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THE FAILURE OF OUR DREAM ?

For the parents of my generation who happened to have a child with a developmental disability (in those days we called it mental retardation) it began as a nightmare and grew into a dream. For the young parents of today with the same problem it has once more turned into a nightmare.

Not quite the gut wrenching fear that I felt on my first visit to Sonoma State Hospital in 1959. Our Barbara was five when I saw my first ward of sixty little girls roughly her age (it seemed that most of them had Down Syndrome), who were clearly starved for affection and touch. Who clustered around me, clung to my knees and called me "mama." That night my nightmare illustrated what I had seen, and I vowed that MY little girl - secure in her bed at home - would never live like that.

I have talked with young mothers and fathers of today, and their nightmares are different. Theirs are disturbed dreams of confusion and mazes - of intimidating interviews, eligibility rejections, cut-backs in Respite Services, and IPPs (individual program planning sessions) that feel more like inquisitions than progress reports. More often than not they aren't at all sure whether the next corner of the Developmental Disabilities Service System's maze <u>can</u> lead them towards a secure, stable dignified life for their child and peace of mind for themselves.

Back in the late fifties and early sixties it seemed like such a "high" to be involved in creating a service system for our Golden State of California. We were pioneering parents and respected for our efforts. We worked our butts off. We traveled miles - not only through the corridors of the State Capitol in Sacramento to besiege the offices of our legislators, but countless miles along the curvy backroads of rural counties to attend parent meetings, and belabor our boards of supervisors.

Our hopes rose when President Kennedy mandated that ALL states were to plan for their citizens with mental retardation. We cheered when Bank Mikkelsen, the pioneering leader of Scandinavia's mental retardation programs came to California and visited our horribly overcrowded institutions. Headlines in California newspapers quoted him as saying: "We treat cows better in Denmark." We contributed to THE plan of The President's Committee on Mental Retardation, THE UNDEVELOPED RESOURCE, which became the cornerstone of our famous Lanterman enabling legislation, the envy of other states, and the foundation of our dream - the dream that is in danger of failing us now.

THE UNDEVELOPED RESOURCE Study Commission Plan was published in 1965. Twenty-six years later its recommendations still ring true. Its ten principles are still valid and the last of the ten seems like an admonition for our current attempts to reform that which no longer serves us well: "The State should provide for and encourage creative flexibility (my underline) in all programs operating for the mentally retarded in California."

The first step in '65 was to be the establishment of a Mental Retardation Program Board which in future years would present recommendations to the Governor and the Legislature for program priorities and appropriations. (This board has now expanded into our network of 13 Area Boards and the State Council on Developmental Disabilities). There was however a great sense of urgency to take pressure off families immediately, for at that time parents had few options except to place their children in state hospitals which had long waiting lists for admission. Day and residential programs as we know them now were virtually non-existent with the exception of those that we parents had begun to create. They were few and far between.

I spent the summer of 1962 as a resident student professional assistant at Sonoma State Hospital. Our chief function was to teach at the then brand new school on the grounds. Only about five hundred of the three thousand plus "patients" were considered "educable" and attended the school. The staff on the wards - or "cottages" as they were called euphemistically - were pretty much in charge and there was little coordination between teachers and ward staff. In fact they rather looked down their noses at us teachers. We were involved in a toilet training program in the "million dollar potty" at the school but - essentially important as this was - it didn't seem to have much carry-over to the wards where our students lived!

In our spare time we had free range of the hospital. We could arrange to visit all of the wards (even the so-called back wards), attend ward team meetings - even admission committee meetings. Dr. Bramwell, the director was nicknamed "The Great White Father." He was a benevolent, kind, warm physician - totally captive to the system in which he worked. I clearly remember one admission meeting. The phone rang. The call was from a State Senator who was trying to have a person with mental retardation - the son or daughter of a constituent - admitted to the hospital. Dr. Bramwell - surrounded by his peers - did his darndest to explain to the senator about the length of his waiting list - how he understood the family's exhaustion, how he appreciated the senator's concern, but "NO" he could not let up the waiting line - "not even for you, Sir!" I will of course never know what Dr. Bramwell did two hours later in the privacy of his office, but I know what was rumbling around in my head. The images of the children on those back wards that I had seen, and once more the pictures of Barbara - now a walking talking eight-year old at home.

