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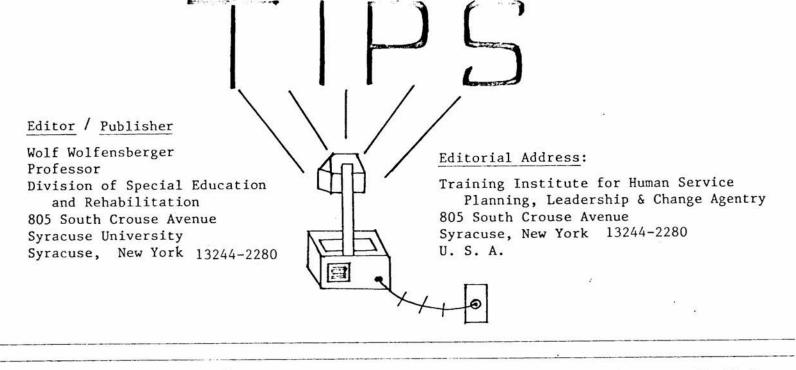
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Social Role Valorization

This issue will repeat part of the theme of the April 83 issue. It will cover Social Role Valorization (SRV) issues. SRV is the concept that has replaced normalization, as explained in several of our publications in recent years. (Send a self-addressed business sized envelope with 44ϕ stamp for reprints.) However, because of the wealth of material that has piled up, we will not be able to include imagery and language use issues (hopefully, this will make a separate issue) nor material on service evaluation, with PASS, PASSING, or otherwise. Fortunately, we have a bit more good news on SRV than we have on many other themes.

The Nature and Power of Social Roles

Social role enhancement/defense has been defined as the crux of SRV. Role expectations and signals are tremendously powerful in getting people to do things for better or for worse.

*In 1949, a mentally unbalanced veteran, Howard B. Unruh, killed thirteen people in a mad rampage on the streets of Camden, NJ and then returned home. Police opened fire on his home with machine guns, shotguns, and tear gas bombs. An editor on the Camden <u>Evening Courier</u> who was covering the case looked up Unruh's name in the telephone directory and rang him up. Unruh stopped firing and answered, "Hello." "This Howard?" "Yes..." "Why are you killing people?" "I don't know. I can't answer that yet. I'll have to talk to you later. I'm too busy now." (Carpenter, E. (1970). <u>They became what they beheld</u>. New York: Ballantine Books.) This episode underlines the power of role habits. Who can resist the role demand of a ringing phone?

*Also, how one will be treated will depend largely on the role(s) one is seen as holding, and how valued these are seen to be. For instance, as told in the second volume of her autobiography, <u>Angel at my Table</u>, the New Zealand novelist Janet Frame was forcibly placed in a psychiatric institution early in her life, subjected to electric shock treatments and was just about to be lobotomized when she was saved by the announcement that she had won a literary award (<u>Canadian</u> <u>Human Rights Advocate</u>, Winter 84). This episode once more underlines that so commonly, the only thing that prevents one from being abused is being perceived as holding at least one valued social role. *Fort Worth's very own captain of Koepenick. There was an electrical failure at the John Peter Smith Hospital in Fort Worth, TX. A young man being treated in the psychiatric ward of the hospital calmly donned a physician's white coat and began to issue orders to the staff. For two days, he ran the hospital. The fact that this happened on a weekend when many regular personnel were absent probably contributed to the fact that no one raised the least question about the authority of the young "intern." In addition to the fact that he did a "super job," he even rendered an account of the situation to a member of the board of directors of the hospital. Additionally amazing is the fact that this news item was apparently not widely disseminated in the American press (Journal de Montreal, 8/7/81; submitted by Ray Lemay).

The Power of Role Casting Positively Exemplified

*When D'Ambrosio was a child, he was put in a special class for the retarded. Because an adult took a special interest in him, his native capacities were both discovered and cultivated so that eventually he became a psychiatrist. In turn, in his later work, he encountered a 12-year old girl, Laura, who was deformed, had been most brutally abused, and was considered retarded. One of her teachers was convinced that she had unactualized intelligence, and he worked with her for 2 years before he began to see results. Suddenly, she began to blossom and to overcome her retardation as well as some of her psychic wounds. Eventually, she graduated from a program in nursing for infants and children and got a job at an institution for handicapped children. The story was told by the psychiatrist in a 1970 book, entitled <u>No Language But a Cry</u>. It dramatically underlines both the importance of positive role expectancies and relationship fidelity and continuity.

*A great example of not only positive role casting but enhancement of role performance is the following vignette. In 1984, 34-year old Scott Wagoner who had Down Syndrome could barely run a hundred yards. In 1985, he ran from the Statue of Liberty in New York City to the Liberty Bell in Philadelphia in 17 days, or an average of 17 miles a day. He was trained to do this by David Nathanson, a passionate runner from Miami (Footnotes, Fall 85).

The Power of Role Casting Negatively Exemplified

*When a male impostor telephoned over fifty women, telling them he was their husband's psychiatrist and that it was very important that they recruit strange young men off the streets and have sex with them in order to save their marriage, 10% of the women complied fully or in part. He also allowed that the hunband's problems had brought him to the brink of suicide, and that it was urgent that the wife comply. As instructed, they called the "psychiatrist" back, reporting either that they were unable to recruit any volunteers for the job, or that they had succeeded and were awaiting further instructions, which the 'psychiatrist" gave over the telephone to the copulating couple (UPI, in <u>Syracuse Herald Journal</u>, 30/10/81).

*A mentally handicapped woman had been attending social gatherings of blind and visually impaired people on a regular basis. Although she was capable of using public transportation, she had been using special transportation for handicapped people to attend these functions. One day, she told the staff at the group home where she lived that she too was blind--although her only vision impairment was that like many people, she needed to wear glasses to see things a little better.

There are at least 4 dynamics which may help explain what was going on. (a) Because she was more intelligent than many of the retarded people in her residential community, she wanted to break out of the retarded identity, but was

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constrained from declaring herself "normal" by the reality of some mobility impairment and her social dependency. (b) Because she was spending so much time with blind people, apparently having a good time, and developing relationships with them, she was probably beginning to identify with them. Via identification, and desires to assume a more "glamourous" handicapped identity, she may literally have come to see herself as blind, and to cast herself into the blind role. (c) Since she was spending so much time with these people, she was at risk of beginning to imitate various of their behaviors, which would of course include their blindness. (d) She may have perceived some benefits to the blind role, and desired these, just as do people who have been cast into the negative role of eternal child. She may have been reluctant to move out of it into much more valuing, but much more challenging and demanding, adult roles. In the same way, this woman may have seen the various benefits of the blind role, namely, being able to participate in these social functions, being more like the people that she had begun to identify with, etc., therefore desired to be cast into the blind role.

*Robert Williams, who has a bachelor's degree in urban affairs from George Washington University, has worked for the US Senate Subcommittee on the Handicapped and for the court monitor overseeing the closing of Forest Haven, the institution for the retarded of the District of Columbia. Yet every once in a while, when leaving an institution where he has been monitoring with his colleagues, staff members have rushed up to him, grabbed him, and said something to the effect that "you can't go with these people. You have to go back to your ward now." The reason for their peculiar behavior is that Williams is cerebrally palsied (TASH Newsletter, 9/85).

*A striking contrast between what Social Role Valorization can offer to handicapped or otherwise societally devalued people and what the human service empires of the world offer them was provided by an article which took up the entire issue of the July/August 1984 <u>Psychiatric Aspects of Mental Retardation Reviews</u>. It was devoted to role playing as a therapeutic approach with the mentally retarded. Social Role Valorization seeks to embed people in valued roles, while particularly the mentally-oriented human service sectors offer "role playing," almost invariably in artificial settings.

Other/Mixed Illustrations of Role Power

*A baby was born with Down Syndrome, and the physicians recommended that the parents institutionalize her. They refused and took her home, but they did believe those who told them that she could not learn, or at any rate would never learn very much. Thus, they made no efforts to enroll her in an education program when she was very young. Furthermore, they rarely went out, because they were afraid to leave their little girl with just any sitter, and so came to rely entirely on one older woman to watch her for them. One day, when the little girl was about four or five years old, there was an emergency which necessitated that the parents leave the house, but their usual sitter was not available to watch the little girl. The parents were forced to ask a teen-aged neighbor girl to stay with their handicapped daughter while they were gone (about two hours), the neighbor girl had taught their handicapped daughter to write her own name. (Item submitted by Joe Osburn)

*The parents of a boy with Down Syndrome in Wales stopped speaking Welsh to each other so that he would not be confused by bilingualism, and would learn English more readily. However, without being aware of it, they had continued to address their cat in Welsh. One day, to their amazement, they overheard their retarded son similarly telling the cat in Welsh to "Come here, Puss." The parents were incr**edulous**, but decided to go back to using Welsh, as a result of which their retarded son became bilingual in at least the everyday idiom (<u>Down's Syndrome News</u>, 1984, <u>8(6)</u>). *Much like deviancy, social status in general can be inherited across generations, even among animals. A study of female baboons showed that in adulthood, they attained a rank among other adults similar to that which had been held by their mothers (Science, 20/8/82).

The Power of Modeling and Imitation

We teach SRV via 7 themes, one of which is the tremendous power of modeling and imitation in shaping behavior to the better or worse. Several of the vignettes below demonstrate this truth rather dramatically.

*A study (Science, 8/10/82) demonstrated rather convincingly that even newborns only 36 hours old could tell the differences between various faces, and could imitate adults who expressed happiness, sadness, or surprise to the infant in their own facial expressions. The article was accompanied by rather startling pictures that showed a baby imitating a model. One of the things such research underlines (assuming that it is cross-validated) is that the power of imitation is thoroughly inborn in humans, and can be activated within hours of birth.

*In order to play the chimpanzees in the Tarzan movie, "Greystoke," a number of actors had to learn for 6 months to function like chimpanzees, going through an arduous regime which included spending a lot of time living with chimpanzees. After a while, some of the actors began to act like chimpanzees (such as baring their teeth or jumping up and down when mad) at times and on occasions when they were supposed to be humans--which shows the power of imitation, role modeling, and role expectancies (Newsweek, 26/3/84).

*There is an Australian punkish rock group called KISS. One of the KISS stars somehow manages to breath fire, so a 14-year old fan of the group filled his mouth with gasoline and spat it into a lighted match. His head blew up, and he was barely saved by emergency treatment, though leaving him with some serious scars.

*In Hamburg, Germany, the smoking behavior of students in some of the more advanced high school classes was studied. In one class, the main teacher and a few of the most popular students were smokers, and eventually almost the entire class ended up as smokers, some of them very heavily so. In a parallel class the only two smokers were unstable youths who were known to have very little willpower, and a nonsmoking teacher told the students how he gave up smoking by an act of the will. None of the other students took up smoking (Volkszeitung Tribune, 1/82).

*In October 1984, NBC television showed the film, "The Burning Bed," in which a battered wife set the bed in which her husband was sleeping afire. Within the next several days, several husbands and wives across North America did the same to their spouses.

*In 1870, the great French psychiatrist Charcot observed that when mental patients were assigned randomly to a ward for people with epilepsy, they began to display epileptic seizures themselves, These turned out to be "mock epilepsy," apparently induced by relentless modeling and the considerable human inclination to imitate.

Integration: Personal Social Integration (PSI) & Valued Social Participation (VSP)

We have declared PSI and VSP the essence of integration. Note how the term "mainstreaming" compares poorly with it, lacking all consensual definition, and being used so superficially.

