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PSYCHOSOCIAL DWARFISM: DETECTION, EVALUATION AND MANAGEMENT

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ABSTRACT

Our experience with 35 children with psychosocial dwarfism (PSD) over five years is reviewed. Diagnosis and management are difficult. A multidisciplinary approach to the evaluation allows for maximal observation of family psychodynamics and intervention. Foster placement remains the intervention of choice in children over four years of age.

INTRODUCTION

Environmentally-induced growth retardation associated with psychosocial deprivation, emotional stress and/or neglect is probably the most common single cause of deviant growth in infants and children in the United States today. All too often, however, the child's small stature is ascribed to other etiologies because environmental factors are unappreciated. In 1967, Powell and associates described 13 young children with severe growth retardation, developmental delay, and bizarre behavior who had histories suggestive of emotional deprivation (1). These children were found to have hypopituitarism which resulved with change in their environment (2). Catch-up in physical and emotional growth was often dramatic. This syndrome of deprivation or psychosocial dwarfism has subsequently become more widely recognized by pediatric endocrinologists but it still remains often undiagnosed by many health professionals. It is important that there be awareness of this condition because earlier detection may help to prevent physical and developmental lags which often appear to be irreversible when intervention is delayed.

We have had wide experience with children with psychosocial dwarfism (PSD) over the age of two years who have had extensive initial medical evaluations and long term follow-up. Family assessment and intervention has often been difficult and frustrating. Our present approach to the evaluation and management of these children is based on this experience and is outlined in this report.

METHODS

The 35 children reported here represent approximately 70 percent of children over the age of two years that the authors have personally seen in whom the diagnosis of PSD was suspected or made between 1973 and 1978. Only the children for whom thorough initial evaluation and/or follow-up information is available have been included. The diagnosis of PSD was made in all instances by demonstration of behavioral, physical and/or hormonal changes during a diagnostic hospitalization and/or during subsequent foster placement. All children were referred to general pediatric or pediatric endocrine clinics or services of the University of Michigan Medical Center, Ann Arbor, Michigan or Children's Hospital, Pittsburgh, Pennsylvania for evaluation of small size. All children were seen and evaluated by one or both authors. Rarely was the family the initiator in seeking medical evaluation. Referral resulted from physicians and community clinics by concerned schools, Protective Service workers, public health nurses, neighbors or relatives. At least 17 children had been known to Children's Protective Services in the past. Three had previously been in foster homes and returned home after 6-18 months when they were less than two years of age.

TABLE 1 Early Developmental History

	Number of Children
Difficult Pregnancy	11
Difficult Birth	10
Neonatal Illness	13
Prematurity	4
Twin	2
Early Feeding Difficulty	7
Slow Developmental Milestones	
Speech	16
Motor	16
Hospitalizations for Failure to Thrive	6
Caretaker First 3 mo. Not Mother	6
Physical Abuse	13
Prior Protective Service Referral	17
Prior Foster Placement < 2 Years of Age	3

Patients

The patient population consisted of 35 children, 21 boys and 14 girls. Mean age was 5.7 years (range 2.0-14.0 years). All had growth retardation (4 to 10 standard deviations below the mean height for chronologic age). There were three sibling pairs. No child had prior evidence of organic illness which might have been a contributing factor to his or her growth retardation. Growth velocities of 14 children were unknown. The remaining 21 children were all growing less than 4.0 cm./year; half of these had essentially no linear gain for 6 to 12 months prior to admission.

Diagnostic Procedures

Thirty-two of the children were hospitalized for periods of two to four weeks for initial diagnostic evaluation; four of these children remained hospitalized for several additional weeks while management plans were being developed. Three children were seen in consultation after hospitalization elsewhere or after placement in foster homes and the evaluation was done in the outpatient clinic. A multidisciplinary team approach was used to evaluate most children and to provide serial observations of the child's behavior, eating pattern, child-parent interaction as well as interpersonal relationships with hospital staff and peer groups. The majority of children were seen by several pediatricians, nursing staff, a social worker, a child psychologist and/or a child psychiatrist. The presence or absence of poor sleeping, hoarding of food, self-destructive behavior, temper tantrums, enuresis, vomiting and abnormal stools were recorded. Diets were unlimited and daily caloric intake was recorded. Periodic team meetings were useful for sharing information, interpretation of the changes in the child, and assessment of the families' ability to change, a factor which determined the basis for subsequent intervention and management.

