The SRV JOURNAL

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STATEMENT OF PURPOSE

WE BELIEVE THAT SOCIAL ROLE VALORIZATION (SRV), when well applied, has potential to help societally devalued people to gain greater access to the good things of life & to be spared at least some 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 & in human services particularly; 3) fostering, extending & deepening dialogue about, & understanding of, SRV; & 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 & others in relationship with or serving formally or informally upon devalued people in order to provide more valued life conditions as well as more relevant & coherent service.

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; & promote the work of the formulator of SRV, Prof. Wolf Wolfensberger of the Syracuse University Training Institute.

EDITORIAL POLICY

INFORMED & OPEN DISCUSSIONS OF SRV, & even constructive debates about it, help to promote its dissemination & application. We encourage people with a range of experience with SRV to submit items for consideration of publication. We hope those with much experience in teaching or implementing SRV, as well as those just beginning to learn about it, will contribute to the *Journal*.

We encourage readers & writers in a variety of roles & from a variety of human service backgrounds to subscribe & to contribute. We 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 (see this issue's training calendar), by studying relevant resources (see the next page of this journal), or both.

We are particularly interested in receiving submissions from family members, friends & 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 has a peer review section.

INFORMATION FOR SUBMISSIONS

WE WELCOME WELL-REASONED, CLEARLY-WRITTEN submissions. Language used should be clear & descriptive. We encourage the use of ordinary grammar & vocabulary that a typical reader would understand. The *Publication Manual of the American Psychological Association* is one easily available general style guide. Academic authors should follow the standards of their field. We will not accept items simultaneously submitted elsewhere for publication or previously electronically posted or distributed.

Submissions are reviewed by members of the editorial board, the editorial advisory board, or external referees. Our double-blind peer review policy is available on request.

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

TYPEFACE

Main text is set in Adobe Garamond Pro and headlines in Myriad Pro, both designed by Robert Slimbach.

A Brief Description of Social Role Valorization

From the Editor

As THIS IS A Social Role Valorization (SRV) journal, we feel it 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 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: Syracuse University Training Institute for Human Service Planning, Leadership & Change Agentry, 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.) ed. Wolf Wolfensberger. (1998). (Available from the Training Institute at 315.473.2978)

• **PASSING: A tool for analyzing service quality according to Social Role Valorization criteria. Ratings manual**, 3rd (rev.) ed. Wolf Wolfensberger & Susan Thomas. (2007). (Available from the Training Institute at 315.473.2978)

• **A quarter-century of Normalization and Social Role Valorization: Evolution and impact.** Ed. by Robert Flynn & Ray Lemay. (1999). Ottawa: University of Ottawa Press. (Available from the Training Institute at 315.473.2978)

• **Social Role Valorization and the English experience.** David Race. (1999). London: Whiting & Birch.

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

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

• **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 & Guy Caruso. (1996). *SRV/VRS: The International Social Role Valorization Journal/La Revue Internationale de la Valorisation des Rôles Sociaux, 2*(2), 12-14.

• **A Social Role Valorization web page** can be accessed at: http://www.socialrolevalorization.com/

FROM THE EDITOR

PLEASE NOTE THE DATE OF THE NEXT SRV CONFERENCE
The 5th International SRV Conference "Getting the good life: From ideas to actions" will be held from September 21-23, 2011 in Canberra, ACT, Australia. For more information, please email *srvconference@koomarri.asn.au*.

ONLINE RESOURCES
We have started a blog relevant to SRV: *http://blog.srvip.org/*.

Take a moment to read the blog and send us a comment. You can also sign up to receive new postings by email.

Regards,
Marc Tumeinski, journal@srvip.org

SRV FOCUS QUESTION

IN EACH ISSUE, we publish a focus question & invite you our readers to submit a 200-300 word response to the question. Commentaries on the question, if accepted, will be published in the following issue. General advice: write clearly; focus on 1 or 2 most important points; share your opinion, backed up by evidence &/or logical argument; incorporate SRV language & concepts.

   All submissions will be reviewed for suitability for publication. Note that submissions are subject to editing for length, clarity & accuracy; authors will have final approval. Please email your answer to *journal@srvip.org* or mail to *SRV Journal*, 74 Elm Street, Worcester, MA 01609 US.

QUESTION
One aspect of the SRV theme of interpersonal identification is that "if devalued people are to have a chance of receiving the good things in life from the rest of society, then it is important that things be done which help valued people to identify with–i.e., to see themselves in, and as similar to–devalued people" (Wolfensberger, 1998, 119).

Think of a time when you were reminded of the humanity you share with a devalued person. What did you think & feel, & what effect did this have on you & on the relationship? How can engaging in interpersonal identification help you to more fully understand the most pressing, immediate & urgent needs of socially devalued people? (cf. Wolfensberger, 1998, 111-112.) Be mindful of both image & competency needs.

What helps interpersonal identification to occur? As well, what barriers get in the way of human service programs a) identifying with socially devalued people & b) understanding their most pressing needs? What can be done to minimize or compensate for these barriers at the level of human service staff, programs, organizations & systems?

Legalize Assisted Suicide? Not So Fast

James McGaughey

A RECENTLY FILED LAWSUIT has renewed debate about legalizing assisted suicide in Connecticut. Plaintiffs are two doctors who want to be able to prescribe lethal doses of drugs if their patients ask them, without having to worry about being prosecuted under Connecticut statutes that prohibit assisting in suicide. They are represented both by local counsel and by lawyers from Compassion & Choices, a successor organization to the Hemlock Society. The State's Division of Criminal Justice, Chief State's Attorney and thirteen State's Attorneys (prosecutors) are all named as defendants. They are being represented by the Office of the Attorney General.

Earlier this year, a similar challenge surfaced in the form of proposed legislation that would have legalized prescribing lethal doses of drugs to people with "terminal diseases." Patterned after legislative proposals that Compassion & Choices is aggressively promoting in a number of other states, the bill was quickly withdrawn amidst indications that it would face a storm of protest from religious groups and disability advocates, and preliminary signals from the mainstream medical establishment that it is decidedly wary. In the wake of that reversal, Compassion & Choices is trying again, this time through the courts.

Proponents of legalizing assisted suicide argue that it's all about compassion and personal autonomy. Citing examples of individuals who have ended, or who apparently want to end their lives by taking lethal doses of prescribed drugs, they propose adoption of the euphemistic term "aid with dying," and suggest that it be seen as a compassionate alternative to suffering intractable pain or endlessly intrusive, de-dignifying medical interventions. If all we hear is their side of the story, it seems reasonable enough. After all, shouldn't we have the option of avoiding an ignoble end? Shouldn't our doctors be able to prescribe drugs that will do the job quietly and professionally? What's wrong with just having the choice?

Leading disability rights groups see plenty of problems with it. A number of well respected organizations, including the National Council on Disability, the American Association of People with Disabilities (AAPD), the National Council on Independent Living (NCIL), the National Spinal Cord Injury Association, the World Institute on Disability, Justice for All, TASH (formerly called The Association of the Severely Handicapped), the Disability Rights Education and Defense Fund (DREDF), and grass roots groups such as ADAPT and Not Dead Yet have all adopted positions opposing legalization of assisted suicide. In fact, members of many of these groups have been teaming up with local independent living centers and state-level advocacy coalitions to challenge Compassion & Choices' state-by-state campaign.

Their opposition is rooted in the realities of the disability experience. Advocates who have worked with newly disabled individuals, or who may re-

member their own experiences, are deeply concerned about the impact legalization would have on people who may be struggling with difficult personal adjustments and, not infrequently, with depression. Even people who have lived with lifelong disabilities may, at some point, find themselves facing anxiety and emotional distress over changing circumstances and difficult transitions. During such times people may feel like their lives are not worth living–a view that, unfortunately, can find support in a world that values strength, speed, youthful appearance, hard-driving, fast-paced achievement and material success, while unconsciously devaluing those who are not possessed of those characteristics.

The annals of the disability rights movement are punctuated with stories of individuals with significant disabilities who "just wanted to die" before coming to realize they could still lead good, contributing lives. Over the past thirty years, the passage of civil rights laws and growth of the independent living movement have helped open doors for people with all types of disabilities to access a rightful place in the human community. So has the increasing availability of adaptive technologies, the emergence of advocacy and service providing organizations that recognize peoples' potential, promote valued social roles (cf. Wolfensberger, 1998) and champion community living. But these changes are only beginning to affect public policy and funding streams. For far too many people with significant disabilities, relevant services and culturally valued options remain elusive, and daily life is defined by the dismal realities of institutional care and low expectations. Part of the problem is that so few people in the health care world are even aware of the possibilities, much less know how to access the "good stuff" (cf. Wolfensberger, Thomas & Caruso, 1996). In fact, most medical professionals remain poorly informed about the life prospects of people who live with disabilities. But there are also major infrastructure problems: lingering architectural barriers, insufficient accessible housing and transportation, and inadequate support for person-

al care assistance. And, while many communities have become more accepting, there has been no widespread moral revolution–no groundswell of outrage over the lives being wasted in facilities; no outpouring of concern and welcome for resettled refugees from the nursing home.

And so, there are also darker stories; stories about people who just couldn't find their way out and who asked to have someone "pull the plug." Instead of the suicide prevention interventions that would ordinarily have been provided to someone seeking to end his or her life, instead of concrete help in securing better living circumstances, the only assistance these individuals received came in the form of court orders protecting their "right to die with dignity." To the extent that response is substantially different than the response afforded suicidal people who do not have disabilities, it is discriminatory. And, as with all types of discrimination, it is rooted in prejudice–an unconscious, pervasive pre-judging of people based on characteristics that are socially perceived as undesirable. Discrimination in the name of compassion and respect for personal choice is still discrimination. As one long-time Connecticut advocate put it: "Why is it that the only right we haven't had to struggle for is the 'right to die with dignity'?"

Given the ambiguous terms that proponents of legalization want written into law, and the considerable confusion that exists–even in the medical world–about the distinctions between disabilities and "terminal diseases," there is a very real risk that people with disabilities who are depressed, but who also have many good years of life ahead of them, will be given lethal prescriptions.

Proponents of legalization say they intend assisted suicide to be available only to people who are within six months of death. But the business of predicting the time frame for an individual's death is just not that precise. In fact, research on the question has demonstrated that medical prognostications regarding death are often unreliable, sometimes missing the mark by years. It doesn't help that proponents insist on legislative language

that defines the process as essentially a private transaction between doctor and patient. Their proposals provide no meaningful external oversight to prevent untoward influence, and require no suicide prevention interventions to help people sort out feelings that may be a result of previous trauma and loss, uninformed assumptions, or the irrational thinking that sometimes accompanies extreme emotional distress. And, it certainly doesn't help that at least some proponents seem to be in the habit of "referring" people who cannot get their own physicians to write them lethal prescriptions to other doctors who are perfectly willing to do so.

But, even if these problems could be cleaned up, ambiguity and social ambivalence concerning distinctions between disability and "terminal disease" would remain. As people with disabilities are well aware, in the medical world the difference between "disease" and "disability" is more a matter of perception than objective diagnosis. Add the emotionally loaded, but diagnostically imprecise term "terminal," and things get even less clear: Are Muscular Dystrophy or Multiple Sclerosis, or any number of other chronic conditions, to be considered progressive disabilities or "terminal diseases"? What about people who are born with disabilities that involve multiple, complex medical issues or genetic syndromes that can, but do not always, result in shortened life expectancy? Or people with physical disabilities who may experience repeated, life-threatening infections or various other serious health issues? What about people who depend on life-support technologies? At what point would these people be considered "terminally ill" or "within six months of death"? Who would get to make those judgments, and how much would their decisions be influenced by stigmatizing stereotypes about "quality of life" and frank ignorance about the possibilities of living a good life with a disability (cf. Wolfensberger, 1994)?

What emerges from the experience in places that have legalized assisted suicide is a highly subjective decision-making calculus that is ap-

plied without independent scrutiny, and which is open to considerable abuse. In the Netherlands, for example, where assisted suicide has been legally tolerated for the past 35 years, many doctors now consider having a long-term disability with a "poor prognosis" for improvement to justify writing a lethal prescription. In addition to practicing active euthanasia–administering lethal injections to newborns with significant disabilities and to older people with dementia–some Dutch physicians see no problem with directly administering deadly doses of drugs at the request of people who have no physical signs of disease, but who are experiencing chronic emotional distress from conditions such as anorexia nervosa. Surveys indicate that at least some doctors admit to not even having bothered to ask–they just made the decision and proceeded to administer the drugs.

The experience in Oregon is also instructive. In Oregon, which legalized assisted suicide over ten years ago, doctors who write lethal prescriptions are required to supply certain after-the-fact data. While there is reason to question whether all of them do so, and the data being collected is minimal, a ten-year statistical summary indicates that most of those who sought lethal prescriptions acted out of fear of future disability, not worries over dying in pain. The "suffering" which people reportedly sought to avoid by committing suicide involved anticipated loss of "dignity" and "autonomy," the prospect of losing control of bodily functions and needing personal care, and worries over the "burden" that continuing to live might place on others. In other words, the same things with which hundreds of thousands of people with disabilities contend on a daily basis. To disability advocates, who have spent decades fighting against negative stereotypes, this sends a frightening message: deliberately causing death is an acceptable, possibly even preferable, alternative to the prospect of living, even briefly, with a disability.

Beyond these issues, advocates are also concerned about the impact legalization would have on health care policy. This question involves not

only the behavior of insurers, providers and regulators; it also goes directly to questions of social acceptance, personal expectations and the realities of "choice" in an ever more complicated and costly health care system. There is so much to consider: Would the fact that a physician authorizes and intentionally assists in taking human life signal a fundamental change in the core ethic of a profession heretofore committed to saving and protecting life? Would the involvement of "professionals" who we traditionally trust for comfort and advice, confer legitimacy on a practice that has been historically discouraged, ultimately resulting in more people seeking to kill themselves? What influence would growing concerns about health care costs have on peoples' perceptions about their "options" or on the practices of providers and insurers? Would legalizing assisted suicide amount to de facto acceptance of the notion that there are some lives not worth living, some people who are just better off dead?

Many leading palliative care specialists oppose legalization, explaining that the examples of pain and suffering cited by suicide proponents are evidence of poor or misinformed medical practice, not of the supposedly "intractable" nature of terminal pain (cf. Chevlen & Smith, 2002). Pointing to recent developments that have significantly expanded the knowledge-base and effectiveness of techniques that manage pain and other symptoms, palliative care physicians are urging a broad-based campaign to educate other practitioners about both these strategies and about existing, lawful decision-making mechanisms that respect patient choice and self-determination. They are also calling for greater investments in specialized palliative care programs and hospice options, and, more importantly, in the basic personal care systems that people need in order to live with dignity, even in their final days.

While everyone seems to agree these investments need to be made, if we begin to accept suicide as an "understandable choice," will we be more or less likely to make them? Again, consider the experience in the Netherlands, where physician awareness and investments in palliative care have lagged behind those of other European countries– a fact that some experts attribute to the prevalence of assisted suicide and euthanasia. Or, closer to home, look at Oregon, where the state Medicaid program makes deliberate, categorical decisions to ration medical care for poor people, and, at the same time, state law explicitly permits physician assisted suicide. Several cancer patients there recently received letters from the State informing them that Medicaid would not pay for the potentially life-prolonging, pain-relieving chemotherapy treatments prescribed by their doctors. However, the letters assured them, if they wished to avail themselves of assisted suicide, the State would pay for those final prescriptions.

This is chilling stuff. Before we glibly accept the notion that legalizing assisted suicide is about "compassion" or respecting personal "choice," we ought to ask ourselves: What kinds of choices are we actually affording people? What would be the impact on social institutions, on government policies, on professional practices and on our collective values? And, above all, what impact would it have on individual human beings? At what point would the availability of this "option" become an expectation–a felt duty to ease the "burden" and cost of care for family members, or for society generally? Wouldn't it be better to invest in truly compassionate care–to assure authentically humane choices for people approaching the ends of their lives–rather than cross into the highly problematic, morally questionable territory of legalized assisted suicide?

Proponents of legalization are right about one thing. This issue is about choice–the choice about what kind of people we are, how much we really care about each other, and what kind of world we want to live (and die) in. ♥

To learn more about this issue, check out the following online resources:

•www.dredf.org/assisted_suicide/index.shtm

•www.psychiatrictimes.com/display/article/10168/54071

•www.michiganlawreview.org/articles/physician-assisted-suicide-in-oregon-a-medicalperspective

•www.notdeadyet.org/docs/supporters/html

THIS ARTICLE IS RICH WITH REFLECTION QUESTIONS. SEE ADDITIONAL DISCUSSION QUESTIONS ON PAGE 53

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JAMES MCGAUGHEY is the Executive Director of the Office of Protection & Advocacy for Persons with Disabilities in Hartford, CT (US).

Invitation to Write Book, Film *&* Article Reviews

From the Editor

I 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; www.srvip.org

Thank you.

Striving for Ordinary: A Mother's Story

Susan Dunnigan

MY HUSBAND NEIL AND I are the parents of two young adults who have left the family home to seek independence and learn their way into the fullness of adulthood. Now at the helm, our son and daughter are charting their own unique courses. Each will experience the hurdles, opportunities and rewards that the sea of life offers. Our eldest Matthew will encounter additional challenges and risks as he has an intellectual disability.

Twenty-five plus years of family experience has convinced us that the key to Matthew having a promising future lies in sustaining meaningful community engagement and facilitating positive reciprocal relationships. Our son's disability clearly shapes his life experience, yet he is so much more than his visible cloak of disability. Like his sister, Matthew wants and deserves a "good life"–having diverse experiences, feeling valued as a person, having countless opportunities for lifelong learning and enjoying reciprocal, caring relationships (cf. Wolfensberger, Thomas & Caruso, 1996).

Raising a child with an intellectual disability is challenging, no matter what path you choose to walk. We chose to advocate for our son to achieve what will come naturally for our daughter–an ordinary life, as an engaged and responsible citizen. It definitely would have been easier to take the path of least resistance and follow professional advice. However, this approach typically leads families down a road that stresses meeting basic needs and

focuses on protection–a world of existence and care. We opted to stress capacity and possibility.

While the idea of pursuing an ordinary life would be considered mundane by many, for people with an intellectual disability it is an elusive dream. An ordinary life is filled with highs, lows and unexpected twists, all of which inherently contain elements of risk. We want Matthew to have no more and no less. Like most warriors who stand for something they believe in, we definitely have battle scars. Some wounds heal quickly while others remain raw for a long time.

My path of promoting inclusion began with Matthew's birth in 1983. In hindsight, I am glad that there was no early diagnosis, only delayed milestones and professional suspicions, coupled with a growing personal awareness of Matthew's struggles. By the time he was formally diagnosed at age nine, we were well aware of his challenges and had developed strategies to meet his additional support needs, within the context of everyday life.

My parental passion aligns well with my education and career in human services. University degrees in the arts and social work provided a firm foundation for almost forty years of public service positions, serving marginalized populations. About twenty of those years focused on the field of supporting adults with intellectual disabilities. Over my career I gained insights into the power of well-intentioned human service systems over the lives of individuals who rely on those systems

for support. Professionally, I influenced as much as I could, while personally putting more faith in people than systems.

Throughout my career, I was extremely fortunate to have many professional development opportunities where I learned about concepts such as inclusion and Social Role Valorization (Wolfensberger, 1998). Professionally, this training proved invaluable as I worked to develop, influence and apply government program policy, to improve its responsiveness to individuals with intellectual disabilities and their families. Personally, it was even more valuable.

After Matthew's diagnosis, our family could readily have accessed disability supports through government programs. People frequently questioned my resistance, especially since I worked for the system, knew of resources and how to access them. For a long time I could not articulate my hesitancy, yet trusted my intuition. Eventually I understood that I feared the power of human service systems and vehemently wanted to avoid that slippery slope. When Matthew was growing up, our family definitely paid a price for not accessing formal supports, yet we do not regret our decision.

Deep in my heart, I have always known that the only way for our son to have a chance at an ordinary life is to be actively engaged in and contribute to society. The challenge became "how." To help level the playing field, I have consistently sought natural pathways that welcome Matthew's knowledge, interests and enthusiasm—his gifts of contribution to the community.

My approach includes daring to ask for something better, beyond what is typically offered. Most recently a seed of possibility was planted that may lead to a work role, in alignment with Matthew's interests and studies. Matthew is enrolled in inclusive post-secondary studies, auditing a respected Radio and Television Arts program. His long-term goal is the same as that of his classmates—to secure work in the television industry. Work experience is a stepping-stone to a job in the industry. When such opportunities arise, I get to sit back and watch things unfold, within a natural community context. It is a beginning that offers possibilities. That is all any of us can ask for in life.

In childhood, active community engagement was fostered through typical resources, while avoiding segregated programs. Like his sister, Matthew was educated in regular classrooms, played community league soccer, went away to summer camps, volunteered for community events, found part-time jobs and so on. As an adult, he follows in Kate's footsteps as a college student.

Providing rich community experiences as a boy helped prepare the foundation for adulthood. While growing up, Matthew interacted naturally with a wide array of people as he filled socially valued roles, such as reliable snow shoveller (part-time job), loyal customer at the corner store and volunteer at community league events. When out and about, our son frequently encountered people he knew. I often overheard him inquiring about family members in hospital, growing children, new jobs and such. I had never met many of these people, but he knew them from his interactions in the community.

