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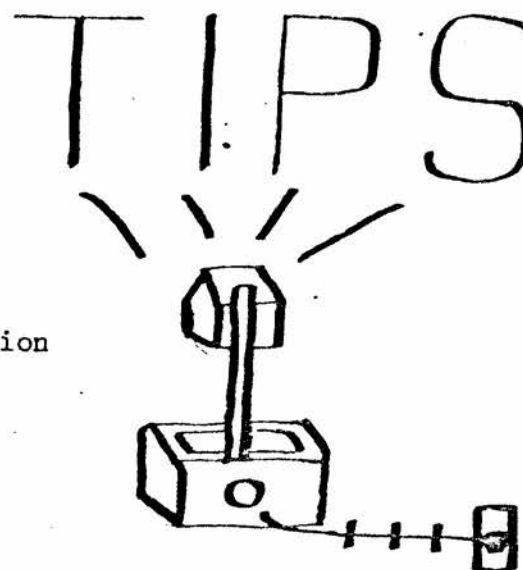
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H A P P Y B I R T H D A Y T I P S !

This is the first issue of the newsletter of the Training Institute for Human Service Planning, Leadership and Change Agency (TI). TIPS stands for Training Institute Publication Series--or at least that is what we say. As you can imagine, there were herculean internal struggles within the TI empire about which name and acronym to choose. We rejected competitors such as TIPSY, CORN, SPLIT, TILT, TIC, and NEWT.

The production of TIPS has been under consideration for many years. In fact, we have saved up copy for it for about two years just in case (as decision theory dictates...). This means we have a backlog of copy. We nevertheless invite reader submissions of items. Please read the section on page nine entitled "Invitation to Submit Items for Publication."

In every issue, efforts will be made to provide a balance of items relating to issues with which the TI is identified, such as new developments in the normalization principle, service quality and evaluation developments and training, moral and values issues and their role in human services, etc. This periodical will make a conscious attempt to highlight positive developments as well as disclosure and analysis of perversions--before, during and after their occurrence. Hopefully, TIPS will provide a support mechanism to people out in the field, as well as a vehicle for information-sharing of common concerns or interests. True to TI form, there will always be a page for "Housekeeping Announcements" which will detail specific information pertinent to TIPS subscriptions, renewals, address changes, etc.

REFLECTIONS ON TRIUMPHS AND TRAGEDIES

A Case of Liberation

(Submitted by Ira Fisher, a social worker at the Syracuse Developmental Center, an institution for people who are mentally retarded, Syracuse, New York)

I'm writing a personal note to bring some historical perspective to the struggle being waged by people living here to get out.

This morning, I got a phone call from a friend of mine. His name isn't important. What is important is that I used to be his social worker, when he lived at Willowbrook State School (on Staten Island, off New York City). My friend called me from the Hotel Syracuse where he was attending a conference on educational opportunities for handicapped children. He has been named to an advisory board to help identify unserved and underserved children. My friend is also employed by the Office of Mental Retardation/Developmental Disabilities in New York.

I stopped at the Hotel Syracuse to see him. We shared some reminiscences about mutual friends, talked about our current activities, and were, in every sense, peers. He joked with others at the conference that he knew me when "I used to be retarded," and said I had come there to commit him to Syracuse State School (as it used to be called).

I was struck immediately by his appearance. My friend has cerebral palsy. When I knew him, even in 1971, after he left Willowbrook, he was thin and had a pallid complexion. The man I saw today was robust, self-assured, vibrant. He spoke clearly and eloquently. When I knew him, I found it very hard to understand his speech.

My friend has his own apartment near Lincoln Center in New York. To understand the magnitude of that accomplishment you would have to have seen the absolute deprivation in which he lived. My friend lived on a segregated ward in a segregated building at Willowbrook. He had 50 or more "room-mates." He ate, or more accurately, was fed, in a loud, barren chow line that more closely resembled the prison dining rooms you see in films than anything most of us experience.

He was called, universally, by a diminutive first name, and although an adult, was referred to as a "working boy." His job, delivering messages and cleaning office corridors, earned him 2 to 5 dollars a week, which he got in the form of a "store card" that could only be spent at an overpriced shop on the grounds of Willowbrook, whose profits went to benefit employees of the school.

