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Report of
An Investigation into the Circumstances Surrounding the Deaths of Ernesto E., Kelli S., and Rachel D.

Lack of Communication, Planning, and Coordination of Services Results in Precipitous Transfer, Suffering, and Death

Note: When this report was originally published, we were known as Protection & Advocacy, Inc. (PAI). In October 2008, we changed our name from PAI to Disability Rights California.

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I. INTRODUCTION

This report presents Protection and Advocacy, Incorporated's (PAI's) investigation into the precipitous transfer of four profoundly developmentally disabled and medically fragile young people (ages 12 to 20) from the Casa Care Nursery for Exceptional Children (Casa Care) in San Jose to Driftwood Convalescent Hospital (Driftwood) in Gilroy on December 30, 1992. The four disabled young people were transferred by San Andreas Regional Center (SARC), on an "emergency" basis, after an extension of Casa Care's license to operate was denied by the California Department of Social Services' Community Care Licensing (CCL). Three of the four individuals died within three weeks of transfer. The lone survivor lost many skills, including the ability to eat by mouth. She now resides at Sonoma Developmental Center.

PAI is an independent, private, nonprofit agency which protects and advocates for the rights of persons with mental or developmental disabilities. Under federal and state law, PAI has the authority to investigate incidents of abuse and neglect of persons with mental or developmental disabilities. 42 U.S.C. §§ 6000 and 10801, et seq.; California Welfare & Institution Code (WIC) § 4902, et seq.

PAI's six-month investigation included:

- Interviewing over 35 persons, including parents, home teachers, physicians, staff from SARC, CCL, Driftwood, Area Board VII (AB VII), California Department of Health Services Licensing and Certification (DHS L&C) and other related individuals and agencies.

- Reviewing the records of Ernesto E., Kelli S., Rachel D., and Regina C. from Casa Care, SARC, Driftwood, and South Valley Hospital (SVH).

- Reviewing CCL public files and limited nonpublic files pertaining to Casa Care from 1990 through 1993.

- Reviewing DHS L&C public files pertaining to Driftwood Convalescent Hospital from 1990 through 1993.

- Reviewing SARC files pertaining to Casa Care from 1989 through 1993.

- Reviewing relevant policies and procedures of CCL, the Department of Developmental Services (DDS), SARC, Driftwood, and Casa Care.

PAI thanks San Andreas Regional Center, Community Care Licensing, Department of Developmental Services, Department of Health Services Licensing and Certification, South Valley Hospital, and Driftwood Convalescent Hospital for their cooperation in this investigation.

In publishing this report, PAI underscores the need for all responsible agencies -- especially CCL and regional centers -- to improve communication and planning so as to avoid the unnecessary "emergency" transfer of persons with developmental disabilities. If the transfer of medically fragile individuals, such as the four remaining residents of Casa Care, becomes inevitable, appropriate discharge planning and follow-up must occur. The dangers of transfer trauma posed by abrupt relocation are real. This investigation also emphasizes the compelling need to ensure appropriate, individualized nuturing living environments for medically fragile persons with developmental disabilities throughout their lifetimes, as required by the Lanterman Developmental Disabilities Act.

II. EXECUTIVE SUMMARY

". . . The State of California accepts a responsibility for persons with developmental disabilities and an obligation to them which it must discharge. . . . The complexities of providing services and supports to persons with developmental disabilities requires the coordination of services of many state departments and community agencies to ensure that no gaps occur in communication or provision of services and supports. . . ." [Emphases added.]

- Lanterman Developmental Disabilities Act, Welfare and Institutions Code, Section 4501 -

On December 30, 1992, four severely medically fragile, developmentally disabled young persons suffered irreparable harm when they were abruptly transferred from the Casa Care Nursery for Exceptional Children in San Jose -- their community home for many years -- to Driftwood Convalescent Hospital (Driftwood), a skilled nursing facility in Gilroy, serving primarily elderly individuals. Within 48 hours of transfer, Ernesto E., Kelli S., Rachel D., and Regina C. -- four young persons who, throughout their lives, had been hand-fed by spoon in their home -- were assessed by staff, unfamiliar with their needs, as being unable to swallow well enough to be fed by mouth. All four of these individuals were then fitted with and fed through nasogastric tubes. They all fell ill with symptoms consistent with aspiration pneumonia and were transferred to South Valley Hospital for emergency medical treatment. Within three weeks, three of the four young people were dead. The quality of the only survivor's life -- Regina C. -- was forever diminished. She lost many skills, including her ability to eat by mouth. Now she is fed through a tube inserted directly into her stomach.

PAI investigated the circumstances surrounding the precipitous transfers and deaths to identify what systemic problems, if corrected, could help prevent such unnecessary suffering from occurring in the future.

PAI's investigation revealed that despite the applicable laws, regulations, policies, and agreements aimed at ensuring interagency communication and the coordination of services to medically fragile youngsters with developmental disabilities, Community Care Licensing (CCL) and the San Andreas Regional Center (SARC) repeatedly failed to fulfill basic responsibilities to the four remaining residents of Casa Care during 1992.

Failure to communicate and coordinate services is primarily responsible for the sequence of events that subsequently resulted in the "emergency"

relocation, suffering, and deaths. During 1992, CCL and SARC failed to communicate effectively with one another, and with the remaining residents' legal representatives, about the actual status of the facility's license. This resulted in confusion, haphazard planning, and, ultimately, in the "emergency" transfers on December 30, 1992.

CCL failed to notify SARC -- either verbally or in writing, as required since 1987 pursuant to a Memorandum of Understanding between the agencies -- of the March and October, 1992, accusations against the facility. Nor did CCL notify SARC of the November, 1992, stipulation-- which, among other things, revoked Casa Care's group home license. And SARC failed to ascertain the actual status of Casa Care's license so that it could object to or plan for its clients' potential transfer in a more appropriate manner.

Although SARC was aware of ongoing "licensing problems" at Casa Care, and had received subpoenas in October, 1992, from DSS regarding the facility, SARC failed to conduct adequate follow-up. According to SARC management, "We knew they were involved in some kind of legal snafu but the subpoenas were cancelled."

Additionally, SARC should have known in 1992 that the remaining residents were facing loss of their home. At the end of 1991, due to a sanction imposed by SARC itself as part of a corrective action plan, the operator agreed to "voluntarily depopulate" to a maximum of six residents. Of the eleven residents then remaining, all but four were relocated with SARC's assistance. This rendered the facility no longer viable economically. The failure to anticipate the potential transfers raises serious concerns about the adequacy of SARC's case management practices.

Sudden deaths do occur among medically fragile clients. According to physicians interviewed by PAI investigators, each day of survival for a medically fragile, developmentally disabled person is a triumph. These physicians further stated that while these deaths could be related to neglect involving inadequate care or supervision at Driftwood, the effects of "transfer trauma" alone could have caused the deaths. "Transfer trauma" is the medically accepted term of art to describe the deleterious effects of abrupt involuntary relocation upon medically fragile individuals, such as the

last remaining residents of Casa Care. The phenomenon is also commonly referred to as "relocation shock."

PAI was unable to conclude exactly what medical problem(s), if any, caused the deaths. At the time of transfer, the health of the remaining four residents was extremely fragile. Because they were taken from familiar hands, voices, and all that they had known for the last decade, their lives were radically dislocated -- the quality of their lives irrevocably diminished. The one young woman who did survive was fortunate enough to have the constant support of her loving family who were able to remain by her side throughout the frightening and traumatic changes in her life.

Despite the known risks of transfer trauma, especially upon medically fragile individuals, SARC did not attempt to involve the residents' treating physician of more than a decade in the discharge. Consequently, the receiving facility was not informed that, in the treating physician's opinion, the placement of nasogastric tubes for feeding the four disabled youngsters was contraindicated. Nor did SARC take adequate steps to ensure appropriate care post-transfer. Indeed, SARC staff did not even accompany the residents to Driftwood. Instead, they relied upon the operator's assistant to convey "what care was needed."

CCL staff denied any obligation whatsoever to weigh the risks of transfer trauma in making a decision whether, how, or when to close a community care facility. Such a contention contravenes the overriding intent of the Legislature and shocks the conscience.

A terrible irony is that the closure of Casa Care by CCL, and the abrupt relocation of its four remaining residents by SARC, was not, at the time of transfer, related to any serious or imminent threat to the health and safety of the four young people. While many of the deficiencies noted at Casa Care in 1991 were indeed serious, those dangerous conditions no longer existed far before the time of the four remaining residents' transfer on December 30, 1992.

Based on its investigation, PAI recommends the following specific actions, some of which are in the process of being implemented.

- SARC should develop and implement more effective quality assurance procedures for identifying potential "emergency" relocations and ensuring the placement needs of its medically fragile clients with developmental disabilities.

- SARC should improve its discharge planning, transfer practices, and related training to protect its clients, to the greatest extent possible, from the dangerous effects of transfer trauma.

- The Memorandums of Understanding at the state and local levels between DSS and DDS, and CCL and the regional centers, should be modified to delineate more clearly the respective responsibilities of all involved agencies so that the coordination of shared monitoring responsibilities and the resolution of interagency disagreements concerning mutual clients with developmental disabilities is addressed properly.

- DSS should ensure that all CCL staff responsible for monitoring and evaluating residential care facilities for medically fragile persons with developmental disabilities receive comprehensive education about the dangers of transfer trauma and specific guidance concerning how to weigh its dangers when making decisions about whether, how, and when to close facilities such as Casa Care.

The residents of Casa Care were representative of a fragile and burgeoning population of developmentally disabled individuals. The day-to-day survival of these medically fragile, developmentally disabled individuals depends significantly on the provision of supportive, nurturing, and highly individualized care and supervision. Such quality care is not as dependent upon the type of license a facility operates under, but rather on the training, commitment, and specialized skills of the care providers.

Until the agencies responsible for monitoring the care of medically fragile persons work more cooperatively to develop, support, and maintain appropriate placements with specially trained and caring staff -- and learn to communicate more openly and effectively with one another so that abrupt, unnecessary relocations can be avoided -- deaths under similar circumstances will likely occur again.

III. INVESTIGATION

A. BACKGROUND

1. CASA CARE

In 1989, a new owner (hereinafter "the operator") purchased Casa Care Nursery for Exceptional Children, a group home in the community serving up to fifteen non-ambulatory, developmentally disabled male and female children. All Casa Care residents were medically fragile, required total care and supervision, and had specialized care needs. As a former administrative assistant at Casa Care, the operator was familiar with the home and its residents, some of whom had lived there for over ten years.

According to CCL, a moratorium had been placed on DD Nurseries, Casa Care's original classification, when the Department of Social Services took over responsibility for monitoring and regulating them. The Department's policy was that existing nurseries would be allowed to continue to operate but that no new nurseries would be licensed. Eventually, all such nurseries would be eliminated by attrition. That policy changed at the beginning of 1992, when statutory and regulatory changes went into effect prohibiting children with special health care needs, such as the residents of Casa Care, from being cared for under a group home license, the type of license under which the facility was operating. Instead, such medically fragile children would have to be cared for in a "small family home," a new licensing category with different requirements.

