

STATE OF VERMONT

HUMAN SERVICES BOARD

In re) Fair Hearing No. 13,618

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Appeal of)

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INTRODUCTION

The petitioners appeal a determination by the Department of Mental Health and Mental Retardation that their fourteen-year-old daughter cannot be admitted to a nursing facility based solely upon her age.

FINDINGS OF FACT

1. The petitioners are the parents of a fourteen- year-old girl, J., who has severe physical and mental disabilities based on a hereditary disorder known as trisomy 18. Her condition, as described by her parents and agreed to by mental health, is as follows:

J. requires care that is equivalent to that of an infant. All her physical needs must be provided by a qualified adult. This includes but is not limited to daily hygiene, feeding, toileting, and administering of medications. Throughout her life she has suffered from seizures as well as several respiratory infections. She has had multiple surgical procedures to correct deformities of her feet and problems with dislocating knee joints. Her right hip is not properly formed and remains dislocated much of the time. This does cause some discomfort occasionally but as of yet has not required corrective action since she is unable to walk or stand. She also has severe scoliosis.

J.'s mental aptitude is reported to be that of a 4-6 month old child as documented by Dr.[Name] and Dr. [Name]. She is unable to speak words however she can communicate minimally smiling, cooing, or whining.

Prior to her illness which required hospitalization in early 1995, J. was cared for in the home primarily by her mother. A minimum allotment for respite care (18 hours/month and Home Health (4 hours/week) was also provided. J. had attended school with varying degrees of success within a program designed specifically for her. One to two individuals saw to her needs during the school day. Since her lengthy hospital stay and transfer to [the nursing home] her care has been provided by professional health care providers.

Prior to hospitalization, J. was fed orally three times daily with each feeding taking one hour to complete. Weight gain and proper nutrition was always an issue and difficult to obtain. During the hospital stay a tube was surgically implanted into her stomach which would allow for direct infusion of nutrients and medication with the hope that this would improve her overall health and make feeding less difficult. Although feeding itself is somewhat easier and weight gain has occurred other problems have not been resolved. Attempts at changing the quantity of food given as well as content of the diet has been altered to try and remedy vomiting and diarrhea attacks which has been a problem since the G-tube was implanted. She is currently fed over a fifteen hour period (4:00 p.m. to 7:00 a.m.) via a "Kangaroo Pump" which will hopefully alleviate some of the problems so J. can be more active during daytime hours thus making OT/PT easier as well as allowing her more social time with less discomfort for her and those around her.

2. The child was hospitalized for twelve weeks in early 1995 because her condition deteriorated. She developed sinusitis which couldn't be cured and which was making it difficult to obtain proper nutrition for her. Her parents noted that she was also unable to maintain an interest in her surroundings. She experienced extended periods of eye rolling, muscle spasms, and continuous verbal moaning and whining which continued after her release from the hospital. Because her parents felt that they could not adequately care for her new medical needs (tube feeding) at home and because her behavior demanded almost incessant attention, which they felt would detract from their ability to care for another child, her parents decided upon her release from the hospital to place J. in a nursing home, at least as a temporary measure. A copy of a post-hospitalization evaluation made by the child's physician is attached hereto and incorporated by reference as Exhibit One.

3. After her placement in the nursing home, a psychologist and a nurse from the Department of Mental Health visited her for the purpose of assessing whether she had been properly placed in a nursing facility. They filled out a report dated April 17, 1995 in which her physical condition and abilities were evaluated and concluded that J. needed a nursing facility level of care but that a nursing home was not an appropriate placement:

[J.] needs medical supervision of her current health problems including elevated temperatures, vomiting, diarrhea, weight loss, and episodes of drying and sweating. Her diagnosis is not certain at present and is being evaluated. However, a nursing home is not an appropriate place for a child to live. She may not be admitted to a nursing home. It is recommended that she remain at the hospital until her health stabilizes. She has been referred to [Name] County Mental Health and the family can work together to develop an alternative to nursing home placement. High tech waiver funding through the Department of Aging and Disability should also be considered.

4. The parents were notified on April 18, 1995 that she could not be admitted to a nursing facility, a decision which they immediately appealed. However, that decision was waived until home care services could be put in place. The petitioners were skeptical that such an arrangement could be made but agreed on June 1, 1995, to postpone their hearing for ninety days and to cooperate in formulating a plan provided J's physical condition improved enough to allow her to come home and that the proposed plan was in the best interests of J and would allow the family to "lead some semblance of a normal life".

