WHERE'S THE JELLO?

The Saga of One Home's Experience with the ICF/MR (Small) Program

by

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RE-PRINT

This is a **re-print** with some updating of an article originally written in the summer of 1985, a few days after a *licensing and certification* visit from California Health Services Licensing. [1] At the time, I was executive director of Bayberry, Inc., a position I retained until April of 1989. In 1985, Bayberry had a single group home (ICF/DD-H).

I sent the earlier paper to a few friends and associates. With my permission, it was distributed widely across the State. Many who read it enjoyed its *comic-tragic anecdotes* and the more serious points that I tried to make.

I learned later that many *resource developers* in various regional centers passed out copies to people contemplating going into the *ICF/DD-H business.* I was told that they wanted potential service providers "to know what they would be getting into." In revising the document, I have remained sensitive to this use. Beyond that use, my hope is that readers will:

- form a much clearer view of some of the things that go on under the rubric of *quality assurance;* and
- assist efforts to reform the ICF/MR (Small) program (if feasible) or to replace it with a much more progressive Medicaid Home and Community-Based Waiver program.[2]

An appendix on Fire/Life/Safety standards was added to the original article in 1990.

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[1] *Bayberry's Experience with the ICF/DD-H Program: A Case Study.*

[2] California has not used the Medicaid waiver possibilities, expressed in the 1981 [federal] Budget Reconciliation Act, for personal care and related services for adults with disabilities choosing to live in their own homes or apartments.

WHERE'S THE JELLO?

The Continuing Saga of One Home's Experience with the ICF/MR (Small) Program[3]

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This paper is organized as follows. It begins with a discussion of my involvement in the ICF/DD-H program, and of my reactions upon first seeing regulations for it. This is followed by an overview of the *regulatory environment,* which will give the reader some idea of the complexity in this state/federal effort. The values evident in the work of ICF/DD-H evaluators are illustrated in the next section of the paper. This is followed by a discussion of evaluation and quality assurance, and of some of the effects of licensing and certification activities. The paper closes with a number of recommendations.

Background

Since 1971, federal legislation has enabled states to use federal Medicaid funds for *facilities* with 4 to 15 residents. Bayberry's home on Calistoga Avenue, in Napa, has been in existence since 1979. Experience there is the basis for this report. The group home (*facility,* in the lingo of officialdom) was one of sixteen pilot efforts, undertaken around 1981, to enable California to get some experience with the new (for California) ICF/MR (Small) Program.

California decided to use this program to meet the needs of people in two categories: (1) those with moderate-to-severe behavior problems, and (2) those with two or more rather serious self-care deficits. Bayberry's group home had residents in the former category. In 1981, a team of federal and state officials visited the program. One federal official commented that staff were serving the kinds of people the new program was designed for, and were providing the kind of quality services expected of ICF/DD-Hs. Government agencies, we were told, simply wanted to give Bayberry "more money to do the kinds of [wonderful things] already being done."

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[3] The initials ICF/MR (Small) stand for *Intermediate Care Facility/Mental Retardation (4-15 bed capacity).* In California, homes in this category are referred to as ICF/DD-Hs or ICF/DD-Ns, where the latter initials stand for *Developmentally Disabled (Habilitative)* and *(Nursing).*

*The views expressed are those of the author, and may (or may not) be shared by others associated with Bayberry Incorporated or with Allen, Shea and Associates. All statements of fact and opinion are the exclusive responsibility of the author.

When given grant money to convert to ICF/DD-H status, little did I know what lay in store. There were no regulations, or at least none that were shared with providers in the pilot project. Months later (in 1982), when I first encountered *draft* State regulations for the ICF/DD-H program, I recall having thought that a group of health-care professionals had written them, and that nurses, medical social workers, pharmacists, dietitians, nursing home administrators, medical records technicians, qualified mental retardation professionals (QMRPs) and a vast army of therapists (physical and occupational therapists, speech pathologists, audiologists, and the like) were seeking to maximize their professional job opportunities. Each professional interest group, except for psychology, a very strange oversight, which was later corrected, seemed to want *a piece of the action.*[4]

Initial Reaction

Upon seeing the regulations for the first time, I thought to myself, this is a health professional's full-employment act.[5]

Orphanages, a Fable

Once upon a time, there were orphanages, where children who had lost their parents went to live. Despite the best efforts of some very good people, the children did not progress as well as had been hoped. Orphanages tended to be large, impersonal, and costly.

Some people decided that foster care or adoptive homes would be better. The people running orphanages were disappointed. They just knew that, if they had enough money, they could provide better care than foster or adoptive families. So, they went to work to convince the citizenry of the advantages of orphanages, and to get more money.

The going was rough. Many legislators and concerned citizens didn't know whom to believe. Were foster and adoptive parents as bad as some said? Was professional oversight as important as they were told?

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[4]I expected to see several matters dealt with, including analysis of baseline data; procedural controls on aversive or restrictive interventions, and the like, but the initial regulations were silent on these matters.

[5]The general observation is not unique to health services. Recently, a parent called me to complain that an organization had submitted a proposal to serve her son, using a paid roommate model in an unlicensed setting, and showed her unemployed son's SSI as a source of income to fund services. Much to her chagrin, proposed budgeted expenditures included no money for rent, utilities, food, clothing, or personal incidentals.

Foster and adoptive care grew in popularity, despite obstacles and road blocks.

Finally, the good people running orphanages decided that, as a condition of their less vocal opposition, foster and adoptive families would have to do exactly the same things the good people in orphanages had tried to do.

After some years had passed, there existed a few big orphanages and many, many small orphanages.

By 1985, as a result of a number of experiences and discussions with peers, I had come to some understanding of the origin of the ICF/MR (Small) regulations, and of their ostensible purpose. Basically, the regulations emerged from efforts to reform large, custodial, congregate-care facilities, such as state institutions for people with mental retardation.[6]

At a high political level, my suspicion has been that representatives of state hospitals (including hospital parents) had insisted that *what's fair for us, is fair for them.* Some people actually think that the regulations are a good thing. It is very clear that practically no one has given attention to *alternative quality assurance (and residential monitoring) schemes* to meet legitimate purposes, a matter taken up later in the paper.

The Regulatory Environment

Several sets of regulations and procedures play themselves out in ICF/DD-H programs. A few, such as recent environmental health regulations, are so minor (at least for Bayberry, Inc.) that they are ignored here.[7] There are reasons for some regulations. Generally, each new regulations is a response to some notorious deviation from *good practice*. Unfortunately, it is good practice that should be the criterion of a

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[6]Being large and complex, organizational arrangements in large institutions had evolved into a set of departmental fiefdoms, each staffed and run by a professional interest group (e.g., Nursing, Pharmacy). Members of each group, understandably, viewed their domain as important, if not vital, to the institution and to its residents (or patients). In the early 1960s there were several scandalous exposes of deplorable conditions in state institutions.