When Matthew was growing up, I relied on the eyes and ears of caring community members as he experienced his community without always being shadowed by family. These citizens did not look after Matthew, but rather looked out for him, as someone who belonged and was valued. When Matthew was in grade four, I met neighbours from the next street while tracking down my enthusiastic pledge gatherer for the Heart and Stroke Foundation. They were strangers to me, yet all knew Matthew by name, updated me on his progress and pointed me towards where he was heading next. Per usual, I was able to track him down. Matthew won his school's top award for collecting the most pledges.

Another example from a few years later involved a bus driver on the route to Matthew' school. He stopped his bus to intervene when he saw my son being bullied by teenage school peers while walk-

ing to the bus stop. He then reported the incident to the principal for disciplinary action. Matthew still speaks fondly of the driver and occasionally sees him when traveling by bus.

I try pushing past my strong parental inclination to over-protect, step beyond my comfort zone and trust in the goodness of fellow citizens. When Matthew was a boy, I did not relinquish all control, nor turn a blind eye. Rather, on the sidelines, I nurtured opportunities for him to interact with others in his own unique way, ever ready to intercede if and when necessary. I rarely needed to do so. This approach reaped Matthew's long-term friendship with John. When they met twenty years ago, John was a grocery store manager who befriended a young child. Matthew clearly states that he would trust John with his life, as would I.

As a boy, Matthew made it clear that he wanted to be the one who asked for store assistance when needed. I learned to take my cue from my child who kept saying, "I am capable." He found the clerk, exchanged names and then proceeded to identify his issue or concern. My job was to stand on the sidelines, poised to step forward on cue. Sometimes he involved me quickly, whereas other times it was later. However, the words were always the same–"And my mum will tell you the rest." Matthew was often an unexpected gift in a stranger's day, challenging the person to stretch and grow. Even if a clerk initially presented as stern and aloof, this often changed as the interaction unfolded.

I have been tested many times and learned countless lessons about the web of complexity that challenges families who strive for inclusion. It is relatively simple to articulate the ordinary life that is wanted for a vulnerable family member, yet it is a huge challenge to walk through the fear, seeking and seizing opportunities that hold promise. Sometimes I am shaking internally as I reach out, sometimes I am confident and yet other times I am too tired to grasp the prize within my reach. It is at those times I have to be gentle with myself and replenish my soul

before being able to execute even the smallest act of advocacy.

The years of this journey have required that I dig deep, unearthing every grain of internal fortitude. I am now branded by the traits of perseverance and resiliency, having survived fires of darkness and despair. A mother aptly compared this resiliency of families to punching bag clowns. You knock them down, yet they come right back at you, sometimes slow and sometimes fast.

Workshops related to inclusion and Social Role Valorization training deepen my conviction and connect me with other like-minded individuals. The social connections I have developed help ground me during those unavoidable times when I feel overwhelmed, vulnerable and alone. Knowing that others share my vision and passion provides the encouragement and strength to face powerful systems. David and Goliath battles are made more bearable by my invisible army of like-minded people standing at my side, urging me to stay the course, when the rest of the world thinks I am mad.

Matthew's life has many similarities to his sister's, particularly related to living arrangements, college, part-time work and pet ownership. Although Matthew definitely experiences key elements of a good life, it is less robust than Kate's and his future is less secure. His inherent vulnerability requires that our family be ever vigilant, protecting hard earned gains, while seizing opportunities to further embed him in the naturalness of community life. I want to be clear that Matthew's life should not be viewed as special; rather it is a life marked by the potential for a typical life. I clearly attribute his successes to his tenacity and our clear vision of a positive future.

At the time of this writing, Matthew is twenty-seven. He has lived on his own for almost five years and is a long-term tenant in a small apartment building near our family home. He is a college student, thanks to Alberta's commitment to inclusive post-secondary education. Matthew audits a Radio and Television Arts program at the Northern

Alberta Institute of Technology, with support. His part-time work role at a local movie theatre (working the concession stands, assembling displays and billboards, cleaning) augments basic benefits from the Alberta government and gives him some consumer power. Matthew shares his apartment with a much-loved companion, his cat named Angelo.

As a family we understand the fragility of Matthew's realities and clearly know the inherent risks. Our vision is clear, the path is tough and there are no guarantees–but there is great promise. Our family has learned, stretched and become stronger as we walk this journey with Matthew. Many experiences are imprinted on my heart. I am capturing the stories in print, believing it important to share true experiences that illuminate universal life lessons, experienced through the disability lens. I look forward to sharing these stories and providing a glimpse behind the curtain of our family's experience in pursuit of an ordinary life. ❦

See Discussion Questions on Page 53

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Susan Dunnigan *integrates her over 35 years of social work training & human service work with a mother's passion to focus on strategies that support the inclusion of people with disabilities as valued citizens within their community.*

The citation for this article is
Dunnigan, S. (2010). Striving for ordinary: A mother's story. *The SRV Journal, 5*(1), 10-13.

Peer-reviewed articles

Issues of the SRV Journal occasionally include a section of double blind 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 may be rejected for publication. The final decision as to whether or not an article is published rests with the Editor.

The average 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.

Almost, But Not Quite There: Failing to Fully Develop Culturally Valued Analogues

Emma Barken

Introduction

MARIA DID NOT WANT to leave her job as a cook's helper at a recreational dinner-time program for adults with mental retardation. Helping to prepare meals at this program, she loved working in the kitchen, and she was skilled at it. She made sure that everything was done on time; she worried that those attending the program would get upset otherwise. She was extremely efficient, almost to a fault. When the cook strayed even a little from the task at hand, Maria sharply reminded her of the time. She made sure that none of the various and ever-changing staff forgot who was diabetic and who had an allergy to this and to that.

One day when the cook was unable to make it to the program and another staff member stepped in to take her place, Maria became very concerned because the routine was disrupted. Contributing to her distress was the absence of a regular staff person who valued her help, as well as her dedication to the job and to the people being served. By the time the top supervisor came in that evening, Maria was distraught about the chaos that had erupted in the program due to the staff change. She was screaming and crying, and was completely unable to calm down. The supervisor sent her out of the kitchen, saying that she needed to calm down before she could return. When she returned a few moments later still very upset, the supervisor ordered her to leave. At this point, Maria threw some dishes on the floor, began yelling and then pushed the supervisor. Due to the unpredictability of the situation, Maria's difficulty in dealing with change, and staff unwillingness or inability to understand how hard all of this was for her, Maria was cast into what Social Role Valorization (SRV) theory calls the menace role (Wolfensberger, 1998). And just like that, Maria lost yet another job.

Reflection

AS WE ATE DINNER TOGETHER a few weeks later, Maria recounted some of the jobs she had had over the years; ultimately she was dismissed from all of them. She worked at a restaurant in a prestigious downtown hotel, at a daycare helping to cook meals and at a sheltered workshop assembling various objects. She worked at an animal shelter for a few days but was fired because, she was told, her arms were too short to reach the backs of the cages, and she was too big to squeeze into them to clean them out. Maria had average-length arms. I pointed out that this job did not sound like a very good one anyway, though she was not so concerned about the quality of the job but more that she had a job. She was the kind of person who always wanted to be busy, she hated having nothing to do, and put a lot of others to shame with her industriousness. I suspect that this was one of the reasons that she went through so many jobs; she completed tasks faster than those around her, which likely annoyed oth-

ers who would have liked to believe that they were more efficient and smarter than she was. She certainly put me to shame, calling me out when I arrived a few minutes late to work–something she never did.

The Culturally Valued Analogue

IN EXAMINING AND WRITING ABOUT several of Maria's life experiences, I want to explore the SRV concept of the culturally valued analogue (CVA). According to the PASSING manual, a culturally valued analogue is defined as "a societal practice (a) which can be encountered with at least regular frequency in the valued sector of society, (b) with which most members of the society would be familiar, (c) of which most members of the society would hold positive expectations and images, (d) which constitutes a valued parallel to a practice performed by or with devalued people" (Wolfensberger *&* Thomas, 2007, 30). The CVA is a useful way to think about what might be appropriate for a person in any given situation based on what is done by socially valued people in a similar context. It can be used as a tool to help service agencies structure their support for someone in such a way that it is most likely to be in accord with a normative practice, e.g., developing culturally valued roles, supporting image and competency enhancement, etc.

The CVA is an important component of a number of the ten themes of Social Role Valorization. For example, if one considers the SRV theme of Interpersonal Identification, it is clear that there is an increased likelihood that valued people will identify with a person whose circumstances most closely resemble the culturally valued analogue, and thus will consequently want, and hopefully help to achieve, the good things in life for that person (Wolfensberger, Thomas *&* Caruso, 1996). It is crucial for those who are attempting to create or provide a normative experience for a devalued person to understand just how nuanced culturally valued analogues are. So many components come together to make an experience whole and genuine, and thus a failure to truly appreciate the various elements will likely lead to phony practice. Being surrounded by such illegitimate life experiences exemplifies the wound not only of impoverishment of experience, but also that of having one's life wasted, because that person is not given the opportunity to develop and create a meaningful existence based on practices we all share.

At SRV workshops, participants learn that one could use SRV effectively to cast someone into more *devalued* roles, which would most likely be easier than applying SRV to help enhance or acquire *valued* roles for a devalued person. This could be done consciously, but as we also learn in longer SRV workshops, most often such things happen more unconsciously. For the purposes of this paper I wish to explore this idea in greater detail, using Maria's story to illustrate how roles become convoluted and perverted when the concept of the CVA is not adequately understood and implemented. An agency that does not understand or acknowledge the principle of SRV may, even with good intentions, attempt to develop positively valued roles for their clients, but when crucial aspects of a particular role or of significant role communicators (such as setting, grouping, activity, personal presentation, etc.) are missing, the role itself and others' perceptions of that role can be perverted. When this happens, a potentially valued role will not lead to the good things in life, as the role does not conform to what members of valued society recognize to be the privileges and responsibilities of a given role.

Maria's Background

ACCORDING TO SRV THEORY, societal devaluation is "devastating because it creates and maintains societally devalued classes who systematically receive poor treatment at the hands of their fellows in society and at the hands of social structures–including formal, organized human services" (Wolfensberger, 1998, 4-5). The vast majority of Maria's life was controlled by sev-

eral social workers and a few long-distance family members. Despite having a significant wound, that of the functional impairment of mental retardation, Maria grew up living with her family, attending both the neighbourhood elementary school as well as the high school, and was proud of the fact that she and her two sisters all graduated from the same schools. Maria lived with her parents until they were institutionalized when they were quite elderly. At this point, a human service agency for people with mental retardation became more heavily involved in Maria's life. Previously this agency provided certain respite services and supplied the family with a social worker. With the increasing needs and dependence of Maria's aging parents on human services for their own needs, Maria became more deeply entrenched in this agency. While she had siblings, aunts and uncles, cousins, nieces and nephews scattered throughout Canada, the United States and further, none of them gave Maria the support that she needed at that point. This exemplifies the wounds of distantiation, of a loss of natural or freely-given relationships, and to a certain degree, of abandonment.

Maria's sister continued to manage her financial matters despite her physical distance (eight hours drive), and some members of her family visited a few times a year, yet Maria was not always considered an integral part of the family. Three years ago, one of Maria's sisters died suddenly in Israel. Because of the suddenness of her death, only a few family members traveled to Israel at the time. A year later, according to the Jewish religion, more family traveled to Israel to participate in an unveiling ceremony honouring this woman's life. Maria was not invited to either of these events, despite having a close relationship with this sister. This represented a further wound of rejection by family members. Because of her distantiated relationships with her family, particularly after she stopped living with her parents, Maria was at a greater risk of being cast into devalued roles and was left almost solely in the hands of a large and chaotic human services agency.

Attempts at Attaining
Culturally Valued Analogues

SRV THEORY EXPLAINS THAT BECAUSE Maria was mentally retarded in a culture that devalues intellectual impairment, she occupied a low social status and experienced multiple forms of social and societal devaluation (Wolfensberger, 1998). She was largely "rejected, not only by society as a whole but quite often even by [her] own family, neighbours, community, and even by the workers in services that are supposed to assist [her]" (Wolfensberger, 1998, 13). Almost all facets of her life were connected to one human service agency, and because of this, she experienced the wound of loss of control and freedom. It was through a human service agency that I met Maria. While the concepts of the culturally valued analogue and Social Role Valorization were almost certainly not understood by this agency, there were some efforts made by the agency to assist those served to achieve positive valued roles. These efforts included recognizing the importance of having a job, a roommate, friends and a summer vacation. To varying degrees these were part of Maria's life. I wish to discuss how each of these aspects, which could and should have led to more socially valued roles and a better life, became perverted, muddled and mystified.

Employment

I OPENED THIS ARTICLE by describing part of Maria's employment history. Here I will examine her last job and how it failed to meet the requirements of the CVA of work, which meant that Maria did not benefit from the good things in life that derive from the valued role of employee. When most people think of what being an employee entails, they might think of the money one makes as an employee, of the responsibilities or duties that are taken on by the worker, of the authority one gains from having a job, of being part of a group of co-workers, and so on. At the recreational dinner-time program mentioned in the introduction, Maria had responsibilities in

the kitchen. She had certain tasks that she was required to do every time she worked. She was also called a staff member, and when there was a staff table at meal times, she sat at it.

Yet her role as staff was compromised by several pertinent factors. She was not paid for her work, unlike other staff. Despite other staff at the program advocating that she get paid, those who controlled her life did not support the idea. To the contrary, Maria had to pay to attend the program, as did the other clients. Maria also hung her coat where the clients did–in lockers, instead of on the coat rack in the kitchen, where all the other staff hung their coats. She left when the other clients did and not an hour later when the staff did. She was never offered a ride home with the other staff, even though we drove right past her house. She did not have keys to the locked doors at the program, something all the other staff members had, despite the fact that some of them frequently forgot to bring them. So while Maria was called a staff member, in many ways she was not treated as one. Many of the other role communicators sent the message that she was in the client role. There was a confusing, haphazard, blurring of her role, making it somewhere between that of client and of staff person.

There are several important points to draw from these examples. While Maria's job role was far from perfect, it was still a valued role that afforded her certain privileges that she otherwise would not have had. She was not paid for her work, which is typically of integral importance within this role. Yet, as Wolfensberger explains, "even where the valued work role does not bring payment, a great deal of valued status and other benefits can thereby be achieved nonetheless" (Wolfensberger, 1998, 60). Despite filling some aspects of the work role, however, Maria experienced both physical and social distancing from the other staff. The hours that she worked, and the ways in which she interacted with other staff members, indicated that she was not fully accepted as a co-worker. These forms of (subtle) rejection diluted the potential access to

the good things of life that Maria could have had through a stronger work role.

Roommate

DURING THE TIME I KNEW MARIA, she always lived with a woman whom she called a roommate, despite many aspects of this relationship that are not usually understood to be part of this role. The roommate role is one that requires complementarity, meaning that you have to have a roommate to be a roommate. The term "roommate" conjures up ideas such as shared space, shared rent, shared 'stuff' and often shared time. All of these characteristics comprise some of the privileges and responsibilities that derive from being a roommate in the valued world. Comparing these few features of the CVA of a roommate to Maria's situation reveals some major discrepancies. Maria's roommate was paid by the agency to live with her, instead of contributing to the cost of the apartment as is usual. Maria's family owned the apartment and paid for it. Typically this kind of disparity might mean that the person paying the rent would have certain extra privileges. This was not the case here, as the roommate's room had a balcony off of it that Maria could not access. Also inaccessible were the answering machine and a computer, as both were in the roommate's room. Maria did not feel comfortable inviting friends over for fear of disrupting her roommate. These concerns were not unfounded: in the past, the agency and the roommate decided that one of her friends was not to come to the apartment anymore because it was disruptive to the roommate's studying. The roommate was almost always said to be studying; it was the reason given for the living room being a bad place to watch television or to spend time in at all after a certain hour. In terms of shared time, almost any time that these two spent together was expected in conjunction with the "job" of being Maria's roommate; their twice weekly "work outs" at the gym was one of them. Maria frequently said she felt very lonely, and that spending so much time alone made her feel like

she was going crazy. Yet living semi-autonomously was deemed a good thing by those who controlled her life. This was clearly not how she felt; she said on numerous occasions that she liked to stay as busy as possible and that she was not the kind of person who was meant to live alone.

Maria's role as a roommate and the following discussion about the friend role point to some of the bad things that typically get done to devalued people. Despite the supposed good things that are usually associated with having roommates and friends, for a devalued person, these relationships do not always follow the same model. For most people, natural relationships lead the way to having a roommate or having friends, yet for Maria these relationships were filled by people who were recruited and/or paid to fill these roles. This contributed to the reality that Maria did not truly fill the valued roles of roommate or of friend (as described in the next section): the CVA of these roles is quite unlike what she experienced. She thus had virtually no chance of gaining access to the good things of life through these roles.

Friendship

TRUE FRIENDS IN MARIA'S LIFE were few. Most were people that she had worked with and that had some position of authority over her, including myself. One of her friends was told not to come over any more, for fear of disturbing the roommate. The role of friend was further distorted for Maria by her participation in a program run through a local university that matched disabled adults with university students, with the stated goal of developing a relationship by regular visits with each other. This program only ran during the school year, so the matches were only expected to be "friends" for 8 months. While for many people, participating in the program created an important connection as it allowed them to have someone to go out with on a regular basis, this did not change the fact that the program perverted the role of friend. The level of human service control held by the program

organizers meant that the CVA for a friend was violated to a significant degree through this program. True friendships are not orchestrated and controlled by a service agency. Volunteer hours are not accumulated by a friend. The two parties participating in a friendship generally have equal standing, or at least a level of respect for the other that is not possible when one is "matched" and has assigned visiting times. There is a high degree of human service control in these scenarios that are not normative in friendships that valued people have with each other. These matches did not tend to last for a long time, and they were often not very stable, as the lives of many of the student volunteers were hectic and subject to change. While a friendship match of this nature may represent some of the things on which friendship is built, such as going out, conversation and fun, it is severely lacking in other ways, including having someone to depend on when times are tough, having someone who knows you well, and having shared values or experiences. It is exceedingly difficult to develop meaningful or merely long-lasting relationships through controlled and regulated programs such as this which do not match the CVA. Instead, the wound of relationship discontinuity is likely, and even more rejection can be expected. This was true for Maria, who enjoyed having someone to go out with on the weekends, but did not look forward to April when her match for that year left to go back to her hometown for the summer.

Vacation

FINALLY, FOR MARIA the culturally valued activity of taking a vacation was perverted by the human service agency that controlled her life. Every summer, the agency organized two-week vacations where 8-12 disabled adults were grouped together, assigned two staff and sent on vacation to a different city or to a cottage. For many these two weeks were eagerly anticipated for the whole year; it was a frequent topic of discussion for the clients of the agency. While Maria

used to go on these vacations, thus occupying the valued role of vacationer, she was not permitted to do so for the past few years. The last time that she went on one of these vacations, she acted aggressively toward a staff person. Instead, for two weeks each summer, she did what the service provider called "in-town vacations." This consisted of day trips in the city for part of the time while the other service recipients were away. Each morning, the "in-town vacationers" met at a day program site in the basement of a hospital, and then the group went on to do different activities both at the hospital location and in the city. The activities ranged from attending local festivals or visiting museums to going for a walk or baking cookies. For Maria this was clearly not the activity of vacationing. She lived in the same city all her life, attended the same festivals and went to the same museums. A walk in a familiar neighbourhood or baking cookies was not her idea of a vacation. She was not in the role of vacationer when she attended the "in-town" vacations.

Maria complained on numerous occasions that for her (as for all of us) a vacation, or being in the role of vacationer or tourist, meant getting out of one's home city and perhaps going somewhere one had not been before. She cited going on a long car or train ride, and sleeping at a hotel or in a different bed, as two examples of things that encompassed a true vacation. It was especially hard for her to stay in the city as most of those around her acquired the role of vacationer, and got to leave the city for their vacations; yet when she complained about her situation, staff reminded her why she no longer went on vacations, making her situation a kind of on-going punishment for something she did quite a while ago. The wounds of rejection and of impoverishment of experience became even more deeply ingrained with every passing year that she was shut out from this opportunity. While Maria was by no means satisfied with her "in-town vacation," she still preferred to attend this program to being alone. Calling these two weeks a vacation was dishonest; it confounded

the CVA of a vacation. Because her "vacation" was not a true one, she was not accorded the valued role of vacationer either by herself or by second and third parties, and did not have greater access to the good things of life.

Conclusion

ALL OF THE SITUATIONS discussed above illustrate how facets of normal life are so often overwhelmingly distorted for a socially devalued person, particularly clients of human service agencies, in such a way that they barely resemble the culturally valued analogue. It is worth noting that culturally valued analogues may appear to be a relatively simple way to create a meaningful experience for a devalued person, yet in reality there are countless aspects of any given CVA that must be adhered to if one wishes to craft a legitimate analogue. In most of the instances discussed above, the human service agency did not adhere to many or most aspects of the CVA. As a tool, the CVA is just as useful for family members, friends and typical citizens. For Maria her previous job, her roommate, her 'connections' through the friendship matching program and her vacation merely paid lip-service to the true meaning of these notions. The roles of employee, roommate, friend and vacationer were deeply tainted to the point where no one could honestly say that she filled any of these roles.

With a deeper understanding and commitment to the notion of the CVA on the part of not only the service agency, but also her family, friends and others in her life, Maria could have had access to more of the good things in life through these roles. As SRV claims, one is more likely to have the good things in life with valued roles. The human service version (or more accurately, perversion) of such roles meant that Maria did not have access to the good things of life, and was further wounded because of a lack of vision on the part of the human service agency to think deeply about what constitutes work, home, friend relationships and vacations. ✌

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EMMA BARKEN is the Provincial Coordinator of People First of Ontario (CAN). She is also a member of the Ontario SRV Study Group.