5. Ninety days passed and no one from the County Mental Health even contacted the petitioners. After the matter was reset for hearing in September, the petitioners were asked again to postpone the hearing to allow some more time to get a plan into place. The mental health agency said that someone had neglected to get the plan going but that now a manager had been assigned and services could be put in

place.

6. At that point, the petitioners refused to delay the hearing any longer. After thirty more days in the nursing home, the petitioners had become convinced that this was the right place for their daughter. She is getting medical care and physical therapy at a level she never got while she is at home and which, they are convinced, is improving her physical condition. She has gained weight since she has been at the home. They visit several times per week and she has regular contact during the day with nurses and nurses aides, other residents, visitors, including children's groups and a tutor sent by the school. (She had been going to the school before this but was isolated from the other students. Most recently she had become unable to physically go out to the school.) As a child functioning at a four month level, her social needs are not sophisticated and they believe are well met within the nursing home environment. They do not believe that J. recognized them but that she knows their voices. Other than that they do not believe she knows what is going on in her environment or that she is not at home. She responds to pleasurable experiences with a smile and to unpleasant ones by crying. Based on their experience of caring for her in the home for fourteen years, neither they, nor her doctors, have seen any improvement in her ability to function and she is not expected to have any in the future. They have been told that she has a life expectancy of sixteen years. They stated at hearing that they would take J. home in a moment if they felt she had anything to gain from it but felt that she did not.

In a letter admitted into evidence the petitioners concluded that:

J.'s needs are great, time consuming, and difficult to provide under a normal home environment. For fourteen years we as a family sacrificed much to meet those needs under some very trying conditions. We love her very much as does her sister and we want her to be where needs can best be met without undue hardship for her or the family. We feel that [the nursing home] meets these needs and that any other setting would be hard pressed to accomplish the task without extreme difficulty. Moving J. to a community based home may make everyone feel better but J. would not gain anything from it and probably would lose quality health care. . . If the argument is made that simply because of her age she should not be a resident of a nursing home and that all these services can be provided in an alternative setting, we would have to ask what additional benefit is provided J. and the rest of the family which is not provided in her current environment? . . . We hope that you are able to understand how we feel and realize many of the decisions we have had to make in the past fourteen years have been difficult to deal with rationally because of the normal human emotions that interfere with the decision making process, but we are confident that our position in this current matter is in the best interest of J. and the rest of our family.

The petitioners' sincerity in this matter was clear at hearing and their motives as expressed above are not challenged by the Department and appear to be in J's best interests.

7. The registered nurse in charge of the petitioner's care at the nursing home confirmed that J's physical needs are being well met at the nursing home (a fact which is not disputed by the Department). She has tube feeding, physical therapy, skin care, and nutritional monitoring on a daily basis. Since her admission her weight has increased from 48 to 55 pounds. The nursing home has 153 residents with 51 on J's unit. Most are aged from sixty to eighty but there are three residents in their early twenties, two of whom have been there since the age of sixteen, and one since the age of nine. J. shares a room with a mentally retarded woman in her mid-seventies and has three aides assigned to her. During the course of a week, she typically has seven different caretakers although it is not apparent that she can distinguish among them or even distinguish the faces of her own parents when they are in the home.

She has observed over the four months of her residency that J. seems calmer and more content. She is "sweet" and is usually relaxed and responds with a smile unless she is overstimulated through bathing or physical therapy which makes her cry. She receives tube feeding every night and is monitored every hour during that activity. In the morning she is bathed and put through a brief range of motion exercise cycle. At ten o'clock she is placed in a wheelchair and taken to activities, which often include schoolchildren. Although children frequently approach her she cannot interact with them. She takes a nap at noontime and in the afternoon has visitors and engages in an extensive physical therapy program. The high school sends a tutor to work with her for about one hour each day. The stimulus she most readily responds to is music which has a calming effect. They play music tapes for her in her room and have a music therapist come to play live music for her several times per week. It is difficult for the nurse to imagine based on J's very low level of cognitive and intellectual functioning and her lack of improvement during fourteen years in a home setting that her emotional or intellectual life could be improved by a different setting. While she agrees that it is possible to provide the physical care she gets now at home, she doubts that it could be provided as efficiently, consistently or effectively outside the nursing home setting.