According to Casa Care's Statement of Need and Philosophy:

> *"Individuals with special needs are often unable to live outside the institutional setting due to the lack of community based facilities capable of meeting their optimum health care needs. Casa Care Nursery seeks to provide an alternative to long term institutionalization of those individuals who would otherwise be placed in [an] intermediate care facility. Casa Care Nursery subscribes to the belief of normalization and the individual potential for growth and development regardless of handicap."*

The purpose of Casa Care's program was, in pertinent part:

> *"To improve the quality of life for non-ambulatory individuals with various physical and mental disorders including the developmentally disabled, children with cerebral palsy, severe profound mentally disabled, epilepsy, children who are medically fragile, who are on Gastrostomy feeding, Naso-gastric feeding, constant suctioning and on O2 [oxygen] administration. . . . To relieve pain and make them as comfortable as possible by constant nurturing, stimulation and touch. . . . To provide the children with a warm, loving home and increase self- esteem, promote good health through proper diet and exercise and to provide the least restrictive environment by encouraging freedom of movement as appropriate for each client."*

According to CCL, at the time the operator purchased Casa Care, the living area for the children was filled with "wall-to-wall cribs", a situation also known to SARC. The operator reportedly intended to alleviate crowding and privacy problems at Casa Care by placing portable screens between each bed and securing a construction loan to add two bedrooms adjacent to an existing room. The operator also reportedly intended to obtain another licensed home so that five to six clients could be moved to and cared for at the new facility. Those plans never materialized.

2. THE RESIDENTS OF CASA CARE

At the end of 1991, in response to deficiencies noted at Casa Care by both CCL and SARC, the operator agreed to "voluntarily depopulate" as part of the corrective action plan. Of the eleven residents remaining at the home, the parents of all but four children, with the assistance of SARC, relocated their sons and daughters. Four residents -- Ernesto E. (age 12), Kelli S. (age 20), Rachel D. (age 16), and Regina C. (age 16) -- remained at Casa Care until they were transferred to Driftwood Convalescent Hospital on December 30, 1992. According to records provided to PAI:

Ernesto E. was born on June 16, 1980, and was placed at Casa Care by SARC on February 28, 1982, three months before his second birthday. He

was described as a dark-haired, dark-eyed youngster with limited voluntary movement. Ernesto E. lived at Casa Care for nearly eleven years.

Ernesto E. was diagnosed as having: Mental Retardation; Diabetes Insipidus (a metabolic disorder resulting in, among other things, constant thirst); Blindness, left eye; a Seizure Disorder; and Tuberous Sclerosis (small plaques or tumors covering the brain, skin, and other organs).

According to a 1992 psychological report, Ernesto E.'s level of development was equivalent to a three- to eight-month-old infant. He had limited voluntary movement and a history of chronic respiratory congestion. Although his left eye was immobile and he was legally blind, he seemed to follow people with his right eye. He appeared to be moderately aware of his immediate environment. Ernesto E. attended East Valley School's "profound special day class" on a regular, full-time basis. According to the report:

> *"He eats strained food and drinks from a cup with assistance. Eating takes a long time because of Ernesto's chronic congestion and choking. . . . Ernesto's communication is a relative strength for him. . . . He turns toward sound and reacts positively to voices. He vocalizes to express emotions and gain attention. He coos and laughs. . . . Ernesto is very alert to people and responsive to human voices. He smiles and laughs spontaneously, vocalizes satisfaction and appears to respond to his name. He is a very happy youngster with a quiet disposition. . . ."*

Kelli S. was born on August 1, 1972. She had blue eyes and blonde hair. Kelli S. was placed at Casa Care by SARC on November 17, 1980, three months after her eighth birthday. She remained at Casa Care for over twelve years.

Kelli S. was diagnosed as having: Epilepsy; Mental Retardation, Profound; a Seizure Disorder; History of Bronchitis; and Scoliosis (a lateral deviation of the backbone). She received home teaching, emphasizing the development of feeding, positioning, and multi- sensory stimulation.

According to a 1992 psychological report, Kelli S.'s level of development was equivalent to a one- to eight-month-old infant. She had asthma and had been hospitalized several times for pneumonia. She had cerebral palsy and scoliosis so severe that sitting in a supported position was problematic. Although her pupils reacted to light, she did not track moving objects and her left eye deviated inward. She turned her head towards the sound of a musical toy or a familiar voice and appeared to reorganize and enjoy the presence of familiar people. According to the psychological report:

> *"She will also smile in the presence of a familiar caregiver. Kelli is a total care child. She can open her mouth when a spoon full of food is presented and she will remove the food with her mouth. She can also drink from a cup with assistance. Kelli appears to recognize familiar people and enjoys being stroked and talked to. . . . Kelli's home care provider reports that Kelli has one to two seizures a day. She also feels that there is some deterioration regarding Kelli's skills and general health. . . ."*

Rachel D. was born on January 4, 1977, and was placed at Casa Care by SARC on February 14, 1983, one month after her sixth birthday. Described by an evaluating psychologist as a "pretty teenager," Rachel D. had blue eyes and brown hair. She remained at Casa Care for almost ten years. She also attended a "profound class" at East Valley School, full-time.

Rachel D. was diagnosed as having: Meningomyelocele (exposed spinal cord and nerve roots resulting in paralysis with increased risk of infection); Blindness; Hydrocephalus (increased cerebrospinal fluid in the brain, resulting in an enlarged head); Mental Retardation; a Seizure Disorder; Spina Bifida (failure of the bony arches which protect the spinal cord to close); Spastic Quadripanosis (weak, underdeveloped, and contracted limbs); and Cerebral Palsy (weakness and incoordination of the limbs). Due to Rachel D.'s hydrocephalus, a tube was inserted surgically between her brain and abdomen in 1977 to allow for drainage of excess fluids.

According to a 1991 psychological report, Rachel D.'s level of development was equivalent to a half-a-month to two-month-old infant. She also had very limited physical movement. According to the report:

> *"She turns to sound but has a delayed response time and holds objects that are placed in her hands. She does relax when she is massaged. She eats pureed food with some coughing and really appears to enjoy being fed. She has a healthy appetite and is able to be fed within a reasonable amount of time. She shows satisfaction by vocalizing and cries when unhappy. Her vocalizations have a cooing quality to them. . . ."*

Regina C. was born on October 22, 1976 and was placed at Casa Care by SARC on August 25, 1980, two months before her fourth birthday. She was described by a school psychologist as a "pretty young lady with long brown hair and blue eyes who is profoundly physically limited." She remained at Casa Care for over twelve years. Depending on the fragility of her health, Regina C. received schooling at her home or at East Valley.

Regina C. was diagnosed as having: Mental Retardation; Cerebral Palsy; Scoliosis; Blindness; and a Seizure Disorder.

According to a 1991 psychological report, Regina C.'s level of development was equivalent to a two- to four and a half-month-old infant. She was diagnosed when she was two and a half months old with Reyes Syndrome with acute toxic encephalopathy (a syndrome that tends to follow some acute viral infections causing inflammation of the brain and dysfunction of the liver, sometimes resulting in permanent neurological damage), cortical blindness, developmental delay, and a seizure disorder. According to the report:

> *"Although Regina requires total care, she is able to suck and swallow food; however, she has episodes of choking which often interfere. As a result, it takes time to feed her. Physically, she moves her head from side to side and holds objects momentarily. . . . When she is feeling good, she smiles in satisfaction and coos. Her physical condition does effect her mood and as mentioned earlier, Regina is often unhappy about being moved. She enjoys being read to and talked to and when sung to, responds with cooing. . . ."*

3. SAN ANDREAS REGIONAL CENTER

The San Andreas Regional Center (SARC) is one of 21 private nonprofit corporations in the state of California under contract with DDS. Regional centers provide, secure, and coordinate comprehensive and individualized services, especially case management services, to persons with developmental disabilities as required under the Lanterman Act. SARC serves developmentally disabled persons from four counties: Monterey, San Benito, Santa Clara, and Santa Cruz.

Regional Centers, such as SARC, are responsible for providing a range of services, including, but not limited to:

- Initial intake and assessment
- Placement and relocation services
- Development, implementation, monitoring, and coordination of an Individual Program Plan (IPP) for each client
- Purchase of services to meet IPP objectives
- Advocacy efforts to secure the protection of their clients' legal, civil and service rights
- Resource development, program evaluation and community education
- Information and referral services

At regional centers, case management services are provided by an assigned Client Program Coordinator (CPC). The CPC's responsibilities include implementing and monitoring the client's IPP, and maintaining the client's regional center record. The placement of all of the young people at Casa Care was monitored by a CPC from SARC. In 1991, the CPC for Casa Care was SARC SP #4. In 1992, SARC SP#2 was assigned as CPC. While assigned as CPC, both staff persons were given the concurrent assignment of Facility Liaison for Casa Care. Their responsibilities included coordinating services between the regional center and the facility.

According to SARC records, SARC SP #2 visited the facility every month to evaluate clients' progress and monitor the facility. Per SARC SP #2, his case load is approximately 80 to 90 clients.

4. COMMUNITY CARE LICENSING

In enacting the California Community Care Facilities Act, the Legislature, in pertinent part, declared "that there is an urgent need to establish a coordinated and comprehensive statewide service system of quality community care for . . . developmentally and physically disabled . . . children and adults. . . ." According to California Health and Safety Code §1501(b):

> *"The Legislature declares it is the intent of the state [to] develop policies and programs designed to: (1) insure a level of care and services in the community which is equal to or better than that provided by the state hospitals; (2) assure that all people who require them are provided with the appropriate range of social rehabilitative, habilitative and treatment services, including residential and nonresidential programs tailored to their needs; (3) protect the legal and human rights of a person in or receiving services from a community care facility; (4) insure continuity of care between the medical-health elements and the supportive care-rehabilitation elements of California's health systems; (5) insure that facilities providing community care are adequate, safe, and sanitary. . . ."*

Under the California Department of Social Services (DSS), CCL licenses residential and day care facilities serving children and dependent adults. CCL District Offices are located throughout the State. The community care facilities that fall under their jurisdiction, by definition, provide "nonmedical" and protective care or supervision to persons unable to care for themselves independently.

CCL is responsible for monitoring the quality of care at community care facilities, enforcing compliance with applicable state laws and regulations, and for investigating complaints about community care facilities, whether

such facilities are licensed or unlicensed. CCL's enforcement authority includes, among other things, requiring compliance with plans of corrections, imposing monetary penalties, and suspending or revoking licenses to operate on a temporary or permanent basis. The San Jose CCL District office was responsible for the licensing of Casa Care.

5. DRIFTWOOD CONVALESCENT HOSPITAL/GILROY

When the four medically fragile young persons were transferred to Driftwood on December 30, 1992, this skilled nursing facility in Gilroy was one of 23 facilities owned by Grand Care (GCI Properties, Incorporated). Driftwood has a maximum capacity of 132 residents, most of whom are elderly and require 24 hour nursing care. After the deaths, Grand Care sold its facilities, including Driftwood. Driftwood has since been owned and operated by Pleasant Care of Northern California, Incorporated. In mid-May 1992, the client census at Driftwood was 110, including approximately ten developmentally disabled clients referred from SARC. These clients share rooms with and participate in activities with Driftwood's primarily geriatric population.