For back at home in the early sixties we were on a roll. Parent- run pre-schools and private schools were gradually being taken into public schools as special classes. The statewide Governor's Study Commission on Mental Retardation held hearings, asked for our input, and gave us hope.

THE UNDEVELOPED RESOURCE report prefaced its sixty specific recommendations FOR IMMEDIATE ATTENTION 1965 with the following words: "Each mentally retarded person is an individual, different from others, yet entitled to the same respect for his dignity as a human being. The State of California should make it possible for every individual to develop and grow to the limits of his capabilities."

The first action proposal for the year 1965-66 became the establishment of Regional Diagnostic and Counseling Centers. They were to be located no more than two hours' driving time from any California family - a one-door entry point for both children and their parents. Assemblyman Frank Lanterman became the champion of our movement, and the legislation named after him the fulfillment of OUR DREAM.

Regional Centers did not spring up immediately all over the California map. Each Center required intensive lobbying of the legislature for funding allocations. The first two were Los Angeles and Golden Gate Regional Centers. Initially there were to have been Regional Centers contiguous with each planning area, but because of population density we eventually wound up with the present twenty-one. It was March of 1972 when we, the parents and citizens of the North Coast, selected the first director and chief counselor for Humboldt, Del Norte, Lake and Mendocino Counties. North Coast Regional Center - now Redwood Coast Regional Center.

And at that point our family thought we had it made. Our future would now be secure. Here was the one-door entry to lifetime services for our daughter Barbara, and comfort and counseling for our family through all of Barbara's crises and life changes "until death do us part!"

So what has happened? What has gone wrong? Why do young parents have to form their own support groups outside of the tried and true original Associations for Retarded Citizens? Why do we need Protection and Advocacy, Inc. to keep many of our sons and daughters from falling through the cracks of the service system? Why do parents feel as if they had lost control over their children's programs? WHY are parents and professionals who began as allies and fellow advocates so often at loggerheads?

I turn to Frank Lanterman again for possible answers. In May of 1971 he answered a letter of inquiry by William Green, the then executive director of the California Association for the Retarded (now "retarded citizens"). Mr. Green was requesting clarification of the intent of the Legislature regarding the direct service functions of Regional Centers.

Assemblyman Lanterman replied as follows: ...."it was never our intention that the Regional Centers provide direct services other than diagnosis and counseling to advise and guide families. The other main functions are to supervise the quality of the various direct services under contract, and to stimulate the development of needed services." He also stated that Regional Centers might do this without becoming large agencies with all the attendant bureaucratic problems. "In my opinion, the Regional Centers should concentrate on securing rather than providing services and should not build up large staffs of licensing and casework personnel. "We must remember," he concludes, "that the purpose of this new program is to guide the retarded and their families in a coordinated program providing the widest scope of available services."

Well, Mr. Lanterman's "widest scope of services" has not happened. Soon it will be thirty years since my summer at Sonoma State Hospital. Much has changed and nothing has changed! My images of those wards became the visions and dreams of community programs WITHOUT large institutions. I learned that state institutions are NOT conducive to growth and development. I saw with my own eyes that for every frail and severely disabled person who has to live <u>inside,</u> there exists a "twin" who lives and thrives in a proper home <u>outside.</u> I witnessed it in Denmark and in England -in Colorado, Minnesota and Nebraska. There is now one state - New Hampshire - that has closed its last institution.

But here in California our consciousness and planning for community programs still lag far behind the cutting edge of knowledge and experience in the field, and my dream of 1962 is still unfilled. True, our State Development Centers (another euphemism) are much smaller now, and the programs have improved, but they are still large, congregate, impersonal places. The thought that our Barbara might have to live there if community programs shrivel and die, is my ultimate nightmare. For there is still abuse inside those"cottage" walls. I have seen the results of it with my own eyes.

Just recently a mother who attends our "housing" meetings in Santa Rosa brought along her teen age son whom she had just taken out of a development center because of such abuse. He sat there quietly - his eyes and nose swollen and bruised. He has autism. He is neither "medically frail," nor did he show any difficult behaviors as he sat through a two hour meeting with us. His Mother has been trying for ages, and would do anything to have him home or near her home. There are many other parents like her whom we have failed in their dreams for their children.