8. The Department has an unwritten policy of denying nursing home placements for children based upon the experience of its personnel with children and their needs and upon scientific literature in this area, although none of the latter was offered into evidence. The testimony of the Chief of Community Services, who is trained as a lawyer and who has had many years advocating for mentally ill patients, was offered as to her experience and knowledge of the PASSAR review process. She stated that the reason for such screening was Congress' concern that persons with mental illness and retardation were inappropriately placed in nursing homes as long-term residences when they had no need for the nursing care and would flourish better in another environment. It was her personal experience from placing children de-institutionalized from the Brandon Training Center that children with severe mental disabilities in general do better in community care placements because of the greater degree of mental stimulation and emotional connection afforded in these smaller settings. It was also her impression from reading the professional literature that adults who had grown up in institutions had severe emotional scars and were more cognitively delayed than those who had not.

The Chief met J. once when she visited her at the nursing home. She noted that she was surrounded by persons who were elderly and that during her visit she sat in a waiting area in a "ray of sunshine" during which time she had no interaction with anyone. She felt that J. needed adults who were specifically there for her care and that she would be a good candidate for community care and that she could find adults willing to care for J. in the community if the burden was too great for her parents. She stated that a plan could be formulated involving nursing care, paraprofessionals, training of the parents and respite back-up care could be put into a package and paid for by the Department in order to allow J. to live at home. She regretted that the commitment to the family to provide these services had fallen through and offered her apologies to the family for their wait and promised to seek sanctions against the agency responsible for the failing. However, she was optimistic that appropriate services could soon be provided and was sympathetic to the difficulty that home care would pose for the family and committed the Department to alleviating that as much as possible.

9. The Director of Case Management Services at the County Mental Health facility stated that he was personally taking full responsibility to implement a plan to keep J. at home (or in another community setting) including in-home nursing services, respite care, physical therapy and whatever J. might need. He also felt based on his experience and training that a child could develop her potential to learn and to emotionally flourish outside of an institutional setting. However, he does not know J. and has not had

day to day experience with any children like her.

ORDER

The decision of the Department of Mental Health finding that a nursing home is inappropriate for the petitioner's child is reversed.

REASONS

States which receive funding through the Medicaid program for nursing facilities are required under federal law to engage in preadmissions screening and annual resident review (the "PASSAR" process) of persons with mental illness or retardation who are being placed in nursing homes. 42 U.S.C. § 1396r (e) (7). Under this statute, no mentally retarded person can be admitted to a nursing facility unless it has been determined by the state review agency that the individual "requires the level of services provided by the nursing facility, and, if the individual requires such level of services, whether the individual requires specialized services for mental retardation." 42 U.S.C. § 1396r (b)(3)(F). The Secretary of Health and Human Services is directed by the statute to promulgate "minimum criteria" for making that determination. 42 U.S.C. §1396r (f)(8).

Criteria were promulgated by the Secretary of HHS and amended, the most recent of which became effective on January 29, 1993. The regulations establish a "basic rule" which has as its purpose:

The preadmission screening and annual resident review process must result in determinations based on a physical and mental evaluation of each individual with mental illness or mental retardation . . .

42 C.F.R. §483.106(c)

The regulations further provide specifically for the
preadmission screening of applicants for admission to
nursing facilities as follows:

(a) Determination of need for NF services. For each NF applicant with MI or MR, the State mental health or mental retardation authority (as appropriate) must determine, in accordance with §483.130, whether, because of the resident's physical and mental condition, the individual requires the level of services provided by a NF.

(b) Determination of need for specialized services. If the individual with mental illness or mental retardation is determined to require a NF level of care, the State mental health or mental retardation authority (as appropriate) must also determine, in accordance with §483.120 whether the individual requires specialized services for the mental illness or mental retardation, as defined in §438.120

42 C.F.R. §483.112

In addition to these two criteria, the Secretary has

also promulgated a regulation which requires review of the

"appropriateness" of any placement:

Placement of an individual with MI or MR in a NF may be considered appropriate only when the individual's needs are such that he or she meets the minimum standards for admission and the individual's needs for treatment do not exceed the level of services which can be delivered in the NF to which the individual is admitted either through NF services alone or, where necessary, through NF services supplemented by specialized services provided by or arranged for by the State.