The Citizen Advocacy Foundation of America

From the Editor

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

The Citizen Advocacy Foundation of America is a non-profit, tax-exempt foundation which solicits financial contributions to be used to make grants to CA-related projects, providing a means for assuring the continuity of CA and CA programs. 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. For more information about the Foundation, contact Susan Thomas at 231 Miles Avenue, Syracuse, NY 13210; 315.478.3797.

To learn more about Citizen Advocacy, three excellent written resources are:

Wolfensberger, W. & Zauha, H. (1973). *Citizen Advocacy and protective services for the impaired and handicapped.* Toronto: National Institute on Mental Retardation.

Hildebrand, A. (2004). *One person at a time.* Brookline, MA: Brookline Books.

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SRV Lessons Learned: A PASSING Visit to a Preschool

Marc Tumeinski

EDITOR'S NOTE: *PASSING is the name of a tool for evaluating a human service along 42 dimensions of SRV (Social Role Valorization) quality according to objective, clearly-spelled out criteria. PASSING can best be learned by attending an introductory SRV workshop followed by an introductory PASSING workshop. In an introductory PASSING workshop, participants under the direction of a trained team leader typically assess two different human service programs. Programs agree voluntarily to be visited. After the assessment, often either the team leader or a report writer will write a report of the assessment(s). In an introductory PASSING workshop, reports are written primarily for the purpose of furthering the learning of the workshop participants about SRV (Wolfensberger, 1998; Osburn, 2006).*

Introduction

THE PURPOSE OF THIS ARTICLE is to share some SRV lessons from a report of an introductory PASSING assessment held in 2002.[1] The site gave permission for the team to share that report. All identifying information has been removed.

PASSING (Wolfensberger & Thomas, 2007) as a human service evaluation tool does not assess administrative or management issues, but rather focuses solely on programmatic issues. PASSING users try to step into the shoes of the people who are being served, and to examine whether service practices are good or bad from the perspective of what these people need in order to have valued roles in society. It is precisely because PASSING looks at service quality only from the perspective of the people who receive it that PASSING does not make allowance for the various reasons why service quality may be less than optimal. Put simply, the PASSING tool looks at *what* is happening for the people served, not *why*.

Overview of the Service

THE SERVICE DESCRIBED IN THIS ARTICLE was an extended day preschool for 30 children aged 3 1/2 to 5 1/2. Two of the children in the preschool had significant intellectual and/or physical impairments. The stated goals of the program were to: provide a needed service to (working) families, give children appropriate play opportunities, and provide necessary teaching in a comfortable and safe environment where the children would feel happy and loved, and where parents would feel comfortable leaving their children. The program had made a consciously-stated decision to include a limited number of children with impairments in the program each year. The PASSING team was told that the numbers of impaired children in the program were intentionally limited to allow for the possibility of more effective teaching, and for positive role modeling from the other children without significant impairments.

A brief explanatory note is perhaps in order at this point in the article. A primary focus of SRV

and PASSING is to explore the most pressing issues in the lives of socially devalued people of all ages, including people with impairments. The PASSING tool in particular is concerned with the impact of a human service in the lives of its clients. (The PASSING tool defines human service very clearly although broadly, and is written so as to be applicable to a service for people with devalued social status, or for a combination of people, some with devalued social status and some with valued status.) That is why much of this article focuses on issues related to the children with impairments. This may be a bit misleading, as the program saw its mission as primarily being a preschool, in a sense regardless of the social status or abilities of its students. By distinguishing between the students with and without impairments, this article may appear to create a dichotomy that as far as we could tell was not in the conscious minds of the program director and teachers. This is done however for purposes of clarity and explanation in terms of understanding the service provided vis-à-vis SRV and the PASSING tool. That is also why this article will often refer to the program as a human service although the preschool personnel may not be used to thinking of it in those terms.

Description of the Children

THIS SECTION OF THE ARTICLE will describe in general all of the children attending the preschool, and also specifically the two children with significant impairments. It is important for the reader of this article to note that the first group includes the second; i.e., when this article talks about the children, it means all the children including those with significant impairments.

All of the children in the program whom the team met were living with their families. Most of the families came from the neighborhood close to the program. Almost all of the families would be considered affluent, in terms of income and possessions. The children of these families were typically accorded valued social roles such as sister, brother, daughter, son,

niece, nephew, grandchild, neighborhood kid, playmate, etc.

When the team visited the preschool program, there were two children in the program with significant impairments: a little boy with cerebral palsy, and a young girl labeled with autism. The team felt very welcomed by all the children. They were curious about us, played and talked with us. Like most kids, they had a wide range of positive personal attributes, i.e., being curious, fun-loving, energetic, wanting to learn, etc.

In addition to the above facts about the children, it is also important to understand their identities and life situations at a somewhat deeper level. The following is a summary of the team's deeper understanding of the existential identities of all the children in the preschool. Note that these are general statements; of course, individual differences did exist among the children.

The first thing to know is that these were all young children, just on the edge of starting their formal school careers. Like all kids, they were growing and learning fast. They were playful, imaginative, silly, open and trusting. They were still at the age of being somewhat self-absorbed, but were learning to be with other people and kids. They wanted to please others, particularly their parents. They wanted to be recognized and noticed by others for who they were and what they were doing. These children were learning about the world and becoming more and more competent as they did so–physically, intellectually, emotionally, socially. They were full of potential for growth and learning, and were happily discovering the world and themselves. Of course, like all children, they were still dependent on their parents primarily for almost everything, and in a broader sense, they were dependent on all of the adults in their lives.

As children mostly from more affluent families, they had been provided a lot more opportunities, stability and social protection than less well-off families can typically provide their children. The team speculated that this type of family and home environment would be beneficial in some impor-

tant ways (as just mentioned), but would also have its potential downsides as well, including some children: seeing their parents less because the parents worked alot, feeling more pressure to succeed and (as they grew older) to live up to a higher standard of living, etc.

The particular children with impairments for the most part shared in almost all of the identity characteristics that we described above. At this point in their lives, they were not socially devalued to a high degree (although the team felt, and the program recognized, that they were highly vulnerable to increasing social devaluation as they grew older).

In general, the children with significant physical and intellectual impairments would probably have an extra hard time communicating with others and learning some things as easily as typically developing kids (although it was perhaps not so significantly different at this age), being more easily distracted, tiring more easily, not as able to focus on certain things, and having an extra hard time getting around (notice the descriptors *extra* and *more* ... since all the children were still developing, each of the children could be at times easily distracted, tired, etc.).

All children (and so all the children whom the team met, whether impaired or not) are vulnerable in the sense of: being physically smaller and weaker, not knowing a lot about the world and its dangers, and not being cherished by contemporary society as a whole in many ways. Sometimes this is true even to the point of children being 'sacrificed' in a sense for other's interests, such as parents making a life decision (about their work, where they live, their marriage, their other obligations–such as to an elder parent in need, etc.) that benefits the parents but perhaps at some expense of their children's current lives and even futures, or governments making particular financial decisions that benefit certain corporations or service sectors while taking away from primary education or children's health care, etc.

The children with significant impairments would likely be vulnerable in all these ways, but also in other ways that the non-impaired children would not be. Such extra or heightened vulnerability would potentially include a future of separate education (segregated and congregated with other children with the same or different kinds of impairments), and to education of lower quality than the typical child gets. For example, a 2000 US federal study found that every state in the US was out of compliance with at least some of the core civil rights requirements of the Individuals with Disabilities Education Act on the local level.[2] That report concludes, and the team agreed, that such noncompliance has meant that students with impairments commonly do not receive the education that the law promises, and that they truly need.

Concretely, such vulnerability has meant a qualitative difference for some other (same age and older) children with impairments similar to the ones enrolled at this preschool. For example, children with impairments typically experience such things as: no or little age-appropriate, competency-appropriate expectations for learning (including lack of schoolwork and homework); lack of an education orientation, and instead an orientation on life skills development and leisure; not graduating from high school at age 18 with a degree; poorer teaching and teachers; poorer educational materials; neglect; abuse; etc.

Given who the children were existentially, the team also spent time reflecting on and considering their needs, i.e., what all of them would likely need, particularly their most pressing needs. The team felt that all the children as a whole generally needed steadfast, committed loving family, home and school, all of which would help provide them, among other things, patient and loving guidance. They needed to play, to have friends, and to have other trustworthy adults in their lives (like extended family, teachers, coaches, etc.). They needed help developing physically, emotionally, perceptually, linguistically, intellectually and creatively. They needed others to give them good moral instruction and teaching.

They also needed, as all kids do, to be kept safe and to know they were safe, to be watched over. Often they still needed physical help with doing different things (i.e., dressing, eating, using the bathroom, chores, etc.). They needed to start learning to help others. A big part of what they needed was help getting ready for schooling, and learning to get along with other people and other kids, which would be for most of them a primary part of their lives for the next twelve years at least. All of this would help the kids to be more likely to have and to know a bright future, partly from their own life experiences and partly also from other people who believed in them enough to provide that.

Being in relationship with others is a natural and necessary part of human life, and particularly important for children in their formative years. The children needed to be in relationship roles such as friend, buddy, peer, etc. Relationships provide an anchor for children, and help them understand who they are and the world around them. For children who are vulnerable to being negatively stereotyped or set apart because of their physical and/or intellectual impairment, relationships can also bring increased social status and presence, as well as offer a measure of protection and stability.

As we have repeatedly stressed in this article, the children with impairments needed all of the above of course because they were children too. However, they also needed, to varying degrees, extra help: learning and maturing, interacting with other kids and people, making friends, being in the valued roles of student and peer, etc. Given the negative experiences of other children with similar impairments in schools, they also needed their family and other people in their lives to have a strong positive vision of who they could be, and they needed their family and other people to act on that vision. They needed their families and other people in their lives to understand the difficulties they would likely face in their school careers; in other words, to know the system and how to effectively advocate for them in it, without

getting caught up in it. They needed their families and other people in their lives to plan and think long-term with their schools, communities and possibly other programs and agencies.

Major Overriding Issues

THIS SECTION OF THE ARTICLE presents the major issues to emerge from the team's analysis of service quality. These issues are strongly rooted in the team's understanding of the identities and needs of the children in the preschool. This analysis took into account both the positive features of the program, as well as its shortcomings in service quality.

Before describing the positive qualities, however, it will be helpful to first discuss a concept widely used in the PASSING tool; namely, the purview of a service, which can best be understood as its scope of responsibility in the lives of its clients. As the team understood it, the purview of this program could be narrowly, although legitimately, defined as providing a safe, nurturing, educational place for young children to be during the day. At the same time, however, the team also came to the conclusion (and believed that others would readily agree) that the preschool program was influenced by, and also potentially shaped or at least reinforced, larger societal patterns and trends affecting all or most young children in the US today (and to a greater or lesser degree, children in most developed countries). In a sense, such trends could be seen to broaden the purview of this program (or any preschool program for that matter) beyond the narrow one defined above.

This is an interesting point which the team is sure most if not all teachers of children are aware of. Some of these social patterns are beneficial to children; others are not. Therefore, some of these trends could potentially negatively affect the particular children and families served by this program, and so at the very least would be a concern, and possibly could affect what they try to do as a preschool. Although these larger social issues are outside the more narrowly defined purview of the program,

the team felt that they were important enough to explore further, in terms of their potential impact on the children, their families and society at large. These broader issues are explored in the later section of the article entitled *Program Issues*.

Generally Positive Qualities of the Program

However, in light of the more narrow purview described above, the team felt that the preschool was addressing many of the pressing needs of the children which they could be held accountable for. In other words, this was a good service for the children and their families, which is commendable.

The team saw a strong match between what the children needed, what the families wanted and what the preschool was providing; a match which was bound to be beneficial in significant ways for the children. One lesson that has been learned from the many PASSING assessments that have been done is that most human services, perhaps understandably on some level, try to create their own approach to addressing the needs of its (socially devalued) clients, which often turn out to be atypical and acultural, rather than building on what is known already to be effective and then adapting it. Such atypical approaches have often stemmed from unconscious negative beliefs or stereotypes which many services hold about the people they serve, i.e., that they are somehow radically different from the typical person, with no or few common needs, and so therefore cannot benefit from the same things, approaches, etc., common to socially valued people. This is clearly what happens in many special education programs and schools, where a prevailing mindset is often that children with impairments cannot learn at all like how typical children learn, and so common educational methods that have stood the test of time are dropped in favor of atypical approaches. This was not the approach taken by this program; rather, they used a typical preschool model and adapted it as necessary.

The team saw that a general strength of this preschool was that it was a very good program for all the children. It was by and large addressing its program goals of helping families, teaching children and providing play opportunities in a safe environment. The team felt that these were indeed important goals, and so, by largely addressing them, the program was benefiting the children and their families. As far as the team could tell, the children generally were safe, enjoying themselves, playing with other kids, learning and growing. This was a good setting in many important ways for all the children the team met and heard about, including the children with impairments.

To refer again to the concept of the purview of a human service program, it is well-known that all children need intense and efficient help to learn and grow, which is well within the purview or scope of responsibility of any school program. The renowned 20th century educator Maria Montessori,[3] for instance, clearly showed this by her example and writing; in fact, she showed that most children need even *more* help to learn and develop than they usually get, and at younger ages too. Without this help and direction, children will not grow to achieve as much of their potential as they could, which is always a loss for them, their families, communities and society. This lesson is even more valid for children with impairments in their physical abilities and/or abilities to learn. In other words, they typically need even more intense help and direction; without which, they are likely to be even worse off than typical kids who did not receive such help, and with which, they can make incredible strides.

The team felt that part of what made this a good preschool program was that they took advantage of these truths about teaching and learning. For example, as far as the team could determine, the staff were excellent teachers overall. The team based this judgment mainly on its classroom observations, as well as on its discussions with teachers, and the results they were achieving in terms of the children's learning. The teachers obviously tried to see each child as able and willing to learn, and worthy of their best teaching efforts. The

teachers had high expectations for the children, made the most of their time there, used good educational materials, and provided activities and opportunities that were challenging to the children.

The preschool was consciously committed to helping all the children to learn, those with and without significant impairments.[4] They often took advantage of obvious as well as subtle learning opportunities with all the children. For example, the team saw teachers actively (as well as indirectly) teaching during: activity times, class time, snack time, meals, the time when children were going home, the time when they were introduced to our team, etc.

Having excellent teachers also had another benefit: it projected a positive image message[5] about all the children, and the children with impairments more particularly, that they needed and what is more deserved good and competent teachers. Such a message is important, because it clearly (even if unconsciously) communicates high positive learning expectations to the children, their families, their teachers and visitors. Expectations are very powerful in shaping what and how much children can learn, and how others perceive and treat children.

The children needed teachers, and that is what they got; as opposed to, for example, baby sitters or nurses, which would have sent the (perhaps unconscious) message that the children did not need to (or could not) learn, or were too sick or impaired to learn. Many special education programs, for example, falter on this point when they hire teachers and aides who in essence act as baby-sitters or nurses for impaired children. This communicates very hurtful messages and sets of expectations to them, their families, teachers and society in general.

The team saw the staff being creative in their teaching approach, while also relying on the well-known, time-tested foundations of good teaching, modifying as necessary for children with a range of learning styles and even different degrees of difficulty learning. For example, the team saw the

teachers use repetition of key concepts, structuring of a good learning environment, encouraging of identification between peers, a Socratic method of questions and answers, hand-over-hand modeling, etc. The teachers were conscious of using their voices well, keeping an even, respectful and pleasant tone. They turned off the lights to get children's attention, rather than raising their voices, and so on. Overall, they had generally high expectations for growth and learning for all the children, relative to their ages and different abilities.

As well, the preschool had provided a place where parents and families could feel good and safe leaving their child for the day or half-day. Part of what helped create this feeling was that parents were welcome to visit. It would also be clear very quickly to an observer that the teachers liked the children and were committed to providing a safe and comfortable environment for them. Parents trusted that their children would be well-taken care of, not come to any harm, have fun, play with other kids and learn some things as well. This is evidenced, for example, in the fact that many families sent all their children to this particular preschool, and may have done so over the course of several years as each successive child came of age, indicating a high level of trust of their services.

As mentioned previously, the program had made a conscious decision and commitment to focus on what the team identified as personal social integration and valued social participation of children with impairments (Wolfensberger, 1998, 122-124). SRV describes personal social integration and valued social participation as adaptive participation by a socially devalued person in a culturally normative quantity of contacts, interactions and relationships, with ordinary citizens, in typical activities, and in socially valued physical and social settings. Efforts along this line are likely to have a number of benefits for the devalued person. This concept is applicable of course to children with impairments in preschool (Sherwin, 2001). The question becomes what are typical and

even valued preschool settings, activities and relationships for children, and then how can children with impairments be supported in these.

Even though they may not have used SRV language or thought about it in those terms, this program purposefully and carefully tried to help the children with significant impairments to be students in the preschool program, i.e., to be in the preschool student role. (Social roles are another very important concept in SRV and PASSING. Roles are very influential in shaping people's lives, as well as other's expectations of the person in the role. A young child in the student role, for example, is expected to be able to learn and to get along with other students and teachers, and so is given plentiful learning and play opportunities, which helps them to learn more and more, which then reinforces the original expectations, and so on.) The children with impairments were carefully included when, for example, the whole class played games, worked on art projects, did chores, cared for plants they were growing as Mother's Day gifts, etc. Staff expected them to belong, to be engaged and to participate. They gave them extra help when they needed to do so, i.e., hand-over-hand help, extra encouragement, more specific directions, etc.

Supporting integration of children with significant physical and/or intellectual impairments is a relatively rare step for a preschool program, and deserves commendation. For example, studies by the US Department of Education (and others) consistently show that children who are significantly intellectually impaired spend most of their time either in a separate school or facility, or outside a regular education class.[6] This is problematic for these children on many levels. In terms of teaching and learning specifically, it essentially gives up on the time-tested methods of learning through role-modeling and imitation of more competent, socially valued peers.

More particularly, and equally commendable, was that the team heard and saw that this program was careful about limiting the number of students with impairments in the preschool, to help ensure proper learning, role modeling and integration. It is well known that for proper role modeling of valued and adaptive behaviors, one thing that helps is to have a lot of good role models surrounding the learner. This preschool had struck a fine balance in this area, with a very small number of children with impairments and a much larger number of children who could act as good role models for them in terms of learning. The size and makeup of the classes also helped each child feel safe and comfortable, able to learn and to meet new children, particularly for the children without impairments to meet children who were different from themselves in potentially significant and negatively perceived ways.

The size and makeup of the classes also helped make it easier for the teachers to teach and to support the integration and participation of the children with impairments in the classes. For example, because there were only a few children who might need alot of extra teaching help at any one time, the teachers were able to accomplish this. If there were many more children with significant impairments in the class, it would have been much more difficult and at some point impossible for the teachers to give each student the help they needed. This is even more rare than the decision to use an integration model in school. Larger numbers of children with impairments in the class, as is common in many special education programs and schools in the US today (and we believe to a greater or lesser degree in other developed countries), would have made teaching and learning at the preschool much more difficult.

The grouping of the children also led to a positive image projection for the children with specific impairments. Because the children with impairments were in classes mostly composed of children without significant impairments and with typical social status, those positive images and higher statuses tended to (even unconsciously) transfer or rub off onto the children with impairments. This is a well-know dynamic in sociology and psychol-

ogy. Part of the problem with most segregated and congregated special education programs and classrooms is that they (unconsciously) set the children up in these classes to more likely be seen by others as different in a negative way, or as more like their own kind (i.e., other impaired children) than as children first and foremost. This kind of negative imaging and stereotyping further keeps many impaired children from ever being helped to learn and reach their individual potential, i.e., because they are seen largely by others as just one of the group of 'those kids,' who all basically have the same level of incompetence. This program did not fall into this trap.

On the contrary, the children with impairments whom the team met were more likely to be seen by their families, other families, other teachers, visitors and society in general as more like regular kids who could learn rather than as needy kids who could not learn, because of where they spent the day (i.e., at a typical preschool), who they spent it with (i.e., mostly with typical kids and teachers), and what they did all day (i.e., played games, ate lunch, did classroom chores, etc.).

The program made strong efforts so that these children were less likely to stand out in a negative way from the other students, but that each student was seen as unique in a positive way. The development and expression of individuality (including of personality, talents, abilities, beliefs, preferences, etc.) is seen in North America as a highly desirable trait, and is also potentially highly competency- and imagery-enhancing. Its beneficial development often starts at a young age. At this preschool, examples of the children's art work were hung around the classrooms. The team felt that the teachers knew each of the children fairly well (i.e., what they liked and did not like, what they were really good at, what they needed to learn, etc.). The teachers and director spoke positively, respectfully and honestly about each child, as a good teacher would. Without such help, children cannot be expected and encouraged to develop a healthy individuality for themselves.

Unfortunately, many contemporary special education services for children with impairments all too commonly display a lack of sufficient potent and relevant help to significantly impaired children around this issue.

The classrooms were generally comfortable and child-friendly, making learning and peer relationship-development more likely. Because of this, parents would also be likely to feel better about their children spending the day there. The furniture was the right size, toys and games were within easy reach, etc. The preschool had a wide range and variety of good classroom materials and playthings that were appropriate for children, fun and educational (e.g., puzzles, a child-height sandbox, construction-type toys, etc.). They were of high quality, there were enough for all the students, they were well kept, and were easily accessible and usable by all the children. There was also a range of materials to meet different children's needs and interests. The program director was conscious of getting the best materials possible, even when that meant paying a higher cost and perhaps waiting a little longer to save enough money to purchase them. All of this added to the learning and fun of the children. It also was beneficial to their image and status in the eyes of others, in the sense that it portrayed the children as wanting and deserving such nice surroundings and nice things.