A general medical diagnostic evaluation was completed for each child to exclude organic illness. In 30 children, investigation of the hypothalamic-pituitary-axis was performed by means of one or more of the following diagnostic tests: arginine-insulin infusion, oral glucose tolerance and/or metapyrone. Whenever possible, these tests were performed on the first or second hospital day and repeated after 10 to 20 days of observation.

RESULTS

Child's History

Early developmental histories were often difficult to obtain due to poor recall by the parent, absence of parent or reluctance to share information. Table 1 lists some of the identified problem areas, all of which are expected to be an underestimate of the true incidence. Developmental milestones, especially expressive language and gross motor skills, were delayed in 16 of the 28 children in whom some history was available. Most often problems were dated retrospectively to age 2-3 years, the time where growth deviation occurred or became more prominent.

TABLE 2 Symptoms and Behavior

	#/35	%
Polyphagia	30	86
Bizzare oral intake	19	54
Abdominal distension	17	49
Stealing or hoarding food	15	48*
Obsession with food	15	43
Vomiting	15	43
Increased number of stools	11	31
Encopresis	10	32*
Decreased food intake	7	20
Malodorous stools	7	20
Constipation	5	14
Enuresis	16	52*
Polydipsia	9	26
Polyuria	6	17
Drinking from toilet bowl	5	14
Temper tantrums	17	49
Withdrawn behavior	17	49
Poor peer or sibling interaction	17	49
Poor sleeping	15	43
Decreased physical activity	14	40
Increased physical activity	13	37
Destructive behavior	10	29
Pain Agnosia	10	29
Self injury	3	9

* Percentage of children over 4 years of age.

Symptoms and behaviors reported by the parents are listed in Table 2. An altered relationship with food was by far the most common symptom. Most children were reported to have a large appetite. Frequently it was voracious. Reports of ingestion of unusual or excessive quantities of food (a jar of mayonnaise, a loaf of bread, two whole pies, etc.) or non-food items (dirt, paper, crayons, hair, garbage, dog food) were common. Abdominal distension, vomiting, diarrhea and/or abnormal stools often followed such ingestions. This eating behavior was frequently accompanied by parental attempts to control types or quantity of food intake and would usually be followed by the child making night raids on the cupboards or refrigerator, hoarding, begging or stealing food from other people. Many of the children preferred to play in the kitchen, talked mostly about food and evidenced considerable animation and excitement in relating to food.

Regressive behaviors such as enuresis and temper tantrums were present in half the children at the time they were seen and had been present in the majority sometime in the past. Many parents reported their children as being withdrawn and seldom playing with siblings or peers. Behavior which alternated between periods of marked passitivity (e.g. sitting in one spot and staring at the floor) and hyperactivity (often leading to destructive behavior and temper tantrums) was common. Several parents complained about poor sleeping as their primary concern. Sometimes poor sleeping was accompanied by night eating, drinking or self-injury such as hair pulling (trichotillomania). Unusual thirst was also present in nine children; five were said to drink from the toilet bowl, one drank out of the fish bowl and another drank his urine.

Even though the histories were probably unreliable for some children, every child had at least one symptom listed in Table 2. The mean number of these behaviors for each child range was 8.7 (range 1-16). The behavioral history elicited often differed with each interviewer. A detailed retrospective review at each time period in the child's development was often necessary because many of the families did not view these behaviors as abnormal or disturbing.

Physical Appearance

All children were below the third percentile on the growth grid for both height and weight. Twenty-seven children were mildly underweight for height when weight age was compared with height age from the growth charts but their appearance suggested undernutrition in less than 10 percent. Head circumference was less than 2 S.D. for age in 12 children. Head circumference age (mean for normal children) was less than height age in 11 children. Immature body proportions, facies and dress were present in almost all children. Many had abdominal distension. While liver enlargement was occasionally noted on initial evaluation, it often became palpable during rapid weight gain. Many children had multiple bruises but only one child had overt evidence of other physical injury (burns) when initially seen.

