The SRV JOURNAL

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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; 3) fostering, extending and deepening dialogue about, and understanding of, SRV; and 4) encouraging the application of SRV, as well as SRV-related research.

We intend the information provided in this journal to be of use to: family, friends, advocates, direct care workers, managers, trainers, educators, researchers, and others in relationship with or serving formally or informally upon devalued people in order to provide more valued life conditions as well as more relevant and coherent service.

Interested persons and 'servers' can do this primarily by helping devalued people to attain and maintain valued social roles. 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 SRV; and promote the work of the formulator of SRV, Prof. Wolf Wolfensberger of the Syracuse University Training Institute.

Editorial Policy:

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 (see for example the last page of this journal), 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 as 'writers.' Members of our editorial boards will be available to help contributors with articles accepted for publication. The journal may also have an academic peer review section for those who are interested.

Information for Submissions:

We welcome well-reasoned and clearly-written submissions. 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. We will not accept items simultaneously submitted elsewhere for publication or previously electronically posted or distributed.

Submissions are reviewed by members of the editorial board, the editorial advisory 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.

Dear reader,

WELCOME to the third issue of *The SRV Journal*. This issue has a number of timely articles, including a description and analysis of a new human service planning approach (also see the training calendar on page 64 for a relevant upcoming workshop on Social Role Valorization [SRV] and Person Centered Planning), the launching of a new SRV study group, as well as a review of a recently premiered film.

A few of the articles in this issue deal with the same topic; for example, we asked two different reviewers to write about the same somewhat controversial book dealing with the mental health field; we have two interviews with agency directors with different depths of experience with SRV; and we also include a critical book review concerning the topic of the article mentioned in the previous paragraph which describes a new service planning approach. This focus on different looks at the same topic was an intentional effort on the part of our editorial board to encourage discussion of important human service issues from an SRV perspective.

FOR THOSE of our readers in supervisory positions within human services, or who teach about human service issues (whether at the college or university level, in workshop format, or within an agency or program), I encourage you to use this journal as a resource for your teaching. For example, readers have told us that they have copied particular journal articles and used them in their teaching, e.g., as a discussion topic during a staff meeting, an exercise for a small group, a handout, etc. (Please see our notice on page 14 regarding the copying of copyrighted *SRV Journal* articles.)

THE 4th International SRV Conference was held in Ottawa in May of 2007. The theme of the conference was *"Crafting Valued Social Roles for Socially Devalued People."* For those of you who presented a paper at this conference, please consider submitting your conference paper for possible publication in this journal. Future journal issues will publish papers from the conference. If you presented but did not prepare a paper, consider submitting a manuscript based on your presentation. If you did not present but attended and were struck by something you heard at the conference, consider submitting a manuscript or letter to us on that particular issue. Contact me at the address below for further information.

I WELCOME in general your submissions of manuscripts for possible publication. Your particular interest in SRV will be instructive for our readers. Our readers are from the US, Canada, Great Britain, Australia, New Zealand, Norway and Germany. They come from a variety of human service backgrounds and interests, and depths of experience with SRV.

We are also open to hearing your suggestions of new formats and ideas for this journal. If you have any suggestions, please send them to the address below. And if you find this journal helpful, why not recommend it to your colleagues? Information on subscribing can be found at our website (www.srvip.org).

Regards,

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Roles Based Planning: A Thoughtful Approach to Social Inclusion and Empowerment

Scott Ramsey

Introduction

ROLES BASED PLANNING is a new, innovative approach to planning that marries the most beneficial components of person-centered planning to the critical thought base associated with Social Role Valorization (Wolfensberger, 1998) and to field best practices for improving social status, social inclusion and employment outcomes for marginalized populations. Since its inception in 2002, Roles Based Planning has led to some of the best employment and social inclusion outcomes for adults with developmental disabilities in North America.

History and Methodology

ROLES BASED PLANNING was first conceptualized and implemented in Calgary, Alberta, Canada during the summer of 2002. It began with a retrospective study aimed at determining the impact of person-centered planning processes within the lives of 200 adults with disabilities. The study looked at results of person-centered plans from a six year period ending in 2001. The retrospective study was conducted from February to April 2002, and included the following components: interviewing adults with disabilities and network members about their experiences; before and after comparative analysis of participant and family

satisfaction survey results; quantitative comparison of outcomes against baseline measures in key areas; reviewing the nature of goals established during 300 planning meetings; and obtaining feedback from planning facilitators and direct support personnel.

While many positive impacts associated with person-centered planning were evident within study results, several problematic areas also emerged that appeared to be either inherent within the process itself and/or its underlying assumptions. As such, Roles Based Planning was developed to reinforce the most beneficial elements of person-centered planning while simultaneously addressing its more problematic components.

Prior to turning to the specific pros and cons associated with person-centered planning, it is important to note that the planning facilitation team involved with this study:

- Received their original training directly from the founders of person-centered planning;
- placed strong emphasis upon adhering to the original tenets of planning as they had been taught;
- received supplementary training and consultation with their mentors to ensure they remained on track;
- pursued person-centered planning as a dedicated six-person team whose entire role surrounded planning facilitation; and
- were employed by a large service provider agency, yet remained intentionally separated from the direct service delivery component to minimize the inherent conflict of interest associated with conducting in-house planning.

Study Findings

On the positive side, the original study results of person-centered planning processes indicated that families and support staff had sig-nificantly increased their knowledge base about what planning participants (i.e., the adults with disabilities) liked, and were able to translate this added knowledge into expanding opportunities for most people within the community, albeit mostly in the form of leisure pursuits. At the individual level, planning participants reported feeling significantly more respected and empowered to make choices in their lives. And finally, at the organizational level, study participants indicated that person-centered planning had been a strong influencing factor in the closure of agency group homes, sheltered workshops, crew sites and work enclaves in favor of more inclusive alternatives.

On the more problematic side, study results also revealed the following ten areas of concern surrounding the person-centered planning process:

1. Planning participants generally chose what they thought would be the most fun or what was most familiar without considering the potential negative impacts of immediate decisions upon: longer term opportunities, societal perceptions, and/or reinforcement of common negative stereotypes.

2. Employment rates plummeted as people chose recreational pursuits over work.

3. Remaining employment roles remained largely devalued, with the majority of roles continuing to involve cleaning, recycling and fast food.

4. Planning participants frequently had not been provided sufficient experience or information upon which to base informed decisions.

5. Planning participants had frequently been manipulated into making specific decisions by support staff and/or network members who possessed an intimate knowledge of how to get them to agree with predetermined options.

6. Plans rarely addressed barriers to supporting people, perhaps for fear of casting anything negative into the planning process, and perhaps also out of the naive assumption that such challenges would disappear if people were really receiving exactly what they wanted.

7. Plan follow through was often not completed, i.e., accountability for plan completion and/or revising plans did not occur naturally within most networks.

8. Many support staff began to use the rationale of 'choice' as justification for continuing questionable support practices, i.e., the word 'choice' became a 'sacred cow.'

9. Despite planning participants' feeling more empowered and having increased physical presence within the community, they really were not becoming any more socially valued or included.

10. Many networks indicated that the person-centered planning process was overly utopian and at times harmful to their son or daughter, reporting that it led them down the proverbial 'garden path' only to be disappointed in the end.

Interpretation of Results

Based upon noted findings, it became evident that while person-centered planning provided many beneficial outcomes for people with disabilities, it did not fully take into account societal dynamics, manipulating influences upon the person and/or the importance of social contribution, and therefore also resulted in the creation of counterbalancing negative impacts. In other words, the potential for person-centered planning to significantly impact people's lives for the positive was strongly correlated with the extent to which such factors listed above had been, or had not been, taken into consideration. Taken as a whole, the 2002 study results indicated that the benefits and

drawbacks of implementing person-centered planning balanced each other out to such an extent that it succeeded in yielding only marginally positive impacts in the lives of most of the 200 planning participants. On the more positive side, however, study results also indicated the potential for such pitfalls to be overcome by placing greater emphasis upon the importance of social contribution, intentional relationship facilitation, valued roles, disproving negative stereotypes and introducing a more critical thought base into the process.

Additional Anecdotal Observations

Based upon the preceding findings, a member of the study team consulted with a variety of service provider organizations locally, nationally and internationally to verify if similar patterns surrounding person-centered planning were being observed elsewhere. Anecdotal evidence suggested that not only were similar outcome patterns being observed on a large scale, but that the self-determination paradigm itself had become severely corrupted within the service sector through service provider misapplication of the paradigm. Since person-centered planning is closely aligned with self-determination principles, many felt that corruption of this paradigm was creeping into planning processes, thereby further eroding the types of outcomes being achieved. Comments also suggested that self-determination and person-centered planning had been around long enough for service providers to locate the loop holes, and corrupt the language and tenets of each to the point where they were no longer what they once had been, or set out to achieve. What person-centered planning and self-determination are today was rarely what their founders had set out for them to be in either intent or practice.

Three prevalent trends surrounding self-de-

termination dominated these discussions, including:

   1. The tendency to view self-determination as an end unto itself, rather than as a tool or means for helping people to build better lives in the community.

   2. The tendency to selectively choose amongst the principles of self-determination; placing emphasis upon only one or a few principles while ignoring the rest. Most commonly, this trend manifested itself in the form of emphasizing the principles of 'freedom' and sometimes 'authority' while nearly always ignoring the principle of 'responsibility.'

   3. The tendency to equate the words 'choice' and 'self-determination' as being one and the same, even where such choices had been uninformed, irresponsible and/ or manipulated by others.

   In summary, consultations with service provider organizations around person-centered planning indicated that not only had the results of the study been borne out by the experience of other service providers who had attempted to stay true to original planning tenets, but that even more problematically, the self-determination and person-centered planning movements were fast becoming subverted in a manner identical to what had happened to the normalization movement (Flynn and Lemay, 1999; Wolfensberger, 1972) decades before. This should in no way be interpreted as detracting from the many benefits and positive impacts that each of these movements or paradigms have had within the disability sector, but rather as an observation that few good things are capable of surviving much more than a decade within the service provision world before becoming subverted by those who fail to study and/or apply their principles thoughtfully in the lives of real people.

Foundational Conclusions
Informed by the preceding study results, the following set of conclusions were established which would later provide the foundational building blocks for the creation of Roles Based Planning:

- Planning needed to be rooted in something deeper than an overly simplified notion of choice -- something that would guarantee critical discussion and provide a stabilizing framework or reference point when things went wrong or got messy.

- Planning needed to consider the culture, times and social realities within which people live. In other words, it needed to pay more attention to the challenges, barriers and stereotypes that would be encountered on a day to day basis rather than ignore their existence, plan for a hypothetical person and hope for the best.

- Planning needed to place additional emphasis upon **informed** decision-making by providing people with extensive exposure to options related to their interests, introducing them to new options in comfortable ways and providing them with sound advice.

- Planning needed to actively promote the importance of work over leisure, and present employment as a societal expectation rather than as a choice or right.

- Planning needed to shift focus from filling schedules with activities and keeping people entertained, to addressing factors that would make more of a positive difference in their lives as its foremost priority, i.e., responding to their most pressing needs. This does not mean that leisure has no place in people's lives, but rather that it receives a far disproportionate amount of attention from human service agencies even when overarching needs -- like having friends in

the community, a means to communicate and employment -- remain unaddressed.

- And finally, planning needed to move beyond being accountable for process only, and hold itself accountable to the higher standard of achieving positive outcomes.

PUT ANOTHER WAY, planning needs to be about more than simply promoting choice and having fun if it is to make a tangible difference in people's lives. Good planning is founded upon each person's interests, dreams and aspirations but also requires consideration of the culture, times, and social realities within which people live. It requires critical discussion and intense debate about societal expectations, the reality of stereotypes and what will make the most positive difference in the life of each person. It requires identifying and planning to surmount the barriers that are sure to be encountered. It requires emphasis upon the importance of social contribution, image and intentional relationship facilitation. It requires providing people with disabilities with the information and experience necessary to make truly 'informed decisions,' including that information which may be difficult to hear.

Based upon such considerations, four additional broad conclusions surrounding field paradigms were also adopted as part of the Roles Based Planning creation process. **First**, radical (mis)application of self-determination principles was likely to result in personal empowerment but usually came at the expense of being devalued and socially excluded by the community. **Second**, radical (mis)application of Social Role Valorization (SRV) principles was likely to result in social valuation and inclusion but usually came at the expense of personal empowerment. **Third**, by marrying the principles of self-determination to those of Social Role Valorization, a win-win situation

could be achieved in which all objectives could be successfully attained, i.e., social valuation, inclusion and empowerment. And **fourth**, when the principles of each paradigm were in conflict, adhering to the principles of informed decision-making would provide the most ethical basis upon which to decide a course of action. By necessity, informed decision-making would also require the presentation of information about anticipated negative ramifications likely to arise from selecting specific options being included as part of the choice process.

What is Roles Based Planning?

ROLES BASED PLANNING is a thoughtful means of personal planning that:

1. Starts with the dreams and interests of each person;

2. ensures each person has been provided with sufficient information and direct experience to make informed decisions about their future;

3. applies critical thought to how each dream or interest can be pursued in ways that will help each person be seen as a valued, contributing citizen and optimize their opportunities for developing friendships;

4. identifies and attempts to overcome the negative impacts of societal stereotypes upon people with disabilities;

5. identifies and responds to each person's most pressing needs and barriers to success as part of the planning process; and

6. shifts focus from filling time with activities to thoughtfully and thoroughly pursuing valued roles (Wolfensberger, 1998, pp. 25-33, 44-49, 82-95, 106-108) and relationships within the community.

In short, it is intended to help people achieve the good things in life (Wolfensberger,

Thomas & Caruso, 1996) and be seen as valued, contributing citizens.

Roles Based Planning Underlying Beliefs

Roles Based Planning is founded upon the following set of underlying beliefs:

- Each person, supported by those closest to them, is capable of dreaming and making important decisions about their future.
- Everyone has the capacity for growth and learning throughout their lifespan (Wolfensberger, 1998, p. 70).
- Service providers bear a heavy obligation to ensure people they support are making informed and non-manipulated decisions.
- Valued roles and friendships within the community provide each person with the best opportunity to achieve the good things in life.
- Any interest can be explored in ways that will optimize opportunities for achieving valued roles and relationships within the community; unfortunately, the opposite is also true.
- The vulnerability of people with disabilities to negative stereotyping, discrimination, and devaluation make it necessary to think deeply upon all issues of support.
- Society is unlikely to adopt the view that people with developmental disabilities have inherent worth on any large scale without efforts to improve the image, skills, societal contributions and types of roles held by people with developmental disabilities.
- Work is a societal expectation, NOT a choice or right.
- Barriers to the success of plans can be addressed positively in empowering ways and must be discussed within the development of any realistic plan.

How is Roles Based Planning Different From Person-Centered Planning?

Roles Based Planning differs from person-centered planning in both underlying beliefs and practical considerations surrounding the planning process itself. The following table highlights additional areas where more significant differences exist between the two approaches.

Person-Centered Planning	Roles Based Planning
Facilitator follows lead of person and network.	Facilitator's role expanded to include challenging networks to apply field best practices and SRV principles when deciding how and where to pursue the person's dreams and interests.
Prioritizes what person wants/enjoys most as foremost priority.	Prioritizes person's most pressing needs, i.e., what will have the most impact in improving their quality of life as top priority, e.g., employment, friends, being able to communicate effectively, etc.
Rarely addresses barriers within the planning process.	Considers addressing barriers an essential element of planning but does so in a respectful and empowering way.
Results in completing lists of activities	Moves beyond activities to holistically pursue valued roles -- considers selection of optimal: • Environments -- to set up conditions where people can be seen at their best and maximize potential for facilitating relationships. • Associations/people/contacts -- to enhance image, increase positive role modeling, network, and improve opportunities for the future. CONTINUED ...

Person-Centered Planning	Roles Based Planning
	• Timing -- to ensure people come into contact with the same people on a regular basis, thereby increasing chances for relationship facilitation. • Activities -- to challenge growth and tear down negative stereotypes, i.e., child, incompetent, nothing-to-offer, drain on society, etc. • Language learning opportunities -- to ensure people are equipped with the language and terminology necessary to be taken seriously within specific roles. • Active and passive learning mechanisms -- to accelerate the learning curve. • Personal image -- to ensure people dress for success and put their best foot forward by creating a positive impression.
Enjoyment of activities often seen as ends unto themselves.	Goes the extra mile by pursuing enjoyable activities at optimal times, in optimal community locations and with maximum effort to actively facilitate relationships.
Does not directly address issue of societal norms or distinguish between legitimate program roles.	Attempts to mirror societal norms as a means to dispel negative stereotypes, promote commonality and social inclusion. Always considers legitimate program roles to avoid making people appear incompetent.
Does not directly address vulnerability to, or potential reinforcement of, negative stereotypes.	Highly conscious of vulnerability to stereotyping, avoids reinforcing negative stereotypes and attempts to prove them wrong through practical example.
Presents employment as an option or choice.	Presents employment/social contribution as a societal expectation.
Action plans generally project one year into the future.	Action plans project no more than three months into the future to increase flexibility and responsiveness.
Accountable for process only.	Accountable for both process and outcomes.
Rooted in self-determination paradigm.	Marries principles of self-determination to those of Social Role Valorization to improve grounding and promote critical thinking.

Additional Safeguards

While remaining cognizant of the manner in which self-determination and person-centered planning have been misapplied and perverted within the human service sector over the past decade, Roles Based Planning proactively attempts to save itself from a similar fate by the following means:

- Ensuring the question of *"What will it take to help each person build a better life in the community?"* remains the central question

of the entire planning process. In this manner, and by ensuring facilitators remain highly conscious of the tendency of service providers to transform means into ends, Roles Based Planning attempts to maintain focus where it belongs -- on the individual and helping them to achieve a better life;

- requiring facilitators to complete a 3-or 4-day SRV workshop, PASSING (Wolfensberger & Thomas, 1983) training, and Roles Based Planning facilitation training as man-

datory training requirements. Planning facilitators are additionally expected to possess strong backgrounds surrounding relationship facilitation, career support, augmentative communication, mediation and negotiation, positive behavior support, community development and self-determination principles. Through the establishment of such rigorous training requirements, Roles Based Planning seeks to avoid the tendency of many to stick to what they know, or to pick and choose amongst principles in favor of considering how all available tools may be best used to each person's benefit; and

- adding the elements of asking critical questions, conducting best practices education and challenging networks as essential elements of the facilitator's role. Through such means, facilitators are expected to expose truth, provide balanced information and ensure that each person has been provided with sufficient direct experience and information upon which to base informed decisions.

DESPITE SUCH additional safeguards, they represent only a stalling action against approaching erosion and subversion within the human service sector. Due to the force and speed with which paradigms and approaches become corrupted within the service provision sector, it would be naïve to assume that any amount of safeguarding will preserve this approach fully from the same fate faced by self-determination and person-centered planning over the long term.

Despite all of this, Roles Based Planning represents a promising development within the current disability sector. Having already produced vastly superior outcomes to person-centered planning, Roles Based Planning is a tool

that will provoke significant positive change in many people's lives over the next decade or two, until such inevitable perversions take sufficient hold.

Roles Based Planning Results

Based upon a subsequent four years experience since the original 2002 study (during which time Roles Based Planning was implemented with the **same** 200 adults from the original study), the following results were achieved, representing what the planning team believes is some of the best outcomes within North America:

- 65% increase in people pursuing all activities during service hours in a fully inclusive manner -- currently 90%.
- 44% increase in people who have at least one friend in the community -- currently 57% .
- 38% increase in people employed above minimum wage within the community -- currently 73%.
- 36% increase in average hourly wages -- currently $8.18 CDN/hour.
- Elimination of wage exemptions.
- Enhanced nature of employment roles being obtained -- micro fiche, data entry, certified daycare worker, security, cashier, retail, skilled trades, manufacturing, etc.
- Highest service provider satisfaction ratings ever achieved within the hosting agency from people with disabilities and their family members.

