devalued roles operate so as to affect the formation of positive perceptions about the people we know and support. This section examines the interplay of roles between people so that a conscious use of this interplay can be used for positive advantage.

We know that many roles occur as complementary to another person's role (Newcomb, Turner & Converse, 1975; Lemay, 1999). This complementarity of roles is a healthy and normative part of our society and occurs in everyday circumstances, such as the roles of parent and child, doctor and patient, employer and employee, or teacher and student. However, a negative interdependency of roles (Berne, 1961; 1964) can also be constructed, such as the roles of addict and supplier. This interplay of roles and expectations is often unconscious and results from a range of subtle social dynamics. It is never the result of just one person's actions, but is based on interdependency and interaction that serve to encourage and reinforce each other's roles.

### **How the Service Interaction Can Facilitate Further Changes**

THE RESPITE MODEL OF SERVICE can create a "drama triangle" (Karpman, 1968) wherein the role of a parent seeking greater amounts of respite can have a negative effect on their son or daughter's role. In the absence of informal supports, the family seeks increasing amounts of formalised arrangements to rescue them from this difficulty. The parent may enter the Victim role<sup>4</sup> - either unconsciously constructing him or herself as a Victim, or being constructed into the role by others. The son or daughter is then identified as the "cause" of the difficulty, and is thus cast into the devalued

role of Burden.

For example, one of the things we know from social science is that anyone can descend into negative roles quicker and easier than ascend into positive roles. We also know that this is especially powerful if certain (often devalued) people have little or no access to valued roles, and fill their *deep* need for a role with even a small role or relatively insignificant feature, or even an entirely negative role. This section examines how that might be possible not only for a disabled son or daughter – but also a parent, and how service interactions could facilitate or strengthen such a process. Of course it would be best if this descent into negative roles were avoided altogether.

The Victim role is more secure the more its contrasting and (negative) complementary role of Burden is demonstrated. Thus the more difficult a child is presented to be, the more convincing the parent's plight. As Victim, the parent is demonstrated to be more deserving of greater paid intervention. The following passage illustrates the construction of the parent as Victim vividly:

*"[A]n increasing number of families are finding it tougher to deal with a catastrophic illness or a family member with a disability. The insidious thing about all this it has been like a rising evening tide, not a tidal wave, so it has caught us out, and it has caught individual families out, and many times we do not hear with clarity the pleas for help, and we do not often understand the magnitude of the problems we are dealing with"* (Botsman, 2000).

The drama triangle is a potentially very damaging dynamic, as the roles can shift and

intensify over time. For example, in Australia, the growth in “managing challenging behaviour” has seen people with disabilities “multiply in deviancies” (cf. Wolfensberger, 1998, p. 17) from the Burden role to also acquire the Menace role. As both parents and their children grow older, there is also increasing evidence of people with disabilities entrapped in the Eternal Child role, or being given the role of already aged or sick with respite models based in Hospitals, Nursing Homes or Senior Citizens centres.

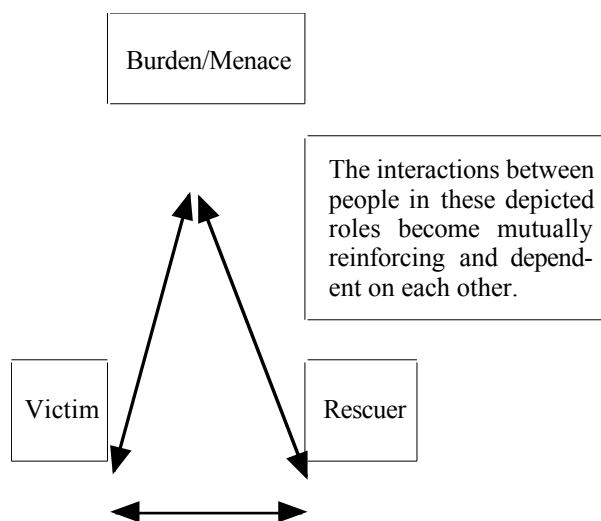
Families may indeed be burdened by the social situation they find themselves in. However, this private experience is very different from the public construction of their loved one as a burden. Over time, the burden role can even be internalised by the person, as the following quote from a young woman with multiple disabilities illustrates:

*“I feel trapped. I’m just between the same two walls all the time. Mum and Dad get sick of me. I’m always in the road. I feel I’m just a pest. They are always having to worry about me”* (QPPD, 1989, p. 61).

Third parties, such as Respite Services and their personnel, can reinforce this drama triangle by providing “emergency” aid, thus adopting the role of Rescuer. This is especially so if the agency and workers subtly emphasise and reinforce how difficult living with this person must be. For some conditions (for example, dementia and acquired brain injury) it is common to see workers identify much more closely with the “carers” than with the impaired person. The service feels and becomes indispensable to the Victims’ circumstances and stops questioning the arrangement as it become internally reinforcing between all three parties. For example, Disability Services Queensland pro-

claims, “Respite services play a *critical role* in keeping families together” (2004, added emphasis).

Psychological theory (Corey, 1991) suggests that this interplay represents a power struggle with the Rescuer (often unconsciously) working to keep others in a dependent position, whilst over time some Victims may grow to resent and even persecute the Rescuer. As the dynamic escalates, the service may begin to construct *itself* as the Victim of the family, creating resentment towards the family or the person with a disability, declaring them no longer eligible for service or referring them onto other agencies “who can meet their needs.”



The Victim role will become especially enlarged if there are few other roles in the parent’s life - especially those of a more normative nature: spouse, worker, colleague, neighbour, expert, craftsman, etc. (Lemay, 1999). Even the language of family: “mum,” “dad,” “brother,” “sister,” etc. can be replaced by “service-oriented” words like “caregiver,” “carer” and even “junior carers” for siblings. The Victim role can even drive out existing valued social roles by depleting the energy needed for such roles as

neighbour, friend, spouse and even parent (to other children).<sup>5</sup> The Victim role can expand to affect every interaction with service providers and the service system in general, even to the extent of notoriety in the service system. Others may shrink and quietly accept their fate as a Victim, perhaps because of some perceived past sin. Some Victims might graduate into the Martyr role and receive (as in one example in Australia) a “Carer Long Service Award.” The point here is not to denigrate parents or to demonise services, but to acknowledge some systemic processes that are not always beneficial. It is also to acknowledge that current service paradigms can limit creative thinking. One can only change what one acknowledges.

### **The Role Dynamics for the Son or Daughter**

THE IMPACT for the son or daughter is that for them too, the Burden role becomes reinforced. One sees this very prominently today with children being diagnosed with so-called “Attention Deficit Disorder” and “Attention Deficit Hyperactivity Disorder.” Descent into these negative roles of behaviour problem or learning disabled child requiring psychotropic drugs can be very quick and easy but can take years to escape from – if ever (Wolfensberger, 1998). Indeed, the role of Burden is antagonistic to most valued roles; such as successful student, regular team member, or best friend, partly because the parents’ assumed Victim role is not sustained by valued roles the child *could* acquire. (This is another example of a negative role complementarity). For example, a parent can not make the claims of a Victim if the child is a successful student or team member. If the child is to acquire valued roles, the parent would have to be prepared to surrender

(or avoid) the Victim role altogether. Some parents are very capable of doing this and even work actively against it; others though depend on that role for identity, reputation and services and may unconsciously and unwittingly undermine efforts to bring a better life to their son and daughter – and to themselves. For example, it is not uncommon for many older parents to keep their disabled adult children *very* dependent on them for even the smallest things, and in a sense they become enslaved together (Wolfensberger, 2003).

Another difficulty created through the use of the respite model is that the nature of some disabilities may mean that respite actually exacerbates rather than resolves difficulties. For example, for some people, removal from familiar environments and familiar routines associated with overnight respite can actually increase anxiety or create a kind of sensory overload (Donnellan & Leary, 1995). The result may be changes to behaviours during the respite experience or upon return to the family home. Longer forms of respite remove people from what is culturally typical, thus further alienating socially devalued people, decreasing competencies, decreasing opportunities for freely-given relationships and enlarging a more devalued identity.

### **Asking Different Questions**

AS NANCY ROSENAU asserts,

*“This is not to suggest that respite is not useful: I am saying that service providers can miss the point when the answers elicited from families identify respite or placement as the need”* (Rosenau, 2002).

The requirement for artificial forms of respite via paid or organised arrangements comes

largely as a result of the devaluation and consequent isolation a family experiences when their child is disabled, combined with the unwillingness and/or incapacity of others to provide freely-given support. As one parent said:

*“If all my kids were normal, I would expect them to be in a crèche if they were young, to spend a night or two with their grandparents, to be playing in the street or in a playgroup, or playing in the backyard or over with their friends. **None of these things are possible** when your child has a significant disability, so you get no break, no respite.”* (Pearson & Moore, 2001, p. 16, added emphasis).

A service (formal or informal) *is* required. The assumption has been that it should be “respite.” Nancy Rosenau encourages us to ask instead, “What would it take so that both the family and the child get a life?” Usually the valued ways of doing things provides a clue.

Respite is a means to something (getting a break, feeling refreshed), but in our current human service culture it tends to be stated as an end: “I need more respite.” Instead of seeing the need for a break as a disability-specific problem, the alternative is to understand that *all* relationships are enhanced by time together as well as some time apart. In the course of everyday life, this need is carefully balanced in a range of ways – rarely would this be referred to as “respite.” Family members or housemates spend time apart through their individual involvement in work, school, and leisure activities, by spending time in the company of friends or other family members, undertaking everyday tasks, receiving formal or informal assistance from others, or going on holidays with friends.

Thus instead of “respite” being viewed as

the ends or purpose of the service, and the means consisting of placements, allotted hours, respite houses or day services, the focus moves to what it takes to assist someone to live their life to the fullest. The means to do so are as varied as life itself. If a person has a range of activities they enjoy, in a range of valued environments, with a range of relationships with differing levels of intimacy, then they naturally will spend time both with and away from family. Real respite occurs as a by-product, a natural consequence of engaging in activities with others inside and outside the home.

SRV challenges us to think about how people might really acquire valued roles and avoid the descent into devalued roles that are often awaiting them. Certainly the use of means consistent with the valued culture (the CVA) will provide some clues, as well as those arrangements that serve the long term interests of a service recipient, their family and community. Circumstances are more likely to prevail and be sustainable if major parties (families and communities, etc.) obtain some reciprocal benefit as well. Valued roles commonly bring such reciprocal benefits. For example, instead of unemployed, one might become volunteer and later worker.

Some recent alternatives implemented by just one respite agency for young people up to age 20, as a deliberate effort to bring them into valued social roles, includes such initiatives as:

- workers supporting improvements to a child's behaviour at home so that their role in the family and their relationship to the parents and other siblings improves;
- a worker accompanying a family on their annual holiday instead of leaving one family member back in respite;
- implementation of a toilet training program at

- home for two children (thus avoiding the negative role of “incontinent” and the many restrictions it produces);
- a worker assisting an unconfident parent to venture out successfully with three children. Scouts and choir activities are now occurring after school as well;
  - a worker teaching a child to travel by bus and to navigate road crossings;
  - a worker teaching three children from one family to plan a menu, go shopping and take part in preparing a meal together;
  - a worker and young person practicing their guitars together;
  - a worker teaching soccer to the whole soccer team that includes the disabled team member he is providing “respite” to. Mum comes to watch; and
  - a worker supporting students in an after-school job in a supermarket.
- host family arrangements for *all* the children to holiday together;
  - a neighbour regularly collecting the mail from the post office, and purchasing bread and milk;
  - an art tutor coming to the home to provide lessons; and
  - an aunt being present at busy times such as meal preparation and bath times.

SRV is not only applicable to formal paid human service arrangements, but will have much to offer for *informal, unpaid and natural circumstances* as well.

Another important requirement for building valued social roles in a service in addition to *relevance* is that of *potency*. You will notice in these examples how potency of delivery is achieved through the judicious and intense use of time, utilising valued and suitably challenging settings, social arrangements with other (usually valued) people, and the use of competency enhancing material supports and equipment, and the right match between the child (in these cases) and the worker.

None of these activities involve bricks and mortar. Yet through these various activities, instead of the negative role of Burden, the person develops a variety of valued social roles – for example: sibling, family member, neighbour, friend, guest, club member, team-mate, colleague, participant, student, volunteer and so forth. The more valued roles a person has, the more likely they are to experience the “Good Things in Life” (Wolfensberger, W., Thomas, S., Caruso, G., 1996) and the more likely the family are to have a “Good Life” too.

In another part of Australia respite is being thought of more flexibly by utilising informal and generic supports to also come into play, including:

- someone accompanying the family to a restaurant to assist the daughter to eat, enabling the rest of the family to simply enjoy her company and the restaurant experience;

Additionally, clarity around the identity of the primary service recipient would bring many benefits, for example, the service being extended to primarily serve the interests of the person with a disability. Thus the direct service serves the primary service recipient (the person with a disability), and the indirect benefits serve the secondary recipients (the family) instead of the other way around.

Notice how the above examples provide a clear and active role for service workers as well. Rather than passively filling time or pursuing activities that have little long term benefit, workers are acting with initiative and purposefully bringing competencies and improved im-



ages to the person. Such an active and responsible role is bound to have positive repercussions for securing and maintaining effective workers. *Everyone* needs to grow.

There may be some initial limitations, as with people who have extensive medical needs or whose situations are threatened by the presence of others, perhaps because of infection risks and the like. But this does not negate the point that formal and informal support arrangements can be used to facilitate positive competencies and images for those people and to explore ways of crafting valued roles, and the ordinary experiences, involvements and relationships they bring into a person's and therefore their family's life. The more that these involvements increase, the more they will provide the break families require to pursue their own roles.

As Nancy Rosenau suggests, we need to ask different questions. These questions are not about what it takes to get respite but about what it might take to "get a life."

#### References:

- Australia's Commonwealth Department of Health & Family Services, Aged & Community Care Division (December 1996). *The respite review report*.
- Berne, E. (1961). *Transactional analysis in psychotherapy*. New York: Grove Press.
- Berne, E. (1964). *Games people play*. New York: Grove Press.
- Botsman, P. (2000). *A speech to the Endeavour Foundation, Brisbane, 1 December 2000*. The Brisbane Institute, Brisbane.
- Corey, G. (1991). *Theory and practice of counseling and psychotherapy*. Pacific Grove, California: Brooks/Cole.
- Disability Services Queensland, (2004). *Future directions of disability services, budget 2003-2004, June 3*. Queensland Government.
- Donnellan, A. M. & Leary, M. R. (1995). *Movement differences and diversity in autism/mental retardation: Appreciating and accommodating people with communication and behaviour challenges*. Pacific Beach, California: DRI Press.
- Hutchinson, P. & McGill, P. (1998). *Leisure, integration and community*. Toronto: Leisurability Publications.
- Ingram, D. (n.d.). *Respite care*. The Arc. Accessed online at <http://www.thearc.org/faqs/respite.html>
- Karpman, S. (1968). Fairy tales and script drama analysis. *Transactional Analysis Bulletin*, 7 (26), 39-44.
- Lemay, R. (1999). Roles, identities, and expectancies: Positive contributions to Normalization and Social Role Valorization. In Flynn, R., and Lemay, R. (Eds.), *A quarter century of Normalization and Social Role Valorization: Evolution and impact*. Ottawa: University of Ottawa Press, pp. 219-240.
- McGill, J. (1996). *Developing leisure identities*. Brampton, Ontario: Brampton Caledon Community Living.
- McNally, S., Ben-Shlomo, Y., Newman, S. (1999). The effects of respite care on informal carers' well being: A systematic review. *Journal of Disability & Rehabilitation*, 21 (1), pp. 1-14.
- National Information Center for Children and Youth with Disabilities (June 1996). *Respite care. NICHCY News Digest, #ND12*, Update.
- Newcombe, T., Turner, R., & Converse, P. (1975). *The study of human interaction*. London: Routledge and Kegan Paul.
- Pearson, J. & Moore, D. (2001). *Research into respite care: The views of carers of young people with severe and profound disabilities in selected rural, remote and indigenous communities of Australia*. Final report prepared for the Commonwealth Department of Family and Community Services.
- Queensland Parents for People with a Disability (QPPD) (1989). *Quality lifestyles: A statement*. Annerley, QPPD.
- Rosenau, N. (2002). Asking the right questions. *Family for Social Change Newsletter*, 3, (9), pp. 4-5.
- 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, Leader-

ship & Change Agency (Syracuse University).

Wolfensberger, W. (2003). *The future of children with significant impairments: What parents fear and want, and what they and others may be able to do about it*. Syracuse, NY: Training Institute for Human Service Planning, Leadership and Change Agency (Syracuse University).

Wolfensberger, W., & Thomas, S. (1983). *Program analysis of service systems' implementation of Normalization goals: Normalization criteria and ratings manual*. Toronto: National Institute on Mental Retardation.