Laboratory Studies

Common biochemical abnormalities included mild elevations of blood eosinophils, sedimentation rate, blood urea nitrogen, and SGOT. Three of 11 children had mild elevations of sweat sodium or chloride; one child had elevation to 73 mEq/L which gradually declined into the normal range during catch-up growth. Only one child had an initially low serum albumin. Stools were negative for ova and parasites in all but one child tested.

Endocrine testing revealed normal serum thyroxine in all except two children who had slightly low levels before but normal levels during catch-up growth. Twenty-four hour urinary 17-hydroxysteroids were less than 1.0 mg/day in 11/16 children, but responses to oral or intravenous metapyrone were usually normal (9/11). Some children had glucose intolerance and a paradoxical rise of serum growth hormone to oral glucose. Half the children tested (14/28) had blunted growth hormone release to provocative stimuli.

Bone maturation was delayed in all but one child and was compatible with height age. Skull roentgenograms were normal; approximately half the children who had repeat roentgenograms during catch-up growth had splitting of cranial sutures (3). Several children were noted to have gastric dilatation (4) and many had evidence of growth lines in the metaphyses of long bones (5).

Twelve children were studied serially for changes in fasting blood lipids after it was noted that marked abnormalities were often present. Turbidity of fasting serum and a distinctive pattern of changing lipids were observed during the first week. A dramatic rise in serum triglyceride (36-594%) occurred during the first four days in 10 children and returned to normal by day 6-8. Cholesterol rose more slowly, then also returned to normal. Lipoprotein electrophoreses were initially normal except for presence of chylomicrons in 6/12; during the first week of hospitalization of pre-beta band frequently appeared. During this time the serum turbidity cleared. Turbidity reoccurred after 13/18 parent visits and cleared again after parent-child separation. This observation was a useful diagnostic aid in assessing the stress of the parent-child interaction and in supporting the diagnosis of PSD.

Family History and Psychodynamics

Family history was often very difficult to obtain. Most families were guarded and were reluctant to share information. Many never admitted there were problems at all. Some parents agreed that discipline of the child was difficult, but in intact families it was unusual for them to admit that marital or other conflicts existed. Initially many of these families presented a facade of stability and appeared nurturing, a factor which had often delayed the correct diagnosis previously.

The natural parents were no longer living together in 14 cases; many of these parents had remarried prior to the onset of symptoms (as stated by the parent) in the child. Birth order in natural families was: first (5), second (19), third (6), fourth (1), fifth (2), sixth (1). Thirteen of the children were the youngest children in the family at the time of evaluation. Two children had been adopted in the first post-natal month. Three were only children.

Important diagnostic clues in the family included maternal depression, marital conflict, an angry-hostile parent, an emotionally absent father, physical abuse between parents or between parent and child, and history of deprivation in parental background. Multiple family stresses which included unemployment, financial difficulties, illness, drug abuse or alcoholism were

common. Poor communication between parents was present in all families interviewed. Power struggles between parent and child usually focused around food. In almost all instances, one or both parents demonstrated denial about the child's small size. Failure-to-thrive was often present in other siblings (12/35) or in the extended family. Scapegoating of the child by the parents and/or siblings was documented in at least ten children. Symbiotic relationships between child and parent were common in the most severely delayed children.

Hospital Observations

All of the children were observed during their hospital stay at least part of the time without parental presence. The comparison of behaviors between child-parent and child-staff was extremely important both for diagnosis as well as for weight gain. Initially, most of the younger children showed decreased stranger anxiety and were indiscriminate in their affections with ward personnel. All children craved attention and preferred adult to peer interaction. Labile age appropriateness was often striking. In parental presence, speech was often immature and indistinct and behavior was frequently regressive. Careful documentation of the variability of behavior was very useful in the total assessment of the family psychopathology. Many children also showed pain agnosia initially to painful diagnostic procedures; usually this disappeared after the first week. Although hoarding of food was not uncommon, the absence of other bizarre behaviors frequently contrasted with parental histories. Weight gain was often dramatic (1-3 kg/week) and caloric intakes high. Some children who had a weight age appropriate for height age did not gain excessively; rather linear growth was detectable during the next four weeks. Psychologic and/or psychiatric evaluation revealed that most children were functioning in the mildly impaired intellectual range. Only three children had an IQ greater than 90 on initial testing. Many children were preoccupied with loss and rejection, appeared frightened, had poor self-esteem and evidence of limited emotional attachments

