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**PSYCHOLOGICAL FACTORS IN THE DEVELOPMENT OF
CEREBRAL PALSIED CHILDREN**

Ph. D. Thesis

BY

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CEREBRAL PALSY AS A MEDICAL PROBLEM

On the rapidly changing face of medicine, where many of the acute and previously often fatal diseases have recently come under control, the developmental disorders are now becoming increasingly an area of concern to the clinician and of interest to the research worker. The challenge of chronic physical or mental handicap is a manifold one, in that it presents not only medical aspects but has important psychological and social implications as well. Thus many disciplines find these conditions a fertile ground for the investigation of a great diversity of problems, and in the study of cerebral palsy in particular an opportunity is held out for contributions from a variety of professions.

Although Little (1862) first described the condition of cerebral palsy a hundred years ago, it is only in the last two decades that much work has been carried out in this area. This was in the first place devoted to a delineation of the problem: the definition of the condition, classification of the disorders subsumed under the generic title of cerebral palsy, and determination of its incidence in the population.

The term Congenital Spastic Paralysis was used initially to describe a rather loosely defined group of conditions having as a common characteristic some degree of locomotor impairment of neurological origin. Oiler (1889) is generally given the credit of having first used the term "the Cerebral Palsies", and the mass of clinical evidence that has accumulated since his day has now resulted in a fair measure of agreement as to the definition to be attached to it. Of the two most widely used definitions, that by the American Academy of Cerebral Palsy holds that cerebral palsy is "any abnormal alteration of movement or motor function arising from defect, injury or disease of the nervous tissues contained in the cranial cavity". The other, by Yannet (1944), considers cerebral palsy to be a "motor defect present or appearing soon after birth and dependent on pathologic abnormalities in the brain". Thus the two factors of brain damage and resulting motor defects are

considered by all the essential characteristics of the syndrome.

The classification of conditions contained within the syndrom has given rise to a rather greater degree of confusion. There is general agreement with the decision by the American Academy of Cerebral Palsy to exclude palsy due to cerebral neoplasm and other progressive disorder, but various writers such as Ingram (1955), Woods (1957), and Illingworth (1958) have each presented his own scheme for ordering the remaining conditions. Three types tend, however, to be recognised by all:

a) Spasticity, in which the pyramidal system is involved and which manifests itself in "clasp-knife" rigidity of the muscles and in exaggerated reflexes. A sub-division according to the limbs involved defines paraplegia as spasticity affecting the lower limbs only, hemiplegia as spasticity affecting both limbs on one side, and quadriplegia as spasticity affecting all four limbs.

b) Athetosis, in which the lesion is sited in the extra-pyramidal system and which is characterised by slow writhing movements.

c) Ataxia, where the lesion is in the cerebellum and therefore shows itself in disturbances of balance.

To these three classes Illingworth (1958) also adds Tremor and Rigidity. In addition a mixed type, containing features of more than one of the above types, is commonly found.

As far as incidence is concerned, a considerable number of studies in various countries all suggest that between one and two cases can be expected to occur for every 1,000 children of school age. The figure given by Asher and Schonell (1950) is 1 per 1,000, that by Ingram (1955) 2 to 2.5, that by Woods (1957) 1.9, and that by Henderson (1958) 2 per 1,000 school aged children. The incidence of the various sub-divisions of cerebral palsy is rather more problematic, and though all writers conclude that the majority of cases fall into the spastic category, the diversity of opinion as regards the actual figures stated reflects a confused state of affairs. Illingworth (1958) summarises these studies in a useful table, from which it emerges that the reported incidence of spasticity found amongst the cerebral palsied varies from a figure as high as 89% to a figure as low as 40%, and that athetosis was diagnosed

by some in as many as 25% and by others in as few as 2%. Difference in diagnostic criteria and the prevalence of mixed cases are thought to explain these divergencies.

Despite the numerous reports which have concerned themselves with the effects of anoxia, prematurity, maternal toxæmia, abnormal deliveries, and other such factors suspected of playing a part in the production of cerebral palsy, we know as yet little about the aetiology of this condition. Moreover, although physiotherapy, drug treatment, and the use of surgical procedures have been found to alleviate the disorder in certain selected cases, cerebral palsy must still be regarded as a malady for which there is no cure. The hope for the future would appear to lie rather in prevention, and the attention given to the expectant mother and to the baby at birth emphasises this direction of thought.

CHAPTER 2

PSYCHOLOGICAL ASPECTS OF CEREBRAL PALSY

The bulk of work on cerebral palsy has naturally concerned itself with its various medical aspects. It is, however, also a condition of particular interest to the psychologist, and this interest may be said to stem from two sources.

In the first place, the presence of brain damage may have a variety of direct effects on psychological functions. Those studied have been almost exclusively in the cognitive field, and the general aim here has been to determine the results of the lesion on the individual's ability to experience and understand his environment. Investigations have therefore concerned themselves with the processes of perception, learning, thinking, concept formation, and the general problem of intelligence, and the data thus obtained are generally found to have definite educational implications.

In the second place, the presence of a physical handicap that may be severe, is often unsightly and generally permanent has certain consequences for the personality development of the individual and his social adjustment to the environment. Our society places a premium both on conformity and on independence, and he who can meet neither requirement is liable to all the difficulties of the deviant. Studies concerned with this aspect tend therefore to have psychiatric implications.

An injury to the brain may therefore have both primary and secondary results: on the one hand it may directly affect functions controlled by the brain, and on the other hand it may bring about certain attitudes, both in the individual himself and in those around him, to the affected functions. We shall now review the studies that have been carried out in these two areas.

Cognitive effects of brain damage amongst the cerebral palsied.

The assumption that intellectual functioning may be interfered with by lesion in the brain was one of the influences that gave rise to

the numerous investigations devoted to this subject. But whereas this was largely a theoretically dictated interest, another influence was of a very practical nature, namely, the need to provide for the education of handicapped children and hence the necessity of ascertaining their special abilities and characteristics. The level of general intelligence to be found amongst the cerebral palsied was therefore of special significance.

Before statements about the intellectual capacity of these children could be made, however, all workers had to face the problems involved in using tests standardised on non-handicapped subjects. How far is it feasible to administer verbal and performance scales to those whose manipulative and speaking skills are adversely affected by their injury? To what extent must allowance be made for the sensory and motor defects, and how far is it justified to modify the usual test procedure in order to make such allowance? Different answers have been provided to these questions. Meyer (1957), for instance, points out that psychological tests cannot be regarded as pure measures of abilities, that they are influenced by peripheral defects, and that the result of a test affected by such defects cannot therefore be regarded as valid. Sarason (1949) warns that a psychological test administered by rigidly following the directions of the manual is likely to reflect the degree of physical handicap rather than the individual's mental capabilities. Nevertheless, the majority of psychologists writing on this subject assert that it is possible to obtain reliable intelligence quotients from all but the most severely handicapped children, provided certain minor modifications are made in the test procedure. Schonell (1956) and Dunsdon (1952) discuss such modifications in detail, and Schonell (1956) further substantiates her point by giving the results of two test-retest reliability studies, which yielded correlation coefficients of .79 and .89 respectively. She concludes that a reliable estimate of intellectual potentiality may be obtained from all but the very young and the very severely handicapped. The problem is, however, by no means settled, and whilst most writers would agree with

Floyer's (1955) contention that the Terman Merrill Scale is the most satisfactory instrument for the purpose, others have felt the need for a specially designed test, such as the Columbia Mental Maturity Scale (Burgemeister et al, 1954), which would produce a result uninfluenced by peripheral defects. Unfortunately personal experience has shown that even this test has grave disadvantages, in that the result is heavily influenced by any tendency towards perseveration and defects of spatial perception which the subject may have. Although for clinical purposes it is usually possible to assign a cerebral palsied child to one of the descriptive intellectual categories in use (average, dull, feeble-minded, etc.), it seems doubtful whether any existing test is able to provide a more precise estimate for all but the lightly handicapped, and it may well be that the differences obtained by the surveys on the intellectual capacities of the cerebral palsied are due in large measure to the inadequacies of present tools of assessment.

There is now in existence a fairly large literature on the incidence of the various intellectual categories amongst the cerebral palsied. The early investigations produced very divergent findings. Smith (quoted by Sarason, 1949) found the incidence of mental deficiency to be 78% among his group of cerebral palsied. Schroeder (1929) reported 66% as mentally retarded, yet in his original study Little (1862) found only 11 out of 63 cases to be mentally defective. Within the last two decades more definitive studies have, however, taken place, and greater attention to problems of sampling and assessment have given these investigations increased authority. The New Jersey survey by McIntyre (1938), based on 146 subjects, found an incidence of 26% mental defect in this group; on the other hand the 1951 New Jersey Survey (Hopkins, Bice and Colton, 1954) gave a figure almost twice as high, namely 49%. This latter figure is in greater agreement with those produced by the majority of the more recent investigations. Cardwell (1956) has drawn up a table summarising the results of 13 studies, and from this it emerges that the lowest incidence of mental deficiency found was 30.5

and the highest 58.6%. As a result, it is now generally accepted that 4 or 5 out of every 10 cases of cerebral palsy may be expected to suffer from some degree of mental handicap.

As for the intelligence of the various sub-groups of cerebral palsy, the fact that the site of the lesion among the spastic cases is in the cortex has led to the expectation that the average I.Q. in this group will be lower than that of the athetoids, where the damage is subcortical. This expectation has not been borne out. All the recent large-scale psychological investigations agree that there is no relationship between types of cerebral palsy and intelligence: thus Hopkins et al. (1954) found only a slight superiority amongst their athetoid group, Asher and Schonell (1950) obtained almost identical mean intelligence quotients for the two main types, Dunsdon (1952) had to conclude that among athetoid children intelligence distribution was weighted heavily in the inferior ranges, and Miller and Rosenfeld (1952) also failed to obtain any significant differences between the various sub-groups.

A considerable number of studies have now been published which concern themselves with a more detailed exploration of intellectual functioning in the brain-injured. Though the experimental subjects very often include those without neuromuscular involvement, there is no reason to believe that the results do not hold for cerebral palsy cases as well. Most of the work has concerned itself with the problems of perception that arise as a result of a lesion in the brain, and especially with two aspects: the ability to perceive parts as related together in meaningful wholes, and the recognition of these wholes as figures against a background. Some very interesting and well-designed experiments have been carried out on these problems, indicating the difficulties that the brain-injured have in both areas. Inability to perceive visual patterns made up of discrete elements has been demonstrated by Dunsdon (1952), who with the aid of the Bender Gestalt Test showed that appreciation of spatial concepts is often defective amongst the cerebral palsied. Lord (1937) was one of the first to draw attention to this dysfunction, and in her book on the examination

of the brain-injured child Taylor (1959) finds that such an inability repeatedly interferes in the successful performance of many tasks. Werner and Thuma (1942) compared a group of exogenous (brain-injured) and a group of endogenous (familial) mental defectives on the ability to perceive apparent motion, and concluded that the poorer performance of the former indicated the adverse effect of brain damage on perceptual integration. The comparison of these two groups has also been fruitfully explored in a number of other studies, such as those of Bensberg (1952), Cassel (1949), Halpin (1955), and Gallagher (1957), all of whom indicate the difficulties that the brain-injured child has in integrating his experience and perceiving the outer world in the same terms as those of an uninjured subject. The educational implications of these findings are followed up by Strauss and Kephart (1955); on the other hand Gallagher (1957) adds a useful warning against regarding such perceptual difficulties as an inevitable consequence of brain injury.