Conclusion

ROLES BASED PLANNING offers a practical alternative to person-centered planning and has achieved significantly improved outcomes over its predecessor. By marrying the critical

thought base of Social Role Valorization to the most beneficial components of person-centered planning and field best practices surrounding relationship facilitation, career support and community inclusion, Roles Based Planning has built upon the work of giants in the field such as Wolf Wolfensberger, John O'Brien, Angela Amado and John McKnight, combined their expertise into a unified approach, and built a stronger, more effective form of planning as a result. Roles Based Planning represents a next evolution in planning and a promising development within the disability sector in terms of helping people with disabilities become more valued and socially included within today's society.

Admittedly, neither the original 2002 study of person-centered planning outcomes, nor the analysis of Roles Based Planning results, identified potential other factors which may also have influenced these results, e.g., different funding levels, differing levels of family or community involvement, experience level of the service workers involved, increased level of experience and knowledge of the planning facilitators, etc. Nonetheless, this does not take away from what is a powerful new planning approach.

Person-centered planning has the potential to significantly increase its positive impacts in the lives of people with disabilities where facilitators have additional training in Social Role Valorization and use this knowledge base to stimulate more critical discussion within the planning process. Such cross-training is rarely seen, as the requirement for facilitators to complete SRV and PASSING (Wolfensberger and Thomas, 1983) training is not built into the process as a safeguarding measure, and in many instances person-centered planning facilitators view the self-determination paradigm as being completely incompatible with SRV principles. As such, Roles Based Planning may provide just the incentive needed for everyone to take another look at what each paradigm has to offer so that people with disabilities themselves benefit to the maximum extent possible.

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ROLES BASED PLANNING: A THOUGHTFUL APPROACH TO SOCIAL INCLUSION AND EMPOWERMENT. By SCOTT RAMSEY. Developmental Disabilities Resource Centre of Calgary, Calgary, Alberta, Canada, 55 pages, 2005. Available for $20 + GST, S&H, from 4831 Richardson Way SW, Calgary, Alberta T3E 7B7, Canada.

Reviewed by
Wolf Wolfensberger & Susan Thomas

THIS MONOGRAPH sketches a roles-based personal planning process in contrast to all sorts of other individualized planning approaches, including so-called person-centered planning. While it flirts with some contemporary crazes, it is one of the few works of its kind that is systematic in sketching out some of the problems and misuses of the rights orientation, the self-determination ideology, the community inclusion movement, etc. Its approach presupposes an understanding of Social Role Valorization (SRV) by the planning participants, and then gives a large number of very useful tips on how to go about role planning.

The emphasis on social roles and what it would take to attain desired roles is to be commended, as this is certainly different from what many kinds of personal futures planning produce.

The book implies, perhaps unintentionally, that this roles-based planning approach is meant for adults. But of course SRV is just as applicable to children and young people, and to the aged, even though the way such a planning meeting would be conducted, how much weight would be given to a child's input, etc., would presumably differ from that with an adult.

Somewhere, it would be helpful if it were acknowledged that while it is important to recognize, take note of, and possibly record (e.g.,

on a chart) the role or roles that a person badly wants, those participating in the planning should take account of what can be deemed feasible (as the SRV implementation steps emphasize), and what is and is not good for the person and for others. This will sometimes mean that roles desired by a person simply cannot be pursued, and maybe should not be pursued, and that instead, maybe an alternative role, or a role that captures only some of what is desired by the unfeasible/not-good-for-the-person role, ought to be crafted or pursued.

We have found the graphics produced during some personal planning meetings to be often very clever, but not necessarily very helpful to people who did not participate in the meetings. Therefore, we suggest that they be printed with a note that these are samples of what a roles-planning group might produce after discussion about a specific individual, but that participants do not *have* to produce such a graph, and that putting things in words rather than pictures can sometimes be more powerful -- or at least acceptable, as long as everyone participating in the meeting can *understand* whatever is produced.

However, one shortcoming of the approach taken in this monograph -- the same as apparently in all other more recent individual planning ones -- is that it does not take into account that such planning needs to be an organically evolving process that is iterated over time as either progress is made with the person planned for, or as no progress occurs, or new obstacles appear. We do not recall having seen that problem adequately addressed in the literature on individual planning. We have always emphasized that the things that need to be identified and worked toward on behalf of a person are the most obvious *immediate next steps*. Going beyond this may provide motivation to all concerned, but contributes little if

anything to what should be done in the short run -- after which the entire scenario may change. Then when either these steps are attained, or fail to be attained, a new round of brainstorming and problem-solving is needed because the situation is likely to have changed considerably.

What also seems missing from this monograph are some of the practical steps and implementations spelled out in Wolfensberger's 1998 monograph entitled *A Brief Introduction to Social Role Valorization: A High-Order Concept For Addressing the Plight of Societally Devalued People, and For Structuring Human Services* (pp. 82-102), and also taught in even yet more updated form in the 3-or 4-day SRV workshops that use the 10-theme formulation of the theory. (EDITOR'S NOTE: *See training calendar on page 64 of this Journal.*) Among other things, that approach makes it clear that there are image and competency sub-goals, but

the competency sub-goals in particular seem to have been severely slighted in this monograph. When efforts are made to develop all sorts of positive roles without paying adequate attention to prerequisite competencies, we suspect that a dead end will eventually be reached, and that people will become disillusioned with the approach, and perhaps even declare SRV a failure.

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Around the Corner: A Neighborhood-Based
Job Initiative for Teenagers

Marc Tumeinski

Introduction

MOST OF US REMEMBER our first job: the thrill of getting a paycheck, the feeling of satisfaction, new relationships and new responsibilities, perhaps some nervousness. Our first jobs as teenagers gave us an entry into the adult world of work. Some can take getting that first important job for granted; for others, that is not so. Impairment, socioeconomic background, or race can put that first job as a teenager essentially out of reach.

In the summer of 2005, the Pleasant Street Neighborhood Network Center (NNC) in Worcester, Massachusetts (US) began running a job matching initiative for neighborhood teenagers. I found out about this program because I live in the Pleasant Street neighborhood. This article describes that program from the perspective of Social Role Valorization (Wolfensberger, 1998).

Program Description

WORCESTER IS A CITY of approximately 170,000 people in central Massachusetts. Like many American cities, Worcester has people living in it from a number of different racial backgrounds (white, black, Latino, Asian and European) and different economic levels (from poor to very wealthy). Major employers in the city include hospitals, colleges and human service organizations, although there are a fair

number of small-business owners as well. Pleasant Street is a major road in Worcester, running from the downtown all the way to the city limits. Along its length, it goes through a number of different kinds of neighborhoods: residential, commercial, rich, poor, busy and not so busy. The downtown area of Pleasant Street faces the typical urban struggles of poverty, crime, drug abuse and dealing, and the violence that comes with it.

The Pleasant Street Neighborhood Network Center is a resource center for neighbors living primarily in the downtown section of Pleasant Street and its surrounding streets. The stated goals of the Center are to: 1. be a resource center that is accessible to all neighbors, 2. improve access to neighborhood services, and 3. strengthen the local community and develop new leaders. Its mission statement places great emphasis on neighbor involvement, as well as on building closer relationships and networks among neighbors. (For more on community development, see for example O'Connell, 1988 & 1990; Carlson, 2000.) Its funding comes primarily from the state and from a national granting organization. The director is a longtime neighborhood resident and mother of three. The part-time employee who worked most directly with the job matching program in the summer of 2005 has also lived in the neighborhood for years.

Both these people over the years have been consciously building up close connections with people living and working in the Pleasant Street

area. In their conversations with neighborhood teenagers, they are often told that finding summer jobs is a high priority. The director said, "We have a strong relationship with the kids in the neighborhood. When we asked them what the greatest need was, they said the need was for jobs for the summer." Recognizing this important need, as well as the advantages from the close-knit nature of the neighborhood and the presence of small-business owners on Pleasant Street, the NNC decided to do something to address that need. Their goal is to support neighborhood teens to have the age-specific valued social role of summer worker, with all the benefits that come with that role.

A first step was to identify priorities. The overarching goal of the initiative is to help neighborhood teens improve their job skills and future employability. Finding neighborhood jobs, particularly ones that the teens can walk to, is a high priority. One of the issues raised by neighborhood teens and their families was the difficulty of getting to work. Many neighborhood families do not have their own transportation, so are not able to help their teenage children get to work. Although city buses are available, some jobs (such as at restaurants) have hours when buses do not run frequently or do not run at all.

Another major goal of the program is to help strengthen neighborhood connections, which includes helping employers get to know local teens in a positive way, and vice versa. This is seen by NNC staff as a way to overcome at least some of the separation between employers and neighborhood residents, and to counter some of the common stereotypes about teenagers, especially ones who are of a racial minority, of lower income, or both. This goal highlights one of the typical benefits of personal social integration and valued social participation as described in SRV (Wolfensberger, 1998,

pp. 122-123). One of the funders said, "Everyone knows jobs are key for kids -- that your first job can be the learning experience that pushes you on to bigger and better opportunities. That's what we are hoping these new relationships will bring about."

The NNC applied for and received a federal grant. This grant covers some operating expenses of the program but primarily is used to pay half of the salary of each worker. The NNC feels that paying half the salary is a selling point for potential employers, while requiring employers on their part to also pay half the worker's salary encourages them to make an investment in their employee. This compares positively with a citywide employment program for Worcester teens which I was told pays the teen workers' full salary, thus requiring little investment from employers. Many of the jobs offered to teens in the citywide program also tend to be more like 'make-work' than a real job and a real valued social role of (summer) worker.

The concrete goal of the Neighborhood Network Center in 2005 was to find jobs for up to eighteen teens, for a ten-week period during that summer. Each teen was to be paid $8 per hour (well above the state minimum wage), half covered by the grant, and the other half paid by the employer.

Once the federal grant was received, the NNC staff looked for local employers willing to participate in the Around the Corner (AtC) Jobs Initiative. They quickly found eleven employers through personal connections, e-mails, newsletter, phone calls, word of mouth, and appeal letters. The employers found that summer included a bank, painting company, high-end restaurant, community garden, medical center, graphics company, local market, paint store, apartment complex, construction company, and one human service (a settlement

house). The NNC found thirteen jobs with these different employers.

Who Were the Teenagers?

Twenty-three teenagers applied for the thirteen available jobs. Their ages ranged from seventeen to nineteen years old. Of the thirteen chosen (in a process described below), two were girls. Many were from either Latino or Albanian families. Most were from families of lower income who tended to be quite transient, e.g., moving often to find work.

Much of this translates into a heightened vulnerability (Wolfensberger, 1998, pp. 124-126) for Pleasant Street neighborhood teens. They are vulnerable to (further) impoverishment, lack of stable well-paying employment with a chance for advancement, isolation from certain more valued sectors of society (i.e., financially better-off societal sectors), being stereotypically perceived as menacing (for young men in the neighborhood), and continuing or even worsening societal devaluation (Wolfensberger, 1998, pp. 3-24; Osburn, 2006).

They are also highly motivated to work. Most of course want to have money to spend but also to save, for things like clothes, or to pay for their high school senior photos.

Program Processes

Many of the teenage applicants heard about AtC that first summer through a local basketball program run by the NNC. The twenty-three applicants went through a fairly rigorous process of interviews and training. The interviews were conducted by two adults and two local teens. The interviewers held very high expectations (Wolfensberger, 1998, pp. 105-106) for the applicants, particularly since only thirteen jobs were available and twenty-three applied that first summer. One of the teenage interviewers said: "Most people did pretty well at the interview. The ones that really stood out were the ones who were really serious about getting a job. I know that the next time I go for a job I will be remembering this experience."

The AtC program focuses explicitly on preparing the teens to be good workers; competency enhancement (Wolfensberger & Thomas, 1983, pp. 26, 339-507; Wolfensberger, 1998, pp. 70-73) related to the role of worker is a high priority. The NNC runs a workshop for successful applicants on how to be a good worker. They teach them how to open a bank account to save their pay. They give them help writing resumés, thinking in particular about future adult employment. AtC arranges a 'meet the employers' breakfast for the applicants and representatives from the employers. The NNC asks each employer to provide written descriptions to help prepare the teens for their role of worker.

NNC staff also make efforts to compensate for the heightened vulnerability of the teens (Wolfensberger, 1998, pp. 126-127). NNC staff meet with employers every two weeks as a check-in, so that the employers see NNC standing behind the workers. NNC staff meet with the teen workers once a week. They budget money as part of AtC to buy alarm clocks for each teen, recognizing the importance of being on time in keeping a job (NB: an expectation of the role of worker), and the reality that at least some of the teens are not able to afford an alarm clock.

One particular vignette illustrates both the high expectations held for worker's competencies, but also the address of vulnerability. One of the teenagers did not show up for work for two days, nor did that teen call the employer. When the employer called the NNC to let them know, the part-time NNC employee went to the teenager's home.

It turned out that on one of those days, the teen worker had a medical appointment at the same time as his work shift. On the second day, the teenager found out that his friend had been shot and killed. (This indicates the level and kind of street violence many of these teens live with day to day.) Obviously, the teen was quite distraught. His family did not have a telephone, so he could not call in to work. (Many of the teens and their families only had intermittent phone service, because they could not always pay their phone bills.)

The NNC staff spoke with the employer and smoothed things over, so that the worker did not lose his job. But they also told the worker later on that even if he had to walk to the employer, or to walk to the NNC offices to use the phone, he always needed to let the employer know when he was not going to come in for work.

The AtC program makes it a point to look for real and challenging jobs, not make-work jobs. For example, after being hired by the management of a neighborhood housing complex, one teen was given the task every day of picking up trash. After a few days of this, and hearing about it from the employee, the NNC negotiated with the employer. They reminded the employer that this kind of work was not what was promised in the initial arrangements, and that the teen needed more challenge. After that, the job situation improved.

Outcomes

All thirteen kids that first summer were matched with local employers in jobs that they could easily get to. The summer jobs found included: bank teller, construction worker, receptionist, office worker, silk-screen printer, prep chef and landscaper. Many of these jobs are on the high-end of the scale when it comes to summer jobs in the US, in terms of future em-

ployability, social status, etc.

The teens are given the support they need to gain and keep the valued social role of worker. And they do good work. One employer said about the teen employee, "He's doing well. He's a hard worker. The customers are enjoying him. It is possible, if there's an opening at the end of the program, that we would hire him on a permanent basis."

The social images (Wolfensberger & Thomas, 1983, pp. 27, 31-337; Wolfensberger, 1998, pp. 70-73) of the teens are enhanced. An article in the local newspaper about the program, for example, emphasized the valued social role of worker, and the level of competency expected and shown by the teens. The picture accompanying the article showed one of the teenagers hard at work with a jackhammer, a task which requires strength, focus and skill. The article referred to the workers respectfully as Mr. and Ms. It described the positive expectations for learning held by AtC and the employers. It included positive comments about workers made by employers.

NNC sees the benefits of such image enhancement in support of the valued role of worker. They describe how the teens get to know employers, and the employers get to know teens. They see evidence of negative stereotypes being overcome, i.e., that teens and especially poor teens are not lazy, that they do want to and can work, that they have a lot to offer, that they are just like other teens in important ways, that teenage males are not all menacing, etc.

The abilities, skills and competencies of the workers are also enhanced. Employers and NNC staff hold high expectations for, and also teach, responsibility. For example, the NNC director told the story of one of the teens who wanted to quit a restaurant job after the first day, because the teen was only doing food

prep and wanted to be more involved in actual cooking. The director sat with the employee and told the teen not to quit, but to be patient and talk with the boss. The NNC director gave the worker advice on just how to do that.

Another example of competency enhancement and high expectations concerned the worker who called the NNC staff and told them to call in sick for her! The staff said no, of course, and told the worker that she had to do it. As a safeguard, they also said to call them back if the teen worker could not get through to the employer. The AtC program also teaches resumé writing to the workers, and then helps them put together strong resumés.

According to the workers and the NNC staff, the teens experience many of the good things of life (Wolfensberger, Thomas & Caruso, 1996) associated with the role of (summer) worker. They are paid, and they gain good work experience. They like their jobs and feel better about themselves. They meet other people. One teen that first summer got rides to work from his coworkers. They receive positive letters of recommendation from employers.

NNC staff also feel that the neighborhood benefits. They sense that the AtC program increases the feeling of belonging and the level of interconnectedness in the neighborhood. Some of the previous walls of isolation and separation are being broken down. New relationships are developing between workers and employers, including relationships between people that otherwise probably would not have met. Negative stereotypes are overcome. The director of the NNC said, "It's all about relationships. We want it to work for everyone." Even on an economic level, the neighborhood is better off, as local residents have more money to spend, which they often do locally, and local businesses/employers are better off.

Only two of the thirteen teens ended up not keeping their jobs the first summer; one left the area when his family moved to another part of the country, and another did not have the proper medical shots required for the job. The worker who moved out of state was sad at having to leave the job, commenting that his employers "really love me."

A couple of the teens worked more than the twenty hours arranged by AtC, which meant that their employers were paying their entire hourly wage for any time beyond the twenty hours. At least one worker was paid more than $8 per hour, again the difference being paid by the employer. Several of the employees were offered the opportunity to stay in their jobs after the summer AtC program was over.

Conclusion

ALL IN ALL, AtC offers relevant and potent support to neighborhood teenagers to get and keep the valued role of (summer) worker, with an eye towards building up to long-term adult employment. This initiative illustrates how the role of worker is one of the most highly valued in US culture, and is quite powerful in addressing social devaluation. The AtC model works on the dual strands of image and competency enhancement in support of the valued social role of worker. NNC staff pay attention to (prospective) employers, offering them a sense of security. Staff themselves are local, and they 'stand behind' the workers, as a resource not only to them but also to their employers. Another strength of the AtC initiative is that it relies on the culturally valued analogue (Wolfensberger & Thomas, 1983, pp. 16-17, 85-105, 485-487) typically associated with finding work; namely, talking with and asking people you know.

In their second year running the program, the NNC found jobs for 26 teens, including a full-time job and an apprenticeship to an electrician. They hired a part-time coordinator who could devote the time needed to the larger number of teen workers and the employers.

According to the NNC director, AtC has two goals for the future. One is to build a closer relationship with the families of the teens. The NNC recognizes how important families are to the success of teen's jobs (i.e., making sure they go to work, are on time, call in when sick, etc.). Family involvement would be an additional, normative safeguard for their children's jobs. The NNC has in mind discussing with the teens and their families work schedules, important phone numbers, etc. The other goal is to advocate for pay raises for those teens who have been part of the AtC initiative for two consecutive years.

There are many SRV lessons to be learned from this program. The successes of the AtC project demonstrate the power of the valued social role of (summer) worker. The initiative began with a conscious effort on the part of the NNC to step into the shoes of neighborhood teenagers. The program points out the validity of culturally valued analogue thinking when it comes to finding work. It shows the benefits of applying the conservatism corollary of SRV by bending over backwards to compensate for the heightened vulnerability of the teens. All in all, SRV theory helps one to clearly identify and explain the foundation and the important elements of this excellent project. Many human service programs, including employment ones, can learn much that is useful from this SRV-based analysis of a neighborhood effort.

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Valued Social Roles and the Necessity of Values-Based Leadership

Michael J. Kendrick

THE SOCIAL ROLE VALORIZATION (SRV) literature has amply demonstrated the many ways that people and groups become socially devalued and deprived of valued social roles (Wolfensberger, 1998; Race, 1999; Osburn, 2006). It has also attempted to generate action strategies that, if pursued with a sense of integrity, would act to confront and reverse social devaluation. It has often remained unclear as to who precisely would undertake such actions, as the potential field of such candidates is vast. Given that all of society is implicated in social devaluation, so are we all theoretically candidates for enacting some sort of SRV action, should this be something that we seek to do.