Management and Follow-up

Initial assessment showed that most families had minimal insight into family psychopathology and very little motivation to change. Seventeen children were discharged from the hospital into foster placements under court order. Three children were removed from the hospital against medical advice before intervention strategy could be completed. In these instances foster placement was delayed several weeks until court hearings could be held. Two children were voluntarily placed in foster care one and three months after discharge because of the striking regression and weight loss they demonstrated at home. Community intervention was attempted in the remaining 15 children. Day care programs, home visits by public health nurses and parental or family counseling were intervention strategies attempted in some instances. Eight of these children were subsequently placed in foster homes because they did not show normal or catch-up growth even when the family appeared to be cooperative. Most often, however, appointments to counseling or medical evaluations were not kept and minimal excuses were given by the parents.

Thirty-one children had evidence of rapid weight gain and/or linear growth during hospitalization. In two children weight gain was not significant but on the first follow-up clinic visit one to two months later, growth acceleration was noted, reflective of changes initiated during the observation period. Three of the older children (age 8, 9, 9 years), had some weight gain and hormonal changes during their hospitalization compatible with reversible hypopituitarism, but failed to have catch-up growth during six to 18 months of foster placement. Permanent hypopituitarism is now suspected.

Seven children remained in their natural homes. Of these, two families moved out of state immediately after hospitalization, and another was lost to follow-up after the family refused to keep appointments at a mental health clinic. One child was made a court ward in her own home, grew poorly, and later moved without trace. The youngest child, age two years, was said to begin to grow after public health nursing visits but has not been seen by us again. A severely delayed four year old boy who had a strong symbiotic relationship with his mother had begun to show catch-up growth when he entered day school prior to hospitalization. The family refused counseling, had marital conflicts and continuing stresses. Two subsequent reports to Protective Services were made by the school because of the presence of bruises. Catch-up growth and developmental progress has continued in the natural home, although at a slower rate than we would have anticipated in foster care. The final child, a five year old girl, remained in her natural home after her parents refused foster placement. Three months later after

marital counseling, the parents separated. The child said shortly thereafter, "my mommy and daddy are no longer mad at me; they are now mad at each other". Only then did she begin to have continued catch-up growth and behavioral changes.

Follow-up of six months to five years ($\bar{x}$ 2.6 yrs) is available for 30 of the children. Parental rights have been terminated for nine children. Six of these children have been subsequently adopted; three of them into their original foster home. With regard to behavior, the children who have been adopted appear to have made the best adjustments. Eight children have had multiple placements due to continued behavior problems. Of these children, three were placed in residential centers at some time in their management. Frequent continued visitation with natural families often precipitated behavioral regression sometimes associated with deceleration in growth velocity. When this association was evident, usually further visitation with family members was limited. Figure 1 shows a development growth curve for the height of a 9 year old boy with PSD who had good initial catch-up in height when placed in a foster home at age 3 years as the only child. When his younger brother, also with PSD, joined him six months later, both boys had marked regressive and destructive behavior and cessation of emotional and physical growth. We saw him initially at age 5.5 years and recommended placement in new and separate environments where good catch-up growth initially occurred in both boys until one brother developed a symbiotic relationship with a member of the residential center staff. Linear growth thereafter was minimal for two years. Repeat hospitalization at age 9 years documented hypopituitarism which did not completely reverse in four weeks observation. An adoptive home subsequently rejected him because of unmanageable behavior after which he remained in a shelter until he entered a second adoptive home. While linear growth seems to be approximating normal, to date no catch-up growth has been demonstrated. It remains to be seen if this child has the potential for rebound growth after so long a period of growth suppression.