According to SARC management, placement of SARC clients in nursing homes, which primarily care for the elderly, is relatively common. This is, in part, based on historical practice. Some developmentally disabled individuals were already residing in nursing homes before they became regional center clients. According to SARC management, clients originally were placed at Driftwood by SARC because the nursing coordinator at that time reportedly had experience in providing care and treatment to clients with developmental disabilities. That nursing coordinator, apparently, was no longer employed at Driftwood when the four remaining Casa Care residents were transferred to the facility on December 30, 1992.

Driftwood's current administrator expressed concern to PAI investigators as to whether Driftwood is an appropriate placement for SARC clients. Reasons for this concern include limited socialization opportunities and the fact that Driftwood staff are not specially trained to work with medically fragile, developmentally disabled persons. Driftwood's current administrator stated that SARC had asked her to accept more clients but that she would not do so because the facility was not equipped to care for them properly.

SARC management also stated to PAI investigators that since Driftwood's change in ownership, the clients placed there have been assessed and may be moved due to lack of appropriate stimulation or programming.

PAI investigators requested from Driftwood's current administrator all existing and prior policies and procedures pertaining specifically to the care and treatment of developmentally disabled persons. None were provided.

B. SEQUENCE OF EVENTS

1. MONITORING OF CASA CARE IN 1991

Both CCL and SARC monitored the quality of services Casa Care provided to the residents who lived there. CCL monitored the home pursuant to their authority under California Code of Regulations (CCR), Title 22, Division 6, while SARC monitored Casa Care pursuant to their quality assurance process under authority of CCR, Title 17, Division 2. From the records, it appears that SARC intensified its 1991 monitoring activities in response to CCL's 1991 reports of deficiencies at Casa Care.

There was considerable monitoring of Casa Care in 1991. It also appears that in 1991, CCL and SARC communicated regularly and frequently, sharing information and, to some extent, coordinating plans of correction.

Between March 4, 1991, and December 8, 1991, CCL made 15 unannounced visits to Casa Care. During these visits, CCL identified a number of serious deficiencies, some of which were considered "inimical to the health, morals, welfare, or safety of residents in or the people of this State." Despite the alleged pattern of serious violations during 1991, CCL never exercised its discretion to obtain a temporary suspension order (TSO) against the facility, which would have stopped Casa Care from operating long before December 30, 1992. (DDS has the authority to issue a TSO prior to any hearing and at any time "necessary to protect residents or clients of the facility from physical or mental abuse, abandonment, or any other substantial threat to health or safety.")

These 1991 deficiencies, which in 1992 served as the basis for two formal accusations against the facility, allegedly included:

- Failure to provide medical care.
  The facility failed to seek medical assistance for a child who reportedly had an elevated body temperature and was ill for three days before he died on September 30, 1991. Another child, according to facility records, had been showing signs of illness for nine days without receiving medical attention. Four residents had sores which staff were treating without physician's orders or documentation that they had consulted a physician.

- Failure to provide safe, healthful and comfortable living environment.
  During 1991, CCL noted numerous deficiencies in this area. CCL noted no procedure for adequately sanitizing tube feeding syringes. CCL observed staff take spoons from a container of soiled feeding syringes and place them in a drainer with clean utensils. Some staff had not received basic first-aid training, even though this had previously been identified as a problem. One staff person worked one month at the home without proper training even though she had no previous experience in caring for developmentally disabled clients. Five clients were sleeping in beds too small for them. And, because there was no designated isolation area, healthy clients were placed "side- by-side" next to sick clients. Staff placed multiple diapers on residents, increasing their risk of skin breakdown. In addition, some staff did not wash their hands after providing care to different residents or sanitize the changing table after changing dressings and diapers. Two contaminated hypodermic syringes with needles still attached were found lying on the suctioning table near the residents' cribs. Staffing levels were inadequate on eleven of the twenty-five evenings preceding one CCL visit.

- Failure to obtain/follow physician orders; inadequate care and supervision. Medications, treatments and dietary supplements ordered by the physician were not administered nor available at the home. Alternately, some treatments, such as gastrostomy feedings and administration of oxygen, given without physician's orders. Procedures such as gastrostomy tube feedings, administration of oxygen and suctioning were being performed by

"unqualified staff" instead of licensed nurses. Areas of skin breakdown were treated at the home without notification to or order from the physician. Weekly enemas were given to residents regardless of need. Staff placed residents on an extremely dirty changing table to change soiled clothing and treat open sores.

- Inadequate care and supervision; incompetent personnel.
  Staff failed to aspirate the stomach contents of residents with gastrostomies prior to feeding them, and unnecessarily pulled on the tubes, causing stress to residents' abdominal walls. Staff fed residents capable of eating by mouth too quickly, without giving them enough time to swallow and without positioning them correctly. Consequently, one resident suffered five or six choking episodes. Residents were not provided adequate personal hygiene care. One child needed oral care. Two children were left in wet clothing and not given adequate covering. Children were not provided basic hygienic eye care to prevent "matted" eyes.

- Inadequate food services.
  At least five children were not regularly provided adequate nutrition. Residents were fed the same amount of food regardless of individual need. There was an inadequate supply of perishable and non-perishable foods available at the home. Meals were not adequately nutritious, did not correlate with the planned menus, and there were not enough snacks on the menu. Food was not refrigerated properly and residents were fed food which had been unrefrigerated for at least three hours. Water temperature was not sufficient to sterilize dishes and equipment.

- Failure to control and dispense medications properly.
  Records of centrally stored medications were incomplete. Antibiotic medications were not administered according to physicians' orders.

- Failure to timely obtain criminal records clearance.
  Fingerprints had not been submitted to Licensing for some employees.

On April 8, 1991, CCL fined the operator $1,500 for failure to correct a previously identified deficiency of not maintaining a two-day supply of perishable and a seven-day supply of nonperishable food.

On April 12, 1991, CPC SARC SP #4 received a call from a CCL evaluator regarding deficiencies noted at Casa Care. As a result, SARC began to monitor Casa Care regularly, issue corrective action reports, and communicate with CCL regarding SARC's quality assurance monitoring activities. SARC's findings were consistent with CCL's reports of deficiencies at Casa Care. On May 22, 1991, SARC wrote a letter to the operator regarding the deficiencies, stating:

> *"The ongoing deficiencies in your facility are of grave concern to all San Andreas staff who have visited your facility throughout the past 3-4 weeks. These concerns continue to be those of Community Care Licensing as well. These deficiencies are considered substantial inadequacies and require your immediate attention for correction. . . . As you know, the process of correcting deficiencies is time consuming and requires your utmost focused attention. Although we sympathize with your current situation, we are mandated to ensure the health, safety and IPP training of residents in your facility. We will continue to work with you and Community Care Licensing on a regular basis to be advised of your progress in correcting the above items. . . ."*

On May 29, 1991, SARC and CCL representatives met at CCL's office for an informal conference with the operator to discuss the deficient areas identified at Casa Care by both agencies. Issues and deficiencies discussed at the informal conference included, but were not limited to: inadequate food service and infection control procedures; misrepresentation of records concerning staff training and the improper use of client monies; failure to, for example, request needed exceptions from CCL to continue to care for a client with a decubitus ulcer and clients receiving tube feedings; physical plant problems, such as overcrowding and the need to install another sink; and the concern that one child was sleeping in a crib that was too small, thus forcing him to sleep in a curled position.

At the May 29, 1991, informal conference, the operator was informed that CCL "highly recommended" that she reduce the capacity of the facility to twelve residents. The following day, CCL wrote the operator a confirmatory letter summarizing the issues that were discussed at the informal conference. The letter reiterated that the operator would be given only a few months to make the corrections and that the facility would be monitored frequently to evaluate its progress. The letter also stated that licensing staff "are willing to work with you to avoid the revocation action." The operator was also advised that if she did not correct the deficiencies, CCL would proceed with action to revoke Casa Care's license to operate.

As noted above, according to CCL reports, a client from Casa Care died on September 30, 1991. CCL determined that the client showed evidence of continuous illness three days prior to his death and that Casa Care failed to summon a physician. According to CCL documents, when Dr. B, the treating physician, was served with a subpoena for the records of the dead child, Dr. B said:

> *". . . she was shocked when the hospital called as she did not expect this. . . . She said there were other children there that would not have surprised her but [this child's death] did. Dr. [B] was asked if she knew the cause of death on the death certificate and she said she had signed it stating the cause of death as cardiac arrest due to pulmonary failure with a contributing cause of sevier (sic) retardation. I asked Dr. [B] if she was aware the facility records indicate that the child . . . was running a fever of 103 degrees on 9/27, had brown secretions from his nose on two occasions and was in their words [referring to Casa Care], 'too congested.' She, Dr. [B] stated that she was not and that it sounded like maybe pneumonia. She also stated there was no autopsy done and the body was cremated."*

After the client's death on September 30, 1991, SARC's quality assurance visits to Casa Care became even more frequent. On October 8, 1991, SARC staff person #1 (SARC SP #1) called CCL regarding Casa Care's apparent lack of follow up to CCL's latest deficiencies report and requested to meet with CCL when CCL's current investigation was complete.

However, SARC SP #2, who later became CPC for the Casa Care clients in 1992, wrote on October 11, 1991: "It is felt that this facility has some inadequacies, however, it is my opinion that they are not grave enough to warrant closing the facility. . . . It is my opinion that these clients are not at any risk by staying in the facility. Consult with administrator in a way that she does not feel intimidated and is constructive. . . ."

Despite SARC SP #2's opinion, on October 28, 1991, SARC sent the operator a certified letter advising her of a sanction to relocate the clients at Casa Care and of her right to file an appeal. SARC chose to proceed with this sanction because, in its opinion, there had been multiple substantial inadequacies at the facility within a six month period:

> *"[D]ue to three Corrective Actions Plans . . . of substantial inadequacies that your facility has received within the last six months, the Regional Center finds it necessary to take sanctions pursuant to Section 56057(b) of Title 17 Administrative Code."*

The letter further stated that "[w]ithin fifteen days following receipt of this letter, we intend to discuss the relocation of the clients with the parents or authorized representatives."

The next day, October 29, 1991, SARC sent a letter to the parents and/or legal representatives of Casa Care residents notifying them of SARC's intention to apply the relocation sanction against the facility. The letter further stated: "We are, therefore, requesting that you meet with us on 11/12/91 at 1:30 p.m. at San Andreas Regional Center to discuss possible relocation of your child and the consequences of refusing location." [Emphasis added in original.] The letter was copied to, among others, CCL and the operator of Casa Care.

The operator appealed SARC's sanction in a letter dated November 8, 1991, stating:

> *"All deficiencies cited by the regional center were either challenged or corrected in a timely manner. None of the deficiencies cited posed an imminent danger to the residents'*

> *health and safety. . . . The general areas indicated as deficiencies are all inherent problems in the operation of a community care facility providing services to nonambulatory, developmentally disabled residents. Specifically, the potential adverse impact on the facility is obvious. The facility would be bankrupt, and thus closed, if the clients residing there, all of whom are developmentally disabled, are relocated. The potential adverse impact on these clients also exists. The facility has existed for over a decade, many of the clients have resided in this home for most of their lives, therefore, the traumatic effect of relocating is real. . . ." [Emphases added.]*

A meeting was held at SARC on November 12, 1991, to discuss relocation with some of the parents/legal representatives of the residents at Casa Care. Representatives from CCL were also present. At this meeting, participants were given information about CCL's findings concerning deficiencies at the facility. The parents of Regina C. told PAI investigators that they chose to keep Regina at Casa Care because they had not noticed any serious problems with Regina's care and that the concerns expressed by CCL and SARC seemed to be matters that could be corrected easily.