Experiments by Werner, Strauss, and their colleagues have clearly demonstrated the figure-background disturbance present in so many children with brain injury. Through the tachistoscopic presentation of geometrical figures, the copying of patterns on marble boards, and the reproduction of drawn designs, such experiments as those by Werner and Strauss (1941), Werner (1945), and Dolphin and Cruickshank (1951) have pointed to the confusion inherent in the perceptual process needed for correct solution on these tasks. The failure here of the brain injured child has been related to forced responsiveness to all stimuli appearing in his sensory field, with the result that the child is so distracted by the background that he is unable to disregard it and to attend only to the foreground figure.

Other perceptual characteristics of the brain-injured child which have been described (e.g. by Miller and Rosenfeld (1952) and Cruickshank and Raus (1955)) refer to his distractibility and his disinhibition. Such tendencies will produce a very characteristic motor syndrome, that of hyperkinesis, which has appeared in many clinical descriptions (e.g. Ingram, 1956). Furthermore, disturbance

in body image perception have been described by Bender and Silver (1948), and a number of studies have also explored the effect of brain pathology on thought processes. Strauss and Werner (1942) used a variety of sorting tests towards this end, and demonstrated the extreme concreteness of brain injured subjects and their inability to assume an abstract attitude. Similarly Cotton (1941) found difficulties in concept formation among spastic children, and Werner and Carrison (1944) also interpreted their finding, that brain-injured children show a greater tendency towards animistic thinking than their endogenous controls, as a function of greater rigidity and concreteness.

The foregoing will indicate that cerebral palsy tends to entail a number of handicaps over and above the peripheral and more obvious ones of locomotor, speech, and sensory disabilities. Although in some areas findings are few or contradictory, a start has nevertheless been made in mapping out the world in which the brain-injured subject lives and the potentialities which he brings to the task of meeting the demands made upon him. Perhaps least is as yet known about the correlation of site of lesion and behaviour, and some of the earlier naive assumptions in this respect have had to be revised. Moreover, many studies still present their data in terms of differences between group means, thus giving the impression that the characteristic described holds for all cases, whereas in fact the overlap in distribution is often one of the most interesting features of the investigation. The fact that some of the above mentioned traits commonly occur amongst brain-injured subjects must not lead one to the assumption that they occur in all: there are many cerebral palsied children without difficulties in spatial organisation and many who do not show any tendency towards distractibility. The situation has obvious clinical implications, but over and above this it emphasises the need to investigate the reason for such individual differences, and it may well be that the next phase of research in this area will be less concerned with comparisons between the cerebral palsied and other groups than with the investigation of the intra-variability of the former.

Effects of cerebral palsy on personality development.

By far the majority of psychological studies on cerebral palsy have

concerned themselves with cognitive problems, and comparatively little has been written about the social and emotional aspects of this condition. To some extent this is due to the fact that society has in the past put far more emphasis on the need for education than on the necessity of mental health, with the result that formal research has been disproportionately stimulated in favour of the former. Yet this state of affairs also reflects the amount of knowledge accumulated and work carried out in the respective fields of psychology, and particularly the availability of tools and methods of assessment: whereas tests and experiments abound on the cognitive side, other areas lag far behind in this respect. As a result there are few scientific studies of personality factors in the development of the cerebral palsied, and though impressionistic picture have been presented by various authors, these have generally been formed merely in the course of investigations concerned with medical or intellectual problems. As Block (1954) has said, children with brain injury have generally been studied out of context, with the emphasis on separate disabilities rather than on the total picture of these disabilities in relation to each other and to their life situation. Klebanoff, Singer, and Wilensky (1954), in a review embracing adult patients as well as children, similarly come to the conclusion that "future research upon the patient with organic brain disease should regard him as a complex individual whose social, economic, and intellectual environmental demands must be considered in order to attain total understanding of the specific consequences of brain pathology".

Those investigations which have attempted rather more than mere impressionistic accounts have had to deal first with the problem of technique of assessment. Frequently they had recourse to one or another projective technique in order to gather data under relatively standardised conditions. In this connection the Rorschach test has been used by Williams (1959), the Children's Apperception Test by Holder (1956), and sentence completion tests by Cruickshank (1951a). The disadvantage of such an approach is, however, that only a highly selected sample can be used. The subjects must be old enough to be capable of participating in

the task, they must be intelligent enough to understand the instructions, and they must have the verbal ability to express their answers. When one considers the number of cerebral palsied children who are likely to be excluded by these three requirements, one will appreciate the impossibility of generalising widely from the findings made. Moreover, the difficulties discussed in the use of intelligence tests also apply to some of the personality tests, namely the extent to which one is justified in using a test standardised on normal children. This emerges, for instance, in Schonell's (1956) discussion of her use of the Vineland Social Maturity Scale, which relies heavily on items involving physical maturation and thus unduly penalises the cerebral palsied child. A similar point is made by Newland (1956), who points to the different cultural and experiential backgrounds of physically handicapped children and the consequent difference in the meaning of many items in tests of social and emotional adjustment. One must conclude that the assessment of personality in cerebral palsied children by means of psychological tests is an even more hazardous and uncertain undertaking than is involved in the use of intellectual tests, and that as yet no means has been found of overcoming the difficulties.

That there are special considerations applying to the personality development of cerebral palsied children is agreed by all. Indeed, some of the cognitive factors that have been reviewed above are alone likely to guide the growing personality in some directions of adjustment rather than others. The rather uncertain topic of "body image" and the problems encountered in this respect by a physically handicapped child have also been raised (cf. Bender and Silver, 1948, and Meerloo, 1950), and Bender (1956) has furthermore discussed in detail the emotional concomitants of motor disequilibrium, claiming that the need which the brain-injured child has for support in motility well beyond the period of infancy will give rise to a prolongation of dependency and clinging behaviour directed towards the mother. This author also asserts that unsolved problems concerning the attainment of security in equilibrium and motility may produce later anxiety neuroses, but her evidence for this statement is hardly convincing. Some authors (e.g. Blumberg,

1959) have even gone so far as to claim that each type of brain damage produces a particular type of emotional reaction, that every cerebral palsy sub-group gives rise to its own distinct personality configuration through the particular motor problems raised by each. Phelps (1948), for instance, holds that spastics are fearful, timid, and introverted, while athetoids are friendly, affectionate, and extroverted. Although Schonell (1956) has come to the same conclusion, other writers feel that such a picture is a gross over-simplification and neglects the many other influences to which a child is exposed and which are likely to shape his personality (Cruikshank and Bice, 1955).

A further source of confusion lies in the uncertain use of terminology. This is seen, for instance, in the assertion made by Dunsdon (1952) and Floyer (1955) that there is a considerable amount of "emotional instability" to be found amongst those with cerebral palsy. Yet this statement appears to be challenged by Gesell and Amatruda (1947), who find "temperamental characteristics" to be the least affected by cerebral injury. "Temperament" is at best an ill-defined concept, while under the term "emotional instability" the above writers include a great many quite unrelated phenomena, such as fits, perseveration, lack of drive, tension, disinhibition, and fluctuation in performance. The difficulty is increased by the attempt to distinguish "emotional instability" in the sense of a constitutionally determined lack of emotional control from "emotional maladjustment", defined as a secondary reaction to the condition or to the environment. Many of the above symptoms included under the heading "emotional instability" may just as well have a functional aetiology, and though most writers believe that brain damage does predispose the individual to stress (Goldstein's (1939) description of the "catastrophic reaction" is a classical example), Bender (1949) is able to assert that she has seen no brain-injured child whose behaviour problems could not be strictly explained on the basis of emotional maladjustment. It may well be that both organic and psychological factors play a part in determining emotional reactions, but to distinguish between them in practice is not easy and can certainly not be done (as is the case with many writers) when only one of the two

aspects is examined by the investigator.

Emotional maladjustment (in the sense used above) is commonly said to occur with considerable frequency amongst the cerebral palsied. As Gibbs (1958) puts it: "The most superficial review of the literature shows clearly that both children and adults with cerebral palsy have problems which may be connected with, but cannot be wholly explained by, their neurological condition". Meyerson (1957), however, after examining many such references, had to come to the conclusion that not one reached acceptable levels of scientific reporting. Again the confusion in terminology, the lack of generally acceptable criteria, and the absence of objective means of assessment must be held responsible for this state of affairs.

With this reservation in mind, we may note that this topic has been approached from a variety of points of view. Such writers as Gibbs (1958) Cardwell, (1956) and Bakwin (1960) have discussed the psychological development of the cerebral palsied child in relation to the basic needs normally found in childhood and the additional needs which such a child has. Discussions such as theirs may often highlight some of the problems entailed by the presence of a motor handicap: the lack of opportunity for experience, the difficulties of self-expression, the tendency towards feelings of inferiority in relation to others, and the problem of setting realistic goals are among some of the topics raised in this way. It must be appreciated, however, that these are not experimental studies, and tend generally to be based on wide but unorganised clinical experience. There are relatively few studies which have taken up these problems and investigated them on an empirical and systematic level.

Glick and Donnell (1953), in an investigation of cerebral palsied adults, found that nearly three quarters showed signs of emotional maladjustment. The signs for such maladjustment included unrealistic attitudes, intense feelings of insecurity, extreme immaturity, excessive fears, strong feelings of inferiority, low frustration tolerance, problems in interpersonal relationships, and lack of motivation. Once again, however, the findings were mainly in the nature of clinical impressions.

Meerloo and Meerloo (1950) noted that there was a tendency among cerebral palsied children to withdraw from reality and take refuge in phantasy. Alternately, they might direct their anger concerning their defects against the outside world and show hostility towards others. They are characterised as emotionally shallow, with rapid changes of mood, and a tendency towards infantile modes of emotional expression. On account of their low frustration tolerance everyday adjustment was often difficult, and they tended to dislike breaks in their routine. This account is unfortunately presented in terms of sweeping generalisations, which makes it difficult to understand under what circumstances a given mode of reaction occurs.

One of the very few experimental investigations is that by Wenar (1953). In a comparison of physically handicapped children with normal children, all of normal intelligence and between eight and ten years old, he found certain interesting differences when submitting his subjects to level of aspiration experiments. The non-handicapped children were able to adjust their levels of aspiration realistically in the light of past experience, whereas the handicapped group were able to maintain their realistic attitudes for only a limited time, and then as a result of frustration adopted goals so high that they assumed merely wishful proportions.

One of the more interesting and significant series of experimental studies has been that by Cruickshank (1951a, 1951b, 1952, 1956). Using a variety of techniques, but particularly sentence completion tests (thereby, of course, again restricting the nature of the sample), he studied the effects of various handicaps on a number of different facets of personality. For physically handicapped children in general he found that there were more fears and feelings of guilt than occurred amongst normal children. These feelings, moreover, had direct impact on the less satisfactory social adjustment which these children themselves felt they were making. They tended to associate unhappiness with their handicap, tended to be less mature than other children, more insecure in relation to other people and more inclined to withdraw from them, and they showed fewer normal interests for their age. Although these findings are again expressed as over-all generalisations, Cruickshank

went on to make a particularly important point (cf. Cruickshank and Bice, 1955). This concerns the distinction between a visible and a non-visible handicap, which arose when various types of physical handicap were compared. Here it emerged clearly that children with cardiac disorder, for instance, were much closer to normal children in all aspects of emotional adjustment than, say, children with cerebral palsy. It appears that it is not so much the handicap itself and its restraining influence on activity which is the vital factor in personality distortion, but rather the social effect of this handicap, and it is the visible handicap to which society tends to react.