Unlike many special education classrooms and special education schools, this setting looked very nice and well kept inside and out, and it looked like a preschool, not a human service program. This setting projected an image message about all the children, including of course the children with impairments, that they needed and deserved a nice preschool to go to. This kind of image message projection is very influential in shaping how others (i.e., in this case, teachers, parents, other children) perceive and treat people they meet in that particular setting.[7] Again, it is worth emphasizing that this and other strengths of the program clearly stemmed from the fact that the program was providing a good preschool for each child, regardless of ability.

The children with impairments were in significant ways benefiting from the services provided by the preschool, and from being in a preschool with children without significant impairments. As well, on reflection, the team recognized that the children without impairments were also benefiting from the experience of being in an integrated preschool with a carefully planned number of well-supported children with impairments. The team felt that this was important to emphasize in this report, as this is a point not commonly recognized in many academic and research discussions of integration, or at best is glossed over. The more typical children (and perhaps indirectly their families) were learning through experience to be more welcoming of people who are typically perceived negatively and with low expectations by society. The children were learning to see Jane or John first, rather than the cerebral palsied girl or the autistic boy. This is a good thing.

They were learning to be in relationship with people different from themselves, and so to be more well-rounded individuals and hopefully gentler, kinder people. They would therefore hopefully be more likely as adults to be open, less judgmental, more compassionate, etc. Some would be better at recognizing the gifts and the personhood of people with impairments. Some would be more open to being friends, co-workers, neighbors, peers, family members, etc. of people with impairments. Over time, as they matured, the team believed that some would have a good chance of being better than many people in society are today at crafting even more integrated life opportunities for physically and intellectually impaired people. In the long run, such positive integrative experiences are a necessary step in building stronger, more closely knit, more welcoming and better adapted communities and societies for people with impairments.

As well, the children without impairments were benefiting from being able to experience and appreciate the gifts and contributions of the children with significant impairments (e.g., Mary is a lot of fun to play games with, John likes the same stories I do, etc.). These are examples of the kind of things that many adults (and children) never get to learn about children and adults with impairments, because they do not often share physical and social environments together.

Overall, the team felt that the preschool addressed many pressing needs for many of the children served, both with and without impairments: teaching, learning, maturing, caring, relationships, positive experiences, to be seen as belonging, positive vision and high expectations for their growth and learning.

Program Issues

As indicated above, the preschool had some less immediate but still important areas for possible improvement in terms of service quality. The team identified three such areas. The first area was related to the quality of the service for the children with impairments in the program. The second was related to the educational future of the children with significant impairments. The third area (as mentioned earlier) concerned some broader social issues outside the narrow purview of the program, and was related to the needs of all the children in the preschool on the one hand, and to the needs of their families, communities and society on the other. These three areas are described below.

First, the team felt that the service could and should improve on trying to build more depthful, mutual and respectful relationships (consistent with their age) between the typically developing children and the children with significant impairments. This was certainly a need of the children with impairments, as described above. The preschool also recognized this as something which they could do better at. A lack of needed relationships would certainly be likely to negatively affect the children with impairments to some degree (for example, in terms of their potentially diminished: social and educational learning, current and future relationships, etc.), and the other students and their families (in terms of their current and

future ability to be more understanding, open and welcoming to people different from themselves; their missing out on the gifts of the children with impairments, etc.).

To be clear, the program was consciously working on this and did have some success with it, so the team's understanding of this issue is more about what else could be done rather than about a lack of any effort at all on the part of the program. In many ways, this is always the hard work of integration. The preschool had many of the preconditions in place for good integration, i.e., the physical presence of kids with impairments in manageable numbers, available classroom roles for impaired students, positive expectations on the part of the teachers, openness on the part of the other students, etc.

Perhaps what was needed could include: one or at most two more teachers and/or aides, even part-time (although there is a balance to be struck here, where too many adults in a classroom can actually inhibit children's learning and interactions); more brainstorming/conversations about specific children with impairments done by the teachers as a team on this issue; learning more about communication styles and approaches for children with difficulty communicating; visiting other successfully integrated preschool programs to share and learn what approaches they use; learning about and trying to implement the concept of valued social roles as it applies to relationship building, etc.

What stands over and above all of the recommended possibilities mentioned in the paragraph above though is the need for the preschool teachers to consciously cultivate and to reinforce a mindset (or a consistently patterned way of believing and thinking) among themselves that each individual student in the class (particularly the children with impairments) is valued, belongs, can enjoy and have mutual relationships with other children, and has something to offer to others. In some important ways, this mindset did exist already at the preschool program. However, when it comes

to building relationships between young students with and without impairments, such a mindset must be crystal clear, explicit, well-thought out, sufficiently depthful not shallow, thoroughly embraced and continually reinforced, plus be backed up by teachers with the skills necessary to translate this mindset into concrete action on a daily even hourly basis in the classroom.

Such a consciously-held positive mindset would do much to help the preschool program and the teachers to brainstorm, for example, how to: bring different children together (i.e., to work on a common art project or puzzle, to have lunch together, etc.); look for and nurture seeds of relationships between children with and without impairments when they arise; grow a culture and an atmosphere of community and mutuality within the classes; etc. This is a very exciting prospect for most teachers, as it is what they are naturally inclined towards already for their students. What is required though, given the needs and vulnerabilities of children with impairments, is extra consciousness and work on the part of the teachers, above and beyond what is typically required of most teachers. Just one small concrete illustration of what might be done very directly to build such a classroom culture could include, for example, the teachers encouraging different parents to invite particular children over to their homes to visit their own children after school (this encouragement could be given both to parents of children with impairments and to parents of children without impairments).

All of this would certainly be a challenge for the program, given some children who have a particular difficulty in communicating and interacting with others. The team realized that not all the children with impairments at the preschool currently or in the future would be able to experience and/or reciprocate relationships in the same way as other children. They can be helped somewhat to learn this; at the same time, the more typical children in the class are the ones who in many ways will also have to change, and to learn about

what it means to be in relationship with someone who does not talk, or make eye contact, or learn the same way as they do, etc. This kind of environment of course is the responsibility of the teachers to help teach and create in the classes.

Second, the team felt that the preschool program was not providing the level of strong encouragement, assistance and when necessary advocacy within an educational context which most of the families of children with significant impairments truly needed; for example, for the children with impairments to (continue to) be included in classroom activities when they left the program and went on to school, and particularly to (continue to) receive relevant and challenging educational opportunities. We learned from the service that often many of the children with impairments were ending up in more segregated educational settings after leaving the preschool. Given the state of so-called special education services in general, this was a concern for the team, especially given the positive strides which this program had clearly made.

The children without impairments and with typical social status and abilities could in a sense take it for granted that they could go to school basically wherever they and/or their parents wanted. Not so for the children with significant impairments. They needed extra help and support on many levels from many people if they were to be able to do so. (The team believed that to do so would be a struggle from start to finish, require much effort from many people, and still in all honesty be rife with disappointments and setbacks.)

Given their heightened vulnerability to ending up in educational settings where they would not really be expected to learn and develop to their full potential, they needed their parents and other people in their lives who would go the extra mile and bend over backwards to support them to do so. Providing effective advocacy is probably one of the more difficult services to offer to needy people of any age in human services. (This is a complex issue, so this article will devote a good amount of

space to discussing it. The issue will be described in its broadest context, and then related to this program specifically.)

Parents obviously would be the first line of direction-setting and advocacy for their children with significant impairments. Parents naturally have the primary legal and moral standing in their children's lives. They are the ones who will most likely be there in the long run for their children. A pressing question for this program then was how could they as a preschool support, encourage and advise the parents in their dealings with schools, particularly when it comes to advocacy for the children's education. There are a number of ways (pre)schools can help to do this. For example, the preschool could: ask the parents of the students with impairments what schools they are thinking of sending their children to; encourage parents towards particular teachers, principals, classes or schools which the program knows are good at integration; introduce the parents of their current students to parents of older (impaired) students who have already been through more of the school system with their children, and who could offer to them needed advice and encouragement; teach families about the various possibilities and benefits of school integration, etc. (Only if the parents are unable or unwilling to provide needed direction and advocacy for their own children with impairments should the preschool consider stepping in and doing it themselves, as best they can.)

The team realized that this preschool program did not necessarily have the legal authority or standing to advocate for these children in the public schools, especially beyond the first grade. (After first grade obviously, their new teachers would have much more standing than the preschool would.) However, the team was told that the program did already have some involvement with different public and private schools in the area, which could open the door to potential advocacy roles. As well, the staff did have firsthand knowledge of the children and how they could be

helped to learn in a typical educational setting for their ages, which did give them the moral standing or authority to help represent them and advocate for their needs.

The team was fully aware of the enormity of the obstacles which would face any service (not to mention family) trying to address these assistance and advocacy needs for the children with significant impairments. Such a service would likely face at least the following difficulties: the overwhelming degree of negative stereotypes and low expectations held by society at large and schools in particular towards children with intellectual impairments, especially as they aged; financial constraints; school policies which largely mitigated addressing many of these needs; the likely resistance of at least some schools to such advocacy efforts, perhaps especially when they are coming from a preschool, which in the US educational structure is normatively outside of the formal school system; and the likely fearfulness and/or resistance of at least some families to pushing schools to address these issues (i.e., perhaps due to families' own low expectations for their child, their lack of knowledge of what is possible and/or available, their sense of isolation in the face of education and school professionals, their fear of being rejected by schools, etc.).

The team also recognized that while it is true that parents have authority and control over their children and rightly so, the preschool, its director and teachers had very high expectations for all the children, as well as experience teaching children with impairments, which is (unfortunately) rare for teachers of impaired children. These factors in a sense gave the teachers a form of authority, albeit different from the parents. These experiences and expectations held by the teachers were worth sharing, in advocating for the children, and also as a way hopefully of being a good role model for other educational programs, principals, teachers, even families, etc. If neither the families nor the teachers try to advocate for these children in terms of their education, it is unlikely anyone else

will, or at least that anyone else could do so as well as the families and teachers could, particularly in partnership, given their experiences and knowledge. Despite all these difficulties, the team felt that trying to address this need for educational advocacy would still be a valid effort on the part of the service, even if it was only partly successful for some children, and could still bear fruit for at least some of the impaired children served, not to mention their families, other children in different schools, the service workers (i.e., teachers) themselves, and society in general.

Third, a broader issue which the team struggled with related to balancing the needs of individual children with the needs of their families and of society. The team truly did struggle with this point; it is an emotionally painful and contentious topic in many circles. We appreciate the struggles and the compromises which many families with school-age children face in our contemporary society. To be clear, the team felt that this was not necessarily a pressing program issue as much a societal one perhaps. However, the team felt that it was something which the program should be aware of (and perhaps already was). In fact, they may not be able to do anything else about it, except be aware of it.

As mentioned previously in this article, all children are potentially vulnerable in many ways. One particular vulnerability is that children are vulnerable to having their needs sacrificed for others' needs. The team has seen, and others have written and talked about extensively, the larger forces which are at work in our society that tend to draw children away from their families, making it possible (and even seem desirable) that families not do things with their children that historically have been within the province of parents. This includes such things as teaching children, raising them, watching them during the day, helping them with homework, feeding them breakfast, etc. The role of preschools and particularly day-cares is one arena where we see this potential conflict playing out more and more in our society, to the poten-

tial detriment of children, families and eventually society. (Obviously, this is more of a risk in situations where children go four or five days a week, especially full days, to a preschool/day-care, versus only one or two days, or only half-days.) In our society, children at younger and younger ages are more and more entering day-care and preschool programs. Often, this is due to economic pressure on families where both parents must work to survive. If other family (e.g., grandparents) or friends are not available to help, as is quite likely today, then day-care/preschool is quite often the option chosen. State and federal governments often set up conditions which in a sense force families to work and subsequently to be separated from child-rearing during the day. Governments may do this for economic reasons, for example, or for values-based reasons. The roots of this type of pressure lie clearly on the societal level. These realities point out some of the terrible dilemmas which many families, including single-parent ones, face.

However, we must also recognize other potential motivations and values at stake in this issue. For example, for some families, the underlying motives are not primarily economic survival per se, but rather the desire to acquire and/or maintain a high(er) standard of living which drives both parents to work, and necessitates placing their child/children in day-care/preschool. Whatever the source or motivation, however, whether government or parental, whether economic or values-based, the children often do pay the biggest costs, particularly over the long run.

The team recognized of course that what is good for parents or even for families as a whole is often good directly or indirectly for the children as well. At the same time, this is not always so, especially in the long-run. Sometimes what is best for the children may in the short- or even long-run cause difficulty for the parents. For example, it may be better for children for their parents to stay home and raise them, even if that means living at a lower economic standard or giving up job satisfaction. In the long-run, such close parental upbringing is

often what most children most need, if there has to be a choice between the two. The consequences of the fact that many or most children are not now getting this are obvious, ominous and tragic.

To relate this issue to this program and to preschool/day-care in general, a question was raised in the minds of some team members of whether in some ways this preschool was satisfying the needs of some parents more than their children's needs, particularly given the overall higher economic status which most of the families using this particular program enjoyed. Was it really better for some parents to have a place they could safely leave their children during the day three or more days a week than it was in the long-run for the children to be able to be primarily cared for by their parents, no matter how nice a place the preschool was (and this program was a good preschool, as described above)? This does not mean that parents who make these decisions are necessarily bad parents; they may also be to greater or lesser degrees confused, desperate, conflicted, ill-informed, mis-informed, isolated, short-sighted, inexperienced, immature, etc.

In the issues described above, empty rhetoric abounds as to how early placement is actually better for children, and so forth. But in reality, the potential for children to lose out and to be hurt in different ways by not growing up and spending their days with their parents and families is incredibly high.[8] For example, throughout much of the history of many different cultures, young children primarily learned from their parents, siblings, grandparents and extended family, more than through any outside schooling. When this is not the case, the question is raised of how well the socially-acceptable substitutes (i.e., preschool, day-care) really work. Many teachers themselves have commented on this issue, that they are being expected to teach children things and address needs that in the past families were responsible for, and that do not seem to have a place in our schools.

The point is not that there may not be some benefits to younger children being in day-care/

preschool, but do the benefits outweigh the drawbacks? As written above, this issue related to the balance between the needs of children, parents, families and society. This article is not the forum to discuss this issue in the length and at the depth it deserves, but hopefully the issue at stake is at least clear. It is hopefully also clear how it is connected to this program, which by its existence, among all the other good things it does, facilitates some families (in this case, mostly well-off families) placing their children in day-care/preschool, and so accelerates those societal forces mentioned above.

Conclusion

OVERALL, THIS WAS A highly instructive service for the PASSING team to visit and analyze from an SRV perspective. We were very thankful to the children and teachers at the program for this opportunity. It powerfully illustrated many of the themes taught in SRV and made them concrete. Visiting a service which scored positively on the PASSING scale also made this a beneficial learning opportunity. Our visit and analysis of this service also raised a number of extra-SRV questions worthy of reflection and discussion. Both these points show once again the power of the introductory PASSING workshop and the PASSING tool in teaching about SRV specifically and human service broadly. As the originator of SRV, Professor Wolf 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)" (Wolfensberger, 2000, 122). ✿

Thanks to Joe Osburn and Darcy Elks for their assistance on the original PASSING report.

ENDNOTES

1. Note that this article is based on a PASSING assessment during which the 2nd version of the PASSING tool was used. See 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. However, the 3rd version (2007) is the most current one.

2. For more on the heightened vulnerability of children with significant impairments in the US educational system, see: National Council on Disability. (2008). *The No Child Left Behind Act and the Individuals with Disabilities Education Act: A progress report*. Washington, DC; National Council on Disability. (2004). *Improving educational outcomes for students with disabilities*. Washington, DC; President's Commission on Excellence in Special Education. (2002). *A new era: Revitalizing special education for children and their families*. Washington, DC; National Council on Disability. (2000). *Back to school on civil rights*. Washington, DC.

3. Montessori was a prolific writer, and many of her writings are still available today. Just one example is her book entitled *The Absorbent Mind* published in 1949.

4. For more on competency enhancement, see Wolfensberger, 1998, pp. 108-111; Wolfensberger & Thomas, 1983, pp. 339-507.

5. For more on image enhancement, see Wolfensberger, 1998, pp. 104-105; Wolfensberger & Thomas, 1983, pp. 31-337.

6. E.g., the resources listed above in endnote # 2.

7. See endnote # 5, or for example, Knapp, M. (1972). *Nonverbal communication in human interaction.* New York: Holt, Rinehart & Winston.

8. See for example, Bennett, W. (2001). *The broken hearth.* New York: Doubleday, for one discussion of this pressing issue.

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Marc Tumeinski is a trainer for the SRV Implementation Project in Worcester, MA (US) & editor of The SRV Journal.

Learning to Teach Social Role Valorization (SRV)

Social Role Valorization, when well applied, has potential to help societally devalued people to gain greater access to the good things of life and to be spared at least some of the negative effects of social devaluation. This is one of the reasons why it is important for people to learn to teach SRV, so that its ideas and strategies are known and available to the right people in the right places who can apply it well. Unless people continue to learn to be SRV trainers, the teaching and dissemination of SRV will cease. Many SRV trainers for example could teach lots of people how to **implement** SRV, but not how to **teach** it to others. At a certain point there might be implementation of aspects of SRV, but the knowledge of SRV itself might not be passed on to others, such as the next generation of human service workers. Teaching about SRV, and learning to teach SRV, can be done in many ways, depending in part on one's abilities, interests, resources and so on.

The North American SRV Safeguarding, Training *&* Development Council has developed a specific model for teaching people to competently do two things: (a) teach Social Role Valorization; and (b) teach other people to teach SRV. People who can do the former, the Council calls "SRV trainers." Those who can do the latter, the Council calls "trainers-of-trainers" of SRV. The Council named this a "Trainer Formation Model," i.e., a model for forming or developing SRV trainers and trainers-of-SRV trainers. A description of the Trainer Formation Model is available if you are interested (http://www.srvip.org/about_mission.php); also see the article referenced below.

To find out more about studying SRV and learning to teach it, please contact Jo Massarelli at *The SRV Implementation Project*, 74 Elm Street, Worcester, MA 01609 USA; 508.752.3670; jo@srvip.org. She will be able to help you or to put you in touch with someone more local to your geographic area who can be of help.

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

Announcing the publication and "appearance" of

APPEAR:
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PERSONAL PHYSICAL APPEARANCE
BY MEANS OF THE APPEAR TOOL

a new publication by Wolf Wolfensberger

Personal appearance (including so-called "self-presentation") is certainly one of the most immediate, and often also one of the most powerful, influences on how a person will be perceived and interpreted by others, and in turn, on how others will respond to and treat the person. Personal appearance is also one of the domains of social imagery, which is a big component of Social Role Valorization (SRV): the more observers positively value a person's appearance, the more likely they are to afford that person opportunities to fill valued roles, and thereby access to the good things in life. Unfortunately, the appearance of many members of societally marginal or devalued classes is far from enhancing, or even outright repellent to many people, and increases the risk that bad things get done to them, or that good things are withheld from them.

This 2009 book explains all this. APPEAR is an acronym for **A P**ersonal **P**hysical Appearance **E**valuation **A**nd **R**ecord. It documents the powerful influence of personal appearance on attitudes, social valuation and social interactions. The book explains the many components of personal appearance and the ways in which these features can be changed for better or worse. It also includes a very detailed checklist, called the APPEAR tool, which identifies over **200 separate elements** of personal physical appearance, so that one can review a person's appearance features from head to toe, noting which are positive, which are neutral, which are negative–all this with a view to perhaps trying to improve selected aspects of a person's appearance about which something can actually be done. The book also explains how such an appearance review, or appearance "audit," would be done.

The book contains a sample APPEAR checklist at the back, and comes with three separate (free) checklist booklets ready for use in conducting an individual appearance audit. Additional checklists may be ordered separately (see order form on next page).

Reading the book, and especially using the APPEAR tool, can be useful as a consciousness-raiser about the importance of appearance, and in pointing out areas for possible appearance improvement. An appearance audit using APPEAR can be conducted by a person's service workers, advocates, family members and even by some people for themselves. It could be very useful in individual service and futures-planning sessions, and in getting a person ready for a new activity, role or engagement (for instance, before entering school or going on a job interview).

Studying and applying the APPEAR tool can also be a very useful follow-up to Introductory SRV training, as it deepens one's understanding of image and appearance issues.

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The Ring of Words: On Rhetoric, Writing & Social Role Valorization Dissemination

Marc Tumeinski

Storytelling is the most powerful way to put ideas into the world today.
~ Robert McKee (b. 1941)

Tell Me a Story

WE ALL LOVE a good story. "Once upon a time …" "And they all lived happily ever after …" "Close your eyes and imagine … " Broadly understood, storytelling is a powerful means of communicating and remembering as well as educating (Pealer, 2008). Telling each other stories can help us get at, not necessarily facts, but truth: reflect for a moment on the power of parables and of fables; remember the stories told around the family dinner table about Aunt Mary and Grandpa John; think about what you learned from reading a favorite short story or from listening to a news story told on the radio.