Rachel D.'s mother told PAI that the risk of transfer trauma upon relocating the medically fragile residents was also discussed at the November 12, 1991, meeting. According to Rachel D.'s mother, SARC staff explained that because the residents were so medically fragile, special care and planning would be required to assure the safest relocation possible. Rachel D.'s mother reportedly left the meeting confused, as she felt two contradictory messages had been conveyed. The first was that SARC wanted to relocate all of the residents; the second was that the facility's license was not likely to be revoked. Furthermore, given the medical fragility of her daughter and related comments made by SARC staff, she was under the impression that a developmental center placement would always be available if there were no other, more appropriate alternatives. Given these considerations, Rachel D.'s mother felt there was no compelling justification to relocate her daughter at that time.

Several parents did, however, relocate their children following the receipt of SARC's October 29, 1991, sanction notice and the November 12, 1991, meeting. One child was taken home by his parents on December, 18, 1991, in anticipation of relocating him to Agnews Developmental Center (ADC). The morning after the child was transferred from Casa Care to his parents' home, they found him dead. According to the child's physician at Casa Care, because of the child's disability, his back was progressively arching backwards, causing his tongue to obstruct his airway. Because of this condition, he had been hospitalized at least three times and was monitored closely at Casa Care.

According to information provided to PAI by SARC, between November 5, 1991, and December 12, 1991, eight other Casa Care residents were relocated by SARC with the consent of their parents and/or legal representatives. Most of the residents were transferred to ADC. These transfers, unlike the December 30, 1992, transfers, or the one above, were planned and steps taken to mitigate against the effects of transfer trauma. One of these eight youngsters died post-transfer at ADC on September 10, 1992 (over 8 months later).

On December 2, 1991, a hearing was held at SARC on Casa Care's appeal of the sanction to relocate clients from its current population of twelve to six. In its appeal papers, the operator stated: "The licensing designation of Nursery no longer exists. The facility was 'grandfathered' in, and retained the Nursery designation, presumably to prevent the potential traumatic relocation of clients."

The operator's appeal also asserted that all but one deficiency noted by SARC was based upon receipt of the licensing reports. According to the operator, detailed corrective action plans and subsequent follow-up were submitted to Licensing and implemented in a timely manner. The operator concluded:

> *"Inasmuch as the regional center's deficiencies report, which is noted as the reason for the action of sanction [to relocate] was based on the licensing reports submitted to the regional center by Licensing, it was reasonable to expect communication between the regional center and Licensing*

> *with regard to the submitted corrective action by the facility. The action of sanction was, therefore, stunning, unwarranted and unprecedented based solely on the reason noted by the regional center."*

According to CCL documents, on December 5, 1991, CCL conducted an office visit with the operator and her representative. The stated purpose of the meeting was to "determine if Licensing would oppose [the operator's] plan to lease another cite (sic) and license it for 6, keeping the present capacity at 15 or reducing the census of the present facility [Casa Care] to 6, keeping the licensed capacity at 15."

The operator was advised that CCL did not support this first plan and would not license an additional six beds at another address, noting:

> *"CCL staff reminded the licensee that the problems with this facility [Casa Care] go beyond physical plant problems and there was no guarantee that the application will be approved. The second plan includes a plan to voluntarily reduce the capacity to 6 at the existing cite (sic). They would get rid of all the GT feeders and one additional child. The capacity on the license would remain 15 until March 1992. If they could not submit an expansion plan [for Casa Care] to meet the needs of 15 the capacity would be reduced then. We stated we would not be opposed to the plan but we once again reminded them that the problems were more than physical plant and that this would not keep us from pursuing any action we felt necessary."*

According to a letter dated December 13, 1991, from SARC to the operator, an agreement was reached between them as follows. Casa Care would depopulate to a maximum of six residents "as soon as possible." The letter further stated that SARC would not support any increase in capacity, even with remodeling. The operator also agreed to work with "a technical assistance team of professionals from Agnews Developmental Center, possibly from Department of Developmental Services headquarters, and SARC staff. The purpose of this collaborative effort would be to develop a safe, healthy environment, with proper safeguards, for the residents. . . ." In that letter, SARC also specified: "[W]e have made no promise to keep your

occupancy at six (6) residents; that is, if parents insist on relocating their children, we would honor their request."

On December 17, 1991, the operator sent a letter to the parents/legal representatives of the facility's remaining residents stating in pertinent part: "[W]e also assure you of our commitment to continue to provide residential services to our special residents. We are modifying our operation plan in an effort to maximize care for those residents that can best be served in a residential setting, therefore, the number of residents will be reduced to a total of six (6). We look forward to serving you for many years to come. . . ."

Another letter, also dated December 17, 1991, from the operator's consultant to SARC management, referred to and enclosed copies of the above-referenced letters from the operator to the remaining residents' parents. The operator's consultant's letter expressed concern about SARC's handling of the relocation sanction, stating, in part:

> *"It now appears evident that the fears expressed throughout this process are evident. If you recall [referring to SARC] from the initial stages of this process, the facility expressed concern that parents would be pressured to relocate clients. At least three (3) parents have indicated 'being confused,' afraid of having the only clients at Casa Care, SARC will not place, 'Casa Care will close' [and] 'SARC will not accept placement responsibility if they do not agree to relocate. . . .'"*

The operator's consultant's letter further stated that:

> *"Whether these parents are accurate in their perceptions is academic; they believe them to be true, and apparently due to some communication with SARC. The forced decision by these parents to relocate, coupled with SARC's position of no promise to keep occupancy at six (6), and the reality of not receiving referrals to replace the vacancies, is tantamount to the decision of removing all clients [referring to the relocation sanction] -- the very decision for which the appeal was filed." [Emphasis added in original.]*

The operator's consultant's letter also stated to SARC management:

> *"The letters to the parents were written in the style and manner you suggested, which portrays constructive thoughtful change in the best interests of the clients. I am not assured that SARC staff understands, or agrees with, your stated goal to assist Casa Care in their efforts to provide quality care. . . ."*

In a letter dated December 20, 1991, responding to the facility's above-stated concerns, SARC management said:

> *"I regret that you believe my staff subtly pressured parents to remove their children from Casa Care. Nothing can be further from the truth. Even before December 13, 1991, staff had taken a very neutral position regarding re-location (sic) of clients, and attempted to get families to wait until after our meeting before making up their minds. . . . What must be decided now is whether [the operator] wishes to remain open with the . . . remaining [four] clients. . . ."*

The letter from SARC to the operator's consultant ended with the statement: "I will be out of the office until January 6, 1992, and I hope that upon my return that plans regarding Casa Care can be finalized."

2. MONITORING OF CASA CARE IN 1992

There is no evidence in SARC's or CCL's records that there were any serious health and safety risks at Casa Care in 1992. According to CCL, it evaluated Casa Care only twice in 1992 -- on March 19 and September 29, 1992. CCL representatives told PAI that placement at Casa Care posed no imminent threat to remaining residents at anytime during 1992 and that no serious violations were alleged as outstanding at the time of closure.

According to CCL's own records which were provided to PAI, the only "serious" deficiencies they found in 1992 were an oven that needed cleaning and suppositories in an unlocked refrigerator that should have been discarded. (A serious deficiency is defined as "any deficiency that presents an immediate or substantial threat to the physical health, mental health, or safety of the clients at a community care facility.") At the same time, CCL representatives stated that since prior patterns of serious

violations existed, there was no reason to believe that such violations would not occur again. Further, representatives from CCL told PAI that once the administrative action against the operator was proceeding, the fact that corrections had been made or the fact that serious allegations did not again arise was not justification for further investigation, as that would have been "administrative overkill."

SARC's records do not reflect any quality assurance monitoring nor technical assistance activities at Casa Care in 1992. Per SARC SP #3, 1992 follow-up was left to the CPC, SARC SP #2, who "consulted with the in-home teachers." According to the in-home teachers, who made at least three visits per week to Casa Care, the quality of care was good. The residents appeared to be clean, did not have any bruises or sores, and seemed to be in their regular state of health. In fact, the consensus opinion of the in-home teachers was that the care provided at the facility was as good or better than that provided at comparable facilities. Towards the end of 1992, the teachers were told by the operator that she was selling the home. According to Regina C.'s teacher, CCL was "always citing" the operator, but the teacher had no idea about the pending action to revoke the operator's license.

The operator's group home license to operate Casa Care expired on March 20, 1992. As noted above, in order to remain open and serve medically fragile youngsters, the operator needed to obtain a license for a small family home. A small family home is defined as: "any residential facility in the licensee's family residence providing 24-hour a day care for six or fewer children who are mentally disordered, developmentally disabled or physically handicapped and who require special care and supervision as a result of such disabilities." CCR, Title 22, §80001(s)(2). (Emphasis added.)

According to a representative for the operator, CCL took action against the operator on the license for fifteen individuals and would not allow her to apply for a license with a lower census after she depopulated. This same representative stated that the operator was unable to meet the small family home licensure requirement of residing at the facility due to lack of space at Casa Care. Representatives of CCL stated to PAI that such requirement could, however, be waived under the appropriate circumstances.

According to CCL records, the original accusation by CCL seeking revocation of the operator's group home license was dated March 20, 1992. On March 24, 1992, CCL denied the operator's renewal application for licensure of a group home. The operator appealed by certified letter dated April 2, 1992. The filing of the appeal allowed the operator to continue operating the facility pending the outcome of the hearing, as a temporary suspension order was never issued. A first amended accusation by CCL also seeking revocation of the operator's group home license was dated October 19, 1992. Both accusations were based on the deficiencies noted in 1991. The only substantive difference between the original and first amended accusation is that the amended accusation alleged that "on September 29, 1992, respondent was operating under a group home license [instead of a family home license] in violation of Welfare and Institutions Code Section 17732(d)." An administrative hearing had been scheduled for October 27-29, 1992, seven months after the filing of the original accusation. That hearing did not occur. Instead, on November 2, 1992, a stipulation between CCL and the operator became effective.

As set forth in the Stipulation, the operator agreed to waive the hearing on the accusation, with the understanding that Casa Care's group home license would be revoked. The operator also agreed to never again apply for a community care license during the balance of her lifetime. Per the stipulation, Casa Care was given a limited-term license to operate the home for 60 additional days. The limited-term license could, at the "sound discretion" of CCL, be extended if the operator could demonstrate in good faith that she was attempting to sell or otherwise transfer ownership of the facility.

A copy of the stipulation was received by the San Jose CCL District office on November 9, 1992. As discussed more fully below, CCL failed to successfully notify SARC of the accusations or the stipulation and limited-term license, either verbally or in writing.

On October 27, 1992, the operator wrote a letter to CCL outlining her activities relating to the stipulation:

> *"With due respect to the Stipulation and Waiver and Order entered into on October 21, 1992, and the terms and*

conditions therein stated and agreed upon, the Licensee, [the operator], will cease operation within the time limit as prescribed.