Integration: Good News

*The inner eye, and the power of role expectancies. An interesting, and possibly model, integration project has been operated at York University in Toronto under the joint sponsorship of the National Institute on Mental Retardation. Eight children with a great variety of handicaps, and twelve non-handicapped children, got together regularly for an educational program from 10 a.m. to 4 p.m. every Saturday. Initially, the children were rather indifferent to each other, but within three months they began to form a caring, non-competitive learning community. Children who, in their weekday special education programs, had been essentially written off were found to have all sorts of talents, as exemplified by the following descriptions from the schools in which they are during the regular weekdays, and the descriptions of their talents and behaviors in the Saturday program. Thus, one 6-year old girl with Down Syndrome had been described as "incapable of working near the level of her classmates, has a very short attention span, and is only interested in playing with toys." However, in the York program, she was described as "a delightful and energetic child who is very strong willed (which serves her well). She is eager to hearn when material is of interest to her. She has been taught by the school how not to learn but she frequently 'slips up' with us and will read or count quite adequately! A 9-year old was described by the school as follows: "He has a severe spatial-perceptual handicap, and his disability will hinder his academic progress as he gets older." The York educators, however, believed "Mike is a shy child with a delightful sense of humour. If allowed to learn through auditory channels rather than visual, he shows the great extent of his potential." For more information, readers can address Profeser Marsha Forest, Special Education, York University, 4700 Keele Street, Downsview, Ontario, Canada M3J 1P3.

*In Vancouver, an 8-year old cerebrally palsied blind boy who has hydrocephely and epilepsy has been integrated into an elementary school class (The Human, No. 1/84).

*In a village in Sweden, all the children learned sign language because one child in the village had been deaf mute since birth. When the child became 11, all the adults decided to learn sign language as well (DPA, in <u>Amerika Woche</u>, 2/9/82).

*A study of 9 handicapped and 21 non-handicapped children mostly between the ages of 4-5 (Ispa, 1981) showed that handicapped children received more help and affection from age peers, and were more affectionate toward peers in turn than were the non-handicapped children. Teachers corrected the behaviors of the handicapped children more, and turned down more of their requests, but also gave more help and affection to them than they did to the non-handicapped ones. (All this seems to bear out the gentling impact handicapped people can have.) The non-handicapped children tended to seek out each other for more complex social play, whereas the handicapped ones did not seek out other handicapped children "on their own level," as is often claimed.

*To be a page in Congress is a very prestigious position. A 16-year old page serving Senator Chaffee from RI happens to have Down Syndrome, and another female teenager serving as a page in the legislature of VT also has Down Syndrome. It was said that no difference from other pages could be noted in her ability to perform her functions (<u>DSN</u>, 10/85).

*Mentor is a private employment service in MA that tries to place handicapped people. Some of its personnel have been to PASS training and have subsequently designed a large ad (positively juxtaposed to a Mercedes Benz ad) that appeals in an image-enhancing fashion to employers to engage in "job-sharing" where a nonhandicapped and a handicapped person work together, with the non-handicapped one receiving a stipend from Mentor for the assistance and supervision s/he provides. Concurrently, Mentor provides ongoing consultation and supervision. Participation costs a sponsoring employer nothing, and may increase the job satisfaction of employees in that they receive a stipend and the stimulation (or even prestige) of assuming a teacher role. (Source item supplied by Jack Yates)

*Japan has a law requiring that at least 6% of a company's work force be over the traditional retirement age of 55. Funds are available to help offices and factories to make architectural adaptations to facilitate the work of older employees (Aging, 1985, No. 348).

*In China there are factories with several hundred employees where half of the employees are handicapped, and the other employees function not only as laborers but also as teachers to the handicapped to enable them to operate all kinds of equipment, often to 100% of the norm or even better. Among other things, assuming that the information is correct, this underlines the power of culturally normative informal helping forms. Some Chinese officials claim that there are 1600 government factories in China for the handicapped, plus another 8000 run by collectives. (Source item from Chuck Burkhouse) However, we do not know whether these are also integrated or not.

*A survey (Margolis & Charitonidis, 1981) which found that apartment landlords were generally willing to have a retarded adult live in apartments advertised as available for rent strongly suggests that people are much less likely to object to an individual devalued person than they are to congregations of such persons in groups, such as group homes or institutions.

*In Beverly, MA, there is a karate class that includes about 25% young students with handicaps. The local newspaper showed a picture of the class where, without being identified as such, a student with Down Syndrome was also included (DS News, Summer 85).

*There are a number of agencies that try to bring handicapped and non-handicapped men and women together in a sort of dating service. The oldest organization is Handicapped Introductions in Coopersburg, PA. Another on is Independent Introductions in New York City (<u>CARC News</u>, 10/85).

*A survey of North Dakotans revealed that they were overwhelmingly in favor of all sorts of measures reflective of community integration of retarded people (<u>The Arc</u>, Winter, 1985).

Integration: Bad News

*Would you believe that in British Columbia, the Western-most Canadian province, the province's largest institution for the mentally retarded (Woodlands) sent 14 transit busloads of residents to an event called the CKNW Orphan's Fund Picnic. Two days later, Woodlands sent a block of 30 residents on a cruise armanged by the Royal Vancouver Yacht Club, on which groups of entertainers toured the boat both "singing and playing special songs for special people." These and similar events were interpreted as "normalizing experiences." On the grounds of the institution itself is a shuttle bus which is called the "Ravine Express," for which residents pay a token (Woodlands Newsletter, July 1981). It all sounds as if the Royal Canadian SRV Marines are badly needed to make a landing at Woodlands and establish a beachhead. Our advice is to also drop a contingent of SRV Paratroopers behind their lines and encircle them. *We have mentioned before that Hospital Audiences is a non-profit organization which, since ca. 1965, has brought generic entertainment performances to people in hospitals, institutions and prisons. Unfortunately, it has deemed it necessary to do so in a highly segregating and congregating fashion. For instance, in fall 1985, it held a concert dance by The Band in New York City for 1000 residents of state and private community residences. Unfortunately, among the songs played was "Up on Cripple Creek" (OMRDD Journal, Fall 85).

*An example of overloading of a social system occurred in Winnipeg when, for two years, a day program for mentally handicapped people sent a group of 20-28 people to a local bowling alley. The owner permitted the group to come bowl at 1/3 of the regular rate. While this went well for a while, when supervisors changed, the handicapped bowlers began to emit less acceptable behavior until a women's bowling league that used the same facilities at the same time complained. Rather than admitting the error of their ways, the agency took to the media and threatened a human rights complaint (Spring 84 Winnipeg News clipping, furnished by David Wetherow).

*A classical case of overloading of social systems occurred at the time of the 1980 federal elections when an institution drove two hundred mentally retarded people to be registered to vote--even though very few of them could read or write. During the voting itself, similar incidences were reported from elsewhere, with large numbers of retarded people being brought to polling places all at the same time, all of them voting excrutiatingly slowly and taxing the patience of the nonretarded citizens who were waiting to vote. It is quite common to hear such things done under the name of normalization.

*A most perverse interpretation of normalization occurred in New Jersey where the North Jersey Developmental Center (an institution for the mentally retarded) participated in the establishment of a junior women's club chapter consisting entirely of retarded women residing at the institution. While the chapter's membership in the larger junior women's club network is prestigious, its segregated nature appears to be totally unnecessary. Furthermore, it is perverse to claim that "the chapter gives the members an atmosphere as close to the community as possible and helps them to develop to the maximum potential," or that it "promotes normalization among members and links them to the community" as claimed by various enthusiasts. One would think that its 29 members could have been accommodated in an integrated fashion in a variety of community organizations. Furthermore, many people who have a lifetime of institutionalization behind them have speht decades of their lives living almost only with members of their own sex, and a sex-segregated community organization cannot automatically be assumed to be the best choice (New Directions clipping furnished by Edward Cohle).

*In the psychiatric department of the Syracuse Veterans Hospital, there was, until September 1984, both an open and a locked ward. At that point, some of the psychiatric nurses were transferred to the medical-surgical service where there was a shortage, and their duties apparently were felt not to be delegatable to anybody else. Accordingly, the open and the closed psychiatric units were "consolidated" into a single closed unit, so that merely for administrative reasons and staff convenience, people who were supposed to have been "treated" in an open atmosphere were now treated the same as those who were felt necessary to be confined. Accordingly, all sharp objects were taken away from them, they were locked out of their bedrooms during the day, the light got turned out at 10 p.m., and so on. One resident, a former prisoner of war, likened his new condition to that of his war time imprisonment. Some residents are said to have regressed as a result of the move. The administration was reassuring and said that they would be able to restart the open unit in "10 weeks at the most" (Syracuse Herald Journal, 9/9/84). This illustrates what we call the "lowest common denominator effect": in heterogeneous programs, the structure deemed needed for the least advanced members ends up controlling the entire setting.

*At one time, the League for the Hard of Hearing in New York City staged a dance every Thursday night. People from the Lighthouse for the Blind came to the dance, and one blind and one deaf person would dance together, with the blind person leading to the rhythm of the music while the deaf person kept watch so that they would not bump into other couples. (Source item supplied by Susan Ruff)

*In CT, near the Seaside Regional Center, there is a beach set aside for the handicapped, prominently marked with threatening signs. When a person failed to notice a sign and harmlessly stepped over the line, a watchful guard with a bullhorn suddenly materialized and barked a threatening order to the effect "you are trespassing; leave the premises at once," much as one might be accosted if one climbed the White House fence or wandered onto a military base.

*A proposal to place small numbers of homeless families in neighborhoods around New York City has generated enormous resistance, and in response, a councilman suggested that the homeless be put into a trailer park in a "bombed out" section of the city (UPI, in SHJ, 16/10/84).

*Most people who perpetrate segregation of societally devalued people at least mouth some support for integration. However, an article in the federal journal <u>Aging</u> (1985, No. 348) was totally upfront in advocating segregated housing of various types for elderly people, reviewed the rationales for it, and dismissed integration rationales as irrational, anti-empirical and "ideological."

Integration: Mixed News

*In Edmonton, there developed a segregated church specifically for the deaf and their families. At least at one time, its membership was 100. The church is tied in with an entire segregated network oriented to the deaf, including a ranch for the deaf and a group home for the deaf. This apppoach might be contrasted to that of a church in another city which for years has routinely had a deaf interpreter up front; where one of the pastors has learned a great deal of sign language, and several of the other pastors have learned some; where some other church staff have moderate sign language skills; and where a sprinkling of parishioners have a range of sign language skills, so that one can occasionally see them singing along in sign throughout the congregation.

*In Canada, the best predictor of whether a minority pocket of Francophones would assimilate with the surrounding Anglophone population was whether or not they had their own social institutions. French groups that had their own social institutions did not integrate themselves, while those without tended to be integrated and assimilated. Transferred to other social groupings, this would suggest that segregated groupings in which a devaluing characteristic constitutes a common bond are **a**pt to perpetuate the devalued identity of that group, and thereby its segregation.

*There was a very informative article on handicapped people working in food service operations in the No. 2, V. 9, 1983 issue of <u>American Rehabilitation</u>. A wide range of such gratifying work settings was reviewed, but what the article did not tell us was that these could be divided as falling into settings where the handicapped served food to other devalued people (e.g., prisoners), and those where they serve valued people, as in ordinary restaurants, donut shops, and neighborhood bakeries.

*The good news is that the Mint Restaurant and Lounge in Seattle is staffed by mentally retarded waiters, several of whom have Down Syndrome. The bad news is that all of them are retarded, making it less integrated than if only some of them were (DSN, 4/83).

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People at social value risk will be image-affected by the other person with whom they are juxtaposed. Below follow some negative examples. Positive examples will be found in the section on integration.

*As has been customary for a long time, institutions for the retarded in NY state have continued to hire retarded workers. Also as before, this practice has been almost universally--though incorrectly--considered to be a positive one (<u>President's Commission on Mental Retardation Newsletter</u>, 9/79). When the job performance of these retarded attendants was rated by supervisors, the ratings were quite positive--except in one area: personal appearance. A major reason this rating was the lowest of all was that the employees were still wearing the clothing that had been donated to them while they were residents at the institution.