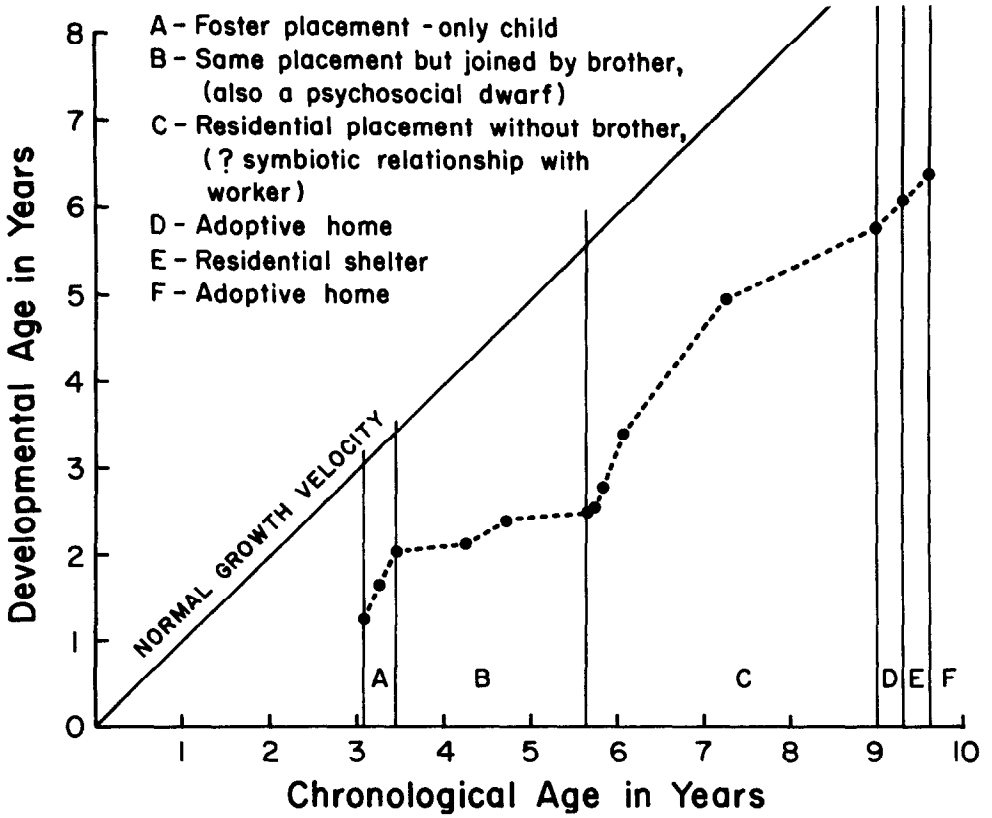

Fig. 1. Course for one of two brothers who had multiple placements (• = height)

Five boys who spent one to two years in foster placement have been returned to their natural homes. Two of these boys have been lost to follow-up. A third boy is said to be having severe behavior problems and remains very small but has not been seen by us. During the two years the fourth boy spent in foster care, his parents separated and divorced. During the first six months back in his mother's home, he continued to have a normal growth velocity but catch-up growth ceased. The family has subsequently failed to keep medical appointments over a nine month period. The fifth boy was returned home by the court after one year in foster placement where catch-up growth was noted. There was no growth or weight gain at all during the next six months in his natural home, necessitating placement into a second foster home where catch-up growth was again noted. The course of a sixth boy who will soon return home is shown in Fig. 2. Reversible hypopituitarism was documented on two occasions at age 4 and 5.5 years. Intervention over two years in the natural home was unsuccessful in reversing deviant velocity and severe developmental lags. After placement in a foster home at 6.5 years, he grew 30 cm. in the next 27 months. Placement of two infants into his foster home led to marked regression of behavior necessitating placement in a second foster home. He is now at the third percentile on the growth chart. Plans are being made for return to his natural home after a period of more frequent home visitations. The last family has been involved in psychotherapy for the past three years whereas in the first four cases, the families refused psychological help or were unmotivated to change.