"During this period, the Licensee will aggressively pursue the sale and/or transfer of the facility, as well as actively assist potential buyers in the process. Any and all potential buyers are being informed of the necessity to meet Small Family Home requirements.

"In the event work-in-progress, with regard to the sale and/or transfer, is delayed due to some unforeseen difficulties, the Licensee will seek an extension of the deadline for that period which is bilaterally deemed necessary to finalize the sale.

"Further, in the event it is apparent by the Licensee that the sale will not materialize, or work-in-progress had not been initiated, the Licensee will:

1) Notify the Department of the date operations will cease.

2) Notify the placement agency with regard to client relocation.

3) Prepare all discharge procedures and/or summaries.

4) Assist, where appropriate, in the orderly relocation of all clients. . . ."

By 1992, however, the closure of Casa Care appeared inevitable. As discussed in the previous section, the operator "voluntarily" lowered the maximum client population from 15 to six. By January of 1992, only four residents remained. The income generated from the four remaining clients was not enough to operate the home. Without additional assistance, funding problems would have necessitated the closure of Casa Care and subsequent transfer of the four young people eventually. The operator was reportedly forced to take a job at night at a local hospital in order to survive financially.

SARC's Response to Licensure Problems

Despite the fact that SARC knew Casa Care had licensing problems, SARC failed to take reasonable steps to ascertain the potential threat to the four remaining residents' home that such problems presented. A September 30, 1992, notation in Regina C.'s Medicaid Eligibility record in her SARC file simply stated: "Still licensing problems."

Subpoenas from CCL -- for SARC SPs #4 and #5 and SARC M.D. #1 to appear at an October 27-29, 1992, DSS proceeding regarding Casa Care -- were received at SARC on October 14, 1992. The subpoenas, which were issued on October 5, 1992, did not state the precise nature or purpose of the hearing. Such subpoenas did, however, put SARC on notice that DSS had initiated proceedings "In the Matter of: [the operator] dba Casa Care Nursery. . . ." According to SARC staff, they did not appear at the proceeding because the subpoenas were "rescinded" by CCL without any further explanation. SARC SP #2, the current CPC for the residents at Casa Care when the subpoenas were received, wrote:

> *"Via the 'grapevine' I became aware that several people at SARC had received subpoenas from Community Care Licensing (CCL). I asked my supervisor, [SARC SP #3], what my responsibility was in regards to the subpoenas. He indicated that if I was not subpoenaed, I was not involved. Via the 'grapevine' sometime later I learned that the subpoenas had been rescinded."*

According to CCR Title 17 § 56020 (a):

> "All regional centers shall develop and maintain procedures to be implemented in the event of emergency situations requiring client placement(s) or relocation(s). The procedures shall include, but not be limited to:
>
> (1) Early identification of potential situations which would require emergency placement(s) or relocation(s);
>
> (2) CPC and other regional center staff responsibilities;
>
> (3) Notification of client(s) authorized client representatives, administrators and other agencies; and

(4) Identification of alternative living arrangements for emergencies." [Emphasis added.]

Although aware of ongoing "licensing problems," there is no indication that SARC made timely efforts to investigate the actual status of Casa Care's license either upon the receiving or the "rescinding" of the subpoenas. Per SARC management, "We knew they were involved in some kind of legal snafu but the subpoenas were cancelled." In addition, SARC's policies provided to PAI regarding emergency placement do not address how to identify potential situations which could result in emergency relocations nor how to identify alternative living arrangements under such circumstances.

Memorandum of Understanding Between CCL and SARC CCL was still responsible for notifying SARC of its activities relating to Casa Care, regardless of any notification obligations of the operator. CCL's obligation to notify SARC was specified in a Memorandum of Understanding (MOU) that was signed by SARC's Executive Director and CCL's District Manager. That MOU had been in effect since November 30, 1987, five years previous to the stipulation signed by CCL and the operator. The MOU, which implements at the local level a similar MOU that exists on the state level between DDS and DSS, sets forth its intended purposes as:

"The San Andreas Regional Center and California State Department of Social Services, Community Care Licensing Division, San Jose District Office recognizes the need to formalize this Agreement regarding services to our mutual clients who reside in Community Care Facilities.

"The intent of this Memo of Understanding between San Andreas Regional Center and Community Care Licensing Division is to facilitate and clarify communication between the two agencies."

According to the monitoring responsibilities agreed upon in the MOU, CCL will:

"A. Advise SARC of facilities (or service provider) against which legal accusations have been filed by Community Care Licensing and provide copies of accusation.

> "B. Report to San Andreas Regional Center any impending intent to discontinue services initiated by the licensee. . . ."

The MOU also outlined SARC's and CCL's shared responsibilities regarding the exchange of information. Per this MOU, SARC and CCL will:

> "B. Develop a written agenda and meet...on a once a monthly basis to discuss:
>
> 1) Problem facilities in which serious deficiencies have been cited.
>
> 2) Health and safety issues concerning SARC clients in Community Care licensed facilities. . . ."

According to SARC management, SARC staff had tried to meet with CCL staff consistently on a monthly basis as required by the MOU, but staff changes at CCL interfered with the scheduling of such meetings. Records reviewed by PAI, however, do not show significant changes in CCL staff responsible for regularly monitoring Casa Care. SARC management added that historically communication between the agencies was quite good even without the monthly meetings. SARC management also indicated that closures of community care facilities involving SARC clients are relatively rare, "maybe once a year." In the past, SARC staff stated that they usually knew when a facility was going to close due to ongoing communication between SARC and CCL. However, the two accusations and stipulation regarding Casa Care were never sent by CCL to SARC. SARC finally obtained a copy of the stipulation, not from CCL but from the operator's consultant in mid-January of 1993. According to SARC management, as a result of CCL's failure to comply with the MOU, by the time they were notified of Casa Care's closure, SARC had no opportunity to develop alternative placements for the Casa Care residents.

During interviews with PAI, CCL staff appeared unaware of any existing MOU. CCL staff told PAI that there was no formal policy or procedure for notifying SARC of pending actions against licensees. CCL stated that they sometimes notify SARC by phone or by sending a copy of the stipulation. When asked by PAI investigators what efforts CCL has taken to prevent

similar incidents in the future: "We've developed an MOU with SARC and are meeting to finalize it."

Communication Attempts Regarding Casa Care's Status Unsuccessful

According to SARC SP #2:

> *"On or about the week of December 1, two calls were made by the writer to CCL to ascertain the status of Casa Care, per the direction of [SARC SP #3]. . . . [CCL SP #1], the assigned Licensing Worker, was not available -- a message was left with the receptionist at CCL for [her] to return my call."*

On December 8, 1992, SARC SP #2 was told by the operator that her assistant was going to purchase Casa Care and was scheduled to attend a CCL orientation. The operator told SARC SP #2 that she "had been given 60 days to find a buyer and that this period could be extended if there was evidence of actively seeking new buyer. She did not state when the 60 days began. [The operator] indicated that she had 2 possibilities for a buyer."

Per SARC SP #2, he again "placed a call to [CCL SP #1], who was not available. Spoke with [CCL SP #2]. . . . He did not know whether application from potential buyer had been received or the status of the appointment of [the operator's assistant] as Administrative Designee. [CCL SP #2] was also unsure of the start date of the '60' days, he only knew that the conference was 10/21/92. I requested that he contact us if there was any firm information or any problems." [Emphasis added.]

According to SARC SP #2, the last day he and his supervisor visited Casa Care was on December 10, 1992. The operator told them that she was actively trying to find a buyer, and they asked that the operator keep them informed of any progress. On December 16th and 17th, SARC SP #2 called Casa Care for an update and left messages requesting an update on their progress. On December 18th, SARC SP #2's vacation began. He did not return to the office until January 11, 1993.

CCL SPs #2 and #3 told PAI investigators that SARC was informed of the stipulation regarding Casa Care in November, and that this was reiterated to SARC SP #2 by CCL in "mid-December." CCL expressed the opinion that SARC staff were aware of the pending revocation and about the stipulation but weren't aware of the "exact date."

According to CCL, CCL SP #1 attempted to contact SARC on Tuesday, December 15th, and Friday, December 18th. However, CCL did not produce any documentation of such attempts. SARC was also unable to find any evidence of such attempts. Per SARC SP #2, he checked his voice mail messages while he was on vacation and was unable to locate any messages from CCL or anyone else.

Meanwhile, the operator received a letter dated December 14, 1992, from CCL SP #4 stating that her request for an extension on the limited-term license had been denied. On December 17, 1992, the operator wrote another letter to CCL requesting an extension and advising CCL of her assistant's application to purchase and operate Casa Care. This letter was stamped as received by CCL on December 17, 1992.

According to CCL, the operator's assistant's application for a small family home license and change of ownership of Casa Care was once returned to him because it was incomplete, and subsequently, a "second application" was received on December 28, 1992 and denied. CCL representatives told PAI that the application appeared to be an attempt for the operator to continue to operate Casa Care illegally, using her assistant as a "straw man." The reason given for this was that the $300.00 processing fee was paid by the operator.

A letter dated January 14, 1993, fifteen days after the four young people were transferred, was signed by CCL SP #4, denying the operator's assistant's application for the following reasons: inadequate experience and education; inadequate financial plan to ensure resources necessary to meet the needs of clients; and failure to submit adequate admission procedures to ensure that appropriate children would be admitted or that their needs would be met.

According to SARC SP #2, on December 18, 1992, he received a call from the operator's assistant "at approximately 9:30 p.m., at my residence, regarding non-expressed concerns about his contacts from CCL. I told him that it is not appropriate for me to do business at home and additionally I was on vacation. I informed him that he should contact [SARC SP #3] . . . and CCL on the following Monday."

Per documentation by CCL SP #3, on December 28, 1992, she received a call from the operator's assistant regarding the status of the facility's license. Per CCL SP #3, she:

> *"Spoke with Legal . . . [CCL SP #2] and [CCL SP #1] regarding status. Application was rejected and handed back . . . per [CCL SP #1]. On December 14 [CCL SP #4] did first denial. I drafted second today for 12/17 per [Legal] (closure date 1/1/92) not 12/27. [The operator's assistant] notified by phone. He seem (sic) to think he has a pending application even tho we don't have it. I explained he does not. He stated, 'we think we have a buyer' but in the meantime 'I am going to run it' and try to get licensed. He was not happy about the denial of [the operator's] request of 12/17/92."*

The next day, December 29, 1992, CCL SP #3 again spoke with the operator's assistant and documented the following:

> *"Call from [the operator's assistant] to request another extension. I told him it was already denied. He said they received a copy already. I told him I did not know if his application was complete and acceptable. Informed him we have 5 days to process initial application."*

A letter dated January 15, 1993, from SARC management to DDS states:

> *"On December 30, 1992, San Andreas Regional Center was informed by [the operator's assistant] that the facility Casa Care which he was involved with, would no longer be licensed after January 2. . . . One Program Manager contacted Community Care Licensing to see if they would extend the license until San Andreas had a chance to assess*

the clients before replacing the clients. Community Care Licensing refused our request."