[7]The reference is to recent efforts to control disposal of hazardous items, such as hypodermic needles and other wastes. No one would fault health and safety officials for inquiring as to whether hypodermic needles and other wastes emanate from the house, since it is a *long-term health care facility.* In fact, to my knowledge, no hypodermic needles, or any other invasive items, have ever been used there. If blood is drawn, for example, to determine serum blood levels for a person taking seizure-control medicine, it is drawn at the physician's office a half-mile away or at a laboratory.

good program, not good paperwork. Some knowledgeable observers feel that these two may be inversely correlated!

FEDERAL CERTIFICATION STANDARDS

A federal survey manual (nearly 100 pages long), together with interpretative guidelines (another 158 pages long), are at the heart of the ICF/MR regulatory system, administered by the Health Care Finance Administration (HCFA), of the U.S. Department of Health and Human Services. With the idea that a small home (e.g., with 6 residents) may operate differently from a state hospital with 1,200 residents, the interpretative guidelines for the ICF/MR (Small) program make a few concessions for small size and community setting.

Nevertheless, the survey manual is the same, and is considerably more detailed than survey manuals used to evaluate skilled nursing and other long-term care facilities funded by the Medicaid program.

Under the Medicaid program, which funds ICF/MR services, HCFA contracts with the State of California. One element of the contract is for state officials to survey facilities in order to certify their eligibility to participate in the Medicaid program. Federal officials audit the work of state officials, reviewing approximately 5% of all facilities each year. In 1984, federal officials audited the work of state licensing evaluators at Bayberry.

STATE LICENSING REGULATIONS

In 1982, California issued state regulations for the ICF/MR (Small) program. In 1986, revised regulations were issued. The original state regulations, some 286 pages in length, tightened up and further restricted what could be done. In the area of behavior management, for example, the first set of state regulations was largely silent on important issues, and simply regurgitated material in the federal survey manual. This meant that ICF/DD-Hs could follow procedures often found in state hospitals -- for example, use of restrictive devices, soft ties, and so forth. Bayberry never used such devices, nor has there ever been any intent to do so. A behavioral psychologist was apparently involved in re-writing the regulations. By 1986, more restrictions had been placed on ICF/DD-H programs than one finds in ordinary board and care homes, some of which handle residents with very severe behavior difficulties.

There was no change in the need for at least quarterly meetings of a human rights committee, since this is required by federal regulations. But, over time, this committee has been charged with responsibility as a *patient-oriented council* under nursing reform legislation, and for approval of the way in which individuals living in ICF/DD-Hs spend their personal and incidental funds, a topic discussed later in this paper.

> *Old regulations never die, they don't even fade away!*
>
> -- Adapted from General Douglas MacArthur

The regulations permit ICF/DD-Hs to use conventional state hospital techniques of physical control and use of psychotropic drugs, but permit only the following *aversive and restrictive interventions:* contingent observation, extinction, withdrawal of social contact, fines, and exclusion time-out with the client in constant visual observation. And, despite strong procedural controls (e.g., the human rights committee), it is more cumbersome to get approval for such *aversives* than in board-and-care and group homes, licensed by Community-Care Licensing. For example, the human rights committee must document the effects of all apparently positive reinforcement strategies and certify that they have not worked. And, if used (as brief **extinction** often is), the resident's Individual Service Plan (ISP) must be expanded by about four pages, single-spaced.

THE MEDI-CAL FIELD OFFICE

At least annually, a physician, social worker, and nurse review Bayberry's program for the Medi-Cal field office, and submit a report, with copies going to the agency's *Utilization Review Committee,* which, fortunately or unfortunately, Bayberry does not have. A Medi-Cal consultant visits the home at least twice a year to review client progress, and to assess whether clients still require ICF/DD-H level and type of care. At that time, beside client records, several pieces of paperwork are presented: (1) a Treatment Authorization Request (TAR), signed by each resident's attending physician; (2) a Certification for Special Treatment Program Services, signed by the Regional Center Director or his designee; and (3) a Prolonged Care Assessment Form, obviously designed for skilled nursing facilities.

THE MEDI-CAL FINANCIAL SYSTEM

The financial payment system is said to be cost-effective. The Medi-Cal financial intermediary distributes a lot of money at an administrative cost (to the Medi-Cal program) which is quite low. The system's apparent efficiency is, however, illusory. The cost to the service provider is simply ignored.

Billing for ICF/DD-H services is quite complicated and cumbersome compared with billing regional centers for services provided by a community-care facility of equivalent size. The Medi-Cal Billing Manual currently in use is the same one used in 1983, and had been in effect for some years before that. With bulletins and updates, this manual fills two 5-inch, 3-ring binders. Every invoice must be precisely accurate, and if a mistake is made, it can take over a year to get it corrected.

Bayberry has been audited by Medi-Cal auditors each year, with one exception, since 1985. The auditor typically spends two weeks reviewing material submitted by each provider earlier in the year. The Medi-Cal cost report runs to about 35 pages, and its submission is required. The accounts are so detailed that it is said that the cost of a load of laundry can be determined. Such costs are said to be important in adjusting rates of reimbursement from time to time.

In 1985, following an earlier tradition of trying to get dollars into the hands of nurses aides and other direct service staff, and to keep such dollars out of the hands of highly paid administrative staff, the ICF/DD-H rate increase took the form of a *wage pass through.* This required a report about 25 pages long, demonstrating adherence to the legislative purpose. And, every year since that time, additional paperwork has been required to demonstrate continued adherence to the wage pass-through law. In time, of course, with *rate freezes* and the like, pressure builds to cut other costs, many of which directly impact the quality of resident lives, but one finds no pressures (or interest) in these indirect effects.[8]

[8]Few people familiar with the system will be surprised at this. After all, one simply has to look at life at the *prototype,* a state institution for people with developmental disabilities. Despite operating expenditures of $70,000 per person per year at California institutions, residents are fed on about $3.00 per day; wear ill-fitting, inexpensive clothing; rarely get to go anywhere; and typically receive a present at Christmas or on their birthday only if the Volunteer Office has talked the neighboring community into donating such items, or families bring something to the hospital.

FIRE AND LIFE SAFETY

Each year, a representative of the State Fire Marshall's Office visits the home, which is a stately, two-story, Victorian, with 2,700 square feet of floor space. In 1985, with new federal standards coming into place, Bayberry had to install a manual fire alarm system and a magnetic door-closing device guarding the corridor upstairs. Total cost: about $1,200. Subsequently, all smoke detectors had to be hard-wired and integrated into the alarm system, making it automatic.

> **What is a Health Facility Anyway?**
>
> *Do you do any operations here?*
>
> -- Deputy Fire Marshall (1983-84)
>
> *Only an occasional frontal lobotomy in the attic.*
>
> -- John Shea (tongue-in-cheek)

In 1985, a local fire official visited the house, and insisted on sprinklers over windows at the rear of the house, where upstairs and downstairs porches, and a stairway in-between provide a second means of egress from the upstairs. In our area, this fire/life/safety code requirement had never been enforced for structures under three stories in height. Through negotiation, and at modest expense, a single sprinkler was installed. Currently, a representative of the State Fire Marshall's Office is demanding that Bayberry take additional steps -- ideally, from his point of view, installation of a full residential sprinkler system throughout the house. Appendix A discusses this recent turn of events.