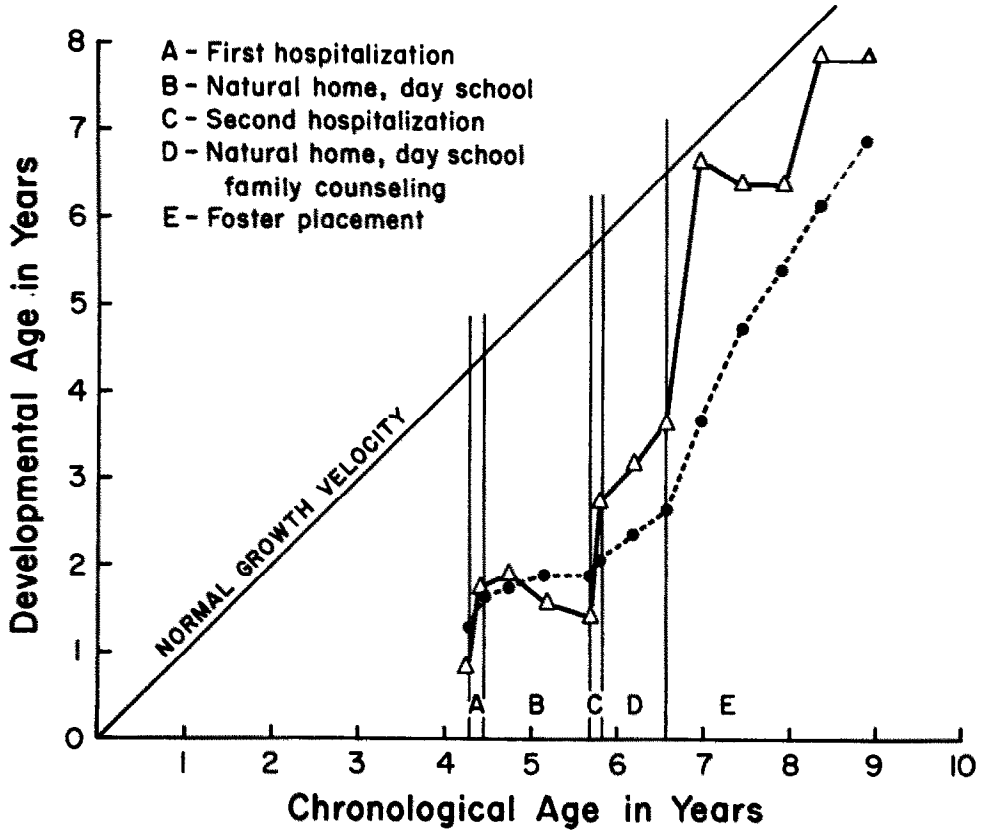

Fig. 2. Follow-up course for a four year old boy who had unsuccessful intervention in the natural home (• = height, △ = weight)

During foster placements 13 children have now reached the third percentile on the growth chart for height and when last seen 11 were still showing catch-up acceleration. Thirteen are still below the third percentile for height; four of these are no longer showing catch-up growth but are maintaining normal growth velocity. Recent height and weight are unknown for the four other children not lost to follow-up. To our surpirse, catch-up in IQ has been minimal in 9

children serially tested; only one child had gains of greater than 10 IQ points. This may reflect decreased potential for intellectual gains at older ages ($\bar{x}$ 6.5 yrs, range 4-10 yrs). Psychological reevaluation of the children remaining in foster care is incomplete. Most children are adapting well to their homes. Almost all have needed special help at school. Immature behavior continues to be a problem in the oldest boy, now age 16, who has reached the 50th percentile in growth. He has had minimal catch-up in emotional or intellectual development during four foster placements over five years.

DISCUSSION AND RECOMMENDATIONS

Psychosocial dwarfism is a perplexing and frustrating disorder for the health professional. The relationship which results in emotional and physical growth arrest is most difficult to detect or if detected to substantiate in an empirical manner. A high degree of significance must be attached to historical and behavioral details. It requires the expertise of a variety of disciplines both from within the hospital and the community to diagnose and develope an intervention program that will reverse the process. Therefore, immediate involvement of a multidisciplinary team who can explore both organic and nonorganic etiologies for the growth retardation simultaneously should be provided during the hospital evaluation. Delay until after exclusion of organic disease leads to loss of valuable observations as well as opportunity to engage with the family. It should be explained that organic and emotional causes of growth retardation are being sought at the onset of the evaluation. Our experience is that families are more willing to consider an emotional etiology if that has been presented in a "matter of fact" manner from the beginning.

