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United Parents Lighting Up Darkness To Aid Retarded

By SIGRID BATHEN
Bee Staff Writer

Rebecca is 15, with wide blue eyes, freckles on the bridge of her nose and thick pigtailed trailing down her back. She was born nearly blind, with brain damage.

An operation has restored most of her sight, but Rebecca still has the mind of a small child.

She lives on a quiet Sacramento street with her parents and her younger brother, Patrick, who is 13 and more severely brain-damaged than his sister.

"We had a double deal," says Sally Stricker with her characteristically easy smile. "When Rebecca was born, we didn't know exactly what was wrong with her until I was pregnant with Patrick. . .

"There was pain. I cried. I just cried. I really felt sorry for myself. But after Patrick was born, I snapped right back. There was just too much to do. At that time, doctors told us to lock them up."

Mrs. Stricker and her husband Bob and the two children have since undergone genetic counseling and examination. "They haven't been able to tell us," she says, "why the children are the way they are."

The Strickers refused to place the children in an institution for the retarded, deciding instead to keep them at home. It was an unusual decision at the time, one which required enormous patience.

"When the children were little, it was very new. The professional people and the public couldn't deal with it. They stared and asked questions. It's still hard often times to get a babysitter or to get medical help

"I disagree altogether with the principle of institutionalization. But it has to be an individual decision. I can't begin to suggest what people can and cannot deal with. It's not the children who are the burden — it's society.

"I can get along just fine if the guy in the grocery store will stay off Rebecca's back."

Not long ago, most parents with retarded children were afraid to speak out if they had complaints about the care being given their sons and daughters. Now, increasingly, they are demanding better treatment. Not only their complaints, but their children as well, are emerging from a shroud of secrecy.

With an increasingly complex network of services available to the parents of retarded children, many youngsters — the actual retarded and those improperly so classified — are now being diagnosed in time to help them. Children like a tiny blonde 8-year-old girl now attending local public school.

She was taken from her family at age 3. Because of neglect, she weighed 19 pounds, could not walk and was still being fed with a bottle. She was classified as retarded.

The girl was lucky. She was placed with a knowledgeable and loving foster mother who patiently taught her to eat and walk and shepherded her through special education classes for the retarded in public schools. She is now in a regular second grade class.

According to Gov. Brown's proposed state budget, 290,000 persons in California fall in the classification "developmentally disabled" — a catch-all term which describes individuals whose physical and/or mental development is impaired at birth or during childhood or adolescence.

Of those 290,000 persons, 204,000 are classified as mentally retarded. Their level of functioning varies from that of a small infant to those with the

See Page A8, Col. 1

Continued from Page A1

capabilities of virtually independent adults who work and live on their own.

The time was, as Sally Stricker says, when parents of retarded or disabled children were advised to "lock them up" in dismal, understaffed institutions where beds were lined up row upon row and "residents" were literally left there to die.

Despite major advances in recent years, such institutions still exist. Sometimes they have been replaced by small "community facilities" and "group homes" where conditions may be less crowded, but not much better. The retarded and disabled sometimes are lumped together with the mentally ill and the senile elderly.

There are large institutions and small community homes which are models of sensitivity, intelligence and humanity in caring for those unable to care for themselves. But their accomplishments are too often overshadowed by places like the Oak Creek Ranch in Castro Valley — where, according to authorities, retarded children were locked overnight in outdoor cages, their soiled underclothing tied over their heads for "discipline."

The beginnings of major advances in care for the retarded generally are tied to the presidency of John Kennedy, whose sister Rosemary is retarded. Kennedy established the President's Panel on Mental Retardation and brought the shrouded subject out of the closet.

But despite the advances, there remain untold numbers of retarded

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children who are cloistered in their homes or institutions and denied the care and treatment available to them.

In one local program for the retarded, for example, there is a 15-year-old boy who until recently was

kept in the home of an elderly relative and had never learned to walk or talk.

"He sat cross-legged on the floor for 14 years," said a teacher in the program where the boy now is learning to stand, walk and communicate with others. "He had very little use of his legs. He moved by kind of hopping."

A decade or so before publicity of the Kennedy family concern with the plight of the retarded, many parents had become involved in what is loosely called the "parent movement" for the rights of the retarded.

Bill Green, onetime South Dakota businessman who is now executive director of the California Association for the Retarded, was one of those parents. He became involved after the birth of his second son in South Dakota in 1944.

The child, Green said, "didn't respond to people. He was slow to do everything. We did what most middle-class families with some resources did. We began touring the country to find someone who could do what little bit of magic they could to make our son normal."

Green wound up at the University of Minnesota where he was told his son was mentally retarded and that his son should be placed in an institution. Green also was referred to a parent group in that area.

With the public schools offering virtually nothing for retarded children ("It's a pretty cold day when the principal comes over and says there's nothing for your son"), Green helped to establish a parent group in Sioux Falls which opened its own school in the teacher's garage.

"Then we began to think what we could do legislatively," Green recalls. "... We formed a state organization. And we started lobbying. It was an overwhelming job."