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 roles sociaux*. 2 (2), pp. 12-14.

*Thanks to our colleague Jane Sherwin, and to the board, staff and parents of FaBRiC in the ACT for their valuable comments on earlier drafts of this work.*

#### Endnotes

1. Whilst some studies do show parents being highly satisfied with their respite service, this is a different question as to the long-term impacts of respite services.

2. Many agencies are aware of the tension between the interests of one party over another, and intend to ensure that the child's interests are represented or even focussed on. Our point here is that there is a tension between what are often competing and even opposing interests.

3. Recently in Australia, one example of collective action claimed that 'carers' saved \$30 billion a year for the government, implying that such care should have been provided by government anyway and that the current arrangement of 'unpaid care' provided by parents netted the government a very significant saving!

4. The Victim role is an "attractive" negative role to many people: it often engenders sympathy from others, it reduces personal responsibility for a circumstance, and may make one eligible for various services. And yet like many negative roles it can entrap the incumbent. The Victim role becomes less attractive over time to others who tire of the interaction with the Victim, and so the role may produce withdrawal, despair and even anger from other parties.

5. It is acknowledged that it is not only the victim role which can drive out other roles, but also the additional demands of being a "good" parent, as well as the normative (rejecting) reactions of family, friends and community.

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#### The citation for this article is:

Armstrong, J. & Shevellar, L. (2006). Re-thinking respite. *The SRV Journal*, 1(1), 14-25.

# Some Helpful Points to Keep in Mind in the Presence of People Who Cannot or Do not Talk

Joe Osburn & Jo Massarelli

AUTHORS' NOTE: *We wish to acknowledge Darcy Elks for her contribution to this article.*

## Introduction

ONE OF THE KEY ELEMENTS of Social Role Valorization (SRV) theory is the importance of interpersonal identification between societally valued and devalued people. Yet, there are certain devalued groups or individuals with whom interpersonal identification is a major challenge to others. There can be many reasons for this; one reason, the focus of this article, is when the people in question cannot or do not communicate in the ordinary ways, such as those who do not speak or whose speech is so idiolectal or peculiar to the person that most others have great difficulty comprehending it.

Many people, even very gregarious ones, often feel quite awkward when in the presence of non-communicating people, and sometimes excruciatingly so, to the point that they may actively avoid such social contact or seek to remove themselves from it as quickly as possible. Having such feelings is an understandable response, especially when people are not accustomed to being in these kinds of situations, but it can also happen even when they are. In other words, people can still experience discomfort being with non-communicating people with whom they live or work or have other regular contact, as well as with those whom they do not know.

These facts are important to SRV promoters and implementers for at least two reasons. First, as a result of these difficulties, people who cannot or do not talk, or whose speech/communication is exceedingly difficult for most others to understand, are inevitably in great need of role-valorizing actions on their behalf. The less a person can speak or communicate, the more rejected, segregated, lonely, and abandoned that person is apt to be, the more that person is likely to be further extruded from society, harmed, and even made dead, and the more difficult it is for others to imagine that person holding valued social roles. A second reason is that because SRV is oriented to devalued people, and because non-communicating people are often devalued, SRV practitioners are highly likely to encounter at least some, and perhaps many, people who cannot or do not talk, and on perhaps many occasions. (For example, for some people, the first -- and possibly only -- such encounters may occur during SRV/PASSING training if they are on teams that conduct practicum assessments of settings that serve non-communicating people.)

It can be a challenge to those who take SRV seriously to "rise above themselves," at least temporarily and on some occasions, and to come to grips with any affective impediments or other distancing inclinations they may have to encounters with people who do not communicate in typical ways. Following are some general considerations and actions intended to facilitate positive interactions be-

tween people on such occasions by (a) helping to raise consciousness about the potential difficulties of being with people who cannot speak or otherwise communicate; and (b) encouraging people to think more about their own strengths/weaknesses, or levels of comfort/discomfort, in this regard.

### General Considerations

1. Human communication is imperfect and limited, even when it takes place between competent people; this is true of human language as well, whether spoken or written, and in spite of its great power to convey meaning.

2. Communication is virtually universal among human beings. Thus, when people encounter another human being, they are highly likely to assume automatically that the other person has a capacity for reciprocal communication with others, even where that may not be the case.

3. People who cannot or do not talk are often the ones who are *most* in need of having others strive to communicate with them and/or for them.

4. Some people do not speak because they are physically or mentally impaired in their ability to do so. When this is the case, two opposite dangers must be acknowledged.

a) One danger is to *wrongly assume* -- as we have seen over and over again historically -- that an impaired person cannot communicate who actually can, but perhaps only with great difficulty or very slowly or in a way that is difficult for others to discern, or only about a limited range of topics.

(b) A second danger is to fall into a *triple pretense* about a person who may not be able to communicate at all -- as may be the case if mental competence is very severely impaired --

that (i) the person can communicate, or (ii) is communicating what he or she in fact cannot, and (iii) what others interpret about that person's communication is real.

5. Lack of speech is not the same as inability to communicate.

6. Talking is only one form of direct personal communication. Other forms include:

- gestures
- emotions and moods
- behaviors
- facial expressions
- signs, signing, signals
- sounds
- reading and writing
- use of pictures, drawings, and other/visual aids.

7. Communication almost always gets "easier" with effort and time, mainly because (as with anyone) the more one gets to know a person, the better one usually understands that person. (Another way to say this is that one's comprehension goes up the better one knows the person.)

8. Human presence is a gift: giving and receiving it is a good that can be realized without talk.

### Actions That May Facilitate Communication

1. Unless one knows for sure that another person possesses no ability to communicate, one should probably assume that the person can rather than cannot communicate. Such a positive assumption is congruent with the developmental model component of SRV, and presumes that communication is much more likely to happen than if one holds a less positive assumption.

2. In like manner, it is probably better to as-

sume that people who cannot or do not talk may nevertheless (perhaps deeply) *want* to communicate rather than that they do not want to. Of course, this is not always the case; certain people may not want to communicate -- at least not at the moment, or with a particular person -- whether or not they can speak.

3. Keep in mind that simply getting started is often the hardest part of any conversation with someone else who cannot/does not speak, and with whom one is not well-acquainted. For example, as noted above, initial feelings of awkwardness, self-consciousness, uncertainty about what to expect, and so on are normal. Thus, one elementary action measure is to acknowledge such feelings, recognize that having them is not "wrong," resolve to overcome them, and then go ahead. Such mental preparation is both facilitative of communication and considerate of others.

4. People need a *reason* to communicate, i.e., things to communicate about -- and finding or providing these can be greatly facilitative to the other person. For example, typical communication may rely, consciously or unconsciously, on such things as common experiences, backgrounds, interests, and goals shared by the communicators, the physical and social contexts in which their communication takes place, and any associated or co-occurring activities. Bringing these supportive elements to consciousness, and engaging them as topics of communication, can often help to facilitate additional and/or otherwise difficult communication.

5. Relatedly, when one anticipates or actually does encounter difficulties in conversing with another person, it is often helpful to change or modify the context in which the conversation takes place, such as by moving from a large or crowded room to a smaller, more intimate space, or by minimizing external distractions

(e.g., turning off the television). Helpful, too, may be engaging in some type of activity with the person where the focus is not so much on "talking" as on "doing," and where the "doing" prompts or even "demands" at least some degree of mutual communication. (Examples of the latter abound: going somewhere together, preparing and sharing a meal, playing a game, working on a common task, assisting the person in some way, etc.)

6. Requesting help from others is certainly appropriate in many instances. It is okay and sometimes necessary to ask others for cues, signals, and other assistance in understanding another person.

7. Relatedly, people who might not be able to converse with each other very well, or even at all, by themselves can very often communicate together quite well when their conversation is mediated by someone else who can communicate with both of them, i.e., an interpreter, interlocutor, or mediator. Sometimes such mediation involves little more than just a third person helping people "get started" and then leaving after they are able to carry on by themselves. However, sometimes a third person has to remain present as an out-and-out interpreter for and with the person, and this situation does not change over time; in other words, there are some people whom very few others can understand without the on-going aid of an interpreter, and where this will always continue to be the case.

8. It is very important to take time to listen, and persevere in one's efforts to understand. Related to the earlier point about the value of human presence, simply spending time in silence with someone who does not communicate can be edifying to the parties involved.

9. Even "talking" with a person about the situation of one's having difficulty understanding him/her is okay and helpful.

10. It is usually far better to ask a person to repeat him/herself, even several times, than to “fake it.”

11. When one does understand what a person is communicating, it is important to confirm to the person that one has gotten the message.

## Conclusion

AS STATED ABOVE, this brief article is intended primarily as a consciousness-raising item. It covers only a very narrow topic, and does not address many other and much more important concerns related to this issue. For example, these few suggestions do not necessarily address how to help other parties to fully relate to a person who cannot talk or otherwise communicate; nor do they tell how to determine what potential capacity, if any, a person has for communicating when that capacity is not now being recognized or realized; nor do they tell how to discover and nurture the hidden and possibly very unique mode by

which a non-speaking person may, indeed, be able to communicate, if at all; nor, lastly, do they provide guidelines for understanding and interpreting correctly what a person may be trying to communicate who does not do so in the normal manner. Thus, one should take caution against oversimplifying the needs of people who cannot or do not talk, or the requirements of adaptively serving or being with them, and while it is hoped that these few suggestions are useful, it is also clear that they are only a very small part of helping people who cannot talk or otherwise communicate to experience the good things in life.

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### The citation for this article is:

Osburn, J. & Massarelli, J. (2006). Some helpful points to keep in mind in the presence of people who cannot or do not talk. *The SRV Journal*, 1(1), 26-29.

## Peer-reviewed articles

Subsequent editions of *The SRV Journal* may include a section of peer-reviewed articles. Full-length manuscripts on research, theory, or reviews of the literature relevant to Social Role Valorization (SRV) are invited. These articles, with no identifying information about the author(s), will be sent by the Editor to appropriate experts for review of academic merit and relevance to SRV theory and application. Reviewers will be drawn largely, but not exclusively, from the editorial board. It is anticipated that the review process will take two to three months, at which time the Editor will communicate directly with the lead author regarding the outcome of the review process. Manuscripts may be accepted as submitted, may be accepted contingent on revisions, or rejected for publication. The final decision as to whether or not an article is published rests with the Editor.

The maximum length for peer reviewed articles is 6000 words. Authors should submit articles as an email attachment. All identifying information about the author(s) should be included in the body of the email that accompanies the attachment, not on the attachment itself. If at all possible, articles should be submitted in Microsoft Word. They should be double-spaced and in 12 point Times New Roman font.

Articles should be sent to the attention of *Marc Tumeinski, The SRV Journal, journal@srvip.org.*

# SRV by Direct Support for Specific Valued Roles

Paul Williams

THE SRV LITERATURE and SRV training are mainly concerned with principles and strategies for avoiding the ascription to people of negative social roles (e.g., nuisance, eternal child, sick person), and generating the general conditions for ascription of valued social roles (e.g., engaging in age-appropriate activities in an aesthetically pleasing building that conforms to its culturally valued analogue). There is relatively little mention of the direct support of people in specific valued roles that may be open to them. (Though there is some; see, for example, pages 84ff in Wolfensberger, 1998.) In this paper I will briefly outline what such support might look like in relation to seven socially valued roles: king, teacher, neighbour, friend, family member, parent, and artist.

CHARLES II OF SPAIN was cast into the role of king at the age of four in 1665 when his father died. He had quite severe physical impairments and learning difficulties. He was late learning to walk, he had difficulty eating because of a deformed jaw, and he had epilepsy. He never learned to read or write and it is said that the maximum amount of time he could concentrate on affairs of state was fifteen minutes. However, he was supported in his role as king by all the panoply of court, and by his mother who acted as his Regent, and a first wife who died and a second wife who outlived him. He was loved and respected by his people, and he reigned on the Spanish throne for 35 years until his death at age 39 in 1700, living

in the magnificent royal palaces in and around Madrid. His valued role not only brought him respect and a good life, but gave him the self-esteem, confidence and opportunity to make a valued social contribution. For example, he encouraged the introduction of science-based medicine to Spain, he freed some slaves in the American colonies, and he commissioned paintings by the best Spanish and Italian artists, especially for the Escorial Palace outside Madrid.

When I was a student I used to visit a residential home for children with learning difficulties, and I got to know one person in particular, John. He did not have any speech and his ability was very limited. However, he demonstrated resilience, patience, tolerance, non-violence, unconditional affection and many other traits that reflect important values in life. I knew him for 40 years until his recent death from epilepsy. I always say that I had two professors from whom I learned the most when I was at university: one taught me psychology and philosophy, the other was John. I really mean that, since when I look back I genuinely did learn equally valuable things from both of them. I hope my portrayal of John as a teacher helped to counteract perceptions of him as weak and unable.

What makes a good neighbour? First of all, it is getting to know the neighbours and being friendly. It is looking out for them to make sure they and their property are OK. It is popping in occasionally to see them, and inviting them

into your home. It is knowing when to mind your own business! It is sending them greetings cards and postcards when on holiday. It is conversing over the garden fence. It is keeping your own property well maintained and pleasing to look at. It is not causing a nuisance through careless parking, noise or discarded rubbish. If we help a person to do all these things, then we support them directly in the specific valued role of good neighbour.

Similarly, a friend is someone we keep in contact with, phoning or writing, exchanging greetings cards, and probably seeing quite often. We visit their home and they visit ours. We are prepared to help them out in times of difficulty, perhaps offering hospitality, food or a bed for the night. We may keep photographs of them. We will share equally in activities with them that express common interests. If we support a person in doing these things we will strengthen their specific role as a friend, and they will be seen to be in that role.

Even more important than being helped to be a good neighbour and a good friend is to be supported to be in an appropriate role as a family member. An adult son or daughter offers hospitality to their parents, keeps an eye on their welfare, and keeps in frequent touch. Telephone messages, letters and greetings cards are made or sent, and presents are given, appropriate to different roles within the family: son or daughter, uncle or aunt, brother or sister. Events are attended, such as christenings, weddings and funerals. Family members visit you and you visit them. You take advice from your parents and are tolerant of them being protective towards you. You visit family members when they are ill. You celebrate achievements within the family. These things all help you to retain a full role as a family member, which is highly socially valued in most cultures.

Being a parent yourself is a highly valued

social role, and much work is being done in various parts of the world to find ways of supporting people in a parental role who might have been thought in the past to be incapable of fulfilling that role. Those of us who are parents will all have had experience of being less than perfect in that role. If we apply a concept of 'good enough parenting' to people with disabilities or limitations, we can help many of them to be as loving and caring for their children as any parent. And this will help them to be seen by others in this very valued role. The help may be practical, advisory, financial, advocacy, instructional, relief-giving, friendship, whatever is required.

Finally, we can consider the role of artist in the broad context of the arts, painting, sculpture, writing, poetry, drama, dancing, music, etc. It is really impressive to see the number of groups of people with learning difficulties that have been established to put on high quality public performances of drama, dance or music. Equally, there have been impressive public exhibitions of painting, sculpture and pottery by people with learning difficulties. One painting by a talented artist with Down's Syndrome was purchased by John Major when he was Prime Minister of Britain, and it hung in 10 Downing Street. Other people with learning difficulties have published books, autobiographies and poetry. Any help we can give people to be in these specific artistic and performing roles, as long as other elements such as age-appropriateness, respect and dignity are in place, supports people in being seen in valued social roles.

THESE EXAMPLES are given to illustrate how SRV can be pursued through support for specific roles that people may have the opportunity or potential to be in. This practical strategy can go alongside the application of the



more general theory and strategies taught through the currently available SRV literature and training.

#### Reference

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 edition). Syracuse, NY: Training Institute for Human Service Planning, Leadership & Change Agency (Syracuse University).

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#### The citation for this article is:

Williams, P. (2006). SRV by direct support for specific valued roles. *The SRV Journal*, 1(1), 30-32.

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# Jesse James: Poster Boy for SRV?

Susan Thomas

JESSE WOODSON JAMES (1847-82) is described in *Colliers' Encyclopedia* as "American outlaw and legendary figure," and his story illustrates the power of these social roles, including how those roles are interpreted by powerful third parties. He was born in Missouri, just before that state's decision (in 1850) to become a "slave state," i.e., one that permitted slavery. His family owned slaves, and declared themselves for the South in the US Civil War (1861-65), in part in order to protect their own wealth. The Federal troops engaged in brutal suppression of those sympathetic to the South, in some instances evacuating entire western Missouri counties. James' mother was wounded in one such action, and subsequently drilled it into her sons that they owed vengeance for her injury. As a teenager, Jesse and one brother joined Quantrill's pro-slavery guerrillas and fought savagely with him until the end of the war, committing torture, butchery, and mutilation on those they attacked. Today, he would be described as a terrorist.

