

The SRV JOURNAL

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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 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.

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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.

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,

IN MY LAST LETTER, I welcomed our readers to the first issue of this new journal. In this letter, I am pleased to say that we have completed our first year of publication and are looking ahead to the next. Things move quickly with just two issues per year!

This particular issue illustrates the range of topics which SRV is relevant to, and I hope you find the articles informative and thought-provoking. Informed discussions of SRV and even constructive debates about it help to promote its dissemination and application, so I welcome your submissions of manuscripts for possible publication. Your particular interest in SRV will be instructive for our readers. As well, we are open to trying new formats and ideas. If you have any suggestions, please feel free to send them to me at the address below.

I also encourage you to write *Letters to the Editor* concerning the journal as well as specific articles. You will find a good example of the kind of discussion that I hope this journal will generate on pages 4-6.

I would like to thank those who have encouraged and supported our efforts in this first year of publication, in particular: the members of the North American SRV Development, Training & Safeguarding Council; our subscribers; our contributing writers; Ann Flynn of Shriver Clinical Services, Betsy Grim of Community Options and Betsy Neuville of Keystone for their generous financial support; an anonymous donor who gave three gift subscriptions; our editors (listed on the reverse of the table of contents page); and our article referees for the first two issues, Jane Barken, Guy Caruso, Carl Cignoni, Peter Dill, Beth French, Mayah Sevink and Jack Yates.

I AM SAD to report that Bengt Nirje, one of the most prominent proponents of Normaliza-

tion, passed away on April 8, 2006. Normalization provided a foundation for Social Role Valorization. Nirje's guiding vision for mentally retarded people (and later impaired people in general) centered around: a normal rhythm of the day, week and year; normal developmental experiences; a normal right to choices; and normal sexual, economic and environmental patterns. The power of his ideas was recognized around the world. Examples of Nirje's writing can be found in *Normalization, Social Integration and Community Services*, edited by Robert Flynn and Kathleen Nitsch (Baltimore, MD: University Park Press, 1980) and *Changing Patterns in Residential Services for the Mentally Retarded*, edited by Robert Kugel (Washington, D.C.: President's Committee on Mental Retardation, 1976).

I HOPE TO SEE many of you at the 4th International SRV Conference which will be held in Ottawa in May of 2007. The theme of the conference is "*Crafting Valued Social Roles for Socially Devalued People.*" A number of excellent speakers, including of course Dr. Wolf Wolfensberger, will be attending. This will be a great opportunity to learn from, and to meet, people from around the world who are working with the ideas of SRV. For more information, visit the conference website <http://www.vrs-srv2007.ca/intro.htm> and see the flyer on page 47 of this journal.

Regards,

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LETTERS TO THE EDITOR

THE ARTICLE “Re-Thinking Respite” was uniquely insightful as well as useful because it connected an astute analysis of the respite service model with related aspects of SRV theory. This helped when reflecting on the way SRV may be used to both inform and guide service development.

The authors zeroed in on many of the common problems in the understanding and management of respite services. We Hoosiers can attest to the easy corruption to which the respite idea is subjected when not informed by a solid, positive ideology. Your authors could have been standing tall in the cornfields of the US heartland and have seen what they see in Australia: if the social service system is incoherent, the provision of respite services will likely follow suit.

Respectfully,
Mike Morton
Executive Director
Community Ventures in Living
Lafayette, Indiana (US)

• • •

CONGRATULATIONS on the first edition of *The SRV Journal!* I read it from cover to cover upon receiving it and was especially pleased to find the articles were written in every day, easy to understand, language. I believe this is an important way to make the ideas of Social Role Valorization accessible and understandable to the ordinary person who may be very interested in the topic, but

not very scholarly.

I was also happy to see other bits of SRV-related information interspersed between the articles, such as the calendar of SRV and related trainings, and Dr. Wolfensberger’s “Social Role Valorization News and Reviews.” Of course, I was thrilled to see Ed Preneta’s review of the West Virginia Developmental Disabilities Council’s book *On the Outside: Extraordinary People in Search of Ordinary Lives*. The *On the Outside* project has always been one of my favorites.

I must say that “Re-Thinking Respite” by John Armstrong and Lynda Shevellar was a difficult read for me personally. *The SRV Journal* arrived just several weeks after the death of our youngest daughter, Maria. Having never reflected upon respite care from an SRV perspective before, I was angered upon first reading. Our family tried very hard to provide a good life for our dearly beloved daughter, and the suggestion that we were causing devaluation by using respite care was more than I was willing to consider. I will always be consoled by the thought that Maria surely knew she was loved very much.

I have re-read the article a couple of times since that first read, and have tried to think about it from a point of view other than my first personal and emotional one. I must agree with the authors that respite care in Australia sounds quite similar to respite care in the US. Although I am not personally familiar with respite being provided in nursing homes and other such facilities, I have no doubt that also occurs here. In our case, respite care was gen-

erally provided in our own home or in the home of a woman who became a very good friend and with whom Maria also enjoyed spending time.

Reading the alternatives initiated by one respite agency a second time helped me to understand one of the main points of the article I think. Many of these simple alternatives may, in fact, be prohibited by the agencies and/or funding sources whose intent initially was to assist. For instance, in our state, a worker could not accompany a family on vacation as an alternative to leaving the family member behind, particularly if the vacation involved crossing state lines.

The examples for utilizing informal and generic supports are not new to me, as funding agencies here are always encouraging families to pursue these. This always makes me laugh! Unfortunately, I live in America where many of us don't know our neighbors well, if at all, and who also work. We don't live near our extended families, who likely couldn't or wouldn't be of assistance anyway, and who also work. We have to pay people to assist with our "valued" children while we work or need time away for other reasons. Those same people very well may not be willing to provide assistance to our family members who have disabilities, particularly if the disability substantially limits the individual's capacity to function independently, and even more so if major health issues are involved. Actually, many of the examples cited in the article are things that staff can be paid to do, such as being present at busy times in the household, coming to the home to provide lessons, or accompanying the family at meal time to assist the person with eating.

All in all, I now appreciate the writers' thoughts on this issue and I understand there are many possible ramifications associated

with asking for respite services, including the risk of further devaluation of our family members. I also know, from personal experience, that our human bodies and minds can only function for so long without rest and that some amount of sleep is a necessity. With this in mind, I can agree with the closing statement. Let's all start talking about what it might take to "get a life!"

I'm eagerly awaiting the next edition!

Best wishes,
Linda S. Higgs
St. Albans, West Virginia (US)

A reply from John Armstrong and Lynda Shevellar:

Thank you to *The SRV Journal* for permitting us response to such an important letter. We were struck by the thoughtfulness of the letter and Mrs. Higgs' willingness to read the article several times -- despite such an initially strong and negative response.

We are actually in strong agreement with many of your points. The intention of the article is to question the legitimacy of the dominant respite model, rather than the legitimacy of families to have a break. It is not our intention to suggest that "respite" is by definition devaluing, or families seeking a "break" are devaluing their family member -- quite the opposite. Anything can be devaluing if it is used to reduce people. The dominant respite model is a centre-based 'minding' model. Our observation is that this respite *model* has reasonable potential to devalue a person's identity and life over the long run, and even the standing of other family members, when it only focuses upon the immediate benefit to one party.

The article is looking at long-term effects more than immediate necessity, and so begs the question as to whether resources might instead be utilised to assist people to grow and advance rather than receive alternative 'minding.' We are keen to explore whether a model might be constructed that better meets the long-term needs of all parties involved and builds capacity, rather than merely responds to and even adds to crisis. Both the article and Mrs. Higgs' response note ways this is happening in some pockets of service, and we are keen to acknowledge and encourage these. We are not the first people to raise this issue, and are interested in seeing whether an SRV lens

would lend additional insights and ways forward.

As we state in our article, we *all* need time together and apart. Our hope is that we might begin to develop better service responses that make both of these experiences nurturing and rewarding and that contribute to richer lives to all involved.

We were very saddened to learn of your daughter's passing. The arrangements you had built around her, having someone close and consistent who she loved and who loved her, sounded to us to be a superb arrangement carrying many ideal features. Thank you for sharing your thoughts and concerns.

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.

Chronic Criminal Disease: An SRV-Based Critique of Drug Addiction Services

Susanne Hartfiel

EDITOR'S NOTE: *The following article touches on a number of pressing issues in a wide variety of contemporary services, including the prevalence of the use of psychotropic drugs and the medical model of service. Although it is written primarily about drug addiction services in two German cities, the lessons drawn are relevant to other services in other countries. While this article is written from the perspective of Social Role Valorization (SRV), it also raises non-SRV issues (i.e., issues outside and above SRV) for consideration.*

Introduction

CONTEMPORARY SOCIETIES define some mind drugs as harmful and as a threat to a well-functioning society, while others are seen as beneficial and even therapeutic. Some drugs are illegal and a lot of energy and resources are spent trying to prevent people from producing, selling and consuming them, while incarcerating those who do. At the same time, ever more people, even young children, are put on supposedly 'beneficial' legal mind drugs with just as much harm being inflicted on individual people, families and society by the legal drugs as by the illegal ones. (For a good overview of the harmful effects of legal mind drugs, see Wolfensberger, 2004).

Perceiving the incoherencies in this approach, some leading academics and human service professionals came up with the equally

faulty assumption that the *only* or the *major* problem with drug use is that it is illegal. Therefore, if one legalized illegal drugs (e.g., cannabis, heroin), legalized their use (e.g., by not prosecuting consumers, and providing them with a place, equipment and an illegal drug to legally consume), or replaced illegal drugs by legal ones (e.g., heroin by codeine, methadone, or polamidone), they argued, then the major problems would be solved.

Many political battles over drugs have been fought in Europe, before the first methadone and later heroin programs (i.e., programs that provide people with methadone or legal heroin as a substitute for illegally bought and consumed heroin) were implemented. They were implemented largely because many groups in society had an interest in such programs. The public and politicians did not want to be confronted with an ever increasing number of wretched-looking homeless drug addicts on the streets of their major cities. The police were tired of chasing lowly drug addicts while not having the manpower and technical means to catch the big dealers. Prisons became overcrowded with drug-addicted people, mostly from lower classes and many different countries, which made the situation in them ever more complex and explosive. Public awareness of the threat of spreading HIV and Hepatitis C increased, with drug addicts being one of the high risk groups. Some doctors and pharmacists saw a new source of income in being able to 'treat' drug addicts with legal drugs. Human

service professionals hoped to be able to 'reach' a group of people who previously had been suspicious of any kind of professional service. Some of the leading academic ideologues hoped such programs would be a step towards a 'free' hedonistic drug-consuming society, evoking sweet memories of the long-past student revolt and hippie era.

Of course, much of this debate was phrased in terms of the benefits that drug addicts would experience: their deaths would be prevented; their health would improve; they would be able to quit using drugs, or consume them in a much more controlled fashion; and they would be re-integrated into society. When the first methadone programs started, they were, like so many other human service schemes, greeted by many as *the* solution to all problems.

ONE OF THE TEN THEMES covered in an introductory Social Role Valorization (SRV) workshop is the concept of service model coherency, with its requirements of relevance and potency (see Wolfensberger, 1998, pp. 111-118). In SRV workshops, a list of common human service models gets introduced, the medical model being probably the one familiar to most people. The four components of every human service model (i.e., fundamental assumptions, the people being served, the program content, and program processes) are explained, as well as how so many human services are incoherent because one or more of these components are in disharmony. Often such disharmony is created because the conscious or unconscious fundamental assumptions which underlie the model are wrong.

In SRV or model coherency language, methadone and heroin programs can be described *first* as an effort to replace the menace-detentive model of dealing with drug-addicted people by the medical model. In other words,

they are efforts to replace the very devalued roles of criminal and menace by the less but still devalued roles of the sick person or patient. In practice, such programs are often an incoherent mixture of these two mutually exclusive models,¹ casting drug-addicted people into a role that one could call the 'criminally sick role,' while their behavior is treated as if it were a 'criminal disease.' *Secondly*, such programs are good illustrations of how the medical model gets used to cast people not only into the patient role but also into the long-term human service client role, creating or maintaining human service jobs in a post-primary production economy (see Wolfensberger, 1997). *Lastly*, such programs are good examples of how, like so often in human services, people tend to address complex problems by very technical means, based on faulty assumptions.

I will illustrate these realities by describing the methadone programs of two major German cities: Bremen and Bremerhaven. My experience with this topic comes from having evaluated the service systems for people addicted to illegal drugs in these two cities (see Quensel & Hartfiel, 1998; Hartfiel, 2000; Schulze & Hartfiel, 2000), and from friendships with people who have been addicted to illegal drugs for many years. The service system of the bigger city (Bremen) had the reputation of being a model system, while the smaller city (Bremerhaven) was considered backwards in terms of serving people with addictions. The studies were funded by the Departments of Health in both cities, and aimed to find out how service recipients and professionals perceived the services provided, and how service quality could be improved. In the course of the two studies, I visited numerous human service programs, clinics and hospitals, as well as the local prison. I interviewed 95 service recipients, 57 professionals (doctors, nurses, counselors, so-

cial workers, prison staff, policemen, administrators) and people from five self-help organizations in long (one to three hour) interviews. Many of the interviews with service recipients were powerful illustrations of the wounding experiences of devalued people (see Wolfensberger, 1998, pp. 12-24), perpetrated by a service system that claimed to help them.

Some of what follows is specific to Germany, but I propose that some of the lessons are relevant not only for people in other countries, but also for people in other fields, as the medical model is one of the most prevalent models in formal human services today.

The People Served

WHEN THINKING about methadone treatment, it is important to consider that the group of people receiving this drug is quite heterogeneous. In Bremen and Bremerhaven it included people from every social and educational background; people of very different ages (16-55); people with a very devalued identity (i.e., having lived on the streets or in very marginalized living situations for decades, having been imprisoned many times, and with practically no freely-given relationships with valued people, and often quite sick physically); as well as people whose lives were still rather typical in terms of holding jobs, being part of a family, having valued people as friends, and so on.

People also had various motivations for enrolling in the methadone program: (a) some hoped it would be a means to become sober and to regain their valued identity; (b) some who had been able to preserve their valued identity to some degree, hoped it would prevent them from entering the downward spiral of heroin addiction, debts, imprisonment, loss of job, friends, health, etc.; (c) some wanted to

use illegal drugs, but reduce or avoid some of the negative circumstances (debts, illegal acts, and/or prostitution); (d) some saw methadone as a last resort to control life-threatening diseases; and (e) some were forced into the methadone program by being imprisoned or hospitalized (where people addicted to heroin automatically receive methadone), or by authorities threatening to place their children into foster care or to prohibit contact with them. Note that many of the reasons mentioned correspond with the hopes proclaimed by professionals of what methadone programs would accomplish (as listed at the beginning of this article): abstinence from drugs, more controlled drug use, improvements in health, and (re)integration into society.

An important concept of SRV is that of service relevance. In order for a service to be relevant, it has to address (at least some of) service recipients' real and significant needs. In response to the questions of what kind of life they would wish to live, and what they would need in order to be able to lead such a 'better life,' most methadone recipients described the 'better life' they envisioned as a combination of some, or most, of the universal "good things of life" described by Wolfensberger, Thomas & Caruso (1996). In order to achieve such a 'better life,' three prerequisites were mentioned most often and considered most important by methadone recipients. *First*, something that they called a 'perspective for their lives,' i.e., knowing why they lived, what was worth living for, how they should live, and so on. In other words, people asked for answers to some of the highest-order questions of life which only a transcendent belief system can give. *Second*, a sense of belonging, that would come through relationships with valued people who are not members of the drug subculture, i.e., especially friends and family. *Lastly*, a sense of

purpose, achievement and financial independence that would come through meaningful work. Depending on individual life circumstances, addressing certain other needs (e.g., for restored health; a [better] place to live; freedom from prosecution by authorities through help with legal issues) was considered pressing as well.

In contrast to service recipients, many professionals, when asked about needs, tended to think much more in terms of what the service system had available. For instance, they would say that people 'needed' detoxification, therapy or counseling.

Assumptions Underlying Methadone Treatment

SRV TEACHES that every human service is based on conscious or unconscious assumptions which shape everything that happens in that service. If the fundamental assumptions are wrong, then one can expect a service that is either not very relevant in terms of addressing service recipients' most fundamental needs, or one that uses inappropriate (i.e., not very potent) means to address their needs, or both. One might even have a service that is outright harmful to recipients.

The following assumptions (and possibly others) underlie methadone treatment in Germany -- and probably in other countries as well. Some of them are not clearly stated in the professional literature, or by professionals in the field, but they are widely held nevertheless. As you will see, some assumptions are conflicting.

- Drug addiction is a disease. Behavioral expressions of that disease are things like: a lack of self-control, lying, cheating, stealing, unreliability (e.g., not being able to be on

time or keep appointments), selfishness, aggressiveness, criminal behavior, prostitution, and inability to work, keep an apartment or maintain typical relationships.

- As drug addiction is a disease, drug addicts are not responsible for their behavior.
- Drug addicts need some kind of therapy to be cured of their disease.
- If one replaces an illegal drug by a legal drug, then the problems that come with illegality (e.g., high drug prices, resulting in debts and/or criminal acts of consumers, as well as loss of jobs, apartments and relationships; drugs mixed with other potentially health-impairing substances; lack of hygiene when administering drugs and resulting illnesses) will cease to exist.
- Drug addicts lack self-control; therefore, external controls need to be imposed on them.
- Professionals are best equipped to 'treat' drug addicts because they have learned to keep their 'professional distance' and distrust the promises made by addicts. Doctors (preferably psychiatrists) are best suited to administer a legal drug and to control its appropriate use. Therapeutically trained non-medical staff (e.g., social workers) are best equipped to provide services in other areas.
- In order to motivate drug addicts to do something about their drug problem, one needs to first accept them as they are, provide them with some sort of space where they can establish contact with the professional service system, offer some basic services (e.g., needle-exchange; free food, clothes and/or condoms; a shower and/or washing-machine), and have staff on the scene who can inform about other available services if asked.
- Drug addiction is a chronic condition, and most drug addicts do not want to change. Therefore, staff should only offer services if

drug addicts explicitly ask for them and know which services they want.

The Services Provided

MOST of the services provided in Bremen and Bremerhaven fell into the following categories:

1. *Clinics, or other kinds of programs, giving out methadone (or polamidone, a similar drug used to replace heroin).* The number of methadone patients treated in such clinics varied from just a few (two or three) to about 100. Most clinics treated other (not-drug addicted) patients as well. The doctors running them were mainly psychiatrists, general practitioners and internists. Typically, methadone patients had to come every day and consume their drug in the presence of a nurse. Most doctors had fixed times for the drugs to be handed out, usually when patients who were not drug-addicted were not present at the clinic. Many performed regular drug screenings and required methadone patients to show up for regular conversations or to sign up for counseling at another program.

On weekends and holidays, doctors and city authorities set up central locations for methadone to be given out to all methadone patients of the respective city. In Bremerhaven this happened in a day program for drug addicts, and in Bremen by using a bus that stopped at several city locations. Methadone recipients gathered around the bus stops to receive their drugs, which were handed out by a doctor and accompanying staff riding in the bus.

Prisoners received methadone through the prison doctor.

2. *Programs that provided counseling or 'therapy,' meaning that staff talked with recipients about their personal situation and how to change it.* Some such programs also informed about or arranged for other services, such as

detoxification in a hospital and long-term abstinence therapies (meaning institutional-type or group home-like facilities that are typically located out in the country, in which people who want to live without drugs are engaged for 6-18 months in various kinds of therapy and a bit of work).

3. *Programs that provided some sort of space for methadone patients to 'hang out' and to receive some basic services.* These fell into two categories: (a) day programs, and (b) residential programs.

a. Day programs were typically opened a few hours a day, several days a week, and provided services such as: coffee and/or meals; the opportunity to shower or to wash clothes; sometimes free condoms; needle-exchange, and basic medical care (e.g., disinfecting and bandaging wounds). Some day programs provided work that courts would accept in lieu of paying fines,² and some individual staff visited methadone recipients when they were hospitalized or imprisoned.

b. The residential programs were group homes for four to eight people, all receiving methadone.

Both day and residential programs had in common that staff tolerated service recipients' use of other drugs besides methadone (e.g., alcohol, cannabis, cocaine, and/or legal mind drugs, such as barbiturates or antidepressants), as long as it did not interfere with the program's operation. If it did interfere (e.g., by somebody being aggressive), people typically were kicked out of the program. Sometimes, such people were given the option to detoxify (from drugs other than methadone) and come back.

The three types of programs just described made up about 95% of the services provided to people receiving methadone in Bremen. The rest of the methadone-related services in that

city consisted of a small program which tried to foster relationships between prisoners and a local soccer fan club by engaging both groups in shared soccer-related activities (described further below); and of an agency which helped five or six people find apartments and provided help with problems as they arose. Bremen also had two short-term shelters for people addicted to illegal drugs which were available to people receiving methadone. Bremerhaven only had programs of the types 1, 2 and 3a.

Both cities had of course a number of programs either aimed at the general public (e.g., unemployment offices that among other things are commissioned to help people find jobs, debt counseling programs, hospitals), or at specific groups (e.g., prisoners or ex-prisoners, people with HIV) which people receiving methadone theoretically were able to use as well. Practically, this was sometimes impossible, either because potential service recipients did not fit the criteria (e.g., had not been imprisoned recently), or because programs aimed at the general public refused to serve them, once the programs learned that they received methadone.

Consequences

IN THE GERMAN professional literature, methadone programs are generally celebrated as great success stories and as accomplishing almost everything they claim to accomplish. The studies cited to support such claims usually have three fundamental flaws. *First*, they are typically quantitative empirical studies with nontransparent methodological processes, raising questions of reliability. *Second*, they miss a number of important issues by not examining certain questions. *Third*, they are almost always funded by parties who have strong po-

litical interests. Practical research studies in which powerful parties have an interest rarely produce honest results because funders tend to put enormous pressure on researchers to get the results that match their political goals.