*The Special Olympics is problematic enough at its best, but more and more, it is getting suffused with perversions. For instance, a new craze sweeping Canada is to run Special Olympics events for the retarded with the help of prisoners, or even in prisons. An example is a Special Olympics held annually since 1983 by the inmates of the Matsqui Prison in British Columbia, thus reinforcing an old public deviancy image juxtaposition stereotype between mental retardation and criminality. (Source item furnished by David Jory)

*The woman who entered the world history of psychiatry as Eve with the three faces (The Three Faces of Eve became a 1957 movie), and eventually was "found" to have 22 personalities eventually became (at least as of 1985)--believe it or not--a mental health counselor in SC.

*A dentist in CA is named Dr. Pullum. A person who worked in the alcohol awareness program of the US State Department was named Drinkard. (Source information supplied by Hank Bersani)

Positive SRV News

SRV News

*Yes, its official now. On Easter 1981, Pope John Paul II spoke to handicapped people and their friends and parents in Lourdes, and lauded them for their "convictions regarding the need for integration 'normalisation' and a greater 'personalisation' of the handicapped from which they must benefit."

*Institutions, Etc. (10/84) carried an article by Stephen Taylor that documents a most phenomenal case of liberation of a retarded man named August. Taylor encountered August in March 1979 at a NY institution. August then was one of the most retarded people one can imagine: could not speak, not toilet trained, unable to dress himself, aggressive, regressive, avoiding of any form of social interaction, resistive of any direction, and called "the worst" and "the most severe behavior problem" the staff had ever encountered.

August had been placed in this institution hundreds of miles away from home in 1940 when he was 6 years old. He soon regressed; by 1948, he was digging at his rectum and smearing feces; by 1949, he was continually ripping off his clothes; by the 1950s, he began to be heavily sedated, sometimes with as many as three different tranquilizers at a time, including some of the most powerful ones available. In time, he had been placed on more than 13 such drugs. Rather than helping things, they made things worse, producing brain injury and Parkinsonism that to this day leaves him with an unsteady gait. Although the ineffectiveness of the drugs was recognized as early as 1961, they continued to be administered until 1979. Somewhere along the line, his teeth became infected and were extracted, and an ear was amputated because after an injury to it, he kept picking at it. In addition, August spent the better part of 20 years in restraint. By the early 1970s, August seemed to be somewhat burned out, becoming dull, lethargic, emaciated and inward-centered. In 1972, August began to live in the shower room. Staff claimed that was his own choice and that it was not possible to get him out, but at least one other staff member claimed that his fellow employees locked August up in the shower room as a convenience.

Taylor first met August in the shower room in 1979, where he was laying on the floor, acting and vocalizing like an animal. Within days, a suit was filed which the state fought for 5 years before surrendering. As of Fall 1984, August was living in a small home together with 6 other people, attending a day activity center though even here, the activities were rather silly and low-level. Nevertheless, August has become a new person. He is toilet trained, dresses himself, keeps his clothes on, and eats with fork and spoon. He socializes with people, recognizes them, and shakes hands with them. He has even begun to exchange physical affections with people so that he is now described as "loving, kind, and gentle," and "everyone likes working with August."

All this was achieved in combat against the human service bureaucracy, and not with its help. Ironically, the institution where August lived has since gradually been turned over into a prison--as if it had not been one before.

*Even casual observation of a group of mentally retarded people in a setting such as a sheltered workshop will reveal that a large proportion, quite often as many as about a third, are over-weight. Obesity in handicapped people is a terrible problem, impairing motion, contributing to other health problems, and erecting an image and attitude barrier towards others, not only because of personal appearance but sometimes also because of bad eating and table manners and habits such as gorging. A few years ago, Dr. Rotatori and colleagues (N. Ill. U.) began to address this issue in a systematic fashion. One of their conclusions has been that retarded people generally grow obese and stay that way for the same reasons as other people do. These investigators have achieved great results in having retarded people keep to diet, making the issue intelligible to them, and in providing them with motivation and supports to control their weight.

*Ed Campbell sent us a most remarkable ad that appeared in 1985 in the (Greenwich) <u>Village Voice</u>. "I am what is described as mildly retarded, M, in mid 40s. I live with my parents in Manhattan but I am quite lonely. I work as a page on Wall St. I am told that I dress well. I enjoy going to the theatre, movies, concerts, arts, museums, and dining out. I attended special schools and graduated with honors (and a ping-pong championship). I love sports and am an ardent Yankee, Giant, and Knicks fan and might like to revive my ping-pong skills. I am told I am reserved and that I have a gentle and considerate manner. I am interested in meeting a female and/or male who is similarly looking for companionship. Please write to me. Village Voice Box VM-4384."

*Kristijana Kristiansen has discovered a chain letter system under which handicapped and nonhandicapped people send each other picture postcards from different parts of the world. This is particularly interesting to people with limited life experiences or confined in institutions. Anyone interested in entering this chain might want to write her at Midtveien 9, Riskokka, Oslo 5, Norway.

*Handicapped Housing, Inc. (we're not sure who they are), has beguntc promise "fun-filled, normalized vacations" for mentally handciapped people in state parks in Ky and TN. As we mentioned before, in Germany there are many such opportunities for handicapped people, and for entire families with handicapped people, whereas in North America there are still very few such opportunities. *The administrator of a unit of the Syracuse Developmental Center wrote a letter to the family members of the residents of his unit, briefly explaining the issue of age-appropriate possessions, and asking them to give their retarded relative adult rather than child-imaged possessions. Such a measure exemplifies how personnel in an institution can contribute to family efforts toward a more normalized life for their institutionalized relative.

*A child with Down Syndrome has appeared in a generic toy catalogue, the Spring/Summer 1984 catalogue of Discovery Toys located in Pleasant Hill, CA.

*In 1968, a German surgeon, Professor Hoehler, began to experiment with the surgical reduction of the stigmata of children with Down Syndrome. In 1977, parents of one such child went public in praise of the positive effects upon the social life of their child. Since then, some 250 children have been operated on. The experts say that the operations work best if performed when the child is between age two and six. In 1982, similar operations began to be undertaken in Israel. (News item from the Jerusalem Post submitted by Jerry Kiracofe)

Actually, there had been attempts several decades ago to reduce the size of the tongue of such children if it appeared to be disproportionately large for the size of the mouth.

These kinds of operations have been very controversial. The fact is that people's appearance will elicit certain social behaviors, and that this should not be so but will never be any different. One might therefore take a middle road approach and support at the very least operations on strabisms and protruding tongues, both of which are not merely image-enhancing but also competency-enhancing. Also, people who object to this kind of operation might examine their own feeling toward other kinds of plastic and/or reconstitutive surgery, especially the kind that does not yield functional improvement but only improvement in appearance, such as has long been carried out with all kinds of congenital anomalies.

*There are many reasons why fire safety is an important issue to community residences. From an SRV standpoint, one importance is that if handicapped persons can be demonstrated to be able to evacuate a residence under stressful conditions in short order, then one can argue forcefully for the use of more normative residences, and against culture-alien features built into the environment for safety. Along this line, a study in <u>Mental Retardation</u> (<u>32(1)</u>, 1985) found that even profoundly retarded persons could be trained to evacuate their residence within 24 seconds by means of daily drills over an eight week period. However, even the initial speed was a very respectable 87 seconds. The peak speed was maintained with as little as one drill a week. One problem in the development of community residences has been that some codes have imposed unnecessary and denormalizing features into the environment. Fire codes, and sometimes arbitrary rulings by fire marshals, have been notorious for this. A much more sensible strategy is to relate design of the environment to the capabilities of the residents as demonstrated by the residents during actual drills under relatively realistic conditions. Such a requirement would have the benefit of, for once, creating a positive feedback loop whereby agencies operating residential programs would actually be relieved of the higher costs of safer environments if they managed to train their residents to demonstrate self-preservation and rapid building evacuation under demanding conditions, such as during the night and without light. For once, we have good news about NY state where the Office of Mental Retardation and Developmental Disabilities has begun to emphasize this strategy and has developed a concern in designing staff training programs on how to train residents to develop and demonstrate self-preservative behavior.

Environmental and Prosthetic Supports for Impaired People

*The Bank of Albuquerque, NM, has launched a special program to meet the banking needs of handicapped people. It has made its facility accessible, makes it possible for blind people to bank via braille or large print, has designed checks with embossed lines which blind people can write on, has given an 8-week sign language course to its staff, has an interpreter for the deaf available, provides classes on finance to retarded citizens, and has hired a person as a consultant and customer service officer for persons with special needs.

*In CA, a baseball field has been built enabling the blind to play. Beepers are installed in the bases and in the softball-size ball. There are also a few adaptations of the rules, e.g., instead of throwing the ball to the bases, the outfielders have to find it and hold it up before the runner hits a base (<u>American</u> <u>Rehabilitation</u> 3-4/82).

*Technological developments, and especially and primarily computers, have made it possible to develop ever more sophisticated systems of enabling paralyzed people to communicate by no more than eye motions. One recent breakthrough has been the development of systems that use a head gear so that eye motions can be read even when the head is engaged in uncontrolled motions. Even though these systems are still only in experimental and prototype stages, they do enable a person to type out letters, and thus messages, with their eyes. The job can be tedious, but not any more tedious than that of people with cerebral palsy who have been known to write entire books over a period of years, typing one letter torturously at a time. (Source item furnished by Rita Samols)

*In NY State, it is possible to get a driver's license without permission to drive. An identity card is issued by the Department of Motor Vehicles, and looks exactly like a driver's license, but is meant to serve only as identification for people who need or can use such an identification card though they are not licensed to drive.(<u>NYS Advocate</u>, 10/85). This is a good break for handicapped people, because so often, a driver's license is almost the only thing short of a passport that will satisfy banks, stores, etc. The utility of the card is further enhanced by the fact that driver's licenses in NY now carry a picture of the person.

Accomplishments by Handicapped Persons

*The Today Show has a weekly Sportsman of the Week feature. During the week of 2/9/81, a young man by the name of Carl Joseph was given this distinction by the sports broadcaster, Bryant Gumbel. Carl Joseph is unique in sports history, as he only has one leg and he participates in sporting events without a second prosthetic leg. In high school, he lettered in track and field due to his high jumping ability, and also played basketball. At the time of this interview, he was on his college football team. His autobiography, entitled <u>Carl Joseph</u>: <u>One of a Kind</u>, was published a few years ago. Bryant Gumbel displayed a very positive attitude toward this young athlete, and the personal interview revealed Mr. Joseph to be a person of strength, character and determination to participate fully in life.

*A dramatic example of the power of role expectancies, high developmental challenges, and social integration appeared in a story entitled "Special Wrestler," in the <u>Ithaca Journal</u> of 15/2/85. It told of a teenage man with athetoid cerebral palsy who is a member of the wrestling team at the typical high school he attends. In addition to wrestling, he also downhill skis bowls, swims, and rides a moped. His family has supported the concept of treating him "normally" ever since he was a child, and he has been integrated into typical educational programs since the 7th grade. Although he may not be as good as his teammates, he still does well enough to be a "real" member of the team, rather than just a token. His teammates treat him normally, teasing him, doing exercises with him, etc. In fact, as a result of his participation in the sport, his bodily flexibility and strength have considerably improved. (Source item furnished by Susan Ruff)

*The NY State legislature in 1984 employed 22 retarded or handicapped persons as messengers, who have done a very satisfactory job at good pay.

*With the cooperation of the presiding judge, a man in Seattle with cerebral palsy and a severe communication disorder requiring artificial speaking aides was able to serve on a jury (The Inside Scoop, 6/82).

*Through a program of physical exercises, a young man with cerebral palsy prepared himself for a full year to make a parachute jump. One day, there he was falling through thin air from 3500 feet. A very clever thing about this jump was that he jumped barefoot and over water, with friends in boats below to fish him out, which they did (<u>UC People</u>, Fall 83).

*A survey of the handicapped employees of Dupont revealed that the great majority performed at average or higher levels in safety, attendance, and performance of duties (Programs for the Handicapped, 3-4/82).