WHEN THE WAR ENDED, he continued to fight, and was 'adopted' by southerners and their allies who refused to admit defeat and submit to the Union. He was interpreted as a victim of federal oppression, and a hero of the war for the Confederate side. Meanwhile, he and his band committed numerous robberies and murders (he was in essence a serial killer), and was declared an outlaw bandit by the gov-

ernment. But his exploits were written up in Confederate-sympathetic papers as a modern-day Robin Hood story (even though he never gave away any of his ill-gotten gains to the poor), and sympathetic parties in rural locales all over the southern states accepted this image and role interpretation of him, hid him, supplied him with food, horses, ammunition, etc. He married an older, plain woman -- but she was described by his sympathizers as young, beautiful, and devout. They had two children (a boy and a girl), and James even settled down to farming in Tennessee for awhile. But apparently, he succumbed to the easy ways of his former life, and to the role story about him that had by now become widespread. For instance, because his story interpreted him as a godly man, he began to carry around a Bible (even though he did not read it or live what it taught), and he began to dress in high-quality clothes.

Numerous efforts were made to arrest him, including by Alan Pinkerton's detective agency, and by townsfolk in Minnesota where he and his band had attempted a bank robbery. But he always escaped, even though many of his gang members did not. Finally, one of his own gang members, Robert Ford, shot him in the back of the head for the 'dead or alive' reward money offered by the governor of Missouri.

BOTH DURING AND AFTER HIS LIFE, he was also interpreted as one of the last of the American frontiersmen, fighting against indus-

trialization and the oppression of the little guy.

According to historians and PBS television's "American Experience" (6 February 2006), James was essentially a bloodthirsty, merciless criminal, inspired by a vengeful mother, both of whom were responsible directly and indirectly for at least scores of deaths. But that is not the role legend that survives even more than a hundred years after his death. And it was the interpretation of him in positively valued roles by powerful third parties while he was alive which

secured his safety and shelter during his long period -- almost 20 years following the Civil War -- as a fugitive from justice.

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**The citation for this article is:**

Thomas, S. (2006). Jesse James: Poster boy for SRV? *The SRV Journal*, 1(1), 33-34.

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### An Invitation to Subscribe to The Training Institute Publication Series (TIPS)

For the past 25 years, the Training Institute for Human Service Planning, Leadership & Change Agency at Syracuse University (TI), directed by Professor Wolf Wolfensberger, has been putting out an informative publication called *TIPS*. Professor Wolfensberger is the author of **Normalization**, the book named as the single most influential text in the field of mental retardation services in the past 50 years. He also developed the concepts of Social Role Valorization and Citizen Advocacy.

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# First Abroad Thoughts From Home: Initial Impressions From a Study Leave

David Race

EDITOR'S NOTE: *David Race has written and edited a number of books and book chapters related to SRV, including Social Role Valorization and the English Experience (London: Whitting & Birch, Ltd., 1999) and Leadership and Change in Human Services: Selected Readings from Wolf Wolfensberger (London: Routledge, 2003). This article describes his recent trip to six countries, looking at services from an SRV perspective. His trip will form the framework for Race's next book, which will be reviewed in this Journal when the book is published.*

## Introduction

THE BRIEF REFLECTIONS which follow in this article are written as I settle down to the first chapter of a book comparing my own country, England, with six others, in terms of their services for people with intellectual disabilities.<sup>1</sup> The book will be based on the findings from a study leave, granted to me by the University of Salford for the whole of semester I of the 2005/6 academic year. My original intention, when the leave was granted some years back, had been for a more empirical study, based on some sort of evaluation of specific services, but discussions with colleagues, especially those in the international SRV network, and especially during and after the 2003 International SRV conference in Calgary, Canada,

led me to the perhaps more ambitious, but also more personal, route of observational visits to the countries concerned. This would then lead to a descriptive comparison that would be written up in the form of an undergraduate textbook.

The countries were intended to be those that had been influenced to a significant degree, in the development of their services from the late 1960s onwards, by the ideas of Normalization and, in some cases, Social Role Valorization. Attendance at all three of the International SRV Conferences, at Ottawa in 1994, Boston in 1999, and Calgary in 2003, had led to the conclusion that the number of countries that fell into this definition was relatively small, and, depending on definition, was somewhere between seven and ten.

Through agreements and contacts, especially around the 2003 Calgary event, but also through other research and teaching links with overseas colleagues, it became possible to arrange a schedule that enabled me to visit six of those countries in the time available. Contacts in those countries also helped my observations by suggesting suitable literature for me to read before the start of the study leave, so that I could arrive in each country with at least a basic grounding in their service system.

Having been back for just under two months, it was suggested that this paper might be prepared, giving "first thoughts" on what I

had seen. It is offered with some trepidation, as already the more detailed analysis involved in writing the proposed book has introduced a number of nuances to those “first thoughts,” but it is hoped that readers will take it in the spirit in which it is written, and look to the book itself<sup>2</sup> for a more reasoned account, with the expected degree of evidence to support the analyses. The paper starts with the basic facts of the study leave, goes on to give a brief account of the way in which information and discussion was generated, followed by one illustrative item from each country. A very preliminary set of emerging issues is then listed.

### **Basic Factual Details of the Study Leave**

TO TRY AND GIVE what follows some context in terms of time, the dates and locations visited, within the various countries, are given below. This list also gives me the first chance to publicly convey my sincere thanks to all those, too numerous to name individually, who made arrangements and introduced me to people and services as I traveled round, as well as showing me wonderful hospitality.

### ***Locations and Dates of Visits***

*2005*

September 19th - October 1st  
Jonkoping, Sweden

October 2nd - 14th  
Trondheim, Norway

October 22nd - 29th  
Winnipeg, Canada

October 29th - November 4th  
Calgary, Canada

November 4th - 6th  
Gananoque, Ontario, Canada

November 6th - 12th  
Syracuse, New York, USA

November 12th - 18th  
Worcester, Massachusetts, USA

November 18th - 20th  
Holyoke, Massachusetts, USA

November 20th - 25th  
Toronto, Canada

November 27th - December 2nd  
Canberra, Australia

December 2nd - 11th  
Brisbane, Australia

December 11th - 18th  
Perth, Australia

*2006*

January 21st - 27th  
Wellington, New Zealand

January 27th - February 4th  
Hamilton, Tauranga and Auckland, New Zealand

### ***Detail of Visits/Discussions***

THE OVERALL OBJECTIVES of the study leave had, as noted in the Introduction, been amended from the original notion of setting up an empirical research project to the collection of impressions of services to produce an undergraduate text. As the visits proceeded, it became clear that the nature of the book would be largely descriptive, that it would cover the whole area of services “from pre-birth to death” and that it should aim to become valuable to carers and staff in services, as well as undergraduate students. This last point was emphasised by the introduction, early in the visits, of the idea of including a section or sec-

tions in each chapter speculating on what would happen to my son, who has Down's Syndrome, at different points in the age spectrum, were he in the various countries. This certainly enabled more subtle and nuanced discussion to take place with the range of people I met in each country, especially, though not exclusively, parents of people with intellectual disabilities.

To this end my hosts in the respective countries set up a number of contacts, visits and events which would enable me to gain as wide a perspective as possible on the services in those countries. In all countries I was based in, or visited, at least two distinct geographical locations, in terms of local or municipal government authorities, and, within those, some or all of the following sorts of contacts.

- Visits to actual services - early childhood, schools, day services, residential, advocacy groups.
- Discussions with responsible local/national government individuals.
- Discussions with leaders of advisory/developmental/campaigning organisations.
- Discussions with leaders/staff of service providing agencies, including, but not only, those whose services were visited.
- Discussions with individual parents/carers.
- Discussions with academics.
- Presentations to student groups, local service groups, parents groups, campaigning groups.
- Discussions with people who use services.

SINCE THE STUDY is aimed at producing an impressionistic description of services in the different countries, no claim is made that the people and groups met constitute a "representative" sample in the strict sense of the word (in many of the countries this would be difficult to achieve in three years of study,

let alone three weeks). By asking about and discussing all aspects of services with all the contacts, however, a wide range of informed views were forthcoming which, taken with basic factual data and the academic literature, will, I believe, provide a broad picture of each country that will be recognised as accurate. The stories below, however, are merely incidents that have stuck in my mind; they may or may not turn out to be more widely illustrative. When I began this section, I had no idea that all the items below would involve people with Down's Syndrome, but such turned out to be the case. There are, of course, many other people, with and without an acknowledged label, who end up in the category of "intellectual disability" or whatever is the language used in various countries, so this is not at all a study only confined to Down's Syndrome - it just so happens that events that sprung to my mind all involved such people.

#### **"First thoughts"- stories from each country**

THESE BRIEF VIGNETTES are presented in the order in which I visited the respective countries, shown in the table above. We therefore begin with Sweden.

##### *Sweden - an unknown housemate*

The city of Jonkoping, more famous for the part of it called Husqvarna, which produces high quality machine tools (and motorcycles) that export worldwide, is situated at the southern end of the longest lake in Sweden, Lake Vattern. As a guest of the university, I was housed in an apartment near the campus, which the university rents to be available for visiting scholars. The university apartment was on the second floor of a four storey block, one of three round a grassed courtyard,

all of which housed a whole range of people. On my second morning, as I was leaving for the ten minute walk to my hosts, I passed the door of a first floor apartment as it opened. Above me, as I reached the ground floor, I could hear somebody saying what I guessed to be the Swedish for "goodbye and have a good day," and as I exited the communal front door of the block, I could see coming down the stairs a woman, probably in her thirties, who had Down's Syndrome. She clearly knew the exit routes from the complex better than I did, for when I emerged on to the busy main road to the university, the woman had already come out, ahead of me, via another exit. I was able to observe, therefore, how she proceeded to cross the main road (not as hard as main roads in some places - Swedish drivers seem much more law-abiding and accommodating of pedestrians) and disappear down another street.

I discovered, in the course of my two weeks, that this was not a remarkable occurrence. The Swedish law gives entitlement to people with intellectual disabilities to their own apartments, subsidised to some extent, but also affordable by their fairly substantial benefits. Such is one of the results of their implementation of "normalization" over the nearly forty years since Bengt Nirje and Karl Grunewald, amongst others, articulated the aims of their service system in those terms.

#### *Norway - mine host*

In my last evening in Trondheim, having visited a number of services in that city and in a neighbouring municipality, I took my host out for a meal. Partly randomly, and partly on the suggestion of another "SRV person" in the city, we went to what was described as a "trendy" restaurant, in

the gentrified former artisan area of town, on the banks of the river. The restaurant was what might be described as "designer basic," i.e., carefully placed bare wood tables and chairs in the two small rooms of the old cottage from which it had been converted. Fortunately early, we took our seats at a table near the entrance, therefore being ready observers of the steady stream of people who arrived for a meal, mostly young students, but also others who in Paris would have been described (by the English) as "bohemian" types. A waitress came to take our order, a young lady in her twenties, who also happened to have Down's Syndrome. Writing the order down, she laid our places, and later delivered the food.

I had seen people with intellectual disabilities in open employment before, so why does this stick in my mind? Mainly because, despite the many advances in services in Norway, they, like Sweden, had not totally cracked the open employment riddle. I had seen, in both countries, people doing "regular work," but, largely because of the way the benefit system operates and the agreement with the unions (a powerful force in Scandinavia though on a more co-operative basis than in many other countries) on the sort of jobs available to disabled people, very few people get paid a regular wage. This young lady was the exception, as was the owner of the restaurant. The story I was told of him was that he had been a post-graduate student in the disability area, and had produced a dissertation demonstrating, from an economic perspective backed up with quantitative data, that it was possible to employ disabled people on full wages, and still run a viable business. Though his thesis was, I gather, received well academically, it did not have

an effect on the service system, so he decided to do something himself. Hence the restaurant and mine host with Down's Syndrome.

*Canada - a short but valued life*

Because of what follows I will not name the particular place where this story is set. It concerns another young woman with Down's Syndrome, but one whom I did not have the pleasure of meeting. Arriving after midnight, following a delayed flight, at one of my Canadian locations, my host told me of her concerns about this woman, who had been admitted to hospital following a particularly virulent and sudden cancer. My host, and the circle of friends around the young woman, which included her devoted parents, had been visiting her regularly in the week or so after her admission, and were most concerned about the future. My jet lagged sleep was briefly disturbed by a telephone ringing at about 4 a.m., and this proved to be the news that the young lady had died in the night.

Though I did not meet the young lady, I was to see pictures and hear about her life over the next week, and they were the reason that her story stuck in my mind. The pictures were not just those alongside the highly positive obituary that appeared in the leading city newspaper, but also in more general information given to me as part of my study. In particular, though this was far from her sole achievement, the young lady was part of a group at the local university, one of the leading universities in the province, that had led the way on inclusive education at that level. This particular woman had been one of the leaders of the group, whose university participation was similar to the North American notion of students "auditing" courses. They also, however,

were able, by mutual consent of the individual class teachers, to undertake modified assignments that were properly evaluated and could gain credits. This sort of group was to be a feature of both US and Canadian higher education services; far from universal, but present in significant numbers, where the original ideas of "integration," present in normalization and also a key theme of SRV, had been developed into a movement under the banner of "inclusion." Canada and the US went further along these lines than some other countries, especially at the tertiary level. Inclusive education will, of course, be a matter of considerable discussion in the forthcoming book, with nuances and complexities raised in the different countries that make it, for me, far from a simple "for or against" issue. For the young lady who so sadly died on my arrival in her city, it certainly represented one of a number of valued roles which she had occupied in her short life, and which, I believe, added to a positive perception of people with intellectual disabilities in that part of Canada.

*USA - a third generation of inclusive education*

The previous story took place some time before my arrival in Syracuse, New York state, but, as in that story, what follows confronted me in my first day there. Syracuse, of course, is known more widely within the worldwide normalization and SRV network as the location of Wolf Wolfensberger's Training Institute, and also the Center for Human Policy, currently led by Professor Steven Taylor, where many of the "names" of the radical end of disability academia have passed through, or are still involved. None of these people would be known to the beautiful four year old young man with



Down's Syndrome whom I met on a visit to Jowonio School in Syracuse. I had, as with "open employment" services, seen a number of "inclusive education" settings before, not least through my own son's progress through the English system, and though Jowonio was an impressive example of a "pre-school" inclusive setting, with the four year old being totally involved with what was going on for all children, yet able to shine out with his own personality, what was more interesting for this piece was that the school had been operating in this fashion for three generations.

Attending a PASSING<sup>3</sup> workshop the following week, I noticed, in the acknowledgments at the beginning of the PASSING manual, thanks to Jowonio School for acting as the pilot location for testing the PASSING instrument. Factors that again will require far more nuanced discussion in the book were raised by people at Jowonio: the proximity to Syracuse University, with both academics and students on placement near at hand; the fact of it being a private school, with somewhat limited access for poorer parents despite the school's best intentions; and the subsequent tensions with the local and state education system, are all significant. Despite this, however, for the school, and more importantly the values behind it, to have lasted the twenty-five years of turbulence in education in the USA, says something, I believe, for the enduring nature of those values.

#### *Australia - meaningful days?*

Two people with Down's Syndrome in two different parts of Australia illustrate an issue that is both a general one that we have already touched on, the notion of employment, and an example of how matters of finance and governance can

give a particular national spin to such matters. Both these people were young men in their thirties, who appeared to have very similar levels of ability. Because of the need for greater verification of my notes I will not name the two places where they spent their weekdays, but hope that the general point is still made, even at this current impressionistic stage. As I understand it, by virtue of the arrangements for finance of services in Australia, "employment" services are largely funded by the federal government, whereas "residential services" and, more relevant here, "community based activities" are funded by the individual states, sometimes on a shared basis with the federal government. Within these definitions, "employment" does not only mean open employment, but also attendance at places that in SRV terms would be called "segregated settings" that carry out "business services" - anything from factory type production to office processes. The financing regimes can therefore produce some anomalies in terms of how very similar people are "classed;" as occurred, I believe, in the case of the two young men I met. One worked in what was very obviously, in terms of the setting, the type of work, and the payment to workers, what an outside observer would call "real work." In SRV terms, the setting would score highly in many aspects of similarity to the "culturally valued analogue" of work in a factory setting, with only the make-up of its employees, in particular the proportions of people with intellectual disabilities and/or mental health problems, being an issue for SRV criticism. I met the young man who worked there in the scheduled coffee break for all workers, kept to time by the factory hooter, and he told me of his work making "day-glo" jackets for people in

jobs involving outdoor working or any positions where they need to be readily seen. We did not have much time to talk about the rest of his life, as the hooter went and he had to return to work.