Notwithstanding the existence of this vast pool of potential actors who might stand in solidarity with devalued people, it is obvious that much of their potential might go untapped without others to catalyze them into taking part in SRV action strategies. Clearly, it would be unrealistic to expect people to commit themselves to action simply on the basis of the fact that this is needed; after all, such needs have been ignored down through time in all manner of ways. The poor and socially devalued are often abandoned to their fate, and frequently perish for want of committed allies (Wolfensberger, 2005). Needs in people can go unmet indefinitely, often accompanied by the most appalling demonstrations of indifference in others and even of their active collusion in oppression.

IN THIS REGARD, it is useful to consider the implications of this observation. One is most certainly that many of us may well need to be mobilized to stand with socially devalued people, as there may be any number of reasons why such acts contain within them their own disincentives to act. For instance, standing with devalued people may well bring the person into conflict with our many social institutions, as it may mean challenging their practices. Many people are wary of entering and upholding such conflicts as they fear that they may be punished in some way.

If the person succumbs to such concerns then they are effectively eliminated from the task of attempting change, albeit from at least this one role. The matter would then sit there, perhaps indefinitely, unless the person either had a change of heart or others were able to persuade them to alter their conduct. This latter option, i.e., of parties that arise to influence people to pursue actions that might help people achieve valued social roles, is very much bound up in the phenomena of leadership (Race, 2003). People who take on either informal or formal leadership roles exist in all societies, though it is doubtful that "all people are leaders" despite the fact that many people enthuse to this effect. Nonetheless, there does exist at least some latent leadership capacity in communities, and it is important to try to link this capacity, i.e., people willing to provide personal leadership, to the task of motivating others to take action that will help disadvan-

taged individuals or groups acquire valued social roles.

The task could be further refined by noting that not all those persons with inherent leadership capacity would have the type of outlook, values and personal engagements that would dispose them to standing with specific devalued persons or groups. Even where such values and capacity for commitment do exist for a given potential leader to take up a leadership role, it still remains for that person to take such a decision to involve themselves or not, and to what degree. Should these matters get resolved it then becomes possible to imagine the activation of leaders whose values and commitments are consistent with taking SRV action, at some level (Wolfensberger, 1998, pp. 78-80), to support the achievement of valued social roles and to try to undo the effects of social devaluation.

TYPICALLY, societal change of the kind foreseen by SRV theory relies heavily on collective action taken through social movements. However, such collective action only appears collective when examined from a distance. For social change activists of various kinds, it is more likely to express itself through micro initiatives tied to very concrete experiences of socially devalued people in various domains of living, whether these be employment, neighborhood, education, rights, roles or any other aspect of life that has been touched by social devaluation.

For instance, if a person was denied or lost a job due to prejudicial attitudes, then addressing that injustice becomes the specific flashpoint for committed actions to address and possibly reverse this harm. The fact that this issue resonates with so many others in terms of the underlying effects of social devaluation may not necessarily have any meaning to some of the actual participants in these particular events.

Nonetheless, the effort itself is still part of a bigger movement towards social role-valorizing goals and will, in its small way, add a measure of momentum to the larger movement.

So the task of values-based leaders, relative to role-valorizing actions, becomes one of mobilizing well-disposed people to first face the choices and possibilities inherent in SRV goals (Wolfensberger, 1998, pp. 58, 62) and to decide to pursue them in some manner of application that is realistically available to them in the context of their lives. The tasks of leadership always revolve around the need to establish direction and purpose within potential action-takers. Having these directions be SRV-related requires that the leader be persuasive in justifying such directions. Otherwise, the potential action-takers will remain un-engaged and uncommitted to social role-valorizing actions.

Naturally, should the actor and the person exercising leadership already share a common frame of SRV perspectives, then their alignment in a common action becomes more likely. Should they not, then the task of leadership would shift to establishing agreement on such perspectives, given that future action would be contingent on these "values" and theory questions being agreeably resolved. For instance, if potential actors are not persuaded that socially devalued persons could and should be able to enjoy full valued social participation within community life (Wolfensberger, 1998, pp. 122-124), then it is doubtful that they would advocate that the community cease and desist its exclusion of people.

VALUES-BASED LEADERS, seen through this lens as being catalysts for change, emerge as crucially important to the realization of the ambitions of SRV-based action strategies. They are the key animators of the base of support needed to bring about significant shifts in the

social order, both at a micro and a more collective or macro level. If such leaders are ineffectual, scarce, or absent, then it would be predictable that the achievement of SRV goals would be impaired.

If the importance of SRV-based leaders to the change process is accepted, then it raises the question of what helps identify, develop and sustain such leaders and whether all of this is in place or needs to be. It also raises the question of the impact of a theory such as SRV, if it cannot attract such leaders to take it up and apply it to concrete problems of existence in the lives of people feeling the hard edge of social devaluation. Theory, as important as it may be, requires adherents and action-takers to have any practical effect on matters. And it is leaders who will be crucial in mobilizing such people.

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INTERVIEWS

Mike Morton, Executive Director of Community Ventures in Living (Indiana, USA)

Joe Osburn

Q: Mike, how long have you been in your present position?

A: I've been the director of Community Ventures in Living (CVL) for about 8 1/2 years, since 1998.

Q: Your background before CVL?

A: Immediately before, I worked in Bloomington (Indiana) at another agency a little like CVL for about 18 months, and prior to that for 18 years, 9 months, and 14 days I worked in state government.

Q: Wow!

A: Yessireebop!

Q: In your current position with CVL, what does your work entail?

A: I oversee the management and provision of the services of the agency.

Q: Please tell us about CVL, what it is, a little bit about its history, and so on.

A: We are a non-profit social service organization. Our mission is to support developmentally disabled people and their families in living in their own home. CVL was founded in 1992 with that mission, and has continued since then trying to carry it out. Our non-profit status is not unique, but the vast majority of residential service providers in Indiana are for-profit corporations, some of them quite large. I answer to a small board comprised of local citizens from the areas we serve, including some family members. Our main administrative office in Lafayette houses the majority of staff. We also have satellite offices in Terre Haute and Indianapolis, which provide places for our CVL staff

in those areas to gather and do 'desk work.'

We have 19 full-time staff which includes our administrative/office staff as well as our program supervisors and case managers. We also have, at any one time, about 60 part-time staff who provide various types of direct support services. Direct services are also provided by our program supervisors and case managers, and by myself as well.

All of the people we serve have a developmental disability. Most are mentally retarded. Some have cerebral palsy, to a pretty severe degree in some cases, but no intellectual impairment. Altogether, the people we serve range in age from very young -- the youngest probably six months old -- to elderly, the oldest being in their 80s. Most of the adults we serve have been with us for a long time and, of course, have grown older with us. I might add that 50% of the individuals we serve now in independent living we have served since the agency began.

Our service 'menu' consists of two main areas. First, there is independent living supports, that I just mentioned. It is also called a variety of other things like "semi-independent living," "independent assistance services," "apartment support," whatever. We use the term broadly as a name by which CVL identifies its programmatic effort to provide support to individuals living either on their own or with other people. In a very few instances there may be two handicapped people living together whom we support. We serve about 50 or so developmentally disabled adults living on their own more or less independently in the community, but needing some supports to sustain that. Many are pretty capable people, since they are living on their own. Our support is mainly in the form of periodic contact with them. For instance, we may only see some people once or twice a week, maybe four or five hours, but for the rest of the time they are making decisions and living their lives on their own. Some have families that might be supportive with them; some don't. A lot of the people we serve live marginally and with a lot of supports necessary, often more than we can really provide. Sometimes our contact is sort of a drop-in or drop-by thing, but more often it is something regular and scheduled around particular issues or things that people need help with. The people that we support have a wide range of functioning in general, but pretty much all of them need help managing their resources, meager as they are, things like dealing with their money, paying their rent on time, making sure their bills are paid, help with food, laundry, shopping, etc. Quite often our support contacts are around something more involved, like dealing with the bureaucracies, or getting medical treatment, or dealing with the legal world, police, courts, jail, etc. It all depends.

Also included under "independent living" is what gets called "foster care," which is not our term, but rather a programmatic label and payment distinction made elsewhere. In a way 'the system' forces us to play its game. We don't have a wide latitude of designing appropriate residential situations. We have to try to sort of cobble something together that meets people's needs, but that is also identifiable to the funders. Anyway, in our case, foster care means handicapped adults living with and in the same home and alongside nonhandicapped caretaking adults who have managerial oversight responsibilities for that handicapped person, and whom we recruit, train, support, and financially compensate. We serve close to 40 adults in foster care. We also have a few situations that resemble traditional foster care where a family takes care of, fosters, and provides a home to a child with impairments.

Our second main program thrust is respite

services for about 70 families with handi-
capped children at home, including some
adults. This is almost all in the form of part-
time relief to the parent(s) or caregiver(s)
where we send a staff member in to substitute
for them temporarily when they need to be do-
ing something else. I read the Armstrong &
Shevellar piece (2006) on respite that you pub-
lished recently, and I found it very well-rea-
soned, compelling even. I must say too that we
consider the provision of respite to families of
handicapped children to be one of the most im-
portant services we can provide to them, and
we think that mainly because this is what fami-
lies tell us.

**Q: You provide residential supports, but so
many other agencies in your state operate
group homes. Could you comment on how
is it that CVL took a different tack?**

A: "Why don't we have group homes" is a
question that has been asked of us in a variety
of administrative ways. There were at one time
many incentives to develop group homes early
on in the history of CVL, and actually during
my tenure as well. There has been some pres-
sure by board members as well as the public to
do that. We do not operate group homes; have
never done so. It is not necessarily so much
that we think group homes are 'bad' per se, but
simply because we think we can do other kinds
of services better than group homes. The
plusses of group homes include that you can
exercise more day-to-day control over people's
lives, and with a positive ideology that can be a
good thing for people. It means you can have
more control over essential things, like their
food, and medication, and all the things that
some people who live independently don't get,
but really need help with.

  Conversely, one of the negatives is that
people don't get or learn to exercise much free-
dom. Again, not many people that we serve
who live alone are severely impaired. And,
frankly, there is a lot of constraint in group
home criteria and management that does not
appeal to us. For example, the rules are federal
rules: they are more difficult to meet. Another
characteristic of group homes that we don't
like is staff going in and out of people's lives
all day long in shifts. The rules are such that
you can't have people as staff living there full-
time. If we could have developed, say, a two-
or three-person group home with staff living
there full time, that might have been a different
thing, but you really can't do that, there are
rules against it. There wasn't really anything
greatly appealing about group homes: the large
size, the congregate activity and outings, atypi-
cal groupings of people, the imagery problems,
and so on, were all part of why we decided we
could do other things better.

**Q: Many people with mental retardation or
physical impairments who live 'indepen-
dently' are not really doing so well, in spite
of receiving outside agency-based supports.
Do you see any of this too, in CVL?**

A: All of that is true with our service as well.
We have people living independently who are
not doing well: they are lonely, they get ex-
ploited, fall in with the wrong crowd, make bad
decisions, stupidly harm themselves, get
thrown in jail, get kicked out of their living
quarters -- all that happens. We try to modify
our support so that when people are in more
need, or dire need, we can respond to it, but as
long as people are living independently, there
are those risks. And, what we don't have, what
we sorely lack, and what Social Role Valoriza-
tion (SRV) (Wolfensberger, 1998) would sug-
gest we do, is to find people to be voluntarily,

not in a paid way, associated with the people we serve. That is very difficult for us to do, and one of our major failings is that we haven't developed non-paid resources as forms of supports to people who live independently, but very much on the edge. They desperately need relationships that are freely given by other good people as advocates, protectors, mentors, friends, role models, and so on (cf., Wolfensberger, Thomas & Caruso, 1996). None of that has been done, and it is to our discredit that that is the case.

Q: Are you serving people now living independently whom you think would be better off in a group home situation?

A: Not in a group home situation for reasons I've mentioned, but in more of a social living situation that would be like foster care, or situations in which they would be with other people, such as nonhandicapped roommates for instance. We do support some situations like that, in which a handicapped person and one or more (usually one) nonhandicapped persons choose to live together but, because of the regulation and payment rules, we call those situations "foster care" in order to enable us to underwrite it. But, yes, other people we serve would, I'm sure, be better off in a situation like that than living alone as they do now.

Q: You personally have been involved in SRV and normalization (Wolfensberger, 1972) for a long time, more than 30 years. Can you talk about the role of SRV in CVL?

A: Well, there was one previous director before me, and he became interested in SRV through training conducted by Indiana Safeguards Initiative (ISI).[1] After he first went to SRV train-

ing, he continued to use ISI as an on-going resource for training for some of his staff, and used SRV as an ideology -- in the sense of a set of big ideas -- to guide agency decisions and services. During that time, I myself was very active with Indiana Safeguards Initiative, being one of its founders as well as its longtime 'patron' while I worked in state government. And before ISI, or CVL for that matter, I had been involved in many other ways in supporting SRV, as you pointed out. And so, both because of my own history with SRV, and the agency's, I kept with that tradition. It was very clear to me and to the previous director that SRV was more informative than any other social theory about what our agency was meant to do, so it made sense just on that level to continue. So when I came to CVL I made a conscious decision to carry on that continuity of SRV-based philosophy, and mission, and practice.

Q: So as far as staff development goes at CVL, you're saying that SRV training is a major part of that?

A: Yes. We try to rely on SRV by training staff in it and by keeping them fairly constantly familiar with the ideology and its implications for our services. I'd say that not only is it important in informing our mission, but also in informing staff about how they should see their own work and how they can orient what they do to the mission and work of the agency -- try to keep in as close connection as possible what individuals think their work is and what the agency's work is in fact.

Q: Specifically, how does CVL go about training people in SRV or inculcating that idea in your staff?

A: We try to familiarize all our staff with SRV, trying to keep people abreast of the theory through contact with SRV training, that's the first thing. We also have people on staff who are strong advocates of SRV, who really know something about it. They've been trained in SRV; they've gone to PASSING (Wolfensberger & Thomas, 2007), and while I wouldn't call them fully informed SRV theoreticians, they have been around it for a long time, lived with it, had practical applications of it, and so on. And, they are in supervisory positions generally, in which they guide new people in regard to what SRV would suggest in their ordinary daily work.

Q: How do you make SRV/PASSING concepts real and practical for the part-time direct service staff, most of whom are young college students or very recent graduates? How do you help them see how these relate to what they do in their ordinary daily work with CVL? (EDITOR'S NOTE: *CVL is located very near the main campus of Purdue University with its 38,000 students*.)

A: Well, it's getting more and more difficult because, again, there is not very much of an opportunity to provide developmental training to staff. The kinds of training that often go on are the functional report-writing and forms-completion training that is required for billing purposes. There is not a great deal of opportunity for them, or time for us, to give over to their training in SRV. So, the only way to make it real for them is to give them positive feedback about the things that they do that are in line with SRV. And the only way to do that is for somebody who knows about SRV to be able to report that to them. I guess what I'm saying is that many of the young staff have not learned SRV anywhere nearly so well that they can

correlate what they are doing to some dimension or aspect of the theory, so their supervisor tries to remind, or point out to, them that this (whatever they are doing) is or is not in line with SRV.

Q: I see. So, it is getting harder and harder for you to get staff people familiarized with SRV. Is there anything else that makes it hard other than the time-robbing paperwork and other bureaucratic requirements?

A: Well, another obstacle is that our part-time staff are deployed on a 'scattered hour' basis, meaning their jobs here are not full-time, but are hours here and hours there as necessary to accommodate families. Respite and other forms of support services happen at different times of the day. Also, staff people come to us not wanting to work necessarily 40 hours a week, but maybe just 10 hours or 15, so we fit their hours in to their already set schedules. Not much of that time can be oriented to training them. And, they don't see themselves necessarily as careerists in the human service field. Mainly they just see that they are in a part-time job that they know is doing good work, and that they may have a talent or facility for. The big irony of this is that so many of the people who do most of the most direct work with the people we serve are our least trained staff.

Q: How do you orient them, then, if they are sort of just 'fresh off the streets' in a sense, and have to go into people's homes and render a very important support or respite service?

A: We have an orientation course that we provide to them. It's a multi-hour introduction to the agency, the service, and their responsibili-

ties as a provider. It sets up pretty clearly what is expected of them and who they are answerable to, and so on. SRV theory is identified in our orientation, but not gone into in depth. We try to follow that up periodically with shorter three-hour orientation sessions specifically about SRV, taught by Indiana Safeguards Initiative. Of course, we know that this doesn't cover SRV in a way that SRV should be covered. We do the best we can and remain burdened with the constant awareness that it is not nearly enough.

We have a pretty clear division in our staff where most of the direct service workers are young people who come and go pretty quickly; then we have this core of people who have been with CVL for quite a long time, some from the very beginning. Most of these old-hands are fairly well trained in SRV, some have been to PASSING, some have helped Indiana Safeguards Initiative conduct 3 and 4-day SRV workshops by leading discussion groups. Of the 19 full-time staff, eight have had more than just introductory contact with SRV. They are the ones I am referring to who hold together the continuity of our philosophy and service approach, and who try to transmit these to the younger, newer, shorter-term, part-time staff people. When we do send staff to SRV and PASSING training, those are major investments for us, so we have to be pretty careful, or try to be, about whom we send.

Q: Could you talk about what accommodations you have to make in order to send any staff, including full-timers, to full introductory SRV or PASSING workshops, which are 3, 4, and 5-day events?

A: Rarely do we ask people to use vacation time or their own time for this. So, it's either CVL-sponsored training that we try to hold 'in-house' here at our agency or nearby, or CVL pays for them to go somewhere else. Either way, we have to make sure that if they are a person with client responsibilities, then those responsibilities are taken up by other CVL staff that are not involved in that particular training event. So that's one of the things that has to be accounted for -- any back-up that is needed. Our agency is one of those that is on 24-hour call: we have a designated contact person on-call at all times to answer the phone. If some staff are away at a training event, we have to make certain that other back-up staff are available to fill in for them and that the on-call function is activated and available to people that the away staff are responsible for. And we have to make sure that the staff going to training have plenty of warning of when and under what conditions they are going to go, so that they can plan their time away as much as possible so that back-up staff won't need to be relied upon. That too is problematic because many things are unpredictable. Of course, the back-ups themselves still have to carry their normal responsibilities. And, we have only a pretty small cadre of people who can be back-ups.

It just is not easy because of the nature of our service in some ways. CVL supervisors and case managers have caseloads of 15 or 20 people, and they are like itinerant workers who spend most of their time 'in the field' going from person to person that they serve. They have to time their absences as much as possible so that they don't need to be in touch with the people they serve, or so that some other staff person will be in touch with their clients if they do need it. It's just logistically more difficult. Probably many agencies experience the same thing. It's not like sending our bookkeeper away for 4 or 5 days, you know? It's a little more complex than that.

Q: We've talked mainly about SRV; can you say anything about the role of PASS-ING in your agency?

A: Well, PASSING is just the best way to learn SRV, I mean in terms of its practical application, in my judgment. It's like an advanced study in SRV, a logical and important step beyond the introductory SRV workshop. And it helps concretize the theory for people, and make explicit what SRV-put-into-practice can mean.

Q: Of course, PASSING training happens less often, and it's harder for you to send staff away to other states for training that might be taking place elsewhere.

A: Right, and we generally only send one person at a time to PASSING. Of the 19 core people with us now, six have been through PASS-ING, roughly a third. And others have been to at least some SRV training, including one (me) who went to the so far only Advanced SRV workshop.

Q: Okay, now some things about the results of SRV/PASSING training. Of course, results are hard to quantify, but, for example, have you seen changes in people as a result of this training in their level of skill or commitment?