If one talks to service recipients and professionals in the field, observes what is going on in human service programs, and uses common sense as well as SRV as an analytical tool for analyzing the services provided, then a very different picture of the many problems, and few benefits, of methadone treatment evolves. I do not suggest that the consequences of methadone treatment which I will describe below automatically apply to each and every methadone program in every location. But I do think that although some problems might vary depending on *how* such programs are implemented, others are inherent in the medical model, and can therefore be expected to exist everywhere methadone is handed out to people.

More But Different Drugs

Abstinence from drugs for some people, and reduction in drug use for others, was one of the hopes associated with methadone programs. It turned out to be utterly unrealistic, for many reasons.

First, methadone as a drug is more addictive than heroin, meaning that its withdrawal effects are worse, making it harder for people to quit.

Second, people who use drugs either enjoy their effects, or they lack the inner strength and maybe outside support to quit. So if one replaces a drug that gives people a positive feeling (as heroin does) by a drug that does not create positive feelings but has a number of unpleasant 'side-effects' and strong withdrawal effects if not taken very regularly (as is the case with methadone), then people certainly experience a lack of positive feelings. Methadone is an opiate, just like heroin. If it is used

as a substitute for heroin, it prevents heroin withdrawal effects, and if people consume heroin *after* having received methadone, they no longer experience the positive feelings that typically come with heroin use. Therefore, heroin becomes an ineffective drug for them. As a consequence, many switched to other drugs (like alcohol, cocaine, legal mind drugs) because the effects of these drugs could still be felt. In other words, people became addicted to yet more drugs (methadone *plus* additional legal and/or illegal drugs), and to drugs that are potentially more harmful to their bodies and minds than heroin. Mixing different kinds of drugs, as many started to do, is also more harmful than taking just one drug. Many people who are part of the drug subculture believe that (at least some of) the increase of cocaine and crack consumption in previous decades has to do with methadone recipients switching to other drugs.

A *third* reason why abstinence or reduction in the overall consumption of drugs was not achieved was that the doctors who gave out the methadone often also prescribed legal mind drugs (e.g., barbiturates, antidepressants), especially so if they were psychiatrists. As their professional approach consisted in treating 'mental illness' (which is what they considered drug addiction or its effects to be) by prescribing drugs, this made sense to them, but it also made a great variety of new drugs easily available for methadone patients. Often, doctors prescribed them to people who did not really want them. As a consequence, the black market became saturated with legal mind drugs, because they became a quick source of income for methadone patients who often were economically poor. In Bremen, several local pharmacists traded methadone patients' prescriptions for HIV medication against prescription mind drugs and a bit of cash, making huge profits be-

cause HIV medicine is very expensive. This too increased the availability of legal mind drugs sold on the streets.

And *lastly*, what made it additionally difficult for people to quit using drugs was that after detoxifying from methadone (and possibly other drugs) in a hospital, and being released, there were few services available to them, other than the service systems' standard response of sending people to 'abstinence therapies.' If people were not willing to spend many months in an institutional or group home setting being engaged in 'therapy,' (i.e., if they rejected the patient role), and if they did not have competent valued people in their lives who were able to help them find jobs, homes, relationships with valued people, etc. (which most did not have), then it was very difficult for them to stay away from their addicted friends and acquaintances who tempted them to continue using drugs. In other words, hospital detoxification helped people to leave their very devalued roles as drug addicts and members of the drug subculture, but the service system offered them very little support to replace these devalued roles by more valued ones. As people can not be without roles (this is the concept of role avidity within SRV; see Lemay, 1999, p. 233), they hurry to fill such a role vacuum created by the loss of devalued roles with new roles. If valued roles are not available, they are forced to (re)enter devalued roles.

Socializing People Into Devalued Roles

Reintegration into society turned out to be an illusion as well. The service system had many ways of making it difficult for people to re-enter their previously lost valued roles or to safeguard their still existing valued (work, relationship, etc.) roles.

Several clinics served a big number of methadone patients, and forced them to pick

up their drugs all at the same times. Those who served fewer methadone patients often also made those few come to their clinic at the same time. During weekend and holiday distribution, hundreds of people gathered at the day program and the bus stops, drawing drug dealers who tried to sell them drugs. These congregations of methadone recipients constituted constant temptations for people to consume other drugs besides methadone that were widely available through the dealers on the scene. They also forced people who had kept some of their valued roles and who had previously not been part of the drug subculture to have daily contact with that subculture, socializing them into it. Additionally, these congregations were very image-impairing, especially for people who tried to keep their addictions secret from their employers or friends who were not drug-addicted, fearing that they would lose their valued work or relationship roles if such people found out. Some clinics were widely known as methadone clinics; therefore, if one was seen in them, maybe even next to some wretched-looking fellow patients, ordinary people almost automatically assumed that one had a serious drug problem.

People who had a job, or tried to find work, often found it difficult to work while receiving methadone. Pickup times at the clinics regularly interfered with work schedules, especially when, as was sometimes the case, pickup times changed from one day to the next without advanced notice; or when at certain times, due to long waiting, people could not get back to their jobs in time. Many doctors did not want to give their patients methadone to take home for several days at a time, assuming they were unable to control taking the right amount regularly. Another problem was that methadone, especially if overdosed, makes people tired. If underdosed, withdrawal effects start before the

person gets the next dosage. Many doctors therefore tended to overdose, rendering people tired and lethargic, which makes most jobs more challenging.

Another way that re-entry into valued roles was prohibited was that the methadone programs effectively socialized people into the patient role. Methadone recipients had to go to a clinic every day; their drug abuse was called a 'disease;' many were engaged in some kind of counseling or therapy, and so on. For many drug addicts, the patient role was not only a role imposed on them by the service system, but also one that they themselves preferred to other devalued roles, such as the drug addict, criminal, burden or menace roles. One of the privileges of the patient role is that people are not considered responsible for their condition and for actions that are caused by that condition. The patient role made it much easier for many people to blame their 'disease' for some of the bad things they had done in their lives, and not feel responsible, ashamed or embarrassed for them. If people do not feel responsible for their lives and for what they have done, then they typically also do not feel in charge of making positive changes. Instead they wait for others to change things *for* them. These others are often professionals (especially doctors and therapists) because they claim to be experts in treating illnesses, including 'mental illnesses.' If what the expert does, does not work, then one of the possible explanations is that one is a hopeless case, or that the 'disease' is so serious or chronic that one will never recover from it.

Additionally, the patient role itself typically comes with low expectations in terms of what people can do and accomplish. For instance, a disease might prevent one from being able to work hard, follow a challenging schedule, and so on. This is especially true for a long-term, or chronic, illness, as drug addiction is considered

to be. As people tend to live up to positive, or down to negative, role expectancies held by others, this was a powerful negative expectation, convincing methadone recipients that they were not able to do much. This expectation was reinforced by the non-medical service system that provided spaces where people could 'hang out,' while receiving none or only few relevant services, essentially wasting their time. "Life-wasting" is one of the common "wounds" of devalued people described in SRV theory (see Wolfensberger, 1998, p. 21).

Healthier Through Methadone?

Another hope was that through receiving methadone, people's health would improve. This seemed to be true for the minority of methadone recipients who *only* took methadone but no other drugs. Even if methadone is more addictive than heroin, there are at least three reasons why it is healthier. *First*, heroin bought on the black market is always mixed with other potentially health-impairing substances that are unknown to the consumer.³ *Second*, in contrast to heroin that most consumers inject, methadone is given orally which is less dangerous than injections that can cause infections and abscesses. And *third*, if health insurers finance substances that people 'need' to satisfy their addictions, then the people are less likely to prostitute themselves in order to earn money for drugs. Apart from its negative emotional and moral impacts, prostitution is also one of the major health threats, especially to drug-addicted women.

METHADONE RECIPIENTS who took additional drugs certainly did *not* enjoy better health. Here again, several reasons worked together:

First, as mentioned, mixing several drugs, and consuming legal mind drugs in addition to

the illegal ones people consumed before, was certainly health-threatening, especially if practiced long-term.

Second, methadone too became a street drug, through people who either smuggled it out of clinics and hospitals, or sold some of the methadone that had been given to them to take home.⁴ When methadone is given to people in clinics or hospitals, it is mixed with fruit juice for people to drink. When people buy it on the streets they tend to inject it, because they are used to injecting heroin as well as dissolved legal mind drugs. Injecting a drug mixed with fruit juice multiplies the risk of life-threatening abscesses.

And *third*, many doctors regularly became nervous when they saw that their patients took many non-prescribed drugs besides methadone. Their typical response was to tolerate it for a time while augmenting the methadone dosage, hoping that this might help their patients to reduce other drugs, then to set a deadline when they had to stop taking additional drugs, and if they did not meet the deadline, to kick them out of the methadone program. If such people did not find another doctor who would give them methadone quickly, they had to consume either heroin or black market methadone in order to combat withdrawal effects. Not having consumed heroin for a while, such people often misjudged how strong the heroin was,⁵ which sometimes led to life-threatening overdoses.

ONE WOULD HOPE that people who show up daily at a clinic, and who see a doctor regularly, would have at least their physical diseases monitored and treated. This was true for some, but not for the majority of methadone recipients. A major reason was that, even if their doctors were general practitioners or internists, people often did not want to be examined and treated by them because they were

afraid that their drug abuse would be discovered and that they would be kicked out of the methadone program. If their doctors were psychiatrists, physical diseases fell outside their purview. Other programs combined methadone distribution with a day program, but the doctors working in these programs were not licensed by health insurances to diagnose and treat physical conditions.

Another major problem was that many doctors assumed that their methadone patients would lie to them and pretend to be sick in order to receive prescription mind drugs. In numerous instances this resulted in serious illnesses not being treated in time, people not being admitted to hospitals when they should have been, and consequently life-threatening situations and sometimes even deaths.⁶

Bringing Out the Worst in People

Giving out methadone in most instances destroyed any positive doctor-patient relationship. In the eyes of most methadone recipients, doctors became the major powers in charge of their lives. They controlled their schedule and time (when to show up at the clinic, how long to wait, when to have conversations with their doctors, when to be able to leave the city for more than a day, whether keeping or finding a job was an option); their drug use (dosage, kinds of drugs, when to or not to withdraw); and the people they associated with (other drug addicts, often drug dealers, sometimes counselors or therapists). All of this resulted in huge resentments by methadone recipients towards their doctors, who often blamed the doctors for their bad situation in life. It also resulted in endless power struggles between doctors and patients, and the doctors being the more powerful party, sometimes in humiliating procedures.⁷ On the part of methadone recipients, this power struggle often brought out the

worst behaviors in them (e.g., lying, aggressiveness), which in turn reinforced the doctors' negative assumptions about drug addicts.

Similarly, many of the accompanying counseling and therapy services, as well as the 'hang out' programs, brought out and reinforced people's bad behaviors. For instance, the counseling and therapy programs expected their clients to be on time, to come regularly, to stick to previously made agreements and so on. As most of their clients did not like to go to their counseling or therapy sessions, but saw it as an obligation, they had very little motivation to be reliable. Again, this reinforced the counselors' and therapists' negative assumptions about methadone recipients (e.g., that they were unreliable and therefore unable to have a real job, or to maintain typical relationships with ordinary people). The main reason why people resented counseling and therapy was that they hoped for some kind of practical help (e.g., in finding a better place to live or a job, in dealing with authorities and/or doctors, etc.), but were instead given endless talk about what was wrong with them and with their lives. Sometimes counseling and therapy programs referred their clients to other programs for practical help, but only few other programs actually provided any practical help, and so people moved around in the service system keeping staff busy talking about their problems. In other words, most programs were essentially irrelevant to what they needed, and therefore methadone recipients did not respond positively.

The 'hang out' programs too rarely referred people to relevant services, but instead conveyed powerful expectations that methadone recipients would continue to be members of the drug subculture. Why would people need to exchange their syringes, receive free condoms, or hang out with other drug addicts, if their goal

was to enter more valued roles? By setting up such negative expectations, these programs perpetuated the negative behaviors they claimed to address.

Criminally Sick or Sick Criminals?

One of the goals of methadone treatment was to replace the very devalued roles of criminal and menace by the role of the sick person. Within SRV theory, this would be considered a positive achievement because the patient role is generally less devalued by society than the criminal or menace roles. What happened though was that the service system successfully socialized drug addicts into the patient role while not freeing them from the menace or criminal roles, essentially adding another devalued role to their already very devalued identity.

Prisons kept being overcrowded with people imprisoned for drug-related offenses. In other words, drug addicts were still in the roles of criminals, menaces, prisoners and ex-convicts. The main difference to pre-methadone-times was that people were prosecuted more often for offenses related to drugs *other* than heroin. A minor benefit of methadone treatment was that *some* methadone recipients committed *fewer* illegal acts, which had to do with using only or mostly legal mind drugs besides methadone paid by health insurances. As a result, such people did not use illegal means to make money to pay for their addiction, or they did so less often, which resulted in fewer conflicts with authorities.

The stereotypes surrounding methadone recipients were essentially the same stereotypes surrounding other drug addicts. They were perceived as dangerous, uncontrollable, criminal, unreliable and so on. Ordinary people who were not able to understand the difference between somebody receiving methadone and somebody consuming heroin treated both

groups very similarly. If they found out that somebody received methadone, they would not rent apartments to them, not hire them, distance themselves from them, refer them to addiction services (instead of general ones), assume they were criminals and so on.

As a result, methadone recipients found themselves in an incoherent and confusing situation. The professional service system considered them to be sick, while the 'world' treated them as criminals. What added to the confusion was that the professional approach was very incoherent as well. For instance, most doctors punished methadone recipients' continued non-prescribed drug use by withdrawing or reducing methadone. If such doctors really believed that heroin addiction was a 'disease' that can be 'healed' by substituting heroin with methadone, then it would make no sense to withdraw the 'medication' (methadone) that can cure the disease (addiction). This would be like asking sick persons to give up their diseases before receiving medication, which in every other case of a (real) disease would be considered absurd by everybody involved. Hospital detoxification units also typically kicked patients out who were discovered to have consumed non-prescribed drugs. If one thinks along the logic of the medical model of addiction, such patients were kicked out for showing expressions of their 'disease.' This would be like cancer patients, when showing signs of growing cancer, being cut off from chemotherapy. Addiction is probably the only existing 'disease' that patients have to keep secret from their doctors if they want to avoid being cut off from 'treatment.'

Despite such obvious contradictions, most medical and human service professionals kept insisting that heroin addiction was a disease, while other authorities (e.g., police, courts) insisted that heroin use was a crime. As a result,

methadone recipients were stuck in a very confusing devalued identity, feeling either unjustly prosecuted (if they accepted their patient role), or perceiving doctors and other medical staff as 'drug dealers in white coats' acting like 'drug-dealing policemen.' SRV teaches that roles often come in complementary pairs (e.g., teacher and student; doctor and patient). If drug addicts are a mixture of patients and criminals then of course it makes sense that they perceive those who serve them in a role that is a mixture of doctor, drug dispenser and policeman.

A Place to Live Paid by Clientage

One of the few benefits of the methadone programs was that they enabled many methadone recipients to have a place to live. They often helped people to leave the devalued role of homeless person and replace it by roles such as tenant or group-home resident. Even people who took a lot of other drugs besides methadone were often able to avoid becoming homeless because their basic 'need' for drugs was covered by health insurance companies. Therefore, they required less money for drugs than before they entered the methadone program and were able to pay rent more regularly. Group home residents had their rent taken out of their monthly welfare automatically which ensured regular payment.

The downside or 'cost' of this was that becoming a methadone recipient almost automatically meant not only patienthood but also clientage. Especially people who had hoped that methadone would help them to regain their valued identity found that now they were stuck in the service system. Instead of working, volunteering, receiving an education, making new friends or being engaged in other kinds of activities that might lead to valued roles, they now spent their days waiting in clinics, hang-

ing out in day programs, talking to counselors, and walking from program to program hoping for services that often turned out to be nonexistent, provided at another time or place, or only after many weeks of waiting. Before receiving methadone, most people's time was filled with 'making' money, consuming drugs and avoiding being caught by police. Methadone treatment freed up a lot of this time which could have been used in constructive ways. Instead, the service system told them that now they were patients who needed to recover and solve all their problems before they were able to live like ordinary people. Most never 'recovered' or solved all their problems, and therefore 'ordinary life' never became a reality.

Glimpses of Beneficial Service

As always, there were a few glimpses of hope in a chaotic system. They came mostly from individual people who managed to use the system in constructive ways and to relate to people in positive ways. I will give a few examples as an illustration of things that helped people enter more valued roles or at least avoid some very devalued ones.

As mentioned above, a social worker set up a project that brought members of a soccer fan club and a small group of prisoners receiving methadone together. The prisoners were allowed to leave the prison once a week for a few hours. The group spent time together each week in soccer-related activities: renovating parts of the local soccer stadium which the fan club was occupying, attending soccer games, preparing for the fan club's annual celebration, and so on. At one point, the fan club's activities were proudly featured in the local newspaper, which was very image-enhancing for the fan club itself as well as for all its members, especially because soccer is the most important sport in Germany and the local team was quite

famous nationwide. This small project not only helped prisoners to form relationships outside the drug subculture to which they could return once they were released from prison, but it also accorded them the valued roles of soccer fans, fan club members, workers and friends.

A psychologist who worked in one of the day programs served a woman who was very sick. The woman had been addicted to drugs for almost 20 years and lived a very marginal life with no relationships to family or other valued people. The psychologist decided to befriend her, and spent much time sitting at her bedside when she was in the hospital, making sure she received good care. As the psychologist was a respected professional, hospital staff were attentive to her requests. When the woman finally died, the psychologist was with her, after having spent many nights at her bedside. She also had managed to find some of the woman's remaining family members and convinced them to visit before she died. In this way, she helped the woman to regain her role of family member and to be in the role of a friend.

A policeman who patrolled an area of the city where many marginal people, including many methadone recipients, met started to watch out for people. He stored their important documents in his office so they would not get lost. He negotiated with the local transportation company and the state attorney to prevent people being sent to jail as a result of not being able to pay fines for riding without tickets. He convinced people who looked sick to go to the hospital. He searched for people whom he had not seen for several days and made sure everything was all right. With his service he protected many people from entering the devalued role of a convict, and he saved at least one man's life by having him transported to a hospital.

Several doctors provided excellent medical care. These doctors made sure to not congregate methadone recipients with other people receiving methadone. They treated them very respectfully as their valued patients, and they took much time to diagnose illnesses and to talk with their patients. If they did not treat patients themselves, they followed up with fellow physicians to whom they had referred them and made sure they were treated correctly. Such medical service not only protected or enhanced people's health, but also afforded them the role of respected citizen who happened to be a patient like others in that doctor's clinic.

A group of citizens, including some service workers and lawyers, set up a group who observed what was going on in the local prison and advocated for reforms. Members of that group either visited the prison or kept in touch with people who had regular access to the prison. When a woman prisoner died after a prison doctor who was notorious for not treating severely ill drug addicts had repeatedly refused to see her, they documented evidence of his neglect. Although they were unsuccessful in getting this doctor removed, their activity at least conveyed the message to prisoners that other people cared about them and considered their lives valuable. It also was an effort to counter the better-off-dead or the deserving-to-die roles into which these prisoners had been cast (see Wolfensberger, 1998, p. 16).

What is Wrong With the Medical Model of Addiction?

MUCH IS WRONG with the medical model of addiction. I will limit my critique to a few general points which are relevant to other service fields as well.

1. *The most fundamental assumption of the medical model is wrong.* Heroin addiction, just as drug addiction in general, is *not* a disease. Drugs can *lead* to many diseases (e.g., harm to bodily systems and the brain); drugs can impair people's functioning which can cause accidents that *lead* to diseases; the methods through which drugs are administered can *lead* to diseases (e.g., various kinds of infections through contaminated needles); and people who are addicted to heroin or other mind drugs experience withdrawal effects for a period of time when they stop taking them, including bodily symptoms. But by itself drug addiction is not a disease.

If one asks drug addicts why they *started* to take drugs, one is most likely to get one or several of the following answers: (a) hedonistic pleasure: people wanted to enjoy euphoric feelings, party, have fun, etc.; (b) curiosity; (c) wanting to have 'religious experiences;' (d) wanting to suppress negative feelings (such as stress, confusion, anxiety) and/or wanting to forget unpleasant realities in life; (e) peer pressure from friends or other important people; and (f) in very rare instances, in order to combat physical pain.⁸

All these reasons have in common that people try to manipulate their experiences and feelings by material means, sometimes imitating others who do the same. Doing this, they treat themselves a bit like machines that can be made to function exactly according to their wishes. If one does not like certain negative feelings (and maybe does not know why one should have to suffer at all in the first place), one decides when to stop these feelings and with what other feeling to replace them. If one wants to experience new feelings, one decides when and how to experience them. If one does not like certain unpleasant realities, one can get away from them in an instant. And if one wants to

experience a certain other kind of reality, one can have it in an instant as well.

Underlying such practices are mindsets of (a) wanting to always be in control; (b) wanting things 'fixed' in an instant, and without much effort; (c) putting oneself and one's feelings first; and, as already mentioned, (d) perceiving oneself and one's life (and probably other people as well) like a manipulable machine. Such practices and mindsets are not unique to drug users. Many people in Western countries hold similar mindsets and engage in similar practices. For instance, people's obsession with extreme sports, fast cars, sex, material wealth, health and beauty of their bodies, etc. are often expressions of such mindsets. Among other things, they are expressions of interior emptiness and restlessness, of 'needing' external thrills to fill that emptiness and restlessness; of having no explanations for human suffering and hardships in life and therefore rejecting it at all cost; of longing for a different kind of life and different kinds of relationships, but without knowing how to bring it about or without wanting to pay the price (i.e., making the effort) for bringing this about; of lacking positive orientation and/or values that are life-sustaining and the discipline needed of working through hard times, or going through long periods of effort without instant gratification.⁹

It is true that humans have always enjoyed mind-altering drugs and experiences -- that is why, for instance, alcohol prohibition never worked. They also have always enjoyed hedonistic pleasures. Yet what is different today is that our culture has accepted drugs and hedonistic pleasures as legitimate means for dealing with almost any kind of problem and situation in life.