*China is reportedly employing deaf people as police officers on the assumption that they see more, which is an obvious asset in a society that tries to keep a close eye on its people (<u>Disability Rag</u>, 5/85).

*We heard the story of a mentally retarded woman who traveled by herself from Vancouver to Nairobi to a conference, changing planes on the way and making an overnight stopover, all without assistance.

*While on his way to work, a retarded resident of a group home noticed smoke coming from a neighboring house. He ran back to the group home to get someone to call the fire department, then rushed to the burning house where he woke up the sleeping family. He accepted the children that were handed out to him by the father, and then rushed into the burning house to help save the mother---who only a week earlier had asked the handicapped man to stay away from her children (<u>CJMR</u>, Autumn 84).

*Dov, born of Jewish parents, was institutionalized because he had Down Syndrome. At age 5, he was adopted by Rabbi Solomon Wulliger and his wife, and at age 13, he celebrated his bar mitzvah in Brooklyn (<u>DS News</u>, Summer 85).

*In England, a 23-year old woman with Down Syndrome has been a scout, has sewed herself a suit, learned to swim, hiked through the countryside staying in youth hostels, fed and bathed handicapped children and blind adults, reads and writes stories, goes shopping and to church on her own, rides, plays table tennis and snooker, has taken a role in a play--and has won the Gold Award from the Duke of Edinborough. (Source item furnished by Paul Williams)

Negative SRV News

While we have some lovely SRV news, the negative news still overwhelms the positive news, even though we can only include a fraction of the awful vignettes that come to our attention.

*It is sometimes absolutely amazing that human service workers will invest enormous amounts of time, energy, and money into the most peculiar and outright bizarre activities, yet at the same time, they find it difficult to muster even a little bit of enthusiasm, energy and hard work to implement SRV measures. A good example comes to us from the newsletter of the West Seneca Developmental Center for the retarded outside Buffalo, NY (The Senecan, 4(6), 12/85). The newsletter reported on ""Haunted House Day," which was celebrated the day before Halloween at one of the buildings in the institution. The day was described as "arduous" because of its schedule: 9:30 to 11:30 a.m., 1:30 to 3:30, and 6:00 to 8:00 p.m. Indeed, this is a longer day than almost any mentally handicapped adult would ever experience for adaptive programming. There were web-filled passageways, people dressed up in various costumes, including as talking convicts and monsters, a devil in a casket, and a screaming head. The article reported that in order to make the day the "success" it was felt to be, cooperation from workers in many areas, including from the director, was required. The day was described as having taken weeks of hard work and preparation. The article closed by stating that "each year the staff and clients rise to a new challenge, surpassing previously successful Halloween celebrations." Just imagine the positive effect if workers from many skill areas and the director of the institution all cooperated in many weeks of hard work in preparation for one or more positively-imaging and competency-enhancing activities for the residents. (Source item furnished by Betty Pieper)

*On one of the local television news programs in Syracuse on 6/7/83, there was a story of a nursing home in which one of the programs was to encourage the residents to choose a collective pet to be called the nursing home's "mascot." The story described the difficulties of having all 40 residents agree on what kind of animal the mascot should be. Staff of the nursing home testified to how good animals were for the residents, but that a major concern was where the animal would be kept once it was selected, since state rggulations prohibit animals living on nursing home premises. The local society for the prevention of cruelty to animals had offered to donate the animal of the residents' choice, once that choice was made.

Apart from the animal imagery that such a story conveys about elderly people, the story is remarkable in demmnstrating the dramatic differences between the way something like choosing and obtaining a pet is done in normative society, and how it is done in non-normative human services. In normative society, the greatest number of people who would have to agree on the type of pet they wanted would probably be the number of children in a family--but trying to get 40 people to agree on one animal is a little much! Furthermore, in normative society, one would only have to go down to the SPCA or a local pet store, pick out an animal, and take it home that same day. In the nursing home, one has to wait for state approval, and then one has to have a special area constructed for the animal because it is not permitted to have animals in this special place where devalued people live. In normative society, the most that would happen is that the animal would be relegated to the basement, or a special little house would be constructed for it in the back yard, but no special permission and licensing of the home would be required unless the animal were very unusual.

*Here is another vignette illustrating the medicalization of just about everything. In Syracuse, there is an Upstate Medical Center which has a pediatric hematology unit, which in turn has a "play therapy center." A newspaper article about all this showed a picture of a woman dressed in white playing with three children. It is very fitting that a pediatric unit should have play facilities for the children it serves, but why does play have to be "play therapy"? Obviously, one of the answers here is that it is either play that (a) is engaged in by sick children and/or (b) that takes place in a medical setting. One wonders if it will come to the point where toilets in medical settings will have signs to the effect that they are "defection therapy centers," or something like that. *Despite three decades of denunciation by writers of the psychiatric practice of placing healthy people in psychiatric residential settings into pajamas during the daytime, 71% of major psychiatric institutions ("hospitals") in Canada were found in 1982 to still continue the practice. In half of these settings, the practice is routine at the time of the client's admission. The practice is also often used as a punishment for infraction of rules, much as parents might put children to bed.

*A 67-year old retarded woman was adopted by a couple aged 54 and 38. Apparently, this unusual and social role devalorizing process was facilitated by the fact that their adoptee was a child-size dwarf, 3' 9" tall (CARC News, 3/84).

*A contemporary Ship of Fools? In TI history workshops, we sometimes refer to the European practice during the Renaissance of paying mariners to fill up their ships with the unwanted local deviant people and to drop them off far away from home, often exhibiting them for money on the way. This practice gave rise to the image of the "Ship of Fools" much portrayed in art and literature. Deeply imbedded themes such as these seem to become archetypal, and to experience resurrection in symbols and metaphors reflective of their own times. An example is a 1982 proposal from Wisconsin (trumpeted as "a once in a lifetime" program and opportunity) under which an entrepreneur proposed on an ongoing basis to fill a ship with handicapped people, the elderly, disadvantaged children, etc., and take them into the watery hinterlands to show them where the wild rice comes from, where the sandy beaches are, and so on. The entrepreneur tried to get local service agencies to subscribe to the cost of this venture in advance by promising to send and recruit clients for it. (Source material furnished by a Wisconsin friend of the TI)

*There is an institution in Central NY State, launched in 1921, that accepts exclusively people with Down Syndrome. Though it has residents of all ages, its name, Pathfinder Village, suggests a scouting, and therefore adolescent, image.

*The Down Syndrome Congress did something that we consider to be a bit phony. Ordinarily, its board members consist of adults--quite commonly, even parents of people with Down Syndrome. Many are not even what one could call younger adults, but people in mid-life or older. Yet in 1985, it accepted on its board two people elected by citizens with Down Syndrome to be their representatives, and both persons were below the legal age of adulthood. One was a 17-year old boy, the other a 14-year old girl. If its other board members all have to be adults, it projects a highly inappropriate image when its retarded board members are children. It almost seems to say that children may be on the board--if they are retarded, but if they are non-retarded, then they must be "real adults."

*The NYS Office of Mental Health has opened yet another "community residence" (for 24 residents!) that is actually an old building on the grounds of an institution, the Rockland Psychiatric Center (This Month in Mental Health, 5/85).

*In Syracuse, the police report on a retarded man accused of a crime was that he "suffered mental and emotional charges" (SHJ, 21/10/84).

*Until convinced to the better by protests, one of the creators of the game, Trivial Pursuit, characterized certain game questions as being designed for "mongies" (i.e., mongoloids) "who are brain dead at one in the morning."

*A 1983 book, entitled The Lives of Mentally Retarded Persons, has been widely acclaimed, but to our utter astonishment it was pointed out to us by Sharon Clark that the book uses the word "tardocide" to refer to the killing of retarded people. Apparently, the author made up the term from the slang word "'tard," which is an abbreviation for yet another slang word, "retard."

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*A TV spot showing mentally retarded children with the message "Don't ignore them" was banned from showing in Australia because seeing these retarded children presumably would "cause undue stress" in the viewers (Link, 1/10/81).

"Pan American airlines had a standard operating procedure for its employees on "abnormal passengers." A recent draft included among these "a person with malodorous condition, gross disfigurement, or other characteristics so unusual as to be unpleasant. These conditions must be considered when determining whether the passenger may be accepted for transportation." The draft also discussed what to do about "stretcher cases," and "passengers of unusual size" which actually refers to people who are extraordinarily high, wide, or heavy; these must not be seated close to the emergency exit. People who appear to be under the influence of drugs or alcohol are to be intercepted within the terminal and "offloaded." Personnel are warned that this is a very delicate problem because "the individual will probably create an unpleasant offloading problem."

*When an attempt is made to place a group home into a neighborhood, and opposition is encountered, virtually all the objections raised are highly predictable. All over the world, one will hear things such as fears of violence or other misconduct; in developed countries, one will commonly hear the concern that there will not be enough parking space; etc. In one instance in England, an objection was voiced that probably had never been heard before: "the sewers might not cope." (CMH. Newsletter, Spring 1985).

*The number of ways in which the devaluation of devalued people can be expressed is absolutely staggering. In CT, a town lowered the property tax of 9 home owners because they lived close to a community residence for the mentally disordered! (APA Monitor, 6/85).

*A hospital near Rochester, NY, has had so many problems maintaining quality that the state's health department eventually closed it down as unredeemable. Soon thereafter it was proposed that it should be reopened as a nursing home and alcohol and drug treatment center. In other words, a facility no longer capable of providing quality medical care for valued people is still perceived as good enough to serve devalued ones (SHJ, 13/9/85).

*A strange phenomenon of our time is the existence of a drug company named Geriatric Pharmaceuticals. (Source item furnished by Susun Thomas) There are hardly any drugs which are uniquely applicable to elderly people, and yet the name of the company would appear to suggest that there are. More likely, the company is capitalizing on the medicalization of aging that has made elderly people into "geriatrics."

*EBSCO Curriculum Materials out of Birmingham, AL, has been selling training kits for "pre-vocational training centers." Some of these kits cost up to \$1240, and yet have very little substance. For instance, one might pay \$250 for a kit containing 15 simple hand tools and a little printed paper to go with it. Amusingly, the materials are advertised as preparing persons for real jobs that they might find "in the community," but then they also mention that the activities were selected by surveying what sheltered workshops were doing.

Mixed SRV News

Some SRV news contains both positive and negative elements.

*Hands-on human service. Many phenomena of the world occur in polarities of goodness and badness. There are now available a tremendous array of ingenious and highly effective prosthetic and assistive devices for (particularly physically) handicapped people. What could possibly be the negative polarity of this

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phenomenon? It is the array of devices used to restrain, control, disable, or punish people. An example is a "hand-control mitt designed to limit the use of the patient's hands." In essence, it is a huge mitten that is strapped to a person's hands, dramatically reducing what the hands can do. Now it is entirely possible that such a device can in fact be useful on very rare occasions, but we know how infinitely more likely such devices are apt to be used for bad than for good once human service workers get their hands on them. Outright perverse is the fact that this device is sold as part of the "Bunny Line" of orthopedic devices of the Dillon Manufacturing Company of Atlanta. (Source item furnished by Kristjana Kristiansen)

*Conroy, J., & Bradley, V. J. (1985). The Pennhurst longitudinal study: A report of five years of research and analysis. Philadelphia: Temple University Developmental Disabilities Center. Too often, human services either go to one extreme of authoritarianly imposing a measure on clients, or to the other extreme of trying to provide them with whatever they want. Those who exalt the latter extreme should take note of a finding from the Pennhurst Longitudinal Study. Eighty-three percent of families of retarded people living at that institution were happy with it, and 72% said that they would not agree to a move of their retarded relative to community residences. Yet 6-12 months after such a move took place, there was an almost complete reversal of family opinion. About 85% agreed to the placement, and that their retarded relative was now happier.