> *The spring work had started, and I needed a long night's rest, or that was my opinion, and I was about to go to bed, but then the telephone rang. It was Elton. He had been getting ready for bed, too, I think, and it had occurred to him then that he was worried. "Andy, when did you see the Rowanberrys?"*
>
> *I knew what he had in mind. The river was in flood. The backwater was over the bottoms, and Art and Mart would not be able to get out except by boat or on foot.*
>
> *"Not since the river came up." "Well, neither have I" … "Well, surely they're all right."*

*"Well, that's what Mary and I have been saying. Surely they are. They've been taking care of themselves a long time. But, then, you never know." "The thing is, we **don't** know" … Elton said, "It's not hard, you know, to think of things that could happen."*

"Well," I said, "do you think we'd better go see about them?" He laughed. "Well, we've thought, haven't we? I guess we'd better go." "All right. I'll meet you at the mailbox." (Berry, 1992, pp. 191-192)

What Are Stories?

THINK ABOUT STORIES quite broadly. They may be as lengthy and complex as a classic fable or as simple and short as a word picture.

> *What would it be like to wake up in a nursing home, to the sound of a medicine cart being pushed down the hall, with a fluorescent light reflecting off the institutional green paint in the hallway, hearing a relative stranger snoring in the other hospital bed behind the curtain in your room?*

How can storytelling be effectively and powerfully connected to Social Role Valorization (SRV) dissemination and application? This first in a series of columns will explore that question. Stories can help us to communicate, to remember, to teach and to learn. Telling and listening to stories can

also inspire us to act. Since SRV and its predecessor Normalization have been taught, stories have been used to help in teaching and learning about social devaluation and the impacts of wounding, often by sharing in concrete detail how devaluation and wounding have affected one person or one family. Stories do not replace but rather are complimented by the theoretical aspect, the facts and the figures of SRV. Many of us remember best the powerful stories we heard at an SRV workshop. Some of these stories inspire us with a vision of what valued roles can help make possible, others haunt us with the way they evoke the devastation of wounding and social devaluation.

> *She was the woman with no name—a mystery for 38 years in the custody of the state of Illinois. This week, they buried her. Only pieces of her tragic life are known. Nobody ever knew her name, although they called her Mary Doefour. There already were at least three other Mary Does in state mental institutions. About 50 years ago, she was a young, attractive school teacher from the Midwest, perhaps Missouri or Iowa. Nobody knows for sure. One day during the Depression, she was found dazed beside a rural road near Chicago ... She was placed in a state hospital for the criminally insane. She had committed no crime. She wasn't insane. She just couldn't remember who she was ... Once an intelligent, articulate woman, she degenerated. Now she blew her nose on her dress, washed herself in the toilet and defecated on the floor ... She shook constantly from 50 years of medication, but appeared to enjoy her new freedom from mental institutions, wearing a ragged pink sweater as she walked around the grounds of the nursing home even in rainstorms ... On Thursday, under a fir tree in a cemetery space reserved for persons with no money and no relatives, they*

> *buried the urn containing the ashes of Mary Doefour. (AP, 10 March 1979)*

Stories can inspire us to act on behalf of vulnerable people and, for our purposes, to act in line with the strategies and themes of SRV. They can help workshop participants, agency staff and parents imagine something better for a vulnerable person. Well-told and relevant stories can add weight and color to the themes and strategies of SRV, helping others to better comprehend how they might apply these ideas in their own service, whether paid or freely-given, to socially devalued and wounded people.

Who Is Storytelling Important For?

Telling and listening to stories can be important for human service workers, those teaching SRV, those trying to apply SRV, as well as family and friends of socially devalued people. Stories can illustrate an SRV point, making it more present and relevant for an audience. They can be used to invite and to deepen interpersonal identification between socially valued and devalued people. Stories can inspire us to act on behalf of another. Stories can also be used to help craft a vision of what is desirable and possible, by describing what we as human service workers want to do or have done on behalf of vulnerable people.

> *The pastor rises at five A.M. She seldom seems to finish work much before ten at night. When people are sick, she takes them to the hospital. When their sons are arrested, she goes with them to the court. When they are born, she baptizes them. When they die, she buries them. This afternoon I saw her with a wet mop and a pail, washing the church floor. Anthony teased her, so she lifted the mop and shook it in his face. He pretended to be scared and ran and hid behind a chair. She gave him a look, as if to say, "Don't mess with me." If she had remained a lawyer, she*

could be at home now getting ready to go out for dinner.

I can see why Anthony feels safe when he is here. (Kozol, 1995, p. 225)

Writing Stories

Human beings have told stories in so many ways in all cultures over the millenia: orally and in writing, by acting or with puppets, by song and with pictures, in poetry and film. My focus in this column is on *writing* stories, stories which are not only good as stories but effective and consistent with the principles of SRV. Over the next few columns, I will reflect on and write about storytelling and SRV, sharing more examples of my favorite storytellers, asking for your examples and experiences with telling stories, offering thoughts about how and when SRV teachers and service workers can use stories effectively, laying out some guidelines and tips which may be helpful in telling a good story in writing. ℰꝋ

Editor's Note: *My thanks to Jack Yates for meeting with me to discuss his love of and experience with storytelling, particularly in the realm of Normalization and Social Role Valorization training and application. This column and several future columns we have planned will draw from Jack's and others' knowledge of storytelling.*

Bright is the ring of words when the right man rings them. ~ Robert Louis Stevenson, **Songs of Travel**

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Marc Tumeinski *is a trainer for the SRV Implementation Project in Worcester, MA (US) & editor of The SRV Journal.*

Announcing the availability of

A SET OF FIVE DVDs OF TWO PRESENTATIONS BY DR. WOLF WOLFENSBERGER ON THE HISTORY OF HUMAN SERVICES

In 2009, the Minnesota Governor's Council on Developmental Disabilities produced a set of DVDs, based on a videotape, of two one-day presentations on the history of human services presented by Dr. Wolf Wolfensberger & Susan Thomas at Millersville University in Pennsylvania. The first day is entitled "An Interpreted Pictorial Presentation on the History of Human Services with Emphasis on the Origins of Some of Our Major Contemporary Service Patterns, & Some Universal Lessons for Planning & Structuring of Services Which Can Be Learned from this History." It constitutes approximately 6:15 running time.

The second day is entitled "Reflections on a Lifetime in Human Services, from Prior to the Reforms of the 1950s-70s to the Present, with Implications for the Future: What Has Gotten Better, What Has Gotten Worse, What Is the Same, & What Lies Ahead." It constitutes approximately 3:50 running time.

Each day consists of lecture presentations on the topic, using many overheads & slides (photos & illustrations). At the end of each day, the presentation draws out some lessons from the coverage to contemporary services.

The set of five DVDs takes about 10 hours to show. The set is available for purchase for US $485.00, which includes permission to show the DVDs to others; for instance, in teaching a class or conducting a seminar. The first 10 purchasers will receive, FREE, a copy of the book *The Origin & Nature of Our Institutional Models*, autographed by the author Wolf Wolfensberger.

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DAY 1: An Interpreted Pictorial Presentation on the History of Human Services
1a   Pre and Post Greco-Roman Times   (26:33)
1b   Early Christianity and the Middle Ages   (28:03)
2a   Medieval Hospice and Hospital Design   (32:01)
2b   The "Menacization" of the Afflicted   (10:35)
2c   The Rise of Pauperism   (29:42)
3a   Deportation and Exile   (16:28)
3b   Containment and Confinement   (15:47)
4a   Degradation and Elimination of the Altar   (11:46)
4b   The Panopticon and Central Observation Stations   (28:11)
5a   Service "Deculturation" and Moral Treatment   (17:09)
5b   "Menacization" Images and Associations with Leprosy and Contagion   (23:58)
6a   The Association of Hospices with Houses of Detention   (13:43)
6b   Various Beliefs That Played a Role in Menacization   (4:59)
6c   Human Service Assumptions Based in Materialism   (14:18)
6d   Further Menacization Through "Treatments" Based on Punishments   (31:23)
6e   Regimentation and the Use of Military Imagery   (17:07)
7a   Historical Lines of Influence in the Perversion of Western Human Services   (14:51)
7b   Core Realities, Strategies and Defining Characteristics of Contemporary Services   (31:21)
7c   Some Conclusions   (10:53)

DAY 2: Reflections on a Lifetime in Human Services

1   The Bad Old Days, Part One   (23:48)

2a   The Bad Old Days, Part Two: The Institutional Scene, Part 1   (33:06)

2b   The Bad Old Days, Part Two: The Institutional Scene, Part 2   (15:59)

3   The Bad Old Days, Part Three: The Educational Scene   (19:54)

4a   What Has Gotten Better, Part One: The Early Reform Era   (27:39)

4b   What Has Gotten Better, Part Two: Normalization   (12:53)

4c   What Has Gotten Better, Part Three: The Rights Movement   (5:55)

4d   What Has Gotten Better, Part Four: Summary of Positive Developments   (17:53)

5   What Is Still the Same, New Problems That Have Arisen & Things That Have Gotten Worse: Part One   (12:30)

6a   What Is Still the Same, New Problems That Have Arisen & Things That Have Gotten Worse: Part Two   (31:18)

6b   What Is Still the Same, New Problems That Have Arisen & Things That Have Gotten Worse: Part Three   (23:27)

6c   A Few Action Implications   (8:19)

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REVIEWS & MORE

ACTS OF CONSCIENCE: WORLD WAR II, MENTAL INSTITUTIONS, AND RELIGIOUS OBJECTORS. By STEVEN J. TAYLOR. Syracuse, NY: Syracuse University Press, 484 pages, 2009. **REVIEW AVAILABLE ONLINE @ www.srvip.org**

Reviewed by David Race

I READ THE GREATER PART of Steven Taylor's fascinating book whilst on holiday in a remote part of Italy. More conventional holiday reading included, for the second time and having seen the movie version in between readings, *The Constant Gardener*, John Le Carre's novel about corruption in the pharmaceutical industry, and the uncovering and attempted exposure of it by an English diplomat following the violent death of his wife, an activist for the rights of African women. The connection that the two books made in my mind concerned the nature of 'acts of conscience' and their effect on the 'principalities and powers' that make up a whole range of societal and multi-national institutions, including, and especially, the world of human services to sick and/or vulnerable people. It also set me thinking about how the medium of transmission of such issues simplified the reality the more it moved from fact to fiction, and from the written word to the visual media of television and cinema.

Le Carre's book, as a novel should, gets further into the complexities of a number of characters than would seem to be possible in a movie, despite this particular one being beautifully filmed and acted. A film also seems to need 'success' for its heroes, at least to some extent, and so the almost totally bleak ending of the novel is softened somewhat in the movie. Taylor's book, as a properly academic piece of work should, goes into the minutiae of the events it is describing, but also brings out, through that very thoroughness, nuggets of gold that give the reader glimpses of people

and situations with which they can identify, even nearly sixty years later.

In summary, Taylor's book is concerned with the situation in World War II where conscientious objectors were obliged to serve in what was called the 'Civilian Public Service' (CPS). This body, mandated by legislation presciently encouraged by President Roosevelt before the USA entered the war, allowed members of the 'historical peace churches'–the Mennonites, Brethren and Friends or Quakers, to be able to keep to the tenets of their churches on eschewing violence and armed conflict, providing they enlisted for 'work of national importance under civilian direction.' Administered by a committee made up of elders of these churches, though usually with individual work groups specific to each, the conscientious objectors (referred to as COs in the book) initially tended to carry out their (unpaid) work in rural projects on farms and in forestry projects. The war then gradually drew in staff from the 'mental institutions,' both those for people with mental health problems and the 'residential schools' for those with intellectual disabilities. The manpower shortages this produced in already understaffed establishments led to a call for some of the CPS groups to assist in this area of work. (The CPS groups, reflecting the similar position of the armed forces at the time, were entirely male, though the wives of many COs were involved in various informal ways in subsequent events.)

The COs' experiences in the institutions, set alongside the beliefs and values that had led to CO status in the first place, caused a number of the COs to, in Taylor's words, 'rattle the psychiatric establishment by beaming a spotlight on the squalid conditions and brutality' in the establishments. For a time, as the book reports, this led, in a number of states, to exposés in the press, to changes of senior personnel, and to an improvement in both treatment at such institu-

tions and in the pay and conditions of the regular staff.

That would be the movie version, and one could spend an amusing pub conversation speculating on who might star in it, and how it would be presented. What Taylor gives us, instead, are the nuances and complexities of what went on, and the details of the use of bureaucratic systems and internal institutional politics rather than a 'good guys and bad guys' metaphorical shoot-out. He also uses interviews with later COs from the Vietnam period, as well as those with the surviving members of the cast of his main story, to provide the reader with much food for reflection on the nature and roots of conscientious objection and the actions, or lack of them, that people are faced with when a real war situation arises, as opposed to an intellectual debate. This, of course, is one of a number of aspects of the book with much relevance to our current times.

Taylor also, I am pleased to report, does not indulge in the sort of historical reporting that generates the view that 'people back then' were evil, and these few saintly people, the COs, were the only unbruised apples in the barrel. He notes, amongst other things, that though the COs objected to the brutality and squalor of the institutions, they did not propose that institutions per se were the problem. He also notes their personal agonising over resorting to violence themselves, often in self defence, but also sometimes in a gradual absorption of the culture of violence in the institutions, so that 'more humane violence' rather than 'no violence' became acceptable. Nor, in contrast to the number of campaigns involving institutions for those with mental health problems, did the COs get seriously involved in questioning the regimes in the 'training schools' for the 'mentally deficient.' Instead, as Taylor rightly points out, their objections came at a much more basic level of the common humanity of the victims of the regimes.

The high point, which of course is a relative term, of the influence of the COs came, in Taylor's account, with the setting up of the Mental Health Foundation, essentially a non-professionally controlled watchdog over mental health institutions, which enjoyed a brief but significant period of influence over policy and funding of mental health care in parts of the USA. This chapter, however, continues the theme of this review, of harsh reality being more believable and involving to the reader than an idealistic movie ending. In fascinating detail for those of us who have served on committees and similar groups, Taylor reveals the rise of the Mental Health Foundation, led initially by key members of the CO group, but then the insidious bureaucratic regaining of the ground by the medical and professional establishment.

A number of readers of this journal, especially those of a certain age, will, I believe, feel much empathy for the rise and fall of the influence of the COs. This would reflect those readers' many experiences of the influence on services of a small determined group, as in the initial period of normalisation, and in developments via Social Role Valorisation (SRV), but then the reality of the continued power of the professional establishments in their various guises to control the lives of people with intellectual disabilities. I hope that they will take heart, as I did, from Taylor's thoughtful conclusion to the book. Though he does not use the phrase, I believe that conclusion can be summed up in the term used by Wolf Wolfensberger in many workshops, but especially those talking about 'moral coherency.' What the COs did, above all, were 'valid acts' that moved people as well as changed some services, albeit short-lived for the latter. So, like the hero of Le Carre's novel, we can feel moved, and humbled, by their actions, not for their 'success' but for their appeal to the spirit of humanity.

This is indeed an 'untold story' that needs telling, and Taylor does it with skill and empathy.

DAVID RACE, PHD, is an Honorary Senior Research Fellow at the University of Salford, the Chair of Values Education & Research Association in the UK & a corresponding member of the North American SRV Development, Training & Safeguarding Council.

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TEACHING CHILDREN GENERALIZED IMITATION SKILLS: A CASE REPORT. By F.J. BROWN, N. PEACE & R. PARSONS. *Journal of Intellectual Disabilities, 13*(1), 9-17, 2009. **REVIEW AVAILABLE ONLINE @ www.srvip.org**

Reviewed by Susan Thomas

THIS ARTICLE REPORTS a successful effort to teach one 13-year old severely mentally retarded boy to imitate specific actions using multiple exemplars (i.e., different adults as models), and to generalize this to the imitation of other behaviors after the training sessions. The authors report this as evidence that even severely retarded children can be taught to imitate, and that once having learned to imitate, the behavior of imitating can be generalized.

While imitation is a 'neutral' learning strategy, so to speak, in that people can and do imitate bad as well as good things, strengthening the capacity and the habit of imitating is a generally adaptive strategy for anyone, as it improves both their ability to learn other things, and the ease with which they may be able to learn at least certain things.

All this is consistent with what is covered in the theme of imitation and modeling in Social Role Valorization (SRV) teaching, namely, that all but the most profoundly intellectually limited people have a capacity to imitate, but that in at least some people, this capacity must be cultivated; and that imitation may need to be both prompted and reinforced (as was done in this experiment). In their article, the authors also cite evidence underlining the importance of interpersonal identification in imitation, namely, that imitation increases the more the models are physically similar to the imitator.

The article is a good example of how the rather sketchy knowledge that is covered in both the SRV monograph (Wolfensberger, 1998), and in the introductory SRV workshop, must be elaborated. SRV underlines the importance of imitation as a strategy for role enhancement, but it does not elaborate how an imitation scenario needs to be structured; that will differ depending on who are the imitators and what they are to imitate. For instance, some people may need very little prompting, others may need much; some people may need to be explicitly instructed what to imitate; some need to have all distracting cues removed so that they can attend to what is to be imitated, while others do not need this; and so on.

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SUSAN THOMAS is the Training Coordinator for the Training Institute for Human Service Planning, Leadership & Change Agentry, Syracuse University, Syracuse, NY (US). She is the co-author of PASSING.

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ATTITUDES OF MOTHERS TOWARDS THEIR CHILD WITH DOWN SYNDROME BEFORE AND AFTER THE INTRODUCTION OF PRENATAL DIAGNOSIS. By W. LENHARD, E. BREITENBACH, H. EBERT, H.J. SCHINDELHAUER-DEUTSCHER, K.D. ZANG & W. HENN. *Journal of Intellectual & Developmental Disabilities, 45*(2), 98-102, 2007. **REVIEW AVAILABLE ONLINE @ www.srvip.org**

Reviewed by Deb Race

This article sets out to describe a survey that was conducted in 1970 and then replicated over thirty years later. The original survey, conducted by one of the authors of this article, asked 147 questions in relation to the attitudes of mothers of children or young people with Down's syndrome. It was conducted in southern Germany in 1970 but never analysed or published. Replication of the survey in 2003 was designed to enable the authors to explore how attitudes had changed between these two time periods and to posit some thoughts about why these changes had occurred, especially in the light of the changes in availability of prenatal diagnosis.

Unfortunately there is very little detail, either about the process of undertaking the original survey or about whether any other information on factors which could influence family attitudes was recorded. With the second survey, the authors describe using a number of screening techniques to ensure valid questions. This reduced the number of questions in the survey from the original 147 to 78. They then also reduced the number of received responses analysed from their second survey by over a third to exclude questionnaires with a strong bias of 'Desirable Responding' (this excludes responses that appear to aim at giving the answers the respondent thinks are wanted rather than being a true reflection of the respondent's views) and there is nothing in the article to suggest that similar techniques were used with the first survey. This causes me concern. The differences that they describe and attribute to attitudinal changes could well be attributable to the different approaches as to the validity of questions and responses taken in the two surveys.

In addition, the discussion describes some societal and service changes that have occurred in the intervening years, such as the growth of parental support groups and the increasing number of public appearances of actors with Down's syndrome, but ignores others, such as changing professional attitudes or the greater availability of educational provision. Nor is there any reference to the Nazi 'euthanasia programme' of the 1940's, which eliminated many people with developmental disabilities, and the profound impact this had on German family attitudes for many decades afterwards. This would certainly still be influencing in 1970 in Germany the attitudes of parents of young people born between 1950 and 1967 (and the professionals who advised and supported them). Any discussion that does not address these wide ranging issues appears limited and superficial.

Having questioned the research methodology, I, as the sister and mother of people with Down's syndrome who were of an age to be part of the survey population if resident in the relevant location, also question the overall conduct and purpose of the research. The questions it appears to be attempting to address, about attitude change since the introduction of prenatal screening, leave me with a major question. Why would anyone conduct research of this type without also looking at the attitudes and language of health professionals? This is for two reasons: one is that I believe professionals, and their approaches to working with parents, have a very significant input into the attitudes of parents; and the other is that personal experience suggests that professionals' knowledge of the positive aspects of life with Down's syndrome is often minimal.

Deb Race is the parent of a son with Down's syndrome. She has worked in academia & social care in the developmental disability field for over 30 years.

The citation for this review is

Race, D. (2010). Review of the article *Attitudes of mothers towards their child with Down Syndrome before and after the introduction of prenatal diagnosis* by W. Lenhard, E. Breitenbach, H. Ebert, H.J. Schindelhauer-Deutscher, K.D. Zang & W. Henn. *The SRV Journal, 5(1),* 45–46.

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Language, Labels and Diagnosis: An Idiot's Guide to Learning Disability. By A. McCli-mens. *Journal of Intellectual Disabilities, 11*(3),

Reviewed by Ray Lemay

THE AUTHOR IS FROM THE UK and at the outset one must understand that the expression "learning disability" refers to what we, in North America, would commonly call mental retardation or intellectual disability or developmental disability, etc., and that's pretty much what the article is about. It is about the problematic language, labels and diagnoses that are used to identify people who have cognitive impairments, and how such labels do not helpfully describe such people.

The author briefly relates the history of naming people with cognitive impairments, showing that names have changed with cultural and scientific fashions. The author reminds us that naming and categorizing are done by those in power (and who, more often than not, are not of these categories of people). Typically, people are usually quite careful about the names they give the groups they themselves belong to (Optimists, Lions, Doctors, Professors, Conservatives, Liberals, Republicans, Democrats, etc.). Obviously–unless one is trying to name a new rock band–one would think twice before calling one's group the "idiots," "schizophrenics" or "autistics."