Once people have been addicted to illegal drugs for some time, and have experienced continued wounding and devaluation as a result,

they have even more reasons to use drugs in order to suppress suffering and to 'escape' from a terrible situation in life -- at least for a certain period of time. One of the paradoxes with drug abuse is that people who first tried to be in control at all cost then completely lose control, and get controlled by drugs, by their bodies, by drug dealers, by service structures and by authorities. Sometimes, if people do not find true answers to their most existential questions in life, and some form of hope that is life-sustaining, then their continued drug abuse becomes an expression of a death wish (or of playing with death), of wanting to be freed of a life that has no positive meaning for them.

The most fundamental problem of the medical model is that it assumes drug abuse to be a material problem and a disease, when it is fundamentally an existential, spiritual and moral problem. Drug abuse is not a disease but a personal and cultural disorientation.

2. *From this fundamental faulty assumption flow many other problems.*

a. *Promoters of the medical model of addiction believe that drug abuse is a material problem and therefore they respond to it with material means.* Drug abuse gets treated by drugs, and by technocratic counseling and therapy. By trying to manipulate people's bodies and minds by material means, professional services essentially follow the same approach which drug addicts themselves have used -- an approach that has not 'worked' in the first place.

Similarly, if what people need most in order to be able to abstain from drugs are a 'perspective for their lives' (i.e., answers to their most existential questions), belonging (to family and friends), and a sense of purpose and achievement (through work), then giving them drugs and talk about how things are not working out in their lives is not going to address these most fundamental needs.

b. *Inherent in the medical model of addiction are negative assumptions about people's characteristics and future prospects.* Because so many service systems are based on such negative assumptions, they set up structures and patterns which will confirm these assumptions. SRV teaches that when negative expectations are communicated through service processes, they set in motion a powerful feedback loop that over time generally brings out in people what was expected of them. For instance, if one expects people to suffer from a chronic condition, part of which includes not *wanting* to change, then one will provide services to them that will make it very difficult for them to be *able* to change. Instead one will offer services that trap people in their present state and condition. If only professionals are considered 'experts' in dealing with a certain group of people, then they are not likely to recruit ordinary people to be with such people. Instead they will set up artificial 'professional' environments that separate their clients from the typical world. If one expects people to always lie and cheat, then one will set up patterns of distrust and control, and people will tend to revolt against these patterns. One of the ways to avoid control is to actually lie and cheat. And so on.

c. *Putting people who are not sick into the patient or the chronic patient role makes it impossible, or at least extremely difficult, for them to enter certain other more valued roles.* As mentioned, people in the chronic patient role are often perceived as being unable to work or at least to only have limited competencies. Therefore many valued work roles become unavailable to them. People in the chronic patient role are not considered responsible for their condition and the behaviors resulting from that condition. They are considered dependent on other people, especially on medical profession-

als, who take over many aspects of their lives. Therefore, many roles that require its incumbents to assume personal responsibility become unavailable. People in the role of short-term patient tend to evoke care and compassion in others. Yet if they are in the patient role too long and do not have many other valued roles as a compensation, other people tend to feel threatened because they assume the condition is hopeless, getting worse, or is maybe even fatal. When people feel threatened, they are apt to distance themselves from the source of the threat; therefore, many valued relationship roles become difficult to maintain or to enter. And so on.

d. The medical model, if applied to people who are not sick, will always be in competition with conflicting assumptions and conflicting service models. This happens because at least some people and/or authorities perceive its obvious incoherencies and try to impose their own interpretation. Sometimes older interpretations continue to exist and conflict with the medical model. When the medical model gets used to serve drug addicts, the most common conflicting model is the menace-detentive model. Services then become a mixture of contradicting expectations for service recipients, hence role conflicts, which is a sure way to perpetuate their confusion about their own identity, further their social devaluation and confuse observers.

Conclusion

IT IS INTERESTING to consider that the services which accompanied methadone treatment in Bremen for many years had no conditions whatsoever attached to their funding. In other words, they received public money and were allowed to do whatever they wanted, i.e.,

what they thought would be beneficial to the people served. Many service workers truly believed that drug addiction was a disease and did their best to serve people. Such servers are good examples of the enormous amount of unconsciousness that exists in human services (see Wolfensberger, 1998, pp. 103-104).

However, on a societal level, it is obvious how much many parties benefitted from casting drug addicts into the sick role. By replacing illegal mind drugs with legal ones, the pharmaceutical industry developed a new market. Pharmacists were able to sell more drugs. Doctors recruited a new group of patients. Although some truly meant to be helpful to individuals and serve them well, other doctors served a huge number of methadone patients, basically handing out drugs and doing little else. Without methadone and other legal mind drugs as a mean to control inmates, most German prisons would have probably collapsed years ago, because the majority of inmates were -- and *still* are, according to prison experts -- drug-addicted. Many administrators, social workers, counselors, therapists, nurses and other human service workers made -- and, despite recent financial cutbacks in human services in Germany, are *still* making -- a living dealing with an ever increasing number of 'sick' or 'chronically sick' people. Because they and society were -- and *still* are, as evidenced by the continuous demand for *more* professional services and *bigger* prisons -- so efficient in perpetuating social devaluation, policemen, state attorneys, judges, prison staff and others were -- and *still* are -- ensured of their continued employment as well. The problems related to drug addiction and methadone treatment were intensively researched by academics and endlessly discussed at conferences. When enough experts finally admitted that methadone turned out to *not* be *the* solution to heroin ad-

diction, another drug -- legalized heroin -- became the new hope. It is not difficult to predict what is likely to happen to such legalized heroin recipients, if more relevant and potent services are absent.

The medical model applied to serve people who are *not* sick seems to be the most prevalent service model today. Almost every imaginable human behavior has been defined as a psychiatric condition and therefore considered a disease. If things do not change, soon everybody will be on mind drugs and people will no longer know what health is.

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Note: All resources on drug addiction, methadone treatment and the related service system on which this article is based are written in German. People who are interested can get a list from: Susanne Hartfiel, SRV Implementation Project, 74 Elm St., Worcester, MA, 01609 USA; or: susanne@srvip.org.

Endnotes

1. They are mutually exclusive because if a certain behavior is the result of a disease, one is not responsible for such a behavior; however, if it is *not*, then typically adults *are* considered responsible, and if they break laws they might be prosecuted.

2. In Germany, small offenses (such as stealing items of little worth, or riding public transportation without a ticket) are punished by fines. If people are unable to pay these fines, they can either go to jail, or work a certain amount of time in a charitable, environmental or cultural organization.

The work provided for methadone recipients typically was either cleaning, or packaging syringes for distribution in exchange for used ones.

3. Drug dealers do this in order to extend the amount they can sell, making more profit. In Germany, only 5-10% of the substance bought in a bag on the black market contains actual heroin.

4. In order to avoid the problems associated with congregating methadone recipients, or with forcing people who worked to show up at the clinic every day, some doctors gave their patients dosages for several days to take home.

5. The concentration of black market heroin varies. People who consume it regularly usually know how strong

it is, and how much they 'need,' but people who have not consumed it for a while can easily misjudge.

6. In one instance, when a prison doctor refused to pay attention to a woman with high fever, paralyzed limbs and constant vomiting until she was found dead in her cell, all possible authorities (police, State Attorney, General Attorney, Justice Department, parliament, medical examiner, Justice Minister) worked together to cover it up and to prevent investigation, even though there was much documented evidence and many witnesses.

7. For instance, some doctors required people to undress and urinate in front of a nurse in order to make sure that the urine sample for drug screening was not fake.

8. Sometimes people received morphine or some other opiate in order to combat pain. When the condition causing the pain was healed, they switched to heroin af-

ter having become addicted to opiates. Such people are rare; most are able to quit once they do not need opiates as pain medication.

9. In a seven day workshop entitled "How to Act With Personal Moral Coherency in a Disfunctional Human Service World," much more of the societal background of such mindsets is explained. The workshop is offered every other year in North America; for further information contact the Training Institute (315 473 2978).

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SRV & NVA: Valorizing Social Roles Through Nonviolent Action

Brian Martin

Introduction

WOLFENSBERGER (1998, p. 58) defines Social Role Valorization (SRV) as “the application of what science has to tell us about the defense or upgrading of the socially-perceived value of people’s roles.” This definition refers to *application* of knowledge, but in practice much material about SRV deals with *analysis*. For example, Wolfensberger (1998) gives much attention to the nature of roles, processes of devaluation, the benefits of having valued roles, methods of conveying social images and identifying role goals. A similar emphasis is found in other treatments (Flynn and Lemay, 1999; Race, 1999; Wolfensberger and Thomas, 1983).

Two areas where *action* is central to SRV are image enhancement and competency enhancement, which are the primary means for getting people into valued social roles (Thomas, 1999, pp. 358-360; Wolfensberger, 1998, pp. 62-77). Action is directly involved in, for example, valorizing a person’s current positive roles and enabling a person to enter valued new roles. Many methods of actualizing SRV have been proposed and used, including personal help for individuals, passing laws and promoting favorable media coverage (Wolfensberger, 1998, pp. 78-80; Wolfensberger and Thomas, 1983). The next section lists some examples.

Some Methods of Actualizing SRV

- *Personal help*. A person helps a devalued individual with hygiene, dress, social skills and a host of other aspects of image and competency enhancement (Wolfensberger, 1998, p. 78).
- *Consciousness raising*. For example, voluntary groups hold discussions and organize actions that increase their members’ awareness of, commitment to and support for devalued people. SRV training is a method of consciousness raising (Reidy, 1999, p. 381).
- *Changes in the social environment*. The immediate situation of a devalued individual is changed, via culturally valued activities, image-enhancing settings and competency-enhancing groupings (Wolfensberger, 1998, p. 79).
- *Changes in practice*. People change their behavior, for example by involving devalued people in their lives and, on a collective level, creating “opportunities for constructive personal contact between a devalued person and others” (Reidy, 1999, p. 382).
- *Formal education*. SRV is incorporated into syllabuses.
- *Changes in policy*. Organizations, including governments, change their guidelines, planning and policies; for example, to integrate devalued people into standard employment

- (Wolfensberger, 1998, p. 80).
- *Changes in technology.* Through appropriate design, technologies can help to increase competencies and image. For example, automatic garage openers, originally designed for people physically unable to handle garage doors, are now widely used and accepted.
 - *Changes in laws.* Laws are passed to improve access, provide support, ban discrimination, etc. (Wolfensberger, 1998, p. 80).
 - *Media coverage.* Sympathetic stories about devalued people can improve their image, as do portrayals, for example in films (Thomas, 1999, pp. 371-372; Wolfensberger, 1998, p. 80).

FOR SOME OF THESE METHODS, such as personal help, it is obvious what an individual actually does. But in others the mechanism is not specified. For example, changing the law is a method, but this does not tell how it is to be accomplished. If you are a lawmaker, then it might be proposing, drafting or supporting suitable legislation. If you are a legal scholar, it might mean publishing recommendations for law reform. If you are a concerned citizen, it might mean writing letters or organizing a pressure group.

The question of what to do is especially challenging when there are significant obstacles to action, typically when bureaucratic organizations, vested interests or entrenched behaviors are involved. For example, if a human service keeps a person in a dependent situation with no opportunity for competency development and with negative imagery, and opposes efforts to allow the person to learn new skills or move elsewhere, then SRV implies some form of action to challenge, transform or eliminate the service. But SRV does not specify the type of action to be taken for organizational

change. In principle, many options are possible.

One especially promising approach to social change that has received little attention in SRV writings is nonviolent action (NVA). The practice and theory of NVA will be outlined here, followed by preliminary comments on how SRV and NVA can be linked.

Nonviolent Action: Practice and Theory

SOME FAMILIAR METHODS of NVA are public speeches, leaflets, meetings, rallies, vigils, picketing, strikes, boycotts, sit-ins and fasts. Other methods include mocking or insulting officials, emigrating as a form of protest, withdrawal of bank deposits, working-to-rule strike (insisting on following all formal procedures at work, to slow down production), sending large electronic files to clog an e-mail system, and occupying uncultivated agricultural land. Gene Sharp (1973, 2005) distinguished 198 methods of NVA, giving examples of each, and there are hundreds more.

NVA can be distinguished from three other modes of communication and action: violence, discourse and conventional politics (Martin and Varney, 2003). NVA does not involve physical force against humans, thus distinguishing it from violence. NVA is a method of action and thus is different from discourse, such as verbal persuasion. NVA is nonconventional political action, as distinguished from conventional political activities such as negotiating, lobbying and voting. NVA is most commonly used to struggle for a desired social goal outside of "formal channels."

There are two broad approaches to nonviolence, called *principled* and *pragmatic*. *Principled* nonviolence, associated with Gandhi, is based on a moral renunciation of violence. This

approach is often linked to nonviolence as a way of life, which means fostering both personal peace as well as harmonious and just relations with others. *Pragmatic* nonviolence treats methods of nonviolent action as instrumental tools to immediate ends. In the pragmatic approach, NVA is chosen because it is more effective than alternative methods of action. My focus here is on pragmatic NVA.

NVA is frequently used by social movements, such as when environmentalists blockade logging operations, feminists protest against rape and peace activists sail into nuclear test zones. NVA has been the primary means used by some liberation movements, most famously from 1915 to the 1940s by the Indian independence movement led by Gandhi and in the 1950s and 1960s by the US civil rights movement. NVA has been used to thwart coups such as in Algeria in 1961 and the Soviet Union in 1991, to topple authoritarian rulers such as in the Philippines in 1986, in Indonesia in 1998 and in Serbia in 2000, and occasionally to oppose military invasion such as in Czechoslovakia in 1968 (Ackerman and DuVall, 2000; Cooney and Michalowski, 1987; Crow, Grant and Ibrahim, 1990; Gandhi, 1927; McAllister, 1991; McManus and Schlabach, 1991; Randle, 1994; Schock, 2005).

NVA is not guaranteed to succeed, as shown by the failure of the 1989 pro-democracy movement in China and of the decade of non-violent resistance in Kosovo to Serbian oppression (Clark, 2000). However, it has several advantages over violent methods. *First*, more people can readily participate in NVA than violence. Participating in a rally or boycott is possible for women, the elderly and children, whereas most soldiers are young, fit men. Greater participation is associated with greater internal democracy and greater resilience against attempts at control by vested interests.

Second, NVA is more likely to win wider support than violence, which often antagonizes targets and disgusts witnesses. For example, the first Palestinian intifada, 1987-1993, was largely unarmed and attracted considerable international support for the Palestinian cause, whereas suicide bombings in the second intifada since 2000 have alienated potential allies. *Third*, NVA usually leads to fewer casualties than violence. Armed liberation struggles, as in Vietnam and Algeria, have resulted in thousands or millions of casualties, whereas unarmed liberation struggles, as in India and Eastern Europe, have had relatively few. *Finally*, the means (nonviolence) are compatible with the goal (a nonviolent society). This is insurance that, should the struggle fail, society at least has not been taken down a damaging road.

Use of NVA does not mean there will be no violence, because opponents may, and often do, use violence against nonviolent protesters. However, this can backfire, since violence against those who are nonviolent often generates increased support from observers. Because of this process of "political jiu-jitsu" (Sharp, 1973), NVA can be effective against even the harshest repression, for example against the Nazis (Semelin, 1993).

Underlying NVA is the consent theory of power (Sharp, 1973, 1980), which in essence sees power as the result of subjects supporting or acquiescing to the actions and roles of rulers. When subjects withdraw their consent, by refusing to cooperate as usual, the power of the ruler collapses. NVA is a challenge to the normal acquiescence that allows dictatorship, war, genocide and systems of oppression to occur. One of the keys to this process is the role of agents of the ruler, such as troops. If they withdraw their support, for example as a result of persuasion or simply their instinctive refusal to harm defenseless people, the system will

collapse, as in the case of Eastern European communist regimes in 1989.

The consent theory of power is a reasonable model when there are obvious rulers, such as in a dictatorship, but it is not so helpful in complex systems of domination such as bureaucratic organizations or market economies, where there are many cross-cutting power relations and no single line of authority. Nevertheless, NVA can still be useful in challenging oppression in such complex systems, though a more sophisticated analysis may be required.

NVA may be taken *by* members of oppressed groups, such as by women or ethnic minorities, such as blacks involved in the US civil rights movement. NVA may also be taken *on behalf of* oppressed groups, by others, such as whites who participated in freedom rides -- buses with both black and white people -- during the 1950s in the US South. On some issues, much or all of the action is on behalf of a different group or category. For example, human rights activists, such as in Amnesty International, act on behalf of people, such as political prisoners and victims of torture, who seldom are in a position to take action themselves.

NVA for SRV

NVA *BY* DEVALUED PEOPLE -- either on their own, or with nondevalued people -- raises a number of complex issues involving image, competencies and consent, discussed later. NVA *on behalf of* devalued people is less problematical.

In practical terms, NVA can be a tool for improving the lives of devalued people. Leaflets, rallies, sit-ins and a host of other techniques of NVA can be used to push for changes in policies, laws and practices. This may indirectly lead to improved social roles for deval-

ued people. More direct connections are possible too. Consider a devalued person for whom a job in a particular workplace would be both image- and competency-enhancing, and assume that some workers are sympathetic but the management is not. One way to proceed would be to use conventional methods such as meetings, submissions and formal appeals. If these are unsuccessful, or as an immediate alternative, NVA could be used, for example, office occupations, strikes, or bringing the devalued person into the workplace to undertake the job.

In an instance such as this, a careful assessment of the situation, of opponents, of supporters, and of the likely consequences, is vital. This is advisable for any use of NVA, but when devalued people are involved or may be affected, there is an extra dimension highlighted by SRV, namely the consequences of heightened vulnerability (Wolfensberger, 1998, p. 124) -- a point further discussed below. This does not necessarily mean NVA is less suitable, but it may affect the choice of methods.

When NVA is successful, it has a range of consequences, of which one of the most important is the psychological impact on the participants, who are very likely to be empowered (Sharp, 1973, pp. 777-799). By being involved in a collective struggle, people gain a sense of agency and solidarity. This is quite different from the experience of voting or lobbying, actions that rely on promoting someone else's agency. How this process of NVA empowerment would affect participants in actions in support of devalued people remains to be investigated.

As theories, SRV and NVA are largely complementary. SRV is primarily a theory of social roles and devalued people. It does not specify a particular method of action. NVA is a theory of action and politics. It makes no mention of social roles nor gives any special notice

to devalued people. Although the theories cover separate realms, they are mostly consistent and mutually supportive. NVA provides practical methods and a framework for developing campaigns to challenge systems of oppression that cause devaluation. SRV is a way of analyzing the situation of devalued people and associated institutional arrangements that can inform nonviolent activists. Both SRV and NVA seek to challenge oppression. Both provide tools to help those with the least power.

How effective is NVA? There are few studies of the comparative effectiveness of NVA, violence and working through formal channels. Certainly NVA has often been vitally important in helping bring about social change, for example in campaigns against slavery, for women's rights, against exploitation of workers and for environmental goals. On a more local scale, there are numerous cases where NVA has rapidly brought about change after little progress had been made after years of providing information, writing letters, making submissions and lobbying. In authoritarian political systems, formal channels such as elections do not have much capacity for bringing about change. A study of dozens of transitions from authoritarian rule in recent decades showed that broad-based nonviolent civic resistance was central to most of them (Karatnycky and Ackerman, 2005).

While there are some good manuals on the practice of NVA (Clark et al., 1984; Coover et al., 1981; Hengren, 1993), there is still much to learn about how to make it more effective. Compared to the vast resources long put into both violence (military and police weapons, training and strategies) and formal channels (including elections, laws and bureaucratic rules and regulations), little social investment has been made into NVA.

Tensions and Complexities

ALTHOUGH SRV and NVA are complementary and largely compatible, especially in their orientation to empowerment, there are some areas where the connection between the two is more problematic. Three important areas where there are some tensions and dilemmas are competency enhancement, image enhancement and vulnerability.

Competency Enhancement

Competency enhancement is not central to NVA theory. However, in practice NVA participants build various competencies, such as in self-control (in the face of provocation), planning, group dynamics and collective decision-making. Partly this occurs through nonviolent action training, often provided for those preparing to engage in NVA, and partly it occurs through the experience of NVA itself. Thus, it could be said that NVA is compatible with SRV in relation to competency enhancement, but only in so far as devalued people are able to participate in NVA and noting that there is only a partial overlap in the competencies seen as most important.

There are also competencies related to particular nonviolent campaigns. For example, to join a rent strike, which involves withholding rent, an understanding of the function of rent, and the consequences of the strike for landlords as well as tenants, is vital. In general, participating in NVA fosters a greater understanding of the dynamics of power in society.

Image Enhancement

Image enhancement is not central to NVA theory. Furthermore, NVA in practice raises various thorny issues. A key question is whether devalued people should become involved in NVA. In particular, is the role of nonviolent

activist a valued one? In the community of nonviolent activists, it is certainly valued, with those taking the most sustained, principled, daring or high-profile roles in direct action commonly being accorded the highest status. But in the wider community, attitudes are more ambivalent, with some people deriding nonviolent activists as troublemakers, malcontents, “rent-a-crowd” (paid protesters), subversives or terrorists. While Gandhi, Martin Luther King, Jr. and Aung San Suu Kyi may be accorded accolades, ordinary activists seldom receive such adulation. Many people do not see being arrested and sent to prison as a valued social role even when it is for civil disobedience. Therefore, whether devalued people should participate in NVA is a difficult question from an SRV perspective.