MISCELLANEOUS *NURSING HOME* REGULATIONS

Because ICF/DD-Hs are classified as *long-term [health] care facilities,* new legislation and regulations intended primarily for nursing homes apply to all. Simply to illustrate, in 1985, I attended a workshop in Oakland, California, on "Implementation of the Provisions of AB 180 and SB 53--Nursing Home Reform Legislation." Among the new requirements were (1) a patient-oriented council (with regular meetings and minutes) and (2) display of a poster which tells of the role of the State Ombudsman.

Wise public policy might have been to have the Agency on Aging design and mail out a generic poster with room to add local information, but was this done? No. Rather, there was what amounted to a *poster contest,* with thousands of facilities having the task of creating their own.

What are the Values in the Current Licensing and Certification Process?

Evaluation and quality assurance rest on some *shared vision* of good lives and good services. Most progressive value statements, these days, emphasize:

- integration (physical presence and meaningful participation);
- productivity (e.g., a regular job);
- independence and participation;
- choice-making;
- warm, caring relationships;
- a congenial lifestyle;
- reasonable health and safety; and
- the like

The values evident in much of the work of Health Care Licensing are *good paperwork, a tidy environment, and safety* in a rather absolute sense. Until recently, HCFA conducted *look behind* surveys, wherein they looked 'behind the paperwork' to see what *really was going on.* Over time, those items in the survey manual *most readily measured* got the lion's share of attention. Surveys focused on physical plant and paperwork. Little interest was paid to client well-being, directly measured, or to progress in reaching a valued lifestyle.

In 1985, I recall discussing *active treatment* with researchers carrying out a study for HCFA. Matters subsumed under this rubric were not getting the attention they deserved. *I think I know active treatment when I see it.* The researchers, however, not wanting to add items to the 693-item survey manual, picked 75 items to serve as indicators of active treatment. *I was appalled.* The items selected had to do with the composition and frequency of interdisciplinary team meetings, the content of Individual Service Plans, and the like. How hard it is to distinguish the reality of life (interactions, training, assistance, etc.) from the paper representation of life!

What's Really Important?

There is reality, and there is the paper representation of reality. Health facility evaluators are taught to focus on the latter.

SAFETY

Over the years, on more than one occasion, Bayberry has been threatened with a citation (and fine) because the hot water in the upstairs bathroom exceeded 110 degrees, Fahrenheit. All residents of the home are sensitive to water temperature, and adjust dials, knobs, and their own bodies, just like the rest of us, to avoid being scalded when taking a shower.

Some individuals entering the home have needed a little time to figure out temperature controls, either because they hadn't mattered in the past (e.g., while living in a state hospital), or the controls were different than those they were used to. Instruction and supervised practice were provided, until the person caught on. I have always felt that restructuring of environments is a two-edge sword. Quite easily, having only tepid water can lull one into inattention. One supposes that the assumption is that *once in an institution, always in an institution.* At Bayberry, however, from the beginning, our job has been to assist people in developing the kind of know-how that would enable more independent living.

Interestingly enough, plumbers I know can relate stories of automatic mixing valves that malfunctioned causing serious injury. To be sure, if individuals were immobile, had no feeling in their bodies, were taking bathes, and couldn't get out of the bathtub on their own, I would be in favor of external temperature controls. But, this is not the case at Bayberry.

One evaluator, fresh from an earlier career as a medical corpsman, suggested that we put signs above every faucet in the house [**HOT, COLD**], so that residents would know which was which. I told him that no one knew how to read even such simple messages. He asked: "Then, how do they know which faucet to turn on?"

Bayberry was 'dinged' in 1984 for having porches front and back without fresh paint. The stated deficiency actually named the condition as one of safety, rather than

esthetics. Silly us, we painted both porches with enamel paint, not knowing to add grainy material to the paint to avoid slipperiness. More than one resident took a few minor spills, until the paint was scuffed up enough to avoid being slippery when wet.

GOOD PAPERWORK

In 1983, in preparation for an initial licensing visit, I naively assumed that in federal and state regulations the adjective *written* meant something. Whenever I encountered this adjective, policies and procedures were written down. When the adjective was missing, I assumed that it would be alright to tell the surveyor what the Agency's policy and procedure was. I quickly learned that anytime policies and procedures were even hinted at, one had to write them down. Bayberry has 200 pages or so of policies and procedures. Evaluators have expressed surprise when told that, with rare exceptions, no one looks at them from one site visit to the next. The reason, of course, is that the home is operated by a small organization, has little staff turnover, and staff talk to one another.

Good Dentistry or Good Paperwork?

May I ask you a hypothetical question? Consider two scenarios. In the first instance, a non-verbal resident with rotten, abscessed teeth is taken to the dentist's office, is uncooperative, and fails to respond to the dentist when asked: 'Any complaints?' The dentist makes an entry in the resident's ***dental progress report*** *that there were no complaints and that the resident was uncooperative, signs and dates the entry.*

In the second instance, the same resident is taken to a university dental clinic in the city, is sedated, and examined. Surgery is scheduled and carried out at a later date, and the resident gives every indication of feeling much better, but no ***dental progress report*** *is forthcoming, after repeated calls to the clinic, 60 miles away.*

If you were forced to choose between these two scenarios, which would you prefer?

-- John Shea

We pay for the paperwork.

-- Health Facility Evaluator

It is all facility evaluators can do to spend a couple of days at a small ICF/DD-H, pouring over paperwork and little else, to complete their assignments. When something is missing (e.g., a written statement that the local fire authority had assisted in the development of a fire and internal disaster plan), I get a name and telephone number and ask the evaluator to call and find out. The response is always the same: *if it is not written down, it doesn't exist*. One time, an evaluator asked me if we had had "infections." I said that we had had some -- colds, flu, etc. "Since you have infections, where are the minutes of the infections committee?," I was asked. I indicated how we handled infections and minimized their occurrence, through frequent hand-washing, insisting that clients use their own towels and washcloths, etc. We were cited for a deficiency for not having an infections committee.

Since it is literally impossible to examine everything covered by law and regulations in the course of a two- to three-day visit by a team of evaluators, how are priorities determined? As best I can tell, the importance is determined by (1) each evaluator's professional background; (2) ease of measurement (the easier, the more important); and (3) what federal auditors might think of their work.

In some circles, there is a move away from regurgitation (from statutes to regulations; and from regulations to policies and procedures), but not among health facility evaluators. One year, evaluators expressed special interest in policies and procedures on *Control and Discipline of Residents* (their term, not mine), which had been rather carefully crafted, is read by new staff, and has been helpful. It lays out exactly what staff are to do (and why) under certain circumstances. It said nothing, however, about what was not done. I was asked about corporal punishment and locking people in rooms. Surprised by the question, I said that, of course, we did not do those things. Bayberry was 'dinged' for not saying that these things are not done. As I told the evaluator, we could list 50 things that we do not do: sticking toothpicks under fingernails; floggings; kicking people in the shins; tripping clients walking down the stairs; etc.