Similar state parent groups were forming around the country and in 1950 the National Association for Retarded Children, now the National Association for Retarded Citizens, was formed. As for Green's son, who is now 32:

"He got his first couple of years of

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education in the garage next to the teacher's house. Then we got legislation for special education classes. We created the first sheltered workshop in Sioux Falls, and he proved to be a very capable worker.

From that workshop experience, he was placed in a job at a hospital. He worked in the kitchen, lived on his own and ate at the hospital. He did very well."

Green's son later worked in the laundry of a veterans hospital in New Mexico. He is now a mail handler at a Sacramento post office.

"His salary now exceeds \$12,000 a year," Green says proudly. "He drives his own car and lives in his own apartment. He is a taxpaying, productive, happy citizen. He needs guidance in some matters, but he is 99 per cent independent without us.

"It's been frustrating, overwhelming, but so gratifying."

For every mildly retarded child like Bill Green's son, there are countless others with varying degrees of mental competence who do not have the benefits of middle-class parental tenacity, or money.

There is a direct relationship between poverty and retardation. Retardation can be traced to such factors as peeling lead-based paint in tenement housing, malnutrition, lack of prenatal care and other income-related factors.

For the poor and nearly poor, retardation is particularly damning.

In California, 1960's legislation to improve care and treatment for the retarded established a complex statewide network of services largely administered by the State Health Department. Much of it was sponsored by Assemblyman Frank Lanterman, R-La Canada, who later this month plans to introduce additional legislation to streamline a system which critics say has not always worked at optimum efficiency.

Since the late 1960s, services to the retarded and other persons who fall

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under the "developmentally disabled" umbrella (persons with cerebral palsy, epilepsy, and other neurological disorders often related to mental retardation) are coordinated through a statewide network of regional centers which provide counseling and placement in community programs and state hospitals.

Under legislation by Lanterman and others, emphasis in recent years

has been on community, rather than state hospital, placement. As a result the population of mentally retarded and other disabled persons in state hospitals has steadily dropped, from 13,335 in 1968 to 9,909 in 1973 (these figures do not include the mentally ill in state hospitals).

As of Jan. 1, however, the population of developmentally disabled (primarily mentally retarded) persons in the state hospitals had risen to 10,294. That rise is a subject of considerable concern among professionals in the field and is one reason for Lanterman's planned legislation.

Don Miller, director of the state hospital system for the Health Department and the father of mentally retarded twin sons, attributes the rise to "a lack of suitable community facilities."

Miller, whose sons live at home and attend the Laurel Ruff School for the mentally retarded in the San Juan Unified School District, believes "there is nothing in a state hospital that cannot be done in a community and within the family setting, and better. Parental contact is very good, and the closer they are to their families, the better."

Why, then, with heavy state emphasis on community care — and enormous amounts of state financing — have community facilities not met the need? Professionals in the retardation field have a variety of answers, from spiraling community care costs to stringent local zoning regulations which some critics suspect are designed to keep community facilities out of the community.

Keeping a severely retarded child — or even a moderately retarded one

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with physical handicaps or the hyperactivity which often goes along with retardation — in the home is difficult for many families.

If there are other, normal children, family life can be seriously disrupted. Retarded children often require constant attention and patient instruction if they are to progress. And that attention requires time and, frequently, professional expertise.

Many professionals in the retardation field believe more parents would be willing to keep their retarded children in the home if adequate community programs existed to help them.

For those children and adults — particularly the profoundly retarded, those often referred to as "crib cases" — whose problems require care in a residential facility, state hospitals are often the only answer. But critics say state hospitals are

understaffed, physically antiquated facilities which — in the final analysis — are impersonal institutions.

The public school system in California currently provides special education programs for retarded children classified as "educable" (mildly retarded) and "trainable" (moderately retarded). In addition, many school districts have special "development centers" for the more severely retarded. Under state law, those development centers will be required in all school districts by 1978.

Beyond age 18 or 21, depending on the district, resources for the mentally retarded — for whom chronological age often has little real meaning — become slimmer. There are so-called "sheltered workshops" sponsored by local associations for the retarded, some programs in

community colleges and some assistance in job training and placement through public agencies such as the State Department of Rehabilitation.

Not long ago, most parents were afraid to speak out about inferior care — or even mistreatment — of their retarded children because they feared retaliation against the children

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or their removal from the few community and state facilities which did exist. Now, as retardation begins to lose its shroud of secrecy, more and more parents are speaking out. Some have staged demonstrations at the Capitol.

One mother, Marie White of San Francisco, whose retarded son was recently removed from a community facility which could no longer afford to provide care, camped out and fasted in the State Health Department for 10 days to dramatize the plight of children like her son. She later moved her fast for a short period of time to Gov. Brown's office.

Mrs. White and others concerned about retardation feel proposed cuts by Brown in the budget for programs to aid the retarded indicate insensitivity to the needs of handicapped people.

Because of the complexities of the current state budget for health care and the proposed budget for the next fiscal year, it is difficult to exactly determine how much money is going and will go to the mentally retarded.

However, the California Association for the Retarded estimates that the proposed budget for the next fiscal year for the developmentally disabled will be cut by \$2.3 million to \$235.7 million.