This is clearly an essential factor which has thus been indicated. One cannot discuss the personality development of a cerebral palsied child in isolation, but must view it in relation to the social environment and the attitudes met therein. For this reason particular attention must be given to the family of the handicapped child, for it is this group which in practice constitutes the community in which the child spends his formative years, and it is the parental attitudes which are likely to have a decisive influence on his adjustment. To this aspect we shall therefore now turn.

Parental attitudes towards the cerebral palsied child.

Some of the previously encountered methodological difficulties occur in this area too. Again direct empirical investigations are few and impressions many, yet all writers agree as to the importance of studying parental influences. Sarason (1949) has put the issue clearly: "In the past the presence of a severe motor defect has obscured the fact that the cerebral palsied child is being responded to and stimulated by people whose behaviour in turn is affected by the severely handicapped child. Although many cerebral palsied children are severely limited in exploratory and locomotor activity, it seems reasonable to assume that parental behaviour may either accentuate or lessen the deleterious effects of such restrictions". And again: "When one considers the possible effects of the presence of a cerebral palsied child on family structure and relationships, the influence of these factors cannot be disregarded. Not all

parents react to the cerebral palsied child in an accepting, warm, consistently affectionate manner. The effects of such a child on the emotional stability of the parents are considerable." These statements emphasise a point which is crucial to the study to be reported here, namely that the influence with which we are concerned is a mutual one: one must take into account both the effect of the child on the parents and that of the parents on the child. As White (1955) has put it: "The meaning of cerebral palsy is unique to each family. A social study which is focused on the child-family-environment complex will yield an understanding of the psychosocial forces." Similarly Cruickshank (1956) points out that most authors believe the behaviour problems of crippled children to be directly related to inadequate parental attitudes rather than the child's inability to encompass psychologically the physical disability per se. He goes on to say that the closeness of the relation between parental attitudes and emotional behaviour in these children is such as to demand that in the study of the development of a handicapped individual the parental attitudes, the cultural attitudes, and the attitudes of peers and siblings must be carefully evaluated.

As to the nature of parental attitudes and their basis, a number of writers have presented us with accounts. Bakwin and Bakwin (1960), for instance, point out that personality changes amongst the cerebral palsied are not highly correlated with the severity of the handicap, but tend to be more associated with the attitudes in the home. There the parents often push the child beyond his true abilities, influenced by the belief that with training the child may become normal or nearly so. They may feel in some way responsible for the condition, and the consequent guilt feelings tend to be associated with overanxiety and overprotection of the child. Parents may blame each other, causing family friction and thus still further add to the child's unhappiness.

Dunsdon (1952), in the course of her investigation on educability, also found that even the most intelligent parents found it difficult to set realistic standards for their handicapped children. They often

expected too rapid progress and then became anxious and discouraged. Others were unaware of the passage of time and continued to treat their children as infants, with the result that the children lost all incentive, became self-centered and ruled the home as autocrats. Under these circumstances it was often the siblings rather than the handicapped child who deserved pity.

Similar observations were made by Floyer (1955), though she admitted that her project included no intensive study of social behaviour. The experience gained during her research, however, led her to the belief that many of a child's emotional and social troubles were the result of interaction between himself and those who cared for him, in particular his mother. As she points out, cerebral palsied children are inevitably handicapped by the abnormal degree of emotional stress to which their parents are subjected by reason of the handicap. They must make some adjustment to the situation, and not only once but time and time again as new stages of development arise. Parental attitudes include ambivalence, rejection (both naked and masked), and complete mature acceptance of the facts. In some families this author found the mother to become so unbalanced that the husband's needs were set aside or the other children neglected, because the mother's emotional interests centered exclusively on the handicapped child. On the whole Floyer believes that an emotionally more balanced situation is found when the cerebral palsied child has siblings. She also confirms what others have stated, that unbalanced attitudes can be found even when the handicap is comparatively mild. "In fact," she concludes, "cerebral palsy in any degree can be seen to create emotional problems for the parents, but especially for the mother." Each situation is thus a family complex, in which each member of the family becomes involved.

The increased dependence of a handicapped child on his mother is a factor which has been particularly associated with the emotional problems of the parents. Crothers (1951) has stated that many of the emotional difficulties of handicapped children are due to the fact that the mother-child unit, which is obligatory in pregnancy and desirable in infancy, cannot be abandoned at the usual time. Bender (1949) makes this point in relation to brain-injured children in general, pointing out the

increased need of such a child for motor support, with regard not only to locomotion, but also to speech, feeding, and dressing. As a result highly intense dependency relationships may be established.

Amongst the few empirical investigations which have been directly concerned with this problem, that of Shere (1954) is particularly noteworthy, for she studied 30 cerebral palsied children and their non-handicapped twins. From her observations she concluded that the personality differences found in the sample emanated from the relationship with the parents rather than from intrinsic factors within the cerebral palsy itself, though cerebral palsy was the factor which disturbed the parent-child relationship. The most striking finding of the study was the differing attitude adopted by the parents towards the handicapped and the normal twin respectively. Parents tended to over-protect the cerebral palsied twin, making him the central figure in the family, whereas they tended to expect the normal child to assume more responsibilities and to act in a more mature manner than consistent with his capacities. As a result the normal child was more stubborn, excitable, jealous, and less cheerful than the handicapped twin.

Although Shere's results would appear to indicate that emotional upset is to be found in the siblings rather than the cerebral palsied child himself, her main point confirms that made by others, namely that cerebral palsy affects the whole family and that it is the parental attitudes within this group that determine the child's adjustment. Another investigation which also found itself led to the study of parental attitudes as the crucial factor is that briefly reported by Williams (1959). This author examined the Rorschach records of 32 cerebral palsied children, aged $8\frac{1}{2}$ to 11 years. When divided into prognostically good and prognostically bad records, comparisons with the case history indicated that the most important single factor influencing personality growth was the quality of parental acceptance of the child. Those who were genuinely accepted managed, despite perceptual disabilities to make the step forward to concept formation in a way that remained blocked to the others. This finding is particularly significant, for it shows how emotional factors can influence even purely cognitive

functions. Increasing recognition is now also given to the fact that progress in the physical field depends in the same way on the total personality of the patient treated. Cooper (1954), for instance, speaking from his experience of 1,500 cerebral palsied patients, believes that the success or failure of medical treatment procedures depend largely on factors other than the physical management or even the degree of physical involvement, listing among these factors social deprivation, emotional disturbance, and limitation of experience.

One further investigation which concerned itself with the parents of cerebral palsied children is that undertaken by Sykes (1958). In describing some of the problems facing the 31 families in her project, she gives special attention to such difficulties as the feeling of social ostracism, the reactions of siblings, the greater fear of mental handicap as compared with physical handicap, and the decision to restrict the family unit after the birth of the cerebral palsied child. Sykes felt that parents were generally able to adjust to the physical handicap, even where severe, once expert advice had been obtained, and that by far the larger problem was the need to understand and help the child as a growing personality. On the whole she considered that in those cases where harmonious and mutually supportive relationships existed in the family the situation of the cerebral palsied child could be faced more successfully than in the rest.

Conclusions arising from review of literature.

Several conclusions suggest themselves from this review of psychological studies of cerebral palsy.

In the first place, it is clear that a considerably greater number of formal research studies have been undertaken in the cognitive field as compared with those concerned with social-emotional aspects. The reasons for this discrepancy have already been mentioned, yet the methodological and conceptual problems which have been encountered can only be solved in the course of further work. The need for more studies of the social and emotional development of the cerebral palsied child, even on a purely descriptive level, is therefore evident.

Secondly, there is an increasing awareness of the fact that one must

deal with the patient as a whole and not with separate symptoms, functions, or disabilities. This recognition parallels a general trend in medicine to view each condition in relation to the whole individual, that his life situation and various intra-psychoic factors may well be relevant to the aetiology and treatment of a physical disease. Moreover, it parallels a trend in psychology itself to deal not merely with isolated systems (perception, motivation, emotion, etc.), but to recognise the influence of these systems on each other and to view them as interlinked parts of a whole. Emphasis is thus thrown on the total personality as context for the study of the various functions of the organism.

In some respects, however, even the concept of personality may provide an artificial unit of study, for the individual must be seen in relation to his social milieu. This is a point which both clinically oriented accounts and research reports have emphasised repeatedly, and it is a point which emerges particularly from the studies reviewed above. That personality development is to a considerable extent a function of parental attitudes is now universally accepted, yet the presence of a congenital defect appears to highlight this situation, for the incidence of extreme pathological attitudes appears to be so much greater, that studies concerned with this type of influence are more likely to provide clear-cut results.

It follows that if one is to understand the adjustment of the cerebral palsied child one must also understand the reactions of those with whom he comes into closest contact during his early and formative years. It is for this reason that attention has been given not only to the effects of cerebral palsy on the individual child thus afflicted, but also to the effects on his parents and, in one or two studies, on his siblings. The developing personality must be assessed in relation to the emotional atmosphere surrounding the child, and the focus of study thus becomes the family group of which the child is one member. As the present writer has put it elsewhere (1958): "Psychologically speaking, cerebral palsy is in the first place the problem, not of an individual, but of a family."

This viewpoint provides the basis for the investigation to be reported here. Instead of regarding the child as an isolated unit, we shall study him in the context of his immediate social environment, i.e., his family, and to do so we must assess the functioning of the family as an organised group when under the impact of cerebral palsy. Having thus defined our area of concern, we must now formulate some means of studying it, and towards this end one would normally examine the existing literature for clues and guide posts. Unfortunately, as we have just seen, there are still so few studies with similar aims to our own that we can get but little help here, and our only alternative is, therefore, to widen our viewpoint. This may be done by regarding the advent of a cerebral palsied child in the family as a potential source of stress, in that it is an unexpected event which confronts the family with a situation quite outside its normal patterns of adjustment. In this way a link is provided with the rather more voluminous literature on the effect of stress on the family, and though the forms of stress studied have generally been of a very different nature from that studied here, a review of the relevant literature should help us to set the present investigation in its proper context and to direct our attention to significant areas and concepts.

C H A P T E R 3

FAMILIES UNDER STRESS: THE LITERATURE

Nearly all the studies which have concerned themselves with the impact of stress on the family have been carried out in either a sociological or a clinical context. Rarely have the two been combined. Most of the sociological studies have investigated the impact of some external event (poverty or war, for instance), whereas clinically oriented studies have generally been concerned with stresses arising within the family, such as those stemming from the failure of one of the family members due to physical or psychiatric illness. The distinction according to source of stress, external or internal to the family, provides a useful means of classifying these studies.

The economic depression which occurred in America in the 1930's with its consequent poverty and unemployment for some and financial insecurity for others, provided the opportunity for several sociological studies of the reaction of families to such hardships. That by Angell (1936) was the earliest of these, and as such set a pattern followed by most subsequent investigators. In describing the reactions of 50 families to the financial crisis of lowered income, he was particularly interested in the individual differences that existed in these reactions, and attempted to isolate the factors which were responsible for the greater ability to adjust successfully on the part of some families faced with, objectively speaking, as great a crisis as other families that failed to adjust. His conclusion was that the vulnerability of the family appeared to vary inversely with its integration and adaptability, that the more integrated and adaptable a family the better its resources to meet a financial and economic crisis. These two concepts of integration and adaptability were more or less intuitively arrived at from a general description of various family characteristics. Integration was defined by Angell as "the bonds of coherence and unity running through family life, of which common interests, affection, and a sense of economic inter-dependence are perhaps the most prominent," while adaptability was regarded as "the capacity to meet obstacles and shift course."