Language is dynamic and quite naturally evolves over time, which is why Shakespeare is somewhat of a challenge to read today. For instance, technical terms invented with the Mental Deficiency Act of 1913 gave us a new classification for people with cognitive limitations. The once scientific sounding "idiots," "imbeciles," "feebleminded" and "moral defectives" have since enriched the vernacular with new pejoratives. McClimens provides us with a bit of history for the term *idiot* which was borrowed from classic Greek, where it is a word that helps distinguish between the expert and his subject as in doctor and patient (idiot). Of course, since then, idiot has been colored in an obviously much more negative way. In other words, over time we all get to be idiots but would rather be called patients, though we all have come to know the feeling.

The story of inventing new, usually negative, words to name people who happen to be devalued is compellingly described in a chapter by James Maddux (2002), in which he argues that the *Diagnostic and Statistical Manual* (DSM) of the American Psychiatric Association invents a whole new unremittingly negative vocabulary for categorizing people. These new words are to be used to name others, not ourselves. He proposes that the DSM is a social construction, that it is not a scientific document but a social one.

Maddux writes that mental disorders are not real, in a sense that they "do not exist and have properties in the same manner that artifacts and viruses do" (p. 16). "Like these other social constructions, our concepts of psychological normality and abnormality are tied ultimately to social values–in particular, the values of society's most powerful individuals, groups and institutions–and the contextual rules for behavior derived from these values" (p. 16). Though the DSM purports to be descriptive, it is rather prescriptive in that it tells us how we should and shouldn't lead our lives. The DSM has gone from 86 pages in 1952 to almost 900 in 1994 and the number of mental disorders has increased from 106 to 297. The author then describes how DSM categories are established.

"First we see a pattern of behaving, thinking, feeling, or desiring that deviates from some fictional social norm or ideal; … we then give the pattern a medical-sounding name, preferably of Greek or Latin origin. Eventually, the new term may be reduced to an acronym, such as OCD (obsessive-compulsive disorder), … the new disorder then takes on a life of its own and becomes a disease like entity. As news about 'it' spreads, people begin thinking they have 'it;' medical and mental health professionals begin diagnosing and treating 'it;' and clinicians and clients begin demanding that health insurance policies cover the 'treatment' of 'it' " (p. 17).

McClimens tells a similar story, that of the expression "learning disabilities" as it is used in England, where the term learning difficulty has also become widespread in replacement of mental retardation.

Where learning disability is a relatively benign expression in North America, in the UK the impact of the label is more dramatic, "… when an individual labeled with learning disability attends a health care appointment they are always in danger of having their disability treated before any more localized or urgent symptoms are taken into account" (p. 261). It is almost as if 'learning disability' in England has the same social consequences as 'mental retardation' in North America. Indeed, sticking such labels on an individual is identity defining; it is what we might call an "ascribed role" (Lemay, 1999), such as one that comes complete with mostly negative stereotypes and expectancies. Citing another author, McClimens tells us "disability is a social category, which legitimates, or at the very least condones, the disempowerment of people with particular mental or physical attributes" (p. 262).

McClimens suggests that it is language that makes the difference and devalues people, but the author seems to misunderstand the story he is telling. Thinking back to 1916 and the new scientific terms of idiot and feeble-minded, it is language that becomes tainted by its association with a group of very devalued people. This is the point of devaluation as described by SRV, where devaluation is a force on its own. From a Social Role Valorisation (SRV) perspective, it is a group's devaluation that leads others to choose a negative technical vocabulary that then over time becomes increasingly pejorative. McClimens proposes that language is a causal agent of devaluation, when in fact it is merely a reflection of the very real devaluation that occurs. Language provides a window on devaluation, but it does not (at least on its own) cause devaluation. Language gets caught up in the vicious cycle of devaluation.

But words are supposed to serve a purpose, and even negative words can help us understand and identify that which we need to speak about. The author tells us that careful attention to language can make a difference in our understanding of learning disability or mental retardation, but the fact of the matter is that McClimens has not really illuminated the issue. After reading this article, we still don't know what intellectual disability, mental retardation, learning disability or learning difficulty might be. There is no description or definition. These are words that have vague meanings and values (note simply how learning disability means something quite different across the Atlantic); however, we are no closer to describing what it is.

In an enlightening passage, the author quotes a man with a learning disability. Harry Green gives us a description of what it means to have a learning disability. "Put another word used for it … people call you backward 'n'all. Think that's what they mean, backward of learning, of being slow. Means so many different words, doesn't it? Daft. Dyslexic. Potty. Stupid or idiot. Whatever you can call it" (p. 263). This is certainly inelegant, quite negative, but here, finally, is an attempt at true communication, grappling with the problem of defining.

The vernacular is usually good enough for communication with and between people of valued classes. The professional behavior of coining a new vocabulary about a given group is quite likely going to end up being negative and is a sure sign that devaluation is occurring. All of this also suggests that living and language are non linear multiple feedback loop systems, and whatever we do about words is bound to have some kind of impact, but we might not be able to predict on what and how. The author's suggestion that we need to be more humane and respectful in our written and spoken descriptions of people is a nice sentiment, but it is unlikely to be helpful if the underlying devaluation is not addressed. However, working from an SRV perspective, with its emphasis on attributing and crafting valued social roles, should encourage one to embrace the vernacular and make technical labeling irrelevant.

Mathematicians have suggested that an infinite number of monkeys, typing on an infinite number of typewriters over an infinite amount of time, could eventually and quite randomly type up the works of Shakespeare. Given the contrived nature of the negative-speak that inspires professional labelers, one would suspect that only a definite number of monkeys working on a definite number of typewriters for a definite number of years could come up with a DSM.

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Ray Lemay is the Executive Director of Integra for Children & Adults & former editor of SRV/VRS: The International Social Role Valorization Journal/La Revue Internationale de la Valorisation des Rôles Sociaux.

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Role Development: An Evidenced-based Intervention for Individuals Diagnosed with Schizophrenia in a Forensic Facility. By V.P. Schindler. *Psychiatric Rehabilitation Journal 28*(4), 391-394, 2005. **REVIEW AVAILABLE ONLINE @ www.srvip.org**

Reviewed by Ray Lemay

Victoria Schindler writes that "individuals diagnosed with schizophrenia often have deficits in developing and/or maintaining social roles and their underlying tasks and interpersonal skills. Commonly available treatment such as medication and activity programs alleviate symptoms and promote improvement, but may not address the development of social roles or the skills nested in these social roles" (p. 391). The author thus highlights the differences in outcome goals of different programmatic initiatives. Some programs of intervention seek symptom reduction or functional improvement; indeed O'Connor (2001) in her doctoral thesis describes how successfully treated (symptom free or at least controlled) ex-psychiatric patients live lives of abject poverty and social isolation in the community; in the community each of these individuals had a role identity that could be summed up as ex-psychiatric patient, nothing more, nothing less. However, in this article, the author describes an approach where a role development program went beyond merely reducing or controlling symptoms and addressed issues that touched upon the quality of life experiences and conditions of inmates.

This article describes a small scale pre-post two group study that compares two methods of intervention. The experimental group involved in the Role Development Program (RDP) was made up of 42 participants. When describing RDP, the author references Wolfensberger's (2000) definition of Social Role Valorization, stating that the program is based on the concept of "role development [which] is a theory-based individualized intervention in which staff and participant work collaboratively to identify and develop the participant's social roles, such as worker, student, friend, and group member, and the task and interpersonal skills associated with these roles" (p. 391). RDP is a manualized intervention approach where employees received extensive training and were monitored for their fidelity to the approach. Staff then helped participants in their development of role relevant skills. "Although Role Development can focus on a variety of roles including community roles, roles for this study are those an individual could develop in this forensic setting (e.g., worker, student, group member, friend)" (p. 392); we could characterize such an intervention as crafting valued activities in a devalued setting in interactions with devalued individuals; or simply crafting valued roles in a devalued and segregated setting. One would want to read more about this intervention approach, but unfortunately the article provides only cursory information about the intervention methodology. Interestingly, Dr Schindler (2004) had previously authored a book on her approach where it is defined as an occupational therapy.

RDP was viewed as an enhancement of the existing treatment program and thus the experimental group was also involved in the regular "Multi-departmental Activity Program" (MAP). The RDP component was not particularly intensive, as it amounted to a total of 15.5 hours per person over a 10 week period, or less than 15 minutes a day.

The comparison group, that also included 42 individuals, participated in the existing MAP. "The MAP is a non-individualized, therapeutic intervention designed to encourage the productive use of time and socialization in a group setting" (p. 392). To ensure that it was the RDP and not individualization (a possible confound) that was producing an effect in the study, a sub-group of the MAP comparison group received a weekly 15-minute period of individual attention: "to discuss their development of roles and skills as part of the RDP, it was important to assess whether individual attention could be the cause for change" (p. 392).

The two groups were assessed using a variety of scales; pretest measures found no differences between the groups on a role functioning scale. However, "participants in the RDP demonstrated greater improvement in social roles than participants in the MAP at 4, 8, and 12 weeks of treatment" (p. 393). "This study demonstrates that individuals living with multiple disabling factors, such as a long psychiatric history, legal charges, and low levels of education, can develop skills and roles when provided with meaningful rehabilitation" (p. 394). Indeed, if we think back to the O'Connor study mentioned above, ex-psychiatric patients living in the community with few valued roles might just be no better off, indeed worse off, than these incarcerated individuals who receive support as they engage in a number of valued roles, such as student, worker and friend, albeit in a segregated setting. Though it is unlikely that social integration is occurring in a forensic psychiatric institution, an interesting question is whether RDP improves the likelihood that the roles attributed in the institution will eventually transfer to the community, thus increasing the likelihood of social integration and access to the good things in life (Wolfensberger, Thomas & Caruso, 1996).

In conclusion, it would seem that specifically and deliberately attending to the development of social roles, even for as little as 15 minutes a day, seems to be more effective than traditional therapeutic approaches, even for people incarcerated in forensic facilities.

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Ray Lemay is the Executive Director of Integra for Children & Adults & former editor of SRV/VRS: The International Social Role Valorization Journal/La Revue Internationale de la Valorisation des Rôles Sociaux.

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Lemay, R. (2010). Review of the article *Role development: An evidenced-based intervention for individuals diagnosed with schizophrenia in a forensic facility* by V.P. Schindler. *The SRV Journal, 5*(1), 49-51.

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THEOLOGY AND DOWN SYNDROME: REIMAGINING DISABILITY IN LATE MODERNITY. By A. YONG. Waco, TX: Baylor University Press, 2007. **REVIEW AVAILABLE ONLINE @ www.srvip.org**

Reviewed by Wolf Wolfensberger

SURPRISINGLY, THIS BOOK HAS HARDLY any content unique to Down's syndrome or relevant to Social Role Valorization. The author is an ethnic Chinese Protestant theologian from Malaysia who ended up in the US, and who grew up with a brother with Down's syndrome who was nearly blind and deaf, had a heart defect and was almost unintelligible.

The author admits that he has little acquaintance with impaired people other than his brother. He tried to make up for it by reading a vast amount of literature, and citing what impaired people have written, or have been claimed to have written.

Despite being highly hailed, this is a most problematic book. It evidences great learning with great incoherency of spirit, and ultimately a most peculiar teaching contrary to Christian tradition, namely that the soul evolves, which he calls "emergentism" (p. 170). It sounds much like Joseph Fletcher's 1970s and later relativistic idea of personhood, with some people having more than others, and some having none. Relatedly, the author defines personhood not in terms of being, but doing.

Among the incoherencies are these. (a) A ridiculous respect for the current mental and neurosciences. (b) A combining of Christianity with a constructionism that grew out of materialism. (c) An ambivalence toward political correctness (PC), and tortuous (often very funny) efforts to walk between it and common sense. This incoherency is also expressed in the conflict between PC and literalist Bible interpretation. (d) An attraction to crazes, craze authors and crazy authors, though most readers would not know that some of the authors cited in seriousness were/are messed-up people.

While the author has read a lot, and tirelessly cites sources, he often does not cite the important sources but very derived ones. It can be startling to see to whom various ideas are attributed, when the writers that are cited were only rehashing other people's work.

WOLF WOLFENSBERGER, PhD, is Professor at Syracuse University & directs the Training Institute for Human Service Planning, Leadership & Change Agentry, Syracuse, NY (US).

THE CITATION FOR THIS REVIEW IS
Wolfensberger, W. (2010). Review of the book *Theology and Down syndrome: Reimagining disability in late modernity* by A. Yong. *The SRV Journal, 5*(1), 51.

LIST OF ITEMS TO BE REVIEWED

IN EACH ISSUE OF *The SRV Journal*, we publish reviews of items relevant to SRV theory, training, research or implementation. These include reviews of books, movies, articles, etc. We encourage our readers to look for and review such items for this journal. We will be happy to send you our guidelines for writing reviews, or they are available on our website (http://www.srvip.org/journal_submissions. php). We are open to reviews of any items you think would be relevant for people interested in SRV. We also have specific items we are seeking reviews of. (We strive to include items which might have relevance to: SRV theory, one or more SRV themes, and/or social devaluation. If, however, a reviewer finds that a particular item is not so relevant, please let us know.) These items include:

SOCIAL INCLUSION AT WORK. By JANIS CHADSEY. Annapolis, MD: AAIDD, 49 pages, 2008.

WHO GETS BORN? Wellington, New Zealand: TOI TE TAIAO: THE BIOETHICS COUNCIL, 64 pages, 2008.

INCLUSIVE LIVABLE COMMUNITIES FOR PEOPLE WITH PSYCHIATRIC DISABILITIES. Washington, DC: NATIONAL COUNCIL ON DISABILITY, 84 pages, 2008.

BODY & SOUL: DIANA & KATHY. By ALICE ELLIOTT (Director). 40 minutes, 2006.

WAITING FOR RONALD. By ELLEN GERSTEIN (Director). 2003.

MODELL, S. & CROPP, D. POLICE OFFICERS & DISABILITY: PERCEPTIONS & ATTITUDES. *Intellectual and Developmental Disabilities, 45*(1), 60-63 (2007).

EISENMAN, L. SOCIAL NETWORKS & CAREERS OF YOUNG ADULTS WITH INTELLECTUAL DISABILITIES. *Intellectual and Developmental Disabilities, 45*(3), 199-208 (2007).

WOLFENSBERGER, W. HOW TO COMPORT OURSELVES IN AN ERA OF SHRINKING RESOURCES. *Intellectual and Developmental Disabilities, 48*(2), 148-162 (2010).

JACKSON, J. CONTEMPORARY CRITICISMS OF ROLE THEORY. *Journal of Occupational Science, 5*(2), 49-55 (1998).

ABERNATHY, T. & TAYLOR, S. TEACHER PERCEPTIONS OF STUDENTS' UNDERSTANDING OF THEIR OWN DISABILITY. *Teacher Education & Special Education, 32*(2), 121-136 (2009).

CARROLL, S., PETROFF, J. & BLUMBERG, R. THE IMPACT OF A COLLEGE COURSE WHERE PRE-SERVICE TEACHERS AND PEERS WITH INTELLECTUAL DISABILITIES STUDY TOGETHER. *Teacher Education & Special Education, 32*(4), 351-364 (2009).

DISCUSSION QUESTIONS

THIS FEATURE PROVIDES, for those who are interested, a way to continue learning from and engaging with a *Journal* article after they are done reading it. We will support such learning by publishing questions based on selected articles, prompting the reader to continue considering, reflecting, discussing and even writing about what they read. Such questions can be useful in deepening a reader's level of understanding of the article content and its SRV implications, whether for teaching or application, and may even lead to a shift in mind-set. We hope that these questions will be used for example by individual readers, as well as by university/college professors in their classes, by program managers during staff meetings, and so on.

LEGALIZE ASSISTED SUICIDE? NOT SO FAST (PP. 5-9) ~ McGAUGHEY

1. What are some of the prevailing values in our society that directly or indirectly encourage or promote 'physician assisted suicide'? In what ways do these prevailing values do that, and to what degree? How are these values reflected in contemporary practices of human service systems, organizations and programs?

2. Connect the insights of this article with what SRV teaches about the socially devalued roles of 'dying,' 'better off dead' or 'already dead.'

3. How can individuals and organizations strive for greater consciousness of the heightened vulnerability of individuals and groups susceptible to 'physician assisted suicide'?

4. What societal factors contribute to the breaking down of the distinction between 'disability' and 'disease,' particularly within the 'physician assisted suicide' debate?

STRIVING FOR ORDINARY: A MOTHER'S STORY (PP. 10-13) ~ DUNNIGAN

1. What particular concerns face families with impaired children today? How does this article illustrate the reality of 'heightened vulnerability' in the lives of children with impairments and their families? What steps has the family taken, with some service help, to address their son's heightened vulnerability?

2. Since the author identified herself as a long-time professional employee of the service system, what did you think of her resistance to engaging her son in that system? Do you understand her reticence? How would you think, feel and react if you were in this family's shoes? How does the author's stance relate to her son's heightened vulnerability (as, for example, was raised in the previous question)?

3. Elaborate on what the author meant by the choice between "existence and care" on the one hand, and "capacity and possibility" on the other. If you work in services, how is this choice or gap reflected: a) in your program or agency; b) in the attitudes and actions of program staff; c) in the roles of program staff? How can an understanding of SRV inform this all-too-common dilemma?

SRV Lessons Learned (pp. 21-35) ~ Tumeinski

1. Consider the typical pattern, which most children experience as they mature, of gaining a greater number of valued roles in different role domains as they move toward their teenage years, young adulthood and mature adulthood. What dynamics *contribute* to this typical pattern, e.g., within families, schools, neighborhoods, communities, workplaces, churches/synagogues/temples, etc.? By contrast, what dynamics *slow down, minimize or even derail* this pattern for children with significant impairments? How can human services take advantage of the contributing dynamics as well as eliminate, reduce or compensate for the 'derailing' dynamics?

2. Compare the more *narrow* purview and the more *broad* purview of the preschool identified within this article. What implications do these different scopes or purviews have for school systems, classrooms, day-care programs, 'special education' programs, etc.?

3. Based on the descriptions given in this article of what the preschool program was doing, identify the major underlying assumptions of the program. Keep in mind that assumptions can be conscious as well as unconscious.

4. What can the experience of the preschool program described in this article teach us about the connection between striving to use the culturally valued analogue with implementing a model coherent service (Wolfensberger, 1998, 111-118)?

CALENDAR OF SRV & RELATED TRAININGS

THIS CALENDAR LISTS UPCOMING SRV & PASSING workshops we are aware of, as well as a number of other workshops relevant to SRV. Each event varies in terms of length & depth of coverage of material; contact the person listed to make sure the workshop fits what you are looking for. Additional training calendars may be accessed at *www.srvip.org & www.socialrolevalorization.com.* To notify us of SRV, PASSING & SRV-related workshops for upcoming issues, send information to: *journal@srvip.org.*

5th International SRV Conference
September 21-23, 2011
Canberra, ACT, AUS
email srvconference@koomarri.asn.au

An Introduction to SRV: A High-Order Schema for Addressing the Plight of Devalued People (*with an emphasis on developing leaders in SRV*)
September 7-10, 2010
University of Calgary, Alberta, CAN
email absafeguards@gmail.com

tentative September 13-16, 2010
Melbourne, VIC, AUS
email Estelle Fyffe ~ Estelle.Fyffe@annecto.org.au

October 11-14, 2010
Indiana, US
email Joe Osburn ~ josephosburn@bellsouth.net

October 18-21, 2010
Winnipeg, MB, CAN
email Reina Soltis ~ rsoltis@stamant.mb.ca

November 15-18, 2010
Troy, NY, US
email info@srvip.org

tentative spring 2011
Syracuse, NY, US
contact Susan Thomas ~ 315.473.2978

An Introduction to Social Role Valorization
July 20, July 27, August 3, 2010
Indooroopilly, QLD, AUS
email viaainc@gmail.com

Practicum With SRV Using the PASSING Tool
prerequisite: attendance at a leadership level SRV workshop
July 12-16, 2010
Rockhampton, QLD, AUS
email Jenni Keerie ~ citizen@irock.com.au

October 4-8, 2010
Indooroopilly, QLD, AUS
email viaainc@gmail.com

October 25-29, 2010
Sydney, NSW, AUS
email foundationsforum@yahoo.com.au

November 8-12, 2010
Fairhaven, MA, US
email info@srvip.org

Understanding Social Devaluation & the Service Worker's Role From an SRV Perspective
August 3-4, 2010
Sandusky, Ohio, US
email info@srvip.org

October 20-21, 2010
Holyoke, MA, US
email info@srvip.org

Towards a Better Life: A Two-Day Introduction to SRV
July 5-6, 2010
Darwin, NT, AUS
email Debbie Bampton ~ DebbieB@somerville.org.au

August 19-20, 2010
Canberra, ACT, AUS
email Veronica Hadfield ~ VHadfield@koomarri.asn.au

August 26-27, 2010
Sydney, NSW, AUS
email foundationsforum@yahoo.com.au

September 6-7, 2010
Indooroopilly, QLD, AUS
email viaainc@gmail.com

One Day Overview of Social Role Valorization
August 18, 2010 (8:15 am to 5 pm)
Adirondacks in NY, US
contact Susan Thomas ~ 315.473.2978

Social Role Valorization News & Reviews

Wolf Wolfensberger

As in earlier issues of this journal, my intent for this column is five-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. Some of these items may serve 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.

(d) Document certain SRV-related events or publications for the historical record.