Assemblyman Lanterman, who is angry about budget cuts in programs for the retarded, is particularly critical of Brown and his staff. "Marching orders were given by the gremlins — the policy makers in the governor's office, the palace guard — to cut," he said. "None of them has any background in this subject."

In an interview, Brown said, "Choices have to be made and that means limits have to be imposed."

"I personally am very deeply concerned about the state's responsibility to care for the developmentally disabled and those seriously handicapped."

But, he continued, "there always will be a desire for a greater state financial commitment than the people are willing to provide. . . It makes for

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very painful and difficult choices." Pointing out the wide range of health care services on the state level, Brown said "It's just part of the process that each particular group has to always hope for more than it expects to get. It's the responsibility of the legislature and governor to make the judgments and I try to make them as compassionately and wisely as I can."

Task Done, Reward Won

Nine-year-old Alexey works at learning to lace and tie a bow. When he gets the job done, he is promptly rewarded with a squirt of soft drink from the bottle held by Stockton State Hospital psychiatric technician Teresa Thomas. The technique is part of a behavior modification program that stresses quick reward for desired action.



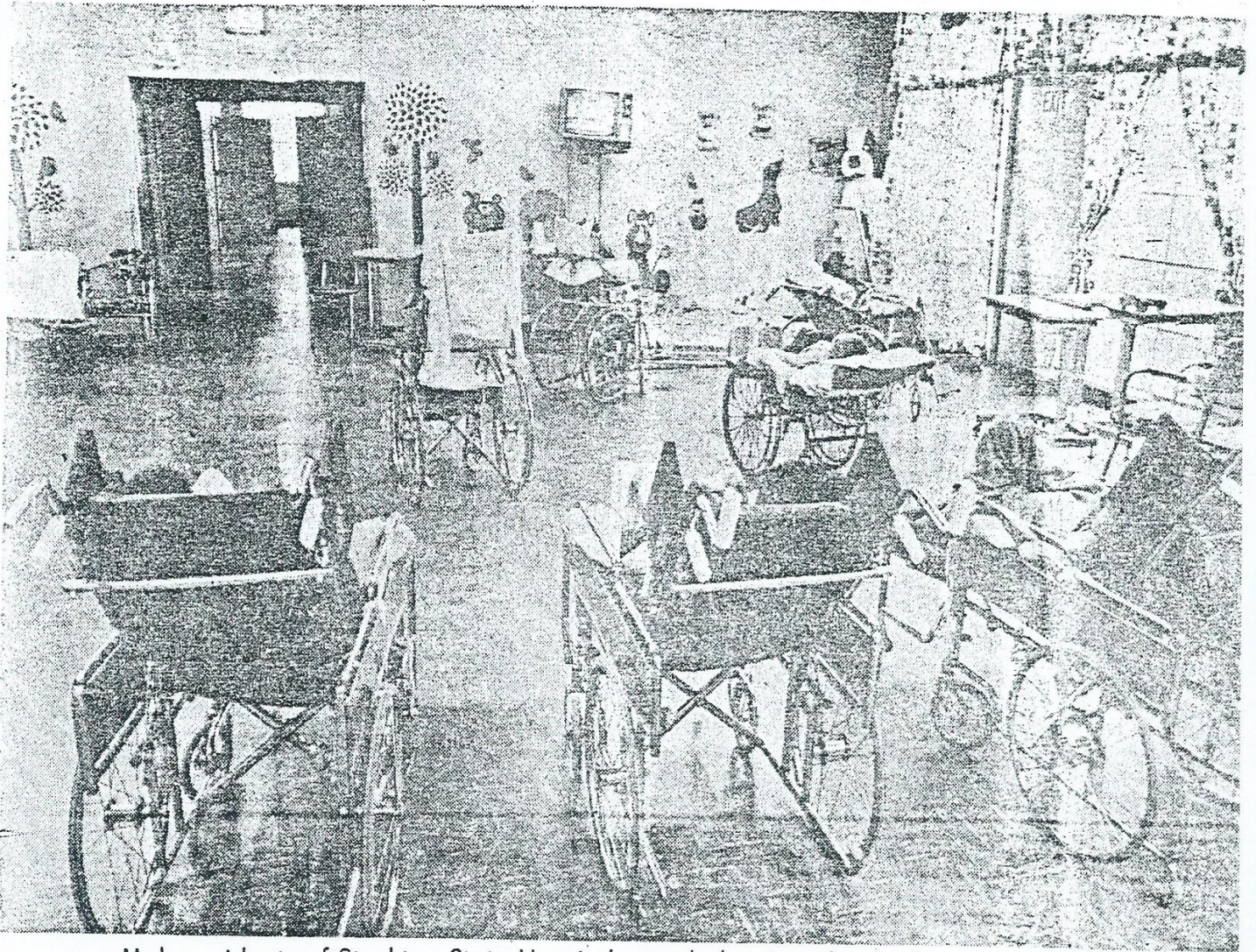
Bee Photos

By Owen Brewer

407



Stockton State Hospital aide helps 19-year-old Sharon down a corridor.



Male residents of Stockton State Hospital retarded unit gather in dayroom before lunch.