Several other mandatory pieces of paper are essentially worthless, . . . or worse. All ICF/DD-Hs have to have a written *transfer agreement* with an acute care hospital. One supposes that the reason is that doctors at one hospital (e.g., a state institution) may not be able to get another hospital to accept their patients. To get a written agreement was a waste of time for us and for the hospital administrator. The reason is that residents have an attending physician, who has privileges at the acute care hospital

in Napa. This means that he can admit any one of his patients, if he chooses. The first transfer agreement, patterned after a nursing home agreement under Medicare, expired in a year. Subsequently, I learned the magic words ("the agreement will be in effect indefinitely, subject to termination by either party upon 30-days written notice") and the document wasted no more of my time.

Another set of rather useless documents (at least for Bayberry) are a series of working agreements with various professionals in the community, who accept Medi-Cal clients and, therefore, are accessible with or without working agreements. Again, one supposes that people who cannot get to a professional's office (e.g., if bedridden) may need the support of a written agreement, since there may have to be added compensation for house calls. By and large, the working agreements, together with copies of professional credentials, have had no value. Exceptions are working agreements with the psychologist, dietitian, pharmacist, and nurse -- all people who come to the home to do much of their work.

Being the *new kid on the block* (and, therefore, suspect), and looking for guidance but getting no new vision, evaluators understandably fall back on old habits and procedures. The regulations for ICF/MR (Small) programs call for a *central records system*. This makes sense, of course. Active records are maintained on units, wards, or floors, but when *patients* go elsewhere, records are transferred to a central records office. What does one do when client records (indeed, all records) are in an office inside a single ICF/DD-H? In an early licensing visit, I was told to get a 3"x5" file box, and to put a card in the box (name, admission date, exit date) for each resident. Tongue-in-cheek, I wrote into the Plan of Correction that Bayberry would do this, *so that no one would forget each client's name.*

When converting to ICF/DD-H status, I had to go to some lengths to get a written agreement with our dentist, since he said that he preferred "to practice dentistry rather than paperwork." Nevertheless, he accommodated our need. What constituted an acceptable 'dental progress report' for the regional center was not acceptable to licensing. However, I solved this problem by designing a form labeled a *Dental Progress Report,* on which the dentist's front office staff simply transcribed, word-for-word, what was already on the other sheet of paper. This was acceptable: same information, but with a proper form name. In 1985, upon examining Bayberry's working agreement with the dentist, an evaluator asked: "How do you know that Dr. ______ is really a dentist?" I answered: "He takes Medi-Cal sticky labels in full payment of his

services. He has a well-established private practice. He has privileges at Queen of the Valley Hospital. And, his name is not on the Medi-Cal List of Suspended or Ineligible Providers, a copy of which I have in my office." I was told to get a copy of his current license. Clearly, if there were genuine concern that Dr. ______ might not be a dentist, a brief visit to his office a few blocks away or a telephone call or two would have provided the answer.

A TIDY ENVIRONMENT

The ICF/DD-H regulations have prompted Bayberry to keep the home looking better than it otherwise would, although most people who enter the house note how clean and attractive it is. Over the years, two parents have asked about moving in, and one detects a touch of envy in many social workers who visit the house for the first time. Quite frankly, the home (and its furnishings) are a cut above the environments in which many middle-class Americans live.

Having said this, there are abundant deficiencies each year related to the physical plant. Almost always, there is a burned-out light bulb or two. With twelve foot ceilings, a few spider webs are not uncommon. Furniture is sometimes chipped. Paint may be peeling. There is some soap residue on shower doors and interior tile, and so forth.

Despite the new focus on *active treatment,* and an attempt to reform health licensing and certification by downplaying paperwork and physical plant, the message is not getting through. Of the 15 pages of deficiencies cited in the most recent review of the home, several dealt with physical plant. Nearly all of the remainder concern paperwork, and the burden is growing.

Quality Assurance and Evaluation

What does it mean to say the health facility evaluators are evaluating programs or assuring quality? In their day, some of the expectations for people with mental retardation, as expressed in licensing and certification standards, were quite visionary: for example, a comfortable mattress, clean linens, working light bulbs. The problem is that no expectation ever leaves the list, and everything is deemed *very important*. Unfortunately, just as the system is trying to downplay the physical plant and paperwork, and upgrade *active treatment,* the field of developmental disabilities has moved on to supported employment, full inclusion, self-determination, choice, and other

values. A less bureaucratic, less professionalized system is needed, if *quality outcomes for consumers (and their families)* is the criterion.

A Role for Parents or Consumers?

Would you like to call a few parents and ask them how well the group home is meeting the needs of their adult children?

-- John Shea

Why would I want to do that? They would feel threatened or coerced, and simply tell me what they think I might like to hear.

-- Health Facility Evaluator

There are many possible approaches to evaluation. In McComb-Oakland Regional Center, Michigan, for example, trained teams of parents evaluate residences, and officials appreciate what they find, report, and recommend. Basically, parents ask: "Would I want my son or daughter to live here?" In answering this question, one can be sure that matters of interest are quite different from the interests of health facility evaluators.

Appendix B to this paper describes the results of an evaluation carried out by a Bayberry Board member, in which over twenty individuals, including residents, parents, and staff, among others, were interviewed. Highlights were:

- What people **liked best** about Bayberry were (1) warm, caring, competent staff, and (2) positive changes in resident lives.
- Recommendations for **improvement** focused on (1) activities and choice; (2) individualization; (3) safety and well-being; (4) staff benefits; and (5) ways to economize on the use of resources.
- Interestingly enough, nothing was said about (1) more or better paperwork or (2) the physical environment, two priority values embedded in the licensing and certification process.

Does the health facility evaluation process, even with recent emphasis on *active treatment,* reflect what is important to individuals served and to their families? Not really. The evaluation model used for the ICF/MR (Small) program is one of **form** and **discrepancy.** That is, one asserts that certain features of programs (e.g., purposes,

program design, staff, consultants, other resources, etc.) are important, and constitute *standards* of excellence (or, at least, of acceptable quality). The question is whether a home adheres to that form, or to those standards. In other words, the question is not whether clients are happy, developing skills, and being productive and involved in community life, but rather "Does the program adhere to federal and state law and regulations?" There is nothing necessarily wrong with **form** evaluation, so long as the model against which the program is judged leads to good outcomes and to a better life for residents.

One evaluator told me that, in the case of poor programs, no matter what licensing and certification personnel do, there is little positive change. Any attempt to discuss the merits of the present system typically brings the retort: *I don't care what you say, if you take the money, you pay the price?* One has to be suspicious of fundamental purposes when the licensing and evaluation system provides no training or technical assistance to improve services. Indeed, one sometimes has the impression that *tough standards* are simply a way to limit expenditures from the public treasury.