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

I have about 20 SRV-related topics, from among which I try to present a selected few in any particular issue.

Aside from being instructive to readers, persons who teach SRV will hopefully find many of the items in this column useful in their teaching.

Personal Appearance

*In the most recent (December 2009) issue of this journal, the editor announced the publication of *APPEAR: Observing, Recording & Addressing Personal Physical Appearance by Means of the APPEAR (A Personal Physical Appearance Evalu-*ation and Record) Tool*, which consists of a text about the size of the 1998 3rd revised edition of *A Brief Introduction to Social Role Valorization*, and a separate checklist of 200+ items to be used in conducting an 'audit' of a person's appearance, so as to identify areas in which that appearance could be improved. The rationale behind APPEAR is two-fold: (a) personal appearance is one of the most powerful and most immediate determiners of how a person will be perceived and valued by others, and (b) the appearance of the vast majority of the members of any devalued class contains many negatively valued elements which, however, could be improved. APPEAR is thus a tool that can be of very practical use in implementing Social Role Valorization in the lives of devalued people.

In this section of the column, we present a few more items that speak to the importance of personal appearance.

*In various historical and human service works, one can read about the ways that convicts or certain prisoners were 'marked.' (Someone could do a study, or even a doctoral dissertation, just on this phenomenon.) This was usually done by branding, distinctive clothes or markings on the clothes, or attachments of certain objects to their bodies. For instance, between at least the mid- to late-1800s, prisoners in some American states had to wear motley clothes. E.g., in Virginia, they were multi-colored; in Vermont, they were

red and black. Also, in Virginia, they had their head hair half-shaven off, as was also the practice in Russia (e.g., Henderson, C.R. [Ed.]. [1910]. *Penal and reformatory institutions.* New York: Charities Publication Committee, Russell Sage Foundation. [One of four volumes on correction and prevention prepared for the 8th International Prison Congress.]).

*Stafford, B.M., La Puma, J. & Schiedermayer, D.L. (1989). One face of beauty, one picture of health: The hidden aesthetic of medical practice. *Journal of Medicine & Philosophy, 14*, 213-230. According to some scholars, a key role in judging personal appearances is played by expectations. While there may be a genetic element to one's expectations of human appearance, these expectations are also shaped by experience and cultural norms. According to these authors, Western society has for so long been preoccupied with issues of mathematical and geometric measurement, forms and proportions, and the belief that beauty can be found in certain of these, that deviations in appearance from the resultant cultural expectations are experienced as disconcerting, hence ugly.

*When persons take on a certain culturally recognized appearance by means of attire, accessories, maybe make-up or tattooing, ornaments, etc., then they often also start emitting the behavior that a culture expects from the type of person that is being represented. Thus, a person may take on both the appearance and behaviors of a lady, a gentleman, a strumpet, a motorcycle gangster, an 'old maid,' etc., etc. A police officer who infiltrated a motorcycle crime gang by looking and acting like a gang member continued to groom, dress and act like one after his assignment was over. The role had become engrained; as he said, "It became who I was" (Conant, E. [2009, March 16]. A very hellish journey. *Newsweek*, pp. 50-51).

*There is plenty of at least anecdotal evidence that people who have known a person of very ne-glected appearance fail to recognize that person after the person has been cleaned up, groomed and put into good clothing appropriate for the occasion. This effect is further strengthened when the person is also presented in a normal–or even prestigious–context after the person had previously been encountered in a deviant context. For instance, when the mayor of Auburn, New York, donned prison clothes and spent a week in prison in order to find out what prison conditions were like, acquaintances who knew him failed to recognize him there. During his stay, the mayor participated in the typical routine of the prisoners as much as possible, following their schedule, eating their meals, wearing their clothes, submitting himself to the same rules and regulations and infringements, working in the basket-weaving shop along with a cadre of prisoners, even spending 12 hours in solitary confinement. The inmates were deeply moved by this act of true solidarity and personal identification with their plight by someone on the outside in a position of privilege and authority (Osborne, T.M. (1921). *Within prison walls, being a narrative of personal experience during a week of voluntary confinement in the state prison at Auburn, New York*. New York: D. Appleton & Co.).

*Some handicapped people seem indifferent to their body abnormalities, while others are very aware of them, and unhappy with them. For example, persons with Prader-Willi syndrome (who are usually obese) were found to be dissatisfied with their bodies. Such dissatisfaction can be a good motivational foundation for a food-intake control program, especially when the parents are also dissatisfied, as in this case they were. (Napolitano, D.A., Zarcone, J., Nielsen, S., Wang, H. & Caliendo, J.M. (2010). Perceptions of body image by persons with Prader-Willi syndrome and their parents. *American Journal on Intellectual and Developmental Disabilities (AJIDD), 115*(1), 43-53.)

*Some devalued people are deeply ashamed of their devalued identity, and wish that they could escape it. Some such persons then also feel ashamed if they are juxtaposed to other devalued persons, either of their own devalued class, or other stigmatized people. One man with Down's syndrome once complained that he "did not want to have to be around a bunch of retards all the time," referring to his peers in a group home. This is one more argument for integration, in that it creates juxtapositions to valued people rather than devalued ones. However, it is not directly an SRV rationale, in that its impact on the person is more intra-psychic than social, though it can eventually have social fall-outs.

*The Blind Boys of Alabama is an African-American singing group (one member is albino) who all wear sunglasses and red suits. This is a mixed image. The sunglasses reinforce stereotypes about the blind, and their joint appearance presents a powerful 'blindness' message. On the other hand, performing as a group with identical conspicuous suits, there is some capitalization on the tradition of singing, dancing and/or music-making groups.

*New York State decided to supply its corrections officers with only one winter coat, rather than two (of different weights), and so ended up with 7,000 surplus coats. Not wanting them to go to waste, it donated them to human services throughout the state, but in big lots so that the service recipients who got them end up all looking alike, and being easily identifiable as a service recipient. For instance, one residence for the mentally disordered got 50 coats, one Rescue Mission got 150 coats, and another 100 coats (*Syracuse Post-Standard*, 25 November 2008, p. B2).

*Chelminski, R. (1980). Forbes Museum's little soldiers aren't playthings. *Smithsonian*, *11*(5), 68-75. When Queen Mary of Great Britain looked at a toy farm scene made by one of the major pro-

ducers of toy soldiers (William Britain), apparently sometime between the two World Wars, she said: "But where is the idiot? No English village is complete without the Idiot." The designer hastened back to the drawing board and produced what people thought was a 'good one:' with ill-fitting clothes, an unkempt shock of hair, large eyes and a big stick. The designer was obviously trying to capture popular stereotypes of what a village idiot would look like. (The largest museum for toy soldiers is at the Forbes Museum in Tangiers, Morocco, where the idiot also resides.)

*In the 1946 film classic, "It's a Wonderful Life," traditionally shown around Christmas time, the evil protagonist is a very wealthy old man by the name of Mr. Potter who gets pushed around in a wheelchair by a servant. While this is a negative image, the wheelchair itself resembles an ordinary chair except that it was elaborately and beautifully carved, and thereby exceedingly image-enhancing. It is an eye-opener to contemplate that there is hardly ever anything beautiful about any of the wheelchairs that we see today.

*Zax, D. (2010, February). Picture of prosperity. *Smithsonian*, *40*(11), 42-47. In 1904, an African-American by the name of Addison Scurlock set up a portrait photography shop in Washington, DC, which stayed in business until 1994. The studio photographed mostly members of the local African-American upper classes, in a way that brought out the best side of each subject. This was done by means of positive settings, classy attire and the coaching of the 'attitude' of the subjects. As a result, the portraits were huge successes in enhancing the images of the subjects, or in seizing upon their already-present positive qualities. The subjects became competitive, in effect saying, "If you can make him or her look this good, you can make me look even better!" (p. 42).

The settings were not only in the studio, but at virtually any African-American social event:

dances, graduations, weddings, baptisms, events at Howard University, etc.

Scurlock demonstrated what our new monograph *APPEAR: Observing, Recording & Addressing Personal Physical Appearance by Means of the APPEAR Tool* and its companion checklist try to teach: that much can be done to improve the appearance of virtually everybody, though this is of course particularly important in the case of people at social value risk, which the DC African-Americans were, the same as handicapped people anywhere at anytime.

To order APPEAR: Canadian purchasers, contact the Valor Institute, 200 Chemin du Comté, Plantagenet, Ontario K0B 1L0 Canada, phone 613/673-5148; all other purchasers, contact the Training Institute, 518 James Street, Suite B3, Syracuse, New York 13203 USA, phone 315/473-2978.

Enhancement of Competencies

*Medical innovations are often very risky in their initial stages when experience with them is limited, and especially if they are introduced with much hype. This includes medical efforts to enable or increase competency development, especially if surgery or drugs are involved. In recent years, children with cerebral palsy have been given (apparently by injection) the anti-wrinkle drug botox, a toxin produced by the botulinum bacteria, in order to paralyze certain nerves and thus reduce spasticity in the legs. This use of botox has not been approved in the US, but has been in some other countries. In some cases, the toxin spread to other parts of the body, and weakened or paralyzed the breathing and swallowing muscles, sometimes resulting in death. The US Federal Drug Administration issued a warning on this in February 2008 (AP in *Syracuse Post-Standard*, 9 February 2008, p. A4).

*Everyone knows of the spectacular competency-enhancement of deaf-blind and mentally stunted Helen Keller (1880-1968) by her full-time live-in tutor, Anne Sullivan. These days, there are no more Anne Sullivans because no one wants to work around-the-clock, and on a live-in basis. The closest thing is euphemistically called an "intervenor" who lives "out" and comes in to work a 40-hour week tutoring a deaf-blind child. There is one 2-year long program in North America that develops "intervenors," but most get a mere 2 days training!! (*Reader's Digest*, February 2008). No wonder we are no longer getting Helen Keller-like competency breakthroughs! I had already pointed out in a previous column (December 2009, p. 82) that Keller would have remained a profoundly retarded child if she had been "included" with other children.

*According to some authorities (e.g., Almazan, 2009), the 2002 US federal "No Child Left Behind" legislation made it mandatory that "pupils with disabilities" gain and receive access to the general education curriculum. This sounds as if specialized curricula are at best optional add-ons, if there is time left for them. Certainly, such a situation would rule out highly successful curricula, such as the one laid out by Edouard Seguin. This strikes one as another instance of doctrinaire ideology triumphing over empiricism.

As I explain elsewhere, this development seems to have been launched by Naomi Norsworthy at Columbia University Teacher's College in the early 1900s, and for many decades resulted in so-called "watered-down education" for retarded pupils. This also demonstrated that one can teach the regular curriculum in a segregated fashion. (Almazan, S. [2009, Summer]. What the state statistics say about inclusive education. *TASH Connections, 35*(3), 7-11.)

*In 1936, Paul Witty wrote a section on "The Feebleminded and the Dull" (pp. 464-469) as part of a chapter on "Intelligence: Its Nature, Development and Measurement." It reported on a 1932 study of 540 special classes, with almost 12,000 children! Essentially, what they got was the so-called "watered-down curriculum." Play in

special classes was said to have been of the kind that had little value. The author said that since almost all teachers will deal with retarded children, they need to be better prepared for it. (Skinner, C. E. (Ed.). [1936; 1937 printing]. *Educational psychology*. New York: Prentice-Hall. [Prentice-Hall Psychology Series].)

*The special education culture has developed a construct of "functional skills" and functional curricula. Curricula are said to be "functional" if they contribute directly to the attainment of pupils' greater independence, self-sufficiency and quality of life (Storey, 2009). If a person is being taught to perform an activity so that no one else has to perform it for the person, the curriculum that teaches it is probably functional.

We were struck by how different the notion of functional skills is from the one of competency in SRV theory. The SRV construct of competency is vastly broader than "functional skills," and all sorts of competency acquisitions would be interpreted as not conveying functional skills, and therefore as being of no pedagogic importance. For example, the Special Olympics activity of accurately throwing a ball onto a target on the ground would be judged nonfunctional and essentially as worthless.

One criterion of functionality is: "Could a pupil function as an adult if the pupil had not acquired the skill at issue?" In consequence, even very difficult performances would be dismissed by this criterion as "nonfunctional." An example is doing back flips on a balance beam. Such an activity benefits the entire body, including facilitating all sorts of skills that are important in life (not stumbling and falling, preventing back injuries, etc., etc.). But according to the functionalists, being able to do such flips contributes nothing to daily living, because no one in daily life goes around doing back flips.

It is frightening to think that an entire developmental system would be built on such narrow notions of functionality, and narrow ideas of what should and should not be taught or fostered for a

person's entire childhood. It is also frightening to think what a false belief system the functionalists have about human nature. One would not want these people to be in charge of informing the public what handicapped people are like. Bring us back Seguin!

*Turner, S.M., Calhoun, K.S. *&* Adams, H.E. (Eds.). (1981). *Handbook of clinical behavior therapy*. New York: John Wiley *&* Sons. (Wiley Series on Personality Processes, I.B. Weiner [Ed.].) While this book is an incoherent mix, it contains a number of facts or conclusions relevant to competency enhancement, including: (a) extinction strategies are said to be largely ineffective; (b) punishment sometimes works, but it has a tendency to suppress behaviors in general; (c) abstraction is linked to stimulus generalization; (d) one strategy is to teach retarded people to follow a series of very simple unimportant instructions; they thereby acquire a habit of following instructions, which generalizes to important ones; and (e) some mentally impaired people have–for various reasons–never developed an imitative mindset, in which case imitativeness itself should be taught, so that in time, desired behaviors can be more systematically modeled, with better chances that they will be imitated.

*The pedagogic regimen of so-called "conductive education" (invented in Hungary, and applied mostly to severely motor-impaired children) aims to achieve an "orthofunctioning personality." I once said that innumerable misunderstandings of the normalization principle would have been prevented if an unintelligible term had been used for it from the beginning. As an example, I suggested "orthofactorization."

*A boy sucked his thumb until the age of 12, despite discouragement from the family. One day, someone offered him what today would amount to about a dollar if he quit–and he quit instantly forever (Maclay, D.T. [1970]. *Treatment for chil-*

dren: *The work of a child guidance clinic.* New York: Science House). This illustrates a culturally normative way of dealing with problems that these days might precipitate a torrent of paid and acultural services.

*In the acquisition of competencies, memory plays a crucial role. Efforts at competency acquisition will fail unless what is attempted to be learned actually gets retained in memory storage. Considering this, it is amazing that educators and political correctness parties have been bad-mouthing memorization. Without memorization, nothing gets learned. One pretense that gets made is that there is rote learning (supposedly bad) and other learning, which is supposedly less worse. The fact is that some things will only be learned well by rote–"repetitio est mater studiorum." That includes multiplication tables; and the declinations, conjugations and vocabularies of foreign languages.

Competency development will not be supported by belittling of memorization!

*A high school teacher began to teach chess to her pupils as a medium for teaching English. The results were "immediate and dramatic: disciplinary issues evaporated. Students with ADD, ADHD, OCD [attention deficit disorder, attention deficit hyperactivity disorder, obsessive compulsive disorder] and dyslexia were transformed into hyper-focused and driven chess-a-holics" (*US Chess Life,* August 2009, 36-37). In other words, a competency led to new and more valued roles. A combination of things probably accounted for this, including high expectancies.

*William John Barrow was diagnosed as autistic at age 2 when he had not yet said a word. One doctor told his father that if he was lucky, he would be able to live in a group home instead of an institution. Six years later, in 1996, his mother abandoned the family, and soon after that, the father's business failed. However, that year, William

learned to play chess, entered tournaments and got a coach, and played in 150 tournaments in five years. By age 17, he had attained the rank of "expert," which puts him roughly in the 99th percentile of tournament players. "His chess prowess enabled him to overcome many of the social stigmas attached to autism. His ever-growing skills helped him gain self-confidence, and as a valued member of his school's team, he earned the respect and friendship of his peers. Meanwhile, William was also discovering his immense talent for the tactics of mathematics" (*US Chess Life*, December 2007, p. 8. The chess reporter wrote this as if he had had SRV training!). He began to make top grades. For 10+ years, he attended speech classes and learned to communicate naturally. In 2007, the Horatio Alger Society gave him a $20,000 scholarship that enabled him to enroll at the Virginia Commonwealth University Honors College in Richmond, Virginia, aiming at bio-medical engineering. This is almost a textbook illustration of how the acquisition of a competency can lead to valued roles, to improved images, and be a springboard to other skills and valued roles.

*One competency-relevant area of research is that which has gone under the names of "resilience," "self-efficacy," and now is called "hardiness." Hardiness is said to be made up of commitment (which means engagement, rather than withdrawal and isolation), control (which means having influence rather than being passive and powerless), and challenge (which refers to learning from experience). The research overall claims that people who are resilient, or "have resilience," who are self-efficacious, and who are "hardy" in the above sense cope much better with the hardships of life than those who are not, which is very consistent with SRV–except SRV points out that having valued roles can also help one to cope with life's hardships even when one is not hardy, resilient or self-efficacious, and even when one has no competencies whatever, because valued roles tend to bring with them resources and protections in

the forms of friends, family, allies, etc. (Maddi, S.R. [2002]. The story of hardiness: Twenty years of theorizing, research, and practice. *Consulting Psychology Journal: Practice and Research, 54*(3), pp. 175-185).

*Advocacy of so-called "self-determination" (a relatively new word when applied to individuals) is rarely linked to issues of competency. In fact, the unnuanced self-determination rhetoric implies that even profoundly mentally impaired people should be given self-determination. However, we now hear a new rhetoric in regard to "self-determination skills," which is also a new term. It refers mostly to what was once called "social maturity," and thereby to all the competencies that were once subsumed under that construct, especially as once measured by the Vineland Social Maturity Scale. Not surprisingly, "self-determination skills" correlated .77 with social skills (Carter, E.W., Owens, L., Trainor, A.A., Sun, Y. *&* Swedeen, B. [2009]. Self-determination skills and opportunities of adolescents with severe intellectual and developmental disabilities. *American Journal on Intellectual & Developmental Disabilities (AJIDD), 114*(3), pp. 179-192).

Imaging Via Language

Names of Settings & Services
*The early schools for retarded children in Germany were informally referred to as dumb schools, idiot schools and simple schools (a simple was an idiot). Official names included Help Schools, School for Weakly Endowed Children and School for Mentally Not Normally-Developed Children. The first such school founded in Meissen, Saxony in 1903, was jointly supported by the Association Against Beggary and Pauperism, a welfare organization named To the Cross, a fencing school and the local Association for the Care of Graduates of the Meissen School for the Retarded.

*One of the earlier idiot asylums founded in 1862 in Britain was the Western Counties Idiot Asylum. Fortunately, it was located at Starcross, but unfortunately, in 1914, it expanded by buying a property called Folly Cottage, of all things!

*In the 1920s, an Oaks School for Borderline Defectives was established in Cook County (Chicago), Illinois.

*Cutten, G.B. (1911). *Three thousand years of mental healing.* New York: Charles Scribner's Sons. This is a history of healing by non-medical means. St. Coleta (sometimes spelled Coletta) acquired fame by raising more than 100 slain infants from death. Thus, when her name is given to an institution for the retarded (as has been the case–there is a famous St. Coletta's in Wisconsin, for example), it implies that they are like dead infants who need to be restored to life.

*In the 1960s and 1970s, there was a Beacon Institute for Defective Delinquents in Beacon, New York. On the back of the young male inmates' shirts was stamped BIDD (source information from Mr. Tom Grace.) This goes into the category of "marking" deviant people.

*In 1896, Dr. James Walk, a Philadelphia charities leader, proposed that people who worked with the "weak" be called "asthenontologists," asthenontology meaning "the science of weak beings." A number of people–including the prominent human service leader Alexander Johnson–tried to popularize the term, but it never caught on (Johnson, A. [1923]. *Adventures in social welfare: Being reminiscences of things, thoughts and folks during forty years of social work.* Fort Wayne, IN: Author; p. 130).

*Strecker, E.A. *&* Ebaugh, F. (1940; 1945 printing). *Practical clinical psychiatry* (5th ed.). Philadelphia: Blakiston. Editions of this book started coming out in 1925. The first author was a pupil

of psychiatrist Adolf Meyer, and represented the "psychobiological" perspective, as then understood. He tried to convey "the psychiatric point of view" to generic physicians, nurses and social workers. Here we learn that manual training classes were sometimes called "Z classes," maybe because Z is the last letter of the alphabet.

*In 1865, only a year before Dr. John Langdon-Down published his treatise on Mongolian idiocy that later would be called Down's syndrome and later Down syndrome, a private asylum for "idiots" was opened in England that was called Downside Lodge (Parry-Jones, 1972)–a not very positive-imaging name, even then. Also, a Quaker physician, Edward Long Fox, started a small private madhouse at Cleeve Hill, Downend, near Bristol, England in 1794.

*We have commented repeatedly that the name "Sunset" continues to be used for nursing homes. In Pennsylvania, there is a nursing home called "Sunrise" (*US News & World Report*, February 2010, p. 68). It takes no more effort to call a nursing home Sunrise than Sunset, so there must be powerful unconscious death-associated motives for selecting the latter.

*For once, we can report on a negatively-imaged acronym that fits: CRAP, which stands for Cornell Refuse Analysis Project, a volunteer litter pick-up effort by valued alumni of Cornell University in New York State (*Syracuse Post-Standard*, 8 October 2007, p. D1).

