

## Briefly Reviewed

### Review of “Agenda for Real Life”

Eastes, S.E. (1994). *Agenda for real life: A blueprint for daily living programs in our communities*. Louisville, KY: Advocado Press.

Review by *Susan Thomas*

This book might be useful to parents, direct care-giver personnel with limited advanced training or at entry level positions, members of so-called “circles of support,” and similar people involved in the lives of handicapped adults. It deals with what handicapped adults do in the daytime, including in vocational and so-called “daily living” programs. The author cites normalization and SRV as being fundamental to good service, and addresses the following four SRV elements in some detail: integration, individualization, age-appropriateness, and the developmental model.

### Review of “Down Stairs that Are Never Your Own”

O’Brien, J. (1994). Down stairs that are never your own: Supporting people with developmental disabilities in their own homes. *Mental Retardation*, 32 (1). pages 1-6.

Review by *Raymond Lemay*

Many people know of John O’Brien and the important work that he has done in the training of human service professionals to provide better services to devalued persons.

In this article, O’Brien describes compellingly what it is to be a “tenant” or “home owner” and the difficulties associated with achieving tenancy and home ownership within the present human service system structure.

He discusses the dangers associated with charting a new course for residential services. As he states, “enthusiasm might dump those individuals into squalid and dangerous dwellings in the name of getting people into their own places...” (page 2). And, of course, others still might simply relabel existing facilities as private homes.

O’Brien goes on to describe the three dimensions which may serve as a litmus test of “home.”

- a) Sense of place - “Individuals with a sense of place comfortably inhabit and personalize their homes” (page 2). “The threshold captures the essence of a sense of place in that it separates an inside that belongs to and defines dwellers from an outside” (page 2).
- b) Control - “Individuals have control of their homes when they have a choice in selecting the place that they live and the individuals that they live with” (page 3).
- c) Security of place - “Individuals who invest in owning their own home occupy a valued social role. Homeowners have more opportunities to increase their material wealth than do tenants with similar incomes” (p.4).

From an SRV perspective, we would argue that all the points above are subsumed within the roles of tenant and home owner. As O’Brien points out, the role of homeowner is more valued than that of tenant.

O’Brien proposes that those interested in pursuing the goals of establishing these important roles will work on three fronts. a) “They will separate support services from facilities,” b) “they will work with

individuals with disabilities in their families to devise ways to increase the material resources at an individual's disposal," and c) "they will seek out and join with other concerned citizens to create a variety of public and civic association approaches to ensuring a decent standard of affordable housing" (p. 5).

O'Brien does not back away from discussing how all of this will apply to even individuals with great cognitive limitations. As he states, some individuals will need assistance for facilitation or guardianship. "Although individuals with profound cognitive disabilities live every minute with the decision others make, they can live in their own homes" (p. 4).

This is certainly an article well worth reading and useful as a resource when teaching about SRV.

## Review of "Impact of Federal Regulations"

Holburn, C.S., & Jacobson, J.W. (1993). Impact of federal regulations on desired processes and outcomes in public residential facilities: National perspectives. *Journal of Developmental & Physical Disabilities*, 5(2), 109-120.

Review by *Wolf Wolfensberger*

Almost 2500 employees of all levels of so-called "Intermediate Care Facilities for the Mentally Retarded" in the US were given questionnaires meant to assess their opinions of how federal regulations impacted on eight service processes and six service outcomes that were assumed to be desirable. One of the processes reported to be most detrimentally affected by the regulations was "normalization." At the same time, "innovation" and "normalization" were ranked first and second among the eight processes that were believed to predict service outcome. In other words, the personnel surveyed here viewed federal regulations as highly detrimental to the most desirable outcomes of their services.

## Review of "Social Integration in Barbados"

Goardt, Ann; (1986). Social Integration of the physically disabled in Barbados. *Social Science and Medicine* 22 (4) 459-466.

Review by *Raymond Lemay*

The author's starting point is the 1981 document on world disability, prevention and rehabilitation which made the claim that social integration of disabled persons is widespread in developing countries often due to deep rooted fears or beliefs originating from age-old cultural and religious convictions. This study using participant observation of 30 physically handicapped individuals in Barbados, a developing country, contradicts these claims. Though these physically handicapped individuals showed some competence in accomplishing mainstream adult roles such as in schooling, employment, contribution to household, sexual relations, relationship and parenting, they had little ongoing access to these roles as a whole and reported less than normative social interaction with other people. Their social networks were quite limited and they lived fairly isolated lives. This despite the fact there were very few formal services for these handicapped individuals. In such circumstances, where the community has not yet been "perverted" by formal services, one might have expected more participation and inclusion.

The findings, of course, were not analyzed for any statistical significance nor are comparative data offered for able bodied Barbadians. The results are nonetheless striking. It is of course possible that the social participation of disabled individuals in Barbados is higher than in developed countries but it is impossible to make the claim based on this data that social ostracization is an artifact of the formalized

service systems. Rather, the author suggests that Barbadians have lower expectations for disabled individuals and are less likely to interact with them. The author concluded that the lack of social integration in Barbados and in developed nations demonstrates that cultural perception of the disabled can limit their participation in normative roles. To insure the social integration of disabled citizens, one must address perception of the disabled as well as the physical impediments imposed by disabilities.