*Stephan Kilsheimer of Durham, NC, became the only person with Down Syndrome to ever attain the rank of Eagle Scout in NC without help from programs for the handicapped. The only bad news here is that the requirement that the Eagle rank must be attained by age 18 was waived, and it took him to age 26 (<u>DS News</u>, Summer 85). Waiver for perhaps one to three years might have done little image damage, but a 26-year old among 16 to 18-year olds is a little much.

*The film "Mask" is loosely based on the real life of a facially disfigured youth. It has received very positive acclaim even by highly critical handicapped people, even though it solved the problem of how he "would get the girl" by getting him a beautiful blind one.

*In Syracuse, an able-bodied man called the police when he saw another ablebodied person park a car in the handicap parking spot. His company, Doyle Detective Bureau, reprimanded him, whereupon he quit in disgust.

*The good news is that the NY (state) School for the Blind in Batavia held an Easter egg hunt. The bad news is that they used egg shaped panty hose containers. The good news is that the containers held an electronic chirping device. The bad news is that the hunt was held two weeks before Easter, thus violating the routines and the rhythms of the year, and denying some people the proper observation of Lent.

*In Syracuse, the Rescue Mission has switched from dumpy-looking donation boxes for discarded objects to neat portable trailer units where attendants accept donations and do some preliminary sorting on the spot. That may be the good news, but the bad news is that these attendents are largely aged and handicapped people including at least one dwarf.

*We admit to being somewhat ambivalent about the 1984 closing of Goodwill Industries in Philadelphia after 65 years, from lack of funding, on top of a large debt. Generally, Goodwill has long been riddled with all sorts of problems and violations of SRV/normalization. It has also tended to be imperial in its attitudes. At the same time, for many handicapped people, it was (perhaps unfortunately) better than "nothing." Whether operations have since been resumed we do not know.

*The Canadian Rehabilitation Council for the Disabled, in partnership with Health and Welfare Canada, has been disseminating a checklist of seven questions which are supposed to reveal to a respondent whether s/he holds negative attitudes towards handicapped people. This little quiz, which is supposed to be an educational and attitude impacting tool, is phenomenally asinine, mostly in its oversimplifications which totally invalidate the majority of the items. For instance, you are considered to have had or negative attitudes if you either avoid a "disabled person" at a social gathering or pay that person special attention, no allowance being made for contingencies such as that the handicapped person might smell bad or that one might have a special interest in people with a certain condition, much as some "gentlemen may prefer blondes." You are also downgraded if you "treat disabled people as less than normal," which is hard to avoid if the person is deaf, blind, retarded, and lacks hands and feet. You are also downgraded if you "feel awkward" in the presence of such a person, and so on. Remarkably, this not very helpful questionnaire was carried in Canada's Mental Health (9/81) which is otherwise one of the better mental health journals.

*Now that we have shot not only men but also women, and even Germans, into outer space, some fanatical advocates for handicapped people are demanding that handicapped people be also shot into space. Some of the arguments are very analogous to the ones for the Star Wars project that quote all sorts of supposed civilian benefits, such as better computers. In this case, the argument is that weightlessness of space will enable handicapped people to overcome at least temporarily some of the limitations to which they are prey on Earth (<u>Rehab. Lit.</u>, 9 & 10/85).

*Ontario has made a giant stride forward by allowing handicapped people, with a special waiver, to be employed at less than the minimum wage. This finally opens up the possibility for handicapped persons who could not produce at a competitive level to be employed nonetheless, and to be paid in accordance with their productivity. Virtually everywhere else, such persons end up in sheltered workshops, or at best in work stations in industry operating under a sheltered workshop umbrella.

Militants who have been advocating for a mandatory minimum wage for handicapped people in sheltered workshops will discover that if such measures were carried through, a large number of handicapped people would simply be dropped from eligibility for workshops and end up dumped without any work opportunities at all, or possibly in day centers that would spring up that provide entertainment, arts and crafts, adult baby sitting, and similar low relevance and low intensity diversions. It is even conceivable that some such centers might masquerade as continuing adult education centers. All this might play right into the hands of the dynamics of a post primary production society that is willing to spend a great deal of money to keep people away from real and remunerative work.

Other SRV News

Some SRV-related news is merely news, neither positive, negative, nor mixed. About yet other items we have not been able to make up our minds where it falls. Both types are included below.

*In one of the last things he wrote for publication, Burton Blatt reminisced on the relationship between Helen Keller, her teacher Ann Sullivan, and their mentor, Alexander Graham Bell. Before Sullivan started teaching her, Keller behaved in a fashion which most people would have considered as characteristic of severe mental retardation. Had Sullivan not appeared on the scene, Keller would certainly not have become famous but would probably have died retarded. Even as deprived and unsocialized as Helen Keller was at first, once she understood what her teacher, Ann Sullivan, was trying to do, she learned to spell 400 words in a single month, and in less than three months learned how to correspond with letters. In 6 weeks, she mastered Braille, and all this while making tremendous progress in mathematics and

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geography. Within a year, Keller was also studying French and German. Four years after that, she was studying Greek and Latin.

Alexander Graham Bell, who had much to do with the early American efforts to educate the deaf and deaf blind, was an opponent of congregation of the handicapped with each other. He said, "The blind become blinder by exclusive association with one another, and the deaf and dumb are made into a class apart by themselves...my heart is deeply moved in the matter because I feel that a gigantic blunder is about to be made and I'm away and cannot prevent it....It would be better to send teachers to these children, rather than send the children to the teachers...as Miss Sullivan was sent to Helen (Keller)."

*In order to understand the overwhelmingly negative attitudes of the leaders in the field of mental retardation toward retarded people between ca. 1880 and 1950, we have to understand one fact: generations of such leaders had not seen retarded people in any positive contexts. Most commonly they had seen them in miserable institutional settings. Occasionally, they saw them in wretched community contexts such as in the homes of the multi-generationally poor. Chances are that none of these leaders had seen retarded persons who had received the benefits of intensive positive expectations in a favorable home environment and in an intensive developmental program, and who had been surrounded by people who held positive attitudes towards the retarded person and extended positive participation to him/her. Not surprisingly, they thus saw retarded people pretty much at their worst, and this profoundly shaped their entire perceptions and attitudes so that it became literally inconceivable for them to imagine alternatives.

All this was still the case with many leaders when I (WW) came into the field. There were many who had never seen any of the positive things that I mentioned above, and who could not even conceive of them. Their thinking and imagination could soar no further than to imagine picayune improvements in institutional settings. They were not even capable of imagining things such as small institutions, and the conceptualization of group homes was entirely beyond them.

*There has been a modest proliferation of handicapped dolls and puppets in recent years. Some are very unreal or even animalistic.

Hal's Pals, in Winter Park, CO, makes handicapped dolls that can come with dark glasses, guide dogs, crutches, braces, hearing aides, wheelchairs, etc. The dolls are outfitted as tennis players, hikers, skiers, and cowboys, thus emphasizing culturally valued roles and activities for them. They can be very much individualized for a particular child, even as to race. The dolls have also been used in classrooms with non-handicapped children in order to stimulate open discussion of facts and attitudes pertaining to handicaps (Newsweek, 9/12/85).

Special Friends is a set of fabric toy dolls of all sorts of animals with handicaps. There is a frog with a leg cast, bears and rabbits with artificial arms and legs, an elephant with hearing aids. a monkey in a wheelchair, etc. They cost between \$15 and \$24 a piece. One supporter of this development said, "Its a wonderful idea for handicapped children so they don't feel alone or different."

In contrast to the animalistic puppet figures widely used these days to supposedly improve attitudes toward handicapped people, there is a set of dolls out called "Bestfriends" that have handicaps. There is a blind girl with a seeing-eye dog, a Boy Scout with a deformed hand, a youth with only one leg who skies with an outrigger ski, and so on. Unfortunately, the dolls are expensive (\$45 to \$75) and not likely to be found on store shelves (Spina Bifida Insights, Fall 84).

*There are a number of areas of human need and/or professional service practice in which SRV has received little or no systematic elaboration in the literature. For instance, we are only aware of one publication (Picket & Flynn, 1984) which has tried to spell out normalization/SEV implications to the area of language assessment, in this case of mentally retarded adults.

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*Only a grim denaturalized hypernormalizer could fail to chuckle at a cartoon in the 27/1/82 issue of the <u>Syracuse New Times</u> that showed a legless Elvis Presley sitting on a cart singing "Don't Step on Ma Blue Suede Shoes" with the director instructing the camera man: "Remember: from the waist up."

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*At the 1985 World Council of Churches International Congress on Disability, Ordination and Theology, held in the Netherlands, one participant demanded that mentally retarded people be ordained to the ministry.

*W. H. Soni of the Bristol Sheltered Workshop (P. O. Box 353, Bristol, TN 37620) has written a position paper proposing that the federal government institute a system of incentives for private industry to function as sheltered work sites. Interested parties should write to him directly. A movement in this direction would certainly be more normalizing than the present pattern, and be more akin to work stations in industry, and perhaps even better. A similar proposal, the so-called "affirmative industry," was thought up by John Durand, and explained in a monograph available from Minnesota Diversified Industries, 666 Pelham Boulevard, St. Paul, MN 55114.

*Instant normalization. An organization in AZ, called Therapeutic Environments has been selling normalization certificates for \$6 each to anyone, in order to raise money for group homes. The certificate looks like a fancy scroll for framing that prominently says "normalization certificate" on the top, and then proceeds to certify that "the holder of this certificate is a sponsor of Therapeutic Environments. As a sponsor, the holder has helped a mentally retarded or developmentally disabled person move into the AZ community to live a more normal lifestyle."

Research Related to Social Role Valorization

*Gibbons, B. N., Gibbons, F. X., & Sawin, L. G. Evaluations of mentally retarded persons: 'Sympathy' or patronization? American Journal of Mental Deficiency, 1979, 84(2), 124-131. The authors evolved an interesting empirically anchored concept of "patronization," which they defined as extending positive valuation towards otherwise devalued persons while at the same time holding low expectations of them. Towards at least some groups of devalued people, some citizens will express positive sentiments at least on the conscious and verbal level, they will explain away the person's failures as due to situational factors, but they will not hold positive expectations in regard to that person's likely future success in life. Calling this interrelated set of sentiments "patronization" appears particularly apt in light of the fact that the people who hold this set of sentiments will even attribute the past successes of the devalued person as being due to situational factors rather than competency. In other words, a devalued person would be given little blame for failure, and little credit for success. Thus, the patronization effect is one of a number of expressions of the role expectancy phenomenon. Patronization stands in contrast to another phenomenon that has sometimes been called the "augmentation principle" or the "sympathy effect," where a person in some disadvantaged state is less likely to be blamed for failure but more likely to be credited for success because they are seen as struggling heroically against some limiting force.

*Green, B. B., & Klein, N. K. (1980). The political values of mentally retarded citizens. <u>Mental Retardation</u>, 18(1), 35-38). Eight human, social and political values of four different groups were compared. The groups were mildly retarded adults in a variety of institutions, mildly retarded adults living at home and attending some day program, fifth and eight grade school children of comparable mental age to that of the retarded adults, and urban college freshman. The values to be rank-ordered by each group were respect, peace, rectitude, well-being, political direction, enlightenment, wealth, and military power. The highest correlation, .93, was found between retarded adults living at home and college freshmen. The two retarded groups correlated .62 with each other, the institutionalized retarded group correlated .55 with the college students and the institutionalized retarded adults correlated .83 with the school children. In essence, this study lends support to the notion that community socialization is a powerful universal force that has similar impacts upon those who are a part of it, regardless whether they are retarded or in college.

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In contrast, people who are not as yet socialized into society are apt to hold more discrepant views, and such groups may include children as well as institutionalized adults. The authors thought that this study strongly supported normalization concepts in underlining that shared values are more likely to occur among people who share experiences and interact with each other in larger society.