These parents, who still prefer to keep their sons and daughters inside, do so, because they do not trust the quality and stability of community homes. They say that abuses exist in the community also, and sadly they are right. I will never forget the tragic death of 31-year old Ray Walker who died locked in a closet in a licensed family care home in Southern California in 1985. Where was our outcry? I said it then, and repeat it now. We should have all shared the shame and the blame. We should have come together in protest and with the kind of passion that launched our efforts in the beginning of this movement.

For I choose to believe that quality, stable community programs CAN be accomplished here in California but it will take another giant effort. Then we will be able to finally achieve a "community placement plan" that works. I continue to put my hope and trust for the future in the brothers and sisters - the friends and neighbors - and especially the ever increasing ranks of peers in PEOPLE FIRST chapters. Parent-Consumer quality control monitoring programs at Macomb-Oakland Regional Center in Michigan are efficient, simple, inexpensive and WORK. We should organize them here.

I try not to think of an increasing return to development centers, but it can and is happening. We may have an idyllic enabling legislation for our people, but without fair and equitable financing we can't possibly accomplish parity or sufficient quality community programs. California's total budget for the Department of Developmental Services is divided just about fifty/fifty - one half for eight thousand residents of state development centers, the other half for approximately ONE HUNDRED THOUSAND people with developmental disabilities who live and work in community programs. This makes for a game of musical chairs, as the Department's "Community Placement Plan" makes attempts to move out some of the residents, while community programs close and residents are returned to state hospitals.

AND the Governor just vetoed the "Wage Fairness Bill" which would have begun to make a plan to even out the incredible inequity that exists between the salaries of institutional and community workers.

I see one of our major problems in the incredible complexity of our overall system. I believe Mr. Lanterman would be turning in his grave if he knew of the divisiveness in the system he launched. I have referred to it as "The Lanterman Dilute" (with apologies to a man whom I highly respected and often quote!). For our constituency has become fragmented into many pieces. We no longer have a unified voice. Consumer advocacy groups and quasi-government bodies like Area Boards, Regional Center Boards of Trustees and the State DD Council frequently have differing agendas. The Organization of Area Boards and the Association of Regional Center Contractors don't always agree. People First is beginning to raise its voice and there's Protection and Advocacy. Rarely do the Legislature and the Governor's office receive a unified message.

We should have seen it coming. I am told that it is a sociological "given" that organizations feed upon themselves - that they become bigger and more top-heavy. Though my parent head can fantasize that an ideal system to support our children and grown-ups with developmental disabilities will gradually integrate them all into mainstream programs (because "the world will have learned to accept them as human beings with the same rights as everybody else) it certainly isn't happening that way, and I am beginning to understand why.

I read an article in the Wall Street Journal (Nov. 11, 1991) by Nobel Prize winner economist Milton Friedman on a British study on health care. He quotes Max Gammon, a British physician's comparison of the input and output in their hospital system. Gammon describes his observations as "the theory of bureaucratic displacement" and states that "in a bureaucratic system... increase in expenditure will be matched by fall in production...such systems will act rather like 'black holes' in the economic universe, simultaneously sucking in resources, and shrinking in terms of 'emitted' production."

Sadly this fate seems to have befallen our Developmental Disabilities System. It has become top heavy, unwieldy, and incredibly expensive. Like the black holes mentioned above, it's been sucking up organization charts full of well paid administrators with voice telephone systems and computers on every desk, while the emitted production in wages for hands-on direct care staff, supports for families, and satisfaction of consumers are steadily shrinking.

With hindsight I can now see some of our blinking warning lights. I can see them in the life of my daughter Barbara who is now thirty-seven.

Her childhood years were spent right here in rural Fort Bragg, where we, the parents made great efforts to run a small school with lots of community volunteer helpers. We wanted our students to be as visible as possible, BUT our small schoolhouse was a private bungalow on a side street. It had to be Barbara herself who asked me: "Why can't I go to Junior High?" and a High School volunteer in our program who said: "And why CAN'T she go to Junior High? It seems to me you are protecting us from something we shouldn't be protected from!"