CCL denied that any such request was ever made to them by SARC. PAI asked CCL representatives whether such a request, if made, would have affected the status of the license or date of closure. CCL responded that SARC had no "standing" to make such a request, but that it would have been evaluated as a factor, as in any other situation, on a "case-by-case basis." CCL emphasized that any extension would have been up to Licensing's sole discretion. PAI further asked whether there was any conflict resolution or grievance procedures available when regional centers disagree with the decisions of CCL. CCL representatives denied any knowledge of any conflict resolution procedures, whether formal or informal. The MOU between DDS and DSS does, however, set forth explicit grievance procedures under certain circumstances.

Poor communication regarding the status of an extension of the operator's limited-term group home license and of the status of her assistant's application for a new small family home license, and a disregard for the risk of abrupt transfer upon Casa Care's residents, resulted in confusion and the exercise of poor judgment by CCL and SARC and in what ultimately became an "emergency" transfer.

Neither CCL's nor SARC's 1992 records indicate that they successfully communicated with each other at all regarding Casa Care until December 30, 1992.

3. DECEMBER 30, 1992

Given the foreseeable risk of transfer trauma posed to the residents and the fact that Casa Care was, as of September 29, 1992, according to CCL's amended accusation, allegedly operating without a proper license, PAI questions the urgency of closing Casa Care and abruptly transferring its residents on December 30, 1992. PAI investigators found no evidence that CCL recognized the potential detrimental effects of transfer trauma upon the residents of Casa Care. Indeed, during interviews with PAI, CCL representatives stated unequivocally that the agency has no responsibility to attempt to prevent or mitigate against the deleterious effects of transfer

trauma. Moreover, as discussed below, the foreseeable dangers of relocation trauma on the four remaining Casa Care residents do not appear to have been given consideration by SARC on December 30, 1992. SARC staff did not even accompany the residents to Driftwood. Nor was the residents' treating physician of over a decade contacted by SARC to be involved directly in the transfer or follow-up care at Driftwood.

At 10:30 AM on December 30, 1992, SARC was contacted -- not by CCL -- but by the assistant at Casa Care who found out that his application for a license and the operator's request for an extension of Casa Care's limited-term license had been denied by CCL. SARC immediately convened a crisis team to determine where the four Casa Care residents were to be placed.

Upon receiving the operator's assistant's desperate call, SARC SP #6 contacted CCL SP #5 and confirmed the imminent closure. Per SARC SP #6, CCL SP #5 seemed "well aware" that Casa Care's license was about to expire and was able to immediately list the reasons why: the operator's assistant's application had been rejected because he did not meet minimum qualifications. CCL SP #5 also stated that there was no way to extend the operator's limited- term license or process a new application before the limited-term license was revoked. SARC SP #6 understood this as meaning that CCL did not intend to allow Casa Care to operate any longer. Therefore, SARC concluded that it had no other option but to relocate the clients.

Per CCL SP #5's documentation of this conversation: "Received call from . . . SARC . . . the 4 clients will be relocated by 1:00 PM today."

Developmental Center as an Alternative Placement

According to DDS Policy Memo #213, regarding emergency closures of community residential facilities:

> *". . . the Department shall actively intervene to assure that a suitable plan is made for each resident who is to be relocated and who comes within the Department's mandate or jurisdiction for services. Developmental Centers shall remain*

> *available as a resource, but initial Developmental Center placement or replacement shall be avoided unless the state facility represents the placement of choice or there is no suitable community alternative. . . ." [Emphases added.]*

According to SARC management, when SARC's crisis team was convened, DDS was contacted to request placement at ADC. (ADC has care providers experienced in caring for medically fragile young persons.) According to SARC SP #2, ADC was viewed as the first choice for placement, followed by a community care facility with properly trained staff, and, if none was available, a skilled nursing facility. According to SARC management, DDS denied the request for placement of the four young persons from Casa Care at ADC. According to DDS, no such request was ever made.

DDS did state to PAI, however, that compelling reasons would have been necessary to effectuate placement of any medically fragile individuals at ADC. To date, pursuant to DDS policy, no new medically fragile individuals have been admitted to ADC, according to DDS, as the facility is still in the process of meeting many challenges to improve the care and treatment the developmental center provides to its residents. DDS further stated that, had such a request for developmental center placement been made and the rationale explained, other alternatives, such as placement at Sonoma Developmental Center, could have been considered.

Driftwood Accepted the Four Young Persons from Casa Care

Although officially on vacation, SARC SP #2 (who was also the Client Program Coordinator at the time) was contacted on December 30, 1992 regarding the need to move the residents from Casa Care. Per SARC SP #2, "I called [SARC SP #6], who asked if I had any suggestions as to places for the clients. I suggested Agnews and he stated that that was not a viable possibility. I suggested the use of a residential care home with enriched staffing. I mentioned Driftwood Convalescent Hospital in Gilroy. He asked that I check to see if Driftwood would consider taking the clients." A statewide search of other community care facilities reportedly was conducted by the SARC crisis team and none were available. Though last choice, Driftwood Convalescent Hospital agreed to take the young people. The standard of medical care provided -- skilled nursing -- was supposed to

be a higher level of care than that provided in a community care facility such as Casa Care.

SARC's Executive Director was quoted as saying in a February 4, 1993 letter to the editor of the San Jose Mercury News: "We were faced with a major challenge: find a suitable placement for four severely medically fragile youngsters in a very short time. I believe we met that challenge and that our choice of Driftwood Convalescent Hospital as an interim placement was the medically correct choice."

Notification of the Four Young Persons' Families Attempted by SARC

According to information from SARC's records and interviews with SARC representatives, attempts were made by the crisis team to contact the four young persons' families on December 30, 1992.

According to Rachel D.'s mother, she was contacted by someone filling in for SARC SP #2 and was told that CCL had shut Casa Care down and that they only had 48 hours to move Rachel D. At this time, she was told about Driftwood as a possible placement because

> *". . . it was the only place he could find. . . . I had been told over and over again that they could not go to Agnews because I kept asking about Agnews and they said Agnews is closed. They cannot go there. . . . He said that Licensing had taken away (Casa Care's) license. I got a call the next day from [the operator's assistant] at Casa Care and he said that he was hoping to get a license that day and was working very, very hard to get the license that day so the kids would not have to be moved. . . . And there really was no time to look into anything at that point, either, with the move taking place in 48 hours. And we were hoping that the move wasn't going to take place at all."*

Per SARC SP #6, Rachel D.'s parents requested that Rachel D. be placed back at Casa Care once the licensing matters were resolved.

Regina C.'s parents were not successfully notified by SARC. According to SARC, when they were unable to reach Regina C.'s parents by phone, SARC SP #6 attempted to deliver a written notice of Regina C.'s relocation to the family's home but was unable to find it. A record of this attempt and a copy of the notice itself are documented in Regina C.'s SARC records. According to Regina C.'s mother, she went to Casa Care after her sister called her and stated that Regina was not at the home. She stated that she found the operator's assistant "lying on the couch asleep with the TV blasting." When Regina C.'s mother called SARC to ask where Regina C. had been taken, she was finally told by SARC SP #6 that Regina had been taken to Driftwood. SARC SP #6 was unable to tell her Driftwood's address. The only formal notification Regina C.'s family ever received regarding Regina's relocation to Driftwood was a letter from SARC postmarked January 8, 1993. On that same date, Regina was transported to South Valley Hospital from Driftwood in acute medical distress. According to the January 15, 1993, letter from SARC to DDS, "Regina's mother called San Andreas on January 8, and was advised of the situation."

According to SARC SP #6, Kelli S.'s family was contacted and they discussed future placement at a facility that would be closer to them. However, SARC's records do not reflect any documentation regarding this contact.

SARC records reflect that multiple attempts were made to contact Ernesto E.'s mother on December 30, 1992, and that SARC SP #6 made a visit to her last known address the following day to deliver a notice of Ernesto E.'s move. SARC later learned that Ernesto's mother had moved to Modesto without notifying them of her new address.

Casa Care Residents Transferred to Driftwood that Afternoon, Unaccompanied by SARC Staff

Preparation for the move to Driftwood, according to SARC SP #6, included: his call to Driftwood to discuss the technical aspects of the move; a call by SARC SP #7 to the charge nurse at Driftwood to discuss the clients' care needs; and the development of referral packets.

On December 30, 1992, two program managers from SARC went to Casa Care at around 1:00 PM and noted that the clients and their charts and medications were prepared to be transported. According to SARC SP #6, the clients appeared to be in their usual state of health that day. He documented that Regina C.'s breathing "sounded raspy," but told PAI investigators that this was not unusual for these clients. The facility seemed cool, but according to SARC SP #6, the front door had been open due to people coming in and out during the preparation for the move. The clients had been fed, were dressed in clean clothes, and the facility appeared clean.

Ernesto E. was transported to Driftwood by ambulance. Regina C. and Kelli S. were transported in a van designed to accommodate clients who use wheelchairs. The fourth client, Rachel D., had too many muscle contractures to be transported in a wheelchair by van. As a result, the operator's assistant transported Rachel D. in his own car to Driftwood.

Per SARC SP #6, the operator's assistant also transported over to Driftwood the clients' medical records from Casa Care and the referral packets that SARC had prepared that day. The delivery of the clients' medical records by the operator's assistant is substantiated by documentation in SARC's and Driftwood's records. An April 12, 1993 letter to Driftwood from the operator's assistant says: "In the state of confusion, records were inadvertently given to the charge nurse of your facility on arrival by the undersigned. . . ." But according to the January 15, 1993, letter from SARC to DDS, "[t]he medical records were given to the van driver to deliver to the facility."

Per SARC management, SARC staff did not accompany the four young people to Driftwood because "[the operator's assistant] went to Driftwood and reported to them what care was necessary."

Per SARC SP #3, the placement of the four young persons was considered temporary, and SARC "was waiting for things to settle down. If we were not satisfied with the care at Driftwood, we would have moved them." SARC SP #2 and SARC management reiterated to PAI that Driftwood was considered a temporary, interim placement in response to an "emergency" relocation.

According to Casa Care records, some of the residents had been treated recently for infections before they were transported to Driftwood. Both Ernesto E. and Rachel D. received Amoxicillin, an antibiotic. Ernesto E. was treated in November, and Rachel D. was treated just one week before she was transported to Driftwood.

Lab reports conducted on October 27, 1992, also indicated some slight abnormalities for the young people before they were transported to Driftwood. For example, reports indicated that Ernesto E. had slightly elevated levels of hemoglobin. Kelli S.'s lab report indicated an elevation in white blood cells and a low differential of lymph cells. Rachel D.'s lab report indicated a slightly elevated white blood cell count. According to the physicians interviewed by PAI, due to the nature of the residents' disabilities and related health problems, respiratory and other infections, accompanied by slightly abnormal lab values, are not uncommon.

4. EVENTS AFTER TRANSFER TO DRIFTWOOD CONVALESCENT HOSPITAL

According to Driftwood's admission policy, ". . . residents under sixteen (16) years of age shall not be admitted except on prior approval by the department. . . ." Ernesto E. was 12 years old, and there is no indication in the records that this requirement was met. As stated earlier, Driftwood's new administrator was unable to produce any previous or current policies and procedures specific to the care and treatment of developmentally disabled individuals.