A: Well, to the extent that I can account for it, it has made them better critics of services. They are more skeptical about the nature of the service system, and they are more careful about the positive hyperbole that gets bandied about in and around the service system. SRV/PASS-ING training makes them a better, more informed skeptic about all of that, and therefore more watchful on behalf of their clients. I don't

think it makes them a 'better listener,' for example, you know, or necessarily more empathetic, some of those people have those qualities anyway, but it does help them become more intellectual about services.

Q: You'd say they are more realistic about services? SRV provides them a way to better understand why certain things do and do not happen for people?

A: Yes. You know one of the things that happens -- you've seen this too -- is that good-hearted people come to SRV training and it puts words and concepts to the feelings they've had about their observations. It kind of helps them with that.

Q: Have you seen any place that SRV has been more impactful or differently impactful in the different services you provide?

A: No, not really one more than another. The way that occurs to me is that it has helped make staff a little more intolerant about accepting failure in regard to helping serve somebody. It has helped in people going the extra mile, having a more positive belief that somebody could be served when they might not otherwise have tried to serve them or might have given up on trying. It has helped a little bit in that way.

Q: Is it fair to say that the main impact of SRV in your agency has been on staff rather than on your board or families?

A: Yes, that's true. I would say that if that were used as a judgment about our spreading the word of SRV, we've failed at that because we haven't gotten families or the board really involved in SRV, at least not in a training sense. I'd like to think that the people we serve bene-

fit from receiving services from staff who are trained in SRV, a vicarious benefit you might say, but that is hard to quantify as you noted. But we do know, because we've seen it time and again, that when staff have to make a choice between things for people, SRV helps them make the better choice.

Q: We've been talking 'inside' the agency. Has your involvement with SRV, your endorsement of it, had an effect on CVL's relationship with outside service providers, funders, or regulating bodies?

A: If it has, I would be hard pressed to identify it. We have, I would say in general, a positive reputation. SRV has clearly helped in keeping that because it has helped us be better support people, and we've gotten a reputation for being good at what we do among other service providers; generally we're seen in a positive light. We're not seen as "the SRV agency" or anything like that, but SRV has helped our staff become more confident I suppose, or more singular in its mission. So, externally, we're seen by some as a good agency; a small but competent agency -- at least that's my general sense, though there's probably some difference of opinion on that.

Q: Can you think of other agencies in your state that have made and maintained a similar commitment to SRV training?

A: Well there were never many, only a very small handful, four or five, who had ever made a serious commitment to it in the first place, but these have fallen by the wayside somehow, either 'bought out' by larger organizations, or gone out of operation, or downgraded their SRV staff development to a much lower-level of intensity, such as on an in-house basis, but

with not sending any staff for outside training as would have to be done to get them full exposure to SRV, even at an introductory level.

Q: Why do you think that is?

A: I don't know. It's beyond me. They always have 'reservations.' If you want to hold on to SRV as a framework for your service, and keep it in the consciousness of the people in your service, then you have to give doing that a pretty high priority; it takes a lot of energy to do just because of all the inertia that you have to fight every day just trying to keep your service going.

Q: Do you mean that sometimes it seems easier to give up that SRV training investment rather than have the hassle of keeping it going?

A: Yes. It's more difficult to commit your staff's time to it, to make that an integral part of your planning processes. But I don't know if that's a good enough explanation as to why. I don't know why. I think there is something to be said about how the more mundane things -- like going after funding, problems that absorb so much time, and so many other things -- try to make themselves as important.

Q: But in your mind, SRV is worth it?

A: Yeah, it's been worth it to us.

Q: As long as you are there anyway?

A: Well that's one of the reasons to try to keep SRV involved in the agency, because you don't know what's going to happen to these people that you've trained up to now. You want at least to have some sort of seeds planted for

staff who want to carry on.

Q: Anything else you want to add about SRV or its role with CVL?

A: It has been very useful. One of the things that makes it hard for me to understand why other agencies aren't continuously involved in SRV is that it is so practical. So practical. It helps in communicating with one another. It helps in making decisions. It helps in so many very direct ways. You know, it's very practical.

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Endnote

1. Indiana Safeguards Initiative is one of the few full-time SRV training projects in the United States. It is now entitled 'Safeguards Initiative.'

JOE OSBURN is director of the Safeguards Initiative, Bardstown, KY, USA, and a member of the North American SRV Council.

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Judy Bilderbeck, Executive Director of Access Ability (New Zealand)

Marc Tumeinski

Q: What is your position at Access Ability?

A: I hold the position of Chief Executive. This is the third year I have held this position. The Chief Executive has accountability to the Board for leading and managing the achievement of the Board's Vision, Mission, Principles and Values.

Our specific function is for the assessment of needs, and the coordination of supports to meet the needs, for disabled people whose disability is one that is categorized as Physical, Sensory, Neurological, Intellectual or Age-related. Access Ability is an indirect provider of service as opposed to a direct provider. Access Ability has as its vision: 'People with disabilities live self-fulfilled lives as valued members of society.' The mission of Access Ability is: 'Individualized support design for people with disabilities.'

Access Ability employs 61 people. This includes one Chief Executive, two Regional Managers, one National Business Manager, two

Managers, three Team Leaders, three Business Analysts, seven additional administrative positions, and 42 Service Facilitators. Access Ability has 10,000 people listed on our database whom we have met and helped to receive support.

Access Ability has contracts funded by the Ministry of Health (MOH) and the District Health Boards to facilitate needs assessments and service coordination for disabled people in four main centers in New Zealand. In Otago and Southland, this is for people with a disability aged less than 65 years. In Taranaki and Wanganui, this is for people of all age groups. In Auckland, we are the Regional Intellectual Disability Care Agency provider in Auckland, Northland, Otago and Southland.

Q: Tell the reader about the history of the program. How did it get started and why?

A: In 1997 Access Ability was established as a not-for-profit, disability-owned organization with a commitment to do 'whatever it takes' to advance the well-being of disabled people in New Zealand. Its establishment coincided with the development in New Zealand of Needs Assessment, Service Coordination (NASC) standards and service contracts. In 1994 the health system in New Zealand introduced a process of Needs Assessment and Service Coordination that was set up to enable people with disabilities to have the choice about whom they live with, where they live and how they live, and to be able to have a good life.

As NASC was the process which all disabled people would be required to go through in order to receive supports, Access Ability believed that this process would be an excellent vehicle by which greater opportunities for positive futures for people with disabilities could arise. This opportunity gave considerable

encouragement as a process that was truly focused on the individual with an opportunity to consider and secure supports that would best meet a person's needs over the longer term.

However, in 2003, changes in NASC by the Ministry of Health left Access Ability feeling less confident that the NASC process would be the most appropriate vehicle to use to attain its own mission over the long term.

Q: When, why and how did the program become involved in Social Role Valorization (SRV)?

A: Access Ability is fortunate to have a close and supportive relationship with Lorna Sullivan.[1] Lorna meets with the leadership team four times a year and is instrumental in providing the stimulation, knowledge and motivation to support the team to hold the vision of the company to the fore. It is she who has been instrumental in exposing the company to the concepts of SRV (Wolfensberger, 1998) and PASSING (Wolfensberger & Thomas, 2007). Recently, Access Ability hired two new employees who have had experience with the principles of SRV. I see this core group being able to provide training to more people within our company. It is such a great opportunity that I believe we will certainly pursue.

Q: Is SRV training a major part of the program's staff training?

A: I probably have to say no to the fact that this is a major part of our agency staff training. Whilst Lorna has been involved with the principles of SRV for 10 years, it has only been recently that we as a company have invested in staff to attend such events. In 2005 the whole Auckland team did attend a two day training event. In 2006, we had two staff attend a

week-long PASSING event. Both events were taught by John Armstrong

Q: Why choose SRV over some other 'best or promising practice'?

A: It was hoped that a greater understanding of the situation of disabled people in society, including wounding, would give us the energy to hold onto our vision and help us refocus on the person, and also provide us an opportunity to engage with other committed people. It is my hope that as we expose more of our staff to SRV and PASSING training, we can work towards achieving our vision and mission.

Q: What did you hope to gain, or hope for the leadership team and staff to gain, from attending SRV training?

A: A fresh perspective on how to support people with an intellectual disability with a view to trialing suggestions made at the workshops.

Q: How did you encourage and support staff to attend?

A: In Auckland, all of the staff were encouraged to attend and on their return present as a team what they learned. The whole team did attend and some difficulties were experienced. Four staff had issues with the content of the material delivered. These issues were culturally specific to New Zealand. They were related to issues of colonization. In New Zealand, we live in a bicultural environment. Although the minority culture is less in numbers, it is striving for equal status. Some people had questions around the place of a minority culture within a larger more dominant culture, and what SRV would say about that.

In Taranaki, the team was exposed to information about what SRV workshops were being offered, and the value of the training was emphasized. Individual staff who had shown an interest in attending were approached.

Q: What are some of the barriers which the program faces in supporting staff to attend SRV and SRV-related training?

A: Barriers identified are staff perceptions of what they already think they know, and that they might not gain anything new. There is also a perception that there is pressure to 'churn out' the work, which can get in the way of staff attending training. Another barrier is explaining to staff that the content of what they will be exposed to during training is not necessarily the only way or the only right way but is a model to take on board and consider.

There is only one training provider in New Zealand, Standards Plus, and the cost of attending training is expensive. In terms of training supervisors to train and support staff around both learning and implementing of SRV, there is a funding problem. We need to bring people over from either the US and Australia, and the opportunity to attend these trainings is only offered in this country by Standards Plus.

As well, there is not currently any evidence that ten years down the track, the initial intent of what NASC agencies were set up to do will have been achieved or even supported by the funder to do so. The principles of SRV thinking will in my view not be a model that the MOH would support or understand.

In terms of how does our agency cope with these barriers, we continue to apply what we have learnt and continue to seek ways of influencing the government. We need to showcase some of our good stories and develop 'pockets of goodness' in spite of any barriers we en-

counter. We are also actively seeking work out-side of our current funder so that we are not totally dependent on the one source of income.

Maintaining traction in New Zealand currently is also problematic.

Q: How do the staff who have not attended SRV-related training react to those who have attended, who have been talking about it around the office or during meetings?

A: In Auckland there was a 90% positive reaction and a 10% negative response. The reaction towards those who attended from those who haven't attended has been a little 'ho hum' actually and in some part ignored. I am not sure whether this is partly due to the ability of individuals to bring back the learning.

Q: What is the biggest struggle which Access Ability faces in thinking about how to support staff to learn about SRV?

A: One of the struggles Access Ability faces is something that I have become aware of since engaging in this interview, which is that only three of the current eight in the leadership team have actually attended any formal SRV workshops. There are also the pressures of the work that has to be completed. This year more than any other a variety of conferences are being offered and so choosing what to attend is a struggle. Another struggle is the amount of funding available to support staff to attend.

There are also some entrenched values and ideas that some staff hold, and this takes time to change. Some staff seemingly don't see training or increasing one's learning as important.

Q: How does your program implement SRV training?

A: On reflection I have to say we probably do not formally support the staff who have attended SRV training as well as we could. We have invested in staff from all our offices to attend; however, the learning that individuals gain can get lost when they return to their work places if we do not consciously work on supporting the actual practical implications from SRV.

Q: Why is this a problem from your perspective? Have you thought about some ways of trying to begin to address this concern?

A: Essentially keeping enthusiasm about new learning requires energy and hard work. This I believe is a good part of any individual personal responsibility, and if each manager and leader in each office can find this energy, I think we could improve in keeping focused. Recently the leadership team went to Brisbane and met with a whole range of providers as well as people and families with disabilities. They have returned with increased vigor and energy. To keep this alive, we have decided to meet again as a group in two weeks to continue to work on what this opportunity can provide us.

Q: As an agency, do you feel there are people and/or networks that you can turn to for help when thinking about trying to learn and implement SRV more?

A: As an agency we are fortunate in that Lorna has access to people who are available to teach the principles of SRV. All Lorna's conferences that she has been hosting for the past four years have a theme and speakers who work from these principles.

Michael Kendrick over the last four years

has run a two-week training called 'Taking a Lead' that we have sent two people in our organization to attend each year.

Q: Have you seen any changes in staff competence and skills because of SRV training?

A: Individuals that have attended SRV and PASSING have been affected significantly by being exposed to this form of thinking. Two staff who recently came back from attending PASSING reported that they basically have had a 180 degree change in their thinking. They were 'off the wall' -- so expressive, so keen to apply what they had learned. They expressed verbally how they thought they had been doing everything back to front. One held his head in shame about some of his behavior prior to attending.

There have been a number of examples of individuals working with people who truly believe it is possible for the people whom we serve to have a good life, like we each potentially can.

Q: Anything else to add?

A: Being involved in answering this questionnaire has highlighted to me a number of ways that we could look at providing staff with an insight to what SRV could mean. This will require an investment. This also has highlighted the need to monitor and follow up on the investment we have made in support to the person to enable them to apply their learning.

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Endnote

1. Lorna Sullivan is the Executive Director of Standards Plus in New Zealand, and a leader and promoter of SRV, PASSING and SRV-related training in New Zealand.

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 Syracuse University Training Institute, in conjunction with the Safeguards Initiative, is pleased to announce a five day workshop on

Crafting a Coherent Moral Stance on the Sanctity of All Human Life, Especially in Light of Contemporary Society's Legitimization & Practice of "Deathmaking" of Unwanted & Devalued People

* on Monday, September 17 through Friday, September 21, 2007 (with evening sessions)
* at the Catherine Spaulding Retreat & Conference Center, Nazareth, Kentucky USA
* to be presented by Dr. Wolfensberger, Susan Thomas, & associates
* cost of tuition, 2 books, handout materials, meals and lodging is $770 USD; fee reductions available

• ***This event is intended for:***
(a) those who perceive that there is a gathering momentum in the world that works toward 'deathmaking;' and
(b) those who are uncomfortable with a 'pick-and-choose' approach that endorses some deathmakings and objects to others, and who would like to work toward a more coherent position on the sanctity of human life.

• ***This event attempts to accomplish four aims:***
(1) Awaken people to the reality that there is growing support in our society for various forms of 'deathmaking' of people who are impaired, elderly, or devalued for any other reason. Deathmaking includes any practices which outright kill people, which greatly hasten death, or which lead other people to act against a person or group so as to bring about the person's or group's death. Many practices that participants see all the time, and may even participate in, will be shown to contribute to deathmaking.
(2) Orient participants to the disguises and interpretations that are given to deathmaking so as to make it less obvious and less repugnant.
(3) Elucidate the societal dynamics and values which have been leading to these developments.
(4) Help people to see the validity -- indeed, the necessity -- of a coherent moral stance in defense of all human life, to see what such a stance would entail, and to work toward such a stance.

• ***Special topic to be discussed:*** Issues of the withholding, withdrawal, and refusal of medical treatment.

• ***Note*** that this five-day workshop (*with evening sessions*) is approved for 54 contact hours of CE for RNs and LPNs by the Ohio Nurses Association, an accredited approver by the American Nurses Credentialling Center's Commission on Accreditation OBN-001-91. Awarded through the sponsorship of Family Lives Nursing Services.

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In Memoriam: R. S., a Wounded Life

Susan Thomas

IN THE TYPICAL 3- or 4-day Introductory Social Role Valorization (SRV) training workshop, participants hear a lengthy presentation on the common 'wounds' of devalued people, especially those who are handicapped, and wounded people's common responses to being wounded (Wolfensberger, 1998, especially pp. 12-24). At the end of that presentation, the workshop teachers often present a vignette that summarizes the infliction of the wounds in the life of one single person. Many SRV teachers read the obituary of 'Mary Doefour,' i.e., the 'woman with no name' found dazed and wandering beside railroad tracks after a presumed rape, who ended up institutionalized for the rest of her life.

Of course, there are *many* such stories. In fact, that is the point of the 'wounds' material: these wounds are universally inflicted on devalued people because the way that people express their devaluation of others is by doing bad things to them. So there is no shortage of such stories to tell. Still, it is good for people who want to address devaluation to continue to learn such stories, because they help to keep the concepts of devaluation and woundedness from becoming mere abstractions. Below, I offer a brief summary of the wounded life of one handicapped woman, R.S., recently deceased.

SHE WAS BORN in a mental institution in the early 1900s in New York City. Why in such a place? Because her mother was locked up in one of the mammoth mental hospitals of New York; the father's identity was not known, or at least was never entered into the records. The only photo she ever had of her mother was one she did not like to show to other people, because in it, her mother was wearing the sack-like uniform clothing then issued to mental institution inmates. She had the face enlarged, and most of the dress cropped out of the picture, but still, the shoulder of the dress was visible, and even that was more than she wanted other people to see.

So that this truth does not get lost in the details that come later, readers should be clear that as far as we know, she was a perfectly normal baby: she had no impairments then; she just happened to be the illegitimate child of an institutionalized mother who was an immigrant from Poland -- and all the bad things that follow got inflicted on her by society, she did not 'come with' any of them.

She was taken from her mother at birth, and placed in one of New York City's big mental retardation institutions on Randall's Island in the middle of the river. She was not retarded, she just happened to have been born of a mother who was said to be insane. Eventually, her mother was deported back to Poland and never heard of again. After about 6 or 7 years at Randall's Island, she was shipped upstate to the state institution for the retarded in Syracuse, where she lived until her early 20s.

She remembered having many nightmares as a young child, and said that when she would awake screaming from them in the middle of the

night, she would be dunked head-first into a tub of cold water. She developed a significant hearing loss as she grew older (which even hearing aids did not really help) and balance problems, and she blamed these on the ice-water 'treatment' she had received as a child.

She went to school at the institution, but said she never really learned anything: at least, not school subjects such as reading, writing and math. She was one of the smarter ones, so the teachers would have her help them keep the students who were younger and not as smart under control. She did, however, learn all sorts of homemaking and domestic skills.

AT ABOUT age 20, she was offered institutional 'parole.' As was a typical practice in those days, she was 'placed out' as a live-in servant in a local home, though technically and on paper, she remained a ward of the state and a resident of the institution. After several years of this arrangement, the social worker came to the house one day and asked if she wanted to be released from the institution, and, as she says, "I dropped to my knees right there in the kitchen, and said thank you." She continued to live with this family for about another decade. Eventually, however, she left because the husband, and the couple's grown son, both made sexual advances to her. She warded them off, however, by -- how to put this delicately? -- threatening to un-man them with a hot iron.

She was red-haired, and said people had always said she had a fiery temper to go with it.

She first rented a small room in a single-room-occupancy-type hotel, and got a job in the kitchen of a local high school. She signed up for night classes in reading and math, figured out by herself the bus route to get there and back, and proudly got for herself the basic education that had been withheld from her at the institution. She learned of a physician, also

connected with the local university, who specialized in speech and hearing problems, and went to see him for help. He was the one who fitted her with her first hearing aids, and she remembered him later as never very warm, but always kind.

She had a portrait photograph taken of herself, which she kept for the rest of her life. She bought a trumpet and tried to teach herself to play, because she always loved the sound of it. She started to knit more (something she had learned at the state school), and eventually created beautiful handmade sweaters for herself, and afghans that she would make and give to selected people.

SHE LEFT HER KITCHEN JOB, and began to hire herself out as a cleaning woman for a few people she had come to know. She maintained this steady but marginal and lonely existence for many years, until eventually, she had to give up the work because it took a physical toll on her arms, shoulders, and knees.

She acquired an 'adult tricycle,' i.e., a big 3-wheeled cycle with baskets which was easier for her to manage, with her balance problems, than a bicycle would have been. Many formerly institutionalized people of her generation could be seen cruising the city streets upon their release with such vehicles; some are still around.