Pernicious Effects of Present Arrangements

The bind is real. In the case of a fundamentally good program, present health service licensing and certification practices either (1) inhibit improvement or (2) waste resources which have better uses elsewhere, or (3) both. In the case of bad programs, little improvement occurs.

Bayberry was encouraged to apply for a change in licensure from a community-care facility (group home) to a health-services facility (ICF/DD-H), and information about the bureaucratic ramifications was hidden from the agency. It looked to be an opportunity to improve services and, thereby, the quality of peoples' lives. In 1985, I reported that "at best, for the 70% increase in funding involved in . . . [conversion] to an ICF/DD-H, the amount and quality of services [has] increased by no more than 10%." At that, I noted other difficulties, including immersion in trivia and a big reduction in the money residents have for themselves (for personal and incidental needs). By policy, Bayberry decided to allocate substantial resources ($4,000 to $5,000 per year) to recreation and other activities, despite the complete absence of such an expenditure category in the initial studies leading to establishment of a rate-of-reimbursement.[9]

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[9]How could such costs be overlooked? It apparently was easy. Perhaps nursing homes spend little on activities in the community. Most state hospitals provide recreation and other activities 'on-campus.'

How can there be such a small improvement in services and lifestyles? The answer is really quite simple. On the one hand, much of the added resources had to be devoted to activities that have little or nothing to do with the quality of client lives. The added funds did permit a small increase in direct service staff hours, but most of the funds had to be used for administration, clerical support, increased visits to high-priced outside professionals, and to offset the loss of personal and incidental funds. Besides ignoring *recreation and training expenses,* the rate setting process ignored administration and clerical support entirely, forcing programs to offer lower pay and benefits for direct service staff than would be optimal.

PASSING THE BUCK, OR WORSE

The ICF/MR (Small) program adds numerous specialists to the staff, and results in somewhat greater division of labor. There may be some advantages here, but there are disadvantages as well. It is quite easy for some staff to defer to others considered more expert. The upshot can be, if one is not careful, that direct-care staff will ignore complaints (e.g., "I scraped my knee. Would you take a look at it?" may bring a response: "Why don't you wait for [the nurse]; she is coming over to see you guys tonight.") Specialization and division of labor can, as we all know, result in "passing the buck."

Figure A shows "Some Things I Learned, but Wish I Hadn't, from Working in an ICF/DD-H." Perhaps I was unbelievably naive. I realized that staff could steal medicine, and that tracking medication subject to potential abuse is important for everyone's well-being. But, both physicians and pharmacists keep track of when re-fills should be needed. Therefore, the very elaborate controls (and tracking) of medicine called for in the ICF/MR (Small) regulations is *over-kill.*

WITHDRAWAL

There are people, and agencies, that trumpet the *good news* of residential service monitoring through practices like health services licensing and certification.

Figure A

Some Things I Learned, but Wish I Hadn't, from Working in an ICF/DD-H

1. Paperwork and reality sometimes diverge. -- A 20 year old prospective staff member asked me: *What does it mean to say that residents take a shower every day?* I learned that at a nursing home where she had worked, she had been expected to take patients to the bathroom; and, if time were short, she dunked their heads under the shower and recorded this event as a shower or bath on a flow sheet. She didn't want to have to do this again.

2. Some Medi-Cal clients do not exist. -- I once asked a Medi-Cal Consultant why she wanted to see each client every other visit. The reason, she said, is that some providers bill for non-existent clients.

3. Some drugs have substantial street value. -- I should have known this about pain relievers, like PERCODAN, but did not until we had a Consulting Pharmacist, who hesitated to destroy left over PERCODAN tablets. He destroyed them, when I insisted.

4. Providers never report untoward incidents (e.g., client abuse). -- In the first year or so of the program, a provider in Southern California took disciplinary action and reported unfortunate incidents (e.g., a staff member striking a client). He quickly learned that the only response from Licensing was a citation and fine. A licensing evaluator confirmed that, despite reports being called for, none is ever submitted, except, as in this case, where a new provider didn't know any better.

Quality assurance is like *motherhood, apple pie,* and *the flag.* Who, in their right mind, would not be for it? Parents who have not taken the time to look and to listen to what *actually takes place,* can, perhaps, be excused. But, after reading this paper, I hope they will never again, simplistically, equate the activities of health licensing and certification personnel with *assurance of quality,* because the latter depends on so much more.

But, what about those who bear the brunt (or burden) of the regulatory system gone awry? If the ***paperwork dragon*** wastes resources or worse, why don't more people try to slay it? Several officials tell me that parents, like myself, have insisted on piling one regulation on top of another.

I am not the only person railing against excessive paperwork, which is absorbing resources with much better uses elsewhere. Many of my colleagues grumble. Indeed, everywhere one looks, in California at least, paperwork accountability requirements are growing by leaps and bounds. This is true for regional centers, day programs, and most everyone else.

Why No Paperwork Rebellion?

Every chance I get, I ask this question. One of the greatest sadnesses in my life has been the slow realization that we often prefer paperwork to working directly with consumers. I see no other reason. If we enjoyed the activities that paperwork keeps us from, we would be far more assertive and demanding in bringing the paperwork boondoggle to a halt, and instituting other mechanisms to carry out legitimate monitoring and review functions.

A friend of mine, who works at a state hospital, is absolutely convinced that what I say is true. Young people, when they join the staff, are energetic and idealistic, looking to improve people's lives, but staff sometimes find interacting with patients and residents punishing, and drift to other activities. When I occasionally visit adult units at

Direct Service or Something Else?

I decided to cut most of the less important seminars. . . . At the state hospital there were seminars scheduled for every hour of the working day. I suppose I could have convinced myself that I was learning about patients by attending, but tell me, what do you learn about patients by avoiding the ward? It was possible for a resident to spend almost no time on his ward and, by putting in an appearance at every conference, to give other people the impression he was really interested in learning. Of course, he might not have any idea what to do with a real live patient, but he could fake it good.

-- David Viscott, M.D.
The Making of a Psychiatrist,
pp. 219-220.

a state hospital, I typically see residents milling around in the corridors or day rooms. Staff on the floor typically are responsible for 9-12 residents. Several staff are ensconced in a glass-enclosed office (the nursing station) sipping coffee, chatting, writing notes in charts, or . . . , as one state hospital worker told me, reading novels.

Bayberry's first recreation therapist, who is a full-time counselor, completed a six-month internship at Napa State Hospital before joining ICF/DD-H staff in 1982. She told me that it was all that she could do to spend half her time with patients and residents of the hospital -- given committee meetings, report writing, and other duties assigned to her.

A FALSE SENSE OF SECURITY

Feelings of insecurity are not uncommon when confronting new and novel situations. I recall a parent saying, one day, that he preferred to have his young son live in a large ICF (50 beds or so), for three reasons. First, if his son were to live with another family, the question as to why he didn't live with his parents would be too troubling. Second, the ICF had people with professional credentials, especially trained (presumably) to meet the needs of children like his. Third, the father felt comfortable opening the door and walking in unannounced, but thought such behavior would be inappropriate, if his son lived with another family or in a small group home.