Participation is more likely to be image-enhancing when there are lots of nondevalued people involved, especially ones with high status. Joining a “pray-in” - analogous to a sit-in - with leading church people is more likely to be image-enhancing than joining a protest disrobing. The way an action is portrayed is crucial. Media reports on NVA are well known to give excessive attention to the slightest hint of violence and to bizarre appearances or behaviors: a single scuffle lasting a few seconds could be the television version of a peaceful protest march involving hundreds of people over a couple of hours. Devalued people might risk further devaluation if they were singled out for trivializing media portrayals. Therefore, in nonviolent actions it would be important to maintain appearances around devalued participants and to promote the organizers’ own framing of events, including through alternative media.

There is a special image risk from NVA involving groups of devalued people if they are displayed as deviant and as behaving in peculiar or threatening ways. On the other hand,

image dilemmas are unlikely to arise in some sorts of NVA, such as boycotts.

Another image issue is that using NVA is usually not perceived to be as prestigious as using formal channels such as submissions, lobbying or courts. Using formal channels often involves interacting with high-status professionals such as lawyers or public officials. In contrast, most people can be involved in NVA. That is one of its greatest strengths, but it also means that the status of participants is not guaranteed to be high. So, although NVA is often far more effective than using formal channels, it may not seem an obvious choice in terms of using the most valued social roles.

The reason for this discrepancy is that formal channels are most effective for those with power, wealth and status, and are least helpful for those with fewest social and material resources. For example, in a court case between an individual and a large organization, the organization can easily use legal means to drag out the process over many years at enormous expense. NVA, in contrast, is a tool available to all on relatively equal terms, and thus can neutralize the advantages of power, wealth and status. For example, if an organization discriminates against devalued people, a court case is likely to be slow, expensive and highly reliant on legal expertise. By comparison, a campaign involving rallies, street theatre and office occupations can be undertaken at the initiative of the activists and involve many people at relatively low cost. Although the methods of NVA are not as prestigious as formal channels, there is more potential for participation and, as a consequence, image and competency enhancement through participation, assuming appropriate actions are chosen.

Heightened Vulnerability

Another vexing issue in relating SRV and NVA

is vulnerability. For a person to make a solitary protest against a powerful organization may heighten the person's vulnerability -- this regularly happens to whistleblowers (Alford, 2001; Glazer and Glazer, 1989) -- and be especially inappropriate for a devalued person. For this reason, collective methods of NVA are usually more advisable, with greater participation reducing individual vulnerability, providing mutual support and increasing the likely impact.

However, even in collective NVA there are significant issues to be addressed about safety and social supports for participants. If people with disabilities are in greater danger, this must be taken into account. For people with severe or profound intellectual disabilities, the question of informed decision-making is vital. Is participation ruled out because a person cannot fully grasp the implications of being involved? Or is participation possible if carers or advocates believe it is in the person's best interests? These are practical questions that need to be considered carefully by all involved (Martin and Varney, 2000).

For example, few people with severe intellectual disabilities would be able to help plan actions, or perhaps even understand what was happening. Some would say that people with severe intellectual disabilities should never be involved in NVA. Others would say that involvement is possible, but only in low-risk and low-cost actions. Yet others would say that every opportunity should be given for their full participation.

People with severe disabilities are at risk of being manipulated by activists, for example being put on the front lines in a protest because police are expected to be worried about being seen to cause them any harm. The opposite risk is being prevented from joining actions because of an exaggerated concern about dangers. There is no easy answer to such matters, which

require discussion, careful judgment and assessment of prior experiences (Martin and Varney, 2000). There are fewer dilemmas when it comes to nondevalued people participating in NVA in support of devalued people.

Conclusion

NVA AND SRV SHARE a concern about oppression, from complementary perspectives. NVA is a participatory form of social action. In contrast, participation in violence -- whether military forces, police or guerrillas -- is typically limited, with preference given to young men who are physically fit. Participation in some formal channels, such as writing submissions or presenting court cases, is largely restricted to those with suitable credentials and expertise. Participation in a boycott, strike or vigil is not nearly so restrictive. A high level of participation in NVA is important for success.

Issues of participation are not salient in SRV. There are no automatic answers to questions of who should take initiatives in helping people into valued roles, but it is important to ask the questions. Looking at issues of participation in relation to NVA can be a model for addressing similar issues in SRV.

Nonviolent activists can learn a number of things from SRV, including the processes of devaluation, the need to act against oppression of devalued people, and ways that image and competency enhancement can change people's lives. Nonviolent activists can also learn to look more carefully at the roles existing or created within their own organizations and by their own actions, for example to build or draw on roles that can make NVA more effective or attractive.

In summary, NVA and SRV have synergies both as theories and as practices, with each

having potential benefits for the other. There are bound to be some tensions, but these can be used creatively to probe assumptions.

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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. and Zauha, H. (1973). *Citizen Advocacy And Protective Services For The Impaired And Handicapped*. Toronto: National Institute on Mental Retardation.

Hildebrand, A. (2004). *One Person At A Time*. Brookline, MA: Brookline Books.

Jake's Story – Through an SRV Lens

Andrea Quinn

EDITOR'S NOTE: *Andrea Quinn is the mother of three-year old Jake. She is also a student in the Developmental Services Worker program at Loyalist College in Belleville, Ontario, Canada. This article was adapted from an assignment for a college course on Social Role Valorization (Wolfensberger, 1998; Race, 1999; Osburn, 2006) taught by Jane Barken. It reflects the experiences of one family. I hope that this article is instructive for other families as well as for service workers in agencies involved with families. I invite readers, particularly other parents, to consider writing to the Journal about their own experiences, with SRV in mind.*

JAKE HAS AUTISM. Not so long ago, that might have been how I described my son. The stereotypical rocking, the glazed eyes looking right through you, the lines of random objects and the spinning, oh Lord the spinning. And when there was no screaming, the utter silence. In a rush to defend against those questioning/pitying/condemning stares, they were often the first words that came to my stumbling lips. These days, I still often describe Jake first as having autism. Now however, we wear the label with a gleeful smile and speak up so that others may see hope.

Jake is a bright, attractive and engaging three-year-old on the cusp of owning the

world. He loves to learn just about anything you care to teach him, is a budding singer, a truck enthusiast and an ardent outdoorsman. He is a runner, a jumper and a dancer in perpetual motion, keeping his Nana and Papa young as they proudly find new ways to show off their first grandson. He enjoys an extensive library of books and considers Curious George to be the comic genius of the ages. Jake adores Bob the Builder and is always up for the job of apprentice whenever mommy is 'fixing' things. He is a talker and a joker who likes laughing out loud and occasionally, when nobody is really watching, a daydreamer. I don't know what he is dreaming about but whatever it is, I'm sure he'll accomplish that too.

Devaluation in Jake's Life

LIFE FOR JAKE is always evolving. As an infant, he was celebrated by all, but as his unusual behaviours started developing, there was a defined shift away from him. People stopped speaking typical 'childspeak' to Jake himself and began directing their comments (which were nearly always limited to what an attractive child he was) to me. It was as if he had been defined by his condition and people were uncomfortable with the nature of it.

In the eyes of society, Jake is devalued due to his role as a developmentally handicapped

child. Roles make a person understandable and predictable, yet the very nature of autism is unpredictable and oftentimes incomprehensible, making it difficult for people to see beyond that one role. People assume that those with autism fall into one of two extremes -- either they are severely mentally handicapped or a "Rainman." Either way, the role is so powerful it causes society to identify Jake firstly as a devalued citizen and only secondly as a child with skills, expectations and possibilities.

Significant Wounding Experiences

TWO OF THE MANY WOUNDS that Jake has experienced are (1) lack of relevant supports and (2) low expectations. To receive services in a timely fashion, you must be wealthy enough to purchase them. While we are more fortunate than many, we are increasing our yearly debt at an alarming rate, and are unable to even dream of paying the thousands of dollars required for treatment. Jake has suffered from terrible delays in service due to exceptionally long wait periods for government funded services. A number of these delays have been the fault of service providers. With autism, every day counts. Jake could have suffered the *immeasurable* effects of delayed diagnosis and treatment due to lack of money if he did not have someone to navigate the system and advocate for him.

Lack of relevant supports has also been a factor in Jake's overall progress. While he is receiving specialized IBI (Intensive Behavioural Intervention) programming, all his other supports are generalized with no specialized support for someone with autism. An example of this is speech therapy. Jake receives one hour of speech therapy per month with no specific tailoring to his unique needs. This completely

discounts the need for constant reinforcement and structure, and the urgent need to develop communication skills. If we don't give these children a way to communicate with us that is acceptable to them, the very nature of their disability means they will often lose interest in communicating altogether!

Others' low expectations of Jake have also been wounding. Right from the start the bar was set too low. Jake's therapists have played a constant game of catch up, trying to come up with new programs as fast as he learns them. Perhaps because of his exceptionally young age, he has been achieving astounding results. However, he has been limited by the fact that no one ever expected so much so quickly. They were unprepared and their low expectations have led to uneven rate of learning as, each time they search for more programs, Jake loses interest and has to be re-engaged.

Each of these wounds has far-reaching effects. The stress over finances, the endless need to find proper support, the time required to develop and apply your own program and the frustration from the continued low expectations of Jake even in light of his capabilities have added up to an unbearable family strain. Lack of family stability can lead to further wounds if not monitored closely.

Positive and Negative Social Roles in Jake's Life

JAKE POSSESSES a tremendous variety of positive social roles. He is a son, a grandson and a nephew, a nature lover, truck admirer and balloon enthusiast. He is also a budding reader, a captivated astronomer and an eager daycare student. Fantastic roles for a three-year-old! Unfortunately, Jake already has several negative social roles as well. He is a person with a

developmental disability (autism), a Behavioural, Speech and Occupational Therapy client, an ACSD (Assistance for Children with Severe Disabilities) and SSH (Special Services at Home) recipient and a heart patient.

While this is a significant number of negative roles, it should be noted that by receiving many of these services/therapies in the short run, Jake may benefit in the long run by adding to his positive roles. Behavioural Therapy may allow Jake to become a Kindergarten student, Speech Therapy may promote social acceptance into groups and Occupational Therapy may increase his ability to eat food, thereby ensuring good health.

The Devaluing Social Role of Human Service Client

TO DATE we have used an ever-increasing number of human services for Jake, all of which have contributed to his being seen by others in the human service client role. There was the *Public Health Nurse* we called for a referral to an *audiologist* and the *Pediatric Specialist* whose confirmation of autism was required in order for us to proceed any further. Once this was received, we proceeded to a *counseling service* who lined us up with a *Psychologist* and enrolled us in *Infant Development*. The *Psychologist* performed a series of tests enabling us to pinpoint Jake's autism as being on the severe end of the scale. A *Waitlist Co-ordinator* was assigned to us while we endured the interminable IBI (Intensive Behavioural Intervention) wait list. *Infant Development* was begun as soon as possible to keep Jake stimulated. However, in January of 2005, we no longer fit the criteria and had to terminate service. IBI began that February, which added three *Instructor Therapists*, a *Senior Instructor The-*

rapist, a *Director of Service* and a *Doctor* specializing in Autism to our little group. At this time Jake also qualified for *Special Services at Home* and *Services for Children with Severe Disabilities*.

While we were proceeding through the above-listed services for official diagnosis and treatment, I was adding other services as I could acquire them. The first was a *Family Consultant*. He was able to provide a Family Service Plan with the recommendation that Jake attend day-care for 'socialization purposes.' This meant we were able to get a *Case Worker* and a subsidy so Jake could go from the two mornings a week we were currently able to afford to five mornings with a lunch. I enrolled him in *Speech and Language Therapy*, which unfortunately required a six-month waiting period. I managed to secure a *Dietitian* to address Jake's dietary issues. He is also receiving *Occupational Therapy*. And we can't forget to include the multiple *Doctors* at two *clinics* and a *hospital* whose service I would say was really no service at all -- which, however, in the light of the local medical crisis and the lack of any real education in autism, can be forgiven I guess.

Strengthening Positive Roles/Lessening Negative Roles

IN ORDER TO STRENGTHEN Jake's current social roles I will continue to supply many opportunities for him to be with his father and grandparents as well as with those who enable him to follow his own pursuits, e.g., walks in the woods, visits to truck stops and the library, etc. He will remain in his current daycare facility, rather than attend 'Junior Kindergarten,' in order to continue the benefits of the higher student/teacher ratio and age-appropri-

ate peers as long as possible without the anxiety of a new setting. We have also begun to learn some of the constellations and have so far taught Jake where to find Venus!

As for the negative roles, we continue to work hard to diminish Jake's role as a client. Occupational Therapy will still take some time. Meanwhile Jake is learning to eat solid food, to perform functional skills such as toileting and dressing on his own, and to manage his motor co-ordination. His language level is above average so Speech Therapy is likely to end in the near future. As well, he is set to be discharged from IBI therapy within the next six months. The overall increase in Jake's competencies and social skills will encourage other people to see him first as a valued individual and only secondly, if at all, as a child with a developmental disability.

Upcoming new roles for Jake will include integrated Kindergarten student, library cardholder, swimmer and perhaps sports team or club member. These will be accomplished as with everything else, one step at a time, with a keen eye to Jake's preferences as an individual, and with high expectations.

Two SRV Themes of Particular Relevance

THE *Conservatism Corollary* states that we must use the *most valued options* and *positive compensation* for individuals. This is something we have always been extremely aware of when it comes to Jake's appearance and manners. The area where we live is notoriously stereotyped as the "armpit of Ontario," "full of teenaged mothers" and "poor people." The imagery of these stereotypes is appalling. In order to keep Jake as far away as possible from these negative connotations, we have always taken great care to dress him well, keep him

tidy and provide him with the best manners possible for a young child. Jake's autism often causes him to have public 'meltdowns' which usually command a great deal of interest from bystanders. However, due to his other positive outward attributes, he is often simply mistaken for a somewhat overindulged child. We can live with that.

Personal social integration and valued social participation is something that has been a difficult decision for us in one regard. While regular Kindergarten was the obvious choice for increasing valued roles, we couldn't disregard the lure of specialized services. What good would it be to send Jake to school only to have him anxious, falling behind and outcast? In a segregated class he would be offered specialized support, an individualized curriculum and peers with equal abilities ... and therein lies the trap.

I came to believe that a significant risk to Jake's well-being would be to attend a 'Special Education' class. These classes are typically the repository for children with behavioural challenges and as such they often receive only basic instruction as a group with low expectations for individuals. Specialized support doesn't offer Jake opportunities to socialize with others. An adapted curriculum only means lowered expectations.

Conclusion

JAKE'S ABILITIES are yet unknown. His potential is yet unlimited. With integration he will be exposed to positive models and shared values. He can receive support through a school support program which teaches the teachers how to support learners with Autism Spectrum Disorder. He won't be in a group maintained solely for those with disabilities. In the

end, we decided to offer Jake the chance at integration and participation to the full extent of his capabilities and desires.

Author's acknowledgment

"If I can stop one heart from breaking, I shall not live in vain." - Emily Dickinson. *"We all want to change the world."* - The Beatles. Thank you Jane, for helping me to accomplish the first in the most satisfying of ways and for supporting my boldness to attempt the last.

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Since you are reading this journal,

then why not tell someone else about it? We believe Social Role Valorization is an important tool that concerned individuals can use to address social devaluation in people's lives. As someone who shares that belief, encourage others to read and subscribe to the only journal dedicated specifically to SRV. Information available at <http://www.srvip.org/>.

INTERVIEW

Chris Liuzzo, Director of Residential Services at the Rensselaer County Chapter ARC (New York, USA)

Guy Caruso

EDITOR'S NOTE: *One of the purposes of this journal is to disseminate relevant information about SRV (Social Role Valorization)¹ and, by extension, about PASSING (Program Analysis of Service Systems' Implementation of Normalization Goals).² Our overall intention in disseminating information about SRV and PASSING is to "diminish the plight of socially -- and especially societally -- devalued people."³ Given our intention and purpose, we thought it would be fruitful to interview human service programs and agencies which are trying to implement SRV.*

This is the first in a series of articles, which will run over several issues of this journal, comprising interviews with directors and managers of human service agencies and programs that try to incorporate SRV theory into their service. We hope that these interviews will prompt further dialogue and cooperation among SRV colleagues, as well as offer valuable insight to those who are new to, or less familiar with, SRV.

Please note that we intend to interview directors and managers from a varied range of human services -- in terms of type, size, location,

people served, history and experience with SRV. Also note that these interviews are essentially unedited (except for format), and thus they are a glimpse into the perspective of the interviewee as regards SRV and their service. These perspectives will likely vary, which we believe will enrich the dialogue about SRV.

I would like to thank Chris Liuzzo for his time and effort spent in answering questions, and for his openness to being interviewed, particularly in this inaugural interview.

Q: What is your position at the Rensselaer County Chapter (RCARC) of NYSARC, Inc.?

A: I have been the Director of Residential Services since 1996, ten years. In this position, I have overall administrative responsibility for 155 people with disabilities living in approximately 70 settings, with 225 to 250 staff.

Q: Tell the reader about the history of RCARC.

A: The RCARC is a little over 50 years old. It was founded by very involved parents as an educational program for their children who were not being appropriately educated in the public schools. As the children became older, the parents created work programs and then residential services as well. The organization has tried to be innovative and progressive. Our founders had a progressive streak in them.

Early on, they adopted progressive ideologies. Our ARC chapter has been blessed with people who think differently.

Q: When, why and how did the RCARC become involved in Normalization, PASS,⁴ SRV and PASSING?

A: Some of our founding parents participated in Wolfensberger-conducted Normalization and PASS events in the 1970s.⁵ This experience was very powerful for them as it supported their vision for their children's future. Staff began attending such events probably as early as the late 70s.

Q: Why did you choose SRV over some other 'best/promising practice'?

A: I believe that all other 'best practices,' consciously or not, are founded on the SRV principles. What else is there really? Person-centered planning is grounded in SRV, as Beth Mount and John O'Brien have indicated. I believe that Tom Nerny, who really promotes self-determination, would say SRV influenced his thinking greatly. The premier writers and leaders I have been influenced by have a direct link back to Syracuse, New York (USA) and the work of Wolfensberger's Training Institute. SRV is the godfather from which the other 'best practices' have sprung. Person-centered planning and self-determination came to mind.

When I was first exposed to Beth Mount's Personal Futures Planning, I thought "this is user-friendly model coherency."⁶ A few years ago, we invited Guy Caruso and Beth Mount to our agency for a two-day event in which they compared and contrasted person-centered planning and SRV theory. We did that to point out that person-centered work is grounded in deep ideology.

Take a look at John O'Brien's 'five accomplishments.'⁷ They were not picked out of the air. They are direct descendants of the 'wounding experiences' taught in SRV workshops. For example, the 'accomplishment' of developing and maintaining relationships is the 'cure' for the wound of relationship loss and discontinuity.

If you are not grounded in the ideology of disempowerment and wounding, then person-centered planning is little more than a cute exercise. You have to understand WHY one engages in such difficult work. Without that deep understanding, one is apt to lack perseverance in the face of failure. You have to understand what you are trying to overcome.

Many leading thinkers were trained in Syracuse or have a connection to Syracuse. I received my Master's degree from Syracuse University, and was tremendously influenced by the training I had then in Normalization and my attendance at PASS workshops. Normalization and then SRV resonated in me from the very beginning and I have found nothing as powerful since.

Q: Is SRV training a major part of the RCARC residential program staff training?

A: Yes, SRV is and has been part of the ideology of our residential services. We do a full three-day SRV event at the agency every other year. Routinely, every other month or so, I do a mini-SRV for all new staff members, covering the wounding life experiences of people with disabilities, and other SRV principles. We have built SRV into our training model. Staff meet with some parents of people we serve, which we feel helps staff be grounded in who the people are we serve and to understand how parents feel and what they want for their children. We do not use SRV language in every

training event, yet the themes of SRV⁸ are definitely part of the training we do.

Q: How does your program implement SRV training?

A: As I said, every other year we do a full fledged three-day in-house SRV event for as many staff who wish to attend. We occasionally send people to out-of-agency SRV training in Massachusetts or Pennsylvania. Episodically, our staff attends PASSING events. Twelve or so management staff have gone to PASS or PASSING. Also, some staff has gone to what I consider SRV-related events that Wolfensberger presents (e.g., How to Function with Personal Moral Coherency in a Disfunctional Human Service World).⁹

All new staff attend a two and a half-hour hors d'oeuvre (an appetizer) of SRV that I personally teach. I cover the wounding life experiences of people with disabilities and devalued roles, especially the eternal child, pity/charity, and less than human roles. I talk about social devaluation of people and how we can help people assume valued roles. I strongly caution staff that this brief event is in no way a true SRV event. If after this event there is a keen interest then staff are encouraged to attend a full three-day SRV workshop.

Q: How does your staff apply what it learns from the training in service to people with disabilities, their families, as well as other staff?

A: SRV, PASSING and other sources of wisdom helped us to realize how far off we are supporting people, especially in group settings. For example, we know that an eight-person group home can only be improved so far: it is inherently problematic in so many ways.

This knowledge has led to the creation of new ways of supporting people as well as new organizational structures.

We also know that smaller, more individualized settings can also fall far short of the quality SRV would demand. We keep trying to ask the right questions, build in safeguards and constantly reevaluate what we are doing.

By applying the SRV-related strategy of person-centered planning, we have been able to design settings that allowed us to close one group home. More recently, with the aid of new funding from the New York State Office of Mental Retardation and Developmental Disabilities, we are in the process of closing another one. Now we struggle to insure those new settings are of higher quality -- and it is a struggle.

When people move from a group home or die, we do all we can not to put another person into that vacancy ... We try to approach things in another way now, starting from scratch on an individual model of support/service. We ask a family/person requesting service what path they would like to take. However, if the family is in crisis, then they are apt to pick a group home model of service because it already exists. If not in a crisis, families are more often willing to do a custom fit model resulting in more individualized services and supports.

Q: What results have you seen from SRV training? For example, have service recipients gotten and held onto valued social roles? What 'good things of life' have they gotten access to¹⁰ as a result of those roles?

A: People have played and continue to play many positive roles: worker, homeowner, spouse, and a vast array of positive community memberships such as in churches, firehouses, social organizations, etc. The 'good

thing' in life is, of course, relationships with others in the community.

