
REVIEWS

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

Reviewed by Jack Pealer

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

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

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

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

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

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

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

dozens, if not hundreds, of other citizens. Which brings me to ...

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

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

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

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

In *The Timeless Way of Building*, Christopher Alexander wrote: “We must simply accept the fact that in the process of evolution, there is no final equilibrium. There are passing phases which approach equilibrium, but that is all. The search for equilibrium, the brush in the dark with a moment of stability, the wave which hesitates a moment before it crashes into the sea again -- that is the closest constancy will ever come to being satisfied.” Those of us who seek a bit of rest amid chaos take little comfort from Mr. Alexander’s words. He wrote,

though, as an architect about buildings and about the “languages” that, he says, lead to the growth of good buildings and good towns -- places that contain and promote life. Those “languages” change, inexorably, restlessly. Perhaps the growth of what we call “community” proceeds with similar restlessness. Community -- people together -- always evolves. Perhaps we can only see the changes at certain times that Mr. Alexander calls “moments of stability” against which we brush in the dark. If that’s so, then *Waddie Welcome and the Beloved Community* reveals one such moment - - the crest of a wave against a turbulent sea. For a magnificent instant, the community we look for -- the beloved community -- reveals itself. Get a copy of *Waddie Welcome and the Beloved Community*, and go there.

Endnote

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

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

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

Reviewed by Jan Doody

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

This is also what it's like to be Christopher. He is a special education student in a segregated school in a suburb of London. He has a pet rat named Toby which is the closest he comes to having a friend. He often finds the world so confusing and difficult to cope with that he hides in a closet, rocking and groaning. He lives with his father who is often impatient with him (and pretty confused about the world as well). He has lost his mother and as the novel opens, Christopher has discovered the murdered body of his neighbor's dog.

The Curious Incident of the Dog in the Night-Time is that rare book that captures with sensitivity, accuracy and quite a lot of humor, the thought processes of a person with a disability. In this case, the disability is "high

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

THE AUTHOR of *The Curious Incident of the Dog in the Night-Time*, Mark Haddon, teaches writing and is a poet, novelist and illustrator living in Oxford, England. His work as a teacher of students with autism informed him about the particular and at times peculiar traits of autistic children. This novel has broad appeal and due to its narrative style, is appropriate for young readers as well. *The Curious Incident* tells a fictional story, that of a young man, his struggles to survive in the midst of a disintegrating family, his attempts to keep himself safe while surrounded by myriad unfamiliar and scary phenomena, and his self-

styled mission to solve the mystery of the dead dog. Its value as a study of social roles is in the inferences one makes from Christopher's descriptions of his home life, his school life, and his forays into his neighborhood and beyond.

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

Of all of these roles, the one of "person with a disability" is the most life-defining for Christopher. While some might question if he indeed even has a disability or is the victim of the social construct of "autism," Christopher is beset with a great number of challenges and is forthright in telling the reader about them. "I make this noise (groaning) when there is too much information coming into my head from the outside world" (p. 7). "I find people confusing" (p. 14). "These are some of my Behavioral Problems: A. Not talking to people for a long time. B. Screaming when I am angry or confused. C. Smashing things when I am angry or confused. D. Groaning. E. Not liking yellow things or brown things and refusing to touch yellow things or brown things. F. Doing stupid things [like emptying a jar of peanut butter onto the table in the kitchen and making it level with a knife so it covers all the table right to the edges]" (pp. 46-47). There are also passages in which he explains how his mind works as a recording device and how he uses reasoning skills to solve math problems. This constellation of characteristics is consistent with current thinking regarding the diagnosis of autism. Christopher sees himself as someone hampered by his inability to understand social rules while relying on his highly developed reasoning skills to make his way in the world.

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

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

What Haddon fails to do, however, is to critique the segregated circumstances of Christopher's life. His enrollment in a segregated school is presented as a given with no other options mentioned. While Christopher talks about going on to college, one is struck by the fact that as a fifteen-year old, he has one teacher in a special class with a curriculum focusing on behavior management and the acquisition of "social skills." This reinforces for the reader that students with Christopher's combination of skills and deficits can only be

taught in segregated settings. His lack of meaningful unpaid relationships is also striking. Christopher's attachment to his pet rat is used as a way to describe his devotion to others, yet the only people in the novel who seem to care about Christopher are his parents and his teacher. This also reinforces the notion that someone like Christopher is unworthy of friendship.