There was still less time to talk to the young man in the other location, however, despite the fact that he was sitting doing not very much, as he had been ten minutes earlier when I was brought into the room of the day centre where he and eight other people were undertaking "community activities" by listening to music from a "boom-box" in the corner. The young man and one other person in the group stood out as different to the rest, in that they were physically able and able to talk, whereas the other people had varying but significant degrees of physical and mental impairment, and very limited speech. I was taken into the room, and given details of the people therein, but not encouraged to talk to them.

It turned out that the two people with Down's Syndrome were in the two different places, not because of their level of need, still less their individual preference, but because of the funding granted to each by the different systems. This was a big issue in Australia, with some people getting no funding at all after leaving school, some getting "transition" money, which then ends after a couple of years, and others offered places in whichever of agencies receiving money from the two funding streams has vacancies. It also illustrates that matters of funding do not just differ between countries, but also within countries, and that the benefits of so-called "individualised funding" are not without their drawbacks, especially in time of financial claw back.

*New Zealand - valued options; learning to*

*drive or meeting the Prime Minister?*

The final story concerns a young man with Down's Syndrome whom I met right at the very end of my five months on the road, when thoughts of home were looming large, but who left me with some positive thoughts for the forty-five hours traveling. I had seen and talked about the full range of services in my time in New Zealand, and arrived in Auckland to meet the young man's mother, a senior person in a leading campaigning organisation in that country. She showed me their latest newsletter, with a picture of her son, then aged seventeen, meeting the Prime Minister at an event organised by the agency. What quickly became clear, however, was that her son's own choice of valued options went well beyond momentary connections in high places. Much of this came as a result of his being the subject of a relatively rare set-up in New Zealand, of which there are more examples elsewhere, namely a so-called "circle of friends." The need for this arrangement had particularly arisen when the young man was beginning to experience difficulties at school. He was attending mainstream school, the first person with Down's Syndrome at this particular establishment, though attendance at mainstream school is not a rare phenomenon in New Zealand.

Once the circle had been set up, however (with the formal title of a "micro-board" which appears to have some significance because of the way services are delivered in New Zealand), they quickly got into wider issues than just his schooling. The benefit to the young man had many aspects, and the story for the "micro-board" was not all plain sailing, but one key aspect that all agreed on was an increase in confidence, so that when he asked his father if, like his elder

brother, he could learn to drive, the request was taken seriously. Currently still off-road in his learning, the probability of his joining the Auckland traffic (the most crowded in New Zealand, though light to an English visitor) is nevertheless high. As well as the specific issue of the driving, this story again raises the more subtle differences between the countries in terms of the degree of activism by parents, and supporting and campaigning groups, to get services that they know exist, which are often trumpeted by governments and agencies as “success stories” but which are often denied to the majority of people. So the question then becomes one of access to services, rather than ignorance or dispute about what represents quality in services. In other words, as I found in all countries, people know what is good - getting it is another matter.

### **Tentative, and very early, thoughts on key issues**

AT THIS STAGE of the analysis, and the writing of the book, the notion of “conclusions” would be clearly premature. We therefore end with a list of tentative issues that seem to be the locus of differences between some of the countries. More will undoubtedly emerge, but these are presented in the hope that they stimulate some response (and feedback, which would be welcomed) from readers. They are presented in the form of my views on how my son Adam would fare at different stages of the life course in the different countries, starting with the issue of whether he would enter that life course at all.

- Adam would have a greater chance of being

born in Sweden and Norway than elsewhere. Screening and pressure for abortion of disabled children is significantly different in the different countries, but all bar those two present a high chance of Adam being “screened out.”

- Adam and his family would get a very similar amount of attention in the early stages of life in all countries, though if he was born to poor parents in the USA and Canada, this might be questionable.
- School options would be very different for Adam in the different countries. The likelihood of access to mainstream schools is also very variable within the countries, though much more consistent in Sweden and Norway where the chances are good.
- Possibilities of open employment, in the full sense of that word, are rare in all the countries, but meaningful daytime occupation seems more prevalent in Sweden, Norway, Australia and New Zealand, despite a few highly radical examples in the USA and Canada.
- Getting a place of his own, and with whom he chooses to live, is again much more likely in Sweden and Norway. Though the other countries have some excellent residential services, they also have issues of access to those services, and the presence of many more institutional living situations.
- As Adam's parents, we would need to be much more active in the USA than any other country, but still strongly so in Canada, Australia and New Zealand, if we were to achieve anything beyond a very basic level of service

(or anything at all).

SUCH ARE the most immediate thoughts from my time in the different countries. My final point, however, is a broader one. In every country, even those with what appear to be a comprehensive range of services, the process of devaluation of people with intellectual disabilities, highlighted by SRV, remains a powerful force.

This was highlighted for me by the reading, following a recommendation from Jack Yates in the USA, a book called *Expecting Adam*<sup>4</sup> by Martha Beck. This book comes from outside of the “service world” and is the account, by the female half of the marriage of two young people making their mark in the competitive academic world of Harvard University (what we in England would call the “Oxford of America”), of their lives before and after they knew that the baby Martha was expecting had Down's Syndrome. The interest to me, of course, will be obvious, and was increased by the fact of Martha Beck's Adam being born in 1987, only two years after “my” Adam. The story has many more facets than devaluation, of course, and can be read at many levels, including a dimension of spirituality and metaphysical experience that some might find hard to deal with, but devaluation is there, in all its power. Especially so, of course, in the high value given to academic achievement in the world of Harvard, and by the couple's families. So my tour of six countries ended with the is-

sue of devaluation still ringing in my ears. This, of course, is hardly a revelation to many people who gave me their time on my travels, and it is heartening to see the efforts of such people, and others, in all the countries visited, to put positive measures into place to counter devaluation. Its continuing power and reality, however, means that even those efforts remain fragile and in need of continuous nurture.

#### Endnotes

1. The term “intellectual disabilities” is the one I will be using in the book, acknowledging the different languages of the various countries to describe the group of people concerned.
2. Hopefully, the book will be launched at the 2007 International SRV Conference to be held in Ottawa; see the description of the conference in this issue.
3. PASSING is an evaluation instrument based on SRV, that is also used in training events which give people an in-depth examination of SRV issues in a real service. The manual was written by Wolf Wolfensberger and Susan Thomas in 1983, and published by NIMR, Canada in that year.
4. Published in 2000 by Berkley Books.

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#### The citation for this article is:

Race, D. (2006). First abroad thoughts from home: Initial impressions from a study leave. *The SRV Journal*, 1 (1), 35-43.

# Not Guilty by Reason of Medication

Christopher D. Ringwald

(Originally published in the Albany Times Union on 9/23/05)

EDITOR'S NOTE: *We are reprinting the following op-ed piece by Ringwald for its relevance to SRV generally, and to a pressing human service and social practice specifically; namely, the widespread acceptance and use of prescription psychoactive drugs. Ringwald examines the socially devaluing and wounding impacts of this practice in the lives of one woman and her family. He acknowledges the heightened vulnerability which the 'poor and disadvantaged' live in regarding psychoactive drugging by the mental health field. Ringwald describes the devalued roles which the mother mentioned in this article is cast into, and the valued social roles which she either loses or is at risk of losing.*

*Ringwald is the author of a well-written and well-researched book on the spiritual dimensions of addiction treatment (Ringwald, C. (2002). The Soul of Recovery. New York: Oxford University Press). Two other excellent resources on mind drugs are: Wolfensberger, W. (2004). Reply To Levitas, McCandleless, Elenewski and Sobel. SRV/VRS: The International Social Role Valorization Journal/La revue internationale de la Valorisation des roles sociaux, 5(1&2), 42-66; and Whitaker, R. (2002). Mad in America. New York: Perseus Publishing. <http://www.madinamerica.com/>.*

A YOUNG MOTHER of three gets away from her violent husband. With help from her tight-knit family, she receives counseling and learns welding at a local equal opportunity center. She graduates, passes the license exam and is hired. She was to start on Monday, June 6. Instead, Maria Cuevas sits in Albany County

Jail accused of poisoning two of her kids, who survived, while District Attorney David Soares decides what to do and her attorney prepares a defense.

It would be easy to blame her mental illness, actually depression. But if the prosecutor, a judge and we as a society had sense and compassion, we'd let Cuevas plead, "Not guilty by reason of medication."

WHAT WENT WRONG for a young lady on the verge of a new life and career? Her sister, Claudia Ruiz, recently recounted her sister's travail.

Cuevas, known as Alejandra to her family, felt low and had problems sleeping. Her ex-husband's abuse was one factor, childhood molestation another. In late 2004, her counselor sent her to a doctor who prescribed sleeping pills, then another drug. These didn't work and the effects scared Cuevas, who stopped. In May of this year Cuevas was put on Zyprexa, a powerful anti-psychotic drug known generically as olanzapine, and amitriptyline, a potent anti-depressant. The effects were worse.

"She couldn't sleep, she was up all night, she was anxious," said Ruiz, speaking calmly in her immaculate apartment while keeping her own children entertained. Her sister's children are cared for by their grandmother and other relatives. The drugs changed Cuevas in other ways. While on the anti-depressants alone, "she was always sleeping," said Ruiz. "She had been very active." While on the later drug combination, in the final week, "she was irritable and screaming at her children for no reason. It was not like her."

THIS SAD LITANY is familiar to millions of Americans who either take or know someone on certain psychiatric medications. Goaded on by pharmaceutical firms, policy-makers, "advocacy" groups and our own passion for scientific solutions, we now believe that most or all emotional and mental problems are caused by "chemical imbalances" in the brain's neurotransmitters that are easily redressed by pills. Up that serotonin, down that dopamine - all better now?

Though this "broken brain" spiel has been recited to patients and families for 30 years, it lacks proof generally and has been discredited, notably for schizophrenia, since the mid-1990s. But boy, it sounds good. Hemmed in by insurance reimbursement formulas, it is often far easier to "fix" a brain than treat a person. And as mental health workers say, "Once on medications, always on medications."

Obviously, medications can help people with mental disorders cope and recover if combined with therapy and other help. More often, people -- especially the poor and disadvantaged -- are given high doses and little else. Like Cuevas, thousands if not millions of Americans have had their composure wrecked and their judgment impaired by psychiatric drugs. Instead of repairing brain chemistry, these dampen or impair brain function -- which sometimes seems like a cure.

The real danger is when a person starts on drugs, changes doses, or ends abruptly, as many do given the horrific side effects, said Bob Whitaker, author of "Mad in America," which surveys hundreds of studies. At such times, anti-psychotics can cause akathisia, an extreme anxiety and restlessness.

Anti-psychotics also diminish workings of our brain's frontal lobe, home to the conscience. The result resembles that in people who, earlier in the 20th century, were lobotomized. Com-

bined, akathisia and an impaired frontal lobe render many people suicidal or homicidal.

"In so many of the high school killings, the kids were newly on drugs, and had akathisia, or they were coming off the drugs, and had a bad reaction," said Whitaker. Anti-depressants can cause the same double whammy, he added. Andrea Yates, the Houston mother who killed her five children, did so after being taken off Haldol, another anti-psychotic. Of course, we blamed her mental illness, not the medication.

IN THE CASE OF CUEVAS, we can know better.

"The week before this all happened she tried to jump out a window," said Ruiz. "She went back to her doctor and said the drugs were not working. The doctor increased the doses. She went back and asked to see a psychiatrist." The doctor made a referral but the appointment wasn't until the week after. Cuevas was told to keep up the drugs. She dutifully filled the prescription that Friday.

"On Sundays we usually all go to church together," said Ruiz, referring to St. Patrick's on Central Avenue, where family members are well-liked regulars. "She said no." That night Cuevas despaired. "She said she was afraid our lives would be ruined if she left the children so she decided to take everybody." Cuevas knew just what to use: the drugs that were ruining her own life. As soon as she saw the effect on one of her kids, Cuevas changed her mind and called for help. Let's heed that call.

**Original reference:**

Ringwald, C. (9/23/05). Not guilty by reason of medication. *Albany Times Union*.

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*CHRISTOPHER RINGWALD is a long-time reporter on mental health, and is a senior writer for Advocates for Human Potential.*

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## Ties That Bind

Ed Wilson

SEVERAL YEARS BACK, late on a hot July afternoon, I had the pleasure of hanging out with a man whom I will call Bob - not his real name. Together we walked down the main street of a seaside community known for its wealth and quaint shopping district. I had known Bob and his family for nearly ten years. A more formal service name for our stroll would be a 'Pre-Individual Service Plan meeting,' but stroll is a better description.

Bob loves being out and part of the life of the town. During the summer the crowds of tourists and cars parked on both sides of the street make for narrow paths on which to walk; summer is a busy time in this town. Bob stopped in to a small kitchen goods and bakery shop. It was the kind of shop you would expect to see in a community like this one. It had wide pine floors polished to a high gloss and glass display cases brimming with an assortment of cookies, turnovers and croissants. The wafting scents of cinnamon and chocolate hung in the air and welcomed you in from the sidewalk. Thermoses of flavored coffee stood side by side. Racks were full of silver kitchen utensils. An attractive tanned woman wearing lots of gold jewelry stood behind the counter.

Bob went over to the air conditioner that was blowing into the middle aisle of the store and began cooling himself in front of it. I whispered to him, "Are you going to buy anything?" He responded in a booming voice, "No Ed Wilson, I would never pay \$20 for a spoon, I just come in here to cool off."

I was horrified, but the woman behind the counter just laughed and agreed. She said, "Yep that's right, every so often around 4 o'clock Bob comes in and takes his place in front of the air conditioner to cool off." I asked meekly, "Well, does he ever make a purchase?" "Oh," she said, "yes, sometimes he stands in front of the air conditioner for so long that he will buy a cup of coffee to warm up. No matter though, I have come to enjoy his company, as this is a slow part of the day and he helps me to get through it."

Bob disappeared into the back of the store to look at something and almost immediately the woman behind the counter motioned me over to her. "Psst -- hey." Oh no, I thought, she is really angry. She just did not want to admit it. Here it comes. She said, "I was just wondering. You know, there are a lot of eccentric people in this town. I have grown used to it, but I was just wondering, where is Bob from?"

I said, "Well, Bob is from the Upper Cape. His mom is the director of the County Fair. His family owns a riding stable and tack shop. He lived there most of his life, but has lived in town here for a couple of years." She immediately knew who his family was, and she even had a niece she thought had taken lessons at their stable.

Later I realized how much different that conversation might have gone if I had said, "I am a Service Coordinator for the Department of Mental Retardation. Bob lives in a staffed

apartment operated by XYZ agency under contract with the state. He lives with two other mentally retarded people and I am meeting with him in preparation for his Individual Service Plan meeting.”

How important it is to get to know the stories of the people we serve. Among other things, these stories can at times be helpful in weaving people back into the life of their communities. When making introductions on behalf of people with disabilities, it is important to share that which is familiar, typical, and ordinary in the lives of people so that the citizen has a reference point which they understand.

It is, after all, not in the celebration of our differences that we find common ground, but rather the things we have in common which bring us together. To the average citizen (or bakery owner), the world of group homes, sheltered workshops, Individual Service Plans, and Service Coordination is like a Visa commercial gone bad - 'It is every place they do not want to be.' It is in ordinary life, not in a special one, that people are most likely to identify with socially devalued people.<sup>1</sup>

It is not our job to weave the citizen into the world of human services. It is our job to support the people we serve in their communities and to assist them to obtain valued roles, so that they might have a better chance of be-

ing accorded the good things in life.<sup>2</sup> We must give the citizens in our communities the gift of uncovering the beauty in the eccentricities of the people we have introduced to them as friend, customer, and neighbor. These social roles are both valued and understood because they are the ones we all have in common.

#### Endnotes

1. For more on this issue, see 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), especially pages 118-124.

2. See 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 roles sociaux*, 2(2), 12-14.

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*ED WILSON works with families of both school- and adult-age children as a Service Coordinator for the Massachusetts Department of Mental Retardation.*

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#### The citation for this article is:

Wilson, E. (2006). Ties that bind. *The SRV Journal*, 1(1), 46-47.

### Invitation to submit letters to the SRV Journal

from the Editor

We welcome, for publication, letters regarding the SRV Journal and/or specific articles, as well as letters sharing well-informed opinions relevant to Social Role Valorization. Please provide a phone number or email address so that we can contact you as necessary. We cannot publish anonymous letters, and we reserve the right not to publish letters. Due to space limitations, all letters are subject to editing. Please send your letters to *Letters to the Editor, The SRV JOURNAL, 74 Elm Street, Worcester, MA 01609 USA.*



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# REVIEWS

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**THE SOUL OF A CHEF.** By MICHAEL RUHLMAN. Penguin Books, New York, 2001

**Reviewed by Marc Tumeinski**

IN READING a non-human service book or article, I have sometimes been pleasantly surprised by an instructive human service lesson. This happened to me while reading *The Soul of a Chef* by Michael Ruhlman. The first half of this entertaining book describes the Certified Master Chef (CMC) examination held in 1997 at the Culinary Institute of America, the premier cooking school in the United States. What struck me in reading about the CMC exam was the rigor, the high expectations of competency, and the dedication taken for granted in something like gaining the title of CMC, but which is normatively lacking in human services.