The executive director of our local Area Board kindly agreed to serve on Bayberry's human rights committee. He was more shocked than I was to learn that, like state hospital superintendents of old, ICF/DD-H administrators were to investigate, determine, and submit any needed reports whenever there were an allegation of client abuse. While I believe in managerial prerogatives, I was easily swayed to my friend's position that such a regulation was unconscionable. Nevertheless, it remains.

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Avoiding Bad Things

Some parents feel a sense of security knowing that standards and quality assurance activities are in place. Viewed from the inside, my guess is that discovering anything untoward happening would be accidental. One evaluator told me that reports of abuse never come from insiders. Is it any wonder, since a citation and invoice to pay a fine would be in the next day's return mail.

The ICF/DD-H regulations, harkening back to the days when an institution's superintendent was 'king of the hill,' name the facility's administrator as investigator, judge, jury, and reporter when allegations of wrong-doing come to his or her attention. It's as if the client rights advocate at the regional center, or the Area Board on Developmental Disabilities, were non-existent.

Careful recruitment, selection, training, and supervision of staff is critically important in minimizing maltreatment. Philosophy and approach are also important. What can parents and other citizens do to minimize maltreatment? In my experience, several things can help:

- a clear open-door policy (e.g., parents are welcome, announced or unannounced, at any time);
- having employment or a training program for consumers away from home, operated by people independent of the home; and
- expressions of interest, and seeing one's son or daughter frequently, in the home and outside.

WASTE OF RESOURCES

By conscious decision, Bayberry spends about $150 per resident per month on food. Bayberry's dietitian consultant, who also works at a near-by state institution, marvels at the quality of Bayberry meals. Halibut Espanol; Super salad with shrimp and crab meat; and many other wonderful entrees are typically on the menu. Again, by conscious policy decision, the leadership of the Agency has chosen how resources are to be used. The state hospital has several dietitians, who perform a number of functions, but patients are fed on about $3.00 per day.

Painters and Nurses: Anything in Common?

Where's the Lysol? Why don't I smell Lysol?

-- Health Facility Evaluator

Why would you expect to smell Lysol? No one here is incontinent. (I learned later, from a friend who is also a nurse, that, like some painters and paint, some nurses enjoy the smell of Lysol.)

-- John Shea

The health facility evaluators that I have encountered have rarely asked how well residents are fed. Interest in nutrition, to the extent that it has been expressed at all, has focused on the dietitian's nutritional evaluation of each resident (a piece of paper) and the dietitian's report of activities and recommendations (a piece of paper).

Real Food for Real People

One has to wonder, at times, whether trade associations sometimes get involved in the writing of regulations for the ICF/MR (Small) program.

Among expressions of interest in the content of meals, two *tales* are worth sharing. About 1984, a health facility evaluator looked at a menu and asked: "Where's the jello?" I didn't know quite how to respond. I noted that occasionally jello was served, but that I wondered why she even asked the question. With a little exploration, I learned that this was the first time the evaluator had been to an ICF/DD-H, and that her question simply reflected having seen jello on the menu of most nursing homes. We talked a little bit about sugar, gelatin, and the nutritional value of jello, and turned to other matters.

Two or three years ago, after training by a Nutritional Consultant, health facility evaluators cited Bayberry for not serving at least 6 ounces of *meat protein* to each resident every day. I asked whether he meant *animal protein,* and he said "No, meat protein." Knowing that residents typically use low-fat milk with cereal in the morning, drink milk at dinner, have eggs typically once or twice a week, and in many other ways get plenty of protein, I initially refused to correct the alleged deficiency.

Do Licensing Personnel Ever Make Mistakes?

Medi-Cal means never having to say you are sorry.

-- Anonymous

I talked with a sports physiologist friend, who said that it would be extremely rare for an American to get inadequate protein. Excessive fat and inadequate complex carbohydrates are the typical problems. I asked our dietitian to analyze our menus, and she reported that 6 oz. of meat protein would be inappropriate. My failure to respond to licensing in the way they wished resulted in my being *called on the carpet.* I met in the regional manager's office, and was promptly accused of being uncooperative. Seeing who had the upper hand (i.e., control of the purse strings), I quickly became cooperative and told them what they wanted to hear. We simply decided to ignore the 6 oz of meat protein rule, and the matter was never mentioned again. It was my distinct impression that evaluators had been coached never to admit a mistake.

What Can Be Done: Reform, Abandonment, Minimizing Effects

SYSTEMIC REFORM

Certain policy recommendations have to do with reform (or abandonment) of the ICF/MR (Small) Program in California. Other recommendations fall into the category of *minimizing the pernicious effects* of existing licensing and certification practices. In the first category are the following:

Recommendation No. 1. -- Submit a Home and Community-Based Services Waiver to federal Medicaid officials, to use federal funds now devoted to shoring up state institutions, ICF, ICF/DD, and ICF/DD-H facilities, and to targeted case management.

Recommendation No. 2 -- End the practice of writing state regulations that are more restrictive than federal regulations; accept federal regulatory requirements until they can be improved.

Recommendation No. 3 -- Advocate for a federal survey manual with no more than 200 items, subject to the proviso that each item be no more encompassing than at present.

When everything is important, nothing is important, or the matters of importance are a reflection of personal whim or professional background. If one were interested in quality of life, one would certainly ask questions of residents, their friends, and their families.

Recommendation No. 4 -- End the practice of citations and fines, or adopt State Community Care Licensing practices in this area. Accompany this change with reporting requirements for special incidents and unusual occurrences, along with investigative practices typical of community (not institutional) services.

Like other parents, I sometimes worry about possible mistreatment. My experience with licensing evaluators is that, if it existed, the chances of them finding it are almost nil, for reasons given earlier.

Recommendation No. 5 -- Experiment with alternative evaluation practices (e.g., parent-consumer monitoring teams), including organizational development, technical assistance, and training, in lieu of traditional approaches to licensing and certification, and spend enough on applied research to ascertain effects on client outcomes.

Facility administrators quickly learn that the evaluation process is wholly negative and punishment in orientation. Organizational development to improve services, through workshops and consultation, is non-existent.[10] This is not to argue that, in the short-run, anything else than the present approach is possible. None of the evaluators that I have met would be credible in an organizational development (consultation) role. Evaluators are apparently directed not to say anything positive about what they see, but to point out only discrepancies from [questionable] norms. I asked one evaluator if bad programs were ever improved as a result of their work, and she said that it was extremely rare. I must say that I was not surprised.

[10] If offered, the chance of any technical assistance focusing on anything having to do with *better lives* is remote. Almost surely, assistance would be directed at ways to make the paperwork burden a little easier for the Health Facility Evaluator and others within the bureaucracy.

What Kind of Clients Do You Serve?

One evaluator, not having seen any of the residents, who were at jobs or training stations in the community, asked me: "What kind of clients do you have?" I replied: "What do you mean, in what respects?" She went on: "Are they low-grades?"