During the expose of the Willowbrook horrors in the early 1970's, he was befriended by a powerful person, Geraldo Rivera of ABC television. Their relationship continues to this day. Secondly, the lawsuit against Willowbrook and the resulting consent decree made it possible for my friend and hundreds of others, many even more capable than he, to leave the catacombs.

If I had been given a description of my friend's current station in life when I knew him at Willowbrook, I would not have believed it possible. The horrors of the system, then as now, place artificial limits on our perceptions of each person's abilities. Another reality now, as then, is that we human service workers, working in that same corrupt system, cannot and should not be trusted to provide services without rigorous monitoring and advocacy.

The horrors of Willowbrook are not remnants of the distant past, or limited to Staten Island. They exist here and now where I work. Whether we welcome them or not (and I am saying that we must welcome them), external advocacy in the form of citizen advocates, program evaluations, advisory committees, and when called for, lawsuits, are the best hope for a change in the lives of people we are claiming to serve.

The Life and Passing of Ms. Cuney

(Submitted by Milton Baker, a Team Leader of the Syracuse Developmental Center, an institution for people who are retarded in Syracuse, New York)

On October 6, 1897, Ms. Cuney was born in Mexico City, Mexico. Throughout her entire lifetime, she was unable to speak and had difficulty in learning. At the age of 21, she was admitted to Willard State Hospital for the mentally ill in New York State. Ms. Cuney lived in five institutions for a total of 62 years. She died on October 7, 1980, at the age of 83, after living at the Syracuse Developmental Center for a number of years.

The suffering which Ms. Cuney endured during her final hours was not unlike that which she had known throughout her life. Ms. Cuney died alone in a hospital, enduring a great deal of pain. She had no family or friends at her side as she faced her last hour on this earth.

Ms. Cuney's family left \$2200 for her burial. The undertaker, in commitment to worldly values, attempted to place Ms. Cuney's body in a "pauper's casket," charging over the usual cost. Through the advocacy of one person, Ms. Cuney was given a metal casket.

Ms. Cuney was laid to rest on Friday, October 10, 1980, on a hillside in a large Syracuse cemetery. Ms. Cuney's final resting place was in a plot of ground owned by the State of New York, specifically designated for handicapped people. Separateness in life, separateness in death!

As the priest led a small group of human service workers and handicapped people in prayer at the grave site, one could not help but notice that Ms. Cuney's casket had a dent in it, and the paint along the bottom was defective. Was Ms. Cuney buried in a casket rejected by the manufacturer as a factory second? Was the casket set aside to be used for a person who didn't matter? Had Ms. Cuney experienced rejection after life, rejection in death?

Now, a few hours after Ms. Cuney's interment, a room in the institution is empty. The only reminders of her many years here are her tattered clothes, a jewelry box and a Bible.

Ms. Cuney's room, although vacant now for a few days, will soon be occupied by another person who in his or her time will travel the same lonely road in the never-ending recycling of people through the institutional system.

HOPE AND COMMENDATIONS

*George Cox, a Quaker, and a former Director of Research and Evaluation in the Georgia Department of Offender Rehabilitation, resigned his position in 1980 because of the state's adamant pursuit of the reinstatement of the death penalty. Since then, Cox has supported himself on a free-lance basis by consulting, has worked on his doctoral dissertation at Emory University, and has participated in efforts to lobby the death penalty to death in the Georgia legislature.

*The Director of the Georgia Advocacy and Protection system, Patricia Powell, and her husband Joe, have adopted a 4-year old girl with Down's syndrome. Patricia took a leave of absence from her position this past winter in order to devote her full-time efforts to this process. Only through an informal contact of another staff person of the Georgia Advocacy Office were Patricia and Joe able to locate the child (i.e. it was not through the help or auspices of an agency).

REVIEW OF A RECENT PUBLICATION

Frodi, A. Contribution of infant characteristics to child abuse. American Journal of Mental Deficiency, 1981, 85, 341-349.