THE CMC EXAM was started in 1981 to help create a recognized, objective standard of excellence in the field of restaurant cooking in the United States. Applicants are tested in a wide curriculum of cooking skills (such as knife skills, preparation, serving, grilling, and baking) and styles (such as classical, Asian, and American). Applicants must also demonstrate knowledge in areas related to restaurant cooking, such as sanitation, restaurant management, table service, employee management, etc.

The test is physically, intellectually, and for most emotionally grueling. It takes 10 days, with each day lasting anywhere from 12 to 16 hours. On top of that, many test takers will re-

turn to their lodgings each evening for further study and preparation. The test costs \$2600 USD to take. Most test takers travel long distances and stay in nearby motels, which brings the total cost closer to \$4000 or \$5000 USD. The test includes written and oral exams, as well as of course actual cooking. The applicants cook on nine of the 10 days, and on one of those nine days they prepare two different meals. Each time they cook, they are timed. If they fail to serve on time, they lose points. Several times during the test, they are given a “mystery basket” of food. They then have 4 1/2 hours to plan and cook a four-course meal for 10 people using *only* the food in the basket. The test also includes classroom instruction by CMCs on a variety of cooking and other related topics. From 1981 to 1997, approximately 170 people have taken the test. Only 53 passed. A small percentage have taken the test more than once. Of these, only one passed the second time.

Each day of the exam is graded on a point scale. Applicants need a minimum amount of points to pass each day and to gain their CMC status. While cooking, they are constantly observed by kitchen proctors, who can take away points for wasting food, dissatisfactory time management, or poor supervision of their kitchen assistant. They are also often watched in the kitchen by the public through a large observation window. Their meals are blind taste-tested and graded on presentation by CMCs and other cooking professionals. After each meal and written or oral exam, they receive im-

mediate feedback and critique of their performance from the judges, of whom many are themselves CMCs.

THIS BOOK illustrates the level of competence and performance normatively expected in excellent classical restaurant cooking. Yet when it comes to offering service to devalued people, in residential or day programs for example, such stringent standards and expectations are not only typically lacking, but would likely be judged as “oppressive,” “insane” or “unachievable.” It is remarkable as well as tragic that something as esoteric as the art of high cuisine would unabashedly require such high standards, yet low or even no standards predominate in our agency-based services to those most in need.

Recent experience with teaching Social Role Valorization (SRV), and with PASSING workshops particularly, is enough to inform us of this woeful situation.<sup>1</sup> Many workshop participants claim that a four-day workshop with 8 1/2-hour days is too long, that lecture style is too demanding, that no one can work the long days and nights during a PASSING workshop and still learn, and so on. Most typical human service trainings today are at most a day long, and the norm is more like two or three hours. The toughest test that many service workers face is a 10-question CPR test, which they take after probably seven or eight hours of instruction spread over one or two days. Reading about the CMC test in *The Soul of a Chef* was a welcome reminder that the kind of developmental model approach we teach and try to implement in SRV and PASSING is not irrelevant, “out of tune with modern learning theory,” or outside human ability, but what is normatively required if one wants to achieve greater competency as a service worker, or to help others become more competent.

#### Endnote

1. For more information on SRV and PASSING, see 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).

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MARC TUMEINSKI is a trainer for the SRV Implementation Project in Worcester, MA, USA, and a member of the North American SRV Council.

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#### The citation for this review is:

Tumeinski, M. (2006). Review of the book *The soul of a chef* by Michael Ruhlman. *The SRV Journal*, 1(1), 48-49.

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**ON THE OUTSIDE: EXTRAORDINARY PEOPLE IN SEARCH OF ORDINARY LIVES.** By JULIE PRATT (Editor). West Virginia Developmental Disabilities Planning Council (published with support from the West Virginia Humanities Council), Charleston, WV, 97 pages, \$6.95, 1998

#### Reviewed by Ed Preneta

BETWEEN 1994 AND 1997, the West Virginia Developmental Disabilities Planning Council recruited a half-dozen writers and social workers to interview people who had moved from West Virginia's state institutions into homes in the community. Council Director Julie Pratt edited their stories. The book is a look at two decades of deinstitutionalization in West Virginia through the eyes of twelve people with developmental disabilities. Their stories are told to help readers understand what it means to be labeled and treated as “different,” so that others might learn from their experiences. While anyone can learn from the wisdom, experience and lessons in the stories, the

book is particularly relevant for professionals and policymakers in the field of disabilities.

The stories tell readers that: (1) holding high expectations about people with disabilities is critical to each person's success; (2) freedom is important to people who leave institutions, despite the ups and downs of living in the community; (3) people can be vulnerable to abuse, exploitation, mistreatment and neglect, wherever they live; and (4) caring relationships keep people safe. It is hoped that readers, professionals and policymakers will learn from these stories because "what happens to people in the future hinges on using what we've learned from their pasts" (page 9).

Since *Christmas In Purgatory* (Blatt, B. & Kaplan, F. (1974). Syracuse, NY: Human Policy Press, Center on Human Policy (Syracuse University)), thousands of stories have been told about the experiences of people all over our country who were labeled and treated as different in a negative way. All the stories have been as compelling, easily grasped, inspiring, sobering and upsetting as the stories in *On The Outside*. What is different about *On The Outside* is what it says about our human service systems "on the outside." *On The Outside* reminds us that we haven't learned from the past.

SEYMOUR B. SARASON of Yale University, in reviewing *Christmas In Purgatory*, said that Dr. Blatt concluded that purgatory is inherent in our concept of institutions. Sarason then concluded that because of our propensity to segregate people who look different, "institutional purgatories" will continue to exist for the foreseeable future. Today, these institutional purgatories aren't just remaining large state and private institutions, they are skilled nursing facilities and intermediate care facilities, to name just two. Such places ware-

house thousands of people including infants, children and elders who have mental disorders, people with intellectual disabilities, people with chronic illnesses, as well as people who are medically fragile and dependent on technology. They are also group homes, halfway houses and other derivatives of institutions.

Our institutional purgatories aren't just bricks and mortar. To paraphrase Ms. Pratt, institutions are more than just buildings, they are our attitudes and practices that live long after the last building is torn down. They are also the poverty of individual and family services and supports in the community, as well as the result of uninvolved citizenry. Today, anyone whom we label as different is at as great a risk of being committed to purgatory as they were decades ago.

*Christmas In Purgatory* shocked Americans and infuriated professionals and policymakers. It changed our thinking, values, practice and planning. *On The Outside* hints that we have new purgatories. Not only has institutionalization in bricks and mortar facilities become more subtle, reading the stories in *On The Outside* hints that institutionalization has crept into our human service delivery systems in the community. *On The Outside* needs to be read so that other stories are told until we have an epiphany about our new purgatories, and make changes accordingly.

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ED PRENETA is the Director of the Connecticut Council on Developmental Disabilities, and a long-time supporter of SRV training in Connecticut.

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EDITOR'S NOTE: Readers are encouraged to also read *The Origin and Nature of Our Institutional Models* by Wolf Wolfensberger (Syracuse, NY: Human Policy Press, 1975) for a powerful history of large institutions for men-

*tally retarded people in the US.*

**The citation for this review is:**

Preneta, E. (2006). Review of the book *On the outside: Extraordinary people in search of ordinary lives* by Julie Pratt (Ed.). *The SRV Journal*, 1(1), 49-51.

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**MURDERBALL.** By HENRY ALEX RUBIN & DANA ADAM SHAPIRO (Directors). Rated R, 88 minutes, 2005

**Reviewed by Marc Tumeinski**

THE DOCUMENTARY FILM *Murderball* follows the US Quad Rugby Team as they compete in the 2002 World Championships, and in the 2004 Paralympic Games held in Athens, Greece. *Murderball* is a fast-paced movie which won both the 2005 Documentary Audience Award and a Special Jury Prize for Editing at the Sundance Film Festival.

QUAD RUGBY is played with a volleyball on a regulation-sized basketball court. The game is played in four eight-minute periods. Each team has four players on the court. Players are assigned a point classification between 0.5 and 3.5, depending on the extent of their physical impairment. The total points of the four players on the court cannot exceed 8.0.

Players must keep the ball in motion, either by passing or dribbling. A game point is scored when a player crosses the goal line with at least two wheels while holding onto the ball. Players use wheelchairs built specifically for quad rugby. Quad rugby is also called wheelchair rugby and, according to the film, was originally called 'murderball' (hence the film title).

THE FILM DOES A GOOD JOB of explaining the sport, and of showing the dedication and hard training it takes to compete at the in-

ternational level. *Murderball* also helps us to get to know the featured players. We meet their families and friends. We see the camaraderie among the US team members, as well as the aggressive spirit of competition between different national teams, most notably the US and Canadian teams. This particular rivalry is largely interpersonal, as one of the star US team members left to become head coach for the Canadian team.

Some of the valued social roles which the movie portrays men and women who are quadriplegic holding include: movie star, world-class athlete, teammate, father, brother, husband, fiancé, employee, friend, coach, and national team spokesman.

In the film, we see how these valued social roles increase access to the 'good things of life' for the players, such as: good health, travel, friends, family, opportunities for challenge and growth, positive social recognition, home, work, positive sense of self, and the opportunity to set and pursue life goals.<sup>1</sup>

The movie does a good job at overcoming some negative stereotypes which surround quadriplegia. For example, it clarifies that being quadriplegic does not mean that you cannot move your limbs at all. Degrees of quadriplegia vary among those who have it; different people have more or less movement in their arms, hands, legs and feet depending on where on the spinal cord the injury occurred. It also portrays people who are quadriplegic and in wheelchairs as sexy, and as interested in and capable of sex. (There are some scenes in this movie which are not appropriate for children.)

One memorable scene late in the film touches on the issue of negative stereotypes. One of the US team members tells the story of how someone once said to him at a wedding that they had heard he was going to compete in the Special Olympics. He describes (essentially

using role language) how after hearing that question, he went from being a man at the wedding to, in his words, “being a retard.” He and a fellow team member then went on at great length to describe how the Special Olympics are different from the Paralympics; for example, that the Special Olympics happen yearly, while the Paralympics are held every four years like the original Olympics. They also emphasized that they were competing to win, not just to participate or to get a hug from a volunteer. This scene illustrates many lessons about stereotypes, including that socially devalued groups often get perceived and treated as if they were the same, i.e., someone in a wheelchair is just like a mentally retarded person.

This is an instructive movie from an SRV

perspective, and an exciting one to boot.

#### Endnote

1. 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 roles sociaux*, 2(2), 12-14.

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#### The citation for this review is:

Tumeinski, M. (2006). Review of the film *Murderball* by Henry Alex Rubin & Dana Adam Shapiro. *The SRV Journal*, 1(1), 51-52.

## Invitation to Write Book, Film and Article Reviews

*from the Editor*

I would like to encourage our readers to submit reviews to the Journal of current films, books and articles. For people who are studying SRV, looking for everyday examples can help deepen one's understanding. For people who are teaching SRV, learning from and using contemporary examples from the media in one's teaching can be very instructive for audiences. For people who are implementing SRV, contemporary examples can provide fruitful ideas to learn from. Some books and articles mention SRV specifically; others do not but are still relevant to SRV. Both are good subjects for reviewing. We have written guidelines for writing book and film reviews. If you would like to get a copy of either set of guidelines, please let me know at: Marc Tumeinski, The SRV Journal, 74 Elm Street, Worcester, MA 01609 USA; 508 752 3670; journal@srvip.org. Thank you.

# Tips for Moderating ‘SRV Council’ and Other Meetings

Guy Caruso

EDITOR’S NOTE: *The document below was originally written as an informal guide to be used by members of the North American SRV Development, Training & Safeguarding Council. The Council meets twice a year, and members take turns facilitating meetings. These notes were intended as a help for meeting facilitators, and were written by one of the members at the request of the Council. Although written for another purpose, many points in this document are relevant to SRV training (e.g., facilitating discussion groups at SRV workshops, leading PASSING teams, etc.) as well as SRV implementation (e.g., moderating family or planning meetings, etc.), which is why we are including it in this Journal.*

THE FOLLOWING TIPS (in alphabetical order) may be useful to moderators facilitating SRV Development, Training & Safeguarding Council meetings, as well as other meetings. Please respond to these and suggest others.

**Ask for Additional Questions and/or Responses on a Topic:** The moderator, to insure that all questions and/or responses have been addressed, should ask the group if they have any additional questions and responses. If so, then these should be addressed.

**Body Language, Reading It:** The moderator not only needs to listen to people in a group, but equally needs to view participants' body language for tiredness, discomfort, anger, boredom, reticence in talking, need for a break, etc. If the moderator notices a person(s) displaying

body language that indicates difficulty in paying attention and participating in the meeting, then the moderator needs to find out what is occurring and decide how to proceed.

**Breaks (Use of and Planning for):** A moderator needs to be mindful of the use of taking breaks during a meeting. A moderator can use a break when he senses the group is tired, when there is a logical break in the meeting agenda, as a calming-down period if there is tension in a meeting, as a “carrot on a stick” -- a way to motivate the group to put energy into finishing a particular task (i.e., the moderator may on occasion say something like, ‘It might be good to take a break when we come to a decision on this issue’), etc. A moderator may preschedule breaks into a meeting, ask the group for their opinion as to when to take a break, or schedule a break when deemed most appropriate to the running of the meeting.

**“Calling On” Strategies:** A moderator can use a “calling on” strategy, to make sure that all group participants are involved in the meeting. There are several “calling on” strategies:

a. *Calling on a person first.* A moderator may decide to call on a person first who he/she feels may have something meaningful to contribute when a topic is first discussed. This could be the most knowledgeable, passionate, impacted, concise or eloquent person on the topic.

b. *Calling people forth.* A moderator may be able to observe a group member’s body messages which imply that he/she may have something to say. For example, a moderator may see

a person shaking their head in agreement or disagreement while someone is speaking to the topic. A group member may become rigid or agitated, may rise and pace, etc. By calling the person forth, the moderator involves the person in the discussion, so their emotional state is less likely to adversely impact the meeting.

c. *Calling on the quiet person.* Some group members are shy or, because of the nature of an active talkative group, are hesitant to talk. When a moderator calls on the quiet person, it gives that person a chance to speak, and in a talkative group, the group may see that the person's input is valuable and the group may in future self-monitor their talking time.

d. *Calling on a particular person.* A moderator may discern that a particular person(s) really has something to offer on a topic at a particular time, and therefore calls on that person to make a comment to what has been said, to help summarize what has been said, or even to propose a motion for decision-making.

e. *Calling on each participant in turn.* If an issue of decision or definition is especially important, and if clarity and consensus are necessary to the group, then the moderator may (rarely) in turn ask for each participant's decision or viewpoint.

**Camaraderie:** The moderator can help build group camaraderie before and during the meeting through well-timed humor, knowing what issues and points connect people, making sure participants are comfortable (e.g., consider food, breaks, temperature, seating & room arrangements, etc.), by engaging people in small but important talk, being present during breaks to talk with people, etc.

**Consensus/Reach Agreement on an Issue:** Depending on the type of meeting being held and the protocol for how the group makes de-

isions (e.g., majority vote), a preferred way to make final group decisions is by consensus. Consensus implies that all participants have agreed on a particular decision. In order to achieve consensus, the moderator should make sure that all participants have had their say, have all agreed to the decision to be made, and have voiced any reservations.

**“Cooling the Mark” (Defusing Potentially Demanding Group Members):** On occasion a moderator knows ahead of time (perhaps forewarned by other participants), or discovers during the course of a meeting, that a particular participant may be demanding because the issue at hand is very important to him/her; he/she desires (consciously or not) to control or run the meeting; he/she is angry or hostile about a certain issue; or other precipitating reasons. Such a person can make moderating the meeting very difficult and even disrupt the group process. A moderator can defuse such a situation by being proactive versus reactive. The moderator can constructively involve the person in the group discussion, ask the person's opinion, meet with the person during a break to resolve or lessen any tension, and do other positive actions that more constructively and less destructively involve the person. In this way the person (i.e., “mark”) is involved in a positive way and any negative involvement is avoided (i.e., “cooling”).

**Decisions Made/Outcomes:** The moderator should strive to help the group make decisions, and/or to determine specific outcomes on the items on the meeting agenda. Therefore, a moderator will need to bring the group to decision by focusing discussion, establishing timelines, summarizing discussion, and having the group reach a decision. The moderator should make sure the decision made by the group is in fact

the decision desired. If so, the moderator should make sure the decision is recorded by the secretary of the group with the necessary information (e.g., what is to be done, by whom, when, etc.) to insure the success of the decision.