Although the young people's records were also apparently transported, Driftwood did not appear to review them adequately. Driftwood's admission records contained inaccurate and incomplete basic information about the clients. According to Regina C.'s mother, Regina C.'s admission sheet at Driftwood originally did not even have her parents' names and address on it. Casa Care's records list the parents' address clearly. Driftwood also failed to inform South Valley Hospital that, because of the family's religious beliefs, Regina C. was not to receive any blood transfusions. This information was listed clearly in Regina C.'s Casa Care emergency fact sheet.

Another example of Driftwood's failure to make use of Casa Care's records is the entry of an incorrect birth date for Rachel D., which made her chronological age 43 years old instead of sixteen. This inaccurate information was repeated throughout Driftwood's records, although the admission nursing notes did remark that she "looks very young." This error still had not been corrected by the time she was transferred nine days later to South Valley Hospital (SVH) on January 8, 1993. According to the consultation report from SVH, "The patient is a teenager, exact age unknown."

Driftwood's failure to make use of Casa Care's records or demonstrate that they were advised properly on how to provide basic care to the four clients is also illustrated by the problems Driftwood experienced in their attempts to assess the feeding needs of the clients. As discussed earlier in this report, Casa Care's records, which included educational and psychological assessments, addressed the four young persons' ability to be fed by hand specifically.

There is no evidence that the physician who provided primary care to the young people for over ten years was consulted by SARC concerning the transfers and follow-up care at Driftwood. SARC representatives told PAI investigators that they instructed Driftwood to contact the treating physician for Casa Care residents but that SARC did not speak with the physician directly. SARC SP #3 told PAI investigators that SARC's understanding was the physician "refused to treat the clients at Driftwood due to the distance." However, the physician for the Casa Care residents, Dr. B, stated to PAI investigators that she had not received a formal phone call from Driftwood requesting consult in caring for the four young persons. Rather, she received one phone call from an unidentified facility in Gilroy stating that they needed her to "sign orders." Dr. B stated that she therefore instructed the caller to have the facility's physician call her to discuss any care issues. Driftwood's records do not document this call.

Clients' Condition Upon Arrival to Driftwood

Per Driftwood's records, the clients arrived, accompanied by transportation staff, between 2:00 PM to 2:30 PM on December 30, 1992. Regina C.'s records note that upon admission, she had a temperature of 100.3, a pulse

of 120, wheezing, and rhonci (an abnormal musical noise produced by air passing through narrowed bronchi). According to the records, Regina was not given her breakfast the following morning due to "Pt. [patient] pushing food and meds out of mouth, or else coughing. Speech therapist here at 2:30 PM today to do swallowing evaluation and make recommendations for feeding."

Kelli S.'s temperature upon arrival was reportedly 96.4 . Driftwood staff noted that she sounded congested, with crackling sounds in both lungs. She reportedly was fed by staff that evening and ate 10% of her dinner. Rachel D.'s records show that her temperature upon arrival was 98 , her lungs clear, and that her feet were cold to the touch. That evening, she was fed a regular pureed diet by staff and ate 50% of her meal. The following morning, staff documented: "Pt. choking on breakfast because head goes back too far. Dysphagic diet ordered for lunch." According to Driftwood's records, Ernesto's temperature was 98.5 upon admission and his lungs sounded congested, with slightly rapid respirations. That evening, he was fed by staff and reportedly ate 80% of his dinner.

According to skilled nursing home regulations: "Each patient requiring help in eating shall be provided with assistance when served, and shall be provided with training or adaptive equipment in accordance with identified needs, based upon patient assessment, to encourage independence in eating." CCR, Title 22, §72315(g). Nevertheless, within 24 to 48 hours after the four young persons were admitted to Driftwood, swallowing evaluations were conducted by a speech therapist, who recommended that nasogastric tubes be inserted. This recommendation was approved over the telephone by Dr. A. and the tube feedings began.

Dr. B, the four young persons' treating physician for at least ten years, stated that if she had been consulted, she would have advised against the placement of nasogastric tubes. This was contraindicated, in her opinion, due to the clients' inability to handle the volume of feedings through the tube. She explained that due to poor muscle control of the gastrointestinal tract, as a result of the clients' severe disabilities, they would most likely regurgitate, thus increasing their susceptibility to aspiration pneumonia. According to Dr. B, she had considered recommending placement of a gastrostomy tube (inserted directly into the stomach through the abdominal

wall instead of down the throat) into Ernesto E. as a result of recent problems with his breathing. Additionally, according to Dr. B, the clients' inability to clear their own secretions and the need for regular suctioning also made the placement of nasogastric tubes ill- advised.

According to late entries noted in Driftwood's records, a charge nurse at Driftwood left messages for SARC SP #6 regarding the insertion of nasogastric tubes in the four clients. However, PAI investigators were told by SARC Program Managers that no SARC staff recalled being contacted by Driftwood regarding placement of the nasogastric tubes.

Additionally, according to Rachel D.'s Driftwood records, a call was placed to SARC SP #6's "message machine" on January 4, 1993, at 2:30 PM, regarding a prescribed medication, Rocephin, an antibiotic, "being held due to Medicare not covering." The first dose of this medication was not authorized until six days later, on January 10th. Driftwood's records indicate that SARC SP #3 apparently was covering as case worker on this date.

SARC assigned no particular staff to monitor the four clients' post-transfer care at Driftwood. Per SARC SP #3, the regular CPC, SARC SP #2, would be responsible for monitoring the four individuals' care at the new placement. However, the regular CPC was on vacation and did not return until January 11, 1993. PAI was told that when a CPC from SARC goes on vacation, specific staff are not assigned to provide alternate coverage during the CPC's absence. Rather, "on-duty" coverage is provided by other available SARC workers.

Clients' Medical Conditions Deteriorated After Admission to Driftwood

On the morning of December 31, 1992, a nasogastric tube was inserted into Ernesto E. At midnight on January 2, 1993, his temperature rose to 102.9 . By January 6, 1993, Ernesto E.'s temperature was 106 . According to SVH records: "Initially the information we were given was that the patient had a temperature of approximately 106 and was being brought in to the Emergency Room. A few minutes after that , we were called again and told that the patient was in full arrest." Ernesto E. arrived at South Valley Hospital in full arrest; his skin was noted to be "cool and somewhat

cyanotic, with signs of venous pooling." The emergency room physician's clinical impressions were "acute cardiopulmonary arrest, acute hypoglycemic episode, and acute febrile illness." Dr. A, Ernesto's physician from Driftwood, was called and agreed to sign the death certificate.

According to the home teachers who visited with Kelli S., Regina C., and Rachel D. at Driftwood on January 6, 1993, they were shocked to find them being fed through nasogastric tubes, considering that right before the school holiday in mid-December, they had been hand- fed without significant problems. According to Teacher #1, around 3:00 PM on January 6th, Rachel D. started to choke. There was no Driftwood staff in the room, so Teacher #2 ran for help. Teacher #1 bent Rachel D. forward and retrieved a "sticky white mass" from Rachel D.'s throat. By that time, Teacher #2 had returned with an attendant who looked into Rachel D.'s room from the doorway and stated, "I'll come back," but reportedly never did. Per Teacher #2, the attendant also failed to document this incident in Rachel D.'s chart. According to Teacher #1, at Casa Care, "someone always had their eyes on the kids." This incident so alarmed Teacher #1 that she reported it to Child Protective Services and DHS L&C. Throughout the four young persons' records at Driftwood, notations were made by staff of various amounts of "whitish secretions" being suctioned from the clients' airways.

According to Teacher #2, when she and Teacher #1 returned the following day to Driftwood on January 7, 1993, there was a marked improvement in the care given to Kelli S., Rachel D., and Regina C. They were propped up at 90 angles per the teachers' suggestion as opposed to the 60 angle as seen the day before. There were notes on the walls above the beds to check on the clients, and an LVN was brought into the room by the head nurse to assist the residents while the teachers were there.

According to Kelli S.'s records from Driftwood, she was transferred to SVH on January 7, 1993. She was evaluated by the emergency room physician, whose clinical impression at the time of admission was "acute left lower lobe pneumonia, rule out sepsis, acute dehydration, severe mental retardation with severe scoliosis." Kelli S. died on January 10, 1993, four days after Ernesto, with symptoms consistent with aspiration pneumonia. An autopsy was performed on Kelli S.'s lungs.

Her discharge summary from SVH stated that she "expired secondary to aspiration pneumonia" and described the events leading to her death:

> *"After admission to Driftwood, an occupational therapy evaluation determined the patient was choking on oral feeding and that a nasogastric feeding tube should be inserted. After several days the patient developed increasing shortness of breath with fever and cough. She was sent to the emergency room and evaluated there. It was determined she was having a left lower lobe pneumonia, most likely secondary to aspiration. . . . Approximately three days after her admission, however, the nurses entered her room and found that the patient had expired. . . . An autopsy was performed which was not conclusive but at least consistent with aspiration pneumonia."*

Rachel D. and Regina C. were both transported to SVH on January 8, 1993, for the treatment of respiratory distress. Rachel D.'s records also note that she died with symptoms consistent with aspiration pneumonia on January 20, 1993. Per a consultation report upon her admission to SVH:

> *"She was transferred on 12/30/92 to skilled nursing unit at Driftwood Convalescent Hospital. Upon arrival to the skilled nursing unit, two of the residents were 'congested.' She had a swallowing evaluation and was determined to be at risk for aspiration. Nasogastric tube was placed. The patient developed fevers and increasing respiratory difficulty. . . ."*

Rachel D.'s records from SVH indicate some difficulties noted with placement of the nasogastric tube. On January 14, 1993, an x-ray revealed that "there is some improvement in the infiltrates at both lung bases. No new abnormalities are noted." On the day of Rachel D.'s death, a chest x-ray reportedly showed that the pneumonia had almost completely been resolved.

Final diagnoses from Rachel D.'s autopsy were: "1) Hydrocephalus; 2) Porencephaly; 3) Multicystic encephalopathy; 4) Plastic shunt from brain subcutaneously; 5) Necrotizing organizing pneumonia."

According to Dr. A, the four young person's treating physician at Driftwood and SVH, Regina C. underwent surgery for a gastrostomy at SVH due to her pyloric sphincter being so open that "everything came back up." Dr. A said, "[t]his certainly could explain the aspiration." Regina C.'s gastric juices were also creating ulcerations. Regina C. was eventually transferred to Sonoma Developmental Center, no longer able to eat by mouth, where she still resides today.

Per Dr. A, the lab reports failed to identify any viral or bacterial agent responsible for the pneumonia-like symptoms among the four young people. Dr. A was unable to state why Regina C. was the sole survivor, except for the fact that she was surrounded by the familiarity of her family throughout the ordeal. According to Dr. A, the young people may have been highly traumatized due to their being placed in a strange environment. Dr. A stated that he learned during his treatment of the four medically fragile youngsters that it is "not unusual for them to die under these circumstances."