COMMENT: One can assume that child abuse may involve either a form of scape-goating of the child by the parent, or a form of parental rejection and distancing. Research has shown that prematurely born or difficult infants and children who are mentally retarded or physically handicapped, are particularly likely to be abused and assaulted by their parents. One dynamic which is apt to elicit parental rejection is the violation of parental expectancies due to infants being small, developmentally retarded, unattractive, crying with high-pitched voices, requiring special care, etc. Even the premature arrival of an infant may shatter parental expectancies, and the common early separation of the premature or handicapped infant from parents may interfere with the process of parent-infant bonding. In one sample of abused children, it was found that 29% showed significant deviations from the norm prior to the time at which they apparently began to be abused. In some studies, it has been shown that parents who responded with abuse to the atypical crying behavior of their infants showed the same physiological response patterns to the infant's crying as would be expected from people who are repeatedly insulted, exposed to noxious sounds, given electric shock, or asked to imagine the things that make them the most angry. Once abuse begins to take place, chances increase dramatically that the abused child will become handicapped, if not already handicapped to begin with. Most of the above findings have been confirmed in numerous studies.

EMPLOYMENT EXCHANGE

Gregor and Donna Smith are returning to Saskatoon, Saskatchewan, and are looking for human service type employment in any of the following areas: Residential Services, Vocational Services, or Advocacy. For more specific information, please contact: Gregor Smith, c/o 5 Kirk Crescent, Saskatoon, Saskatchewan, Canada S7H 3B1.

GLOOM/DOOM/DISASTER---WHAT IS TO BECOME OF US?

Heaven Protect Us From Protective Services

Protective service placements which result in the supposedly protected person being severely abused are by no means practices of the distant past. As recently as in October 1980, elderly people in Wisconsin who were placed under protective services were apt to find themselves committed to acute care wards of psychiatric institutions, where they were in much danger of being hurt. Many such individuals were also apt to be placed into the chronic care sections of such facilities, at least some of which are licensed as nursing homes (Milwaukee Journal, 30 October 1980). Thus, even under favorable conditions, receiving a protective service in effect meant that one is institutionalized for life in a so-called geriatric psychiatric institution. Another way of putting this is that the kind of archaic institutionalization which we have read and heard so much about has re surfaced under the progressive euphemism of "protective services."

The Fruits of Nature-Alienated Hypertechnical Complexity---
Cr is it Hypercomplex Technology?

The Earth Sciences building at one of the major citadels of American technology and science, the Massachusetts Institute of Technology, was constructed by the architect Pei as one of the tallest buildings in Cambridge, attempting to illustrate a number of design capacities, including the ability to stand on slender pylons without having any floors on the lower levels. However, it turned out that the stresses within the building caused its very costly windows to crack so that the courtyard around the building had to be roped off to protect pedestrians from the work of one of the illustrious graduates of the university. Furthermore the building obstructed the air flow in such a fashion as to funnel it downward so that many people were not strong enough to open the doors of the building, and new doors, inharmonious with the structure, had to be installed. Finally, the daylight was shut out of the building by bronzed windows so that even on bright days, electric lights often had to be turned on, while the life giving sun was blurred out during winter. It is unlikely that a traditional Chinese architect would have violated the harmony of nature to create such a building. Yet this alienation vividly expresses the status of American technology and academic science, and underlines the hazards of attempting to elevate technology to idolatrous heights.

Our society's alienation from the realities of nature are so great that on July 3, 1980, a news report that there might be major farm crop disasters in the belt of states stretching from border to border up and down the middle of the United States was placed on the 9th page of the Syracuse Herald Journal. The news that extreme heat and drought might destroy key elements of the 1980 crop was also mixed in with other less important local weather news. Not mentioned was the fact that events of this nature might imbalance the entire world nutrition, and thereby economic and political, systems; and the relationship of weather to world political stability was apparently not recognized. We in human services must, of course, realize that political developments have extensive impacts upon human services.

On Futurism

*The shortsightedness of even our highest leaders was underlined in an Associated Press report (published in the Syracuse Herald-Journal in Sept. 1980) that at the time of the report, there was "a huge cushion of surplus oil" in the world that would postpone another oil crunch for several years. Upon closer reading, it turned out that the "huge surplus" consisted of inventories which, in some of the more prominent oil-consuming nations, would last somewhere between 75 and 120 days. In other words, the presence of ten weeks' supply of oil was sufficient to be seen as a "huge surplus," and as pretty much absolving all sorts of leaders from any acute anxieties about energy. This extremely modest reserve was referred to in the headline of the report as a "glut." It is hard to be futuristic in human services if the top leaders in business, economics and government view 10 weeks as an unimaginably remote stretch of time.