EVENTUALLY, after her retirement, she moved into a small but neat one-bedroom apartment in a government-subsidized apartment complex run by a Catholic Charities agency. In that same building lived another older woman, a widow, whom I had met at church; we would walk the three blocks back from church each Sunday morning and have tea together in her apartment. One Sunday, on our way back from church, we noticed a short,

slightly plump and wobbly woman with glasses and curly reddish-grey hair a few steps behind us. It was R.S., who, it turned out, lived in the same building, and had followed the widow to church that morning. She said she had always wanted to be a Catholic, but didn't think she would be allowed in a Catholic church because she was Jewish. That day, she had decided to take a chance anyway, and was pleasantly surprised that when she entered, no one asked if she was Jewish, and no one turned her away. She was then almost 75 years old, and later said that even as a young child in the state institution, she always wanted to go to the Catholic services that were held there, but was never permitted to do so.

She enrolled in instruction classes in the Catholic faith, with myself as her sponsor. One evening, at one class, all the participants had to engage in an exercise in which they were to remember someone who had loved them, and what that someone had done to show their love. Presumably, the point of the exercise was to show how these acts of human love could help us to understand God's love for us -- but I only remember R.'s response when it came her turn, going around the circle, to tell about someone who had loved her. She said that though there had been people who had been kind to her in life, and people she liked and people who liked her, there had never been anyone who had loved her. She said it matter-of-factly, with no tears or anger. There was a big pause and silence -- and then the instructor moved on to the next person in the circle.

On Easter eve in her 76th year, she was received as a member into the Catholic church. A big party was held for her in the church basement afterward, the biggest -- perhaps the only big party -- ever thrown in her honor. She looked beautiful in the prettiest outfit she had ever owned: an ivory dress, with matching heels and purse, bought for her by one of the women for whom she had cleaned long ago, who still kept in touch with her.

EVEN WELL INTO HER 70s, she wished she knew more about her mother, and showed me correspondence with a social worker in New York City from the late 1930s, when she had tried on her own to find something out. We made some further efforts but nothing paid off. As part of this effort, I obtained for her what remained of her records from the Syracuse state institution -- once she had looked through them, she promptly tore them up, and made it very clear she wanted no one to ever see them.

One day, we were discussing her concerns, and I made a passing remark that in heaven, she would be able to hear perfectly, and even meet her mother. She was thunder-struck: no one had ever told her that, and I believe I could never have given her a greater gift than that knowledge, had I spent months and much money seeking out the best present I could find.

Soon thereafter, she had surgery for cataracts -- and the surgery was a disaster, leaving her with poorer sight than before. Not even new glasses could correct it, so her much-valued independence became severely curtailed. Now she could no longer ride her bike or take a walk where and when she wanted, since she could not see where she was going.

Someone she met at church who had taken an interest in her had arranged the cataract surgery, and while R. was in the hospital, this person had gone through her apartment and 'cleaned up the clutter.' She had probably meant well -- but to R., she had overstepped her bounds; among other things, without asking, she had thrown out many things that appeared to her to be 'junk' but were meaningful to R. Upon her return, R. said about this, "It's like they're putting me in my grave."

BY NOW, she had acquired a social worker, and she was soon moved into a yet smaller apartment in a new 24-apartment complex for senior citizens. She now began to have daily home aide service, but she began to lose bladder control. Soon (about a year later), she was in a nursing home -- virtually blind and deaf. Eventually, whether because of natural decline, or because of the mind drugs the service people had put her on for the past two or so years, or both, she did not know where she was. Luckily, this did not seem to disturb her: whenever I visited, she was always in good spirits, laughing, singing, remembering some pleasant moments from her past. She had never ever wanted to go back to an institution, so at least if she had to be in one, she was not aware of it. Here she lived for about two years.

One day, she had a heart attack and died before she could be taken to the hospital. She was buried a few days later in a plot she had purchased for herself with the very first money she had ever earned, because she did not want to be buried in a pauper's grave, or one of the unmarked institution cemeteries. The plot she had purchased was next to that of the family with whom she had been placed when she first left the institution.

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Invitation to Submit Letters to the Editor of *The SRV JOURNAL*

We welcome for publication Letters to the Editor regarding *The SRV Journal* itself and/or 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;* or email *journal@srvip.org.*

Remembering Mr. Sinclair

James Brunault

IN 1985 I WAS AN UNDERGRAD at the local community college, not sure what I wanted to study, not sure what I wanted to do in life, not even sure if I wanted to be in college. But there I was taking a smattering of classes, majoring in theater, with some vague notion of living the life of a disassociated artist in New York City … someday.

I don't remember now why I signed up to take *Introduction to Sociology 101;* I can only assume that it fulfilled some core requirement. But there I was sitting in class three days a week. The teacher was a Mr. Sinclair; I remember being pleasantly surprised by how good the class was. Mr. Sinclair was funny and engaging, and told some good stories, but really I don't remember all that much of the class except one day.

Mr. Sinclair came in and said we were going to talk about how people in society relate to one another, how we get along, and even how our place in society is determined. He had my attention. Social roles, he said, we all relate to one another by social roles. We meet people almost always in their role, we know people in their roles, and we talk about people and their roles as if they are interchangeable. I don't know why, I had never heard of SRV or Dr. Wolfensberger,[1] but this discussion captivated me. I still remember the story that he told about going to a party where he didn't know people and was meeting them for the first time.

MR. SINCLAIR went to a party with his wife where he knew almost no one except her. She for some reason left him on his own at the party, and he decided to have fun with the situation. As various people introduced themselves to him they all asked that inevitable question, "so what do you do?" For fun, he told us, he tried various responses. Well I like to play tennis, he told some people, or I enjoy crosswords and would like to be able to do the New York Times puzzle in pen someday, he told others. I could picture the odd looks people were giving him. He said some folks really persisted. "No, no, what do you **do**?" They asked as if he had not understood the question. Some got more specific. "No, for a living? What do you do for a living?" "Oh," he replied, "I'm a teacher." He said some people visibly relaxed, finally getting the type of answer they were looking for.

As Mr. Sinclair pointed out to us, all his other answers were correct. The question was, what do you do? All his replies were things he did. So why were people upset, why repeat a question that had been answered already? Because, he said, the real question was "what is your role in society?" Our role or roles are what people want to know when trying to define us. All of Mr. Sinclair's answers addressed the question that was ostensibly asked but none of them answered the real question. None of them defined his role in society, none of them said "this is how you relate to me."

WHY THIS LESSON hit me strongly, why I can still see him in front of the class telling us this story, I do not know, but it did. And that is the day that I began thinking about how important it is how we answer that question. "Hi,

nice to meet you, so what do you do?" Or as Mr. Sinclair helped me to see, "Hi, what's your role, how do I relate to you?"

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Endnote

1. SRV stands for Social Role Valorization. It is a set of ideas concerning how human service is transacted. SRV was developed by Dr. W. Wolfensberger of the Syracuse University Training Institute for Human Service Planning, Leadership & Change Agentry. For more on SRV, see Wolfensberger, 1998; Race, 1999; and Osburn, 2006.

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The Citizen Advocacy Foundation of America:
A Note on a New Citizen Advocacy-Related Organization

From the Editor

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

Established in 2006, the Citizen Advocacy Foundation of America is a non-profit, tax-exempt foundation. It solicits donations, bequests and other financial contributions to be used to make grants to CA-related projects, thereby providing a means for assuring the continuity of CA and CA programs. Historically, CA programs have had great difficulty finding initial and ongoing funding. The Foundation will only fund projects closely related to CA, striving to achieve the greatest benefit to the CA movement overall.

The viability of this Foundation depends on financial contributions made to it by generous donors. We ask readers of this Journal to please consider making a donation, and/or to share this information with others who may be able to make a donation. All contributions are exempt from US taxes.

For more information about the Foundation, requesting a grant, or making a donation, please contact Susan Thomas at: 231 Miles Avenue, Syracuse, NY 13210, USA. Telephone number 315 478 3797.

To learn more about Citizen Advocacy, two excellent resources are:

Wolfensberger, W., & 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.

REVIEWS

SOCIAL WORK WITH PEOPLE WITH LEARNING DIFFICULTIES. By PAUL WILLIAMS. Exeter: Learning Matters Ltd., 155 pages, 2006.

Reviewed by Aimee Lunden

PAUL WILLIAMS wrote the textbook *Social Work with People with Learning Difficulties* for social work students. Each chapter begins with an outline of the UK National Occupational Standards for Social Work which the chapter addresses. These are the standards that social workers in the UK must be taught to, although the concepts would be familiar to US social workers as well.

The author, according to the jacket of his book, "has forty years' experience of working with people with learning difficulties ... Since 1991 he has been a lecturer in Social Work at the University of Reading where he teaches working with people with learning difficulties and anti-oppressive practice." This book links the practice of social work with a values-based approach to supporting people with learning difficulties.

THE BOOK IS BROKEN UP into seven chapters. It begins with the question, as well as the ever changing answer, "Who are the people with learning difficulties?" Williams gives an in-depth account of how the answer to this question is not clear, and why. Although short, the chapters provide the reader with opportunities to learn more about their topic by suggesting different activities as well as other resources, including some basic SRV texts (although one omission is that Williams fails to mention Wolfensberger's key role in formulating Citizen Advocacy; see for example Wolfensberger & Zauha, 1973; and O'Brien & Wolfensberger, 1988).

This book is very relevant to Social Role Valorization (SRV). It adeptly introduces the 'themes' of SRV (Wolfensberger, 1998) to the social work student. It discusses wounds and devalued roles (chapter 5), various models of work with people with learning difficulties (chapter 1), roles (chapter 4) and the evaluation of services (chapter 5), including information about PASS (Wolfensberger & Glenn, 1975) and PASSING (Wolfensberger & Thomas, 2007).

In my opinion, this book could have a much larger target audience than just social work students. It is clear, concise and well-written. It appears to be written to workers who have some work-related exposure to people with learning difficulties, but not necessarily a lot of experience. This book could easily be used as a basic book for service workers that are not in a social work program. It has multiple exercises for the reader in each chapter that help to apply theory, as well as challenge assumptions and practice. For example, in the chapter (4) on a life-stage perspective on needs, the social work student is asked to think about valued roles for people with learning difficulties, with

an eye on basic SRV principles (described in chapter 2). This activity surely has relevance beyond the realm of social work.

A powerful message in the book for people learning to be social workers is that "We often hanker after official looking proformas and charts to guide our assessments, but in many cases the best tool is a plain sheet of paper on which a flexible amount of space can be devoted to recording information under whatever headings are felt to be necessary" (p. 77). This message is all the more necessary in that the opposite trend exists in the field of social work.

As a social worker, I was happy to read a book that challenges social workers to think about Social Role Valorization. In my own 60 credit graduate degree, it never came up once.

WHILE READING THE BOOK, I was concerned about some of Williams' use of language. The term 'people with learning difficulties' is used consistently in the book. I used the phrase in this review to be consistent with the book, but that being said, the term 'people with learning difficulties' is one that is not often or ever used in the United States when referring to a person with mental retardation, which is who Williams is writing about. He chose the term 'learning difficulties' as it is how people in the self-advocacy movement in the United Kingdom prefer to be referred (p. 2). My concern with this language construct is that as social workers, we sometimes accommodate people in the name of empowerment -- and then observe as this same act of empowerment further separates people; e.g., like women who respell the word 'womyn,' or the chapter of a book I read in my final year of graduate school that referred to people with impairments as "disAbilities." I find that this rift in language is not particularly helpful for encour-

aging identification with socially devalued people (Wolfensberger, 1997; Wolfensberger, 1998, pp. 2, 67).

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EDITOR'S NOTE: *The following two reviews are by different reviewers but are about the same book. I am thankful to John Ford and Cheryl MacNeil for the time, interest and care they took in reviewing the book and writing up their thoughts. The issues described in the book are clearly ones they are professionally but also personally involved with.*

The reviewers have quite disparate perspectives on the same text. This is not surprising, as discussions around the field of mental disorder, which is the topic of the book, are often diverse if not divisive. I hope these reviews provide an opportunity and an incentive for our readers to reflect on the important issues raised by the reality of mental disorder and by services to mentally disordered people. As always, we welcome your comments and letters about anything published in the Journal.

MAD IN AMERICA: BAD SCIENCE, BAD MEDICINE, AND THE ENDURING MIS-TREATMENT OF THE MENTALLY ILL. By ROBERT WHITAKER. Basic Books, New York, 334 pages, $17.95, 2002.

Reviewed by John R. Ford

ROBERT WHITAKER is an award-winning medical journalist and a finalist for the 1998 Pulitzer Prize for a series on medical experimentation on the mentally ill. In *Mad In America* he has written a polemical and one-sided history of the plight of the mentally ill. Whitaker's view of our treatment of the mentally ill is summed up in the following quote from page 253, "One of the enduring staples in mad medicine has been the rise and fall of cures. Rarely has psychiatry been totally without a remedy advertised as effective. Whether it be whipping the mentally ill, bleeding them, making them vomit, feeding them sheep thyroids, putting them in continuous baths, stunning them with shock therapies or severing their frontal lobes. All such therapies worked at one time, and then, when a new therapy came along, they were seen in a new light and their shortcomings revealed."

DIVIDING THE BOOK into four parts: The Original Bedlam (1750 to 1900), The Darkest Era (1900 to 1950), Back to Bedlam (1950 to 1990s), and Today (1990's to present), Whitaker signals his take on the misfortune of being mad in America. The author scorns physicians and pharmaceutical companies as the oppressors of the mentally ill while indicting society for allowing abuses to linger with little apparent interest. His thesis is that the medicalizing of schizophrenia has been a sad mistake broken only by the mid-nineteenth century era of "moral treatment." As mental illness came to be seen as medical in nature, physicians became the experts, establishing hospitals that were profitable for the trade but did little but abuse patients with various treatments meant only to make them passive and pliant.

In Whitaker's view, only when "moral treatment" came into vogue were patients treated humanely and cure rates were substantial. Moral treatment, grounded in Quaker principles and calling for treating one's fellow man with dignity and respect, first appeared in Philadelphia about 1810 and spread as the reformers of the time such as Dorothea Dix convinced states to open specialized hospitals for the mentally ill. Moral treatment required small institutions where kindness and respect coupled with pleasant and productive activities ruled the day. A family atmosphere existed with staff living at the institution, eating together and sharing social events with the patients. High cure and improvement rates were

reported. The professional literature of the time stressed respect for patients, good manners, positive staff-patient interaction, productive activity and dignified dress. The cruel therapies of earlier times were absent. "Moral treatment had represented a profound shift in America's attitude toward the mentally ill. For a brief shining moment the mentally ill were welcomed into the human family" (page 33).

ON A PERSONAL NOTE, the writer of this review researched the history of the Worcester, MA State Hospital at the time of the 150th anniversary of its founding (1832). While moral therapy held sway, many patients came from affluent families and appeared to spend time while at the hospital involved in the social activities of the affluent community. It appeared that some of the patients may not have suffered from severe mental illness, but neurotic or life event crises brought them to this welcoming place, thus contributing to the high cure and improvement rates reported at the time. However, as time passed the hospitals became overcrowded; alcoholics, syphilitics, criminals and patients with organic conditions and little hope of recovery were admitted, destroying the milieu that had allowed moral therapy to prosper. Soon the superintendents of the hospitals became pessimistic about cures and tended to pay more attention to the production of the farms maintained by state hospitals than to the welfare of their patients. Moral therapy's time was coming to an end.

Beginning in the 1870s into the mid-twentieth century, physicians reasserted themselves as masters of the mental hospitals. This change coincided with the period following the Civil War when the new medical specialty of neurology developed to treat the large number of soldiers with head wounds. As the number of veterans with head wounds diminished, neurolo-

gists turned to the asylums where patients were plentiful and profitable. The neurologists decried the "non-scientific" approach of moral therapy and proclaimed schizophrenia to be a brain disease. At the same time, eugenic theory was gaining wide acceptance and the neurologists latched onto it. In an atmosphere where the mentally ill were seen as defective, worthless human beings, anything was fair game. Sterilization and lobotomy would help cure society of its defectives. "Why do we preserve these useless and harmful beings? The abnormal prevent the development of the normal. Why should society not dispose of the criminal and the insane in a more economical manner?" (Nobel Prize-winner Dr. Alexis Carrel quoted on p. 41). If patients are worthless defectives and if schizophrenia is a brain disease, then surgery is justified no matter the effect on the patient. Lobotomy and other treatments were effective as long as the patient was rendered passive and not troublesome for the staff.

With the 1950s dawned the age of the neuroleptic medications. In Whitaker's view, medications such as Thorazine and Haldol simply rendered patients passive and unmotivated, thus becoming a chemical form of lobotomy. He dismisses the development of the atypical medications in the 1990s as simply more of the same. All medications are harmful and only for the benefit of doctors and pharmaceutical firms.

WHITAKER IS CORRECT to assail the abuses that have hurt patients many times over. However, on balance, there is no balance in this book. The community movement of the present time, including Fountain House-type clubhouses, employment and residential alternatives, community treatment teams and the efforts of psychiatrists to use the lowest possible dose of medication, are not mentioned. He

presents no alternatives to present treatment except to turn us back to the era of moral treatment without medication. He views medication as the cause of mental illness, not part of an attempt to alleviate it. By ignoring the respect and partnership explicit in the clubhouse movement and other programs, he fails to see the contribution of moral therapy to the present day. As a muckraking broadside at the medical profession and the pharmaceutical industry, the book reads well. As a serious look at the current mental health system in all its strengths and weaknesses, it is lacking.

JOHN FORD, MSW, is a human service consultant and was the Undersecretary of Health and Human Services in Massachusetts, USA.

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Ford, J. (2007). Review of the book *Mad in America: Bad science, bad medicine, and the enduring mistreatment of the mentally ill* by Robert Whitaker. *The SRV Journal, 2(1),* 47-49.

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MAD IN AMERICA: BAD SCIENCE, BAD MEDICINE, AND THE ENDURING MISTREATMENT OF THE MENTALLY ILL. By ROBERT WHITAKER. Perseus Publishing, Cambridge, MA, 334 pages, $17.50 US/ $26.95 CAN, 2002.

Reviewed by Cheryl MacNeil

Boston Globe reporter Robert Whitaker attempts to 'right a wrong' in telling a different kind of story about psychiatric treatment in *Mad in America*. Whitaker uncovers two centuries of evidence to demonstrate how knowledge about mental illness has been manufactured to produce societal consent for the mistreatment of the mentally ill. His writings conjure up familiar images akin to Ken Kesey's

One Flew Over the Cuckoo's Nest, and his method of critical reconstruction stylistically mirrors that of linguist and war critic Noam Chomsky. Whitaker was also a highly regarded medical reporter for the *Albany Times Union* and a finalist for the Pulitzer Prize in 1998 for a series he co-wrote on harmful psychiatric research.

Mad in America examines the traditions of a mental health system where care is not simply given, but is managed and is a great source of profit. Whitaker uses a host of credible sources such as scientific journals, federal reports, scholarly bulletins and personal accounts to offer a bold institutional analysis of psychiatric mistreatment, particularly related to people diagnosed with schizophrenia. For most, this will not be a comfortable read but it is an important examination. Consumers and survivors, family and community members, and all helping professionals can benefit from reflecting on Whitaker's provoking representations.

AS A REVIEWER, I wear multiple lenses in sifting through the data presented. I have many close relationships with people who come into contact with the mental health system and have been a witness to the methods of the psychiatric establishment. I have apprenticed with Dr. Wolf Wolfensberger and his associates, spending a number of years studying and teaching the theory of Social Role Valorization (SRV). Today I am a researcher who operates within a critical theory paradigm. For me, the nature of inquiry is to critique and transform the sociopolitical and economic structures that constrain or exploit humankind. These are the filters I bring to my commentary.