We were remarking just the other day how little we sometimes know about the connections people make. Sometimes, when a person we support dies, we meet people at their funerals we had no idea were part of their lives. And we are gratified by that.

Of course, the struggle is to expand the numbers of people for whom these positive things are happening. We are entirely cognizant that they happen for too few people and that even for those for whom it happens, the results are often meager, or short lived.

SRV sets a very high bar. We miss it all the time, graze it often and grab and hold it all too infrequently.

Q: How does your program take the SRV concepts and make them practical to staff?

A: We don't always use the language of SRV, but the concepts are routinely used. For example, we may not use the phrase 'life-wasting,'¹¹ but when we look at someone's day, we have that concept in mind. Management provides opportunities for discussion with staff using SRV concepts, often an 'if this, then that' perspective.¹²

The practical application of SRV theory is not always readily apparent to staff -- or to me, for that matter. What we try to do is to reinforce one another to use it in daily problem solving, the design of new supports and in evaluating what we do.

Q: What follow-up do you have for the SRV training?

A: We hold retreats that stress SRV ideology. For example, we used an article by Michael Kendrick on 'right relationships' for staff dis-

ussion on how we can better support people who are becoming older citizens. In March of 2006, we sent a key staff member for a week to Michael Kendrick's and Jeff Strully's leadership institute in California.

For me, SRV flows through everything we do. I am always using it as my framework of thought. While I may be the spark plug for this, other competent staff have become leaders who are well versed in SRV theory and person-centered planning.

Beth Mount will be here to conduct a 'Circles of Support' retreat, which I believe has a direct line to SRV ideology woven all through its fabric. We try to have Beth present once or twice a year. We have sent staff to her apartment in New York City to discuss and work on specific issues or a particular problem. I find her to be one of the most sincere, approachable and humble proponents of SRV and person-centered work in the country.

Q: What supports do you have in place to nurture learning and implementation of SRV training?

A: We used to have an SRV learning group for people who had attended a full SRV training and PASSING. We have not done this much recently. I recommend doing so as it helps people sort through their experience, and supports people as they change how they provide supports/services and how they work within an agency to do so.

Q: Have you seen any changes in staff competence and skill at different levels because of SRV/PASSING training?

A: Yes, I have seen changes particularly at the supervisory level and up. We now have more sophisticated thinking by our supervisory

staff. For example, about half of the people we support are now aging, and staff struggle and sweat to apply SRV theory to their thinking about services for older adults. This is a great challenge for us and for the entire society. We work hard to mold our supports and services around a person, based on that person's needs, versus the needs of a group.

We have used Appreciative Inquiry (AI) -- which, by the way, looks and feels an awful lot like person-centered planning -- as a tool to examine organizational issues. AI is a technique of organizational change. I believe its creator is David Cooperrider of Case Western Reserve University. Quoting him, it "involves the discovery of what gives 'life' to a living system when it is most effective, alive and constructively capable in economic, ecological and human terms." It is based on the "simple assumption that every organization has something that works well and these strengths can be the starting point for creating positive change."

Sounds a lot like the basis of person-centered planning techniques, doesn't it? When I read the AI literature, it resonated deeply because it sounded so much like person-centered planning ideology.

SRV has helped us form the questions we want to ask during the AI process. Those questions help move us in the direction we want to go. For example, if we want to get smaller and be more intimate as a residential service, then we have to look at what we do (e.g., operate group homes) and ask how we can transform from them to supports far more individualized. If you don't ask the questions, then you don't move. SRV provides the framework for those questions.

A great book to read is the New York Times bestseller *Good to Great* (2001) by Jim Collins. Collins points out that great organizations

don't become great overnight. What they seem to do is ask the same questions over and over, slowly making progress until one day, at some magical and often unrecognized moment, it surges forward. We do this by asking SRV-related questions. I truly believe that organizations move in the direction of the questions that they ask of themselves.

Q: Have you tried to build in any organizational processes for holding the organization and staff accountable for SRV implementation? Like what? Have you seen any benefits from these efforts? Any struggles?

A: Accountability: everyone uses the term, but what a hard thing to get a hold of. We hold ourselves accountable on 3 levels:

1. The 'good things,' such as those that SRV would demand;
2. Things driven by funding sources and other oversight bodies;
3. Things driven by our own internal fears and anxieties.

Unfortunately, the latter 2 categories often consume us.

Yes, we have tried to hold ourselves accountable for achieving positive outcomes for people. We have tried, over and over, using relatively easily understood outcomes (e.g., the well-known 'Five O'Brien Accomplishments,'⁷ to which we have added a sixth of 'health and wellness' as benchmarks).

It is an ongoing struggle to hold our feet to the SRV fire. We measure many things which have little to do with those accomplishments: medication issues, money issues, physical safety issues, critical incidents, and on and on. The time and energy to take these measurements -- some required by regulation, some self-imposed -- detract from our ability to 'measure' the so-called 'good things.'

It is a constant balancing act ... measure what 'we have to' or what we are driven to measure by fear and anxiety, versus measuring more meaningful things. We are aware of the struggle and are incredibly self-conscious of our daily failures to get at the good things.

Q: Has SRV training helped in forming future leadership for the agency?

A: Without a doubt, no question! Anyone we consider a potential leader has been or will go to SRV training. We developed a 2005 - 2006 leadership development program for six direct support staff we thought had leadership ability. Part of this leadership program required the participants to read SRV materials (e.g., handouts from a full-fledged SRV workshop, and a Wolfensberger article on SRV) and to write a paper on how they would implement SRV theory in their work at the agency.

Q: What has been the hardest about using SRV as a training curriculum?

A: It is hard to get staff together for three days. For direct service participants it means finding coverage for their positions, which means paying the participants, paying for the coverage and often at overtime rates. So the duration of a full-fledged SRV event and the cost for us is one hardship. It is less expensive to send one person to an out-of-agency training than to hold a full-fledged SRV event at the agency.

Also, in New York State, there is no active community around SRV training, and we are solo in our efforts. SRV seems to have a cloud around it and some people feel it is old stuff.

In addition, when people experience SRV and especially PASSING, some may have difficulty in implementing it. They may become focused on an issue and misinterpret it or over-

emphasize it, for example, age-appropriateness -- taking away a teddy bear from an adult. We have to help people sort out their SRV experience; the PASSING experience seems to help people finally get what the issues are and how better to implement them.

Q: What has been the easiest about using SRV as a training curriculum?

A: I do not know if SRV is ever easy. It is long, expensive, intellectually demanding, and it turns people on. Turned on people become internal champions at our agency and they really push me and the agency. Because we find that so few new people we hire have heard of, or experienced, SRV, they have no bias against it and are very open to what SRV teaches them.

Q: What would you recommend to other agencies possibly interested in providing SRV learning opportunities?

A: Get wired to the SRV network in Pennsylvania or Massachusetts and call SRV trainers. Send people to SRV, PASSING, and Wolfensberger workshops. Get ready to take cover as some people will come back from such training and push you and question you on why you and the agency are doing what it is doing in serving and supporting people. As an administrator you need to be prepared to be pushed and should not punish the pushers, but support them. You need to be personally prepared to nurture people (especially after PASSING) as staff learn truths that can make them cry about what we/they do to the people that they serve. Staff can be emotionally hurt from what they see when on a PASSING visit (e.g., to a nursing home facility) as it touches their hearts and sensibilities. I find people are both charged up to create change, and are also sensing some

despair as to how much has to be done by them and our agency to really create change for people. We do a lot of emotional hand holding.

Q: How have staff, families, people served, and others reacted to the program's investment in SRV training, especially when others have downplayed such teaching?

A: I have personally downplayed this somewhat. By that I mean I do not actively advocate in New York State for agencies or the larger trade associations to begin teaching SRV or sponsor learning events. The audience is not there. I focus internally, on my own organization. As well, the climate in New York State to do such training is neutral at best. I have found that most people who attend the short SRV event I do, or the full-fledged SRV events, are very positive about the experience and want to learn more and move forward.

I have found that some of the SRV teaching has raised issues among women as well as staff who are gay/lesbian in that they sense bigotry in the material. This has occurred enough times to make me ask why this is the case and why SRV material raises such issues. This is something I believe that SRV trainers need to address.

Q: What do you see as the future for your program and its involvement with SRV?

A: I want us to maintain what we are doing, which is an internal short SRV training for all new staff, as well as our doing a full SRV every other year for the agency. I will still send people outside the agency to SRV, PASSING, and related Wolfensberger events (e.g., How to Function with Personal Moral Coherency in a Disfunctional Human Service World).

I wonder, when I retire, will SRV training at

the program also be retired, fall off the map both at the agency and in New York State? Time will tell if new leadership will carry on SRV. I hope so and that my efforts in some way make this occur.

Q: Why are you so personally invested in SRV?

A: I was exposed to Normalization at a very impressionable time in my life (i.e., graduate school) and it hit me like a ton of bricks. I immediately understood its impact on how I would serve people. Normalization and then PASS training completely shaped me and how I look at people I serve. Normalization, and later SRV, grounded me in what I do in my work and I believe has helped in the formulation of my positive reputation in New York State as an innovator and leader. SRV has shaped all my professional work.

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Endnotes

1. For more information on SRV, see Wolfensberger, 1998; Race, 1999; and Osburn, 2006.

2. For more information on PASSING, see Wolfensberger & Thomas, 1983; and a July 1999 handout available from the Training Institute (315 473 2978) entitled *Overview of "PASSING:" A Social Role Valorization-based human service evaluation tool*.

3. SRV Council (North American Social Role Valorization Development, Training & Safeguarding Council), 2004, p. 83.

4. Normalization is the set of ideas out of which SRV developed, and PASS is in a sense the predecessor of PASSING.

5. Professor Wolf Wolfensberger was the foremost proponent of Normalization in North America, and the

author of PASS. See Wolfensberger, 1972; and Wolfensberger & Glenn, 1975a & b.

6. Model coherency can be described in a colloquial way thusly: "The right servers should be using the right materials, methods, and language, in the right settings, in order to do the right thing for the right recipients, who are grouped in the right way" (Wolfensberger, 1998, p. 116). Various elements of model coherency are included in PASS and PASSING.

7. O'Brien's 'five accomplishments' are described in O'Brien, 1989, pp. 19-23.

8. The most current themes of SRV include: the role of (un)consciousness; the dynamics and relevance of social imagery; the power of mindsets and expectancies; the relevance of role expectancy and role circularity to deviancy-making and deviancy-unmaking; personal competency enhancement and the developmental model; the concepts of relevance, potency, and model coherency of measures and services; the importance of interpersonal identification between valued and devalued people; the pedagogic power of imitation, via modeling and interpersonal identification; the importance of personal social integration and valued social participation, especially for people at risk of social devaluation; and the 'conservatism corollary,' or the concept of positive compensation for devalued status.

9. To find out more about this and other SRV-related workshops, please contact the Training Institute at: 800 South Wilbur Avenue, Suite 3B1, Syracuse, NY 13204 USA; 315 473 2978.

10. See Wolfensberger, Thomas & Caruso, 1996.

11. 'Life wasting' is a phrase used to describe one of the major results of the wounding of socially devalued people; namely, that devalued people's lifetimes go by while they are denied valued opportunities and experiences, and their potential is destroyed. See Wolfensberger (1998), p. 21.

12. See Wolfensberger, 1995.

Dr. GUY CARUSO is the Western Coordinator for the Institute on Disabilities at Temple University in Pennsylvania (USA), a consultant for the Commonwealth Institute, and a member of the North American SRV Development, Training & Safeguarding Council.

The citation for this interview is:

Caruso, G. (2006). Interview: Chris Liuzzo, Director of Residential Services at the Rensselaer County Chapter ARC (New York, USA). *The SRV Journal*, 1(2), 39-46.

Plan on attending...

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Another Social Role Valorization Lesson Drawn From the Public Media

Susan Thomas

IN AN ARTICLE in the forerunner of this Journal (see Thomas, 2001), I had tried to identify items in the news and ordinary media that teach a Social Role Valorization (SRV) lesson, or support an SRV claim, or otherwise show SRV's applicability in 'the real world' (For more information on SRV, see Wolfensberger, 1998; Race, 1999; and Osburn, 2006). Having apparently found a role-niche for myself by doing so, I continue this tradition with another installment of such a lesson.

The January 1997 *Reader's Digest* (see McCabe, 1997) carried the story of Walt Kennedy, a former college basketball legend, and later a member of the world-famous Harlem Globetrotters. He had also coached several high-profile high school basketball teams in Washington, DC. When multiple sclerosis confined him to a wheelchair, he at first kept up his high school coaching career until it seemed impossible to continue. For 10 years, he ceased coaching, but said that he grew 'hungry' to coach again. (Note how the concept of role avidity or role hunger [see Lemay, 1999, p. 233] is not just a sociological or academic concept, but is so real that people not schooled in role theory will use that very language.) So, after a 10-year hiatus, he returned to a coaching job, but at a much lower profile school. Interestingly, and mentioned only almost as a footnote in the article, Kennedy coached this team for no pay -- another example of an unpaid but valued work role, and one that to Kennedy himself was even more important than his paid

job as a teacher (at a different school).

Coach Kennedy was very demanding of the team, and stinting rather than lavish with praise, even when his team won. For this reason, it took a while for the boys on the team to grow to like him. But he never wavered in his very high expectations of them, and though the team did lose some games, he was so competent as a coach -- and had such a prestigious background -- that he kept the position.

At one play-off game held at an opponent's school, the locker room was in the basement. It was only then, after approximately half a year of working intensely under this man's coaching, that the team noticed "for the first time in five months something about Kennedy they'd completely forgotten: he was in a wheelchair" (p. 220). This illustrates how the competent carrying out of a valued role can overcome or at least compensate for a condition for which a person would otherwise be devalued, to the point that people who engage with the person in that role no longer even notice the devalued condition.

The team Kennedy coached won second-place in the Alabama state basketball finals in March 1994. Kennedy continued to coach the school's basketball team for two more seasons, despite his very visible and confining impairment.

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SUSAN THOMAS is the Training Coordinator for the Training Institute for Human Service Planning, Leadership & Change Agency, Syracuse University, Syracuse, NY, USA. She is also the co-author of PASSING.

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Thomas, S. (2006). Another Social Role Valorization lesson drawn from the public media. *The SRV Journal*, 1(2), 48-49.

Andrew

*Tall, thin, and handsome once,
 he sat in the cafeteria and spoke of the time
 before fear and Haldol had purchased his mind.
 He sang of cars and a red-haired wife
 in the time before the voices came to stay
 in the room behind his brain.
 He told of a blow to the head at fourteen
 which horrified a guileless cousin
 and awakened the whispers for his ears alone.*

*This sharecropper's son who never once met a psychiatrist with
 skin to match his, pleaded in his blues baritone
 to convince me of his mental illness.
 The pain he described beat in his blood
 where there is no drug to call up forgiveness,
 no coaxing of tenderness for a child long grown.
 The misery of diagnosis is pumped into these rooms
 through vents, like a pestilence
 in desperate need of exorcism.*

*O Christ, come down and be in this place.
 Drink some coffee and have a smoke.
 Kiss the nurses and send them to bed while you host a dance in the dayroom.
 At night give him sweet untranquilized sleep.
 Grant him natural dreams of Arkansas and automobiles.*

Save him with a found father's embrace.

Jo Massarelli

“Rudolph the Red-Nosed Reindeer:” A 1939 Christmas Story on the Positive Influence of a Valued Social Role

Carl Cignoni

EDITOR’S NOTE: *The article in this issue by Susan Thomas entitled “Another Social Role Valorization Lesson Drawn From the Public Media” examines items relevant to SRV in the news and ordinary media. This article takes a similar tack but in the realm of cultural tales and music. I received the following article from an author who apparently was inspired by the spirit of Christmas. The author points out how the well-known children’s story of Rudolph can entertain but also can illustrate how valued roles are part of the fabric of our society, embodied in songs, fables and tales, for example. Although a bit more of a lighthearted approach than a typical four-day SRV workshop, simple stories including children’s ones can be instructive in their own way. We welcome your letters to the editor or manuscripts describing similar cultural tales, songs or poems which you are familiar with, as well as your comments about this article.*

MOST NORTH AMERICANS as well as many others around the world probably know the song and story of Rudolph the Red-Nosed Reindeer. I certainly do from my childhood, but it was not until several years ago, watching a cartoon of the story on videotape with my children, that I realized it is a story of Social Role Valorization (SRV). The following is an analysis of the story from an SRV perspective.

THE STORY was written by Robert L. May in 1939 for the Montgomery Ward department stores and published in a book to be given to

children at Christmas time. Johnny Marks, May’s brother-in-law, adapted the story into a song which has been recorded by many artists, the most popular by Gene Autry in 1949.

You know Dasher and Dancer
And Prancer and Vixen
Comet and Cupid
And Donner and Blitzen
But do you recall
The most famous reindeer of all?

Rudolph the Red-Nosed Reindeer
Had a very shiny nose
And if you ever saw it
You would even say it glows
All of the other reindeer
Used to laugh and call him names
They never let poor Rudolph
Play in any reindeer games

Then one foggy Christmas Eve
Santa came to say
Rudolph with your nose so bright
Won’t you guide my sleigh tonight?

Then all the reindeer loved him
As they shouted out with glee
Rudolph the Red-Nosed Reindeer
You’ll go down in history

AN UNDERSTANDING of social devaluation teaches us that a person becomes devalued when they have a significant difference that is negatively valued by the majority or ruling seg-

ment of their society. Rudolph's red nose is valued negatively by the other reindeer, causing him to be devalued. His devalued status is expressed through the treatment of him by the other reindeer. They reject and ridicule Rudolph and drive him away. Thus Rudolph experiences the wounds of rejection, distantiation, being an object of pity ("poor Rudolph") and ridicule, a lack of typical experiences of playing in any reindeer games, and the loneliness of having no friends.

The video cartoon which I watched with my children expands on the basic story and adds visual images that reinforce both Rudolph's devaluation and wounding as well as his ultimate valued status. The video shows a sad Rudolph being driven away by the other reindeer as they torment him, referring to his nose as "Twice as big and twice as bright" and telling him "Go home Rudolph, I hear your mother calling." In another cartoon video, Rudolph's father kicks him out of the house because of his nose, after first trying to cover up his glowing nose with dirt.

The song and story tell us that, fortunately for Rudolph, one Christmas Eve became very foggy and Santa Claus was unable to fly his sleigh. Santa then recognized Rudolph's glowing red nose as an asset. Santa invited Rudolph to fill the valued role of guide of Santa's sleigh. In the video Rudolph's red nose shone through the fog like a beacon. Rudolph returned home on Christmas day to a hero's welcome and his name "will go down in history." In the video I saw with my children, Rudolph is carried into Santa's village on the shoulders of the other reindeer to a resounding welcome with lots of hoopla.

THIS STORY is also an example of how one's negative difference can be turned into an asset

if someone recognizes and promotes the opportunity. In this case it was not Rudolph, but Santa who saw this. Santa not only had the capacity to see Rudolph's gift, but also had the authority as the "ruling segment" of his society to elevate Rudolph into the valued leadership role.

WHILE PREPARING this article I could not help but wonder what experiences might have led Robert May to think of such a story. The author could not have had SRV in mind when he wrote the story in 1939, as Dr. Wolfensberger had not put forth the theory yet. The story supports the premise of SRV, that gaining valued social roles can lift one out of devalued status and increase the opportunities for the good things in life of one's culture. I couldn't find any documented influences on May, such as an impairment that he had or that someone close to him had, to produce such a story. I could propose, however, that the premise of SRV is ingrained in our culture, even though not articulated in a formal way.

My limited research found few other such stories, although if anyone can find other examples, I would be interested in learning about them. The lessons of "Rudolph the Red-Nosed Reindeer" are quite positive, and as it is still a well-known Christmas song and tale, the moral of the story could be drawn out for our children.

CARL CIGNONI is a long-term SRV and PASSING teacher. He currently works in a house of correction helping prisoners to be (re)integrated into valued society after they serve their sentence.

The citation for this article is:

Cignoni, C. (2006). "Rudolph the red-nosed reindeer." A 1939 Christmas story on the positive influence of a valued social role. *The SRV Journal*, 1(2), 50-51.

Where Were We?

James Brunault

I STOOD AT Steve's wake, looking around at the various people who showed up. I listened to people reminiscing about his life and I wondered ... where were you when Steve was still alive?

I HAD BEEN WORKING with Steve about five years when he died. Steve had a seizure disorder. One night while he was sleeping, he had a severe grand mal, and it interrupted the electrical impulses to his heart. He had a heart attack and died. The staff person working with Steve had immediately called 911 and also performed C.P.R. in an attempt to help keep Steve alive, but it was too late.

In the five years that I worked with Steve, first as a direct care overnight staff in the house where he lived and later as the house manager, I had come to know Steve pretty well. He worked at Pizzeria Uno, and loved to explain to me the various aspects of his job and what he had done that day. Steve was a big guy, but a gentle guy. He felt a lot of responsibility for other people and loved to give presents. He would often present things to people with a shy smile, saying something like, "I thought you might be able to use this." I'm not sure that I have a better way to say it than Steve was a good guy, he cared for people, he felt a sense of responsibility for others, and he was a thoughtful friend.

He would tell me stories about his late mother, and things he remembered about her; he would tell me about his old neighborhood

where he grew up, and about his aunt and his cousins and taking walks with his mother to visit them. He would occasionally get a Christmas card or a birthday card from his aunt, but that was it. During the time that I knew Steve, he had little or no social involvement with anyone outside his paid support staff and the people he lived with.

NOW I WAS AT HIS WAKE, and his aunt was there and so were his cousins. A city councilor who had known Steve years before through a Citizen Advocacy program¹ came to offer his condolences. During the years I had worked with Steve, I had never known any of these people to have any involvement with him. I couldn't help but wonder, where were you when Steve was alive? I couldn't help but think about how Steve liked people. I couldn't help but think about Steve's birthday a few weeks earlier when nobody had shown up (truth be told, myself included; I'd been busy and didn't want to go by work). Steve would have been a good friend to all these people. He would have loved to pass on more of his gifts, and to have had someone else to reminisce with. He would have been a good friend to us all.