MISCELLANEOUS

*In 1980, Columbia Hospital for Women in Washington initiated its "Comprehensive Betty Ford Breast Diagnostic Center."

*During the 1970's, the United States sold industrial hardware and software for the production of tanks to Russia. As a result, by 1980, Russia was mass producing very modern tanks on a moving belt, enabling the American military and government to demand an acceleration in its own armament program in turn. In turn, this means a drastic reduction in support for human services, and an impetus to inflation.

*According to some analyses, the percentage of federal funds going to community rather than institutional services has actually declined since 1970, with greater incentives going to institutional services (This Month in Mental Health, December 1979).

*In early 1981, one could read an ad for "health care security" in Health Care News, (1981, 3(9) p.2). Interestingly, the ad did not explain any further just what "health care security" provided, other than "ultimate quality in uniformed security guards and safety measures, including on-premises theft investigation." Might "health care security officers" some day escort debilitated people to their "mercy deaths"?

*John Lennon was widely reported to once have said that the Beatles had become more important, or at least more popular (the reports are somewhat unclear on this point), than Jesus Christ. Insofar as mass entertainment has become so totally identity-absorbing for so many people, the statement is actually accurate in a certain sense.

*An American firm introduced a line of very much needed portable toilets which it called "Here's Johnny." In 1977, Johnny Carson, host of NBC's Tonight Show, filed a \$1.1 million law suit against the manufacturer, claiming that he had usurped Carson's slogan, once more demonstrating the sensitivity of people in show business and the business world to imagery. Would that people in human services were equally as sensitive to the images of their clients.

NORMALIZATION TIPS

Some Interesting Violations of the Normalization Corollary of Culture-Appropriate Routines and Rhythms

Culture-appropriate expectations for routines and rhythms of the year can be violated in all sorts of ways. A few examples follow:

- Holding a "Christmas in July" for handicapped people, usually to "make them happy."
- Staging Thanksgiving dinners for handicapped people and nursing home residents two weeks before Thanksgiving.
- In some human service settings, the birthdays of everybody who has a birthday in a specific month are celebrated all on the same day of the month. This custom would of course also de-individualize a person.
- Holding church services on Friday afternoons instead of Sunday (or even Saturday afternoons for Catholic masses as do many Catholic churches) in nursing homes. (Maybe no one thought of actually taking someone "out" to services.)

Normalization at AAMD

The flyer mailed out in 1980 to announce the 1981 annual meeting of the American Association on Mental Deficiency (AAMD) listed as one of the features of the upcoming convention a program on "normalizing feeding training for severely and profoundly retarded persons." This program title was only a few lines removed from another one promising "art therapy, music therapy, and dance therapy."

Ein Lumpendevianat?

In German, Lumpen means rag, and derivatively, a bum. Karl Marx used the term Lumpenproletariat to refer to one of the lower socioeconomic classes of people. Various forms of this term have been used since, e.g., Lumpenprofessoriat, to refer to academicians who function on a low level. It almost seems that a new lumpen group has now been established by the National Federation of the Blind. In an unbelievably inappropriate (1980 or 1981) public education flyer, the Federation complained that blind people had been "lumped" with other people who are widely considered to be dependent on societal charity. (So far so good.) However, as an alternative, it called for a "new lumping," by the blind and for the blind, into their own national federation of the blind. The single biggest word on this news release was the word "lumping," presented in letters approximately seven times larger than those of the rest of the text.

Mandatory Death Therapy For Patients Diagnosed as Suffering From the Killing Syndrome?

After a number of youngsters had been murdered in Atlanta in 1980, medical authorities began to refer to these events as "an epidemic of murder" that was considered to be a "health hazard." Accordingly, the federal Centers for Disease Control were called in to help solve these crimes through the application of epidemiological techniques. Obviously, the possibilities for applying the medical model to crime are unlimited (Newsweek, 22 December 1980, p.62).