THERE ARE MANY STRONG connections between the findings of Whitaker's research and the theory of Social Role Valorization

(Wolfensberger, 1998; Race, 1999; Osburn, 2006). SRV theory teaches us that society judges and treats people in particular ways based on the presence or absence of certain competencies and characteristics. When people are judged to be of lesser value, they become vulnerable to losing whatever valued social roles they may have and are likely to be cast into devalued negative social roles. *Mad in America* serves as an historical case study of how this has happened to a group of people who act and speak outside the acceptable societal norms.

Whitaker's historical research begins in the mid-eighteenth century when "lunatics" and "maniacs" were segregated from the rest of society into hospitals that acted as jails to 'protect society from them.' The hospital jails were run by people who held highly valued social roles. They were "learned man" and "doctor." Over the course of history, these valued medical doctors were joined by others who were similarly awarded high social esteem and power: heads of foundations, the clergy, scientists, psychiatrists and the pharmaceutical industry. Together, they sculpted stories of brain maladies and chemical imbalances that further cast lunatics into a host of devalued roles: "Lab rat," "burden," "household pet," "defective," "malignant biological growth," and "poisonous slime."

SRV theory tells us that bad things are likely to happen to persons cast into such problematic and socially devalued roles. But one might wonder, 'How could bad things happen to people under the care of the highest learned and most socially valued citizens?' If as Whitaker claims, "treatments for the mentally ill inevitably reflect the societal and philosophical values of the day" (p. xv), then it follows that people cast into the roles of "germ plasm" and "social wastage" would be forced

to be sterilized or put to death, as happened to the mentally ill during the period of eugenics. Another finding central to *Mad in America* is that the objectification of the lunatic as a 'commodity' has been one of the most perilous social role assignments in the history of madness. Throughout Whitaker's research one question keeps arising: Do people with mental illness need doctors more than the doctors need them?

IN THIS EXPLORATION of madness, issues of power, money, imagery and role expectations are at the forefront. The most notable example is found in the competing ideologies between the moral treatment approach of the Quaker community and the biological deficiency model of the medical community. After losing one of their own under the care of the lunatic doctors, it was the Quakers who first proclaimed, "It would be the needs of the ill, and not the needs of those who managed the retreat, that would guide their care." In their moral treatment paradigm, the Quakers assumed that mental illness was a response to the "shocks of life." They placed persons with mental illness into social roles of "brethren" and "family member," and surrounded them with expectations of getting better. The imagery projected about the mentally ill was that of people who could "develop friendships, dress well and rethink their behavior." The Quakers expected people to recover and assumed that the power of recovery was within the person, not the medical profession.

This transfer of power to the person was vastly threatening to the professionals who had a stake in maintaining their biological deficiency model. And while Whitaker's research indicates that people were getting better with the care and dignity provided through a moral treatment approach, the approach was never given suffi-

cient time to demonstrate potential long term impacts. Medicine reclaimed its domain. Physicians took charge of the moral treatment asylums. And the social construction and marketing of mental illness as a biological deficiency prevailed.

It is in the history of the medical model's 'therapy' for the mentally ill where lessons about language practices are transparent. SRV teaches us to listen with a critical ear and move beyond what something is called, to defining what that means in the life of a devalued person. It is frightening to acknowledge the role that therapeutic language has played in the lives of people with mental illness. Trap doors are dropped beneath people as they are plunged into ice baths in the name of "hydrotherapy." People are strapped to a board and spun around as a condoned practice called "confusional therapy." Icepicks are plunged beneath the eyelid into the brain, people are bled to the point of fainting, drowned and brought back to life, vomiting and comas are induced, electricity is jolted into brains and numbing neuroleptics ("chemical lobotomy") are ingested. All, at one time or another, have been socially acceptable "therapeutic" practices. Whitaker's research concludes there has never been any evidence-based justification for the delivery of these 'therapies,' nor have any of these 'therapies' ever been scientifically demonstrated to be curative.

ONE OF THE BIGGEST LESSONS we can take away from *Mad in America* is the understanding that we are not value-neutral human beings and we do not make judgments nor conduct our activities outside the realm of values. I applaud Whitaker's efforts to challenge the dominant scientific paradigm and dispel the myth that scientific investigations of psychiatric issues have been neutral. The fashioning of

inquiries and treatments has consistently been backed by powerful foundations and pharmaceutical industries that have a great investment in cultivating the message that 'mental illness = broken brain.' Not only has the broken brain theory never been scientifically proven, claims Whitaker, but the activities of psychiatric investigations have produced a track record of "bad science, bad medicine, and the enduring mistreatment of the mentally ill."

I am mad about *Mad in America*. I am crazy about this book. I admire Whitaker for shining a bright light on a dark matter. Most honorable is that when Whitaker began his research, he believed in the story of progress that psychiatry had been telling the public for decades.

Understanding the nature of mental health and mental illness is an incredibly complex task. If we take the time to listen to people who have come into contact with the treatment system and elevate their voices into the discourse, as Whitaker has done, we might better understand 'what is the case' and 'what is helpful.' After reading *Mad in America*, I am left to wonder what would happen if we seriously started exploring the alternatives. What if we finally rejected the hypothesis that 'mental illness = broken brain' and rigorously examined the hypothesis that 'psychiatric institutions = repositories for our social ills'? What would happen if treatment came in the form of providing sanctuary, validation and empathy? What if we assigned the role of brethren and valued human being first and foremost to the mentally ill? What if vast resources were directed into constructing a universal narrative about recovery? What if the Quakers were on the right track?

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DO NOT GO GENTLY. By MELISSA GODOY (Director). Rated PG, 57 minutes, 2007.

Reviewed by Jack Pealer

TEACHERS OF Social Role Valorization (Wolfensberger, 1998) are more successful if they use examples of people who customarily endure societal devaluation but who are shown filling highly valued social roles. I stumbled on a set of such examples when I went to the world premiere of a new documentary film by a filmmaker from Cincinnati.

Do Not Go Gently (yes, I know, Dylan Thomas readers -- it ought to be "do not go gentle") by filmmaker Melissa Godoy introduces viewers to the continuing and expanding power of creativity and imagination demonstrated by people of advanced age. Godoy's aim is to confront and counter customary expectations that human imagination and creativity weaken and fail in older people. She accomplishes her aim by showing (mostly) and telling -- through

people's own voices -- the artistic stories of quilt maker Arlonzia Pettway (age 82) from Gee's Bend, Alabama; dancer and choreographer Frederic Franklin (age 92) from New York City; and composer/pianist Leo Ornstein (age 109) from Green Bay, Wisconsin.

Arlonzia Pettway has been making quilts since she was a girl. Recently, quilts that she and some of her neighbors and colleagues from rural southwest Alabama created have been exhibited in a number of North American museums. The exhibition's organizer remarks, in the film, about the similarity of the quilters' designs to paintings from highly-regarded modern painters. The quilts' designs predate the paintings, which may be why the organizer comments: "Abstraction wasn't invented in New York." In *Do Not Go Gently* we see Ms. Pettway executing her designs and listen in on her conversations with her colleagues about their work.

Leo Ornstein's public music career began nearly 100 years ago. Early in the 20th century he was renowned, in Russia and later in America, both as a pianist and as a modernist composer. He discontinued public performance in the 1920's and, with his wife (also a musician), began a music school in Philadelphia, which operated until 1953. During all those years, Ornstein continued composing. In the 1970's a music historian (who appears in *Do Not Go Gently*) found Leo Ornstein and his wife wintering in a trailer park in Texas. *Do Not Go Gently* shows Ornstein, in his 90's, working on new compositions with his wife as transcriber. The filmmaker interviews a vibrant Ornstein shortly before the composer's death at age 109, when he was living in a nursing home in Green Bay. That interview is one of the highlights of the film.

Dancer Frederic Franklin was born in England and began to dance when he was very

young. He became a leading dancer and ballet master with Ballet Russe de Monte Carlo and a founder of both the Slavenska-Franklin Ballet and the National Ballet of Washington, D.C. He has partnered with such other dancers as Josephine Baker (1931), Maria Tallchief, Agnes de Mille, and most notably Alexandra Danilova. He has worked with most of the 20th century's leading choreographers. *Do Not Go Gently* shows Mr. Franklin at age 90 dancing the part of the Friar in Prokofiev's *Romeo and Juliet* with the Cincinnati Ballet. He is also seen coaching the premier dancers from Cincinnati. Those who came to the world premiere of *Do Not Go Gently* (March 3, 2007 at the Cincinnati Art Museum) were treated by Frederic Franklin's presence for the afternoon. He appeared onstage after the film with two of the premier dancers from the ballet and with the filmmaker Melissa Godoy. Mr. Franklin ("Freddie" to his colleagues) told stories about his career and about the process of making the film. He was, at age 92, a living lesson in Social Role Valorization.

IT'S PRETTY EASY to identify the valued social roles that this film sets before its audiences. People of advanced age are shown (not just talked about) as teachers, composers, designers, performers, sages, and elicitors of admiration from other, younger people. Adherents of Social Role Valorization will spend a few uncomfortable minutes watching what promises to be a "rhythm band" in a day-activity program for elderly people. Even this scene, though, is partially redeemed as the people, who are issued various rhythm band instruments, suddenly are energized by the drumming and all get up to dance. It's an odd but strangely compelling scene, where people's vitality violates most of the other messages in the surroundings. Clients turn into dancers.

In this brief review I've used forms of the verb "to show" often. That's because of the success of *Do Not Go Gently* at showing (as contrasted with merely talking about) people as active, imaginative, creative beings. Few "talking heads" appear in the film. Leo Ornstein composes and is a raconteur. Frederic Franklin dances. Arlonzia Pettway quilts. Donal McLaughlin, an architect older than 90 years of age, shares the design he submitted for the "9-11 Memorial" in New York City.

Do Not Go Gently is now in the final stages of preparation for its release. It will, apparently, be shown in selected theaters in North America. It also will appear on public television in the United States. As they say: check your local listings for its appearance in your area. Even if you have to wait a while to see it, *Do Not Go Gently* is worth the wait. You can learn about possible showings through the website: *http://donotgogently.com*.

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EDITOR'S NOTE: The Safeguards Letter *(a publication of Ohio Safeguards) is an excellent resource, well worth reading. It contains thoughtful articles, stories, opinion pieces, quotes, book reviews, etc. It is available in print or by email. Contact the Editor, The Safeguards Letter, 3421 Dawn Drive, Hamilton, OH 45011 USA. jackjr158@earthlink.net. http://www.ohiosafeguards.org/*

Do not go gentle into that good night,

Old age should burn and rave at close of day;

Rage, rage against the dying of the light.

Dylan Thomas, 1951

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COMMON ASSETS OF MENTALLY RE-TARDED PEOPLE THAT ARE COMMONLY NOT ACKNOWLEDGED. By WOLF WOLFENSBERGER. *Mental Retardation*, Vol. 26, No. 2, 63-70, 1988.

Reviewed by Raymond Lemay

IN SOME OF his three- to five-day introductory Social Role Valorization (SRV) workshops, Wolfensberger has presented some twenty-two reasons why it is a good idea to implement social integration (cf., Wolfensberger, 1998, pp. 122-124). Most of these reasons are described as benefits to people who are at risk of social devaluation, including persons with mental retardation and other developmental disabilities. However, at the end, there are a few reasons that Wolfensberger highlights as being benefits to society. According to Wolfensberger, people with mental retardation have their rightful place in society: they have a contribution to make that communities and societies need. Thus, in this 1988 article, Wolfensberger presents the "strengths, virtues, gifts, capacities, prosocial dispositions, and re-sources, here called 'assets,' that one can find not only in a few retarded people, but among a goodly proportion" (p. 63). It is these assets that communities do without when such individuals are excluded.

Wolfensberger tells us that, at first, people in mainstream society, particularly professionals, will doubt the possibility that individuals with mental retardation have a positive contribution to make. Part of the reason for this is the "eugenic alarm" period that so devastatingly characterized individuals with mental handicaps as not worthy of life (Wolfensberger, 1975). Moreover, individuals with intellectual handicaps have been systematically segregated away from community life (Wolfensberger, 1998, p. 18) and thus we have had very little experience of them and particularly of their qualities. Moreover, "professional practice is still preoccupied with their deficits (once called 'inferiorities'), as exemplified by all sorts of 'fault-finding' problem checklists and widely used incident reports that record only negative behavior" (p. 69).

Moreover, many individuals with mental retardation experience dehumanizing and brutalizing conditions, such as those to be found in institutions, and others live lives of idleness and social isolation in so-called "community residences." At the very least, such social contexts are not at all normative and thus inhibit the expression of many of the qualities that Wolfensberger lists in the article. By and large, the assets that individuals with handicaps are able to demonstrate require nurturing environments, for instance, loving homes.

Wolfensberger lists fifteen assets that are briefly described hereafter. Many of the assets listed come from the reality that people with mental retardation have diminished intellectual capacity, and Wolfensberger argues that this leaves room for the growth of what he calls

"heart qualities." "This implies that mental energies and other resources are more concentrated on relationships -- sometimes for worse, but sometimes also for better" (p. 63).

1) Thus, the first asset is a focus on relationship and what Jean Vanier has called "to give life and warmth and to recognize another person and his or her needs" (p. 64).

2) Spontaneity: Wolfensberger describes this as natural and positive. However, he also suggests that there is a tendency in human services and amongst sophisticates to repress such spontaneity and even try to "normalize it out of them" (p. 64). Wolfensberger tells us that many persons with mental retardation have joy and seem to share it willingly.

3) Responsiveness: Such persons tend to "respond quickly, generously, and warmly to kindly human contact, approval, and encouragement" (p. 64). Wolfensberger tells us that this often blossoms remarkably despite the fact that many such persons have lived long histories of rejection and brutalization and "deprivations of positive affectional relationships that they open up to such relationships like a flower famished for water" (p. 64). Wolfensberger reports that "many people remark on the fact that relating to a retarded person involves their emotions more than their intellect and challenges their sensitivities" (p. 64).

4) Individuals with mental retardation see the person rather than their status or appearance. They are thus more accepting of others as they are.

5) Solicitude: "Many retarded persons have a genuine concern for things being well in the world" (p. 65).

6) Unconditional love: Love is given freely in an uncalculating way.

7) Trusting, "even when their trust is not warranted" (p. 65).

8) Unmaterialistic: "The overwhelming majority of retarded persons are poor and always will be poor. In some, this generates a possessiveness and materialism that can be pathological or a vice, but others are remarkably detached from worldly possessions" (p. 65).

9) Peacemakers: "Some retarded people have a capacity to call forth gentleness, patience, and tolerance from other people, to dissipate the anger and rage of others, and, thus, to be peacemakers" (p. 66).

10) Enjoyment: "Some retarded persons have a gift that enables them to engage in unfettered enjoyment of life's gifts and pleasures, including the simple ones" (p. 66).

11) Honesty: Wolfensberger points out that "lying requires at least some degree of abstracting capabilities, and, therefore, retarded persons have a strong tendency to be direct and concretely honest and a concomitant low inclination -- or even ability -- to dissemble" (p. 66).

12) Linear and concrete thinking: "Retarded people apparently have a remarkable tendency to follow an issue, development, or idea in a rigorous, concrete sequentiality to its 'logical' conclusion" (p. 67).

13) They don't get bored: "Many retarded persons have the capacity to engage in a single and/or simple activity for an extended period of time, far beyond when it would become boring and tedious to nonretarded persons" (p. 67).

14) Not easily sidetracked or misled.

15) Spiritual: "Retarded people have fewer intellectual barriers and, therefore, less resistance to a relationship with the divine" (p. 67).

WOLFENSBERGER points out that he is describing general virtues and qualities that are applicable to many persons with mental retardation though not necessarily to all. Moreover, many individuals might not today manifest

such qualities, but given the right conditions and life experiences, these may blossom. Indeed, he suggests certain "positive preconditions" (p. 69) which must be present for such qualities to emerge. They must have the "opportunity to function under reasonably normative life conditions" (p. 69).

Moreover, such life conditions should include the experience of "integration that includes nonretarded people in loving and friendship relationships" (p. 69). And there is a requirement for reciprocity, "the nonretarded people need to possess certain positive gifts and talents; and if they possess them, they must exercise them in the presence of, and vis-à-vis, retarded persons, something that does not always happen" (p. 69). Given the very prevailing social isolation of individuals with mental retardation, even for those living in the community (Lemay, 2006), the opportunities for reciprocal relationships and the practice of these assets is very much constrained.

Resilience

It is quite striking that what Wolfensberger seems to be describing here is another instance of resilience (Lemay & Ghazal, 2001), which is quite consistent with his descriptions of the developmental model (Wolfensberger, 1998, pp. 108-111; Lemay, 2005). On the one hand, he suggests that for these positive qualities to emerge, adversity must end, a first requirement for resilience and positive development. Moreover, if provided with more positive life conditions and experiences, a person's developmental potential will be in a position of maximization. Thus, the potentiality for such qualities is there but they require the presence of positive life conditions and experiences to emerge. "Many retarded people today still are not afforded liberating life conditions, and many of the remainder experience them only partially and/or for time-limited periods. Accordingly, a significant proportion of workers in our field (and in others as well) have also not had the opportunity to see the assets of retarded people sufficiently displayed or to act appropriately in light of the many positive and negative realities that such experiences reveal" (p. 69).

A Contribution to Society

This article points out the fact that the long absence of individuals with cognitive disabilities from our midst has been a tremendous loss. Such individuals living in nurturing environments, in a relationship with others, will often demonstrate qualities and virtues that will positively animate the social environment. Can there be such a thing as too much warmth, spontaneity, joy, solicitude and peacemaking? These are certainly qualities and behaviors that can enrich community life. Moreover, the vulnerability and positiveness of such individuals may call forth the best in each and every one of us, as it has the potential of gentling individuals in a society that is much too enamored with competence and material success.

Neighborhoods, groups, and other social settings that open up social space and social activities to such individuals will undoubtedly benefit; however, it is likely that such benefit will only be attained if social space is opened up deliberately and with the full knowledge of what one gains.

Conclusion

This article is a call upon human services and communities generally to open up social roles that are most appropriately and most particularly within the skill-set and attributes of individuals with mental handicaps. With this article, Wolfensberger make a moving statement about a very positive stereotype concerning in-

dividuals with cognitive disabilities. As with all stereotypes, this is a general description of a class of individuals that applies more or less to each individual, and with such a statement of stereotype comes the possibility of self-fulfilling prophecy. The realization of such a stereotype for each individual can only be viewed as a good. Thus, Wolfensberger has ascribed positive and contributory roles to individuals with mental retardation.

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Invitation to Write
Book, Film and Article Reviews

From the Editor

I would like to encourage our readers to submit reviews to *The SRV 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.

The New (3rd, 2007) Edition of PASSING

Susan Thomas & Wolf Wolfensberger

IN FEBRUARY 2007, the new, revised, 3rd edition of PASSING was published (Wolfensberger & Thomas, 2007). Below, we give a brief history of PASSING, and an overview of the differences between this new revision of PASSING, and the previous (1983) edition.

The History and Background of PASSING

IN 1969, in connection with what was then the brand-new effort to shift from institutional to community services for retarded people in the US state of Nebraska, an evaluation instrument called PASS (Wolfensberger & Glenn, 1969) was developed. PASS stood for **P**rogram **A**nalysis of **S**ervice **S**ystems. This first edition of PASS was printed on a mimeograph machine, and was not widely available. It was intended to be applied to services that were vying for newly-available (for the first time) state money to support community services for the mentally retarded. In order to prevent the pirating of this new money by institutions, universities, and non-normalized services, PASS was structured to evaluate how well a service measured up to the requirements of the new state plan and what was then the brand-new service approach of "normalization" (Nirje, 1969; Wolfensberger, 1972), as well as to some additional criteria for good service administration and management practices. This first version of PASS was used only within Nebraska, and to make funding decisions for one funding cycle.