She said this about twenty-five years ago. But "Mainstreaming" is <u>still</u> a debated concept in our schools. "Total Inclusion" has now taken its place as a new buzz word, but the two bureaucracies that deal with the two main components of the lives of our people (The Department of Education and the Department of Developmental Services) are <u>still</u> not pooling the wisdom of their disciplines. The largest number of requests for assistance to Protection & Advocacy consists of problems related to special education. School life (which takes up about six hours of the day) is still treated as if it were apart from the rest of life which consists of home and friends, part time jobs and recreation and how to get there if there's no transportation. Both of these bureaucracies should have made it possible long ago for our sons and daughters to have full access to general community services.

But on to the next stage in Barbara's life. She moved away from home into a licensed care home in another Regional Center area when she was eighteen, and went to a larger and more stimulating school. She was exposed to greater risks and was sexually molested - at a time when the system had very little recourse or access to the justice system. Our family and supportive friends saw her through this shaky period of her life. Today our young adults will tell you loud and clear that they <u>still</u> do not receive enough support to live a rich private and social life. They say that we fail them in their attempts to have intimate friendships and sexual relations with privacy and the prospect of marriage.

We have begun to work with law enforcement and the justice system in the area of sexual abuse of our people. Our people <u>are</u> more vulnerable, and we must assure them of the same level of protection as their peers.

Barbara now has a boyfriend, and when their caretaker enabled her and Fred to room together in their licensed care home, the Licensing Department took exception to "this conjugal arrangement" and it was a sensitive and sensible Regional Counselor who rescued them by writing the "arrangement" into their program plan. Two bureaucracies at odds over a real life problem that should have been cooperatively considered years ago.

It is in the area of living arrangements that our family have encountered and experienced the greatest difficulties. Barbara's case managers have come and gone over the years. A few have been less than competent - others have been warm and committed and well informed, but gradually they have all become so swamped with the size of their case load and the requirements of pencil pushing paper work, that they have long since ceased to do proper social work, and with that their advocacy role and program development efforts have become all "washed up." At present neither Barbara nor I have met or talked with her current counselor. I have her name on a list, and Barbara occasionally wonders who and where she is!

Professor Gunnar Dybwad, who is truly one of the giants of the parent movement and my most significant teacher, recently delivered a speech to the Down Syndrome Congress. He called it "The Revolutionary Vision Unfolds." In it he says: "So far I have dealt with visions from past revolutions but in our vibrant, ever changing field, we must be prepared to deal with emerging revolutions which may bring us new visions of changes greatly affecting our work and the lives of those we aim to assist."

He then refers to an article by the Chairman of the New York State Commission on the Quality of Care titled "Regulations - Have We All Gone Mad?" and says: "Over the past years, everyone actively involved in this field, whether as parent, recipient of services, counselor, case manager, or provider is faced with a mountain of paperwork prescribed as the result of mountains of regulations, all supposedly geared to enhance health and safety, to the protections of rights and to improve the quality of life. And they all require ample documentation in quadruplicate." (my emphasis)

One particular time period stands out as "THE BETRAYAL OF BARBARA" year, and as a clear illustration of the failure of Regional Centers "to stimulate the development of needed services." Barbara literally spent most of one year living out of a suitcase when the house in which she had lived contentedly for several years could no longer keep her, due to funding cuts. She was bounced here and there temporarily, and internalized the disruption in her life as, "they do not want me here," or, "they need more money for me," while her work performance went downhill along with her self-esteem. She, her sister Karen, and I visited numerous other possible homes. We found one which she liked and where they wanted her, but Regional Center regulations nixed that placement because of a new board policy that required a mix of ambulant and non-ambulant residents and Barbara could walk!

One prospective new home was so entangled in Licensing and Regional Center start-up procedures that we could not wait for their opening - nor am I sure that these good people ever managed to open. I suspect they gave up for fear of going broke before they got a green go-ahead light from Licensing and Regional Center. Program development of homes which are so desperately needed, is virtually non-existent, and well intentioned persons who are qualified and dedicated to the idea of opening a home for our people often cannot possibly afford the waiting period nor the hassle of the paperwork. That sad situation is one of the greatest worries for parents. Both for those with sons and daughters in state hospitals who cannot get them out, and for families like us, who STILL have to sleep with the classic worry: "what will happen to him/her after I die?"