**Ground Rules and Expectations:** It is important (especially for new groups one may moderate) to establish at the onset of the meeting what ground rules and expectations are to be in place for the group, and to set clear expectations regarding conduct with one another during the meeting(s). A moderator can either share an already-established set of rules and expectations that he/she has used before, or have the group develop their own rules and expectations. Another option is to use an established set of rules and have the group add to it. Whichever option is used, it is important to have a group agree to ground rules and expectations before the start of a meeting, so that it is very clear to all involved how the meeting will be conducted, and what is expected of all participants. Such a set of rules and expectations greatly helps the moderator, who can point to these when a participant is not adhering to the rules established by the group. In this way, the moderator will not be singled out as the “bad guy,” but rather as the keeper of the rules established by the entire group. Also, group members can use the rules to monitor group members who have gone outside of the established and agreed-upon expectations.

**Listening Skills:** A moderator needs to carefully listen to what people have to say and when necessary restate what he/she has heard to make sure he/she has heard correctly. The moderator should instruct group members to do the same. (*Another ground rule.*)

**Moderator Role, and Stepping Out of It:**

The moderator role is to facilitate the group process during their meeting, make sure that the group acts in an orderly fashion, and make sure that the group is effective in reaching decisions. Occasionally, a moderator has something specific to offer the group that possibly jeopardizes his/her role as moderator. Typically a moderator is expected to be neutral and not to make decisions for the group, but to help the group to decision making. If the moderator feels that he/she has something important to say which is outside the role of being a moderator, then the moderator needs to say to the group, “I wish to step outside of my moderating role, and if you approve, I’ll share my opinion on the issue at hand.” The group can then decide to allow the moderator to step out of role or not.

**Passing on a Speaking Turn:** A moderator can remind people that it is all right to pass on their time to speak, especially if what they were going to speak about has already been covered by someone else’s remarks.

**Point of Order/Rule to Process:** The moderator should be mindful that participants can ask to halt the process of discussion, and even be recognized out of turn if a point of order is raised. In order to ask the moderator for a point of order, the participant must have a question that is not specifically about the topic at hand, but rather is about clarification of the group process.

**Recognizing Speakers/Keeping Speaker**

**Order:** A moderator needs to keep, as much as possible, an order of speakers so that everyone feels that they have had an equal opportunity to speak during a meeting. A moderator can keep a written list of speaker order or have an-



other participant do so for him/her. A nod of the moderator's head can indicate to a person desiring to speak that his/her name has been written down. Every so often, a moderator can inform the group of the order of the next few speakers.

**Reflection and Silence; Ways to Compose a Response to an Issue:** A moderator can use a set time of reflection and silence for the group to contemplate a discussion, decision to be made, point of tension, etc. Such time can help focus or refocus a group. It is also a good strategy to get a group to think more deeply and not just to talk with no direction.

**Respect:** The moderator needs to be a model in respecting all group members, even when disagreeing with a participant's viewpoints. The moderator needs to insure that all group members show respect for one another. (*Respect would be one of the ground rules and expectations for participation in the group.*)

**Respect Tension Over an Issue:** If it arises, a moderator should respect tension over an issue and not avoid or try to minimize the tension. The moderator does have serious responsibility to insure that the tension does not lead to disrespect of participants by one another, outright verbal nastiness, or even fighting. Tension can lead to a participant(s) leaving the room for a time period, even leaving the meeting entirely. Tension could also lead to a participant deciding to end membership in the group.

A moderator needs to find out what is behind the tension. Is it a personal issue between participants, a strong difference of opinion, etc.? The moderator needs to make sure that the group adheres to the agreed-upon ground rules for the process of the meeting. Often referring to the agreed-upon ground rules can

help participants to return to civility.

A moderator needs to "balance the tension" and help the group get beyond it to what the issue is, and what can be done to resolve the issue in a manner acceptable to all parties. Sometimes a moderator needs to "embrace the tension" and use it as a way to get beyond a difficult point in discussion and to resolution of an issue.

**Responding to Harsh Comments and/or Criticism:** If it arises, a moderator needs to recognize when a participant(s) becomes angry about an issue, or at a group member. Such anger can take the form of a personal attack of words, negative gestures and/or body language, and even threats. If the moderator avoids such conflict or tries to placate the parties, this may work for the short-term, but may reappear even with more intensity later on. In such a situation, the moderator needs to stop the flow of the meeting and have the person(s) process what is occurring. The moderator needs to ask both parties to share what it is that they are feeling in a respectful fashion, keeping in mind the agreed-upon group ground rules. The moderator's role is to restore respect, order and honesty to the meeting before it is too late, and major damage is done to group solidarity and camaraderie. Often, after such a personal and honest sharing by group participants that leads to resolution of heated emotions, the moderator may wish to take a break. A break at this time can allow the group to settle, perhaps nurture the parties who were in conflict, and allow the conflicted parties to personally "make up."

**Restating What Has Been Said:** A moderator may want to restate what a person has said to ensure accuracy, give the group another opportunity to hear what has been said, as well as help a group member struggling to get their

message across. The moderator can also ask another group member to restate what he/she has heard, if it is all right with the original speaker.

**Setting the Stage:** A moderator should be at the meeting location ahead of time to make sure that the room seating and other necessary meeting room requirements are set for the type of meeting being conducted, i.e., refreshments are prepared for participants to partake of before the start, and during the course, of the meeting; room temperature is comfortable (and know how, or whom to quickly ask, to properly adjust room temperature); bathroom locations; etc. In addition, the moderator or an identified person(s) should be present to greet people as they arrive so as to relax people, provide a hospitable atmosphere, as well as find out from people any circumstances that may cause them not to fully participate in the meeting.

**Side Bar, Use of:** When the group is discussing a particular topic, a participant may raise another topic that has relevance to the original topic. The moderator can ask the group's permission or use his/her discretion and put the original topic on hold to briefly address the new topic (i.e., begin a "side bar"). The intent of a side bar is to add to the original topic. Therefore, a moderator needs to make clear to the group that the side bar must relate back to the original topic. When the side bar is concluded, the moderator will explain that the discussion is returning to the original track, and will resume the original order of speakers.

**Silence Implies Consent:** Moderators should set clear expectations with a group that any person who remains silent during a topic discussion, and when a group's final decision is being made, understands that their silence

means that they have given consent to the final decision.

**Solidarity:** The moderator can remind the group of its shared mission and by so doing reinforce and continue to build a sense of group solidarity.

**Summary Statements (Processing as the Meeting Progresses):** It can be very helpful to a group when the moderator summarizes, or asks a group member to summarize, points that have been made by the group or decisions the group has come to. The liberal use of summary statements can save time by curtailing discussion that is becoming repetitive, and help the group focus on where they are now within a discussion.

**Time-Mindedness:** Moderators need to be masters of the use of time they have for a meeting. Moderators either alone or with group consensus and opinion can decide the time period for a meeting, possible breaks, and ending time.

**Touching Base Comments/"Are We OK?":** A moderator can take time to occasionally ask the group how everyone is doing - are we OK? This asking can be about group process, room arrangements and comfort, need for a break, tension felt or real, tiredness, moderator effectiveness, etc.

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**The citation for this article is:**

Caruso, G. (2006). Tips for Moderating 'SRV Council' and Other Meetings. *The SRV Journal*, 1(1), 53-57.

# **A Brief Overview Of The North American SRV Council's Trainer Formation Model (November 2005)**

## **SRV Development, Training & Safeguarding Council**

THE ABOVE North American SRV Development, Training, and Safeguarding Council (SRV Council) has prepared a lengthy written description of its "Trainer Formation Model," or TFM. The lengthy description spells out the purpose of the model, each element in it, how it all fits together and would be implemented, and also contains a number of appendices that are supplements or enrichments to the overall model description. This brief overview is intended as a summary of the lengthier description.

SINCE shortly after its founding in 1992, the above Council has been working on the development of a model for producing people who could competently do two things: (a) teach Social Role Valorization (abbreviated SRV); and even more importantly, (b) teach other people to teach SRV. People who can do the former--(a)--the Council calls "SRV trainers." Those who can do the latter--(b)--the Council calls "trainers-of-trainers" of SRV. The Council named this model a "Trainer Formation Model," i.e., a model for forming or developing SRV trainers and trainers-of-SRV trainers. It is abbreviated TFM.

Much more elaboration of SRV is available elsewhere (e.g., Wolfensberger, 1998, 2000).

But in brief, SRV is the application of empirical knowledge in order to enhance people's social roles, so that they will be more likely to be valued by others, and to receive the good things of life (Wolfensberger, Thomas, & Caruso, 1996). Role enhancement is accomplished primarily via image enhancement and competency enhancement.

The Council wants to develop trainers-of-trainers of SRV because unless there continue to be SRV trainers coming along, the teaching and dissemination of SRV will die. After all, there could be many SRV trainers who all teach lots of people how to implement SRV, but not how to teach it to others. So at a certain point, there might be implementation of aspects of SRV, but the knowledge of SRV itself might not be passed on to others, such as the next generation of human service workers.

In order to develop this model, the Council used the concept of model coherency, as most recently conceptualized by Wolfensberger (1994), which consists of four components:

- a. the beliefs and assumptions underlying the model;
- b. the characteristics of the people to whom the model is applied, i.e., its recipients;
- c. the content, i.e., what the model delivers to the people to whom it is applied;

- d. the processes, i.e., the methods used to deliver the content. These processes themselves consist of 5 components:
- d1. methods and technologies, including “tools”;
  - d2. settings in which the content is delivered;
  - d3. ways in which the people to whom the model is applied (the recipients) are grouped;
  - d4. people who deliver the content;
  - d5. language used in the model.

For the purposes of the TFM, we can translate these elements into the following:

- a. beliefs and assumptions relevant to SRV, SRV training, the Trainer Formation Model, its purposes, and what it can and should accomplish;
- b. what people would be like who enter the model so as to develop into competent trainers-of-trainers of SRV;
- c. what has to be given, provided, and/or offered to these people in order to develop them into competent trainers-of-trainers of SRV;
- d. how this content will be delivered to the candidates so that the Trainer Formation Model actually produces competent trainers-of-trainers of SRV:
  - d1. what methods and technologies, including tools, should or can be used (e.g., instruction and study, observation and modeling);
  - d2. in what settings the development of people into trainers-of-trainers of SRV should take place (e.g., colleges and universities, human service conferences);
  - d3. how the candidates should be grouped as they are being developed (e.g., with other trainer-candidates, with novices to SRV);

- d4. who should be the people who develop the trainers-of-trainers of SRV (e.g., already qualified trainers-of-trainers, PASSING team leaders and floaters);
- d5. what language should be employed within the TFM for the development of trainers-of-trainers of SRV (e.g., candidate, mentor, trainer formation).

THOSE WHO aspire to become trainers-of-trainers and undertake such development are referred to as candidates or trainer-candidates. Those who bring such candidates along through the TFM are called mentors.

The Council identified the crafts guild as its analogue for its Trainer Formation Model. In such guilds, the fully qualified practitioner of the craft was a master, with journeymen and apprentices being those who were working towards mastery of the craft. In the TFM, trainer-candidates would be apprentices and journeymen, until such time as they themselves qualify as competent trainers-of-trainers of SRV, at which point they themselves would be judged to be masters. During their development towards mastery, they are mentored by more advanced people who may themselves already be masters, or merely more advanced apprentices and journeymen.

In order to qualify as a trainer-candidate, a person has to possess certain qualities and characteristics, such as: intelligence; motivation to address social devaluation and to progress through the TFM; desire to teach SRV to others, and to teach others how to teach SRV to yet others; at least a basic understanding of SRV, most likely acquired through previous training; and various leadership capacities, or at least the capacity and willingness to develop such. The TFM spells out in much more detail the characteristics that would qualify someone to be a candidate for SRV trainership and

trainer-of-trainership, categorized into the six domains of: motives and commitments, beliefs and assumptions, knowledge, other competencies, miscellaneous personal qualities, and consciousness.

The Council also envisions that people who, by actually going through the TFM, are deemed to qualify as SRV trainers and trainers-of-trainers, would have to possess certain specified qualities and characteristics in these same domains, such as: motivation to address social devaluation by teaching SRV and teaching others how to teach SRV; thorough knowledge of SRV, including in all its nuances and subtleties; both willingness and ability to bring other people along into the roles of SRV trainer and trainer-of-trainers; and actually doing so. Again, the TFM spells out in much more detail what a qualified SRV trainer and trainer-of-trainers would look like.

Some candidates will present themselves to undertake trainer formation already possessing many of the qualities that a competent trainer-of-trainers of SRV should have. Others will possess fewer of these. The TFM is envisioned to develop whichever of these necessary qualities a candidate lacks, and for most candidates, this will take some time, though exactly how long depends on the candidate and the formation opportunities available to him or her.

The Council has also established a committee, called the Credentialing Committee, which would keep track of candidates as they develop through the TFM, review the status of candidates, make recommendations to the Council about candidates, and so on. However, it is the Council as a whole that gives final approval to candidates aspiring to a particular rank or qualification on their way to becoming trainers-of-trainers.

IF YOU THINK you might be interested in becoming a trainer-candidate, in sponsoring someone to enter the TFM, or for any other reason want more information on the TFM, there are several members of the Council you can contact.

**In Canada, contact:**

Bill Forman  
Consortium for Values in Action  
1929 Third Avenue NW  
Calgary, Alberta T2N 0K1 CANADA  
phone: 403/283-0380  
email: forman@telusplanet.net

Zana Lutfiyya  
Faculty of Education  
University of Manitoba  
Winnipeg, Manitoba R3T 2N2 CANADA  
phone: 204/474-9009  
fax: 204/474-7564  
email: zana@umanitoba.ca

Beth French  
Brockville & District Association for  
Community Involvement  
2495 Parkedale Avenue, Unit #4  
Brockville, Ontario K6V 3H2 CANADA  
phone: 613/345-4092, extension 36  
fax: 613/345-7469  
email: bdaci@ripnet.com

**In the United States, contact:**

Jo Massarelli  
SRV Implementation Project  
74 Elm Street  
Worcester, MA 01609 USA  
phone: 508/752-3670  
fax: 508/752-4279  
email: jo@srvip.org

Joe Osburn  
Safeguards Initiative  
114 Woodhill Road  
Bardstown, KY 40004 USA  
phone: 502/348-1168  
fax: 502/348-1193  
email: joeosburn@spitfire.net

Any of these people can also provide you with the full-length document on the TFM, and will be happy to discuss it with you.

**A Description of the North American  
Social Role Valorization Development,  
Training & Safeguarding Council's Trainer Formation Model**

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**References**

Wolfensberger, W. (1994). *The rating of model coherency impact*. Unpublished manuscript.

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 rev. ed.). Syracuse, NY: Syracuse University Training Institute for Human Service Planning, Leadership & Change Agency.

Wolfensberger, W. (2000). A brief overview of Social Role Valorization. *Mental Retardation*, 38 (2), 105-123.

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 Roles Sociaux*, 2 (2), 12-14.

**The citation for this article is:**

SRV Development, Training & Safeguarding Council (2006). A Brief Overview of the North American SRV Council's Trainer Formation Model (November 2005). *The SRV Journal* 1(1), 58-62.

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***A Note on an SRV-relevant Concept ...***

***from the Editor***

Citizen Advocacy is an advocacy model developed by Wolf Wolfensberger which in practice is informed by, and relevant to, SRV. Citizen Advocacy arranges and supports relationships between socially valued competent citizens, and individuals who are socially devalued. The intent is for the typical citizen to respond to, and to represent, the devalued person's needs and interests as if they were their own.

The description of social devaluation given in most SRV workshops helps explain why Citizen Advocacy is relevant and even crucial in the lives of socially devalued persons. One way of understanding some of the positive impacts of Citizen Advocacy is to look at the way that Citizen Advocacy invites and supports valued social roles for devalued people, particularly valued relationship roles. Those who teach or are trying to implement SRV would do well to learn from Citizen Advocacy, and vice versa. Three excellent Citizen Advocacy resources are:

Wolfensberger, W. and Zauha, H. (1973). *Citizen Advocacy and Protective Services for the Impaired and Handicapped*. Toronto: National Institute on Mental Retardation.

Hildebrand, A. (2004). *One Person at a Time*. Brookline, MA: Brookline Books. (Ed. note: watch for a review of this book in an upcoming issue of *The SRV Journal*.)

Cullen, J. and Peters, M. (eds.). *Citizen Advocacy Forum*. Available by contacting *Citizen Advocacy Forum*, c/o Mitchel Peters, PO Box 6027, Girrawheen WA 6064 AUSTRALIA.