Schmidt, M. G. (1979). Patient as volunteer: An assault on chronicity. Hospital & Community Psychiatry, 30, 404-406. A somewhat peculiar approach to normalization was taken by Schmidt in a study of a certain practice in psychiatric institutions. In several such settings, residents who were released but retained or "outpatient" status were asked to become "volunteers" to the institution. As such, if they were women, they would wear the pink uniforms of the regular volunteer women ("pink ladies") and come to the institution on a regular basis in order to perform various of the typical institutional volunteer chores. Thereby, "these patients are integrated into the hospital's regular volunteer program" (p. 405), while as outpatients, they are able to secure medication, transportation and other needed services. A number of theories were examined by the author in support of this program, including those which dealt with client power versus client feelings of helplessness. Indeed, as one of the "volunteers" put it, "it feels good to have the keys." The author concluded that this practice "normalized" the patient/ volunteer's continuing relationship with the hospital, which to a certain degree is true, but which fails to address entirely any of the other normalization issues, such as deviancy image and deviant staff juxtaposition.

*Researchers have not only found that personal interactions must be experienced as positive if positive attitude change is to ensue, but also that a party that feels disadvantaged during an interaction may not improve in positiveness as a result of peronal interactions.

*Algozzine, B., & Ysseldyke, J. E. (1981). Special education services for normal children: Better safe than sorry? Exceptional Children, 48(3), 238-243. This is a very revealing but also disturbing research study: 224 educationassociated professionals with a variety of backgrounds and identities were presented with children's records data indicating that their performance and behavior were within the average range. However, parental socioeconomic data were also provided, plus photographs of the children designed to portray them either as attractive or unattractive. An astonishing 51% of the professionals concluded that children with unfavorable identities were eligible for special education (including resource room placement, special class placement, and even placement outside the school) even though their academic performance was described as average. Descriptions of, or complaints about, child behavior and performance carried a vastly greater weight in the minds of the judges than actual hard data about the purported problem areas. Analyses of the contributions of different case data to the ; judgment of the professionals indicated that attractive girls from high SES homes were much less likely to be considered eligible for special education. This study underlines once again the importance played by stereotypes, expectancies, images, etc.

*The June 1984 issue of <u>Mental Retardation</u> carried a 9-page article that proved that in order for institutionalized people to learn to use bus transportation, the best method was for them to actually use the bus in the community, second best was to practice bus use on the institution grounds, and third best was classroom instruction. We have long taught that the principle of pedagogic verisimilitude (our name) had already been sufficiently established as valid. This principle says that one learns things best by learning them in the context in which the behaviors are to be performed. Thus, a pedagogy should employ verisimilitude, in contrast to the creation of artificial substitutes and approximitions of the real thing (dissimilitude?).

*Gresham, F. M. (1982). Misguided mainstreaming: The case for social skills training with handicapped children. Exceptional Children, 48(5), 422-433. In an article that attempts to analyze the research literature pertaining to educational "mainstreaming" practices and rationales, Gresham claims that mainstreaming is based on three "faulty assumptions": the placement of handicapped children in regular classrooms will result in increased social interactions between handicapped and nonhandicapped children, that it will result in increased social acceptance of handicapped children by their peers; and that the handicapped children will model the behavior of their peers. He claimed to find considerable negative evidence for these three assumptions, but failed to allow for the "faulty assumptions" associated with "the faulty assumptions," including the many faulty assumptions incorporated into most of the negative research studies, and which render these largely irrelevant. The study of placement of handicapped children in a regular class is rather meaningless and irrelevant to the issue if the placement is not accompanied by suitable preparation, support, interpretation, etc., including the presence of a positively motivated teacher. Otherwise, such placement is merely "dumping," and while such dumping is almost universal, relatively few people appear to propose that it will lead to better attitudes by potential assimilators. Insofar as the author did not examine to what degree the studies had these positive preconditions, the review and its conclusions are themselves faulty. This leaves only the third issue at issue: whether modeling works. Again, it is known that the modeling effect is by no means automatic, and that certain preconditions must exist. The author shows some, but only limited, awareness of this. But what is even worse is that the author claims that modeling only works where the observer of the model has imitative skills and the capacity to retain information -and he then denies this capacity to handicapped children. Much more correctly, the author notes that many classrooms are not structured so that positive modeling and imitation is likely to take place. However, again, the studies cited seemed largely irrelevant in that they did not differentiate among classes in which suitable or unsuitable preconditions existed. Paradoxically, the author then cited a number of studies that show that modeling has been used explicitly and successfully to teach skills to handicapped children. All in all, this is a poorly conceptualized review that is also poorly organized, and that totally fails to separate relevant from irrelevant research studies. This critique also reveals how important it is to carefully analyze the analysis of literature reviews.

*Childs, R. E. (1979). A drastic change in curriculum for the educable mentally retarded child. <u>Mental Retardation</u>, <u>17</u>, 299-301. Childs incorrectly equates the placement of retarded children into regular grades as constituting "normalization." He raises some reasonable questions about the ongoing practices along this line, but then asks where the research is that supports regular class placement. At the same time, his article is fairly clear that there really never existed any research to support any number of a series of educational strategies for such children that succeeded each other during the preceding 50 years. Once more, phenomenal unconsciousness is evidenced when a scholar can document 50 years of programming and program changes without a meaningful research base, while then challenging as lacking a research base, one specific program strategy that does not agree with him. *Reiss, S., & Benson, B. (1985). Psychosocial correlates of depression in mentally retarded adults: I. Minimal social support and stigmatization. American Journal of Mental Deficiency, 89(4), 333-337. This article is another scientification of the obvious. It found that retarded people without "social supports" were more apt to be "depressed" than those who had such supports. Interestingly, with social supports held constant, a person's stigmatization did not seem to be correlated with "being depressed." This makes sense, in that stigmatization would probably only become relevant if it lead to social abandonment or rejection.

*This is hard to believe, but a highly scientificated article (with second floor plans) in the most scientific of all US scientific publications (Science, 27/4/84), reported that hospital patients who had windows overlooking natural scenes appeared to recover more rapidly from surgery than patients whose windows faced a brick wall.

*An article in Science Digest (1-2/82) discussed "music therapy." A series effective in of studies have found that music can be reducing pain in people under various painful conditions, such as those having dental work done, and what is one to think of a finding that terminally ill cancer patients could be taken off pain killers if they were put on classical music? Perhaps it means that involvement in a normative activity can be more effective than the institution of artificial technologies. Supposedly, music beats at the level of heart rate are soothing, faster ones raise tension and lower ones build suspense. According to the article, the Rolling Stones use a beat sequence which is exactly the opposite of the heartbeat, which temporarily decreases the muscle strength of its listeners, creates tension, and causes them perceptual problems. The article also referred to music therapy as "melodies for maladies." and made fun of a common medical cliche by prescribing to a person in distress to "listen to two sonatas and call me in the morning."

*Every once in a while, a professional in the field who previously may have had limited contact with retarded people discovers that retarded people are human, bleed when they are stuck, and rejoice when good things happen. A good example is an article in a 1/84 issue of the American Journal of Psychiatry. It reported with amazement that mildly retarded people, even if emotionally disturbed, can be very much aware of all the awful things that get done to them, such as stigmatization, life discontinuities, unemployment, etc. It then cited three case studies to buttress its points. In the first of these, a retarded adult objected to being called a "retard" and treated like a baby, the second one complained of being ridiculed and rejected, and the third was lonely from lack of friends. Perhaps such articles serve a purpose when they are directed at the psychiatric community that often seems unaware of these basic human realities, but astonishingly, the authors called for "more research" (don't they all) "on the possible effect of prolonged exposure to negative social conditions on the mental health of mentally retarded persons." Truly and literally unbelievable! This is a good example of how bad good news these days can be.

The Boundaries of SRV

*Doubts are often raised about the utility or limitations of SRV. Criticisms along these lines are often based on ignorance, misunderstanding, or all kinds of negative ideologies. However, an interesting vignette has demonstrated the very real limitation of SRV. The vignette was contained in a study of two basketball teams of young adults in CA, where the team members were comparable in many ways except that one team was retarded and the other one was not. The non-retarded team played in a league where they were exhorted to win, but to keep it clean, and where they were told that "the best team will win." The retarded team played under a slightly modified set of both rules and instructions in a league with

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other retarded teams. They were challenged to improve their pride, to make sure that everybody had a positive experience, little was said about winning or losing, and it was emphasized that participating was more important than winning. Accordingly, the rules required that all team members were entitled to play a fair share of the time, even though this reduced the strategies available to a team to win. The coaches were more active on the sidelines, providing morale-supporting chatter to players who were not doing too well. Referees were more lenient with losing than winning teams, the retarded players were more even-tempered, and confrontations between referees and players were much lower than with the nonretarded teams. Retarded players hardly ever contested the referee (<u>American</u> <u>Journal of Mental Deficiency</u>, 3/83). All in all, it sounds as if the game structure for the retarded players was much more conducive to both personal and societal well-being, which illustrates one of the few overriding limitations of SRV, namely that the principle declines in utility to the degree that a society does not hold positively relevant values.

SRV Perversions, Misunderstandings, Confusions

*As late as 1981, Shafter (1981) referred to normalization as a "simplistic term to describe what programmers have tried to do for years," and asked "where are the emperor's clothes?"

*Normalization according to whom? Trace and Davis of Ellsworth College have been distributing an annotated 16-page bibliography on "Normalization and Least Restrictive Alternatives." It contains a good number of the ill-conceptualized or misinformed critiques of the normalization principle refuted by Wolfensberger in Flynn, R., & Nitsch, K. (Eds.), Normalization, social integration, and community services. Baltimore: University Park Press, 1980. Furthermore, the bibliography did not contain one single item by Wolfensberger, or by any of the other major formulators or summarizers of normalization (e.g., Bank-Mikkelsen, Nirje, the National Institute on Mental Retardation, Bronston, O'Brien). What do things like this (drawn to our attention by Joe Osburn) mean?

*Dougherty and Morah (1983) are among the many people who erroneously have concluded that the more retarded or the younger a person is, the less relevance has the principle of normalization for him/her.

*For an amazing accumulation of misconceptions and misrepresentations of the principle of normalization, the reader is referred to the proceedings of a "national conference on normalization and contemporary practice in mental retardation" (Foss & Nesson, 1982) which was staged at the Rehabilitation Research and Training Center in Mental Retardation, University of Oregon, to "examine the state of the art of normalization." Symptomatic of the level of his examination was the fact that the many references cited did not contain a single one of the publications on normalization by Wolfensberger after 1972.

*A 1980 film ("Structuring the Learning Environment") that is part of a training package ("Effective Behavioral Programming") has been advertised as having been originally produced by Dr. Richard Foxx "for staff training in the Macomb (MI) Intermediate School District," and as now being "a comprehensive training tool for special education teachers and aides in public schools as well a as institutions." The film is interpreted as covering the "concept of normalization." It only presents a lecture by Foxx in which he talks at the wiewers, except towards the end when he demonstrates a restraint technique using a non-retarded model. Foxx defined normalization as ""a mandate which we have : received as educators to take severely and profoundly retarded students and to take their behavior and to try to get it to approximate or approach the behavior of normal individuals." He then analyzed what he termed "the problems" with normalization. He said normalization means: treating retarded people exactly the

same as everyone else, group teaching only, and "everything for everybody," by which he means no specialization of goals or processes. Another way he said this is that normalization has too many goals at once. He said that normalization means "structuring the environment" to look the same, and he argued against normalization in this regard because he believes that environment should be structured to produce learning gains. In conclusion, he stated that "if we want normalization, we've got to reject the normalization model to a certain extent." He then listed his 10-part plan for increasing desirable behavior, and finished with a demonstration of how to handle disruptive students. Throughout the film, there was excremental imagery (e.g.: "A child who can say that the brown feces is on the green couch and he or she put it there"), animal imagery (e.g.: re "edible reinforcers"), and menace imagery (e.g.: "disruptives"). He also differentiated between mentally retarded people as being either "toilet trainable" or "non-toilet trainable," and at one point in referring to mentally retarded people he asked, "do they have what they had for lunch all over them?" The film is very useful as an illustration of how people purported to be leaders in the field misunderstand, misinterpret and misrepresent the normalization principle--at the same time as they routinely negatively image mentally retarded people.