*In late 2008, we saw a van for a community center in or near Syracuse that serves primarily poor African-Americans with its name in large print on the side, and on the driver's door the acronym C.R.A.P.P. We don't know what it stood for, but it was most certainly a negatively-imaging language juxtaposition to poor people–indeed, an almost worst-case acronym scenario.

*A health care program in Wisconsin is called Badgercare, which elicits animal images. Another one is called GAMP, which is a clang association to gimp, usually signifying a limping or crippled person.

*Imagine naming a psychiatric clinic the Rip Van Winkle Clinic (presently or formerly in Hudson, NY). Van Winkle was the man who, according to the legend written by Washington Irving, went into a long deep sleep, and woke up after his world had changed and no one knew him any more.

*The Syracuse Children's Chorus includes singers "from ages of 8 to 80." This is an example of how the contemporary practice of no longer calling things what they are can put people at image-risk.

Names & Symbols for Conditions

*In England and the US, the term "feebly-gifted" was sometimes used around 1900 for people of low intelligence since birth or early age (Barr, 1904). This meant that the person's mental gifts were feeble, and not like today where gifted is used as a euphemism, such as "differently gifted."

Today, there are entire articles on the "challenged gifted" (e.g., *Connections* [Anabaptist Disabilities Network], December 2008, pp. 1-2), which underlines the absurdity of using the word "challenged" (as in "living with challenges," etc.) as a code word for impaired or handicapped.

*The phrase "special needs" has become a euphemism for impaired or handicapped. It has also been pressed into adjectival use, as in "a special needs person;" and into use as a noun signifying a handicapped person, as in the headline "Discrimination Against Special Needs Unacceptable" (*Syracuse Post-Standard*, 8 August 2008, p. A11). Parents have begun to write books on their "special needs child," leaving potential readers to guess what impairment the child has. Insofar as this is a meaningless code word, why not call them by a real code, such as "xyz children" or "327 children"?

The term "special needs" may also be attached to all sorts of programs, such as "special needs confirmation class." (One infers that there must also be a "no special needs confirmation class.") There is also a book out on "Caregivers of People with Special Needs," so there must also be caregivers of people without special needs, or with no needs at all.

There is actually a Special Needs Soccer Association in the St. Louis, Missouri, area, apparently for "special needs people." Is all this much of an improvement over earlier language uses?

*The noun "diversity" has been transformed by politically correct idiom into an adjective referring to people. A person can now be said to be "diverse," with the specific code meaning that the person is not light-skinned, and/or is a foreigner, homosexual or at least female. Individuals may now also be called "a diversity." In the PC discourse, one would not call a person "diverse" for having many interests or being a polymath. Further, the adjective has begun to be applied to whole classes or groups of people, and to such classes or groups who are homogeneous. E.g., a group made up 100% of people of dark skin may be said to be "diverse." In *Newsweek* (1 December 2008, p. 35), a private school was said to have a "39% enrollment of diverse students."

*In schools, students may be defined as "being CLD," meaning being "culturally and/or linguistically diverse." This sounds like a pathology diagnosis, and care must be taken not to say that someone "has CLD."

*There are efforts underfoot (apparently mostly by mentally disordered persons) to reformulate mental disturbance as a "mental diversity" or "a different mind." This development is going hand-in-hand with efforts to normalize the deviancy of mental disturbance, by pointing to the mental travails that all people have, and building something like "mad pride."

*In SRV teaching, it is emphasized that there is a middle ground between attaching negatively-imaged terms to a person's devalued condition, and being deceptive–and even misleading–about the presence of that condition. In the *Syracuse Post-Standard* (3 June 2009, p. A4), a woman minister with a doctorate wrote that she had "drunk her way through college," been variously diagnosed to have depression, attention deficit disorder and rapid-cycling bipolar disorder, but that she and others having "mental illnesses" were "not crazy." Whatever this kind of discourse may do for people like her, it is apt to drive listeners crazy.

Similarly, a feature in the same paper (25 May 2009, p. C3) reported on a young woman who said, "I have three mental illnesses; bipolar (manic depressive disorder), ADHD (attention deficit hyperactivity disorder) and anorexia," all these starting in the 3rd grade. She has been to a psychiatric emergency service three times. She also hurts herself and has set a fire in her home. She said, "having mental illness doesn't make me crazy, it just makes me different."

Maybe all of this also means that there is a "psychiatric difference disorder."

*Some behaviors might be called "self-stimulating," and a person may be said to "be stimming," which does not sound good. In fact, it isn't good, because it refers to allegedly self-stimulating abnormal behaviors. We had never heard the expression "he stims," "he is stimming," etc., before April 2009. This is an abbreviation for "stimulus" and "stimulate." However, even if the proper English word were used, it is being used wrongly to refer to obsessive focusing on something, which is closer to responding than stimulating. Hopefully, readers of this journal are too analytic to start using this new craze phrase. As with the "people first" language, it sets up a segregated language. Also, some people are soon apt to be called "stimmers."

*The N-word, or "Nigger" is another no-no word–except when used in and by the African-

American culture and certain of its music genres. *Time* (28 July 2008) printed it as NI**ER. The media usually refer to the F-word as "f…". Now is NI**ER more role-valorizing, or more role defensive, than N*****? Maybe there are too many stars and not enough consonants to make the euphemism recognizable. But why not NIG**R, or *IGGER, or *IGGE*? This calls for more systematic analysis and some rational explicit guidelines.

*A person who has leprosy (Hansen's disease) was furious because a writer reported that in 1908, a leprasorium was opened in the Philippines. The protester referred to "the L word," and demanded that "lepers" be referred to as "individuals battling a bacterial infection" (*Scientific American*, October 2008, p. 14). Of course, in 1908, the term "Hansen's disease" did not yet exist, nor was the responsible bacterium identified yet.

*For hundreds of years, the English-speaking merchant navies had an occupational title, "able seaman," often abbreviated AB. Able seamen were distinguished by their skills from other seamen, who were often men grabbed almost randomly off the streets and "impressed" by a "press gang" into a departing ship's crew. Ironically, one could be what these days is called "disabled" or "having a disability" (lacking an eye, a few fingers, etc.) and still be an able seaman. Today, in many circles (some politically correct), it is frowned upon to call anyone "able," and some "disabled" people wickedly refer to other people as "temporarily able-bodied." Should one give up the title "able seaman," maybe in favor of "temporarily able-bodied seaman"? Has there been a campaign to recruit "disabled" or "non-able seamen"? Should the title be changed to "non-challenged seaman"? Again, a little more analysis of this one would be welcomed.

*Trachtenberg, I. (1983). *Three R's for tardies*. Ashley, PA: New Horizons. This book was written by an early pioneer in the education of severely retarded children in Pennsylvania. It was meant to be positive and hopeful, but still suffered under old attitude burdens. The "tardies" in the title referred to a colloquial reference to mentally retarded people, though it is not one that was commonly heard.

*There is now a campaign on to get rid of the dreaded "R-word," including by people who think nothing of liberally using the F-word, and in public yet. What is the R-word? It is "retarded" or "retardation." As some campaigners say, "Why go negative?" (Note the current practice of sloganeering in phrases of at most 7 words.) The campaigners also no longer want to hear the words "typical" or "normal" applied to children in classrooms, because that implies that other children are atypical or abnormal (*Syracuse Post-Standard*, 21 February 2008, p. D1), and in the fictional Lake Woebegon, Minnesota, everyone was normal or average, until they all became above average. The amusing alternatives being proposed include "differently abled," and "children without diagnosed disabilities," as in, "I am taking my 8-year old son who is not diagnosed to have a disability to his soccer practice." As we have pointed out elsewhere, inherently disagreeable realities of life can not be made pleasant by couching them in a positive idiom. Eventually, new positive (or less negative) terms given to such realities acquire the same noxiousness as the unpleasant realities, and as the negative terms previously used to signify them. A good example is the term "idiot," which once meant an apolitical private person, or "imbecile," which once merely meant a person weak or feeble in mind, and that for at least 1000 years.

In 2008, the film "Tropic Thunder" came out, to much positive acclaim. *Newsweek* (11 August 2008) devoted three pages to it, and called it the "funniest movie of the summer," plus many other accolades. The film is studded with obscenities, including the F-word, and also contains discourse on "retards." A real sign of the times is that the latter brought forth a firestorm of protests, even public demonstrations, but the F-word did not–

in fact, its use seemed to please progressive minds, and add to the positivity of their reviews.

*For hundreds of years before the term "mentally retarded" arose, people in the watch-and-clockmaking business were concerned with regulating timepieces so that they would run neither too fast nor too slow. On the regulator were the letters R and A, R standing for (French) "retarder" and A for "avancer." A slow timepiece was said to be retarded, and needing to be advanced. We still speak of "advancing" the clock in Spring, but no longer of retarding it in Fall. Instead, we use the term "setting it back."

*In 2009, the members of the association started by parents of retarded persons in Jefferson County (Louisville), Kentucky (US) were asked whether they wanted to change the name of their organization, the Council on Mental Retardation. One member said that it should be changed to the Council on Developmental Delays–as if this meant something different than mental retardation (*Hope, Vision, Voice* [newsletter for the Council on Mental Retardation], June 2009, p. 8). People's language craziness, and lack of critical thinking, is amazing.

*The term "mental retardation" has just about bitten the dust–and what have we got instead? Intellectual disability, developmental disability, mental challenge, learning difficulty and cognitive disability. A funny thing happened on the way to "cognitive disability": we picked up "Alzheimer's," autism and brain injury on the way. For instance, in September 2008 there was a conference on "Cognitive Disability: A Challenge to Moral Philosophy" that dealt with "Alzheimer's, autism and 'mental retardation'." This image-links mental retardation with dementia and senility. Is this a step up?

*From the beginning of the "discovery" of what was long known (since 1866) as Mongolian idi-

ocy or mongolism, there had been a debate as to what to call it. One early name suggested by Edouard Seguin had been furfuraceous cretinism (in the 1840s), another was Kalmuc idiocy (in the 1870s). Proposals to call it Down's syndrome seem to have come relatively late. Then at the 18th General Assembly of the World Health Organization in 1985, the syndrome of "mongolism" was referred to in one of the sessions. Up sprang delegates from Mongolia who protested, and that turned the tide to the adoption of the term Down's syndrome, and more recently (and illogically) Down syndrome. Now we discover that there are actually people whose last name is Downs, a businessman in Syracuse, New York (US) being an example. When a medical condition is named after one of these people, it will presumedly be called either Downs' syndrome or Downs syndrome. Also, anyone who is a member of the Downs family is a Downs person.

The term Down's syndrome is much less image-jeopardizing than the term Down syndrome, because up and down are polarities, with "down" having a negative image–more negative than Down's, which is not as readily perceived as the lower end pole of a vertical continuum, but looks instead like the possessive form it is meant to be.

The term "down" acquired even greater negative connotations in mental retardation once the mental age and IQ were invented, that gave "up" and "higher" positive connotations, and low, lower, down, etc., a more negative one.

A body of research has found that at least in Western society, ideas about God, heaven and goodness are linked to the spatial concept of "up," and ideas about the devil, and hell and badness, to "down." This is as true of irreligious as religious people, and is deeply embedded in the collective unconscious. When viewing pictures of people on a TV screen, viewers even judged those seen in the upper half as more likely to believe in God than those shown in the lower half (*Monitor on Psychology,* November 2007, p. 10). All this is a good reason not

to associate devalued people with the notion of "down" and "downwards."

Just how unthinking it was to change Down's syndrome (with the possessive s) to Down syndrome (without it) is illustrated by the fact that the media (e.g., *Washington Post*, reprinted in *Syracuse Post-Standard*, 12 April 2008, p. D4) have begun to refer to "Down babies," which is infinitely worse than "Down's babies." Maybe a Down baby should be put down, but one does not as readily think of putting down a Down's baby. Also, even many language fanatics who are so proud of, and militant about, using "people first" grammar and the term Down syndrome, and who keep correcting other people's language, think nothing of referring to such children as "Down babies" or "Down persons." Even the very politically correct *Newsweek* (15 December 2008, p. 60) referred to the "Down population" and to "Down activists," which is a bad-imaged language convention (showing that the PC phrasings are empty knee-jerks), and which raises questions as to what Up populations and Up activists are.

A Note on the Word 'Compensate'

The 'Conservatism Corollary' of Social Role Valorization (SRV) teaches that "it is particularly important to positively compensate for a party's impairment, devalued status, or what we call 'heightened vulnerability' " (Wolfensberger, 1998, 124). This is a key concept in teaching SRV. It is applicable broadly in implementing SRV: at the individual and group level, in image and competency enhancement, in crafting new valued roles as well as shoring up existing valued social roles, in eliminating or minimizing the effects of devalued roles, etc.

In longer SRV workshops, typical metaphors and images used to describe heightened vulnerability include that of a devalued person or group being loaded down by bricks, to the point that even a bit more weight can become the 'straw that broke the camel's back.' Accordingly, the conservatism corollary is often imaged graphically as removing bricks, building in external supports (like tying balloons to the bricks to lighten the load), and helping the vulnerable person become stronger ('adding muscles') so they are better able to bear their devaluation (i.e., the load of bricks).

The verb 'compensate' can mean to counterbalance, make up for, or make amends for. The British historian and novelist James Anthony Froude, in his *Life of Caesar* (1879), wrote that "skill might compensate for defective numbers." In this example, the idea is that the skill of Caesar's army could make up for or counterbalance their small numbers.

The word compensate derives from a Latin verb, compensare, which means to poise or weigh several things with one another.

In psychology, compensate can also mean "to conceal or to counterbalance a defect of character, physique, etc., or to make up for the frustration of a tendency or desire, by developing or exaggerating some other (sometimes more desirable) characteristic." Note by contrast that SRV stresses *positive* compensation for *devalued status*. The idea is to develop positive image and competency characteristics to help address the particular vulnerabilities of an individual or group. These characteristics may be internal to the person as well as external helps.

Related words include compensator (a person or thing that compensates). Synonyms include counterpoise and countervail.

Source information from the Oxford English Dictionary.

*Miles, M. (1995). Disability in an Eastern religious context: Historical perspectives. *Disability & Society, 10*, pp. 49-69. In the Indo-Aryan languages, it was common to refer to impaired and devalued people with rhyme words, and that may be the origin of the same custom in today's Indo-European languages, exemplified in English by silly Billy, howdy-doody, ninny, nitwit, nignog, etc.

In some Asian cultures, a child might be given a very negative name, such as perhaps "shitheap." This was done in order to trick demons into leaving the child alone.

*At politically correct universities (which means almost all of them) in Ontario, students may now (since at least 2008) be designated as "facilitators," who are to go around the campus and the community and listen for any use of terms about devalued people that are considered politically incorrect or not progressive. If they hear such, they are to instruct the people who use them. The term "facilitator" is deceptive, considering that this is actually a form of legitimized eavesdropping, spying or even language police, and is not far removed from the widespread practice under Communism of having everyone spy on everyone else for offenses against the party line.

At any rate, some language conventions concordant with Social Role Valorization would be deemed politically incorrect.

*It seems that we first heard the term "gravely disabled," with its death images, in the 1970s, and only rarely since–until poor celebrity Britney Spears was described as "gravely disabled" by the shrinks at the University of California at Los Angeles Medical Center. It did not help that the police department, while taking her there, radioed "the package is on the way," with its objectifying connotations (*Newsweek*, 11 February 2008, p. 23).

*In 2008 (if not earlier), the National Reye's Syndrome Foundation in Britain used a logo showing a boy and a girl, each with a hole in both the head and the torso, signifying that the disease affects the brain and the liver.

*We are very fortunate that the disastrous respiratory disease that broke out in a hotel in Philadelphia in 1976 happened during a convention of the American Legion; otherwise the Legionnaires' Disease might have been named the Bar Association Disease, the Elks or Moose Disease, the Medical Association Disease, etc.

Naming of Persons

*SRV teaches that a balance needs to be struck between not negatively imaging a party via terminology, while also not being deceptive or uncommunicative where communication is relevant. Language ideologues (including ordinary misguided people) are beginning to tilt the language to avoid all references to anyone doing or being something that is devalued by at least a segment of the population. For instance, a letter to the Syracuse, New York newspaper, signed by many people, objected to the newspaper referring to a physician who does many abortions as an "abortionist." The newspaper replied that the term was "technically correct," but agreed it should not have been used because it has "pejorative connotations" (*Syracuse Post-Standard*, 7 June 2009, p. E3). There are innumerable terms, adjectives, appellations, etc., in any language that would be considered pejorative by some people, but neutral or positive by others, especially in a pluralistic society. If the PC logic above were implemented across the board, one would no longer use the terms "Jew," "Christian," "politician," "fundamentalist" or even "street cleaner." It would be hard to argue that there is any SRV warrant in such a language strategy.

*Adrienne Asch of Yeshiva University, a "pro-choice feminist" and "bioethicist," spoke in Syracuse in February 2009. A news item about her talk used the peculiar phrasing that parents "routinely select against embryos and fetuses expected to become children with disabilities" (*Syracuse Record*, 23 February 2009, p. 4). Here we go again: the

PC convention of using the phrasing, "children with disabilities," is meticulously observed, while referring to unborn such children as embryos and fetuses, and to killing them as "selection."

*The Jewish name Schlemiel or Schlemihl means as much as Theopil, i.e., friend of God. It was a name often given as an epithet to awkward, bumbling or unlucky persons who never seemed to succeed at anything in the world. The idea was that God must have a special love for such people. The Franco-German writer Adalbert von Chamisso (1781-1837) entitled his highly-acclaimed and much-translated novel about a man who sold his shadow to the devil Peter Schlemihl, which popularized the term.

*Names given to children convey images about them. Consider the image of a name such as Lolita, Caesar, Hercules or Lulabelle. Woody Allen (not a good name to give to a child) speculated that people with certain given names would have trouble becoming Supreme Court justices or presidents. In fact, there have been studies that showed that some employers will select or deselect certain job candidates for interviews on the basis of their first names. In Germany, children have now been getting names of objects, such as Joy-Zoe, Marlin-Finn, Nevio, Pepsi-Carola, etc. The Germans coined a word for this: "Kevinism."

*On the one hand, political correctness tells us that we must refer to people in whatever terminology they demand to be referred to, but on the other hand, many countries (and states) have laws that forbid naming children by names that stigmatize them. In New Zealand, authorities prevented parents from naming their children Fish and Chips, and Sex Fruit, though Number 16 Bus Shelter slipped by them, as did Talula Does the Hula From Hawaii. Talula was so embarrassed she never used her real name, but told people to call her "K" (*Syracuse Post-Standard*, 28 July 2008, p. A2). Aside from deviancy-imaging,

we would also put such naming into the category of child-junking.

*A study in *Social Science Quarterly* claims that people with less popular first names are more likely to end up in prison (*Time*, 7 December 2009, p. 71). This could be an artifact of more "blacks" committing crimes, since, around the 1960s, they began to be given unconventional names. If it were true, it would say a lot about names raising expectations that become self-fulfilling.

*The parents of a child with Down's syndrome referred to her as Jo-Jo (*Speak Out*, March 2004), which is very problematic in that for generations, Jo-Jo was the name given to a type of freak (the "dog-faced boy" or "dog boy") on the sideshow circuit.

*We suggest that readers give some thought to the difference between saying that somebody "has x" versus that somebody "is x," as perhaps in "he has autism" versus "he is autistic," or "she has dyslexia" or "is dyslexic." "Has" subtly implies the presence of a disease or medical diagnosis; "is" seems more descriptive. "Has" also implies the need for others to "intervene," which is much less implied in "is." Compare these phrases: "So-and-so has stinginess" versus "so-and-so is stingy." Perhaps someone would like to write a lengthy analysis of this issue for this *Journal*.

*Leland, J. (2008, October 27). In "sweetie" and "dear," a hurt for the elderly. *The New York Times*. We have always been a little touchy about calls for "research evidence" to support the claims of SRV, because the research is vast–mountainous, even–but rarely contains references to role-valorization, devaluation, deathmaking, image juxtaposition, etc. As noted at the beginning of this column, this column is intended in part to point out research evidence for SRV's claims. This newspaper article reported on research out of Yale University on the effects of belittling forms of address–called "elderspeak"–on the life expectancy

of older people. It found that older people who receive negative images of aging, including those conveyed by elderspeak, perform worse on memory and balance tests, show higher levels of stress and depression, have worse health over time, and become more dependent. In contrast, those who are exposed to positive perceptions of aging live 7.5 years longer.

*We noticed that in some professional journals, what used to be called experimental subjects, and abbreviated Ss, are now referred to as "targets" (e.g., *AJIDD*, March 2009), for which as yet there is no abbreviation. (The equivalent abbreviation would have been Ts.) Are targets an improvement over subjects?

*A humor columnist (Dave Barry) has poked fun at the supposedly "inclusive" and oh-so-progressive left on the political spectrum, who nonetheless interpret those on the political right as "ignorant racist fascist knuckle-dragging NASCAR-obsessed cousin-marrying road-kill-eating tobacco-juice-dribbling gun-fondling religious fanatic rednecks;" and at those on the political right who interpret the leftists as "godless unpatriotic pierced-nose Volvo-driving France-loving leftwing Communist latte-sucking tofu-chomping holistic-wacko neurotic vegan weenie perverts" (*Newsweek*, 31 December 2007 *&* 7 January 2008, p. 60). While this is virtually a worst-case of image degradation via language, it also illustrates a point underlying SRV, namely that stereotypes tend to have at least a kernel of truth to them. ❧

Wolf Wolfensberger, PhD, is Professor at Syracuse University & directs the Training Institute for Human Service Planning, Leadership & Change Agentry, Syracuse, NY (US).

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