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# CALENDAR OF SRV AND RELATED TRAININGS

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This calendar lists upcoming SRV and PASSING workshops which we are aware of, as well as a limited number of other workshops specifically relevant to SRV. To notify us of workshops for calendars in upcoming issues of this Journal, please send the information to: [journal@srvip.org](mailto:journal@srvip.org). Additional training calendars may also be accessed online at [www.socialrolevalorization.com](http://www.socialrolevalorization.com) and [www.srvip.org](http://www.srvip.org).

**A Revised Conceptualization of Social Role Valorization (SRV), Including 10 Related Themes**

*NB: this workshop is specifically oriented to leadership development*

October 16 - 19, 2006  
Western Massachusetts, USA  
call Susanne Hartfiel at 508 752 3670

February 5 - 8, 2007  
Shrewsbury, Massachusetts, USA  
call Susanne Hartfiel at 508 752 3670

February 26 - 28, 2007  
Syracuse, New York, USA  
call Susan Thomas at 315 473 2978

March 26 - 29, 2007  
Southeastern Massachusetts, USA  
call Susanne Hartfiel at 508 752 3670

**Practicum With SRV Using the PASSING Tool**

*NB: attendance at an SRV workshop is a prerequisite for this course*

July 10 - 14, 2006  
Adelaide, AUS  
call Jayne Barrett at 0408 550 123

September 18 - 22, 2006  
Darwin, Northern Territories, AUS  
Cherry Cameron ~ [Cherryc@somerville.org.au](mailto:Cherryc@somerville.org.au)

April 2007 (dates to be determined)  
Hamilton, Ontario, CAN  
call Donna Marcaccio at 905 525 4311

May 6 - 11, 2007  
Shrewsbury, Massachusetts, USA  
call Susanne Hartfiel at 508 752 3670

**A One-Day Overview of Social Role Valorization**

May 15, 2007  
Ottawa, Ontario CAN  
call Susan Thomas at 315 473 2978

**Towards a Better Life: A Two-Day Basic Introduction to SRV**

September 7 - 8, 2006  
Adelaide, AUS  
call Peter Millier at 0418 830 347

September 14 - 15, 2006  
Darwin, Northern Territories, AUS  
Cherry Cameron ~ [Cherryc@somerville.org.au](mailto:Cherryc@somerville.org.au)

**A Three-Day Introductory Workshop on SRV, Using Seven Themes**

*NB: this workshop has small group discussions*

November 9 - 11, 2006  
Hamilton, Ontario, CAN  
call Donna Marcaccio at 905 525 4311

**A Relevant One-Day Workshop Taught by Prof. Wolf Wolfensberger and Associates of the Training Institute**

Most Powerful Means of Influence ("Pedagogies") for Affecting, Shaping, Changing Human Behavior  
September 28, 2006  
Ottawa, Ontario area, CAN  
call Susan Thomas at 315 473 2978



# Social Role Valorization News and Reviews

## Wolf Wolfensberger

AS IN THE EARLIER ISSUES of *SRV/VRS: The International Social Role Valorization Journal/La revue internationale de la Valorisation des roles sociaux*, my intent for this column is four-fold, at least across multiple journal issues if not in each one.

(a) Briefly annotate publications that have relevance to SRV. Conceivably, some of these might be reviewed in greater depth in a later issue of this journal. Many of these annotations should be useful not only as teaching resources, but as pointers to research relevant to SRV theory.

(b) Present brief sketches of media items that illustrate an SRV issue.

(c) Present vignettes from public life that illustrate or teach something about SRV. Aside from being instructive to readers, persons who teach SRV will hopefully find many of the items in this column useful in their teaching.

(d) By all the above, I hope to illustrate and teach the art and craft of spotting, analyzing, and interpreting phenomena that have SRV relevance.

### **The Treatment of Normalization in the Professional Literature Before the Reconceptualization to Social Role Valorization**

THIS SECTION is meant to serve primarily archival purposes, briefly reviewing what vari-

ous writers said when allegedly discoursing about the principle of normalization, before it was reconceptualized by Wolfensberger in 1983 as Social Role Valorization.

The publications under this heading are arranged in chronological order.

\*Koch, R., & Koch, K. J. (1974). *Understanding the mentally retarded child: A new approach*. New York: Random House. Of the 15 chapters, Chapter 12 is entitled "Progress Toward Normalization: Care of the Mentally Handicapped Today in California" (pp. 219-230). Normalization is here defined as being entitled to the same rights and privileges enjoyed by the normal populace. There is really no systematic elaboration of the normalization principle, but a number of measures that might be consistent with it or with any number of other ideologies are mentioned, such as giving mentally retarded adults in institutions a voice as to whether they want to live outside or not. Abolishment of large institutions is called for, but a need for small institutions for the multiply handicapped profoundly retarded is envisioned. Among the most vigorous opponents of the normalization principle are said to be employee associations of state bureaucracies, and parents of children in institutions.

Somewhat erroneously, it is claimed that the movement toward normalization in California began in 1965 with legislation to establish a re-

gional center system. However, the gradual phasing in of these centers did dramatically reduce admissions to the state institutions. This underlines that to many people, normalization meant mostly deinstitutionalization, though not necessarily the abolishment of institutions.

In many respects, this chapter is more about the regional center system in California than about the principle of normalization.

\*Jones, K. (with Brown, J., Cunningham, W. J., Roberts, J., & Williams, P.) (1975). *Opening the door: A study of new policies for the mentally handicapped*. London: Routledge & Kegan Paul. (International Library of Social Policy Series, K. Jones, Gen. Ed.). Rather amusingly, this book claimed that normalization "has its origin in Professor Tizard's Brooklands study" of the 1950s, and then referred rather quickly to the "excesses of normalization" (pp. 190-191). However, no references to normalization were given, which was a common phenomenon in the early literature by writers outside the culture of normalization teaching and theory-development.

\*Zipperlen, H. R. (1975). Normalization. In J. Wortis (Ed.), *Mental retardation and developmental disabilities: An annual review* (Vol. 7) (pp. 265-288). New York: Brunner/Mazel. This literate, well written, and thoughtful chapter is by a leader of a Camphill village in Pennsylvania. However, in regard to the normalization principle, it did not make recourse to the PASS publications which greatly clarified the principle of normalization, but did make reference to certain planning concepts which Wolfensberger taught, but which are not essential expressions of normalization. The critique apparently also does not take into account that the normalization principle strongly calls for focusing not merely upon change in a

devalued person's behavior or appearance, but also changes in the physical as well as social environment. Still, of all the critiques of the normalization principle, this is one of the longest and most cultured ones, in its references to a wide range of thinking, sources, etc. The chapter also presents a great deal of information about the Camphill approach which, for a while, saw itself threatened by the implementation of normalization.

\*Rosen, M., Clark, G. G., & Kivitz, M. S. (1977). *Habilitation of the handicapped: New dimensions in programs for the developmentally disabled*. Baltimore: University Park Press. Of the 21 chapters divided into seven sections, Section 3 has two chapters and is entitled "The Residential Institution and Attempts at Normalization." Chapter 7, "Institutions and Their Effects," noted that the authors of *Christmas in Purgatory* were subjected to severe criticism because the pictures allegedly did not do justice to the many fine programs that existed at the very same institutions that the authors had photographed. Chapter 8, entitled "Beyond Normalization," is rather funny because the authors had never really been proponents of normalization to begin with. There is a great deal of rhetoric about normality, and a little working with the Wolfensberger definition of normalization, but no referencing at all to PASS as a rather detailed operationalization of Wolfensberger's definition. As an alternative to ("beyond") normalization, a construct of "personal adjustment" is proposed here with seven dimensions: self-concept, independence, reality testing, emotional development, goal-directed behavior, interpersonal relationships and sexual development.

\*Baker, B. L., Seltzer, G. B., & Seltzer, M. M. (1977). *As close as possible: Community residences for retarded adults*. Boston: Little, Brown. The first part of the title of this book is a phrase that occurs in Nirje's definition of normalization. Of special interest is a chapter on "Sheltered Villages," which looks at nine of them located in seven US states. Another unusual chapter is on so-called "Workshop Dormitories" that one rarely reads about. While there is a great deal of emphasis placed in this book on the normalization principle, it is fuzzy as to the distinction between Nirje's and Wolfensberger's definitions, and how these might clash.

\*Braddock, D. (1977). *Opening closed doors: The deinstitutionalization of disabled individuals*. Reston, VA: Council for Exceptional Children. There is some good material on normalization and deinstitutionalization. Also, tables on pp. 9-10 show who resided in what kinds of institutions in 1960 and 1970. One can see in the kinds of statistics presented here the author's later interest in collecting data on the "state of the states." As models of deinstitutionalization, Nebraska, California and Massachusetts are more closely examined. There is a lengthy annotated bibliography and a list of films.

\*Curry, J. B., & Peppe, K. K. (Eds.). (1978). *Mental retardation: Nursing approaches to care*. St. Louis, MO: C. V. Mosby. Perhaps surprisingly, with 21 chapters, Chapter 4 is on "Principles of Normalization," by Kay F. Engelhardt (pp. 33-41). The author quotes Bank-Mikkelsen, Nirje, Wolfensberger, and others. Some of the key elements of deviancy are briefly reviewed. Normalization is variously interpreted as the right to a more normal existence, an average lifestyle,

and greater integration into the community. Even the concept of "analogies" is introduced, in the sense of the culturally valued analogue.

This is a fairly good simple introduction to the concept, and reminds nurses that services are often based on outdated rationales that persist from mere momentum. Nurses are also reminded to individualize their approaches and not to think in terms of group norms and group management. Readers are also reminded of what a normal lifestyle entails for different age groups, and how this can be used as a reference point for planning on behalf of retarded individuals and their families. In many ways, this material is concordant with the individual planning culture, and even anticipates its later incarnations.

Normalization is also mentioned in many other chapters.

\*Novak, A. R., & Heal, L. W. (Eds.). (1980). *Integration of developmentally disabled individuals into the community*. Baltimore: Paul H. Brookes. Many of the chapters from various contributors to this book had been published at least in part earlier.

Even though the book gives a great deal of emphasis to normalization, and devotes quite a few pages to the PASS instrument, surprisingly it fails to come to grips with the integration construct that is supposed to be the major focus of the book. For instance, there is a great deal on enhancing the competencies of retarded persons, but there is very little on what one must actually do systematically and concurrently in order to maximize the likelihood that integration will occur, the way PASS and PASSING lay this out systematically.

\*Wehman, P., & Schleien, S. J. (with Reynolds, R. P.). (1981). *Leisure programs for handicapped persons*. Austin, TX: PRO-ED.

It only came to our attention in 2005 that this book endeavored to base its entire approach to leisure programs for handicapped persons (including a lot of athletic activities) on the principle of normalization, to which the entire first chapter (pp. 1-18) was devoted. The one element of normalization that was stressed more than all the others was integration, though also very prominent was what amounts to the culturally valued analogue, though that expression itself was not used.

\*Bruininks, R. H., Meyers, C. E., Sigford, B. B., & Lakin, K. C. (Eds.). (1981). *Deinstitutionalization and community adjustment of mentally retarded people*. Washington, DC: American Association on Mental Deficiency. (AAMD Monograph Series No. 4, C. E. Meyers, Series Editor). There are 26 chapters in this book. Several are of interest, but many are of the academic "must publish" type. Many refer to normalization, but often in casual and superficial ways. Similarly, PASS is often misinterpreted.

One error that seems to occur several times throughout the book is denial of the power of the environment to shape people's behaviors. For instance, one chapter claims that "environmental normalization" cannot be expected to result in "client normalization" which of course then calls for a lot of academic research (pp. 247-248, but also p. 338 in another chapter). However, the authors seem to contradict themselves on p. 252.

This distinction is also made much of in the chapter starting on p. 337. If one followed the model of this book, one would use millions of researchers to study the subject matter to death and not do anything in the meantime, not to mention that the results might not even be valid ones.

In the studies reported here where PASS

was applied, it was apparently applied by people who had not gone through the standard training, and probably not in a standardized fashion.

One chapter (Crime, deviance and normalization: Reconsidered; pp. 145-166) is by the sociologist R. B. Edgerton. It documents how mentally retarded persons are often victimized, which a great deal of the literature otherwise ignores. However, at the same time, retarded people also commit a great many petty crimes. Amazingly, despite scores of references, not a one is to a normalization publication!

### **The Treatment of Normalization in the Professional Literature After the Reconceptualization to Social Role Valorization**

THIS SECTION TOO is meant to be mostly an archival snapshot of how normalization theory was treated by several writers after the advent of Social Role Valorization in 1983.

\*Gardner, J. F., & Chapman, M. S. (with invited contributors). (1990). *Program issues in developmental disabilities: A guide to effective habilitation and active treatment*. (2nd ed.). Baltimore: Paul H. Brookes. Much of this book of 14 chapters is centered around standards for "intermediate care facilities for the mentally retarded" (ICF/MR), but the editors do not seem to have pointed out how risky that can be. Also, the title of the book should have made its purpose explicit. Chapter 3 by James Gardner and John O'Brien is entitled "The Principle of Normalization" (pp. 39-57). After an introduction that is rather good (with a few minor exceptions), normalization is presented according to an O'Brien scheme of "5 dimensions": community presence, community participation, skill enhancement, image en-

hancement, and autonomy and empowerment. The chapter then lists 14 ICF/MR standards, and how normalization related to them. This discussion brings to bear many of the points that have long been taught in normalization and Social Role Valorization courses. The chapter then explains a number of other normalization corollaries, such as groupings, age-appropriateness, language, etc., and how these might be recruited into ICF/MR programming. Separating the discussion of the 5 dimensions from the rest of the normalization coverage makes the chapter quite choppy, and poorly integrated. Nonetheless, this could be an instructive chapter considering its brevity.

\*Eisenberger, J., Hahn, M. T., Hall, C., Koepp, A., & Krueger, C. (Eds.). (1999). *Das Normalisierungsprinzip -- vier Jahrzehnte danach: Veraenderungsprozesse stationaerer Einrichtungen fuer Menschen mit geistiger Behinderung*. Reutlingen, Germany: Diakonie. (Berliner Beitrage zur Paedagogik und Andragogik von Menschen mit geistiger Behinderung, Vol. 7). The title promises a look at physical settings for retarded people after 40 years of normalization, but anyone who expects this book to deal with that topic will get a very unpleasant surprise. There is hardly any treatment of normalization in the book at all, and what little there is is almost entirely in one chapter by Neumann, and much of it has nothing to do with normalization but rambles on about all sorts of other issues. The part of it that does have to do with normalization is somewhat irrelevantly preoccupied with the construct of normality, nor does it give a reasonable overview of either the early normalization construct, or its evolution. Nowhere in the book is Social Role Valorization mentioned.

\*A letter to the *New York Times* (13 April 2005, front page) by the former director of the psychiatric clinic at St. Luke's-Roosevelt Hospital in New York City called the "new antidepressant" drugs "brain normalizers" (source item from Raymond Lemay).

## Deviancy

\*Dumont, L. (1970). *Homo Hierarchicus: The caste system and its implications*. London: Paladin. This book is all about the caste system in India. The cover shows one head with the red mark designating a higher caste than the others. While this book is only about the caste system in India, it has a lot to teach about social stratification, deviancy, and distantiation.

\*Scheper-Hughes, N. (1979). *Saints, scholars, and schizophrenics: Mental illness in rural Ireland*. Berkeley, CA: University of California Press. The author documented life in a rural village on the West Coast of Ireland in the 1970s, focusing especially on the amount of identified mental disorder, and the institutionalization of persons with such disorders. There, the treatment consisted almost entirely of mind drugs (p. 86). She found that many more males than females ended up so identified and then put away, and many of these the youngest sons of the family. She attributes this to the need to identify a scapegoat for the family problems, and since the eldest son(s) are favored, and both these sons and daughters often emigrate to make a better life, that leaves the youngest son, who often also remains a bachelor and takes care of both his old parents at home.

On pp. 77-78, she talks about most villages having had people who filled "the sanctioned role of fool, entertainer, and clown or village

idiot,” and how only one person out of many eccentrics would be singled out as “the fool,” suggesting only one was “needed” per village. She refers to certain roles as being “disvalued” (p. 180), and also notes that certain role niches were saved for physically handicapped people (p. 180).

\*Hendershott, A. B. (2002). *The politics of deviance*. San Francisco: Encounter Books. This book powerfully underlines the ideological foundation of the so-called social sciences, and how they are buffeted by whatever “religion” happens to be prominent in academic or intellectual circles at a given point in time. For instance, once these circles began to exalt multi-culturalism and diversity as just about the highest religion, they began to make war on the huge amount of scholarship that had been devoted for many decades to the construct of deviancy. Under the previous religion, deviancy had much to do with the construct of degeneracy associated with social Darwinism, but to the religion of political correctness, the former deviancies were actually things to be celebrated. Furthermore, the constructionists and so-called post-modern mentality of the elite has become ever more reluctant to judge the beliefs and behavior of others -- except that it has made dissent from multi-culturalism one of the few deviancies to be condemned. The new religion also has much to do with the medicalization of deviancies. For instance, drug addiction is now interpreted as a disease akin to cancer, which makes drug-addicts victims rather than offenders.