Once the diagnosis has been made a plan for intervention must be developed. All too often simplistic solutions are offered to the community and family for these extremely complex cases. Because a major symptomatology of these children is centered around their bizarre relationship to food many people erroneously believe that a failure to feed the children or failure to feed appropriately is the cause and therefore the solution becomes one of feeding the child. The marked rebound in linear growth that many of these children demonstrate on removal from their home environment is not usually due to nutritional improvement in the hospital or in foster care. The rebound seems to be due to relief from stress present in the home environment which interferes with the child's ability to grow through some as yet unexplained process.

Only one out of 35 children in our group had initiation of catch-up growth while in the natural home. In addition, catch-up growth after discharge continued in only one child over four years of age when the child returned to the same home environment. Therefore, we feel that initial separation of the child from his or her family through a diagnostic evaluation is essential. Unless given strong evidence of parental motivation and ability to change (and we are increasingly pessimistic about this possibility) our recommendation is that the children be placed in a foster placement at a minimum until they reach the third percentile in height. Usually this is accomplished in 1-1/2 to 2 years. Affected siblings should receive separate placements at least initially for maximal success. Three of our cases provide clear evidence for deceleration of growth or cessation of catch-up growth once natural siblings were reunited. After placement in separate homes two brothers (Fig. 1) met accidentally at a clinic visit. Foster parents reported enuresis and temper tantrums thereafter for almost a month. Because of our observation that the presence of younger foster siblings can also precipitate regressive behavior, we encourage a placement into a home with limited children, preferably none younger than the affected child.

Our initial recommendations are usually for a maximum visitation with natural parents of once a month for several hours. Even then, many children become anxious in anticipation of these visits. Foster parents often report behavior and school problems surrounding these visits. Likewise, contact initiated by the natural parents through phone calls, letters and/or presents is discouraged. As this type of recommendation is opposite to how physicians, psychologists and social workers have been trained, we have to repeatedly remind ourselves that the parent is stressful to the child.

Criteria for success is difficult to establish because long term evaluations have been infrequent in this condition. We have been impressed that emotional growth does not proceed without physical growth. We therefore recommend frequent monitoring (every 3 months) of weight gain and linear growth. Most children show dramatic emotional gains which parallel this rebound physical growth. Unfortunately in those children who have had unstable or poor parent-

ing in foster homes due to poor placements, frequent moves or due to the child's lack of attachment to natural or foster parents, emotional development usually lags appreciably behind physical growth. Repeat psychological evaluations at yearly intervals can be helpful in assessing the child's emotional needs.

Continued reassessment of the natural family while the child is in foster care is important to determine if it will ever be possible to reunite the child and family. In order for this to be determined it is essential that full community intervention and psychological help for the family be offered when the child is first placed in foster care and not after one or two years when return home is being considered. The family will need more time for change than the child and this time must not be wasted. It is also crucial that the family's therapist be familiar with the syndrome affecting the child.

With the few exceptions mentioned in the paper, it is our experience that therapy has not been successful in bringing about enough of a change in these families that the child is able to grow. Factors affecting this failure must be further evaluated but it seems that some families are resistent to change and refuse help of any type. Others are isolated and referral agencies unavailable. Another reason is the lack of trained mental health professionals who can deal with these very difficult families. We could cite several instances wherein the therapist clearly became caught up in the family system and denied what was happening to the child while defending the parents. The mother of the child in Fig. 2 was extremely depressed. The father and the helpers in the community feared total mental collapse if the mother-child symbiosis was interrupted. During the second hospitalization, the mother was 8 months pregnant and she stated "if you take -- away, the next one will be the same". It was only after outside placement of the child took place that the mother began to deal with her depression and her isolation noticably decreased. What will happen to this child, soon to be returned again on a trial basis after 2 1/2 years remains to be seen.

The concept of time is important to consider when planning for the child (6). A delay of six months or a year before the child has an opportunity to grow may well represent a fourth or fifth of the child's lifetime. In addition, it may be that the child has a finite capacity to reverse this process over time and each delay or the longer the delay adds to the ultimate damage done. In our group of children, the older the child was at the time of placement, the less the significant change noted. The child cannot wait for this family to change. When family change is limited, a decision to seek permanent custody should be made and made as quickly as possible. This would free the child for adoption at a young enough age to permit stability and improved prognosis for emotional adjustment.

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