However, as interest in normalization spread, and as normalization began to be more widely taught, PASS was revised twice (Wolfensberger & Glenn, 1973, 1975), and published by a "real" publisher (what was then called the Canadian National Institute on Mental Retardation in Toronto). Tens of thousands of copies of PASS were sold, and several thousand people attended training workshops (usually lasting five days) in PASS, given in the US, Canada, England, Australia, and some French-speaking countries.

In 1978, the Syracuse University Training Institute for Human Service Planning, Leadership, and Change Agentry, headed by Wolf Wolfensberger, was approached by the Developmental Disabilities Services Board of the County of Dane, in the US state of Wisconsin, to produce an adaptation of PASS that was meant to be easier to apply to services, in part by not assessing management practices as PASS had done, and by providing much more (and easily understandable) text for each evaluation criterion. It was called PASSING, which stood for **P**rogram **A**nalysis of **S**ervice **S**ystems' **I**mplementation of **N**ormalization **G**oals. The first (1980) version of this adaptation was available and used only within that county, but a second version was again published by a "real" publisher (the same Canadian National Institute on Mental Retardation) in 1983; and, as with PASS, many people have attended training in it since 1983. However, just at the time that PASSING was published and training in it was begun, the senior author of both PASS and PASSING (Wolfensberger) reconceptualized normalization as Social Role

Valorization -- and this was unfortunate for PASSING because PASSING was already in print with the word "normalization" in its name, and with normalization language instead of Social Role Valorization language throughout the text, even though it reflected a great deal of Social Role Valorization conceptually. This meant that people who learned PASSING had to be taught to, in essence, ignore the normalization terminology in PASSING, and mentally substitute Social Role Valorization language for it.

In 1989, a French translation of PASSING was published (Wolfensberger & Thomas, 1989), with the title *PASSING (Programme d'Analyses des Systèmes de Services Application des Buts de la Valorisation des Rôles Sociaux): Manuel des critères et des mesures de la Valorisation des Rôles Sociaux.*

In the late 1990s, the National Institute on Mental Retardation (by then renamed the Roeher Institute) ceased publishing all the items authored by Wolfensberger which it used to publish, and that included PASSING. This made training in it difficult, since copies of the book were increasingly hard to come by. This is the situation that prevailed through 2006.

Revision of PASSING

EVER SINCE PASS was published, and then PASSING, the authors had collected notes for revising the instruments. Some of these notes were submitted by users, teachers, and trainers of the instruments. However, the authors were unable to attend to any major work of revising PASSING until prompted by the crisis of the unavailability of PASSING. How could people be trained in PASSING without the book?

Beginning in 2005, revision work was finally intensified, and then rapidly accelerated in

2006 by a subsidy from the Prescott-Russell Services to Children & Adults of Plantagenet, Ontario, Canada. This enabled the third edition to be published in early 2007. This subsidy also made it possible to sell the book at a much lower price than books of its size (424 pages of 8 1/2 x 11 inches) ordinarily sell for these days.

The new edition contains many changes -- and what are hoped to be improvements -- over the 1983 version. Some of the changes are briefly noted below, but elaborated in the 3rd edition of PASSING itself.

1. The terms normalization and normalizing have been replaced throughout the text by Social Role Valorization (SRV), and a role-valorizing idiom. Also, there was much revision in the text to reflect the theoretical developments in Social Role Valorization that had taken place since 1983.

2. PASSING is no longer an acronym, as in the previous edition, but a name, and the book has a new subtitle: *A Tool For Analyzing Service Quality According to Social Role Valorization Criteria. Ratings Manual.* This allows continuity with the previous edition, but without having to come up with a contrived new name to fit the pre-existing acronym.

3. Generally, the language has been changed so as to no longer imply that the service being assessed is necessarily run by a formal service agency, or that the servers are paid service workers. Accordingly, the term "service client" has been changed to "service recipient;" and the terms "service worker" and "service staff" have been changed to "server" in those instances where the text is meant to include either people who work for pay and can therefore be considered employed or hired staff, or people who serve voluntarily or for free and can therefore not be considered employees.

4. There were also some changes in the names of several ratings and rating clusters, so

that the identifying number of the rating or rating cluster is now more important than its name in relating the new PASSING to the contents of the 1983 edition of the *Guidelines for Evaluators During a PASS, PASSING, or Similar Assessment of Human Service Quality* (Wolfensberger, 1983).

5. A very significant amount of editing and changing of both text and examples was done, though this is more obvious in certain sections and ratings than in others. Some improvements were major, some minor.

6. There were some significant content changes in certain ratings, some of these reflected in their names. One of these had to do with tying the issue of social integration in PASSING more cleanly to Social Role Valorization criteria, and separating it from ideological (i.e., non-empirical) rationales.

7. The relationship among certain ratings was greatly clarified.

8. Texts which apply to all the ratings in several rating clusters were consolidated, and moved to a spot where it is easier to tell that they do, in fact, apply to all ratings in a cluster.

9. All the statements of criteria for the five levels of each rating (called "Criteria and Examples for Level Assignments") have been revised. While the essence of the levels is not changed much thereby, the level statements have all been reworded so as to make the principle of each level, and the distinctions among levels, clearer for raters.

Even more than before, the rating criteria imply that it will be easier for some services to get higher scores than others. Uncomplicated services with a single narrow function, and/or that serve recipients who are not devalued, are more likely to score higher, in part because they face fewer pitfalls, especially in the image domain.

10. Examples have been one of the sources

of complaint from previous PASSING users. Some users did want, and some did not want, examples that they thought were culture-specific or time-specific; or some did want examples of specific kinds of services in which they were very interested, and which they felt had been slighted. There has been extensive editing of examples, but this will not appease all critics, in part because there are very good reasons (further explained in PASSING itself) for keeping certain examples and not including others that were suggested.

11. This edition contains some changes in the set-up of the book, in response to feedback from users. These format changes are a trade-off: they eliminate certain features of a practical nature, but considerably reduce the bulk of the book, which is an advantage when it is carried around during an evaluation, and also keeps the cost down.

12. The section that described normalization in detail on pp. 23-29 of the 2nd (1983) edition of PASSING was eliminated. This is because SRV has been refined and elaborated in several separate publications since 1983, especially in Wolfensberger (1998, 2000) and Race (1999); and users of PASSING are referred to these.

13. Because the names of some of the ratings and rating clusters have been changed, all the scoring and reporting forms (including the *Checklist* and *Scoresheet/Overall Service Performance Form*) have been revised.

Implications for Future Use of PASSING

THE ARRIVAL of this new version of PASSING has several implications, including the following.

1. Even more than with the previous edition of PASSING, this edition can serve as an SRV

reference text that can be useful even for people who never conduct a PASSING assessment of a service. Even more than before, PASSING is not only a major text on SRV and its application, but also a major text on what makes a service good or bad. We therefore strongly recommend that every service agency purchase a copy for their staff development library. Of course, many people would want to have their own personal copy as well.

2. People who are well familiar with the 2nd (1983) edition of PASSING **must study** this new one, especially before applying it to a service, because the changes in it are not merely superficial or cosmetic ones, but also entail changes in content. It is often easier for people who are new to something to learn it fresh than for people to have to "unlearn" something with which they are already familiar, and relearn it with changes.

3. However, people who are well-skilled in the application of PASSING (site visit, observation, interviewing workers and recipients, individual ratings followed by team conciliation) will be able to apply the new version of PASSING in the same way, once they have studied it.

4. People who sponsor, host, and conduct PASSING workshops should now make every effort to have each participant own a PASSING book when they leave the workshop, so that they can have and use it as an SRV reference book, and make sense of the written reports that they should be receiving of the services that they helped assess.

How to Obtain PASSING

PASSING can be purchased from the Syracuse University Training Institute for Human Service Planning, Leadership & Change Agentry,

800 South Wilbur Ave., Suite 3B1, Syracuse, New York 13204 USA, phone 315/473-2978; fax 315/473-2963. The price is $55 US funds per copy, plus 15% postage and handling charge within North America, and 20% outside North America. Quantity discounts are available (15% for 25 to 49 copies, 20% for 50 or more copies).

EDITOR'S NOTE: *Please see the training calendar on page 64 for information on a one-day orientation to the new edition of PASSING.*

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A NOTE ON THE ORIGINS OF THE WORD 'ROLE'

From the Editor

The word 'role,' meaning a part one plays or assumes, including figuratively in society or life, derives from a French translation of the English word 'rowle.' The word 'rowle' referred to a roll of papers on which were written a stage actor's lines and entrance/exit cues.

Written references to the word 'role,' as in a behavior appropriate to a particular social position or interaction, began to appear in the 20th century (e.g., G. H. Mead, 1913; R. Linton, 1936; R. K. Merton, 1949; Parsons & Shils, 1951; E. Goffman, 1961; etc.).

[Thanks to Joe Osburn for bringing this to my attention; he read it in *Will in the World* by Stephen Greenblatt (Norton & Co., 2004). Additional information from the *Oxford English Dictionary.*]

Report From a Newly-Formed SRV Study Group in Ontario

AT THE 2003 Third International SRV Conference in Calgary, one of the presenters, Kathryn Smith, called for the establishment of Social Role Valorization study groups (SRVSG). The North American SRV Training, Safeguarding & Development Council enthusiastically took up this suggestion and put together a written proposal for such study groups. Suggestions for possible formats, and practical logistics, for an SRV study group were part of this initial proposal. The proposal envisioned two types of persons being invited to join the proposed SRVSG:

1. Young people who are interested in learning more about SRV, regardless whether they are or want to be on an SRV trainer formation track or not, provided that they show promise.

2. People of any age who are on the SRV trainership formation track, though participation in the study group should not be made a prerequisite for continued advancement on the trainership track.

IN RESPONSE TO this proposal, Erica Baker agreed to begin and facilitate a local SRVSG in the Ontario, Canada area. The first get-together of this new group was held on March 10-11, 2007, in Gananoque, Ontario. About 20 people attended. Study group members met over a weekend, from Saturday at 10 am to Sunday at 2 pm. Members cooked and ate together. For those who needed it, low cost or free accommodations were found.

The first day of the get-together started with an opportunity for each member to reflect upon and then discuss the following questions:

Something in you must have resonated with SRV and the invitation to join this study group. That does not happen to everyone. What was that in you which SRV and this invitation echoed with? Where do you think it came from?

After that, Wolf Wolfensberger and Susan Thomas presented briefly on two different SRV-relevant topics: 1) empirical and non-empirical issues in SRV implementation, and 2) drawing SRV lessons from contemporary media. Erica Baker then described an SRV workshop she developed for and gave to high-school students. Part of the weekend was also spent discussing how the study group should function. The next get-together is planned for October 20-21, 2007 in Oshawa, Ontario. For more information on the new study group, please contact Erica Baker at erica.bdaci@ripnet.com. This particular SRVSG was the topic of a presentation at the 4th International SRV Conference held in Ottawa, Ontario, Canada, in May 2007.

WE ENCOURAGE any other SRV study groups to please write in to the Journal about their own history, format and experiences. The study group model fits in well with the overall thrust of leadership development within the SRV movement. Being a resource for this study group, and encouraging the formation of other local study groups, is a high priority for the SRV Council, within the overall context of leadership development. If you are interested in learning more about the idea of forming a local SRV study group, please contact Marc Tumeinski at 508 752 3670 or marc@srvip.org.

CALENDAR OF SRV AND RELATED TRAININGS

This calendar lists upcoming SRV and PASSING workshops which we are aware of, as well as a limited number of other workshops relevant to SRV. Note that each event varies in terms of length and depth of coverage of material; please contact the person listed to make sure the workshop fits what you are looking for. Additional training calendars may be accessed online at *www.srvip.org* and *www.socialrolevalorization.com.* To notify us of SRV and SRV-related workshops for calendars in up-coming issues of this Journal, please send information to: *journal@srvip.org.*

A Revised Conceptualization of Social Role Valorization (SRV), Including 10 Related Themes
June 18 - 21, 2007
Morrisburg, Ontario, CANADA
call Amanda Fenlong at 613 345 4092

October 15 - 18, 2007
Western Massachusetts, USA
email Marc Tumeinski ~ marc@srvip.org

An Introduction to Social Role Valorization
September 19 - 21, 2007
Harrisburg, Pennsylvania, USA
contact ~ registerki@kss.org

A One-Day Orientation to the New 3rd Edition of PASSING
July 21, 2007
Syracuse, NY, USA
call Susan Thomas at 315 473 2978

August 14, 2007
Ottawa, Ontario, Canada
call Susan Thomas at 315 473 2978

Practicum With SRV Using the PASSING Tool
NB: attendance at an SRV workshop is a prerequisite for this course
October 8 - 12, 2007
Quarryville, Pennsylvania, USA
contact ~ registerki@kss.org

October 15 - 19, 2007
Rockhampton, Queensland, AUS
email Merrill Coram ~ m.coram@homesupport.org.au

October 22 - 26, 2007
Brisbane, Queensland, AUS
email Yvonne Donnan ~ viaa@viaa.org.au

A Three-Day Introductory Reflective Workshop on SRV, Using Seven Themes
August 21, August 28, & September 4, 2007
Brisbane, Queensland, AUS
email Jim Haywood ~ viaa@viaa.org.au

Towards a Better Life: A Two-Day Basic Introduction to SRV
June 4 - 5, 2007
Rockhampton, Queensland, AUS
email Merrill Coram ~ m.coram@homesupport.org.au

August 16 - 17, 2007
Epping, New South Wales, AUS
contact ~ foundationsforum@yahoo.com.au

A One-Day Overview of Social Role Valorization
September 28, 2007 (8:15 am to 5 pm)
Syracuse, New York, USA
call Susan Thomas at 315 473 2978

The Power of Roles
October 4, 2007
Harrisburg, Pennsylvania, USA
contact ~ registerki@kss.org

What Parents and Families Can Do to Increase the Likelihood That an Impaired Family Member Will Be Accepted by Society, and Will Be Given Opportunities to Fill Valued Social Roles
December 7, 2007 (1:00 to approx. 4:30 pm)
Syracuse, New York, USA
call Susan Thomas at 315 473 2978

Coherency of SRV and Person Centered Planning
November 6, 2007 (9 am to 3 pm)
Harrisburg, Pennsylvania, USA
contact ~ registerki@kss.org

Crafting a Coherent Moral Stance on the Sanctity of All Human Life
September 17 - 21, 2007
Nazareth, Kentucky, USA
email Joe Osburn ~ josephosburn@bellsouth.net

Social Role Valorization News and Reviews

Wolf Wolfensberger

AS IN EARLIER ISSUES of this journal, 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 Social Role Valorization (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.

More on the Early Treatment of Normalization in the Literature

IN THE JUNE 2006 issue of this journal, I documented how various writers had discoursed about the normalization principle before the appearance of SRV in 1983. Here are a few more items along this line.

*Maloney, M. P., & Ward, M. P. (1979). *Mental retardation and modern society.* New York: Oxford University Press. This is only the second pre-SRV era text on mental retardation that has a truly meaningful amount of material on the normalization principle. However, it interprets the principle as being applicable primarily to institutions, and comments that the abolishment of institutions is both unrealistic and inappropriate, because some of the more severely retarded will "require institutional care." Furthermore, it is implied that the more abnormal people are, the less is it possible to bring normalization to them. The authors also make the astonishing claim that the applicability of normalization to the non-institutionalized is "vague," except for the mainstreaming possibilities in education. All this was said despite the fact that PASS had been out in two editions since 1973. Not surprisingly, PASS was not listed in the references.

*Popovich, D. (1981). *Effective educational and behavioral programming for severely and profoundly handicapped students: A manual for teachers and aides.* Baltimore: Paul H. Brookes. Normalization is defined as retarded students **becoming** as much like their "normal" peers as possible (p. 3). Later, on p. 33, it is implied that one-to-one teaching is a "giant stride toward normalization." On p. 92, "administering contingencies with variable intervals schedules" is also said to "help program the student for learning contingencies toward normalization." On pp. 224-225 is a section headed "Overcorrection: A Step Toward Normalization." To most people, the pedagogic strategy of overcorrection would look highly abnormal.

The Treatment of Normalization in the Literature After 1983

*Boxhill, E. H. (1989). *Music therapy for living: The principle of normalization embodied in music therapy.* St. Louis, MO: MMB Music. (MMB Horizon Series). Amazingly, we had never run across this publication until 4/02. This is even more amazing considering that the author had an affiliation with New York University in New York City. However, the material has only the most tenuous ties to normalization, and does not differ from much other material on the same topic that has been published without reference to normalization.

*Beirne-Smith, M., Ittenbach, R. F., & Patton, J. R. (1998). *Mental retardation* (5th ed.). Upper Saddle River, NJ: Merrill (an imprint of Prentice Hall). Normalization and Wolfensberger are only mentioned twice briefly, while the "new philosophy in service delivery" was said to be "due to a single publication which had a great impact on professionals in the US" (p. 47), but it never mentions who authored this publication (Kugel, R. & Wolfensberger, W. (1969). *Changing patterns in residential services for the mentally retarded.* Washington, DC: US Government Printing Office), and does not carry it among the references.

On p. 246, the developmental model and the principle of normalization are linked as providing "a remarkable improvement over its predecessors." The next page (p. 247) says that "unfortunately, tenets put forth by the developmental model were based on a faulty premise." Apparently, the authors thought that the developmental model implied that retarded people would eventually reach normal attainments.

*McWhorter, L. (1999). *Bodies and pleasure: Foucault and the politics of sexual normalization.* To the French thinker Michel Foucault, "normalization" was a bad thing. In this book, a women's studies professor explains some of Foucault's thinking on this point, and enlarges on it.

*O'Connor, E. M. (2001, December). Medicating ADHD: Too much? Too soon? *Monitor on Psychology,* 50-51. This article reviews some studies (presented at the 2001 annual convention of the American Psychology Association) on the impact of mind drugs (sometimes in combination with behavior approaches) on children "diagnosed" to "have" "attention deficit hyperactivity disorder." Several such studies reported the percentage of children whose behavior had been "normalized" by the treatment regimens, who had met "normalization criteria" or "reached normalization." Obviously, the term normalization here referred to an outcome, not a process. Wolfensberger always emphasized that normalization could be either a process or an outcome, but many people -- in mental retardation at least -- have insisted that it should only refer to the process, presumably because they could not conceive of retarded people becoming normal, or as they often explicated, that they thought it illegitimate to try to "make someone normal."

The Term Social Role Valorization

*Wolfensberger once (in 1980) suggested in jest (though taken in earnest by some who obviously do not know him) that normalization should have been called "orthofactorization," so that people would have to look it up and could not say, as they erroneously did with

normalization all the time, "Oh, I know what that means," even though they had never read the literature. Soon after the term Social Role Valorization appeared, another jester suggested that Social Role Valorization be named "ortho-factorization of social roles."

*In two issues (1994 and 1996) of the fore-runner to this journal, *SRV/VRS: The International Social Role Valorization Journal: La Revue Internationale de la Valorisation des Rôles Sociaux,* there had been a debate on the wisdom of calling the successor of the normalization principle "Social Role Valorization." The main objection was that the term "valorization" was alien to the English tongue, or carried too much of a commercial meaning. However, the word "valorization" has since become quite popular at least in certain educated circles, in part because of its growing popularity in French, and in part because of its spread from SRV into other circles, as illustrated below.

*Faderman, L. (1995). Queer. In G. Goshgarian (Ed.), *Exploring language* (7th ed., pp. 341-345). New York: Harper Collins. In the introduction to this chapter, the book editor stated that "many gays and lesbians have taken back the enemy's prime insult, queer, and 'valorized it,' as Lillian Faderman explains below."

*Hamington, M. (1995). *Hail Mary: The struggle for ultimate womanhood in Catholicism.* New York: Routledge, Chapman & Hall. In this book, a Catholic feminist complained that the veneration of Mary in Catholic tradition has served "to perpetuate compulsory heterosexuality, the valorization of virginity, and the denigration of female sexuality" (p. 74). Obviously, the term "valorization" was used here in the same sense as in Social Role Valori-

zation, and on the assumption that readers of at least this type of literature would know what it meant.