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*In its annual report for 1979-1980, the Medico-educational and Psycho-social Commission of the International Catholic Child Eureau addressed the issue of integration and institutionalization, and referred to the concept of normalization as being "obsolete," pointing out that "In some institutions...handicapped and maladjusted children are perfectly integrated in a neighborhood or in a village." Before integrating handicapped children any further, and "before investing millions in such schemes, a sufficiently great number of conclusive experiments should be carried on." (Source material furnished by Jacques Pelletier)

*One of our Australian correspondents and Syracuse University doctoral graduates (Michael Steer) sent us an advertisement from an Australian newspaper announcing an opening for a medical officer in an institution for 800 "congenital mentally handicapped persons" that supposedly "provides normalisation programmes... and is actively involved in their placement in nursing care homes...."

*Should we laugh or cry? The Central Indiana Council on Aging has had a reputation for being relatively progressive, and has had a number of its members at TI workshops. However, we are not sure what to make of the following condition which it placed on one of its grantees: "all services will be based on the principle of normalization; e.g., do not place a luncheon site in a dirty and dark room." That was the extent of all specifications pertaining to normalization.

"Normalization at Wilton (NYS) Developmental Center. Consider the following policy statement. "All citizens have a basic human right to personal safety and security. When a citizen, due to developmental disabilities, cannot fully assure his or her own self-preservation independently, we have an obligation to address this need. In addressing this need, the principles of "normalization" and least restrictive environment" must be strictly applied. This means that methods designed to protect those who can't protect themselves be as non-obtrusive, normalizing, and non-stigmatizing as possible. Therefore, only those people who require special assistance in this area should participate in any such program."

You would never guess what the provision is that this 8/82 policy statement justifies: a device which emits electronic signals (in other words, a form of radio) securely attached to clients so that their movements can be tracked, they can be kept under surveillance, and their whereabouts are known at all times. We can fully expect this sort of thing to become very popular in other institutions. It has also been proposed for use on paroled prisoners. *One writer (Vyse, 1982) proposed that during the 1970s, the normalization principle had completed one phase in its development by spurring the creation of many community services, and that the limit of deinstitutionalization had been reached. In its "second phase," the author saw a need to now normalize institutional settings so that they constitute better environment for the severely and profoundly handicapped.

*One private institution for the mentally retarded advertises for customers in national journals with the slogan "Love is the life-style. Normalization is the goal."

*At one institution for the mentally retarded which prides itself on its normalizing attitudes toward sexual practices of its residents, staff have been given a set of instructions on how to respond when encountering residents in sexual acts. For instance, when staff bluader into somebody's bedroom and find two residents engaged in sexual intercourse with one another, the staff, in the name of normalizating, is supposed to say, "Oh," and walk out again.

*A hilarious example of phony hyper-normalization is the vignette told by one of our acquaintances who visited a living unit where one of the retarded men sat stark naked, but the guide formally introduced the man and the visitor to each other by last names as if they were at a cocktail party.

*An interesting version--and possibly perversion--of SRV has been applied by certain mental health services that have employed folk treatment methods for those of their clients who were from certain ethnic minorities--not because they believed in these methods but because they wanted to provide "culturally relevant treatment methods." For instance, after traditional counseling and sleeping pills did not work with an emotionally troubled Chinese man, one mental health center in CA would apply acupuncture. Several of their clients were considered to be schizophrenic, and their condition was also treated with acupuncture (Innovations, 1979, $\underline{6}(2)$, 14-15).

*One perversion is to treat emotionally disturbed clients of mental health centers by teaching them "gunpersonship." They are taught shooting in something called a "life-skills class program," such as one being operated in Great Falls, MT (UPI, in <u>Indianapolis Star</u>, 6/9/82). A peculiar rationale is that the local area is "hunter-oriented," and a lot of people are talking hunting. One wonders whether these perverters of the normalization principle have were heard of the conservatism corollary. Also, what is to keep them from walking in on their insane therapists and shooting them? After all, they <u>can</u> plead insanity with impunity.

*Perversions of SRV/normalization, as of many other things, are particularly likely to happen when they appear to be very plausible and morally positive. An example is training societally devalued people in assertiveness, analogous to the kinds of assertiveness training we have seen promoted in recent years. Indeed, many devalued people badly do need assertiveness training, but because of the high dangers contained in the precarious situation of many devalued people, training them to be assertive can easily lead to their being even more rejected and brutalized, and can thus become a perversion. For instance, programs have trained retarded people to become more assertive (e.g., Klein & Babcock, 1979). In itself, such an aspiration does not appear unreasonable, but is nevertheless overwhelmingly likely to lead to perversion and disaster. A great many retarded people have been poorly socialized, and have difficulty in accommodating themselves to the kind of supervision and instruction that many of them will always require in their lives. When a retarded person needs to learn obedience and how to follow instructions, it would serve very poorly for that person to be trained in becoming assertive. Unfortunately, the proper balance between valid but competing measures is rarely maintained, and never is by people who implement a pro-

gram mechanistically, without sensitivity, and without having the proper ideology to begin with--which is often the case.

*The terribly indiscriminate and loose way in which the term normalization is being used was illustrated in an address by Ettarp (1980) at the World Congress of Rehabilitation International, Winnipeg, entitled <u>Outpatient Amenities as an</u> <u>Instrument of Normalization for Psoriasis Patients</u>. In the treatment of people with psoriasis, normalization was equated with the following practices: running an outpatient clinic in which no appointments were necessary, and serving clients at any time it suited them; having the clinic open in the evenings, and avoiding the appearance of a hospital--whereas according to our formulation of the normalization principle, it would be eminently suitable to provide medical treatment for medical conditions in a medically-imaged facility.

*Among the perverted exaggerations of the normalization principle are the celebrations of peculiar or even almost bizarre attainments by people with various types of handicaps. Since some hypernormalizers deny that handicapped people have a handicap, some retarded people have even been sent to college or trained for "leadership."

In 1978, a man who had spent six years of his life in institutions for the mentally retarded received a bachelor's degree from a Canadian university, to the accompaniment of a great deal of publicity. Had one learned that he graduated in the departments of mathematics, physics, or even English, history, psychology, etc., one might reasonably question whether this individual had ever been retarded. But one's image and expectations are somewhat shaken when one learns that he graduated from--the department of religion, especially when one also learns that as late as in his young adulthood, he had had only a fourth grade reading level.

*Another perversion of normalization ideas is the initiation of a driver education program for totally blind students. One such program was initiated as an affirmation of "mainstreaming." Textbooks were developed in Braille, special films were developed, and students were actually taught to drive on a high-school driving range. The rationale under which this travesty was perpetrated was that it might give "students confidence in stopping an automobile in the event they were alone." One can easily anticipate the hostile reactions such an absurd and wasteful program would evoke from the public, and how this hostility might end up being directed at the victims, i.e., blind people, rather than at the agencies and human service workers who perpetrated such stupidity.

*Blind, deaf, quadruply-amputated, retarded, and disturbed: You too can drive! Send 25¢ for reprint to Center On Normalization (CON).

*Lay 'em as they come, especially if they can't get away. Ted F. wrote to a sex advice column in ARISE, wondering how to comport himself vis-a-vis a cerebrally palsied young woman to whom he was attracted. The advisor responded: "Dear Mr. F. If you want a sexual adventure with a cerebral palsied woman, you should take a chance, just as you would with any woman. Some CP women are very active sexually at the drop of a hat...". Non-discriminating male seeks (and finds) non-discrimininating female...What a relief! For a minute there, we thought at least <u>some</u> people might be chaste!

SRV-Related Resources

*English National Board for Nursing, Mid-Wifery and Health Visiting. (1983). Caring for People with Mental Handicap. Brochure No. 2: Evaluating Services. The English National Board for Nursing has published a boxed set of monographs in 1985 designed mostly for personnel in institutions who care for mentally handicapped people. The set would not be particularly interesting to a North American audience except that brochure No. 2 of the set, on evaluating services, is de facto an outstanding tool for teaching people who are not academically schooled or overly intelligent about SRV. The material was up-to-date with 1985 SRV concepts, which is exceedingly rare. It emphasizes valued roles and reflects extensive utilization of the 7 core themes of SRV. Actually, it only deals peripherally with evaluation, but is definitely somewhat slanted toward residential services. Unfortunately, the brochure is apparently not sold by itself.

*In Search of the Monkey Girl by Levenson & Gray (1982) is a photographic tour of circus and fair side shows during the 1970s, with a modest amount of text. NYS passed a law, apparently in the early 1970s, that prohibited the exhibition of freaks for money. Even though the State Supreme Court voided the law, freaks pretty much disappeared from the NY fair and circus scene. The photographer reported abandoning his assignment at the day on which a circus got swamped by "groups of retarded people and paraplegics in wheelchairs and stretchers" who had apparently been brought to attend <u>en bloc</u> (Levenson & Gray, 1982). He liked freaks and geeks (crazy-acting freaks), but not "handicapped" people.

*The Disability Rag (5/84) noted how things that are currently stigmatizing and associated almost only with handicapped people could become universal and social role valorizing. For instance, it suggested that aerodynamic power chairs be designed so that people would want to buy them in order to use them for their own regular transportation purposes to and from work or between distant offices. As our world gets louder, everyone may have to learn sign language as a second language. It also pointed out that there have been a large number of catalogues a and reference sources on prosthetic aids and similar resources for handicapped people. Now, two catalogues are out which do not emphasize that their products are for handicapped people, but that they make life easier for a lot of people in general, some of whom may have difficulties doing certain things. One of these catalogues is called <u>Comfortably Yours</u>, and the other one is <u>Tools and Techniques</u> for <u>Easier Gardening</u>.

*John O'Brien (93-D Treeview Lane, Decatur, GA 30038) has authored a small monograph entitled <u>A Guide to Lifestyle Planning</u>. The guide looks very solid to us, though we are not optimistic that the vast majority of human services will be able or willing to adopt this strategy, particularly since it requires quite a bit of time and commitment. Lifestyle planning is a bit similar to a strategy we had advocated some years ago for elderly persons, namely making available a fixed point of expertise and wisdom to which elderly people could go in order to work out a plan for their old age. We saw such a fixed point as emphasizing existential perspectives more than narrow technical counseling. Further, O'Brien's lifestyle planning process also contains some elements of what we call clinical problem solving, as well as of the process of constructing services for model coherency, plus other elements.

TIPS Employment Exchange

A. J. Hildebrand, from the Pittsburgh, PA, area has been involved with our TI for a number of years, first as a workshop sponsor, then a participant, and then a trainer. Like some other friends of ours, he did too many right things that the imperial service system could not tolerate, so he is now seeking work that he would be able to carry out with a clear conscience in the areas of training, advocacy on behalf of handicapped people, and/or residential services to the handicapped that stress community. He can be contacted at 35 L Street, Beaver, PA 15009, 412/728-6568.

Miscellaneous

Paradoxically, one of the worst things farmers have done in 1985 is to produce another bumper crop, which will drive even more of them into bankruptcy than if the crop had been a failure. We really need to learn to appreciate the perversity in these realities (<u>Time</u>, 26/8/85).

Abortion

*In 9/85, Syracuse public television brought a 3-hour program on abortion. It showed two abortions being performed on young women, and one of the insights that struck the TIPS editor very powerfully was what an obscene analogue to life-giving sexual intercourse death-dealing suction abortions are. The program showed the women spread out on a gynecological examination table with the abortionist inserting a penis-like contrivance into the women's vaginas and then turning on the suction apparatus. This produced prolonged jerky vibratory motions in the device, and in one instance in a woman, bringing her to convulsive movements that were like a parody of orgasm. Some of the passages also suggested the hypothesis that some homosexual physicians become abortionists out of a hatred of reproduction.