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

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

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

Reviewed by Norberto Alvarez, M.D.

THIS 100 page monograph started as a 22 page appendix in *The New Genocide of Handicapped and Afflicted People*, written in 1987 by Dr.

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

The introductory chapter defines this monograph as "a set of guidelines that can be given to a prospective hospital patient, and/or to the person's family, friends and allies, especially where the patient is a member of a group or a class that is societally disadvantaged, or generally held in low esteem" (p. 2). Even though the guidelines are based on the above-mentioned SRV approach, the reader will not find in this book a detailed description

of the theoretical basis of SRV theory. This will be found in other books written by Dr. Wolfensberger, or other professionals associated with his work, that are mentioned in the references at the end of the *Guideline*.

THIS MONOGRAPH is mostly the practical application of what the analysis of hospital care, under the scrutiny of the SRV principles, teaches regarding the deficits of the care provided, especially to devalued people, and how to avoid or at least to minimize these deficits. However the concepts of SRV, as expected, are present in the different sections of the book. For example in the section about “Enhancing and Monitoring the Quality of Medical/ Nursing Care,” one of the issues addressed has to do with “imaging” the “look” of the patient. The reality of imagery is one of the themes of great relevance in understanding and applying SRV. The way people see you affects the way they value you. Improving the appearance (via shaving, grooming, washing, providing good clothing) of the patient makes the patient more valued in the eyes of the attending personnel. “Humanizing” the relationship between care providers and the patient by describing his/her interests, achievements and skills; keeping pictures of the patient when he/she was in good health; seeing that the patient receives get well cards, flowers and the like would result in a positive impression. Such efforts help support hospital patients to be in valued roles.

I STRONGLY AGREE with the statement under the “General Considerations” section that “The single most effective strategy for protecting the health and well-being of a hospitalized person is to have at the patient’s bedside at all times a competent and vigilant person who is committed to the defense of that patient’s welfare and life” (p. 18). As a Medical Director of an institution for persons

with developmental disabilities, I can testify to the importance of having a person at the bedside during the entire length of the hospitalization. The book is also very useful and explicit in the characteristics, training and role of these advocates/protectors. This is an important and very useful contribution. The book provides guidelines that cover from what to do before the patient is admitted to the hospital to how to prepare for the discharge from the hospital and the return of the patient to his/her home. These sections, presented under “Measures to Prepare a Patient for Hospitalization or Visits to an Emergency Service” and especially the guidelines presented as “Suggested Guidelines for Carrying Out the Functions of Advocates/Protectors” are very detailed and are worth reading by those who care for individuals that need hospital care.

It would be too long to comment about each particular section, however it is worth expanding the discussion of some of them. While not against the use of mind drugs or restraints, the section on “Monitoring the Prescription (Mind) Drugging of the Patient” alerts advocates about the premature and inappropriate use of these procedures, a real risk, especially for people with developmental disabilities. The section “Special Considerations When the Patient Appears to be Nearing Death, or is Interpreted as Dying or as Lacking ‘Quality of Life’” addresses issues that have received a lot of attention by Dr. Wolfensberger and his associates (Wolfensberger, 1994; Wolfensberger, 2005). The perception that persons with disabilities have a “quality of life” that is poor to start with, and is much poorer when they are sick, might lead to early implementation of “Do Not Resuscitate” orders that could result in early discontinuance of treatments, which could then hasten death. For example, the discontinuance of nourishment or liquids which the *Guideline* presents as “being justifiable in

only **extremely** few cases: (a) when the provision ... is itself very harmful, and maybe even hastens death; and (b) when it is intolerably invasive or torturous **to the patient**" (p. 73). Probably the statement "When in doubt, opt for treatment and life" (p. 75) in this section is a short and concise summary of the philosophy underlining the efforts of SRV advocates in this area.

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

I FOUND these guidelines very useful. They are written in a way that is very simple to understand, there is an order in the presentation, and each section can be read independently. Persons responsible for the care of people that require (frequent) hospitalizations, independently of the presence of developmental disabilities or not, will find these guidelines extremely helpful.

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

are remnants of old editions of the *Guideline* that will be updated in the future.

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

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