The (Positive or Negative) Image Juxtapositions of the Month

*We are very familiar with situations where a human service has been sited on top of, or adjacent to, a garbage dump or similar place of discard. Somewhat less common, but perhaps even more symbolic, is the location of a garbage disposal process on the site of a human service setting. For example, efforts were made in 1980 to construct a garbage incinerator on the grounds of the Pilgrim Psychiatric Center near New York City--once one of the largest mental institutions in the world, and at that time still accomodating 4,000 residents, more than 60% of which were over 65 years of age. It is ironic that the garbage to be burned in this incinerator would come from the relatively affluent residents of Suffolk and Nassau counties on Long Island.

*One subtle fashion in which a menace image can be projected on handicapped or devalued people would be by any administrative or legal provisions which permits a person to apply time spent in a human service institution against the length of a sentence imposed upon them for a legal offense. For instance, a 1979 revision of the Juvenile Delinquent Law of New York State provided that when a juvenile was sentenced to some kind of correctional facility, any time that s/he spent in a local hospital or mental facility would be credited toward the length of the person's sentence. The remarkable implication of such a provision is that residence in a mental health or mental retardation institution, or on a psychiatric ward of a general hospital, constitutes imprisonment and punishment. It is remarkable that there has not been a massive outcry by human service workers against this kind of implication, which appears to validate claims made by vociferous debunkers of our prevailing human service myths, such as Thomas Szasz.

*The symbolism of the "no exit" sign on a narrow one-way entrance to the Millhaven Maximum Security Penitentiary in Ontario did not escape a journalist for the Ottawa newspaper The Citizen Focus (8 November 1980), who observed that the sign was a grim reminder that for many inmates, it was indeed a one-way street, and that many find freedom only in the back of a long black hearse.

Let's Vote, Not Load

One of the normalization corollaries is not to congregate more societally devalued people together than the surrounding social systems can absorb. A classical case of overloading of social systems occurred at the time of the 1980 federal elections when an institution drove 200 mentally retarded people to be registered to vote--even though very few of them could read or write, and required massive and systems disabling amounts of assistance, apt to generate hostility in citizens forced to wait endlessly in line. 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 excruciatingly slowly, and taxing the patience of the non-retarded citizens who were waiting to vote. It is quite common to hear such things done under the name of normalization.

Miscellaneous Normalization TIPS of Interest

*In some instances, it has been found that agencies charged their federal funders a certain fee for providing "one dose of bowling therapy." In the early 1970s (when prices were lower), this might have amounted to \$15 per dose.

*What is one to say about an outdoor educational center that serves handicapped people, their families, and the professionals concerned if it is called "Hemlocks"? For well over 2000 years, educated people in the western world have associated hemlock with a poison that Socrates was forced to drink for having "seduced the youth of the state." Hank Bersani, Syracuse, N.Y.

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"HOUSEKEEPING ANNOUNCEMENTS"

Address Changes. You must let us know if you change your address. TIPS is in the class of trash mail that is neither likely to be forwarded nor returned to the sender. Thus once you change your address without telling us, this will probably be the last we ever hear from each other. We will also not be able to furnish replacement copies for those lost during your move. However, we will replace a copy that arrived in severely mutilated condition.

The Training Institute. The Training Institute for Human Service Planning, Leadership and Change Agency (TI), directed by Wolf Wolfensberger, PhD, functions under the auspices of the Division of Special Education and Rehabilitation of Syracuse University's School of Education. Dr. Wolfensberger is a professor in the Mental Retardation Area of the Division. Since its founding in 1973, the TI has been supported primarily from fees earned from speaking events and workshops (across the world as well as in Syracuse), and to a small extent from consulting, evaluations of services, and the sale of certain publications and planning and change agency tools. There have been no federal grants. TI training has (a) been aimed primarily at people who are, and who aspire to be, leaders and change agents, be they professionals, public decision-makers, members of voluntary citizen action groups, students, etc.; and (b) primarily emphasized values related to human services, the rendering of compassionate and comprehensive community services, and the achieving of greater societal acceptance of impaired and devalued citizens.

Training Institute (TI) Publications. The TI sells a number of items, disseminates a "publication list," and updates it about 2 times a year. If you want one or more copies, please let us know.

TIPS Back-Issues Available. TIPS tries to have a supply of back issues available for new subscribers who wish to complete their set of issues. Let us know what you need, and we will offer you a package price for whatever back issues we have of those that you need.

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