A few days later, after Steve's funeral, I was with some friends of my parents when one of them asked about Steve. They thought they had heard that he passed away. I was surprised, not knowing that they knew him. They explained that years before, their son had

worked with Steve and that he used to spend the holidays with them; but they hadn't seen him in years. "Too bad," they said, "he was a nice guy."

I HAVE THOUGHT about Steve often since that January of 1997. Every time I can't seem to find time to visit someone, I try to remember that I still always seem to have time to get to their wake or to their funeral after they have passed away -- sometimes even leaving work early or rearranging other things on my schedule so that I can get there.

But where were we, and where was I, when Steve was still alive? When, just a couple weeks before, he had had a birthday party and nobody came? I still try to go to wakes and funerals when people pass away; like many people I need the ritual of saying good-bye. But I also try to go before that time. If we, if I, can

make the time to attend the funerals ... but where were we, when they were still alive?

Endnote

1. Citizen Advocacy 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 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.

JAMES BRUNAUTL works for Goodwill Industries in Springfield, MA, USA, directing a residential and a family supports program. He helps teach SRV workshops in Massachusetts.

The citation for this article is:

Brunault, J. (2006). Where were we? *The SRV Journal*, 1(2), 52-53.

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*

• ***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 Credentialing Center's Commission on Accreditation OBN-001-91. Awarded through the sponsorship of Family Lives Nursing Services.

• ***For information about fees, overnight accommodations, registration, etc., contact :*** Joe Osburn at the Safeguards Initiative, 114 Woodhill Road, Bardstown, KY 40004 USA ***or call*** 502 348 1168 ***or email*** josephosburn@bellsouth.net.

More Willing Citizens Needed

Ed Wilson

THE PROLIFERATION of human service programs over the last 25 - 30 years paradoxically may well have had a negative impact on the citizens in our communities. Often when I am facilitating a 'Whole Life Planning Session' for a socially devalued person, I hear, "Well, isn't there a program or a service that could do that?" The prevalence of human services and programs has disenfranchised the average citizen from taking a personal role to solve a particular problem for someone in their neighborhood, or even from recognizing that they may be what is needed. 'Let the professionals handle it!'¹

This is also true of human service professionals themselves, however. How many of us, myself included, drive through several towns and commute many miles to an office to fulfill our human service role? Meanwhile, people living in our own hometowns could be benefiting from our personal network of connections. As just one example, there are hundreds of Department of Mental Retardation employees in Massachusetts, who all have relationships with other people in their communities, but how is that resource tapped into in a way that benefits the poor or devalued in those same communities?

It is difficult to help people understand that we all hold some of the solutions to the very problems we wish to solve. We should view ourselves as willing "citizens" instead of just committed "professionals." All too often peo-

ple turn to government agencies or professionals because it is easier -- or sadly because they truly believe formal programs are the only or most appropriate mechanism for meeting devalued people's needs -- rather than turning to the very things that work for most people.²

Changing attitudes, hearts and minds as to how we see ourselves in relation to people who are marginalized, devalued or handicapped is fundamental. We must not focus solely on changing the person with the disability. In changing how we see ourselves, we can also change our perception of our fellow citizens and how they too could be helpful.

I ONCE ATTENDED A MEETING at a local school where the Guidance Counselor was making a referral for a student to receive 'job development assistance.' While waiting for the meeting to begin we chatted about this and that, and she let on that she was a waitress on the weekends in a very busy and well-known breakfast and lunch place in the very town the student lived. As it turned out, she had worked there for years. She knew everybody, from local town officials to business owners. Some of the most prominent and influential people in town passed through this restaurant, and she had their ear every Saturday and Sunday. Yet, she never put together how her own connections and good word could be powerfully used to get this student a job. So often, we are unaware of what is really going on inside of us;

for example, our feelings about and perceptions of devalued people, or what they might need. We often believe (even if unconsciously) that devalued people are so different from us that what works for most people won't work for them.³

That guidance counselor, like many human service professionals, was miles away fulfilling her professional role, which required the completion of a referral form -- to be submitted to a private non-profit agency -- that would then seek funding from a large bureaucratic government body -- which would review the request to insure partial reimbursement from the federal government -- then lobby the legislature to appropriate funds -- so the private non-profit agency could assign a person to complete a skills assessment -- and upon its completion assign a Job Developer, who lived many miles away, to spend 5 - 10 hours per week looking for work for this student -- with the most likely job outcome being the person becoming a bagger at the local grocery store. When it could be as simple as the waitress talking to the boat yard owner and putting in a good word, asking him to give this kid a shot at some work which she knew he would love because "boats are his thing." Yet how often our formal service roles inhibit us from seeing or considering more informal, typical approaches. How often our (unconscious) perception that only paid service workers are willing or able to help devalued people gets in the way of us seeking out informal or freely-given help for people in need.

True human service does not come with the successful billing of Medicaid nor the comple-

tion of a referral form, but rather with the humbling of ourselves to vulnerable people and with taking personal action on their behalf.

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Endnotes

1. For more on this issue of the unintended role that services can play in society, see McKnight, 1995.
2. See Wolfensberger & Thomas, 1983, pp. 16-17, to learn more about this idea; namely, the Social Role Valorization concept of the Culturally Valued Analogue.
3. For more on this issue of unconsciousness, see Wolfensberger, 1998, especially pp. 103-104.

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

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REVIEWS

WADDIE WELCOME AND THE BELOVED COMMUNITY. By TOM KOHLER & SUSAN EARL. Inclusion Press, Toronto, 2005. Available from Inclusion Press (website: www.inclusion.com) or Chatham-Savannah Citizen Advocacy, 7 East Congress Street, Suite 500 B, Savannah, GA 31401, USA.

Reviewed by Jack Pealer

TEACHERS of Social Role Valorization know that the precision of language that frames the principle is sometimes not enough to convince readers and listeners of its power. Sometimes only a good story will do. Tom Kohler and Susan Earl have given us a compendium of good stories, within a larger photo essay, in *Waddie Welcome and the Beloved Community*. The book shows and tells about a Georgia native and citizen, the town where he lived, and the people whom this Georgian drew together in a common but radical enterprise. In only a minor way is the book about human services; organized agencies appear mostly by default, omission, or as opponents to Mr. Welcome's ambition.

WADDIE WELCOME was born in south Georgia 138 years to the day after the publication of the Declaration of Independence. He was born 88 years exactly after the deaths of John Adams and Thomas Jefferson; he is only one lifetime removed from the founding fathers. Mr. Welcome lived all his life in southeast

Georgia -- more than 70 years with his immediate family and more than 80 years in Savannah. After Mr. Welcome passed his 80th birthday, people in his neighborhood who knew him and his family worried that remaining family members were unable to take care of him well enough any more. A usual thing to do when people have those worries is to contact local human service agencies, and that's what happened. The outcome of the contact was Mr. Welcome's moves, first to a local nursing home, and later, when that home's license was taken away, to another nursing home about 150 miles from Savannah. Mr. Welcome did not agree with those choices, but his disagreement apparently went unheard. *Waddie Welcome and the Beloved Community* shows and tells how he met people who shared his disagreement, who called others to act in his interest, and who worked and schemed with Mr. Welcome to get him home -- a place in Mr. Welcome's imagination and memory where he could smell food cooking and hear children at play.

The social roles that Waddie Welcome held certainly changed during the part of his life that the book describes. Lester Johnson, a Savannah attorney, acted as Waddie Welcome's citizen advocate and guardian. When he was a young boy, Mr. Johnson lived and went to school in the same neighborhood where Mr. Welcome lived with his family. Mr. Johnson recalled one role to which Mr. Welcome was assigned: "... in the 1950s kids would go around the corner

to a little corner store and get candy ... and sometimes they would go to a house, where you could get things a little cheaper. But if you went there, you might see 'the monster' -- the monster being Waddie Welcome -- watching over his mother's sale goods on the porch" (p. 67).

Look at the photos in the book, though, and you will see that Waddie Welcome left that role far behind. He also shed the nursing-home-patient role in favor of others that allowed the man he was to shine. For example, the book describes the following roles that Mr. Welcome came to fulfill:

- **Historian.** As Mr. Welcome met with "The Storytellers" and slowly told of his own 79 years, he enriched the picture of the past in his Savannah neighborhood.
- **Teacher.** Mr. Welcome helped local citizens learn a fuller meaning for "community," and his story told through film helped politicians in Georgia and elsewhere consider a different range of responses for people who need regular support to live.
- **Traveler and Award Winner.** Read Mr. Welcome's speech to accept an award given to him at the 1998 TASH International Conference in Seattle, WA. In the book you can see him on the plane between Atlanta and Seattle.
- **Seducer/"Cooter."** Tom Kohler described Mr. Welcome as a "kidnapper" in the sense that Mr. Welcome captured people to himself. Tom also noted that, in the southern US, "cooter" is the term given to an older man who has an obvious "eye for the ladies." Some might question whether these are unambiguously valued roles. Mr. Wel-

come's skill in them, though, brought others to his side and helped endear him to dozens, if not hundreds, of other citizens. Which brings me to ...

- **Lover and Loved One.** The circle of affection that enclosed Waddie Welcome grew wider by multiples as he came to know more people.
- **One of "10 Who Made a Difference."** *Connect Savannah* (a local newspaper) selected Waddie Welcome as one of Savannah's ten most influential people of the 1990s. The paper described Mr. Welcome as "an agent of change, a surprising new leader" (p. 55).

Waddie Welcome and the Beloved Community contains surprises; it provokes tears and smiles, sometimes together. Just by studying a photo I learned that I'd like to join the Savannah Checker Club. I was astounded by the almost casual reference to Mr. Welcome's guardian who spent many hours asking and listening to Mr. Welcome about his preferences around ways his health would be safeguarded. I never before heard about a guardian who personally selected a cardiologist, from among the guardian's associates, to work with his "ward." I could both cry and laugh with the occasion of Mr. Welcome's funeral, when his community gathered to honor him. I want to remember -- and employ when I can -- the "social research" methods of Mr. W. W. Law, who walked Susan Earl through Mr. Welcome's old neighborhood and interviewed neighbors on porches, in living rooms and kitchens and, once, through the screen in a street-level bedroom window. I can appreciate Tom Kohler's discomfiture when he was first confronted with the direct style of Mr. Welcome's life-long friend Mrs.

Addie Reeves. And, I can almost taste Mrs. Reeves' cake.

Waddie Welcome and the Beloved Community is a testimony about quiet radical social change. There are no position papers and no protest marches (although people probably thought about it along the way). No years of speeches at legislative hearings. Instead, change took place through the daily-ness of sharing meals, telling stories, or celebrating the moving of a bed. And, people did it together. As the authors put it, they "kept the 'social' in social change."

They also underlined the "social" in social integration. It's hard to tell from a book about the intensity of personal connections. *Waddie Welcome and the Beloved Community* leaves little doubt, though, about the ties that came to bind Mr. Welcome and a number of the members of his circle. The photos tell us that folks helped Mr. Welcome look his best -- shirts and ties, jazz musician shades -- so that his smile could complete his conquest of new people. And, someone made sure that many of the introductions he received to others involved people who had and deserved prestige in Savannah -- political leaders, reporters, clergy and church members, a leading attorney, a respected judge, and so on. For many years Wolf Wolfensberger has offered a list of ideas about opportunities to "engineer" socially integrative activity.¹ Some good engineers worked together in Waddie Welcome's life.

In *The Timeless Way of Building*, Christopher Alexander wrote: "We must simply accept the fact that in the process of evolution, there is no final equilibrium. There are passing phases which approach equilibrium, but that is all. The search for equilibrium, the brush in the dark with a moment of stability, the wave which

hesitates a moment before it crashes into the sea again -- that is the closest constancy will ever come to being satisfied." Those of us who seek a bit of rest amid chaos take little comfort from Mr. Alexander's words. He wrote, though, as an architect about buildings and about the "languages" that, he says, lead to the growth of good buildings and good towns -- places that contain and promote life. Those "languages" change, inexorably, restlessly. Perhaps the growth of what we call "community" proceeds with similar restlessness. Community -- people together -- always evolves. Perhaps we can only see the changes at certain times that Mr. Alexander calls "moments of stability" against which we brush in the dark. If that's so, then *Waddie Welcome and the Beloved Community* reveals one such moment -- the crest of a wave against a turbulent sea. For a magnificent instant, the community we look for -- the beloved community -- reveals itself. Get a copy of *Waddie Welcome and the Beloved Community*, and go there.

Endnote

1. See, for example, Wolfensberger, W. (1998). *A brief introduction to Social Role Valorization: A high-order concept for addressing the plight of societally devalued people, and for structuring human services* (3rd ed.). Syracuse, NY: Training Institute for Human Service Planning, Leadership & Change Agency (Syracuse University), pp. 122-124; and Wolfensberger, W., & Thomas, S. (1983). *PASSING (Program analysis of service systems' implementation of Normalization goals): Normalization criteria and ratings manual* (2nd ed.). Toronto: National Institute on Mental Retardation, particularly the information on social image enhancement and on integrative relationships.

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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/>

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Pealer, J. (2006). Review of the book *Waddie Welcome and the beloved community* by Tom Kohler & Susan Earl. *The SRV Journal*, 1(2), 57-60.

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THE CURIOUS INCIDENT OF THE DOG IN THE NIGHT-TIME. By MARK HADDON. Vintage Books, New York, 226 pages, \$12.95, 2003.

Reviewed by Jan Doody

THIS IS WHAT it's like to be Christopher Boone, the fifteen-year old boy at the heart of this novel. Christopher doesn't like to be touched. He won't eat or wear anything that is yellow. He relaxes by reciting algebraic equations, the more complex the better. He enumerates items (like the chapters in this book) by prime numbers. He has memorized the names of all the countries in the world and their capitals. He has trouble reading facial expressions such as a scowl or a raised eyebrow. He doesn't understand jokes and struggles with metaphors such as "he had a skeleton in his closet" (p. 15).

This is also what it's like to be Christopher. He is a special education student in a segregated school in a suburb of London. He has a pet rat named Toby which is the closest he comes to having a friend. He often finds the world so confusing and difficult to cope with that he hides in a closet, rocking and groaning. He lives with his father who is often impatient

with him (and pretty confused about the world as well). He has lost his mother and as the novel opens, Christopher has discovered the murdered body of his neighbor's dog.

The Curious Incident of the Dog in the Night-Time is that rare book that captures with sensitivity, accuracy and quite a lot of humor, the thought processes of a person with a disability. In this case, the disability is "high functioning autism," although the word "autism" is never mentioned. Those familiar with people so labeled will not take long to figure out Christopher's disability. His cadence of speech in this first person narrative is a dead give away. For example, here is Christopher explaining why he would make a good astronaut: "To be a good astronaut, you have to be intelligent and I'm intelligent. You also have to understand how machines work and I'm good at understanding how machines work. You also have to be someone who would like being on their own in a tiny space-craft thousands and thousands of miles away from the surface of the earth and not panic or get claustrophobic or homesick or insane. And I like really little spaces, so long as there is no one else in them with me" (p. 50). There is also Christopher's extreme reliance on order and sameness: he eats the same foods day after day, which must be arranged on his plate in a particular manner or dinner is ruined. And despite his seemingly high level of intelligence and ability to memorize math equations and mountains of facts, Christopher has a great deal of difficulty in conversing with others or in understanding others' intentions, which as the story progresses, gets him into some interesting situations.

THE AUTHOR of *The Curious Incident of the Dog in the Night-Time*, Mark Haddon, teaches writing and is a poet, novelist and illustrator living in Oxford, England. His work as a teacher

of students with autism informed him about the particular and at times peculiar traits of autistic children. This novel has broad appeal and due to its narrative style, is appropriate for young readers as well. *The Curious Incident* tells a fictional story, that of a young man, his struggles to survive in the midst of a disintegrating family, his attempts to keep himself safe while surrounded by myriad unfamiliar and scary phenomena, and his self-styled mission to solve the mystery of the dead dog. Its value as a study of social roles is in the inferences one makes from Christopher's descriptions of his home life, his school life, and his forays into his neighborhood and beyond.

IF ONE were to enumerate Christopher's social roles, the list would include the following: 1. Special Education student. 2. Math whiz. 3. Person with behavior problems. 4. Son. 5. Only child from a broken home. 6. Neighbor. 7. Person with a disability. 8. Caretaker of Toby, a pet rat. 9. Teenager.

Of all of these roles, the one of "person with a disability" is the most life-defining for Christopher. While some might question if he indeed even has a disability or is the victim of the social construct of "autism," Christopher is beset with a great number of challenges and is forthright in telling the reader about them. "I make this noise (groaning) when there is too much information coming into my head from the outside world" (p. 7). "I find people confusing" (p. 14). "These are some of my Behavioral Problems: A. Not talking to people for a long time. B. Screaming when I am angry or confused. C. Smashing things when I am angry or confused. D. Groaning. E. Not liking yellow things or brown things and refusing to touch yellow things or brown things. F. Doing stupid things [like emptying a jar of peanut butter onto the table in the kitchen and making it level

with a knife so it covers all the table right to the edges]" (pp. 46-47). There are also passages in which he explains how his mind works as a recording device and how he uses reasoning skills to solve math problems. This constellation of characteristics is consistent with current thinking regarding the diagnosis of autism. Christopher sees himself as someone hampered by his inability to understand social rules while relying on his highly developed reasoning skills to make his way in the world.

Others' responses to Christopher relegate him to the devalued social roles of deviant ("weirdo" in the parlance of the book), special education student and social outcast. He is aware of these roles and the reader senses much self-loathing in Christopher, even as he expresses pride in passing the Level A mathematics exam. He sees himself surrounded by other students who are "stupid." "Except I'm not meant to call them stupid, even though this is what they are. I'm meant to say that they have learning difficulties or that they have special needs" (p. 43). His willingness to see himself as not like "the others" and at the same time grouped with these other "special" students is one of Christopher's struggles in understanding who he is and where he fits in. We get a sense of Christopher's loneliness and his over-reliance on his teacher, the one person who communicates with him on his level and understands his needs.

THUS HADDON provides a valuable reading experience as he guides us through Christopher's day-to-day life, his detailed thought processes and his realization that adults, including his parents, make lots of mistakes and also have trouble making sense of the world. We come to respect Christopher for his tenacity and courage and cheer him on as he solves the mystery of the dead dog and achieves aca-

demic success.

What Haddon fails to do, however, is to critique the segregated circumstances of Christopher's life. His enrollment in a segregated school is presented as a given with no other options mentioned. While Christopher talks about going on to college, one is struck by the fact that as a fifteen-year old, he has one teacher in a special class with a curriculum focusing on behavior management and the acquisition of "social skills." This reinforces for the reader that students with Christopher's combination of skills and deficits can only be taught in segregated settings. His lack of meaningful unpaid relationships is also striking. Christopher's attachment to his pet rat is used as a way to describe his devotion to others, yet the only people in the novel who seem to care about Christopher are his parents and his teacher. This also reinforces the notion that someone like Christopher is unworthy of friendship.

Despite these shortcomings, I highly recommend this book for its touching portrayal of a young man with autism fighting for his life.

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EDITOR'S NOTE: *Reading the book and this review together would be instructive for a book club, and/or as a follow-up to an SRV or PASSING workshop.*

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Doody, J. (2006). Review of the book *The curious incident of the dog in the night-time* by Mark Haddon. *The SRV Journal*, 1(2), 60-62.

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

Reviewed by Norberto Alvarez, M.D.

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

example being perceived as deviant, being rejected, being considered a burden to society, being the object of abuse, and even being 'made dead'), besides not having access to the good things in life.

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

THIS MONOGRAPH is mostly the practical application of what the analysis of hospital care, under the scrutiny of the SRV principles, teaches regarding the deficits of the care provided, especially to devalued people, and how to avoid or at least to minimize these deficits. However the concepts of SRV, as expected, are present in the different sections of the book. For example in the section about "Enhancing and Monitoring the Quality of Medical/ Nursing Care," one of the issues addressed has to do with "imaging" the "look" of the patient. The reality of imagery is one of the themes of great relevance in understanding and applying SRV. The way people see you affects the way they value you. Improving the appearance (via shaving, grooming, washing, providing good clothing) of the patient makes the patient more valued in the eyes of the attending personnel. "Humanizing" the relationship between care providers and the patient by describing his/her

interests, achievements and skills; keeping pictures of the patient when he/she was in good health; seeing that the patient receives get well cards, flowers and the like would result in a positive impression. Such efforts help support hospital patients to be in valued roles.

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

It would be too long to comment about each particular section, however it is worth expanding the discussion of some of them. While not against the use of mind drugs or restraints, the section on "Monitoring the Prescription (Mind) Drugging of the Patient" alerts advocates about the premature and inappropriate use of these procedures, a real risk, especially

for people with developmental disabilities. The section “Special Considerations When the Patient Appears to be Nearing Death, or is Interpreted as Dying or as Lacking ‘Quality of Life’” addresses issues that have received a lot of attention by Dr. Wolfensberger and his associates (Wolfensberger, 1994; Wolfensberger, 2005). The perception that persons with disabilities have a “quality of life” that is poor to start with, and is much poorer when they are sick, might lead to early implementation of “Do Not Resuscitate” orders that could result in early discontinuance of treatments, which could then hasten death. For example, the discontinuance of nourishment or liquids which the *Guideline* presents as “being justifiable in only **extremely** few cases: (a) when the provision ... is itself very harmful, and maybe even hastens death; and (b) when it is intolerably invasive or torturous **to the patient**” (p. 73). Probably the statement “When in doubt, opt for treatment and life” (p. 75) in this section is a short and concise summary of the philosophy underlining the efforts of SRV advocates in this area.