It was also very impactful to observe that suction abortions took less than a minute to perform, and that during this process, the jar which eventually absorbed the parts of the dismembered baby was covered by a sheet, and after the abortion was over it was carried out of the room under cover so as to spare everybody the hideous reality.

Further noteworthy was that in some abortion clinics, the receptionist may also function as a counselor to the women, and then as an assistant to the abortionist during the abortion. A woman in these combined roles was shown wearing ordinary street clothes throughout all phases, even during the abortion itself where one ordinarily would expect more medicalized attire.

Among the pro and con commentators on the program was Nathanson who claimed that the Mafia has gotten into the abortion clinic business because it is so profitable.

The program showed an abortion clinic in a building that looked like a church in Chester, PA (near Philadelphia), which at one time had actually been a seminary.

*One of the cases before the US Supreme Court now is an IL law that would require physicians to inform women whether the birth control device prescribed prevents conception or prevents birth. Even though this kind of information would increase a woman's autonomy of reproduction, as clamoured for by most feminists, the very same feminists are apt to oppose the provision for the simple reason that it does lead to better informed consent by women.

*The Community Living Association of Canada (formerly the Canadian Association for the Mentally Retarded) passed a resolution at its 1985 annual meeting opposing the legalization of abortion merely because the unborn appears to have congenital impairments (NIMR, 85-4).

"In Montreal, a lawyer who had been working without charge in an effort to close abortion clinics which he and many others thought were operating illegally was sought out by an assassin who pumped five bullets into him as he left his office late one night in October 85 (Interim, 12/85).

*Not long ago the very influential editor of the Greenwich <u>Village Voice</u>, Nat Hentoff, came out against infanticide, complaining among other things that the handicapped newborns were being "treated like fetuses." In the meantime, he has taken yet another step and has come out against abortion too, which is probably one of the most dramatic turn-arounds among abortion leaders since Dr. Nathanson made a similar turn-around. However, this has not endeared him to the <u>pro-life</u> forces, because he has perceived the underlying continuities in deathmaking, and has shamed the pro-life forces by pointing out the inconsistencies in their very common support of war, capital punishment, and wide-spread support for the Reagan administration which, in turn, contributes mightily to deathmaking of the children of the poor.

Hentoff may have gone one step further than Nathanson who is not opposed to abortion in principle, but only in practice, and who makes a great deal about whether the infant being aborted feels pain or not. Hentoff points out correctly that that is the wrong issue to draw. He has challenged the left to come out in support of life, and referred to their support of abortion as "the hole in the soul of the Left." (Village Voice, 16/7/85).

Child Killing

*In 1970, Urie Bronfenbrenner, a prominent Cornell University child specialist, said "One of the signs that a society is beginning to lose its vitality is that children cease to be central in the lives of people."

*One element of the controversial 1984 Baby Jane Doe case was a public broadcast of an interview between a news reporter and the parents of the infant. The father was a well-dressed professional man in his 30s at whose side stood his wife who, every so often, waved her arms up and down and screamed "Where are my rights? What happened to my rights?" Thus, withholding treatment from one's baby was perceived from a very narrow, technical and legal perspective as one's rights, reflecting the modern extreme individualism of our age.

*Whereas some people are now referring to very premature babies as "living abortions," there is also reason to believe that severely impaired newborns may be falsely interpreted as having been aborted, and made dead. This possibility was dramatically revealed in Wichita, KS, in 1982 when a malformed but subsequently additionally mutilated dead baby of normal birth size was found among the bodics of aborted and still-born infants that were being sent to the incinerator.

*A \$30 million class action law suit was filed on behalf of 24 infants born with spina bifida who were "allowed to die" without treatment over a 5 year period between ca. 1977 and 1983 in a "quality of life" experiment at the Oklahoma Children's Memorial Hospital, a state-run teaching hospital. This is the project under Dr. Shaw that used an utterly ridiculous pseudo-scientific formula for deciding who should receive treatment and who should not (NCR, 1/11/85).

Deathmaking: "Euthanasia"

*On 5/1/86, the CBS investigative news program "60 Minutes" carried a segment on the nearly universal acceptance of "euthanasia" in the Netherlands. In 1985, 1/6 of all people who died in the Netherlands, or about 20,000, were said to have died from acts of "euthanasia" performed by, or in collusion with, their physicians. The program interviewed a number of such physicians, one of whom admitted having performed 100 "euthanasias," and another one about 20, and one of these even claimed that "euthanasia is not killing," which illustrates dramatically the detoxifying power of language. Another physician who was interviewed objected to the "euthanasia," but only because physicians were doing it. He said that civil servants should be trained to do it instead. Presumably, what he means is that the government should do the killing through one of its employees. Even though "euthanasia" is still against the law in the Netherlands, the law in essence has abdicated its responsibility for the issue, in response to overwhelming popular approval for "euthanasia." The churches also go along with the "euthanasia trend." The program even showed a Catholic priest who functioned as part of a "euthanasia" team. Interestingly, a great proportion of the people who planned their own "euthanasia" did so because of their fear of nursing homes, even though nursing

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homes in the Netherlands are on the average much better than those in North America. Also, many of these acts of "euthanasia" were performed on the basis of so-called "living wills." A fascinating element of naivety in all of this is that all of the pro-"euthanasia" advocates seemed absolutely convinced that the current program of voluntary "euthanasia" could not possibly degenerate into involuntary "euthanasia." Of course, on the other hand, hardly anybody even 10 years ago would have believed that voluntary "euthanasia" could have gone as far in the Netherlands as it has. A common strategy of the forces of death is to announce that the current mode of deathmaking will be the last, much as Hitler always promised that his most recent annexation was the last.

*Just about the same time that it was revealed that Dutch physicians commit "euthanasia" on at least 7000 persons annually, the Dutch government has proposed lowering the age of sexual consent from 16 to 12.

*In Germany, <u>Der Spiegel</u> is the equivalent of <u>Time</u> magazine. In a 10/85 issue, it commented on how common "mercy killing" was in the US. It also claimed that 35 states now have so-called living will legislation, and that 5 million Americans have signed such a will. It noted that Medicare spends a fifth of its monies for people in the last year of life, and that this is a powerful incentive for pressuring people to sign a living will that would permit the early withdrawal of life supports. A position paper promoting such a policy has actually already circulated in the US Department of Health and Human Services.

*Florida may be developing as the US capital of "euthanasia." Perhaps this should not surprise us because in the 1970s, the state legislature almost passed a "euthanasia" bill that would have legitimized the killing of many of its retarded institution residents. In 1/86, a Vero Beach, FL man called the police and admitted that in 1982, he had given a drug overdose to his cancer-ridden wife. The death had been ruled a suicide, and as a result of his confession, the man pleaded guilty to manslaughter but was merely given probation. Efforts to legalize "euthanasia" in FL will soon be renewed (Fort Lauderdale Sun Centennial, 7/1/86; source item from Brian Silberberg).

*Ever since Medicare put a new payment plan into effect in 10/83, hospitals are being paid a set amount based on a patient's age, sex and diagnosis, and the hospital therefore has a powerful incentive to spend no more than its allowance, or even to spend less so as to make a profit. Thus, hospitals may discharge patients prematurely, or even do things that de facto make them dead.

One distinct possibility is that since denial of food and water is becoming more frequent and involves a great deal of suffering, not only will more and more sedatives be administered so that a patient in essence spends the last days of his or her life unconscious, or that even toxic levels of drugs, or outright poisons, may be used to bring about a patient's death on the rationale that this is more merciful than letting a patient die slowly from a lack of food and water.

Deathmaking: Miscellaneous

*We reported earlier on the increasing danger of salmonella poisoning, and some actual poisonings that did happen. One of these took place in 1984 at the Oxford Regional Centre for the Mentally Retarded in Ontario, apparently due to eggs, exactly as we had mentioned, and several people died. The Ontario government responded with a set of regulations about "The use of raw shell eggs, pasteurized frozen eggs, dried whole egg powder and powdered egg nog mix in uncooked products and dietary supplementation," and another set of regulations on how to prepare pureed foods. Facilities not obliged to abide by these regulations were urged to do so. One implication of these regulations is that handicapped people whose diets are controlled by these regulations would never again in their lives have lemon meringue pie. (Source item supplied by one of our agents in Ontario) *People are phenomenally insensitive to juxtapositions in their environments that constitute profound messages. A MA paper (<u>Morning Union</u>) of 2/1/86 carried one news item that announced that "Society Ends Euthanasia," meaning that in order to reduce stress on its workers, the CT Humane Society would no longer destroy animals, while another article in the same issue announced that "Ending Dialysis Treatment may Become More Common" for humans. A third article in the same issue noted that the Behavior Research Institute in Providence, RI, sought permission to resume the kind of extremely aversive punishments that a few months earlier had led to the death of one of its clients. (Source items furnished by Michael Kendrick)

*A physician in Israel has been studying cometose patients since 1960, and has concluded that they die of two causes: bronchoaspiration and starvation. The best way of giving comatose people food by mouth is while they are seated upright (<u>RTL</u>, 6/85; source item furnished by John Morris).

*These days, we hear a great deal about arson, and a great deal of that takes place in the rundown sections of cities. What we do not often hear is that some of the people who die in such fires are people whom the service system has dumped. For instance, when 2 residents of an arsoned home in Syracuse died around Christmas 1985, their identity was scarcely mentioned in the news media.

*How ready the medical sector is to give up on a devalued patient was revealed by the death of a 57-year old woman who had been in family care in NYS because of a 20-year history of mental disorder. The woman had been out shopping during the day and had gotten ill in the evening. When she was taken to a hospital on an emergency basis, her medical complaints were very poorly handled by two different physicians. One of them had been her family physician, but paradoxically, he claimed that he had always known her as mute, though this was most definitely not the case. She was diagnosed by one of the physicians as having a respiratory infection (which proved to be incorrect), and by the other one as being constipated and dehydrated. Neither physician did an adequate physical examination, ordered relevant tests or sought relevant background data. They both pumped her full of various psychoactive drugs on top of 3 others she was already taking, and when her vital signs continued to fail, one of them ordered a "no code" over the phone without any further discussion with the patient, family, colleagues or caretakers. The woman died that night--the same day during which she had been out shopping in the afternoon. An autopsy discovered that she had died from gangrene of the bowel due to an intestinal obstruction which apparently resulted from a previous operation she had had a year earlier for a prolapsed rectum-during which a retractor had been left in her abdomen which had required a second operation. ("In the Matter of Florence Austin," by the NYS Commission on Quality of Care for the Mentally Disabled, 9/85).

*In 10/85, the University of Calgary faculty of medicine hosted a most peculiarly named symposium on "Human Embryo Experimentation and Childhood Cancer: The Right to Die." Generally, the panel, consisting of physicians, lawyers, media representatives and ethicists, endorsed human embryo experimentation, experimentation on dying children, and deathmaking, whereas the vast majority of the audience was strongly opposed to most of these, underlining the growing alienation between the public and the medical profession (Interim, 12/85).

*It is rather vexing to see pictures of a very youthful-looking Nobel Prize winner Christiaan Baraard, age 63, cavorting with a 22-year old girl friend, and promoting cosmetics that supposedly slow down the aging process--at the same time as Barnard promotes "euthanasia" and the killing of the unborn and the handicapped newborn, i.e., those who do not live up to our hedonistic values and standards of human beauty (Newsweek, 2/12/85).

*In Mexico City alone, 30,000 children are killed every year by chemical and biological poisons which induce respiratory and gastro-intestinal diseases. Overall, pollution is believed to account for about 100,000 deaths a year in the city (<u>Time</u>, 6/8/84.

"HOUSEKEEPING ANNOUNCEMENTS"

Sec. 1

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