## Review of Housing and Supports for Persons with Mental Illness

Carling, P.J. (1993). Housing and supports for persons with mental illness: Emerging approaches to research and practice. *Hospital and Community Psychiatry*, 44(5), 439-449.

Review by *Deborah Reidy*

There is little concordance between Social Role Valorization theory and many of the values and practices of traditional mental health service delivery. However, in the emerging field of what has been termed "supported housing," one can find a high degree of compatibility. The May 1993 issue of *Hospital and Community Psychiatry* contains a series of articles on housing and support services for people with mental illness. The majority of these were written at the request of guest editor Paul Carling, director of the Center for Community Change through Housing and Support, in Burlington, Vermont.

The Center has been a leader in research and policy development on the housing and support preferences and needs of people with psychiatric disabilities. The Center began jointly with the Boston University Center for Psychiatric Rehabilitation in 1984, and has been affiliated with the University of Vermont and then Trinity College since 1987. After initiating a study of consumers' housing and support preferences in Vermont in 1988, the Center continued to gather data from similar studies conducted in other states, and developed a data base of more than 4,000 journal articles and book chapters published over the past 15 years.

Many of the articles in the May 1993 issue of *Hospital and Community Psychiatry* draw upon this work. The cornerstone article is Carling's "Housing and Supports for Persons with Mental Illness: Emerging Approaches to Research and Practice." Companion articles include "An overview of surveys of mental health consumers' preferences for housing and support services" (Tanzman), "Implementing supported housing in state and local mental health systems" (Knisley and Fleming), "The psychiatrist's role in supported housing" (Diamond), and an editorial prepared by "Howie the Harp", entitled "Taking a new approach to independent living."

Supported housing, according to Carling, is organized around three central principles; consumers choosing their own living situations; they live in integrated stable housing, not in mental health programs; and they receive the services and supports required to maximize their opportunities for success over time.

Carling makes the case that there is a high degree of compatibility between the preferences of consumers and what we could recognize as some of the fundamental aspects of SRV; "...people with psychiatric disabilities generally want the same kinds of housing that other citizens want...most people with psychiatric disabilities...generally place the highest value on privacy and autonomy; prefer not to live with other mental health consumers, despite prevailing placement policies; want integrated housing; want mental health services but not on a live-in basis; and see a lack of income as a major barrier to achieving their housing goals" (p. 442).

Tanzman's article describes in more detail the preferences of consumers by summarizing the results of 26 studies conducted between 1986 and 1992 in 17 states in the U.S. Midwest, Northeast, West, South,

and in one Canadian province. The highlights of the findings are as follows:

1. A majority of consumers prefer to live in their own apartments or houses and not in residential mental health programs or facilities.
2. Most respondents would prefer to live alone or with a spouse or romantic partner or friends.
3. People preferred not to live with other mental health consumers.
4. Although people strongly prefer independent living arrangements, they also desired support from mental health staff, friends, and family.
5. People preferred support that was available on an as-needed basis, rather than those that were consistently available.
6. People needed more material supports, such as income, housing subsidies, transportation, and telephones. Success in their chosen housing situation had much to do with the availability of such material assistance (p.453).

While Social Role Valorization has often found little support within the “mainline” mental health system, it may find greater receptivity among its service recipients and those professionals who are listening to their preferences.

## Review of “Drugs: A Case for Normalization”

Engelsman, E.L. (1989, November). *Drugs: A case for normalization*. Paper presented at a conference of the Victorian Drug Rehabilitation & Research Fund, Melbourne, Australia, 10-12 November 1989.

Review by *Wolf Wolfensberger*

A most peculiar definition of normalization was given by Englesman (1989) from the Netherlands. In regard to drug control, he said that normalization means “a realistic and practical approach... and not...a moralistic and dramatized one” (p.3), and that it means that while drug use is not decriminalized, it is not treated as a “big deal” or as “deviant,” and thereby the users supposedly are enabled to see themselves as normal, and get treated as normal. The Dutch make methadone available free, and try to treat the problem as a medical/habilitation one rather than a criminal one.

## Review of “Putting People First”

Brandon, D., & Brandon, A. (1988). *Putting people first: A handbook on the practical application of ordinary living principles*. London: Good Impressions. (Distributed by Hexagon Publishing, Surbiton, Surrey, UK).

Review by *Wolf Wolfensberger*

This is an attempt at a simplified interpretation of normalization revolving around five “main principles aimed at the improvement of quality of service”: (a) increasing choices, (b) improving relationships, (c) increasing personal development, (d) extending integration, and (e) improving participation, by which is meant giving the participant more power, though this seems to overlap with the first principle. These five principles seem to be very much based on John O’Brien’s similarly-named “Five Accomplishments,” which are community presence (d and e), protection of rights/promotion of autonomy (a), developing competency (c), respect, and support for relationships (b).