It is interesting that Cavan and Ranok (1938), in a survey of 100 families and their reactions to the economic depression, independently reached somewhat similar conclusions. They too found considerable individual differences in reaction, which could not be explained on the basis of the severity of the external pressures, but which the authors claim to be associated with the adequacy of organisation of the family. They give three criteria for a well-organised family: (a) a high degree of unity, which is evidenced in the unity of family objectives, the subordination of personal to family goals, unity of family ideals and the degree to which family members find satisfaction for their interests within the family group, (b) reciprocal functioning of members, i.e., complementary roles, and (c) a definite function in the larger community. Adjustment or failure to adjust was shown to have both social and psychic consequences: on the one hand there were changes in family roles, standards, and objectives, and on the other hand there were nervous breakdowns, anxiety, and suicide attempts. Rarely, however, did the crisis cause completely new reaction patterns. Rather, it caused an exaggeration of previously existing family and personal habits: the man who occasionally drank began to drink to excess, or the family that was harmoniously organised became more unified.

Another, somewhat similar study, was that by Koos (1946). He investigated the "troubles" of 62 low-income families in New York, and the way they met such troubles. The families were observed over a 2-year period, during which frequent contacts were made in unstructured interviews. "Troubles" were regarded by Koos as all situations which "create a sharpened insecurity or which block the usual patterns of action and call for new ones," and again economic and financial crises were prominent here. Koos was especially interested in the effects of these crises on the internal relationships of the family, and here made use of a concept which has been found to be particularly useful in this type of research - the concept of role. Starting from the premise that the family succeeds, as a family, largely in terms of the adequate role performance of its members, he pointed out that one of the major effects

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of crises was to cause changes in these role patterns. "As the role performances change, as the individuals concerned do not live up to the expectations of other members of the family (or in some cases surpass these expectations), the usual patterns of action are distorted or abolished, and the family finds it necessary to work out new patterns." Koos, like the other investigators already mentioned, also found considerable differences within his sample as to ability to meet crises, and he too linked it to the already existing adequacy of family organisation. The family that was relatively trouble-proof was described by him as having a strong role-structure, with acceptance by each member of his role, as being willing to accept some common definition of the good of the family in preference to the good of the individual members, as providing satisfaction for the members within the family unit, and finally as having a sense of direction and thus being a "going concern." These criteria are concerned only with intra-family relations and not with the functions of the family in the community. It was found, however, that if a family had an adequate intra-family organisation its relation with other families would also be adequate. Yet Koos later goes on to say that the families which he ranked as being below average in organisation suffered least displacement of their inter-family contacts (as these were generally with similar types of families), while the better-than-average families felt the troubles more keenly and as a result withdrew from most contacts with the outside world and kept very much to themselves. There was marked correlation between withdrawal from friends and withdrawal from organisation activities. These statements appear to be contradictory; on the other they draw attention to an aspect which other studies have tended to neglect, namely the effect of stress on the pattern and amount of community participation of the family. Angell (1936), for instance, had merely touched on this problem, describing how some families tend to withdraw in the face of "shame" and become more than ever closed systems, whereas others become quite unbuttoned in their open-door policy.

A rather different type of stress was examined by Hill (1949), and also a somewhat different methodology was used in his investigation.

The stress in this project referred to the effects of war, with particular reference to the effects of the separation of the husband from the rest of the family. A much larger sample was used, contacts with the families were much fewer and less intensive than, for example, in Koos' study, and attempts were made to quantify the information obtained by the administration of information schedules and questionnaires and by the use of scales to measure various relevant dimensions. Although many of the correlation coefficients thus obtained are of an unimpressive size, and although one wonders how far the particular approach used did not sacrifice the validity of the data collected to its quantifiability, the author did reach certain conclusions. Amongst these the most outstanding refers once again to the individual variability within his sample. Although Hill agrees that the number and severity of the hardships attendant on the crisis influenced the adequacy of the family's adjustment, he believes that the most important factor is in the manner in which the family defines the situation. Both in the present study and in a subsequent theoretical article (Hill, 1958), he distinguishes three variables which determine whether an event becomes a crisis for any given family: the hardships of the event itself, the resources of the family, and the definition the family makes of the event (i.e., whether family members treat the event as if it were or were not a threat to their status, their goals, and their objectives). This third factor is regarded as an intervening variable and can only be inferred from the effects produced by the event. On the other hand the second factor, the resources of the family, was directly measured, and Hill concluded that family integration, family adaptability, and marital adjustment constituted the most important statistically identifiable factors making for successful adjustment to crisis in his investigation. Finally, he attempted to view the adjustment process to the crisis longitudinally, and concluded that a roller-coaster type of profile could be discerned, in that the impact of the stress produced an initial period of disorganisation, which was followed by a stage of recovery and trial-and-error modes of adjustment, and this in turn was succeeded by a phase of reorganisation.

These studies illustrate the kind of approach used by sociologically oriented workers and the concepts favoured by them. Turning now to the stresses originating mainly within the family itself and thus to the more clinically oriented studies, we find here a greater preoccupation with the interaction of three levels of study: that of the family group as a whole, that of the interpersonal relationships within it, and that of the personalities of the individual members of the group. This is especially apparent in the work of Ackerman (e.g., Ackerman and Behrens, 1956 and 1957), whose aim has been to understand the integration of the emotionally disturbed child with the psychosocial structure of the family. The stress here takes the form of the individual family member (a child) with socially undesirable symptoms, and Ackerman has attempted to establish criteria for carrying out "family diagnosis", which would enable one to correlate the pathology of the individual with the pathology of the family unit. Ackerman's thesis is that the family is the cradle of personality, that it has power to enhance or impair the mental health of the individual, and that for each case one must therefore establish how the interaction processes of the family affect the development and behaviour of the individual and conversely what influence the individual has on the family. This formulation is in many ways highly appropriate to the present investigation, but unfortunately Ackerman's discussion remains on a theoretical and discursive level, and he fails to present a schema and methodology which would enable one to carry out "family diagnosis". His presentation of seven types of family structure, each related to the child's personality adjustment, is arrived at on an a priori basis and would make the classification of other cases by other workers most difficult.

Although studies of the families of mental patients have frequently been carried out, they have mostly aimed at tracing the aetiology of the illness, and few have attempted to analyse what happens within the family group when a member develops a mental illness. Clausen and Yarrow (1955) report a study in which the impact of such a situation was investigated in 33 families. From intensive interviews with the wives of the patients they traced the wife's initial reactions to the manifestations of the illness, the manner in which professional help was sought, and her attempt

to reconstruct the psychological future. Relevant to our present interests were the authors' efforts to trace the effect on patterning of relationships with the family, and on the wife's orientation towards other people, both within and outside the family. The findings highlight the drastic changes which overtook the wife's role in both these areas, and comparison is made between the family under the (felt) social stigma of mental illness and certain minority groups threatened by their "not-belonging" feelings.

A number of other publications have also discussed the impact of the psychiatrically ill individual on his family. Rapaport and Rosow (1957) point out that psychiatric illness leads to failure in family role, especially when the failure concerns a supportive role. They maintain that the role failure depends not only on the individual's personality, but also on the way in which the personality interacts with the personality needs of the other family members. A similar point is made by Morris (1958), who found that the psychiatric illness of one member of a family presented a distinct social problem to the rest of the family, in that the balance of interpersonal relationships in the group was disturbed by this crisis. Although many families will deny that this is so, the fact may be observed in a variety of ways, ranging from the changing perceptions and tolerance of the patients' behaviour to subtle changes in the performance of different members in their social roles.

A very different type of study is that undertaken by Farber (1959), for here an attempt is made to use a much more rigorous methodology and far larger numbers. Farber set out to describe the effects of a severely mentally retarded child on family integration: a situation closer to that investigated here than any other type of stress as yet described in the literature. 240 families with a mental defective child of 16 years or under formed the sample. Each family was visited by two research workers simultaneously, who interviewed husband and wife separately. The interview consisted in part of a structured series of questions, and in part of a questionnaire of the multi-choice kind. A statistical analysis was then prepared in which age, sex, social status, and institutionalising of the child were used as independent variables,

and marital integration and sibling tension were regarded as the dependent variables. The effects of community attitudes were also investigated. Viewing the family as a system of triads, each triad representing a mother-father-child relationship unit, Farber argued that the mother-father components are common to all triads in a family, as it is primarily through the parents that the children affect each other. The core of family integration is thus the marital integration, and it is the latter which is therefore specifically examined in this study. This integration is regarded by the author as consisting of two factors: the consensus of its members as to domestic values, and a lack of role tension in the interpersonal relationships between family members. Accordingly, his index of marital integration is based on the degree of consensus in the rank order of 10 values, the ranking carried out separately by husband and wife, and their ratings of personality items referring to interpersonal tension. The index of sibling role tension was obtained from the mother's rating for each normal child on ten personality traits.

The results of this study reflect to some extent the complexity of variables found in such a situation, and it is perhaps not surprising that, as in Hill's project, the statistical indexes reflect only tendencies and do not permit firm conclusions. Thus Farber found that marital integration was more affected when the mental defective child was a boy than a girl, this being especially so in lower-class families, but not applying when the child was in an institution. There was little difference in the marital integration between parents with a young defective boy at home and a young defective boy in an institution, whereas those with an older boy at an institution had a higher integration score than those with an older boy at home. There was thus greater effect with increasing age of the boy. Among non-Catholics, parents with a defective son at home were more affected than those with a son in an institution, but this difference was not found amongst Catholics. Marital integration did not vary with amount of church attendance, but was adversely affected by high interaction between the father and his own mother. On the other hand, frequent interaction between the wife and

her mother was associated with high marital integration. Men who were active in formal organisations were found in marriages with lower integration, but this was not the case with women. As far as sibling tension scores were concerned, the defective child's sex and the family's social status made little difference to adjustment of normal siblings. The normal sister was helped by placing the mental defective child in an institution, but this did not affect the normal brother.

Clear-cut generalisations are not easy to make on the basis of these findings. It is, however, worth while quoting Farber's view that the presence of a mentally defective child can be regarded essentially as a factor in the arrest of the family cycle. With normal children parents continually redefine their roles, obligations, and values to adjust to the changing roles of the child. With mentally defective children the parental role is fairly constant, for regardless of birth order the defective child eventually becomes the youngest child socially. Thus the family becomes arrested in the preadolescent stage of its life cycle, and this affects both the domestic and the community life of the parents. Moreover, all triads in the family will be affected, for any marked change in the role of one member of a triad (the defective child, for instance) will necessitate an adjustment of roles of the other members (the parents, who form the common factor in all the triads).

Comments.

The above studies on the family under stress illustrate some of the trends in this area. There is considerable variation in the type of stress investigated, the size of the sample used, the clinical and methodological sophistication, and the theoretical assumptions underlying the work. Nevertheless, certain generalisations emerge which may be regarded as relevant to the setting up of the present project.