DHS L&C investigated the deaths. They found that Driftwood staff failed to document that the nasogastric tubes were checked every four hours, as required. DHS L&C issued a "Class B" citation on February 10, 1993, against Driftwood for this deficiency. The citation noted:

> *"The facility lacked a current policy and procedure governing the 16 hour closed feeding system. . . . Information from the nutrition company stated residual check once per shift to minimize potential complications with vomiting, distention and aspiration. . . . The facility failed to develop a comprehensive procedure regarding the closed feeding system and failed to document residuals, consistently, to provide a complete record of the residents response to and tolerance of tube feedings. . . ."*

However, DHS L&C evaluators indicated to PAI investigators that they were unable to attribute the three young persons' deaths directly to acts or omissions on the part of Driftwood staff.

Actions Taken in Response to the Deaths by SARC and CCL

According to SARC representatives, SARC and CCL are in the process of implementing corrective measures since the deaths of Ernesto E., Kelli S., and Rachel D., which include:

- Updating the MOU between SARC and CCL;
- Reinstating the monthly meetings between SARC and CCL, as per the original MOU;
- Conducting joint investigations, as appropriate; and
- Establishing "chain of command" procedures so that each agency knows who to contact in the event the person they are trying to reach is unavailable.

IV. FINDINGS AND CONCLUSIONS

SARC's failure to anticipate the need to plan for the four remaining Casa Care residents' transfer raises serious concerns about SARC's case management practices.

SARC should have known that the remaining residents' placement in the home was seriously threatened and should have planned accordingly. Rather than assuming that the licensure problems would resolve themselves, SARC should have investigated more thoroughly to determine the nature and scope of such problems. SARC received subpoenas from CCL regarding Casa Care on October 14, 1992, but did not conduct adequate follow-up because they were later "rescinded." In addition, SARC itself had initiated the sanction that led to the relocation of all but four of the remaining residents. Given that fact, SARC should have known, long before December 30, 1992, that the facility could no longer survive economically and that the residents would therefore have to be moved.

SARC's failure to implement appropriate discharge and transfer procedures on December 30, 1992, indicates a lack of appreciation of and an inability to protect clients adequately from the dangerous effects of transfer trauma.

SARC should have known that the abrupt relocation of the four remaining residents posed a serious threat of morbidity and mortality. PAI was told that the risk of transfer trauma upon medically fragile youngsters was discussed at the November 12, 1991, meeting regarding the relocation sanction. During that meeting, according to Rachel D.'s mother, SARC staff explained that because Casa Care's residents were so medically fragile, special care and planning would be required to attempt to assure residents' safe relocation. Yet, when SARC's crisis management team convened concerning Casa Care's closure, it failed to even attempt to involve the remaining residents' treating physician of over ten years in the transfer, discharge, or follow-up planning. Consequently, Driftwood was not informed of the physician's opinion regarding the potential risks of feeding Ernesto E., Kelli S., Rachel D., and Regina C. through nasogastric tubes instead of by mouth. SARC staff did not even accompany the former Casa Care residents to Driftwood. Instead, SARC relied upon the operator's assistant to inform Driftwood, the receiving facility, of "what care was necessary."

There is also a conflict in the evidence as to whether SARC challenged CCL concerning the urgency of relocating the residents on December 30, 1992 -- in the middle of the holidays when critical SARC staff were on

vacation -- and whether the crisis team pursued more appropriate alternatives as vigorously as they should have. According to DDS, transfer to one of the developmental centers could have been considered if the rationale for such placement would have been articulated clearly. Moreover, DDS stated that if it had been fully informed, it would have considered intervening to stop the precipitous transfers. DDS stated that although such intervention is rare, such action can and has been undertaken in other exceptional circumstances.

CCL's failure to communicate with SARC, as required, during 1992 helped create the "emergency" that resulted in the abrupt relocation of Casa Care's remaining residents, and raises substantial concerns about CCL's judgment as it relates to protecting the health and safety of medically fragile, developmentally disabled youngsters.

During 1991, CCL and SARC communicated regularly and coordinated, to some extent, their respective monitoring activities. In 1992, however, communication about Casa Care and coordination of respective monitoring responsibilities ceased. CCL failed to advise SARC of and provide copies of the March and October, 1992, accusations against Casa Care, as required under the MOU since 1987. According to CCL, its only attempts to inform SARC of the status of the facility's license following the stipulation was twice by telephone. SARC never received copies of the accusations from CCL and finally received a copy of the stipulation in January, 1993 -- not from CCL, but from the operator's consultant.

In addition, CCL told PAI that "[the operator] had plenty of notice to work with SARC on the transfers." Any obligations that the operator had pursuant to the stipulation, or otherwise, in no way relieved CCL from its obligations to notify SARC of its licensing activities that threatened the residents' home of more than ten years. Moreover, given the fact that CCL was closing Casa Care based on a history of an alleged pattern of serious violations, including, according to CCL's own statements, misrepresenting the training of staff and the operator using her assistant as a "straw man" to continue operating illegally, it was unreasonable to assume that the operator would fulfill such obligations.

CCL's failure to weigh the risks of transfer trauma and monitor Casa Care more closely during 1992 raises significant concerns about the soundness of CCL's decision-making regarding whether, how, and when to close community care facilities serving medically fragile youngsters with developmental disabilities.

During interviews with PAI, CCL denied any obligation whatsoever to weigh the effects of transfer trauma upon medically fragile, developmentally disabled individuals. This contention is at odds with the overriding intent of state law, and shocks the conscience. Transfer trauma is defined under applicable regulation as "the consequences of the stress and emotional shock caused by an abrupt, involuntary relocation of a client or resident from one facility to another." CCR Title 22, § 80001t(l). See also Health and Safety Code § 1556. The substantive and procedural due process rights of individuals similarly situated to the former residents of Casa Care in avoiding the unnecessary deleterious effects of transfer trauma resulting from licensing revocation or other governmental regulatory action has long been recognized. See, e.g., Newland, et al., v. Kizer, et al., 209 Cal.App.3d 647, 257 Cal.Rptr. 450 (1989).

It appears that by 1992, CCL intended to exercise its discretion to close Casa Care. If that was CCL's intention, as discussed earlier, it should have communicated that clearly to all agencies and individuals responsible for protecting the remaining residents' rights to appropriate care, supervision, and placement -- especially SARC.

According to CCL records, and statements made to PAI, continued placement at Casa Care during 1992 posed no imminent or substantial threat to the remaining residents' health or safety. CCL further stated that given the prior 1991 pattern of serious deficiencies, there was no reason to believe that such violations would not occur again. Given these stated concerns, PAI questions the appropriateness of CCL's assertion that more frequent evaluation, investigation, and monitoring of Casa Care during 1992, while the facility continued to operate pending appeal, would have been "administrative overkill."

V. RECOMMENDATIONS

SARC, with the oversight and assistance of DDS, should develop and implement more effective case management procedures to identify potential situations requiring transfer so as to avoid unnecessary "emergency" relocation.

PAI understands that DDS is in the process of reviewing SARC case management practices. DDS should take whatever steps are necessary to ensure that SARC clients receive case management services that meet professional standards. Such steps should include, but not be limited to, providing needed technical assistance and evaluating staffing patterns, training, and managerial competence.

SARC needs to improve its case management practices by implementing effective, comprehensive quality assurance procedures designed specifically to identify and address potential placement dislocations. The so-called "emergency" relocation of December 30, 1992, could have been avoided altogether if SARC and, especially CCL, had communicated properly. Nonetheless, SARC's failure to anticipate the potential transfers and the manner in which the transfers were conducted shows the need for improved client placement and relocation services. Such improved case management services would help assure that the needs and desires of the clients and their representatives are addressed more appropriately. To avoid haphazard planning and confused communication in the future, staff responsibilities for ensuring effective notice, transfer, discharge planning, and post-transfer after-care, including the training of receiving staff, must be delineated clearly. Thorough, efficient procedures for identifying alternative, appropriate living arrangements for residents at risk for transfer, and mechanisms for overcoming obstacles to attain them, should be implemented without delay.

Far before the date of transfer on December 30, 1992, SARC should have known that placement at ADC would require certain compelling rationale or not be feasible. Reasonable alternatives, such as placement at Sonoma Developmental Center, could then have been explored in a timely fashion with DDS and other appropriate entities.

SARC should improve its discharge planning, transfer procedures, and related training to address specifically the steps that should be taken to mitigate against the effects of transfer trauma.

Even with the best planning, the relocation of the medically fragile residents of Casa Care from their home of more than ten years would have been risky. As discussed above, some basic safeguards were not put in place. Discharge planning and transfer procedures should ensure, to the greatest extent possible, that those individuals who best know how to protect residents from unnecessary trauma, such as the treating physician, the CPC, involved family members and friends, are involved in the discharge planning and transfer itself. Moreover, given the extreme fragility and dependence of some of SARC's clients, it is imperative that every transfer be as tailored to the individuals' needs as possible. Such individualization must occur at the crucial junctures of discharging and receiving the medically fragile individual upon transfer. Quality assurance and monitoring procedures should ensure that critical medical and care information is conveyed effectively to staff at the receiving facility. Such information includes, but is not limited to, for example, how to feed a particular individual by mouth and the known contraindications of certain medical procedures (e.g., insertion of nasogastric tubes). Had the residents' treating physician been involved directly in the transfer, receiving staff at Driftwood could have been more fully informed of the potential risks of feeding the four former residents through nasogastric tubes and more appropriate alternatives could have been considered. Much suffering and three lives might have been saved.

DSS, DDS, CCL, and SARC should modify their respective Memorandums of Understanding and implement effective measures to assure accountability and compliance with respective responsibilities so that coordination of interrelated monitoring services to mutual clients is guaranteed.

The MOUs on the state and local levels should be modified to ensure uniformity of standards and more explicit delineation of agency responsibilities. The MOU between DDS and DSS specifies a conflict resolution process to address disagreements between regional centers and CCL. There is no comparable conflict resolution provision in the existing MOU between SARC and CCL. Uniform procedures for resolving disagreements effectively between these agencies should be developed and implemented at the state and local levels. However, the subject matter areas to be addressed through such conflict resolution procedures need to

be reevaluated to ensure that they are inclusive enough of the clients' health and safety interests. It is not clear under the existing state level MOU between DDS and DSS whether a regional center, for example, could use the existing process to ensure that the foreseeable risks of transfer trauma are weighed as a factor in CCL's decision to extend a limited-term license or take other action to allow more time for planning transfers by placement agencies.

Moreover, local MOUs between CCLs and regional centers throughout the state should specify that regional centers receive copies of accusations and stipulations (or any other appropriate CCL documents) that pertain to the potential cessation of client services by the licensee. When CCL takes action that may result in the discontinuation of community care services to regional center clients, CCL should inform DDS as well as the regional centers. This will promote greater oversight at the state level and provide more opportunity for needed intervention to protect residents facing abrupt relocation.

DSS should ensure that those CCL staff responsible for monitoring, evaluating, and licensing residential care facilities for the developmentally disabled receive comprehensive education and training regarding transfer trauma and CCL's obligation to mitigate against its potentially life-threatening effects.

Decisions regarding whether, how, and when to relocate medically fragile, developmentally disabled individuals should be made in an objective, fully-informed manner. That cannot be done unless the risk to the individual resident of remaining in an allegedly substandard facility is weighed against the dangers of relocation to another, and in this case, arguably inappropriate facility. The fact is that transfer to Driftwood was considered "interim" and the "least desirable" of all the potential placement alternatives.