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

I FOUND these guidelines very useful. They are written in a way that is very simple to un-

derstand, there is an order in the presentation, and each section can be read independently. Persons responsible for the care of people that require (frequent) hospitalizations, independently of the presence of developmental disabilities or not, will find these guidelines extremely helpful.

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

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

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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.

Preparation for Introductory PASSING Team Leaders: An Example of SRV Leadership Development

Marc Tumeinski

Introduction

THE DEVELOPMENT of leaders in Social Role Valorization (SRV) has been a high priority since its formulation by Professor Wolf Wolfensberger. Many written materials for learning about SRV are available for the aspiring leader or even just the interested reader.¹ However, as Wolfensberger has pointed out, “the most detailed exposition of SRV is not found in print, but at SRV training courses (from introductory to advanced levels).”² One of the most effective ways of learning SRV is to take an introductory SRV workshop followed by an introductory PASSING workshop (PASSING stands for Program Analysis of Service Systems’ Implementation of Normalization Goals).³ An introductory SRV workshop lays out the theory of SRV, including an exposition of social devaluation and wounding, and the ten themes of understanding and applying SRV.⁴ Attendance at a PASSING workshop after an SRV workshop (which is a prerequisite) tends to bring home the lessons of SRV and make them more concrete, as many workshop participants attest.

To make both these workshops available, competent SRV and PASSING teachers are

needed. This article will discuss one particular aspect of developing skilled PASSING workshop teachers; namely, a process of offering specific training sessions for PASSING leadership.

Some background information about the PASSING workshop is in order at this point. In most introductory PASSING workshops, attendees are organized into teams. Each team visits two different human service programs (‘sites’) and analyzes them from an SRV perspective using the PASSING tool, as laid out in the PASSING Manual (see Wolfensberger & Thomas, 1983). PASSING is divided into 42 different content areas (or ‘ratings’), each of which covers some aspect of service provision from an SRV perspective. For example, one such content area looks at how well a service identifies and addresses the fundamental and pressing needs of its service recipients (rating R231 Program Address of Clients’ Service Needs, PASSING Manual, pp. 473-484). The major division in the 42 ratings is between ratings dealing with image and with competence. Image and competency enhancement are the two major SRV strategies for gaining and keeping valued social roles.

In an introductory PASSING workshop, each team of participants is guided and facili-

tated by a team leader, under the direction of a more experienced trainer known as a 'floater.' The team leader is with his/her team of PASSING attendees throughout the workshop, while the floater acts more as a consultant and adviser to one or more teams and team leaders, joining in their work periodically and as necessary.⁵

The Importance of Preparation

A PASSING TEAM LEADER is an SRV teacher, and his/her role is a demanding one. A good team leader requires a variety of habits and skills (see Osburn, 1996), many of which can be practiced. A team leader's role performance has a significant impact on the depth and quality of individual team member's learning about SRV.

Thoughtful preparation for each team leading experience is an absolute prerequisite to good team leader-role performance, even for highly experienced team leaders. Such preparation can take a variety of forms. For example, before any PASSING workshop begins, the overall trainer for the workshop should meet with the floater(s) and the team leader(s) to prepare and orient them for the upcoming workshop. As well, team leaders are encouraged to do their own individual preparation in the time leading up to a workshop; for example, by reading *and rereading* the PASSING Manual. In addition to these other forms of preparation, many trainers and training groups which sponsor PASSING workshops have found it helpful to regularly conduct introductory PASSING team leader training sessions outside of, and apart from, a specific workshop. Such focused training can greatly help team leaders develop and hone their skills so that they are better able to fulfill their role dur-

ing an actual PASSING event, i.e., a workshop or other type of assessment.

Introductory PASSING Team Leader Training

THE SRV IMPLEMENTATION PROJECT (SRVIP), an SRV-based training project,⁶ has been conducting one-day introductory PASSING team leader training sessions for both active and aspiring or neophyte team leaders since the project began in 1989. In my role as a trainer for the SRVIP, I help conduct such trainings. This article will outline some of the *content* which we covered during recent team leader training sessions conducted by the SRVIP, some of the *processes* we have used, and some of the *outcomes* of such training for the (aspiring) team leaders who have attended. Note that these preparation days are not meant to replace the orientation given by the overall workshop trainer to team leaders prior to a workshop (mentioned above) nor individual preparation, but rather are meant to supplement such preparation.

I am indebted to each of my past team leaders and floaters for teaching me so much about PASSING and about team leading. I would also like to acknowledge Darcy Elks and Joe Osburn who as far as I know conducted some of the earliest PASSING team leader training sessions in the US.

Examples of Topics Covered During PASSING Team Leader Training Conducted by the SRVIP

The following sections describe some of the topics which we at the SRVIP have covered during multiple PASSING team leader training sessions. The topics listed below were discussed during different sessions. For any one

particular session, we limited the number of topics that we covered to allow for deeper learning, more discussion and more practice time. We encourage new team leaders to attend as many sessions as possible; more experienced team leaders often choose specific sessions which are going to cover particular topics which they are interested in.

Clarification of the role of team leader.

When (potential) team leaders attend one of our training days for the first time, we ask them to write down why they want to be a PASSING team leader. We intend this to be a clarifying exercise for them. We also believe it can offer positive reinforcement for team leaders. We believe that greater consciousness of one's team leading goals and motivations can help bolster a team leader's resolve during stressful team leading situations; for example, if during a workshop one visits a complex human service program which requires extra-hard work on one's part and the team's part, or if one leads a team that for whatever reason requires extra effort and energy to manage. Whenever one runs into difficulty, it helps one to keep going if one knows *why* one is doing what one is doing. Also we ask team leaders to think about what skills, habits and abilities they want to work on to become better team leaders. This helps us to tailor our training sessions to the particular needs and interests of the attendees.

Using the PASSING texts. At every team leader training day, we rely heavily on the two main PASSING texts; namely, the PASSING Manual (Wolfensberger & Thomas, 1983) and the PASSING *Guidelines* (Wolfensberger, 1983). The manual was described above; the *Guidelines* book is a companion volume to the Manual which helps guide people using the

tool through a PASSING assessment. The *Guidelines* book contains many chapters of useful information about human service assessments, including practical suggestions, a glossary, assessment role descriptions, assessment guidelines, copy-ready forms, etc. We try to instill in team leaders the habit of reading and using the Manual, with the expectation that they will then teach the same habit to team members during PASSING workshops and assessments. This habit is also a good one to carry home from the workshop into one's everyday human service involvement; i.e., to continue to refer to the PASSING Manual when looking at one's own service or other human services.

Good team leader habits. For those who have not team led yet but want to, and of course for those who have team led and want to become better at it, we discuss some of the habits that have helped more practiced team leaders to become better SRV teachers generally and better team leaders specifically. Examples include such things as (a) personalizing one's PASSING Manual, such as by highlighting especially relevant, helpful or important words or passages; writing instructive notes for oneself into one's personal copy; etc., (b) looking for opportunities to team lead with different floaters, in different locales, and with many types of services, all of which will help deepen a team leader's abilities, and (c) using the Checklist of Essential Activities for a Team Leader during a PASS, PASSING, or Similar Assessment (found on pages 93-104 in the PASS and PASSING *Guidelines*).

Consciousness of the forces at play during a PASSING workshop. Another area which our project has covered in our team leader training days is to discuss some of the 'forces'

to consciously work *with* and to work *against* to help make a good learning experience for team members.⁷ An example of one of the forces to work *with* is the new terminology which SRV and especially PASSING provides to workshop participants. Many SRV and PASSING workshop participants have described how SRV has given them a new language to describe important realities in human services and in the lives of socially devalued people. Language is a powerful tool.

An example of one of the forces to work *against* is the unfamiliarity many people have with contemplating what would be ideal when offering service to vulnerable people. Often what will happen is that PASSING team members (and even new team leaders) will have a hard time going beyond the status quo in human service generally or in their own personal service experiences. Many find it difficult to conceptualize the excellent, feasible, but possibly rare or even nonexistent ideal when it comes to identifying what service recipients need and what might address their need(s) in a relevant and coherent way. Rather, many team members will reflexively and unconsciously think that a service recipient just needs more human service involvement, and that will fix everything. A good team leader will consciously invite team members to try another way of thinking about this, a way based in SRV.

Importance of the concept of social roles.

Another key skill for team leaders that we often practice during team leader preparation is building the concept of valued and devalued social roles and role dynamics into all parts of the PASSING workshop process. According to Professor Wolfensberger, the key premise of SRV is that people who fill valued social roles will generally be afforded the good things of

life, while people who fill devalued social roles will typically get badly treated (see Wolfensberger, 2000, p. 105).

This concept is fundamental to SRV, and therefore should obviously be taught as effectively as possible throughout a PASSING workshop. For example, for each service visited at a workshop, a team leader helps his/her team members to think about who are the people that are receiving the service, and what do they need. The concept of devalued and valued roles is immensely helpful for gaining a good understanding of these realities. (NB: It is helpful for team leaders to be familiar with the major domains which social roles typically fall into; see Wolfensberger, 1998, p. 30.)

At every PASSING workshop, team leaders facilitate a process whereby team members look at the service they assessed from the perspective of the 42 ratings in the Manual. The concept of social roles is either implicitly or explicitly built into each of these ratings. Often, a team leader will help the team to craft ideas for how the service they assessed could be improved in light of SRV theory. Again, valued social roles is an essential component of crafting those ideas.

Toward the end of a PASSING workshop, a team leader typically offers a brief plenary presentation to all the workshop attendees to convey a sense of what his/her team learned. Describing roles, valued and devalued, can be an instructive part of these plenary reports. Overall, a good team leader has to have a strong understanding of social roles, and a habit of teaching a team about roles in every step of the PASSING workshop process.

Writing good rating summary statements.

One of the best learning opportunities at a PASSING workshop is the process of writing what are called rating or conciliation summary

statements. This is how the process of writing conciliation summary statements typically occurs in a workshop. After visiting a service, the team goes through a process of analyzing it from an SRV perspective using the PASSING ratings. This process is called conciliation. For each rating, the team gathers the information from its visit which is relevant to the rating. A very helpful practice is for the team leader to write this information on chart paper so everyone on the team can see it. After the information is recorded, most team leaders also write a brief summary statement of the information, including the likely impacts of what the team saw on the recipients of the service. A good team leader tries to link this information, again in writing, to the issue at stake in the specific PASSING rating at hand. This is an excellent leadership development process for team leaders and team members. It encourages focused, rational analysis, and the ability to write and think clearly.

During many of our PASSING team leader training sessions, we have discussed and practiced implementing the principles of writing clear conciliation summary statements, because these summary statements are such an effective tool for helping team members learn about SRV. When we practice this skill, we ask the team leaders attending the training session to take turns writing practice summary statements using the principles we laid out. Afterwards, we give feedback to one another about the statements -- what was good and what could be improved.

Studying particular PASSING ratings. At each training session, we set aside a certain amount of time to study particularly complex or conceptually difficult ratings, and ratings which team leaders said they had difficulty in conciliating at past PASSING workshops. We

read all of the information relevant to the rating, ask questions, share notes on it, talk about examples from past workshops, discuss potential difficulties and brainstorm responses to them, and sometimes practice conciliating it.

We often practice conciliating specific ratings, where one participant takes the role of team leader and the others take the roles of team members. This is a 'safe' way to practice this task and to get instant feedback. The person in the team member role picks a particular kind of service, i.e., classroom, nursing home ward, group home, mental health clubhouse, etc. The participant in the team leader role goes through the conciliation process for one rating. Sometimes, those participants in the team member role go along with the process willingly to help the 'team leader' get the rhythm down. Other times, some of those in attendance consciously play the role of a 'difficult' team member (i.e., who talks over other team members, keeps bringing up different ratings than the one being worked on, argues loudly with other team members, etc.) to give the 'team leader' some valuable experience at facilitating groups. After we finish the conciliation of one rating, we give feedback to the person in the team leader role. We also rotate who is in the team leader role so every participant gets a chance to practice.

Conducting PASSING site interviews. Part of the process of an introductory PASSING workshop is for the team leader to interview staff at the service being assessed. This step occurs twice, for about three hours each, during an introductory PASSING workshop -- once for each service. Many new team leaders do not have much experience at conducting interviews. Therefore, we have found it helpful to devote time during team leader training to talk about principles of conducting good interviews

(‘inquiries’ in PASSING terminology) and then to practice interviewing one another. If the person practicing has had lots of team leading experience, those being interviewed try to act the part of a ‘difficult’ interviewee (i.e., who only answers questions with a ‘yes’ or ‘no,’ who tends to ramble on and on, who strays off topic on every question, etc.). We also make sure to occasionally ask the person in the role of interviewer to rephrase the question, which is a common experience in actual inquiries and thus good practice for team leaders.

Another ability which we focus on in particular is how to redirect talkative or unfocused interviewees. Another is how to probe for ‘consciousness’ when services appear to be doing something that is role-valorizing and would potentially score very high on PASSING. The PASSING ratings are designed to ‘reward’ services which (a) are doing something consistent with SRV principles relative to the issue at stake in a particular rating, and (b) know why the issue is important. For example, if a service optimally supports its service recipients to convey a positive personal impression (this particular rating is described on pages 277-285 of the PASSING manual), and does this because the service knows that it is an important part of supporting service recipients to be responded to more positively by others, and so that they are more likely to be integrated into the valued life of the community, then the PASSING tool gives that service a higher score on that particular rating. Such consciousness is important for a number of reasons, primarily as a necessary safeguard for ongoing relevant and effective service.

Using chart paper as a teaching tool. PASSING team leaders do a lot of writing on large sheets of chart paper during a workshop. The chart paper is an essential learning aid for the

team and helps the process go much smoother. It is also a helpful tool for the team consultant (floater). The floater’s role involves being present at team discussions at different intervals throughout the workshop. A floater can read the chart paper as a way of quickly getting oriented to where the team is in the process and what they are discussing.

One of the skills we talk about and practice during team leader training is how to manage the chart paper to most effectively help the team learn. We often ask each person to share some examples of what has worked well for him/her in the past. Some of these tips include basic mechanics like using different color markers for different topics, where to place the chart paper in the room, writing clearly so the team can read it, etc.

Stand-alone PASSING Team Leader Training

One thing to note in terms of our process: although it is beneficial to attend as many of these training sessions as possible, we make them ‘stand-alone’ so that someone can still participate even if they miss some sessions. This format allows us the flexibility of an open-ended process covering many topics in depth, while giving local team leaders the flexibility to attend as often as they can. We have decided for the present that it would be hard for team leaders to attend a full week of preparation, for example; although that would have other potential benefits, such as greater opportunity for repetition and practice, lots of time to deepen and solidify one’s learning, more time to practice different skills, etc.

Future Goals for SRVIP Team Leader Training

In the near future, we intend to cover at least the following topics: how to present a good plenary report to participants near the end of a

workshop (described above), writing PASSING reports, how to take advantage of the experience and 'outside' perspective which the team consultant (floater) can bring to the team's learning, tips on facilitating groups (see for example Caruso, 2006), and crafting the ideal (mentioned above).

Outcomes and Conclusion

THOSE WHO have attended our training days have voiced their appreciation of what they have learned, and their appreciation of the opportunity to learn and discuss team leading with other, often more experienced, team leaders and floaters. This process has also helped to build solidarity among local people invested in SRV training, given experienced team leaders the chance to share what they have learned (often the hard way) about the role, provided an opportunity for team leaders to keep their skills sharp between actual PASSING workshops, and helped to mitigate some of the nervousness which (first-time) team leaders often feel.

We have found that preparation days can improve a team leader's subsequent performance at PASSING workshops, and we encourage other trainers and training groups to use this strategy. We know that some already do.

A positive outcome for our training project as a result of conducting these sessions has been that we have written up some of the things we have learned about different aspects of the team leader role into handouts which we give to PASSING team leaders at our workshops.

If you are interested to learn more about our experiences in regard to these team leader training sessions, feel free to contact us at the email address at the bottom of this article. For those

who have tried a similar approach to provide additional training to (potential) team leaders, and can offer us suggestions or recommendations, we invite you to share those with us or even to submit an article about your own experiences to *The SRV Journal*.

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Endnotes

1. For example, see Wolfensberger, 1998; Race, 1999; and Flynn, R. J., & Lemay, R., A., 1999 (note the bibliography on pages 507-547).

2. Wolfensberger, 2000, p. 122. For calendars of upcoming SRV trainings, see www.srvip.org and www.socialrolevalorization.com, or call Susan Thomas at 315 473 2978.

3. See a July 1999 handout available from the Training Institute (315 473 2978) entitled *Overview of "PASSING:" A Social Role Valorization-based human service evaluation tool*.

4. See Osburn, 2006, p. 10, for a sequence of topics taught in introductory leadership-oriented SRV workshops.

5. See Wolfensberger, 1983, pp. 24-28, for more on the roles of team leader and floater.

6. See <http://www.srvip.org/> for more on the SRV Implementation Project.

7. Thanks to Darcy Elks and John O'Brien for this concept of forces to work *with* and *against*.

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Peer-Reviewed Articles

From the Editor

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

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

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

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 specifically relevant to SRV. To notify us of workshops for calendars in upcoming issues of this Journal, please send the information to: journal@srvip.org. Additional training calendars may also be accessed online at www.socialrolevalorization.com and www.srvip.org.

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

NB: This workshop is specifically oriented to leadership development

February 5 - 8, 2007
Shrewsbury, Massachusetts, USA
call Susanne Hartfiel at 508 752 3670; or email:
susanne@srvip.org

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

March 12 - 14, 2007
Farmington, Connecticut, USA
contact ~ Pseetoo@keystonehumanservices.org

March 26 - 29, 2007
Raynham, Massachusetts, USA
call Susanne Hartfiel at 508 752 3670; or email:
susanne@srvip.org

May 2 - 4, 2007
Harrisburg, Pennsylvania, USA
contact ~ Pseetoo@keystonehumanservices.org

Practicum With SRV Using the PASSING Tool

NB: Attendance at a multi-day SRV workshop is a prerequisite for this course

March 5 - 9, 2007
Hobart, Tasmania, AUS
contact Dianne Turner ~ planetree@trump.net.au

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

April 30 - May 4, 2007
Epping, New South Wales, AUS
contact ~ foundationforum@yahoo.com.au

May 6 - 11, 2007
Shrewsbury, Massachusetts, USA
call Susanne Hartfiel at 508 752 3670; or email:
susanne@srvip.org

Spring 2007 (exact dates to be determined)
Winnipeg, Manitoba, CAN
contact Janet Forbes ~ jforbes@aclwpg.ca

A One-Day Overview of Social Role Valorization

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

The Power of Roles

February 22, 2007
Harrisburg, Pennsylvania, USA
contact ~ Pseetoo@keystonehumanservices.org

A Four-Day Introductory Workshop on SRV, Using Seven Themes

NB: This workshop will be taught in two 2-day sessions

February or March 2007
Indianapolis, Indiana, USA
contact Joe Osburn ~ josephosburn@bellsouth.net

Social Role Valorization News and Reviews

Wolf Wolfensberger

AS IN AN EARLIER ISSUE 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.

The SRV Theme of Personal Social Integration & Valued Social Participation

WE WILL LOOK at how this theme applies to schooling contexts, followed by miscellaneous other contexts.

In Schooling

*Larrivee, B., & Horne, M. D. (1991). Social status: A comparison of mainstreamed students with peers of different ability levels. *Journal of Special Education, 25*(1), 90-101. This study is both bad news and good news. On the one hand, it found that mentally retarded special education pupils who had been 'mainstreamed' into an elementary school were significantly less well accepted than most other pupils in their classes, but on the other hand, they were no less well accepted than those of their peer pupils of low ability who had never been in special education.

*Farmer, T. W., & Farmer, E. M. Z. (1996). Social relationship of students with exceptionalities in mainstream classrooms: Social networks and homophily. *Exceptional Children, 62*, 431-450. This study found that when handicapped students were in regular elementary school classes, how well they were integrated depended more on the characteristics that they shared with other students than on their impairment. The authors referred to the tendency of people to associate with others whom they see as similar to themselves as "homophily." In SRV terms, we would probably talk about how perceived similarity increases interpersonal identification.

*Hughes, C., Rodi, M. S., Lorden, S. W., Pitkin, S. E., Derer, K. R., Bogseon, H., & Cai, X. (1999). Social interactions of high school students with mental retardation and their general education peers. *American Journal on Mental Retardation*, 104, 533-544. This study found that 12 mentally retarded high school students had hardly any social interaction with the approximately 500 general education students with whom they shared a common lunch room, which underlines the relevance of the distinction between physical integration and social integration, and how little social integration may take place in an environment that many people would describe as an 'inclusive' one.

*Mamlin, N. (1999). Despite best intentions: When inclusion fails. *Journal of Special Education*, 33(1), 36-49. This study discovered (not at all surprisingly to us) that the word 'inclusion' had absolutely no specific meaning to teachers and other actors in a school, so that when people used this term, one could not correctly infer what they meant.

*A 1996 book, entitled *Children and Youth Assisted by Medical Technology in Educational Settings: Guidelines for Care* (2nd ed.), listed the kinds of things that may have to be done to/for "students with special health care needs during the school day," as the advertising flyer put it. This includes attending to/performing: gastrostomy tube and drip; skin-level gastrostomy indwelling feeding device; nasogastric tube; jejunostomy tube; intravenous lines; central venous catheter; heparin lock intermittent intravenous device and lock flush; hemodialysis; peritoneal dialysis; ileostomy, urostomy and colostomy care; tracheal tube changes; oxygen use; tracheostomy; tracheal suctioning; tracheostomy tube changes; manual resuscitation

bag; nose and mouth suctioning; nebulizer treatments; use of mechanical ventilators; and all sorts of emergency measures. If we were teachers, we would wonder about 'inclusion rights,' and whether one should have gone to nursing or medical school instead of for teacher's education. A book such as this could be used as powerful evidence against 'inclusion' by opponents thereof, especially if one adds the latest twists that if health-jeopardized students start expiring in their classrooms, teachers are expected *not* to provide even the simplest first aid to them if the students had been slapped with a 'do not resuscitate' (DNR) order. What insanity is all this?