In the first place, there is general agreement among all writers that the degree of severity of the stress impinging on the family cannot by itself explain the degree of reaction. There are wide individual differences to be found in the response to what objectively may be regarded as the same stressful situation. One consequence of this is methodological: it is less useful to investigate the difference between

an experimental sample of families under stress and a control group of families that have not come up against this particular stress, than it is to study the fluctuations within the former group and to investigate the manner in which individual differences manifest themselves and the conditions with which they are associated. The other consequence is that, in order to account for the differences, it becomes necessary to hypothesise intervening variables. A number of these have been suggested: the "meaning" of the crisis to the family, its previous experience of crises, the supportive or non-supportive attitude of the community, and the adequacy of the family organisation (its crisis-meeting resources, as Hill (1958) calls it).

The use of this latter concept, however, brings up another problem, namely the extent to which it is possible to have recourse to historical explanations in this type of research. The adequacy of family organisation generally refers to the condition of the family before the crisis - thus both Angell (1936) and Cavan and Ranck (1938) have stated that a family that is well organised before the crisis tends to be relatively invulnerable. Similarly Farber (1959) attempted to measure the degree of marital integration that existed before the arrival of the mental defective child and relate this to his consequent variables. Of necessity, however, this procedure involves a retrospective approach, for access is not usually gained to a family until it has come up against a crisis. The assessment of its pre-crisis condition will then in all likelihood be highly influenced by its present state, and correlations found will thus be affected by the lack of independence in the assessment of the two situations. Rather than attempt such a before-after comparison, an a-historical approach would appear to be indicated, where the focus of study is the analysis of the here-and-now situation and comparison is made between co-existing variables and not between historically successive conditions.

When one considers the nature of the variables which may be selected for study in this manner, the existing literature is most useful as a guide. There are certain areas to which attention has been drawn by many of these studies and which yield a greater sensitivity in the face of stress than other dimensions. Amongst these one may mention

the dominance pattern within the family, the marital adjustment, consensus as to domestic values, the relative balance of task-related activity and expressive behaviour (Klein, 1958), the cohesiveness of the family group as a whole, and the degree and type of its participation in community activities. It may be noted, however, that apart from rather discursive discussion in some of the more clinically oriented papers, little attention has been paid to the association between these group phenomena on the one hand and phenomena occurring either on the interpersonal or the individual level on the other hand. Almost no empirical data can be found which attempt such an integration, apart from such scattered and not well-documented references as that by Angell (1937), that changes in parent-child relationships occurred as a result of stress in the less well-integrated families, or the finding by Cavan and Ranck (1938), that psychiatric symptoms tended to accompany social disintegration. The plea made by Schroeder and Burgess, in their introduction to Cavan and Ranck's (1938) monograph, that a joint effort should be made by psychologists and sociologists to systematically analyse family relationships and thus establish how individuals are integrated into the family structure, has still not resulted in any empirical, systematic investigation, though Parsons and Bales (1956) have presented a theoretical schema which aims to make such an integration possible. Kerr's (1958) study perhaps comes nearest to a rapprochement between social and psychological levels of analysis, but in the field which we have been surveying there has been little concern with the mutual influence of family and individual.

One final generalisation emerges. Increasing interest has been shown in the possibility of conceptualising the process of stress and the reaction of the family to this impact, and this has involved a most useful integration with general sociological and social psychological theory. This applies particularly to the nature of the family itself, with regard to both its internal and external characteristics, and also to its function as a socialising agent. Some of the concepts that have been found useful in research on the family under stress, as for instance

those of role and cohesiveness, have also been discussed and used in other fields, especially in the experimental study of small laboratory groups. An examination of these concepts is necessary before they can be used, and in the following chapter we shall therefore attempt to set up a conceptual framework within which the study may take place.

CHAPTER 4.
CONCEPTUAL FRAMEWORK

The claim has often been made by sociologists that the family, through being a small group, provides a very simple social system and that the study of its functions and structure encounters relatively clear-cut phenomena. In relation to other social systems this claim may be justified, yet the predominant impression gleaned from a study of the literature on the family, in both its sociological and its psychological setting, is one of complexity of variables, of differences in approach and terminology, and of the variety of aspects that may be studied.

It is a curious reflection that until recently we knew a great deal more about the family systems of remote and primitive cultures than about the type of family organisation encountered in Western civilisation. The reason probably lies in the fact that the family system is so basic to our way of life that it tended to be taken for granted and had therefore not aroused scientific curiosity. It was not until considerable anthropological material had accumulated and been absorbed that the need for comparative study with our own culture pattern of family organisation began to be felt by social scientists, so that gradually it was recognised as important to carry out field studies in the East End of London or in a Liverpool housing estate as it had been to send out research workers to New Guinea or to West Africa. There was, however, also another influence at work, namely the growing social conscience about the "broken" and "problem" families in our midst. Just as, on the level of the individual, psychopathology has provided access to the study of the normal personality, so the family in need of help has given us the opportunity to examine the functions of the modern family, to list its activities and needs, and to study the variability to be found within our culture.

Both the form which the family takes and its function in the community tend to vary considerably from society to society. This is by now a well documented fact, but it is also agreed that in our own culture the family has been undergoing certain marked changes within the last few generations. It has, on the one hand, lost certain of its functions (economic, protective, recreational, educational, etc.), most of which have been taken

over by more complex social organisations, and on the other hand the remainder of its functions have been concentrated far more in the hands of the "nuclear" family, to the detriment of the ties holding together the "extended" family. Thus the nuclear family (i.e., the married couple and its children) has become the most fundamental unit in our social life, and it is to this unit that the term "family" will refer in the remainder of this report.

The family is essentially a small group of interacting individuals, each of whom occupies a particular social position in this group, defined by age and sex, the name of which (father-husband, mother-wife, son brother, and daughter-sister) reflects the interrelationships of these positions. A number of social positions related to each other may be said to form a social system, and the type of interrelationship defines the structural properties of the system. In the case of the family the social structure is easily defined, depending on the presence of both parents and on the number of sons and daughters they have. The social scientist is, however, not merely content to study the structure of a social system, but is also concerned with its functions, and here the range and variability to be found is infinitely greater and more difficult to define. The functional aspect of a social system must be related to the activities which the individual members carry out in virtue of their occupation of certain positions within the system, and to help one in the task of defining these activities the concept of role has been developed.

This concept is one of the most fundamental and frequently used in social psychology and sociology, and as it will frequently occur in the present report, it is appropriate that some attention to its usage should be given. More than any other writer Linton (1936, 1945) did much to popularise the usage of this term. In his definition he linked it to the concept of status (which he used in the sense that social position is used here). Thus statuses are "the polar positions in ... patterns of reciprocal behaviour. A status, as distinct from the individual who

may occupy it, is simply a collection of rights and duties." (1936). "A role represents the dynamic aspect of status ... When the individual puts the rights and duties which constitute the status into effect, he is performing a role." (1936). The linkage between status (or social position) and role has been preserved by most authors, but differences have arisen as to the most useful definition to be attached to role. Gross, Mason, and McEachern (1958) distinguish three categories of such definitions. There are, in the first place, those which equate the concept of role to normative culture patterns. The above quoted definition of Linton is an example of this class, and an even more explicit one is that by Bennet and Tumin (1958), who regard role as "what the society expects of an individual occupying a given status." Another category contains those definitions which treat role as "an individual's definition of his situation with reference to his and others' social positions." Sargent (1951), for instance, says: "A person's role is a pattern or type of social behaviour which seems situationally appropriate to him in terms of the demands and expectations of those in his group." In the third group finally are those definitions which stress the actual behaviour of an individual occupying a certain social position, as seen in Newcomb's (1952) reference to role as "the behaviour of the occupants of a position - not to all their behaviour, as persons, but to what they do as occupants of the positions."

The fundamental difference between these definitions appears to concern the phenomena to which they actually refer - whether these are the expectations (generally culturally defined) which others have of those occupying a certain social position, or whether they are the actual activities and behaviour performed by an individual in virtue of his occupancy of a social position. This is an important distinction in any investigation concerning roles, as it will determine the direction of one's enquiries, and as long as the distinction is clearly made it is an arbitrary matter whether the term role is used for the one or the other. As in this investigation we shall be dealing with what people actually do as position occupants rather than with what they are expected to do, it is proposed to limit the term role to the behaviour of an individual

occupying a certain social position, and use the term role expectations for the definitions assigned by other people to the behaviour linked to a social position.

The difference between social position and role now becomes clear. The former is essentially a structural concept, while the latter represents the dynamic aspect attached to a position. Role refers to the actual functions performed by the individual position occupant, and as such may reflect factors other than the requirements and stipulations of the position itself. An individual holding the social position of, say, army officer will in certain situations (the parade ground, for instance) perform a role that is rigidly tied to his position and invariable as between different occupants of the same position; whereas in other situations (as on the battlefield, for example) the role adopted by him will depend on many other factors and thus be much more flexible and prone to idiosyncratic differences.

The same distinction also applies to the family roles. In some societies the role played by any given occupant of a position within the family group will be completely defined by the position itself, and this rigid delineation of duties will thus deprive the individual of the exercise of choice or of the opportunity to express idiosyncratic tendencies. In such a case the terms role and position are virtually equivalent. In our society, however, there is no such closely agreed definition of role playing attached to any of the family positions, and individual differences between various occupants of the same role are therefore far greater. It is true that certain cultural stipulations are still widely accepted - thus the father-husband is generally the breadwinner who goes out to work, while the mother-wife is responsible for home making and for bringing up the children. A family where these roles are reversed would generally be regarded as deviant. On the other hand, there may be considerable overlap in these roles - most husbands not only help in bringing up the children, but will also regard it as their obligation to perform certain household duties, and similarly many married women go out to work nowadays and will assume equal status as decision makers in family affairs. Role patterns are subject to temporal changes, but even within one and the same generation the differences that exist between families in this respect are striking.

This is made clear by Bott (1956) in her analysis of conjugal roles - even in her small sample of 20 families the extent to which husband and wife carried out tasks and activities separately from each other varied considerably, ranging from a sharp division of labour between the couple to very great overlap in their performance of roles. This indicates that the cultural norms attached to the various family roles are so vague, that personal needs and preferences can fairly easily be catered for and that the role system of a family will therefore yield a relatively sensitive indicator of events impinging on the family: a fact of which advantage has been taken by students of the effects of crisis and stress on the family, and which will also be used in this investigation when the variability in role patterns as between the different families of the research sample will be investigated. If the roles of the various family members had been so rigidly laid down by custom that no variability existed, an opportunity would not have been held out to the research worker to use this area in his search for suitable dependent variables that will reflect the impact of external events. As it is, however, the ambiguity attached to the enactment of these roles enables one to study the effects on this system under varying conditions.

The family, then, may be regarded as a small social system, the structural properties of which are given by the positions held by the group members. These positions are generally clearly defined by age and sex, and in virtue of these positions members play certain roles, the nature of which varies to some extent as between different individual occupants of the same social position. The family can, moreover, like all other social systems, be studied from two points of view: It can either be seen from the point of view of its constituent members and their relations to each other, or it may be regarded as a unit which is in interaction with other social systems and agencies. These two points of view refer respectively to internal and to external relationships, and we shall now proceed to discuss certain aspects of each of these areas which are of particular significance to this investigation.

Internal aspects - cohesiveness.