-- John Shea

Recommendation No. 6 -- Recruit and train health facility evaluators who have modern, progressive ideals, and who know the difference between reality and the paper representation of reality.

The health facility evaluators that I have met are incredibly out-of-date. If they have any background in developmental disabilities, it has generally been in impersonal environments (e.g., large congregate care facilities), often ten or twenty years ago. Without prompting, two visitors have described themselves as being *old bughousers.*

Recommendation No. 7 -- Simplify! Simplify! Simplify! End the practice of adding layers of bureaucratic oversight whenever improvements are made in policies and procedures.

Just to illustrate the broader problem, consider client *personal and incidental funds.* Last December, the California Departments of Developmental Services and of Health Services published guidelines on appropriate use of client funds in ICF/MR facilities. These funds amount to $35 per person per month. The guidelines are three pages in length, and were developed with input from DDS, Medi-Cal Benefits, Medi-Cal Audits and Investigations, and Medi-Cal Rate Development.

In effect, the new guidelines *require* that a facility's Interdisciplinary Team (IDT), Human Rights Committees (HRC), *and* the client or his or her legal representative (regional center case manager, if no court-appointed conservator), approve quarterly how each client, by name, spends his or her money on anything except clothing and items that facilitate communication with the outside world. In other words, if a consumer wants to buy a milkshake or stereo headphones, he cannot do it without the expressed authorization of several individuals. Not only is this a serious constraint on autonomy and self-determination, but a colossal waste of the time of individuals who should have much better things to do.

FACILITY REFORM

Many service providers seem to feel that so long as the money is forthcoming to pay for so-called *quality assurance* activities, who are they to object. My own view is less sanguine, especially in the case of well-run homes that have been enticed into converting to ICF/DD-H or N status.

> ***Recommendation No. 8. -- Assign responsibility for as much of the paperwork as possible to one or at most two individuals, and keep the paperwork from spilling over into the workload of direct-service staff.***

The leader of another agency that converted homes to ICF/DD-H status back in the early 1980s told me once, some years ago, that the homes had become a *blizzard of paperwork*. She had delegated responsibility to a sizeable number of staff members.

> ***Recommendation No. 9. -- Put the 'office' (nursing station in hospital parlance) where it is difficult to get to; keep heat, air-conditioning, coffee pots, and other 'goodies' somewhere else; make sure it it impossible to do paperwork and interact with consumers simultaneously; and reward staff for staying away from the office.***

> ***Recommendation No. 10. -- Retain, for the benefit of staff, a psychiatrist or psychologist to assist the administrator and staff in maintaining a clear commitment to 'regular lives' in what is a very 'irregular setting,' with absurd paperwork and other requirements.***

Administrators and key staff spend an enormous amount of time satisfying the bureaucracy. Unless one steels against it, the constant bombardment of minutia can deflect the organization from meeting the *real* needs of residents. A psychiatrist (or psychologist) completely divorced from the unreal world of *institutional life,* should be able to assist staff in keeping the focus of their efforts on quality relationships; active, balanced lifestyles; consumer choice; full participation in home, neighborhood, and community; etc.

> ***Recommendation No. 11. -- Commit the organization, at all levels, to assign priority to expenditures which directly impact the quality of client lives. In a well-run program, this means good food; good, fashionable clothing; substantial dollar allocation to recreation and training expenses (over and above what consumers can buy with their personal and incidental funds); and allocation of significant funds (e.g., $150 to $200 per resident per year) for presents on birthdays and other gift-sharing days. Beyond these expenditures, the quality of direct-service staff is crucial to quality lives.***

APPENDIX A
NOTES ON FIRE/LIFE/SAFETY

Since 1985, a new procedure has been used in determining *how much fire safety is needed.* It involves an assessment of the facility and a report on the capabilities of each resident. Three times since 1985, the home has been rated ***prompt,*** which is the best rating possible. Last year, with a new surveyor but the same residents, the home was reclassified ***slow,*** and this rating is undergoing review based on an informal appeal. The third category, ***impractical,*** has never been used to describe the household.

The deputy fire marshall is requiring that Bayberry take one of three actions:

- install a residential sprinkler system throughout the house;
- have an awake staff member at night; or
- install 1&1/2" solid core doors, each with a automatic door closing device, at each of the bedrooms upstairs.

Clearly, from a conversation in the deputy's office, the game plan (and desire) is for Bayberry to install a sprinkler system, and no one objects to this if money is available for that purpose. The other options are considered less desirable from a fire protection point of view. Nevertheless, the implications of various possible actions may be of interest to the reader. When the new federal regulations were put into place, the California Department of Developmental Services (DDS) provided funds for two years to facilities, so that they could add alarm and sprinkler systems. Now, Bayberry has been told that the money is gone. One estimate for a complete sprinkler system is $9,000.

In the case of an awake staff member (which is not presently required), there would be additional operating costs, thereby taking resources away from other uses. Solid-core doors, in a 1896-vintage Victorian, with automatic door closure devices, are not a good idea for four reasons. First, it would be difficult for two residents to get out of their rooms, because the doors are so heavy. Second, it adds another layer of 'institutional feeling' to the house. Third, given how hot it can be in the summer, closed doors are inconsistent with comfort and health. Fourth, open doors (held open by automatic closure devices) are inconsistent with privacy.

One of the good things coming out of the ICF/DD-H experience has been improved performance of residents and staff in caring for their own safety. Fire drills are more common, and the training has been improved. Like *mother, apple pie,* and *the flag,* it is hard to be against safety, but let me try to indicate the sources of my concern.

Like many other parents of my generation, I took Persky's concept of the dignity of risk, and Wolfensburger's normalization principle to heart. I do <u>not</u> value 'striving for absolute safety' to the exclusion of other values. To me, having a staff member in the house, a no smoking policy, fire drills, hard-wired detectors, an automatic alarm system, and a solid core door at the head of the stairs to the bedroom corridor are quite sufficient to meet legitimate needs. I have no objection to sprinklers, so long as the money does not come out of on-going operating revenues (directly or indirectly), which are meant to fund on-going services. The 2-hour fire rated doors (typically installed in large nursing homes and institutions with masonry structures) makes no sense. Indeed, the whole house would burn down well before the doors.

The Executive Director of Bayberry decided to appeal the most recent action of the deputy fire marshall, and I was asked to go along. We met the deputy at his office in Santa Rosa, an hour away from Napa. After the meeting, I jotted down a few notes and reflections of what was taking place.

The deputy fire marshall talked of the importance of solid-core, 2-hour rated doors, if a fire were to start in an upstairs bedroom, in the upstairs bathroom, or in the corridor itself. I asked whether sprinklers for just these rooms and the corridor would suffice, and he said "No, what if the fire started in the kitchen?" To which I responded, "That is what the solid-core door at the head of the stairs is for." Anyway, the conversation got nowhere. He seems to be adhering to what he believes to be the letter of the law.