*The fact that 70% of US school children 'diagnosed' to have a 'disability' spend some or all of their class time in ordinary classes should not fool us, because 73% of these have been diagnosed with vague conditions such as 'learning disabilities' and/or 'speech or language impairments,' which are the kinds of conditions that increase or decrease depending on the availability of program funding (*Disabilities Statistics Abstract*, July 1997). In fact, 5.5% of 'disabled' children during the 1992-93 school year were in separate schools or facilities altogether, and 24% attended separate classes in regular schools. Furthermore, the proportion of pupils in separate facilities or separate classes hardly changed between 1988-89 and 1992-93. One surprising datum was that students with mental retardation were the least likely to be in a regular class, followed by students with multiple impairments, while about 40% of children with emotional disturbance were in regular class, and more than half of the deaf-blind children were!

*Some schools of education, and similar educational institutions, require all students

who formerly would have received a special education teaching certificate to become certified both as regular *and* special education teachers, which is called 'dual certification,' a bit parallel with so-called 'dual diagnosis.' Some schools of education are even requiring *all* of their elementary education students to also be certified in special education. All this is seen as the answer to the integration of handicapped children, usually in conjunction with the abolishment of special classes. However, we have not noticed that such dual certification programs have become any more rigorous in screening students. After all, one would assume that a student would have to be much more competent to become certified in two areas than in one. By failing to increase expectations and standards, institutes of higher learning in effect are betraying this kind of strategy, despite their sometimes vehement ideological rhetoric to the contrary.

*For decades now, giving teachers educational aides was seen as one of the keys for integrating handicapped children into regular classrooms. But one has rarely heard the caution, noted by some authorities (*Contemporary Psychology*, 2003, No. 1), that the aide can become a "virtual partition between the child and peers, constantly redirecting, mediating or otherwise containing the child."

In Other Contexts

**Disability Statistics Abstract* (May 1998) published by the US government concluded that even though handicapped Americans say they lead better lives since the 1990 passage of the Americans With Disabilities Act, their levels of participation in social, cultural and economic activities do not seem to have increased. Handicapped people had lower rates of participation in virtually every kind of mainstream

engagement, with the gaps being smallest in church participation and largest in sporting events. There has also been a *widening* gap in income level between handicapped and non-handicapped people.

*In 1982, a service agency in Massachusetts (now called Beta Community Service) reflected on the fact that many of the clients which it served in a residential capacity did not have one single person in their life who was not paid to be there. The agency therefore launched a program which it called "community of friends" to foster one-to-one relationships between the people it served and individuals from the community. By 1992, it had 40 people actively involved in the lives of 31 of its clients, with some of these relationships having endured for up to nine years (source material from Michael Kendrick).

*There is a growing body of mythology in human service and advocacy circles that the failure of mentally retarded people to experience integration and acquire friends who are not other handicapped people and paid human service workers is due to any number of things other than impaired mentality and its manifestations. For instance, instead of admitting that people generally like to socialize with persons with similar backgrounds and interests, and with mental content that permits an active sharing of interests and activities, the mythology is that the above is *all* due to lack of social skills, lack of opportunities, problems with reading other people's social cues or facial expressions -- and that all these are things that can be remediated with proper training. While indeed much can be done to optimize the pre-conditions for greater genuine social integration, we have to recognize that at the same time, the very essence of this particular human impair-

ment poses great obstacles and constraints which are much less likely to be overcome, especially once a person has reached the adult years.

One of the biggest things that *can* be done is to match retarded persons up with other persons or circles where everybody shares the same interest, and where there are activities that can be engaged in even by retarded members in pursuit or enactment of that interest.

*Ross Womersley sent us a November 1990 clipping about a young man with Down's syndrome who lived in an Australian group home and who attended a course in modeling at a private modeling school, together with 230 other young men and women who were not handicapped. Among other things, the members of his course learned etiquette, how to carry oneself, and of course, how to wear clothes. No special concessions were made for the young man's handicap. For him, this was the first time he had functioned with non-handicapped people of his own age in an enterprise not revolving around handicap.

*Since 1990, the National Jewish Council for the Disabled has run a program called Yachad Good Sports, in which handicapped and non-handicapped Jewish children and young adults would participate together one day a month in various athletic games, the study of Jewish traditions, and socialization. This sounds like it could potentially be very integrative and developmental for both handicapped and non-handicapped participants, and within the context of one particular religious/cultural tradition. It could also be an alternative to the Special Olympics. However, we hear that there may be great variability -- including in quality -- in how this program is carried out on the local level. It may not always rely on

peer children, or be integrated. For information, contact 212/613-8229.

*As far as is known, New Zealand has been the first country (in April 1992) to include a mentally retarded person on one of its international Olympic teams, namely the one on weight lifting. Amazingly, this retarded person had Down's syndrome (*DSN*, June 1992). The young man had initially been involved in the Special Olympics as a gymnast, then began to lift weights to strengthen his arms, and was eventually found to be so strong as to compete in generic sport contests.

*What started out as a 'special' (segregated) camp for children with cancer in the Syracuse area, Camp Good Days and Special Times, expanded to holding special camping sessions for children with other diseases, or who had been burned; and then to hosting special camping sessions not only for those children, but also for siblings of cancer patients, for children of cancer patients, for adults with cancer, for children with sickle cell anemia, and for youths with cancer from other countries. Supposedly, the camp's mission is "to make the fun of camping the dominant issue in their lives, rather than the disease" -- yet having camp sessions only for people who all have the same affliction, or relationship to a person with a specific affliction, seems precisely to make the disease the dominant issue in their lives.

*The choir of a Catholic church in Evansville, Indiana, included a paraplegic singer, and in a true manifestation of Christian communalism, the members of the choir carried this person up 18 steps to the choir loft every time they sang. Then somebody thought that this was too dangerous, probably with legal considerations in mind, and complained, all the way

up to the bishop. The choir members began to raise money for an elevator, but the parish members voted against it. The choir would not give up its handicapped member, and so the pastor disbanded the choir with the approval of the bishop (AP, in *Indianapolis Star*, 3 Feb. 1990; source item from Joe Osburn), and with bitterness all around. Apparently no one thought to simply have the choir sing down below, and for some of the congregation to use the space above for pews.

*Ballinger, C. (1998). Do smaller homes result in increased integration? *Mental Handicap Research*, 6(4), 303-311. This study found that severely and profoundly retarded people living in residential units that had between 7 and 10 'beds' had significantly more community contact than those who lived in a unit with 24 'beds.' This is consistent with SRV theory which posits that congregation of devalued people is apt to become an obstacle to integration -- not only image-wise, but also by becoming too self-sufficient and inward-oriented. However, SRV makes no specific prediction as to whether there are critical group sizes. Thus, it is quite possible that units less than seven will be even more conducive to fostering integrated contacts, while at a certain point of largeness, so many integration obstacles may be posed that yet larger units may add very little if anything to integration barriers. Of course, size alone is not the only variable bearing on integration, since SRV theory also has something to say about things such as -- for instance -- access to and from a setting, and the availability of potential assimilators. After all, in a small village, there would be many fewer potential assimilators even for a relatively small congregation of devalued people.

*In Germany, a music teacher lived next door to a group home for seven severely impaired people. He went to court because the residents would be brought out into the garden where they would emit "inarticulate cries, calls, gargles, moans, laughter and babble," and he wanted some noise relief. Of course, rather than admit that seven such people together are too many and that this probably accounted in part for the music teacher's umbrage, all the politically correct parties fell upon the hapless teacher, and upon the court when it ruled that the operators of the group home should assure that at least during some parts of each day during the summer, there should be no noise nuisance (January 1998 source item from Hanno Wolfensberger).

*We have a friend who has a very large family, which is why the family owns a small van so that they can all go places together. To his surprise, he noted that whenever he drove somewhere, handicapped people on the street would stop and wave at the van. It turned out that handicapped people automatically assumed that a van full of people ranging from adults down to little children must be from an institution or group home, or must belong to some service that transports handicapped people.

*It is extremely unlikely that a mentally retarded person would be refused service in a pub in England merely for being, or appearing to be, retarded -- but when *ten* showed up in one such pub, the landlady did refuse service. The way people do things these days, a suit was lodged on behalf of the *ten*, and the court ordered the landlady to pay each of them approximately \$1,200 compensation (*Speak Out*, March 1998) which strikes us as an absurd sentence. If the handicapped people had shown

up in a smaller group, they would probably have been gladly served. In SRV language, this is an issue of 'congregation and assimilation potential.' The question here is not one of rights but of wisdom and common sense.

*In many places in North America, direct care workers increasingly are not only of the just barely employable class, but also cannot speak English. Many service leaders have conceptualized such servers as agents of social integration, but people who speak little or no English can hardly enable others to be integrated into English-speaking society.

Other Issues Related to SRV of Grouping of People

IN SRV THEORY, issues of how groupings of people can be role-valORIZING or deVALORIZING are treated under the rubrics of both imagery and competency.

*Dörner, K. (1994). Wir verstehen die Geschichte der Moderne nur mit den Behinderten vollständig. *Leviathan: Zeitschrift für Sozialwissenschaft*, 22, 367-390. This long article is a very illuminating contribution to the history of handicap and human service. Of relevance to SRV is a section on the congregation of devalued people. We learn that one of the earliest articulations of the importance of dispersion of devalued people was rendered by the German physician Johann Autenrieth (1772-1835). On a visit to the US around 1800, he noted that mentally disturbed people began to be congregated there, which he probably saw in almshouses and the few then-existing insane asylums. In 1806, he warned that the same tendencies were underfoot in Germany, and that they were wrong. Instead, he said, one should dis-

perse the mentally disordered across the entire society so that their care can be distributed across many shoulders, and that thereby, their positive characteristics and capabilities would also be noted and permitted to flourish. He succeeded in having at least one disturbed person taken care of that way instead of being sent to an insane asylum, but his judgment was otherwise ignored and the congregatory tendency took its course.

*As early as 1839, a British publication pointed out that no matter how well-appointed an insane asylum was, how varied the treatments and how excellent the setting, "the association of lunatics with each other, and the infrequency of any communication between a patient and persons of sound mind mars the whole design" (Scull, 1979, pp. 96-97).

*Howe, S. G. (1874). *Report of the superintendent to the Trustees of the Massachusetts School for Idiotic Children*. Boston, MA: Wright & Potter. It is sobering to recall that as long ago as in 1874, Samuel Gridley Howe recited the ills of grouping together too many people with maladaptive mental functions or behaviors. He said that "the morbid peculiarities of each are intensified by constant and close association of others of his class."

*In 2000, we learned of a boy who, at age 3 and 1/2, had developed very little speech. He was placed in day care and promptly put into a grouping with other children who either also did not speak, or had big speech problems. Apparently, someone thought that all such children should be with each other rather than with children who could model good speech for them and motivate them to talk. This underlines how little the dynamics of grouping are known, or recruited for the good, in human

services, despite the fact that few people dispute that imitation is commonly elicited in and by group contexts.

*A nursing home in Illinois allocated some empty beds to some young homeless drug-addicted people from the Chicago area, who promptly began to terrorize the debilitated elderly residents and even staff. Even though the facility was very small, the state had to close it down for the safety of the more debilitated residents (AP in *SHJ*, 31 March 2000). This is a striking example of why appropriate kinds of groupings are so terribly important in SRV. This grouping obviously was a threat both to the competency (and even life), as well as the image, of elderly nursing home residents. Why were the troublemakers not simply removed? Quite possibly because that would have opened the door to charges of racism, or discrimination, lawsuits, etc.

Note that in today's politically correct environment, it would not do to simply exclude young troublemakers, especially if they come from a 'protected' devalued class. So the only 'safe' way to correct the mistake of letting them in was to close the place down entirely. This reflects what in SRV teaching is called the 'lowest common denominator' phenomenon: all members of a group will be subjected to whatever bad thing one has to do to deal with the least adaptive member(s) of a group.

Similarly, a psychiatric 'hospital' in Syracuse began to admit supposedly disturbed youths from the ghetto culture, some with records of severe troubles, who promptly began to bring the ghetto youth street culture and a 'gang mentality' into the facility, which would not have happened if there had been only a few of them interspersed among the other youths. The result was constant fights, fire alarms being pulled all the time, and the other children

living in fear. This got so bad that parents of the other children pulled their children out, and the staff retreated behind the closed and windowless doors of 'nurses' stations' (*SPS*, 16 March 2002).

*There seems to be no end of programs that unite mentally handicapped people with prisoners. In Canada, the first such program was begun in 1977 at the Collins Bay prison in Kingston, Ontario (Kingston is the site of several prisons and institutions), and has since spread across Canada to other federal prisons. This program is called a special sports day, and is described as a "day-long get-together of food and frolic." It includes -- no surprise -- the presence of clowns, though in this instance they are prisoners dressed up as clowns. As always, it is claimed that the prisoners gain an awful lot from these occasions, especially from the fact that mentally limited people do not judge them. However, one prisoner said about the mentally retarded youths, "They aren't complete, but they are happy" (*The Recorder & Times*, 10 July 2004, p. 8; source item from Erica Baker).

Scholarly Works Relevant to Several SRV Themes

*Manusov, V., & Harvey, J. H. (Eds.). (2001). *Attribution, communication behavior, and close relationships*. Cambridge, United Kingdom: Cambridge University Press. So-called attribution theory was launched in the 1960s by Harold H. Kelley, and has been alive ever since, spawning innumerable empirical and theoretical publications. Unlike with some new ways of theorizing in the social and behavioral fields, publications concerned with 'attribution' have continued to increase steadily over the decades.

One way scholarly work on attributions can be divided is into questions about the characteristics and dimensions of attribution, and what makes people attribute something to others or themselves.

Attribution theory addresses phenomena which SRV would treat under headings such as expectancy, and those aspects of imagery that either create or reflect attributions.

SRV does not stand or fall with the fate of attribution theory, but draws on the research generated by this theory. Some of the SRV assertions about expectancy are supported by attribution theory research. However, attribution scholars have been remarkably sterile in not relating their work more to application and behavior change, the way SRV has.

Miscellaneous

*The Mental Retardation Definition, Classification, and Systems of Supports manual of the American Association on Mental Retardation is constantly being revised, and in 2002, the 10th edition came out. One of the changes it made was to add a dimension of "participation, interactions, and social roles" to its theoretical model. The addition of social roles was undoubtedly in response to the growing awareness of the importance of social roles, as taught by SRV.

*Smith, L. (1954). *The journey*. Cleveland, OH & New York: World Publishing. The author is a Southern lady who apparently got a bit 'hoity-toity' and what we today would call politically correct without losing her Southern culture and ties to her roots. The journey mentioned here refers to her efforts to recover her roots and childhood memories, in part by a car tour through Southern states. Despite certain

weaknesses, this is a very worthwhile autobiographical book for people dealing with deviancy and human services.

Many different kinds of handicapped people either occur in the book, or are described in it as having once been encountered by the author; and there is much discourse on how ordinary people in the rural US south used to interpret various kinds of afflictions, or responded to them. There are also inspiring stories of the achievements of certain handicapped persons through their strength of will. A book on what we now call cerebral palsy by Dr. W. J. Little, written in 1853, plays a certain role here. Cerebral palsy was long called "Little's disease" after him. He believed that much could be done for such persons, but for almost 100 years, not much was in fact done.

One character who makes a brief appearance is Midge, a 'deaf and dumb' woman who could however talk on her fingers, and taught some of her finger talk to her peers.

A character called Carl, clearly mentally retarded and virtually word-less, is somewhat in the role of the oversized retarded person who might be perceived as a menace, and is also interpreted somewhat along the lines of a village idiot. Lunatic asylums are also repeatedly referred to.

On p. 245, the author mentions a group of mothers of blind children with whom she had met, and a group of parents of children with speech difficulties.

A series of leaders of fields dealing with various afflictions is mentioned on pp. 247-248.

One of the passages (pp. 8-9) is so instructive about the developmental model, and the power of certain pedagogies, as to deserve being cited verbatim:

"I watched a young man whose body was paralyzed learn to move again. I had ne-

ver before seen the creative spirit spelling itself out so plainly. Then it was that I learned, with a paraplegic, the passionate meaning of movement. I watched him the day they tied him to a board as if he were a mummy and stood him on end, on nerveless feet that were as full of emptiness as a wraith. He blacked out. But the next day, he stayed in this world and participated in his bright triumph. He was a man, standing up. Bound to a board but here. And slowly, I saw the change come. He learned to sit; to get in a wheel chair and slide out again. Inch by inch he was regaining his universe. Then came the morning when he stood on his feet, alone, clinging to the bars, but he stood. I went away for a few months. When I came back, he was walking slowly down the parallel bars; sliding himself from end to end of that strict little path. Then, almost suddenly it seemed to me, he was on crutches, standing; not walking but standing as he learned to swing his crutches above his head, in front, behind, above his head: getting what they call 'crutch balance.' One day, he walked. I stood there watching him with the same deep feeling of miracle that I have each time I see Martha Graham dance. It was so beautiful a movement, rigorously disciplined, God knows, bound by an iron reality; but within the limits set by dead nerves he moved with grace, and with what I think of as an immense inner freedom. As I watched this man I thought, Martha Graham could understand this triumph. For she, at the other end of the arc of human

movement, has the same mastery of body and spirit that he now has. A paraplegic and a great dancer -- each pushing back the frontiers of the body, and the mind, each with a free and bold imagination clearing the way for the human spirit to move to levels not yet attained."

*In the 1950s, John Forbes Nash did some brilliant work in mathematical economics and game theory, but then changed from being just odd to being 'schizophrenic,' unemployed, and sometimes institutionalized. He became a tragic figure, roaming academic halls and scribbling idiosyncratic formulae onto blackboards. Then in 1994, at age 66, he received the Nobel Prize in economics, which cast upon him what one reporter very insightfully called 'the mantle of extra protection' (*Globe & Mail*, 19 November 1994; source item from Judith Sandys). In SRV terms, one can call this the recruitment of former positive roles for a person at value risk, and/or the bestowal of positive imagery, to say nothing of the fact that the prize money will be a great protection against all sorts of degradations in his old age. Nash not only became more protected, he actually began to become vastly more normal, and also became capable of discussing his previous mental state rationally.

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A Brief Description of Social Role Valorization

From the Editor

Given that this is a Social Role Valorization (SRV) journal, we felt it was important to print in every issue a few brief descriptions of our understanding of what SRV is. This by no means replaces more thorough explanations of SRV, but it does set a helpful framework for the content of this journal.

The following is taken from: Wolfensberger, W. (1998). *A brief introduction to Social Role Valorization: A high-order concept for addressing the plight of societally devalued people, and for structuring human services* (3rd ed). Syracuse, NY: Training Institute for Human Service Planning, Leadership & Change Agency (Syracuse University), p. 58.

“... in order for people to be treated well by others, it is very important that they be seen as occupying valued roles, because otherwise, things are apt to go ill with them. Further, the greater the number of valued roles a person, group or class occupies, or the more valued the roles that such a party occupies, the more likely it is that the party will be accorded those good things of life that others are in a position to accord, or to withhold.”

The following is taken from: SRV Council [North American Social Role Valorization Development, Training & Safeguarding Council] (2004). A proposed definition of Social Role Valorization, with various background materials and elaborations. *SRV-VRS: The International Social Role Valorization Journal/La revue internationale de la Valorisation des rôles sociaux*, 5(1&2), p. 85.

“SRV is a systematic way of dealing with the facts of social perception and evaluation, so as to enhance the roles of people who are apt to be devalued, by upgrading their competencies and social image in the eyes of others.”

The following is taken from: Wolfensberger, W. (2000). A brief overview of Social Role Valorization. *Mental Retardation*, 38(2), p. 105.

“The key premise of SRV is that people’s welfare depends extensively on the social roles they occupy: People who fill roles that are positively valued by others will generally be afforded by the latter the good things of life, but people who fill roles that are devalued by others will typically get badly treated by them. This implies that in the case of people whose life situations are very bad,

and whose bad situations are bound up with occupancy of devalued roles, then if the social roles they are seen as occupying can somehow be upgraded in the eyes of perceivers, their life conditions will usually improve, and often dramatically so.”

Resource List

- **A Brief Introduction to Social Role Valorization**, 3rd (rev.) edition. Wolf Wolfensberger. (1998) (available from the Training Institute at 315 473 2978)
- **PASSING (Program Analysis of Service Systems’ Implementation of Normalization Goals): Normalization Criteria and Ratings Manual**, 2nd edition. Wolf Wolfensberger and Susan Thomas. (1983) (available from the Training Institute at 315 473 2978) (NOTE: We anticipate a new revised edition of PASSING to be published in 2007. The title will be **PASSING: A Tool for Analyzing Service Quality According to Social Role Valorization Criteria. Ratings Manual**, (3rd rev. ed.). Watch future issues of this journal for more information.)
- **A Quarter-Century of Normalization and Social Role Valorization: Evolution and Impact**. Edited by Robert Flynn and Ray Lemay. Ottawa: University of Ottawa Press. (1999) (available from the Training Institute at 315 473 2978)
- **Social Role Valorization and the English Experience**. David Race. London: Whiting & Birch. (1999)
- **A Brief Overview of Social Role Valorization**. Wolf Wolfensberger. *Mental Retardation*, 38(2), 105-123. (2000)
- **An Overview of Social Role Valorization Theory**. Joe Osburn. *The SRV Journal*, 1(1), 4-13. (2006)
- **Some of the Universal ‘Good Things of Life’ Which the Implementation of Social Role Valorization Can Be Expected to Make More Accessible to Devalued People**. Wolf Wolfensberger, Susan Thomas and Guy Caruso. *SRV/VRS: The International Social Role Valorization Journal/La revue internationale de la Valorisation des rôles sociaux*, 2(2), 12-14. (1996)
- **A Social Role Valorization web page** can be accessed at: <http://www.socialrolevalorization.com/>