When one examines the relationships of the members of a group with one another there are many aspects that may be isolated for study. Our review of the literature of the family under stress has, however, drawn attention particularly to one aspect as being sensitive to the impact of crisis, namely that characteristic of a group which has been variously referred to as cohesiveness, solidarity, unity, integration, and even "sticking-togetherness." We shall use the first of these terms, cohesiveness, for it is this term which has been preferred in the literature dealing with psychological experiments on small groups, and we can thus underline our conviction that such laboratory studies may often throw light on the functioning of "real" groups like the family. This probably applies more to cohesiveness than to any other group characteristic so far studied, and we shall therefore briefly examine some of these studies in order to clarify the usage of this concept.

The literature on cohesiveness may be said to fall into three main groups: those studies concerned with the nature of this concept and its scientific usage, those dealing with its determinants, and those dealing with its consequences. Most of the work has been carried out on the consequences of varying degrees of cohesiveness - largely because of the stimulus given by one particular series of studies, namely those which have emerged from the University of Michigan by Festinger and his co-workers. In an investigation of the friendship groups formed in a housing project, Festinger, Schachter, and Back (1950) showed that the more cohesive the group the more uniform the behaviour of its members on issues relevant to the group as a whole is likely to be. This consequent, the "power" of the group over the individual, has been further explored in a number of laboratory studies (e.g., by Back (1951), by Berkowitz (1954), and by Schachter et al. (1951)), all of which have indicated what must now be regarded as one of the best established characteristics of cohesiveness, namely that the degree of uniformity in the behaviour of individual group members tends to be correlated with the degree of cohesiveness of the group as a whole, and that the more effective the influence of the group the fewer will be the number of deviates within it.

Amongst other consequents that have been investigated is that of hostility and its expression both within the group and outside it. From such studies as those of Wright (1943) and of Pepitone and Reichlinger (1955) it appears that the relationship between cohesiveness and the expression of hostility towards outsiders is likely to be a complex one and dependent on a considerable number of variables. The relationship between cohesiveness and intro-group hostility is, however, a close and indeed, as Newcomb (1951) suggests, a circular one: the more cohesive a group the more members will tend to like one another and thus avoid conflict within the group, and the greater the degree of personal liking the greater the degree of cohesiveness. This no doubt explains the relationship suggested by Seashore (1954) between membership of a cohesive group and the mental health, feelings of security, and reduction of some forms of anxiety in the individual members. The personal adjustment of the individual in relation to groups of varying cohesiveness is, however, a condition which has as yet received little attention in empirical studies.

Rather less has been done on the determinants of cohesiveness, and most investigators have been content to manipulate the degree of cohesiveness in a rather arbitrary manner by, for instance, telling individual subjects that they will like the other members of the group to which they have been allocated. That one of the determinants of a friendship group may simply be physical accessibility was demonstrated by Festinger et al. (1950), but on a more general basis these same authors suggest that two main types of determinants can be distinguished - one being the attractiveness of the group, i.e., the extent to which the group is a goal in itself and has positive valence as such, the other being the "means control" of the group, i.e., the extent to which the group mediates goals which are of importance to the members. Thus the greater the valence of the group and the greater the number and importance of the goals mediated by it, the more cohesive the group will be. Back (1951) put this in a somewhat different and more concrete form when he distinguished three factors: personal attraction between members, an attractive activity mediated by the group, and the prestige of belonging to the group.

Another suggestion has been made by Gross (1956), who distinguished between two sets of determinants: symbiotic ties and consensual ties. In the former case people cohere as a group because of interdependence of needs, whereas in the latter case they are held together by agreement and their group therefore tends to be marked by like characteristics.

Of special interest are those studies which have concerned themselves with the effect of stress on the cohesiveness of the group. We have already drawn attention to the study of this factor in relation to the family, but unfortunately there appears to have been little mutual influence between this type of investigation and those occurring under laboratory conditions. As in the former, the main issue in the latter has been the extent to which stress produces changes in the cohesiveness of the group and the direction in which these changes take place. Durkheim (1897), in his famous work on suicide, had originally suggested that group integration increases during a crisis. The experimental studies which have followed up this suggestion have, however, reached rather contradictory conclusions. Lanzetta (1955), for instance, found that in his groups there was an increase in cohesiveness with stress, that group-oriented behaviour tended to increase under such conditions. Hamblin (1958), however, has suggested that such an increase may only take place when the available solution depends on the cooperation of the group members, and in an experiment showed that group integration actually decreases when no solution at all is available. The relation between cohesiveness and stress is therefore no simple one - a point further emphasised by the study of Pepitone and Kleiner (1954) involving groups of boys under graded threat (the threat being loss in group status). In this case the writers find that cohesiveness is an inverse function of the expectation of status loss, i.e., as threat is reduced cohesiveness increases. They rightly add the warning, however, that this finding may well apply only to the particular conditions described, where the group members perceive each other as responsible for reduction in status. We must conclude that stress has been shown by these studies to be associated with changes in cohesiveness, but that the direction of

the change depends on the nature of the stress and probably also on a number of other associated conditions. This reinforces the conclusion reached after our review of studies of the family under stress, namely that the individual variability to be found, even when the stress situation itself is held constant, shows reactions to be multi-determined.

As to the nature of the concept of cohesiveness and its scientific usage, considerable controversy has taken place in the literature, as a result of which it has been shown that this is by no means a simple and uncomplicated issue. Of the many general definitions that may be quoted, that by Bales (1954) is perhaps the fullest: cohesiveness (or solidarity, as Bales calls it) consists in an obligation and a right: the obligation to identify one's self cognitively, affectively, and conatively with the other, to perceive one's self as part of a larger whole, to feel the other's concerns as one's own, to cooperate with the other, to share the other's fate; and the right to expect these attitudes and actions from the other. Definitions couched in such terms do not, unfortunately, make it easy to assess this phenomenon in an empirical investigation, and indeed one of the main points of controversy concerns the gap between the nominal and the operational definition of cohesiveness. Festinger et al. (1950), using a Lewinian framework, defined cohesiveness nominally as the total field, or resultant, of forces acting on members to remain in a group, or, in other words, as the attraction of a group for its members. Gross and Martin (1952) have, however, severely criticized Festinger for failing to use an operational definition of cohesiveness which adequately represents the nominal definition. They point out that only one of the possible total number of forces is used to measure cohesiveness in his study (namely a sociometric index of friendship choices), and that this is chosen on a priori grounds. Both Gross and Martin (1952) and, in a subsequent study, Eisman (1959), substantiate this criticism by showing that the correlation coefficients obtained between different operational measures of the cohesiveness of the same groups fail to reach statistical significance. Using one single index of cohesiveness is therefore unreliable when other equally relevant indexes are not highly correlated with that measure on the same group.

The difficulty here is once again that of the multi-determined nature

of cohesiveness. From this point of view cohesiveness cannot be regarded as a unitary concept, and, as Eisman (1959) suggests, would have to be measured, not by one, but by a composite of several instruments. Gross and Martin, however, rightly point out that it is unlikely that one can ever define the total field of forces determining attraction to a group. Their suggestion to solve this problem is to disregard the specific reasons for the valence and simply place each of the members of the group on some point of a continuum from "very great attractiveness" to "no attractiveness." Then the most logical operational definition is to ask each member to indicate how attractive the group is by responding to a series of categories from high to low or to indicate his place on a linear scale. This would allow the respondent to utilise his own frame of reference rather than impose a highly questionable single index developed a priori by the investigator. We shall later discuss how this argument bears on the attempt to assess cohesiveness in a family group.

Gross and Martin raise one further important point when they criticise the Festinger definition as being an additive conception of the phenomenon, i.e., a group characteristic is viewed in terms of the sum total or average of the perceptions of its individual members. In fact, Gross and Martin's own suggestion falls into the same category, and perusal of the literature indicates that nearly all studies have dealt with this phenomenon on an individual level. For this reason attention should be drawn to a useful distinction made by Bergen and Knockebakker (1959) and by Newcomb (1951). The former authors suggest that cohesiveness should be reserved exclusively for group phenomena, and that it would be more advisable to use a quite different term for its expression on an individual level. They suggest "attraction-to-group" for this purpose. Similarly Newcomb (1951) has made a distinction between cohesiveness and belongingness, using the latter term for the attraction which the individual member feels for a group. The two concepts are, of course, related, as Newcomb (1951) points out: a group becomes more cohesive as belongingness increases on the part of more of its individual members. The larger the proportion of members whose belongingness increases, the

more cohesive a group becomes."

Cohesiveness is, then, a function of individual belongingness. It is essentially a group characteristic, but it is determined by the activities of the individual members of the group. Festinger was right in pointing out that cohesiveness is the resultant of many forces, for even within any one individual member belongingness is the function of a number of different motives. With Gross and Martin's criticism, however, that cohesiveness cannot be measured by selecting any one of these forces, one must also agree - just as intelligence cannot be reliably assessed by merely measuring the ability for immediate recall of digits. Moreover, as in the case of intelligence testing, some way must be found of pooling the observations of individual items, so that inference can be made from combined individual behaviour to the group phenomenon. To assess the group phenomenon directly, as is implied in Gross and Martin's suggestion, by observing some accomplishment of the group, is unsatisfactory because it introduces a circular argument: cohesiveness would then be inferred from its effects, which in turn are explained by cohesiveness.

We must conclude that cohesiveness is a highly complex concept. Though the "common-sense" recognition of groups at the extremes of the cohesiveness continuum is fairly easy, more accurate assessment and analysis are likely to follow only considerable more empirical work, even though somewhat make-shift formulations will have to be used in the course of such work. We shall return to these problems in our discussion of the assessment of cohesiveness for the purposes of the present research.

External aspects - community participation.

When we turn to the relationships of the family group to outsiders, we encounter once again a number of phenomena that might lend themselves for study in a project dealing with the effects of stress. Amongst these one might mention the pattern of external relations, the types of individuals or groups with whom there is interaction, the motivation behind the interaction, its affective tone (hostility, for example), and the sheer amount of such interaction. To some extent all these are relevant, but suggestions in the literature on the effects of stress on

on the family, that some families under these conditions become socially isolated whereas others become quite "unbuttoned" in their external relations, draw our attention particularly to the last mentioned of these aspects. This variable will be referred to henceforth as the amount of community participation.

Rather less attention has been paid in the literature to the empirical study of the external relationships of families than to their internal relationships, and the few studies that exist have all appeared only within the last few years. Shaw (1954), for instance, described the external contacts made by 100 London suburban families, and found little organised community life in this sample. Most were on somewhat distant terms with their neighbours, and though they usually relied on them in times of trouble, no friendships were formed on this basis. The leisure time of these people was generally devoted to watching TV, "doing the pools", and visiting relatives. This latter activity took a particularly important place in their lives, and this was especially the case with contacts involving the wife's mother (and to a lesser extent the husband's mother). Visiting here was mutual and frequent.

This reliance on the grandmother, and particularly the maternal grandmother, is a finding which has emerged from other studies. "Mum" has been found to exert a powerful influence on the family life of several generations simultaneously in places as far apart as a Liverpool slum inhabited mainly by Irish descendants (Kerr, 1958) and the East End of London (Young and Willmott, 1957). In Kerr's sample the importance of "Mum" was indeed such that she functioned as the focus of all family activities, whatever her personal qualities. Her dominance was such that married daughters tended to rely on her completely for all decisions, and sometimes even continued to live with her after marriage. Outside the extended family human relations were conducted on a superficial level, and little participation in other external activities was observed apart from those in which the individual could either be solitary or else be just one unit in a crowd - such as involved in visits to the cinema, the pub, or a football match.

