

**REQUIEM OR REVIVAL?
THE GOARC-ENCOR STRUGGLE**

by: Ed Skarnulis

"We know enough about the lurching progress of social reform to take the question seriously; if we do not get our provision as right as we possibly can this time, who knows when we will get the social enthusiasm, for a reform as major as the one we are now living through?"

"But I have promises to keep. And miles to go before I sleep, and miles to go before I sleep." 2

Many of us have experienced a growing sense of concern over the events of the past few years. During that time, we have seen massive staff reductions and budget cuts in the community-based service system called ENCOR, a gradual decline in interest among parents and professionals who were previously involved in GOARC, and more "uncomfortable" press coverage than any of us would like. We have seen wholesale denial by our detractors of enormous accomplishments achieved over a period of eight years by hundreds of dedicated parents and professionals. In private conversations, I have listened to people criticize some of the creators and builders of the parent organization (GOARC) and the service organization (ENCOR). One can almost sense a need to disassociate oneself from the debacle of the past year, and out of this embarrassment comes a maligning of one's history.

The question needs to be asked "of what are we ashamed?" Are we ashamed because political officials attacked the agency's administrative leaders? Are we ashamed because the press gave a knee-jerk litany of sins without even a mention of the proud accomplishments of ENCOR? Was someone in ENCOR lining his/her pockets with taxpayer's money? Were there cruises to the Bahamas?

We can't afford the luxury of licking our wounds forever. We can't afford to become fawning, cringing, whipping boys or girls for all of the people who have come out of the woodwork, saying "I told you so." Before we beg forgiveness from anyone, before we allow GOARC and ENCOR to lapse into antiquity as "the Camelot experience," we need to review what has really happened in the past eight years.

I would like to remind the press, politicians, and general public of the thousands upon thousands of hours donated by parents of mentally retarded children and adults to make GOARC and ENCOR a reality. I would like for

1 Shearer, Ann. "No Place Like Home?" Paper given at 6th Congress of the International League of Societies for the Mentally Handicapped, Dublin, Ire.1975.
2 Frost, Robert. "Stopping By the Woods on a Snowy Evening."

people to remember the enormous personal sacrifices made by two young people, Brian Lensink and Linda Glenn. As Executive Directors of ENCOR they devoted themselves completely to mentally retarded people. Their salaries were pathetically low, the demands on them inordinately high.

Do we apologize for an agency that has achieved international acclaim? Did the taxpayers get their money's worth from the funds expended at ENCOR? Did county and State politicians receive favorable publicity about their agency over those eight years? The state achieved national recognition at virtually hundreds of conferences and seminars, in papers written by professional publications still being reprinted by their authors. ENCOR is a living legend.

There are now family-like homes outside Beatrice for over 250 people who were residing there in 1968, there have been schools of hundreds of kids who once stayed home or went to Beatrice. There are now jobs for hundreds of adults who are self-supporting and living decent, normal lives. There has been transportation provided for all the mentally retarded citizens in this area, as well as speech therapy, medical services, recreation programs, advisors for parents and mentally retarded adults. Because of the efforts of these parents and professionals, a library of the most advanced ideas in the field has been developed, a toy-lending library exists, we had psychologists, volunteers, and on-the-job education for hundreds of students from colleges and universities who came to ENCOR for training. There have been special services for people in trouble with the law. There were special programs for children with severe behavior problems or severe medical problems, there have been adoptions of mentally retarded children, there has been audio visual equipment made available to people from all over the community, and there has been intensive training on the needs of our mentally retarded citizens which was provided for employees, parents, and the public. We now have integrated pre-school programs so handicapped and non-handicapped kids can live and learn with each other. The universities and the general public have benefited from scores of visiting lecturers and dignitaries who have brought this community the most advanced ideas available in the field.

Truly, we got our money's worth from the eight year effort! Can we blithely forget Brian Linsink, Bill Falls, Bob Clark, Bob Osborn, Linda Glenn, Jane Lonnquist, Linda Tarrant, Charlie Galloway, and Wolf Wolfensburger? Those are just a few of the people who participated from the professional end. But we need to remember as well our friends in the parent group such as Bill Higgins, Jim Jacoby, Leighton Goodrich, Bill and Wilma Wills, Sally Swancutt, and a host of non-parents such as Dan Lynch, Bob Kugel, and others.

An agency undergoes baptism by fire. Politicians have a field day, old enemies come out from under their rocks to join in the attack, people begin witch-hunting and an agency either survives or dies. ENCOR has survived. GOARC has survived.

So, where do we go from here? Two hundred human beings from this part of the state are still at Beatrice State Home and the number admitted may increase if we don't get off our backsides. We cannot expect to be named again by the President's Committee on Mental Retardation as an "Island of Excellence", nor can we expect the Christian Science Monitor to highlight this agency, and we can scarcely hope that we will be mentioned in Time, Newsweek, or the Journal of Exceptional Person's, as we once were, unless we begin telling our story of what we still have and of the exciting things which are yet to occur. It's absolutely certain that we can't afford to stand still:

"Judge Judd of the District Court approved a consent degree last year (May 5, 1975) securing the constitutional rights of the residents of the institution to protection from harm. Judge Judd added a memo of his own. It relates to constitutional rights and to our social policy. He said,

'The consent judgement reflects the fact that protection from harm requires relief more extensive than their court originally contemplated, because harm can result not only from neglect but from conditions which cause regression or which prevent development of an individual's capabilities.'

He accepted the argument of plaintiffs that in an institution for the mentally retarded, it is impossible for the condition of a resident to remain Static. If his functioning is not improving, it will deteriorate. (Italics mine) Thus, to keep the residents from being harmed, it may well be necessary to provide the full range of affirmative relief, which has been ordered in some court cases, under a theory of right to treatment." 1

There must be some fresh faces of parents out there in Omaha and Bellevue who can step forward and help bring new leadership to stem our ruminating about the past, and inject us with adrenaline for the future. Virtually every committee of GOARC needs that leadership. We need parents with a renewed vigor and enthusiasm who are willing to demand what is right for their children. Without them, where will our children turn to? Without them, the crumbling of families under stress might not be heard as a loud roar, but as a sort of quiet decay.

"Celebrate your successes." We need to get together with one another and overlook the petty differences of the past in order to take on the challenges of the future. We need to ignore the detractors, and doom sayers. The indignities suffered by our mentally handicapped citizens have occurred before, and those of us who advocate for them must take as a matter of course that we will have to put up with their suffering, but not forever! Pieces

will fall into place if we begin. If we take the first step, if we join a committee and begin to devote a few hours, if we help each other along the way, we may begin to see a Phoenix arising from the ashes. Join us!

1 Lynch, Francis X., "The Developmentally Disabled Assistance and Bill of Rights Act.