It seems to me that these five “principles” are very debatable as to their optimality. Perhaps this is

because the monograph may be confused about whether it wants to emphasize how services can be better, or whether things that can be done in the lives of needy people are to be emphasized, even if there is no service or where the action takes place outside a service context. For instance, an obvious major emphasis could be personal appearance. With an emphasis on people action rather than agency action, one would also have wanted a simple format even yet more suitable for use by families. As is the case with so many “simplifications,” this one could certainly have been much simpler still if only more care had been taken with it.

## Review of “Normalisation: Theory and Practice”

Race, D.G. (1987). *Normalisation: Theory and practice*. In N. Malin (Ed.), *Reassessing community care* (pp. 62-79). London: Croom Helm. (Paperback edition issued in 1988)

Review by *Wolf Wolfensberger*

This is a very simple but well-written introduction to normalization for relatively naive readers. The examples and small charts are tilted toward a British audience, and well-chosen. The bulk of the article explains the seven themes taught by Wolfensberger, but the transition of normalization to Social Role Valorization is not mentioned.

## Review of “What if...facilitated communication”

Levine, K., Shane, H., & Wharton, R. (1994). What if...: A plea to professionals to consider the risk benefit ratio of facilitated communication. *Mental Retardation*, 32, 300-304.

Review by *Raymond Lemay*

The authors start by noting that most studies refute the notion that facilitated communication (FC) represents the unexpected thoughts of non-verbal individuals. “With only few exceptions, the authors of these studies have concluded that FC is not a valid means of communication” (p.300).

The authors go on to suggest that, even in the absence of proof, some methods of therapy might be used because they do no harm and, in a sense, they do have some positive impact.

On the other hand, they suggest that FC presents many risks to individuals with disabilities and thus should not be used until more compelling evidence of its usefulness and beneficence is provided. These risks include 1) the creation of a false persona and obscuring of the individual’s true personality, 2) non-preferred life changes, 3) the elimination of previously effective communication, 4) the delivery of inappropriate education and instruction, and elimination of appropriate instruction, and 5) a shift in the limited education resources away from essential services.

The authors also list risks of FC to families and teachers. These include 1) loss and disillusionment for parents, 2) guilt around previous interaction style, 3) rejection of important family members and teachers, 4) false abuse allegations, and 5) guilt, confusion and anger of facilitators who have been “debriefed.”

Finally, they note some important risks to society where there has been some improvement in the acceptance of individuals who cannot communicate. FC will further confuse the issue suggesting that all people can communicate, thus increasing the likelihood that we will not value those who cannot communicate. “As a society, we have come so far in learning to value individuals as equals regardless of cognitive or communicative skills” (page 304).

## Review of “Her shoes are brown”

Hicks, C., Leavitt, B., & Peacock, D. (1993). *Her shoes are brown and other stories*. Milverton, Ontario: Community Involvement Council.

This book has a companion volume, *Jumping the Gap: More Stories and Ideas*, by the same authors.

Review by *Susan Thomas*

This is a collection of stories by and about handicapped people in southwestern Ontario, most of them just a few pages long. The stories are told by the handicapped person him/herself, by some family member or friend, or by a service worker who is close to the person. Some of the stories tell of a person's woundedness, of institutionalization, of being liberated into a decent life in the community, of family conflicts and struggles, of parents' fears.

Some of the stories are very moving. Some are instructive in some regard. They all interpret handicapped people in positive ways, and help to underline what they have in common with other people, rather than their differences. The book might be useful as a resource for “wounds” presentations, for certain discussion groups or exercises at workshops, or for presentations to handicapped people and discussions afterwards.

## Review of “I’m not Handicapped—I’m different”

Candappa, M. & Burgess, R.G. (1989). “I’m not handicapped—I’m different”: “Normalisation,” hospital-care, and mental handicap. In L. Barton (Ed.), *Disability and dependency* (pp. 69-83). London: Falmer Press. (Disability, Handicap., and Life Chances Series).

Review by *Susan Thomas*

This chapter reports on a “participant observation” study done by the first author under the supervision of the second author at an institution for 125 “mentally handicapped” (probably mostly mentally retarded) people in England. The District Health Authority that ran the facility claimed normalization as its official policy, but recognized that normalization is often neither believed in nor implemented by those directly on the scene. The study shows that indeed many of the practices of the institution and its staff were far from normalizing, though it would be possible to incorporate much of normalization even into a very normalization-constrained setting such as an institution.

The authors cite Wolfensberger's publications in Flynn & Nitsch (1980 ) for their definitions of normalization, and unlike many other writers, do seem to show some understanding of what normalization according to Wolfensberger's formulation would imply. One error they make is to claim that changing the perceptions and values of the perceiver is accomplished primarily by minimizing the differentness of stigma or deviancy of a devalued party (p. 71), which is not quite true.

The authors note that the normalization principle assumes that “the people putting it into practice perceive the client group as valued” (p.73), which is another way of stating what SRV training has tried to make clear, namely, that a value decision has to be made first before one adopts SRV (or normalization).