In a study of a Yorkshire mining community, Dennis et al. (1956) note

that the strict division of roles within the home (according to which the wife is almost solely responsible for household and child care activities) is also found in the pattern of community participation characterising most married couples. Thus the majority of leisure facilities cater for men only, whereas the social activities of women concern mainly contacts with relatives and neighbours. The total amount of community participation described by this study is clearly considerable: men are rarely at home except to eat and sleep, and hardly a day passes when a woman does not see at least one of her neighbours or kinfolk.

Young and Willmott (1957) undertook an investigation which involved the observation of families, first in their old habitat in the East End of London, and then again after their removal to a new housing estate outside London. In the former the data to some extent are similar to those obtained by Kerr, for here too the lives of families tended to centre round "Mum", so that the domestic unit of the greatest importance was generally made up of the families of marriage of the daughters and their common family or origin. The maternal grandmother was thus the head of this unit, her house was used as meeting place, and the daughters relied for help and advice almost exclusively on her. There was, however, no isolation from the rest of the community on account of this close contact with the extended family - on the contrary, kindred were found to act as a bridge to the community, and it was through relatives that a person generally made friends and formed outside contacts. Attachment to relatives therefore was not at the expense of attachment to others. On the other hand, when these families moved to the housing estate, a very different pattern of community contact had to be worked out. The removal generally entailed separation from relatives, and the family of marriage now became far more the focus of people's lives. Contacts with neighbours were not many, and the lack of social facilities like pubs meant that people spent their leisure time mainly at home. This increased social isolation shows clearly that the degree of community participation is a function of many different conditions, that there is no generally accepted mode of behaviour which is found irrespective of place of residence, group mores, or personality. As we have noted before, it

is this ambiguity, this absence of a rigid framework of behaviour, which gives us the opportunity to examine individual variability in the face of stress.

Individual variability is also one of the main findings in a study conducted by Bott (1957). As already noted above, Bott had observed considerable differences in the degree of conjugal role segregation in her sample of 20 families, and she went on to suggest that these differences were associated with the pattern of external relationships, with particular reference to the differences in "network-connectedness". By this term Bott referred to the extent to which the people with whom the family maintains relationships carry on relationships with one another, and she suggested that in those cases where husband and wife come to marriage with close-knit networks, the marriage is superimposed on these existing relationships and the partners will therefore continue to derive emotional support from outsiders and correspondingly less from each other.

Although these investigations agree in certain respects, we are still far from having a satisfactory picture of the norms of community participation in our society. One difficulty may well be that there are no over-all norms, that the amount and type of contact with external agents differ from place to place and class to class. Willmott and Young's (1960) latest book suggests that this is so, for when they compared social activities in Woodford, a distinctly middle-class London suburb, with those previously reported for their working class sample in Bethnal Green, several striking differences emerged. Kinship in Woodford, for instance, appeared to be less important, and though the wife's tie with her mother was still strong, families tended to interact rather less with relatives than was common in Bethnal Green. On the other hand there was in Woodford far greater participation in formal organisations (clubs, societies, political parties, etc.), together with considerable stress on the exclusiveness of these organisations.

The picture is further complicated by the fact there are changes from generation to generation in the amount and pattern of community participation, that with the growing urbanisation of our society there has taken place an increase in the social isolation of the nuclear family. To some

extent this may well be, particularly among middle-class families of whom we know rather less than we do of working-class families. On the other hand, no family can live in complete isolation, and in some respects the increasing tendency for the state to assume responsibility for the welfare and education of the family entails an actual increase in contact with external bodies and agencies.

Community participation, then, refers to the fact that a family is not a completely isolated social unit, but is part of a larger society and must interact within this society with other social systems and individuals. Hill's (1958) formulation may be quoted in this connection: "Viewed externally the family often appears as a "closed corporation," especially in urban areas where the nuclear group is clearly differentiated from kinship extensions. Such a family presents a common front of solidarity to the world, handling internal differences in private, protecting the reputation of members by keeping family secrets, and standing together under attack. Nevertheless, the closed nature of the family is selectively opened for transacting business with other agencies, e.g., kinship, friends, neighbours, physicians, ministers, lawyers. Viewed externally, the family is an organised group interacting with other agencies."

The groups and individuals with whom the family chooses to interact will depend on a number of different factors, amongst which the cultural mores, the particular needs of the family, and physical availability are the more outstanding. For our purposes, however, the community of a family will be regarded as all those social systems external to the family which are, potentially at least, accessible to that family. In some cases interaction will involve the family as a whole (e.g., visits to relatives), in others it will involve only one member (e.g., father's attendance at work). The result is, however, that for any given individual we find a system of multiple group membership. Thus a man will not only hold his familial roles (as father and husband), but will simultaneously hold the roles of, say, employee, member of a trade union, church attender, member of a drama club, secretary of a tenants' association, and son, brother, cousin, etc., in his kinship group. From

this point of view, the amount of community participation of a family becomes a matter of the number of extra-familial roles played by the various family members.

One further point may be made. Multiple group membership introduces the possibility of role conflict. The varying demands and standards of different groups may put the individual in a position where multiple group membership no longer becomes possible for him, and one or another role must be dropped. Thus community participation is not only a function of the factors mentioned above, but also of the need to avoid such conflict. These considerations may well have relevance for the parents of handicapped children, for if such an individual were to feel that his parental role is at variance with the demands made by society for perfect children, a clear instance of role conflict would ensue, and, depending on the manner of solution, the amount of community participation would then be affected in one direction or the other.

Socialising techniques and role ascribing.

The roles adopted by the parents in a family depend on many factors - individual, situational, and social. In the case of children, however, the nature of roles played is particularly closely associated with one set of determinants, namely the parental socialising techniques.

Here we turn to what is perhaps the most important function of the family, the rearing of children. That this is a highly complex area is amply attested by the voluminous literature on this subject. We shall, however, only be concerned with one aspect, namely the way in which parental role expectations are expressed through socialising techniques and the manner in which roles thus become ascribed to the child.

The family has often been described as the transmitting agent of culture. What a particular society expects and what it prohibits are primarily learned in the early years, and the family provides at first the sole and afterwards still the main classroom of life. In order to take his place in society as a reasonably well-adjusted individual, the child must learn that there are certain situations which call forth particular patterns of behaviour and not others - that he can demand affection from his parents but not from complete strangers, that he must obey adults but

but can assert himself over younger children, that at school he must learn and not play. In this way the child finds out gradually and often painfully that he must conform to the expectations of those around him to play a number of roles, each geared towards a particular situation, and that what is appropriate in one situation is not necessarily appropriate in another. At the same time he also acquires expectations as to the roles played by others, that a minister is likely to behave in one way and a school teacher in another, and that even his father and mother are each likely to assume different roles in their relations to him.

From the parents' point of view, the process of ascribing roles to the child is generally a more or less unconscious and non-verbalised activity. To some extent the nature of their expectations will depend on certain given factors in the child himself, of which the child's sex, his age, and his primogeniture are probably the most important. To what extent and in what way roles should differ according to these variables depends largely on the particular culture within which the parents themselves have been brought up. This latter point has been made most strongly by anthropological reports of societies very different from our own, which have shown that many of the roles, so deeply ingrained in our own culture that they have often been taken for innately determined, are in fact learned. The best known example is probably Margaret Mead's (1935) study of sex-appropriate behaviour in three different primitive societies, as a result of which we now realise that what has been regarded as "typical" behaviour of the sexes is to a considerable degree culturally determined, thus leading our attention to the particular manner in which such behaviour is acquired - namely to the investigation of parental attitudes and the differing demands made on boys and girls.

Similarly, the expectations and demands of parents will influence age-appropriate roles. All parents believe that there are certain patterns of behaviour which are "right for this age", yet what parents believe to be "right" will vary again from culture to culture and even from class to class. Whiting and Child's (1953) cross-cultural comparison of socialisation techniques and Davis and Havighurst's (1946)

investigation of the influence of social status on child rearing practice illustrate this generalisation, and the wide differences to be found in such practices as toilet training and weaning may be quoted as some of its more obvious examples. Thus each set of parents approach their newborn child with a framework of expectations into which his development is to be fitted - a framework which may be handed down from generation to generation or gleaned from friends, neighbours, magazines and radio talks, and which will determine the demands made of the child at various ages. Around the age of 12 months, for instance, he will be expected to begin walking and talking, by 2 years he is (in our culture) regarded as old enough to help in feeding himself and to have achieved some measure of bladder and bowel control, and by the time he is 5 we consider him to be ready for schooling.

These beliefs and demands are, as already mentioned, largely a matter of social convention. They are not, however, completely divorced from the child's actual capacities and abilities. The culturally determined framework of expectations will be further influenced and modified by the sensitivity of the parents towards the needs and abilities of the individual child, and idiosyncratic variations in both parents and children must therefore also be taken into account in studying the socialisation process in any given family. These variations can, however, take place only within certain limits, as otherwise they become no longer socially acceptable and are regarded as pathological, requiring the attention of psychiatrist or magistrate. Thus to breast-feed a child of 3 years is in our society regarded just as abnormal and undesirable as it is to wean a child at the age of 6 months amongst the Arapesh. Speeding up the developmental process may be considered permissible and indeed often desirable, but to lag behind and to ascribe roles to a child which are appropriate to a much younger age will evoke the disapproval of society and flout the conventions laid down for the rearing of children. Societies differ as to the extent to which deviations are still regarded as tolerable, but it has often been suggested that in our own urban society pressures towards conformity are particularly great.

The main theme in ascribing age-appropriate roles concerns the severity of pressures to develop from a completely dependent state to a completely independent state. The dependency theme runs indeed throughout the course of childhood, and the role of child-in-family and of child-in-society depends largely on the judgment of the parents and others as to the point on the dependence-independence continuum where a child of given age may be placed. Anthropological evidence again illustrates clearly that such judgments are relative to cultural mores, and indeed history shows that within our own culture striking differences occur in this respect within relatively short periods: only 150 years ago, for instance, children were considered advanced enough at the age of 7 to assume the role of worker and wage earner. Even more striking are the individual differences which can be found at the present time in our society - Levy's (1943) classical work on maternal overprotection supplies ample data illustrating the varying perceptions parents have of the dependency needs of their children and the consequent difference in their treatment. Yet by and large most people will agree that it is the task of parents to help the child in the gradual acquisition of independence, that although in the early months the child is almost completely dependent and a relatively passive recipient of attention, his role in the family will gradually change with increasing age and with increasing ability to make his own adjustments to life situations, and that to this end the parents must help to equip him with the necessary skills. Thus, guided by the cultural frame of reference, parents will make gradually increasing demands for independence, and their treatment of the child will in this way reflect the expectations they have of his ability to assume the roles which are generally considered appropriate to his age.