42 U.S.C. §483.126

It is this provision which the Department invokes as authority for its decision to deny admission to the nursing facility for the petitioners' child. The Department does not argue that she does not have physical needs which make the level of care unsuitable or that she is not being provided specialized services (services geared especially to her mental retardation) as reasons for the denial. Rather the Department states that it has determined that such a setting is inappropriate for all children based upon criteria in the regulations for evaluating the need for nursing facility services:

(a) Basic rule. For each applicant for admission to a NF and each NF resident who has MI or MR, the evaluator must assess whether--

- (1) The individual's total needs are such that his or her needs can be met in an appropriate community setting;
- (2) The individual's total needs are such that they can be met only on an inpatient basis, which may include the option of placement in a home and community-based services waiver program, but for which the inpatient care would be required;
- (3) If inpatient care is appropriate and desired, the NF is an appropriate institutional setting for meeting those needs in accordance with §483.126; or,
- (4) If the inpatient care is appropriate and desired but the NF is not the appropriate setting for meeting the individual's needs in accordance with § 483.126, another setting such as an ICF/MR (including small, community-based facilities), an IMD providing services to individuals aged 65 or older, or a psychiatric hospital is an appropriate institutional setting for meeting those needs.

(b) Determining appropriate placement. In determining appropriate placement, the evaluator must prioritize the physical and mental needs of the individual being evaluated, taking into account the severity of each condition.

(c) Data. At a minimum, the data relied on to make a determination must include:

- (1) Evaluation of physical status (for example, diagnoses, date of onset, medical history, and prognosis);
- (2) Evaluation of mental status (for example, diagnoses, date of onset, medical history, likelihood that

the individual may be a danger to himself/herself or others); and

(3) Functional assessment (activities of daily living)

(d) Based on the data . . . the State mental health or mental retardation authority must determine whether an NF level of services is needed.

42 C.F.R. § 483.132

The above regulation provides ample authority for the Department to consider whether a placement is appropriate and to consider whether the total need can be met in a community setting, if the agency feels that is preferable. However, the regulation also makes it clear that such a determination must be based on data reflecting an individual evaluation of the patient's mental health needs. There is nothing in the regulations which suggest that such an evaluation can be made based on membership in a group, i.e. children.

Other sections of the regulations deal specifically with this issue. 42 C.F.R. § 483.10 is particularly instructive in that it requires that all determinations be based "on an evaluation of data concerning the individual" and specifies that these determinations be done in the "appropriate placement" category by individualized determinations based on extensive individualized evaluations or by category only with regard to the positive need for nursing facility services (i.e. convalescent care or terminal illness) or the lack of need for specialized services. There is nothing which would allow a determination on "appropriateness" based on any category.

In this case, the applicant is a fourteen-year-old child who is indisputably in need of the medical services provided in the nursing home but is being refused admission solely because of her age. There has been no individual evaluation of the impact of placement in a nursing facility on her. The Department used its own informal "guidelines" (appended hereto as Exhibit One) to justify its actions. In its blanket determination that mentally retarded children cannot reside in nursing homes the Department apparently relies on the fourth paragraph of its "guidelines", which states that admission may be denied if total needs for care and habilitation exceed the nursing home's capacity, even with specialized services. The Department's reliance upon this principle is obviously well-intentioned and based upon its general experience and may well be based upon sound research in this area. Its concern for the emotional and intellectual well-being of children who may have physical handicaps which cause them to be needlessly institutionalized is appropriate under their statutory mandate.

However, what is clear even in its own "guidelines" is the need for an independent evaluation of the needs of each "individual" who seeks nursing facility level care as required under the federal statutes and regulations above. That individual evaluation is sorely lacking in this case. The child's parents maintain that her social and emotional needs are well-addressed in her current environment. There is no evidence that they are insincere in any way or that they don't have the best interests of their child at heart. Their opinion, based upon an intimate fourteen year knowledge of their child, is certainly informed and should be accorded great weight. This opinion and that of their doctor is the only evidence relevant to the individual evaluation standard.

It is entirely possible that the parents may be mistaken about the degree of psychological or emotional dysfunction this placement might cause for their daughter. If the Department feels this is so, it is incumbent upon it to present evidence from a competent medical professional who has examined and

evaluated this particular child with regard to the appropriateness of this type of facility for her particular needs. Extrapolations about the needs of this child based on the needs of other children with no individual examination of this child's psychological needs is not sufficient to meet this burden. The extant evidence which does personally relate to this child indicates that she has extremely limited psychological and social needs that can be and are being met in the nursing home environment. Therefore, the Department's decision that she cannot be admitted to this facility based solely on her age cannot be upheld.

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