*In a 1997 catalogue (by John Gach) of antiquarian psychology texts, a 1958 book was said to document the increasing "valorization of the father figure" between 1750-1850.

*In the July 1997 issue of *Books & Culture* (a journal of reviews), an author was said to be trying to "invert the common valorization of Paul's most radical claim … that there is no longer Jew or Greek, slave or free, male and female …"

*In the 5 September 1998 issue of the Canadian national newspaper, *Globe and Mail,* an art critic said that in the schools, art "is not particularly valorized" (source item submitted by Bill Forman).

***Eureka**! In the March 2007 issue of the very intellectual monthly *First Things*, its editor-in-chief, the very visible Richard John Neuhaus, wrote that "the metaphysical religion of the later 19th century and thereafter would continue to valorize the role of women" (p. 28). Now where did he get this expression from? And this should settle the debate whether "social role valorization" was a good choice of terminology.

Role Theory

*Davis, J. E. (2005). *Accounts of innocence: Sexual abuse, trauma, and the self.* Chicago: University of Chicago Press. This book is on the problematic victim role, a role that has become very prominent in recent decades, and that can probably be said to have both valued

and devalued elements.

The victim role has become so popular that ever more people -- even privileged ones -- claim it for themselves, despite its devalued elements. An example is the writer Ellen Bass who, in her "survivorship" anthology, claimed that "we were all sexually abused" even when no sexual abuse actually occurred. Perhaps it is the "survivor" part of some victim roles that has contributed to making it so appealing.

*It has been pointed out to us that the arguments about legal recognition of homosexual relationships boils down to a "roles war:" Can two men or two women be "spouses," can men be "wives" and "mothers," and can women be "husbands" and "fathers"? Similarly, a person was always able to have more than one father or mother as a step or adoptive parent, but never two or more real mothers or fathers at the same time. Now, laws are being passed (or court rulings handed down) that would allow a birth certificate to declare multiple mothers or fathers.

*While role theory has much to say about incompatible roles, SRV teaching so far has not emphasized very much how a particular role can squeeze out and drive out other roles. For instance, it was pointed out to us that the role of "heroin addict" can drive out almost all other roles, or at least positive ones, both because an addict's behavior becomes incompatible with most other roles except crime-related ones, and because in the minds of observers, the addiction dominates everything else.

Research on, or Related to, SRV

*Bartlett, F. (1932). *Remembering: A study in experimental and social psychology*. New York: Cambridge University Press. The impact of early impressions was already documented by the prominent British experimental psychologist Frederick Bartlett in this landmark book. He found that when subjects were asked to describe a picture that they had been shown very briefly, they would later hardly ever change their first interpretation of what they had seen even when they were given as many as 38 additional exposures to the picture. This led him to conclude that "a great amount of what is said to be perceived is actually inferred." His research also led him to conclude that what people infer is much more likely to be remembered later than what people actually perceived.

*Stanley Milgram's research on the topic "Obedience to Authority," completed in 1962 and repeatedly published, soon became the most widely influential experiment ever conducted in social psychology, but Harvard University nonetheless denied him tenure a few years later, and he ended his days not too happily at the second-rung City University of New York, dying early of a heart attack at age 51.

What is widely considered to be the second most famous study in the history of social psychology was the so-called Stanford prison experiment by Philip Zimbardo (Zimbardo, P. G. (1971). *Stanford prison experiment*. Stanford, CA: Zimbardo Inc.). Zimbardo is still active.

Both studies -- often cited in SRV teaching on role expectancies -- could no longer be conducted today in most First World countries because of so-called ethical concerns.

*Harris, C. R. (2006). Embarrassment: A form of social pain. *American Scientist, 94,* 524-533. Current research is shedding light on

how the universal human phenomenon of embarrassment ties in with SRV theory. While there are at least three classes of embarrassment, one is where the social image one would like to project, or once had, has been undermined, and one feels at risk of negative valuation. Another class is where a social situation arises in which one is disoriented, and does not quite (or right away) know what the social expectations are, and what the proper thing to do is.

Apparently, only those humans can be embarrassed who have developed a clear sense of self. This is why young children have no sense of embarrassment, and retarded people, and people who are demented or gone insane, may have little or none.

*Wilson, C. (Undated; probably 1996). *The legacy of normalization and Social Role Valorisation: Application of the principles of normalization and Social Role Valorisation in supported community residential units for people with intellectual disabilities, Victoria, Australia.* Unpublished doctoral dissertation, Monash University, Melbourne, Victoria, Australia.

The state government of Victoria, Australia, has claimed to base its community services on normalization and SRV. This doctoral dissertation examined the understanding held by community residence staff in Victoria of normalization and SRV, and how these two concepts affected what they did with the residents in these group homes.

Three group homes were studied by a participant observation technique, accompanied by written surveys and in-depth interviews. Only one staff member in each residence -- the supervisor -- had had normalization or SRV training. The author found that merely asking staff what they understood by these terms was not very revealing, because staff answered al-

most always based on what the term sounded like -- e.g., making people more normal, or giving people (valued) social roles -- even when they had no good grasp of the theories the terms stood for. Nonetheless, the author found that some concepts associated with normalization and SRV had in fact penetrated into staff's mentality and actions, e.g., concerns with people's appearance, their acceptance by others in society, integration, and the issue of rights. But she also found that the more impaired a resident was, the more difficulty staff had relating to that person, and the less they saw normalization/SRV as being applicable. And she discovered -- not surprisingly -- that staff engaged in many interactions with residents of which they were not aware, e.g., unconsciously reinforcing maladaptive and even aggressive behavior when staff said they were trying to get rid of it.

The second chapter -- "Critical Review of Normalization and SRV" -- is actually a pretty fair summary of the criticisms that have been leveled against normalization and SRV, and of the weaknesses in these charges. This is worth noting because so many of at least the written critiques of normalization/SRV have not been well-founded, often criticizing a misunderstanding or misinterpretation of normalization/SRV rather than what normalization/SRV actually are or say. Also, many critics have confused whatever Wolfensberger writes on any topic (e.g., on deathmaking, societal developments, issues of religion and the handicapped) with what he teaches on SRV. Similarly, many people have confused the ways standard introductory SRV training events are conducted as being the content of SRV theory, even though these also are not the same. But Wilson appears to be clear that while Wolfensberger's other writings may provide a context or framework for what he says about SRV, they are not

the same.

Interestingly, Wilson focuses more on recent criticisms, and these mostly of Wolfensberger's formulations of normalization and of SRV, rather than on criticisms of other formulations of normalization, or those prior to the mid-1980s that were systematically inventoried in one of Wolfensberger's chapters in the 1980 book by Flynn and Nitsch (*Normalization, Community Services, and Social Integration*). However, despite the general fairness and accuracy of this chapter, the author commits two major errors.

1. She accepts the much later (we would even say historically revisionist) interpretations of Nirje as to what he had said early on (in the late 1960s and early 1970s) that normalization was (e.g., p. 14). This has become a common mistake by people who apparently did not actually compare Nirje's original writings with his (or Perrin's) later revisionist interpretations. (This issue was brought out in the proceedings of the 1994 25th anniversary conference on normalization and SRV that took place in Ottawa.)

2. She equates what Wolfensberger would call deviancy-making or social devaluation with "labeling," going so far as to imply (e.g., p. 23) that Wolfensberger bases his whole theory of SRV on "labeling." This erroneous interpretation comes up repeatedly throughout the dissertation. A passage on p. 193 gives a clue as to at least one possible source of this error; namely, when Wolfensberger speaks about someone being perceived or identified in a certain way (e.g., as "elderly"), Wilson seems to equate that with someone being "labeled" (in the case of the above example, "labeled elderly").

As well, a number of times she states in a rather unnuanced fashion that SRV or Wolfensberger says something when SRV -- at least as

Wolfensberger teaches it -- says it in a much more qualified, nuanced manner. For instance, on p. 12, Wilson states, "Wolfensberger and Thomas (1983) assume that people who have a visible disability will not be seriously stigmatized if they present other valuing images and/or occupy roles that are not typically associated with each person's impairment." Both in their writing and teaching, Wolfensberger and Thomas would actually say that people will be less devalued, or less likely to be devalued, if they present valued images and fill valued roles. Similarly on p. 34, Wilson states that "Choice ... is assumed to be a basic corollary of the SRV principle and as such should be respected as much as possible." It is true that in Wolfensberger's earlier writings on normalization (1972), and in PASS (Wolfensberger & Glenn, 1973, 1975), this issue was much less nuanced than in his subsequent teachings and writings. Now, Wolfensberger does not talk about "choice" at all because it has become such a loaded word, with much excess meaning, and has even acquired religious overtones. Instead, in Wolfensberger's SRV teaching, the language is one of autonomy and rights, and these are carefully parsed into those that are strictly SRV issues, and all others. SRV issues of autonomy and rights are whether the possession and exercise of autonomy, and/or of a right, affect a party's competency or image, and relate to the party's role(s). But issues of whether anybody should have rights, whence those rights derive, how ruthlessly people should be self-determining, how many options for doing something they should have (700 flavors of ice cream?), and the moral legitimacy of any curbs on normative autonomy and rights, are all issues in the domain of values, world-views, and hence *de facto* religion, and therefore are outside SRV.

On p. 35, Wilson says that "deciding what

is and is not highly valued in society is essentially a subjective judgment." We have to disagree most strongly on this, at least in the sense that one can easily find wide agreement among members of a society as to what is valued, admired, and aspired to in their society, even if each individual member may not agree with those specific prevailing valuations. In other words, personal perspectives may differ on whether a cultural value ought to be endorsed or not, but even the most primitive survey methods can ascertain what is held in high value on a population-wide basis, and innumerable studies have dealt with this. The issue of "choice," mentioned earlier, is a good example: it is very easy to determine that in contemporary Western societies, having a wide range of "choices" about almost everything is in fact highly valued and aspired to, and has assumed the status of a cultural religion. In fact, it is a bit amusing that the author seems to consistently uphold having "choices" as something positive, but without showing an awareness that this is a very widely shared *value* in contemporary societies, and how easy it is to show that this is so.

The SRV Theme of Personal Competency Enhancement & the Developmental Model

*Billingsley, F. F., & Albertson, L. R. (1999). Finding a future for functional skills. *JASH (Journal of the Association for Persons With Severe Handicaps), 24,* 298-302. Marc Gold was a popular writer, and even more popular teacher, in the 1970s and 1980s. His multi-day workshops were among the most popular of his day, attended by vastly larger crowds than came to normalization (or later SRV) workshops. One of his teachings was that people were apt to overlook or even ac-

cept the deviancies of a person who displayed wanted competencies. He called this the "deviancy/competency hypothesis." This was, of course, merely a subset of the conservatism corollary of normalization, which may even have inspired this teaching. He incarnated his hypothesis by often going around in public in an undershirt, and people put up with it.

The point is that the mindless "mainstreaming," and later equally mindless "inclusion" ideology, has just about exhausted itself, as people are awakening to the reality long taught by normalization and SRV that merely "mainstreaming" or "including" devalued people with valued ones does not guarantee either their acceptance or their participation, plus that socially-engineered "friendships" tend not to last if there are no shared interests, and shared activities based on these interests. Furthermore, as SRV has posited, and as Lemay has greatly elaborated (Lemay, R. (2006). Social Role Valorization insights into the social integration conundrum. *Mental Retardation, 1,* 1-12), the integration and participation must be based on roles that are identifiable and intelligible to actors and observers, and usually valued by them. Especially as a child gets older, it is important that these roles are competency-based, or at least based on *some* competency.

In the article reviewed here, we witness an "aha" rediscovery of some of these realities. We are told that competencies really do matter "in residential independence, overall community adaptation, vocational stability, and perceived quality of life," as well as in "the development of a friendship" (p. 298). If only the authors had cited the normalization or SRV literature, but as we keep pointing out, that rarely happens.

*McDermott, S., Martin, M., Butkus, S. (1999). What individual, provider, and commu-

nity characteristics predict employment of in-dividuals with mental retardation? *American Journal on Mental Retardation, 104,* 346-355. This article suggests that health enhancement programs for retarded persons might increase the likelihood that they will obtain and retain employment. In SRV theory, health is consid-ered a competency, and employment as holding one or more valued roles. Hence, once more we have here suggestive evidence that health pro-motion facilitates access to valued roles. Not mentioned in the article was that poor health leads to patienthood and sick roles, which are devalued. So if nothing else, health promotion might enable escape from devalued roles, or prevent entries into such.

To those of us in the SRV culture, this is all so obvious. To others, these seem to be eye-opening new discoveries requiring much learned research.

*Vaillant, G. R., & Vaillant, C. O. (1981). Natural history of male psychological health, X: Work as a predictor of positive mental health. *The American Journal of Psychiatry, 138*(11), 1433-1440. Engagement in work dur-ing childhood has been found to be one of the best predictors of mental stability in adulthood (source item submitted by Raymond Lemay).

*Giangreco, M. F., Smith, C. S., & Pinck-ney, E. (2006). Addressing the paraprofes-sional dilemma in an inclusive school: A pro-gram description. *Research & Practice for Per-sons With Severe Disabilities, 31,* 215-229. (The Journal of TASH). School practices with impaired pupils have huge impacts on their competencies. This study reports on the growth of the use of so-called "paraprofes-sionals" in schools that include impaired pu-pils. At one time, the term paraprofessional was often applied euphemistically to workers on school bus duty, playground supervision, materials preparation, etc. Then it was increas-ingly applied to untrained (or minimally-trained) teachers' helpers in classrooms. Also, the number of paraprofessionals exploded, be-ing possibly as high as a million in the US.

An early practice (though still common) was to assign a paraprofessional to work with one specific impaired child in a regular classroom. Some people called this "having a paraprofes-sional attached to your elbow." However, this practice sometimes became an outright obstacle to a child interacting with (non-impaired) peers. Also, it often meant that the paraprofes-sional became the child's almost exclusive teacher. This was widely deemed illogical, in that the least-trained person was put in charge of the most challenging pupils. Also, systemic problems in the school often got obscured and were left unaddressed by relying on the para-professional to deal with problematic children. Now, in some schools, paraprofessionals may work with several students, and not necessarily only impaired ones.

This entire arrangement is a good illustration of unintended consequences, and how throwing more money unthinkingly at a problem may create new -- and possibly bigger -- problems.

*Prisons and detentive facilities are, by defi-nition, limited in the kinds and amounts of image-enhancement they can achieve for their settings and their inmates, even if they wanted to. However, they can do a great deal about competency-enhancement if they so decide. In one instance, a man who was imprisoned for dealing cocaine worked in prison kitchens for almost 9 years, first cleaning pots and pans but eventually learning to prepare meals, and trad-ing food he had prepared for services such as haircuts. After his release, he became a high-end chef, and wrote a memoir, *From Cocaine to*

Foie Gras. He says his time in prison "rescued" him (*Newsweek*, 6 March 2006).

*Popovich, D. (1981). *Effective educational and behavioral programming for severely and profoundly handicapped students: A manual for teachers and aides.* Baltimore: Paul H. Brookes. This author (also cited in an earlier section above) relates an incident where a teacher tried to teach a newly-enrolled eight-year-old moderately retarded girl, Jenny, "entering behaviors." She meticulously recorded that the girl had completed the objectives of 1) stack blocks, 2) sort two shapes, and 3) point to colors red and brown. While she was doing this, Jenny, playing on a mat near-by, exclaimed "brown, brown," and pointed to a pile of feces that she had deposited on her mat. This made the teacher "acutely aware of the absurdity of educational evaluations that neglect to consider normalization" (meaning self-help) "when measuring students' 'entering behavior'." We would add that Jenny was obviously not only able to point to the color brown, but also name the color. However, we disagree with the mentality displayed by Popovich -- which is a very old one in education -- that children cannot learn all sorts of things before they are toilet trained, or if they are never toilet trained, as if there were nerve pathways from the anus that control the entire brain. This mentality used to keep innumerable children out of school, and served a "life-wasting" function.

The SRV Theme of (Un)Consciousness

*Kunzendorf, R. G., & Wallace, B. (Eds.). (2000). *Individual differences in conscious experience.* Philadelphia: John Benjamins. Consciousness is one of the greatest mysteries in psychology, with many theories trying to account for it, which this book reviews. Some thinkers say consciousness is like a collection of elements such as ideas and images, others liken it to a stream, yet others to an ocean. This is where psychology and philosophy sometimes kiss, and sometimes spit at each other as psychology goes awhoring after physiology.

Contrary to the expectations of some early psychologists, there are huge differences in the conscious experiences of people. However, it is now pretty well accepted that experiences can register in the brain and mind while by-passing conscious awareness, and people have different thresholds for processing experiences consciously or unconsciously.

*Wexler, B. E. (2006). *Brain and culture: Neurobiology, ideology, and social change.* Cambridge, MA: MIT Press. This is yet another work that documents, and tries to explain, why humans repress mind content. Namely, when people are faced with information that does not agree with their "internal structures," they deny, discredit, reinterpret or "forget" that information. Also, a person's internal structures can be so severely challenged by changes in the environment that the person first gets extremely stressed, then maybe even crazified, and may erupt in violence, as for instance by encountering people who do not fit one's ideas of humanness.

As regards human perceptions of people who are different, Wexler argues that until relatively recently in history, it did not occur very often.

*Bayley, P. J., Frascino, J. C., & Squire, L. R. (2005). Robust habit learning in the absence of awareness and independent of the medial temporal lobe. *Nature, 436,* 550-553. We con-

tinue to be mystified by scholars who deny the existence of unconscious mind content, and the mechanism of repression of unpleasant perceptions or experiences. Here is what the above authors have to say about this: "Humans have a robust capacity for gradual trial-and-error learning that operates outside awareness for what is learned" (source item submitted by Marc Tumeinski).

Miscellaneous Items Related to SRV

*We continue our commentary on the Special Olympics for handicapped (mostly retarded) participants, which has both good and bad elements. In 2006, the winter Special Olympics for New York State opened on the same weekend as the "real" Olympics -- a positive juxtaposition. In fact, if one quickly glanced at newspaper photos of the Special Olympians, one might have though they were "real" Olympians, unless one looked very closely.

One mother testified that she did not think her daughter would be able to ice skate because of balance problems; she finally agreed to skating lessons when the daughter was 17, and the daughter learned to skate well enough to compete, illustrating yet once again the power of expectancies (and the disastrous consequences of low expectancies), and people rising to the challenges and opportunities given to them.

Considering the cut-throat nature of some of the "real" Olympics competition, the Special Olympians could stand as models in many respects. For instance, one figure skater fell during her routine, and just got up, brushed herself off, smiled and waved to the spectators. Another skater waved to the judges during her performance, and later tried to encourage one to take up skating (Syracuse *Post-Standard*, 12 Feb. 2006, B1).

*In 2004, a new Catholic order, devoted entirely to ministry to the deaf via sign language, was founded. It is called Dominican Missionaries for the Deaf Apostolate. Its founder is a deaf Dominican priest, who was joined by six other people. From an SRV perspective, one can cite both positive and negative features of this development. Among the positive ones is that there are people who have access to -- and hold -- valued roles who choose to associate themselves with deaf people. Negative is that some of these people are deaf themselves, creating a deviancy image juxtaposition, and possibly contributing to a segregated subculture.

*Jane Barken, who is a college teacher, told us that she gets some doozies when her students write about human services and SRV. These have included "the slippery slop," "kind, loving, neutering parents," "attention defecate disorder," and "social role vaporization," which latter she thinks may have been spit out by a spell check program.

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► The SRV JOURNAL ►

*A journal for those interested in applying Social Role Valorization
with the goal of making positive change
for societally devalued people*

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