The Fair Hearing that resulted from this residential placement impass was amicable but energy and time consuming. Barbara, Karen and I were asked to visit several more homes. After each visit we asked Barbara if she wanted to live there, and each time she had a good reason for saying "no." I myself used the yardstick of "would I want to live there myself?"

At the next meeting of the Fair Hearing Team I heard a veiled threat. "Well, you realize, Lotte, that we COULD find a place for her in Napa County!" (miles away from Sonoma County and from her home in Fort Bragg where she likes to come regularly). This would have meant a total dislocation from familiar neighborhoods and a further disruption of Barbara's and our family's lives. A total violation of the intent of the Lanterman Act which had assured us that this would never again happen.

This incident - though apparently insignificant - is really symptomatic of yet another fundamental change in parents' relationship to Regional Centers. There is good reason for parents to be reluctant to go to Fair Hearing. We know that the process is intended to help us accomplish our children's program goals when there are differences of opinion, and we would put up with the travel and the time it takes, but there is more to it. FEAR has become a factor. I have experienced it myself and have heard many other parents say so. FEAR OF RETRIBUTION! "This Fair Hearing is going to be an adversarial meeting, and what if they take it out on my son or daughter?" It is indeed sad when our vision of a good life for our people has turned into a power struggle.

There are other power struggles and conflicts inherent in a bureaucracy that cannot see the need for change. The sheltered workshop mind set is changing only slowly to an awareness that our people can grow into capable and reliable employees in the mainstream of their home towns. Parents of young children are again having to be assertive and persuasive in order to convince schools that their sons and daughters need to begin their training for transitioning from school to work very early in their school lives.

I have just met one twenty-one year old girl whose life virtually ended when she graduated from High School two years ago. With low motivation and low self-esteem and nothing but unhappy memories of her school experience, she now falls between the cracks of the California definition of eligibility for Regional Center services and the bureaucratic regulations of the Department of Rehabilitation which tend to be exclusionary rather than welcoming to our people. So she sits at home with nothing to do and her mother is frantic. There must be a way in which we can do some intelligent, joint planning between departments and disciplines, so that we the parents, and our sons and daughters can solve the multi-faceted problems of living with disability. This could be accomplished by having more liaison representatives from different agencies on policy setting boards and committees where decisions are made.

There is another anachronism that originated in the early days of California's Developmental Disabilities System but has long since outlived its usefulness. We were told that the "medical model" is for institutions, and "bad" for community based programs. As a result we have few physicians as partners in policy making, and many whose clinical expertise is being preempted by Regional Center inter-disciplinary teams. This then robs the Regional Center's client, who is also the patient of his local physician, of a valuable relationship and Regional Center of a generic resource. Reality is that times have changed and many physicians have learned about our people and are committed to their care. Since many of our people do have medical needs that can range from mild to severe, from acute to chronic, it is essential that we include local physicians as full partners in our planning for them.

I don't know at which juncture we as a constituency should have cried "whoa! "to the creeping bureaucracy. All I know is that somewhere along the way we lost our loud and unified voice which launched the effort of the fifties and sixties. We are now faced with resistance to the winds of change by Regional Center management administrators whose positions we created.

Significant changes will have to be made in the structure and management of Regional Centers A group of vendors of services have come up with recommendations that I heartily support. They suggest reducing office space, using satellite and store front offices. We must reduce management personnel in favor of case managers, so that Regional Centers can provide real social work, for which they are trained. Social workers who are qualified and know their stuff do not require a heavy layer of supervision. It IS possible to reduce transportation costs by using Senior Citizens and persons with a disability as transportation coaches. Community program staff people are on the front lines every day. They have struggled against odds for years. We need to let them take back a large share of the Regional Center system.

Senator McCorquodale, his staff, the Blue Ribbon Committee of Lanterman 2000, and many parents and professionals, together with the Department of Developmental Services, are working hard to recapture the dream of the Lanterman Act. All of this gives me a glimmer of hope that it may not be too late to change our system. But my greatest hope for the future lies in the Self Advocacy movement - in the members of PEOPLE FIRST. They have lived most of their lives with our mistakes. They have made our dreams their own, and - I trust - will not fail them.