<u>Question:</u> *How come Deputy Fire Marshalls in the past rated the household* ***Prompt,*** *but you rated the household* ***Slow?***

The inspector noted that he is a Deputy Fire Marshall III, while the others were Is or IIs, with less experience. I was told that he (the visiting marshall) had better training and more experience, and that one of the earlier Marshalls seems to have "bent over to be helpful." I observed that zero risk is unattainable, and that individuals and society always must judge whether any reduction in risk is worth the cost of achieving such a

reduction. If this were not so, citizens would insist on having emergency medical teams stationed at every street corner, for this would surely reduce deaths from heart attacks and other events, such as fires. My argument made no difference to the deputy.

<u>Question:</u> *On what basis did you rate residents?*

The deputy indicated that if people with developmental disabilities are living in ICF/DD-Hs, does this not mean that they are unlikely to respond appropriately to real emergencies? I took issue with painting every person with a disability as necessarily lacking in competence or judgment as to what actions to take in the event of a real emergency. Lack of competence is, of course, a long-standing cultural stereotype. One does not call people idiots, dumbbells, or stupid for nothing. The deputy's observation is no different from saying "Women are nurturing," or "Blacks are good dancers," and I called him on it, but without alluding to these analogies.

The deputy said that he took 'worst case scenarios' as the basis of the rating. Asked whether it made a difference that the fire station is three blocks away, the deputy said that he knew of a case where the engines had responded to a fire across town and a vehicle caught on fire and burned right in front of a fire house. Questioned on the logic of an awake staff member, the deputy said 'What if a fire were to start in the staff bedroom?' And, so forth. Taking only 'worst case scenarios' means, of course, that every human being would fail. We would all have to have solid-core doors whether we wanted (or could afford) them or not. Quite frankly, I doubt whether any self-respecting citizen would accept the deputy's position for himself and for his family.

<u>Question</u>: *How and why were existing regulations put into place?*

In response to this question, the deputy said that parents had asked for them. (As with the question above, parents were portrayed as a homogeneous group.) Again, I questioned the deputy on this point. Clearly, such a statement is biased, prejudiced, and discriminatory. I told the deputy that I, as a parent, had not asked him to put such regulations in place, and that few (if any) of the parents that I know would be inclined to do so.

<u>Question:</u> *What if your action results in shutting down of the home, and residents are forced to live elsewhere?*

The deputy seemed positively gleeful. He saw this as highly desirable, since it might add some leverage in getting the regional center or the California Department of

Developmental Services to fund purchase of a sprinkler system. In my experience, the deputy's position is not uncommon. Perhaps with any group of dehumanized, devalued, powerless individuals, some people in the 'service system' come to believe that their personal needs come first, and that the desires and needs of the people ostensibly there to receive services are secondary or even trivial. If aimed at us, I venture to guess that none of us would stand for the kind of treatment that the deputy dished out.

APPENDIX B
ALTERNATIVE WAYS TO EVALUATE QUALITY

Bayberry is noted, within the Napa area, as an outstanding group home. It has many of the limitations implicit in *six packs,* situations wherein six unrelated people with disabilities live together. Some residents have regular jobs in the community. Three use public transportation. There has been a heavy emphasis on physical fitness and nutrition. Three residents have run full marathons (26.2 mile footraces), two under four hours and one (a woman) under five.

There is nothing synthetic or artificial about training. The house is very close to downtown, to stores and offices. Nearly everyone has a bank account and several do their own banking, with little or no support needed at this time.

What values undergird the program. An initial value (in 1979) was that everyone who worked for the agency would have *direct-service* responsibilities. Other values are *integration; choice-making; independence; warm, caring relationships; being a valued member of the community; looking and feeling good; health and reasonable safety.*

In 1985, to generate information of use to me (and to the Board of Directors) in shaping the program in desired directions, I asked a board member to conduct an evaluation, by talking with residents, families, and 'significant others,' emphasizing three questions:

- What do you like about [the home, or the program]?
- What concerns do you have?
- What changes or improvements would you like to see?

The board member interviewed, at length, over 20 individuals. Not having been approached in this way, some parents were reluctant to be critical, but did share their concerns when assured that the information was *wanted* in order to improve the program.

What people liked about the program was not *good paperwork,* but typically had to do with staff and relationships. The evaluator reported: "As I conducted this evaluation, I have been awed by the incredible amount of respect and love that the people I've talked with have for . . . staff. . . . Almost every person I spoke with stated in

one form or another what one parent said: '. . . staff are so kind and caring. They're the real strength of Bayberry'." The progress made by residents was also salient. Statements like "Bayberry has done 100% more for _____ than all the others (state hospital, other facilities) put together" were common.

Concerns focused typically on the future. "Bayberry partly scares me and partly pleases me. It pleases me that ______ is doing so fantastic, but it scares me that s/he might have to leave, and I don't think s/he is responsible enough."

The predominant recommendation for improvement was to continue a good thing. One parent, for example, said: "What they're doing works. Don't change anything." If this is all that came from the evaluation, it would not have served its purpose. By waiting for respondents, and by reassuring them, several specific recommendations were made. They included:

- going to camp once a year;
- getting a lock on the bedroom door;
- getting a job at the sheltered workshop;
- more sports: soccer, volleyball;
- living in the same town as mom and dad (40 miles away);
- better benefit plan for staff (e.g., payment for some holidays);
- more education: reading, writing, diction classes;
- more fire drills;
- more choice among chores around the house;
- vegetable garden in back yard;
- purchase of a freezer;
- more staff meetings;
- better minutes of staff meetings; and
- closer age range of residents.

These straight-forward recommendations for improvement were as helpful in improving the quality of life of both residents and staff, as multi-page *lists of deficiencies* handed to the agency by health facility evaluators. The focus of recommendation was:

activities and choice
individualization
safety and well-being
staff benefits
ways to economize on use of resources

Interestingly enough, nothing was said about *more or better paperwork,* or even about *the physical plant* -- the priority values embedded in the quality assurance process, and in licensing and certification practices.

About the Author

John Shea

John Shea, Partner in the firm of Allen, Shea, and Associates, spent nearly 10 years, from 1979 to 1989, providing residential services for adults with developmental disabilities. The non-profit agency he headed, Bayberry Incorporated, has two group homes: one, an ICF/DD-H; the other, a Level 4, *negotiated rate* home. John has a Ph.D., in economics from Ohio State University; taught and did research at the University of Santa Clara, The Ohio State University, and the University of California-Berkeley. From 1973 to 1979, John was a Senior Fellow with the Carnegie Commission (and Carnegie Policy Council) on Higher Education. He is the author of over 40 books, articles, and reports. One related to this booklet is *Looking at Licensed Residential Services in Your Community: A Guide for Californians with Developmental Disabilities, Their Families and Friends.* John has several children. His son Joe, who is challenged by autism and severe mental retardation, lives in the ICF/DD-H John helped create. At home, John and his wife care for six *foster children* with developmental disabilities, along with their own children, in a small family care home.