### Social Role Theory and SRV

\*Stenius, V. M. K., Veysey, B. M., Hamilton, Z., & Andersen, R. (2005). Social roles in

women’s lives: Changing conceptions of self. *Journal of Behavioral Health Services & Research*, 32(2), 182-198. This seems to be one of the first studies from outside the normalization/Social Role Valorization (SRV) culture that (a) is clear that SRV is indeed solidly tied to role theory; that (b) used SRV concepts in order to shed light on the roles of women in an empirical five-year study of 225 women in two locations; and that (c) brought out the positive impact to these women of holding or gaining valued roles, and the negative impact of moving into devalued roles. It also brought out how a change in one role often brings about a change in another, as asserted by SRV. However, as was also the case with a lot of literature about normalization, the study does not explain the origins of SRV, and does not cite primary SRV overview publications.

\*Parsons, G., Elkins, J., & Sigafos, J. (2000). Are people with intellectual disabilities just another customer? Interviews with business owners and staff. *Mental Retardation*, 38, 244-252. Quite obviously, there are some social roles that preclude occupancy of other social roles, at least at the same time, while many other social roles can be held in parallel. For instance, a player in a sports game cannot simultaneously be a spectator and fan thereof, though he or she might very well be a spectator or fan at another game in which the person is not performing as a player. At least until recently, and perhaps in certain circles, a brother could not also be a person’s sister. Some roles that can be held concurrently are very rarely held thusly, such as outstanding model citizen and imprisoned felon.

In light of this, it is interesting to contemplate that many people are apt to withhold all sorts of positive roles from persons whom they perceive as holding significantly deviant

roles. For instance, to the degree that there are such things as a village idiot role or a recluse role, people would be somewhat surprised to have the same person interpreted in any number of other -- and mostly positive -- roles. However, there are some roles that override the significance of holding certain devalued roles. For instance, the authors found that when mentally retarded people had money to spend and came to stores and shops to spend it, then their role of "customer" was vastly more significant in the eyes of the merchants than any number of deviant roles the same people might have held at the same time, and even if they looked and acted oddly. One might have attributed this to the commercial interest of merchants, but surprisingly, other customers without such interests at the same establishments viewed the retarded customers much the same as the merchants did. The authors interpreted this as a validation of SRV.

### **Social Imagery: Person Perception**

\*All cultures throughout history seem to have believed that the outer appearance of people reveals things about their minds. The book of Ecclesiasticus (also called Sirach) in the Old Testament was written probably between 200-175 BC. It said "You can tell a person by his appearance, you can tell a thinker by the look on his face. The way a person dresses, the way he laughs, the way he walks, tell you what he is" (19:25-26).

\*Tagiuri, R., & Petrullo, L. (Eds.). (1958). *Person perception and interpersonal behavior*. Stanford, CA: Stanford University Press. While there have been writings on the meaning of human appearance, the bumps on one's head, and facial features, the impact of peo-

ple's appearance on perceivers only began to be researched extensively in an experimental way after World War II, and under various topic headings such as social perception, interpersonal perception, person perception, the perception of people, perceiving the other person, and impression management. This sizeable book, based on a research symposium held at Harvard in 1957, may have been the first to use the phrase "person perception." Among its 26 contributors from psychology, sociology, and anthropology were some of the big names of their time.

\*Goffman, E. (1959). *The presentation of self in everyday life*. Garden City, NY: Doubleday Anchor Books. This is another early work -- based on yet earlier ones by the author -- on self-presentation. However, we need to keep in mind that the term "self-presentation" suggests that one is in charge of how one presents oneself, which is not the case with little children and many impaired people. In fact, Goffman chose to use the metaphor of theatrical performance as the framework for his analysis. Therefore, the term "personal appearance" would be more neutral, since it says nothing about who or what is responsible for the way one looks. However, it does imply that the appearance is perceived by sight, whereas "self-presentation" can also subsume references to other sense modalities, such as how one speaks, or what one smells like. There may not be a single term in English to subsume all of these.

\*Etcoff, N. (1999). *Survival of the prettiest: The science of beauty*. New York: Anchor Books. Surprisingly, it is only since the early 1980s that there has been systematic study of what makes physical and facial features attractive to others. Since then, studies from several

continents support the notion that there are “hard-wired” criteria in the human brain for judging people’s attractiveness.

\*The domain of personal appearance is at the same time incredibly fascinating, rich in empirical studies, and highly controverted. Research has amply demonstrated that people hold very strong internalized standards of what is beautiful and attractive in other human beings. To some degree, these standards may vary between cultures, but at the same time, all cultures have very strong standards. In other words, that some personal appearances are ugly and others beautiful is a universally-agreed fact, and the only thing that varies to some degree between cultures is what it is that makes a person appear attractive or ugly to others.

However, despite these differences, there is also increasing evidence that there is at least one universal beauty standard that not only cuts across human cultures but even across species barriers, and that is the criterion of symmetry. In all sorts of animal species, individuals prefer symmetric specimens as a mate. Research has also discovered why this is so, namely symmetry is highly correlated with indices of adaptiveness and health, while asymmetry is correlated with the opposite. There are very good reasons for this as well, insofar as individuals with asymmetric features are likely to have suffered either genetic impairment, disease, or accidents, and these are in turn correlated with lowered health and adaptability. Symmetry may also be an index of a well-functioning immune system capable of resisting infection by parasites which, in the animal kingdom, commonly cause uneven growth of bone, wings, fur or feathers. It may also be a signal of capability to withstand scarcity of food, extreme temperatures, or toxins. More often than not, it is the female who examines

the male for maximum possible balance between the left and right halves of the body (miscellaneous sources).

\*Anybody interested in recent research on human judgment of the attractiveness of the human face should read the cover story of the February 2000 issue of the science magazine *Discover*. This has much relevance to SRV. Among other things, it brings out that there is a great deal of unconsciousness both in people’s enhancement of their own appearance, as well as in one’s perception of the appearance of others; and that there are universal appearance appeals that transcend human culture, contrary to what some people have claimed. Appearance plays such a powerful role because of its intimate link to reproductive promise. We also learn from this article that when races first encounter each other, they see each other as unattractive, but when one race acquires economic or political power, members of other races tend to emulate their characteristics, including those of appearance.

\*As we had also noted in earlier columns, how even a single feature of physical appearance can contribute to valued social roles is dramatically underlined by all sorts of studies that show that tall people have a much higher likelihood of being advanced to societally valued positions. US Presidents have historically tended to be tall, business executives and bank presidents are taller than average, and bishops are taller on the average than priests. In fact, each inch of growth in childhood is “worth” several thousand dollars a year in income as an adult (*Science*, 3 October 1986, p. 23). No man between 1888 and the date of this article had become US President who was not at least 5 foot 7 inches tall. Height has become an even yet greater selection criterion since the advent



of television, during which the taller of the competing candidates have been elected 80% of the time. In the 11 presidential races between 1952-1992, the tallest candidate won in 82% of the races (*Time*, 27 May 1996).

\*Giacalone, R. A., & Rosenfeld, P. (Eds.). (1991). *Applied impression management: How image-making affects managerial decisions*. Newbury Park, CA: Sage. So-called impression management is one of the innumerable sub-specialties in psychology and sociology that is very relevant to SRV, and particularly to the entire issue of social image. It deals with the impressions that people convey about themselves to other parties. However, the term "impression management" does not reveal whether a party's impression is self-managed, as in "the presentation of self" discussed above, or is managed by others. Giacalone and Rosenfeld bring out how impression management can influence processes and outcomes in organizations, can make managers and consultants more effective, and can create self-fulfilling prophecies of enhanced performance. Impression management can, of course, also convey negative impressions and reinforce pre-existing negative stereotypes. This book includes information about how one's own definition of an interaction is likely to make one behave, and how it tends to constrain the ways in which other persons are likely to respond. As should be obvious, impression management can be used to malicious ends, as exemplified by people playing con games.

\*Matkin, R., & Riggan, T. F. (1985). The Emperor's new clothes: A preppy pilot. *Rehabilitation Literature*, 46(1-2), 12-15. This article underlines just how neglected the personal appearance of handicapped people has been in the rehabilitation field. The authors were able

to identify only two articles in the professional literature that addressed the importance of enhancing personal attire. They conducted a survey of 119 rehabilitation professionals, apparently from throughout the US and holding a wide range of positions, in order to assess their attitudes toward personal attire. 86% reported that they thought that personal attire contributes to a "professional image" and projects messages about the wearer's competencies and quality of service. Further, 82% reported that their own attitudes towards others were affected by the clothing that the others wore. Interestingly, 47% of respondents believed that the rehabilitation personnel dressed worse than business persons. Unfortunately, the survey did not ask the respondents what efforts they had been making in their own careers to improve the personal appearance and attire of their clients. The survey also yielded a rank-ordering of the elements of personal appearance that the rehab professionals paid attention to. Cleanliness ranked highest in the list of 14, followed by neatness. The quality of the clothes worn, and the jewelry accessories, ranked lowest. However, one has to keep in mind that these are merely verbal reports which may be far off the mark because the impact of people's appearance generally involves a great deal of unconsciousness. Interestingly, 17% of the respondents commented negatively on the entire area of inquiry, thus apparently revealing their own lack of awareness of the role that personal appearance played not only in the lives of devalued people but also in the process of image transfer from those who serve such persons to those whom they serve.

\*In his 1963 book, *Stigma*, Erving Goffman coined the term "courtesy stigma," which was one of those awful terms of which sociology is full, in that the term not only has no readily

recognizable meaning, but is even apt to suggest something other than its definition. The term refers to the fact that those who are closely associated -- or viewed as identified -- with a devalued ("stigmatized") person acquire some of the same devaluation ("stigma") in the eyes of observers as the devalued person him/herself. Of course, this is the same as what Wolfensberger's version of normalization theory and Social Role Valorization has called (in language that is much more descriptive and intelligible) "deviancy image juxtaposition" and "image transfer." However, the image juxtaposition and transfer realities have been dealt with in much broader and higher-level (more universal) fashion in normalization and SRV theory than Goffman did, though both are indebted to him a great deal.

### **The SRV Theme of Mind-Sets & Expectancies**

\*Weinstein, R. S. (2002). *Reaching higher: The power of expectations in schooling*. Cambridge, MA: Harvard University Press. The construct of expectations plays a very important role in SRV. This book looks at one kind of expectancy, namely that of educators in schools for students. There has been a tendency to confuse teacher expectations with expectations conveyed or imposed by higher levels, such as entire schools, curricula, etc. High teacher expectations cannot by themselves overcome structural defeatism, as when schools almost abandon academic subjects. Another confusion has been between low expectations of children generally, versus only of certain types of children.

\*Gest, S. D., Domitrovich, C. E., & Welsh, J. A. (2005). Peer academic reputation in ele-

mentary school: Associations with changes in self-concept and academic skills. *Journal of Educational Psychology*, 97(3), 337-347. A longitudinal study of 400 children in grades 3, 4, and 5 found that students who were thought by their peers to be academically talented improved their grades, whereas those under negative reputations went downhill. This seems to be an example of an expectancy feedback loop.

\*Workers at a New York City food kitchen were quite used to men from the street culture coming in for a meal wearing women's clothes. One day, a person came in dressed in a traditional nun's full habit. Because the workers knew men who dressed like that, they assumed that the person was a transvestite. However, it eventually turned out that it was actually a real woman nun. This vignette illustrates both the power of expectations based on earlier experience, and how a physical setting can influence one's expectancies as to who one will find in it (*CW*, May 1998).

\*A schizophrenic young man (Michael Laudor) was urged by his father to go to law school, because the father thought that this would distract him from his schizophrenic mentation. The father proved to be right, and the son benefited more from law school at Yale University than from any mental health establishment. The young man then became somewhat of a culture hero for allegedly having recovered from schizophrenia, until he did have a relapse and murdered his fiancée (e.g., *Time*, 29 June 1998). Obviously, he should have continued to occupy the student role that did so much good for him.

\*A panda escaped from a zoo in the Netherlands, but was struck dead almost right away by a train only a few yards into his escape.

However, before his body was found, the public was alerted that a panda was on the loose, and in no time at all, a hundred sightings were called in, all of them of course false. What this underlines is that when people are told that they can expect to see pandas (or for that matter, monsters, witches, or UFOs), they will look for them -- and see them (*Discover*, April 1998, p. 91).

\*Certain personal appearance features also trigger certain expectancies in observers. For instance, a red-headed guest columnist in *Newsweek* (14 October 1996) discoursed at length on the fact that all of his life, he had been subjected to the expectancy that because he was a redhead, he must be a clown. He said that it is "amazing how quickly a child called carrot-top learns to act silly."

### The SRV Theme of Modeling & Imitation

\*That people imitate and learn by imitation, and that modeling can be powerful in eliciting imitation, has been known forever, well before the age of "research."

An old poem from the Islamic Sufi tradition has the lines, "Have I lived among the lame for so long that I have begun to limp myself?" This underlines that the power of modeling and imitation is rather universally understood. To us, such a comment from the past, especially if united with a large number of similar comments from many other people over a long span of history, constitutes empirical evidence of the power of modeling/imitation, even when this evidence does not come from what mis-trained social scientists consider "research."

\*Bandura, A., & Walters, R. H. (1964). *Social learning and personality development*.

New York: Holt, Rinehart & Winston. The power of modeling/imitation in learning had already been extensively discoursed upon in early texts, and particularly in the theorizing, research and literature on so-called social learning that became popular in the 1950s and 1960s. However, this literature focused mostly on the explanation of learning processes rather than on the conversion of theory and research to practical pedagogy or human services.

\*Meltzoff, A. N., & Prinz, W. (Eds.). (2002). *The imitative mind: Development, evolution, and brain*. New York: Cambridge University Press. This book is extremely relevant to the modeling and imitation theme of SRV. It goes as far as to characterize the human mind itself as being an imitative one by nature. However, people trying to study imitation scientifically would emphasize different things than would those who try to recruit imitation tendencies to develop adaptive behaviors. The latter class would be much more concerned with deliberately reducing the presence of bad models while increasing the presence of adaptive models, and encouraging the people it is trying to influence to imitate the latter.

\*Provine, R. R. (1996). Laughter. *American Scientist*, 84(1), 38-45. It is rather well-known that some kinds of behaviors are much more likely to be imitated than others. A good example is laughter. All it takes is for one person to laugh, and one or more other persons in that individual's presence are apt to also laugh, or at least begin to smile. One of the reasons may be that laughter-related behavior is one of the first ones that babies are able to imitate. For instance, even within hours of birth, healthy babies are able to imitate an adult who models mouth-opening or gaping, and this is certainly a big component of laughter.

Provine reports that in 1962, there was a very bizarre outbreak of contagious laughter in Tanganyika, Africa. It started with isolated fits of laughter -- and sometimes crying -- in a group of 12- to 18-year-old school girls, but it rapidly spread and attained epidemic proportions, traveling from one individual to the next and from one community to adjacent communities. The behavior was so disruptive that eventually, the schools were closed, and it took six months for normality to return.

\*The strongest predictor of whether a teenager will take to booze is whether he or she has friends who already drink (*Time*, 12 Feb. 2001).

\*According to CBS "60 Minutes" (19 March 1995), the "Virginia Slim" ads are the single biggest reason why teenage girls smoke, apparently in part on the unconscious assumption that (a) if they smoke, they will be slim too, and that (b) this is a good thing. This underlines the power of imitation as well as that of unconscious influence exerted consciously by others.

\*In 2004, esteemed baseball player Derek Jeter of the New York Yankees made a spectacular leap into the stand to catch a ball and save the game, but acquired a bruise under his right eye, and had to have his chin bandaged. At the next Yankee game, several fans showed up with bandaged chins, and bruises painted

under their right eyes. This illustrates how people will sometimes affect the afflictions of persons in valued roles (source item from Carl Cignoni).

\*A special adaptation of the modeling/imitation method of teaching and learning was designed by Dietmar Todt, a German psychologist, in the 1970s. The learner gets so positioned as to observe another learner being tutored by an instructor, and being rewarded for correct answers and rebuked for incorrect ones. Periodically, the learner roles are exchanged so that the learner who had observed gets tutored while the person tutored previously is in the observer role. Thus, not only is acquisition modeling set up for both learners, but also an element of motivating competition, as each learner wants to do as well as, or better than, the other one. Of course, this works best where both learners are of about equal aptitude in respect to what is to be learned. Presumably, this tactic would also work with more than two learners, but possibly with diminishing effectiveness.

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**The citation for this article is:**

Wolfensberger, W. (2006). Social Role Valorization News and Reviews. *The SRV Journal*, 1(1), 64-75.