Levy's (1953) study shows that this orderly progression in the role-ascribing process may sometimes be interfered with by pathological factors in the parents. There is, however, another possible source of interference, namely the condition of the child himself and his ability to meet the demands which society makes of him. Where mental or

physical handicap exists, the conventional framework which guides socialisation may no longer be applicable - whatever pressures are put on the child, he may, to a greater or less degree, be unable to assume the roles considered to be appropriate to his chronological age. This creates a dilemma for the parents: discarding the conventional norms of child development means that the situation is no longer structured for them, than an element of ambiguity has been introduced in that they must now find a new pattern of child rearing. If a child cannot assume the roles appropriate for his age (and, for that matter, his primogeniture, for his developmental progress may be slower than that of younger siblings), what roles are to be ascribed to him? Or, alternately, to what extent are the parents to attempt to force him into conventional roles despite his handicap? How far is the child's progress along the dependence-independence continuum affected? If the use of cultural norms as guideposts has been lost, the parents are able to use only their own sensitivity to what this child is in fact capable of doing. Without the security of the conventional framework, far greater demands are thus made on the capacities of the parents, and this applies particularly to those with cerebral palsied children. Where a child suffers from mental handicap, uncomplicated by physical defects, developmental progress, though slower, is still orderly and patterned; whereas in cases of cerebral palsy the total picture may be much more chaotic and disorganised, with different functions developing at different rates and some perhaps not developing at all. The parent is then continually faced with the problem of how much he can expect from the child and what demands he can make of him: when, for instance, to toilet train a child as yet unable to sit independently, or when to demand of a child with poor manipulation that he should feed himself. Whereas in normal children chronological age is generally taken as the criterion whereby the relevant point on the dependence-independence continuum is fixed, in the cerebral palsied child such a criterion cannot be used, and the situation confronting the parents accordingly lacks the clarity which is associated with the rearing of a non-handicapped child.

As already pointed out in connection with the role system of the family group, it is when behaviour patterns are not rigidly laid down, when a social situation lacks structure (either because society has not defined it clearly or because society's definitions are, for one reason or another, not applicable), that there is room for idiosyncratic variation and thus the possibility of studying the manner in which individuals define the situation for themselves. As far as the socialising techniques of parents with cerebral palsied children are concerned, several courses are possible: the parents may attempt to force the child beyond his real capacities into the conventional age-appropriate roles, or they may disregard convention and gear their demands solely to the child's real abilities and needs, or they may go to the other extreme and make no or little demands on the child at all and thus not even use those capacities that he does have. Whatever way is chosen, the parents reveal by the severity of their socialising techniques their own particular definition of the manner in which this child is to be fitted into the family and the role he is to play in it: whether his handicap is to be disregarded and he is to be forced to assume an independent status in keeping only with his chronological age; or whether due allowance is to be made for the presence of the handicap, but, within its limits, the child is still to be helped towards independence; or, finally, whether the handicapped nature of the child is to be exaggerated to such an extent that he is treated as a completely dependent being and thus assigned an age role which is even younger than that of his functional age.

The child in relation to the social environment.

So far we have been concerned with certain group phenomena on the one hand, and some aspects of interpersonal relationships on the other. In turning now to the child as the focus in this field of social forces, we add a third level of study: that of the individual in relation to the group.

That individual behaviour is to a considerable extent a function of the social environment is too well known a fact to need amplifying.

Such studies as Sherif's (1935) classical experiment on the auto-kinetic phenomenon have illustrated how subtle and pervasive this influence can be, and nowhere is this more vividly seen than in the effects of socialisation during childhood. These effects are manifold and cannot possibly all be considered here, and we shall therefore concern ourselves only with the child's social characteristics, i.e., those phenomena which define the role that he plays as member of his social group, and in particular his assumption of age-appropriate roles within the family group.

That a change occurs with increasing age in the roles played by a child has already been pointed out in the last section. Two aspects characterise this change, namely those referring respectively to the nature of the roles adopted, and to the range of roles which the child is capable of playing.

As for the nature of roles found in childhood, a particularly valuable discussion has been provided by Newcomb (1950). Three stages in role development, based largely on the work of Piaget (1932), are for convenience sake distinguished by him. At the beginning of life the infant's social behaviour is characterised by "autism", i.e., persons are like objects in that they are perceived as opportunities or as obstacles to drive relief, or, "in social-psychological terms, the infant has not yet acquired habits of responding to others." Wants are all exclusively autistic, in that they are related to the immediate relief of the child's own drives and take no account of social custom. Gradually, however, this stage gives rise to the next stage, that of "absolutism." The change takes place partly because the child meets resistance to his autistic demands from other people, who will demand that he should inhibit some of his impulses and perform certain acts (e.g. use a spoon instead of his fingers) which at first provide no satisfaction at all; and partly because he becomes able to make more discriminations, particularly among people. As a result, he finds that each of the individuals with whom he commonly interacts plays a more distinctive part in relation to his needs, so that gradually he learns to anticipate different behaviour from different people and, conversely, begins to adopt different roles himself according to the circumstances

in which he finds himself. On the other hand, the child has as yet little sense of "reciprocity" between himself and others. This does not occur until the last of the three stages, when the child learns that his own perspective is not absolute, but that in social intercourse he must make allowance for the differences in perspective as between different people. Others are then no longer seen as extensions of his own needs, and the child may then be said to have achieved true separation from others and gained an independent position in his own right.

This conceptualisation helps to clarify the nature of age-appropriate roles. Again the dependence-independence theme emerges: the infantile omnipotence of the autistic stage, when the child's own adjustment to others can yet be barely distinguished and he is still a creature with many rights and no obligations, gradually changes under the impact of the demands made upon him. He can no longer entirely rely on other people to supply immediate gratification for his desires: more and more is he expected to assume responsibility for his own welfare and, in so doing, to respect the welfare of others. Increasingly his social role involves not only rights, but also obligations. Thus the role of child-in-family is in fact an umbrella name for many different roles which the child must assume at different ages right until the day that he achieves independence and emancipation. That this process may, in some cases, never be completed has been vividly illustrated by Kerr's (1958) study (previously mentioned), in which the degree of dependence of adults on the mother was gross enough to prevent truly individual behaviour.

Simultaneously with changes occurring in the nature of the child's roles, there is an increasing ability to assume an ever wider range of roles. As Newcomb points out in relation to the second of his stages of role development, the child becomes able to make more discriminations between people and to learn in this way different sets of expectations. A great deal will therefore depend on the wealth of his experience: the number of people with whom the child must interact and the number of other social systems into which he is introduced. His play will then gradually show the wider range of his indentifications: not only can he play at being mother or father, but also at being postman, teacher, shop-

keeper, and farmer. Moreover, in virtue of the fact that other family members hold extra-family roles as well, new areas of experience are opened up to him. If his father, for instance, is also a lawyer, a member of a golf club, a church warden, and an Officer in the Territorial Army, he will learn, either directly or indirectly, of other social systems and the functions performed therein. The link with our previous discussion on the community participation of the family is obvious.

Thus throughout childhood certain systematic changes take place in the individual's social behaviour, and these changes may be judged in the light of the more or less explicit norms which prevail for this area in each community. A child of five, for instance, who still depends on his mother to wash, dress, and feed him, who still clings to her to such an extent that he cannot let her out of sight and is unable to participate in other groups, shows a pattern of behaviour that is much more appropriate to a younger child, and has clearly failed to change his social behaviour at the required rate. Such a child will be considered immature in contrast to a child who shows age-appropriate behaviour patterns and whom we regard therefore as socially mature.

The concept of maturity may thus be used to summarise a child's progress. Maturity is often taken to denote the fully developed state of an organism, and from this point of view all children would be considered immature. Here we shall use it rather in its relative sense, i.e., to denote a child's status in relation to his peers and the norms which are regarded as appropriate to his age group. By defining the standing of any given individual on the maturity-immaturity continuum, we can indicate the progress he has made in the development of the particular function under consideration, and thus assess him in relation to the norms which are considered optimal for his age group.

All aspects of an individual which are subject to growth and development - physical, intellectual, emotional, and social - can be approached in this way. In concerning ourselves only with social aspects, however, we cannot overlook the fact that the division between the various aspects is not an absolute one. This issue arises particularly in the study of cerebral palsied children, all of whom are

physically handicapped and many of whom are also intellectually handicapped. A child who cannot walk must be carried like an infant; a child who cannot talk must have his needs "read" by his parents - again like an infant. The organic condition of the child is thus bound to impose a certain degree of social immaturity on him. Yet it must be appreciated that social maturity is not necessarily a unitary concept, that it represents an over-all judgment and that unevenness in development is a common clinical experience. A priori, the dependence imposed by the child's physical condition need not be accompanied by immaturity in all other sectors of behaviour, and only empirical investigation can determine how widespread in fact the effect on the child's personality is.

Summary.

We have looked at the family from three points of view: that of the total family group, that of the interaction processes which take place between parents and children, and that of the individual who develops within the group. At each of these levels cultural norms determine behaviour to some extent, yet in our society these norms are not so rigidly laid down as to exclude idiosyncratic variation, and it is therefore possible for extraneous factors (such as cerebral palsy) to influence these patterns of behaviour.

Each of the above levels may be studied in its own right; yet, as the recurrent usage of the concept of role indicates, they may also be regarded as interlinked parts of one organic whole and they can therefore be expected to vary together. If the family is to be conceptualised as a role system, with a certain degree of internal cohesiveness and a certain pattern of interaction with other groups, then the child is likely to be reared in such a way as to fit into this role system. The nature of socialising demands will thus vary with the nature of the group as a whole, and the social behaviour of the child will accordingly be the resultant of these various social forces impinging on him.

This view of the family parallels the functionalist view adopted by anthropologists like Malinowski and Mead in discussing the association between culture and personality. To understand a particular aspect one must study it in the context of the whole, and though the three levels

indicated form suitable divisions for separate investigation, their inter-connectedness must be stressed at all points. Each family has a certain "style of life", which represents the functional integration of multiple elements found in group activities, interpersonal relationships, and individual characteristics, and only comprehension of the whole will help one to gain understanding of the isolated items.

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CHAPTER 5.
AIMS AND METHODOLOGY.

Statement of aims.

At the end of Chapter 2 we had already stated our intention to regard the child, not as an isolated unit, but in relation to his immediate social environment, namely his family, and thus analyse the emotional atmosphere in which cerebral palsied children are reared. As "emotional atmosphere" is hardly a useful working concept, however, we examined in the following two chapters the manner in which others have approached this kind of problem and the type of conceptual framework that may be used in order to direct our attention to significant and specific issues within the area of concern. As a result we are now in a position to give a more precise statement of aims.

The main purpose of this project is to examine the social concomitants of cerebral palsy, by analysing the social situation in which children thus afflicted find themselves and by studying the effects of this situation on the child's own development. In order to narrow our investigation, only the immediate social environment of the child, namely his family, will be studied directly, as for the young child it is this group which constitutes his main and indeed initially his sole environment.

Taking, therefore, the family group as our field of investigation, we shall enquire as to the characteristics of social activities, both within the family circle and outside it, when a cerebral palsied child is present, and the kinds of roles which are played by family members under such circumstances. This problem will be examined in relation to two rather more specific questions, namely what characteristics can be found as to the cohesiveness of these family groups, and what kind of community participation is to be seen amongst them. These two questions are concerned respectively with the internal and the external relationships formed by family members, and degree of cohesiveness and amount of community participation will be used as the two dimensions

around which the discussion will center.

The family group provides, as we have seen, the setting for the socialising and development of the individual child's personality. Within the context of the group we shall therefore turn to the other two levels of phenomena, namely that describing the nature of the interaction between parent and handicapped child and that concerned with the characteristics of the individual cerebral palsied child himself. On the interpersonal level we shall ask how, within a given type of family group, parents carry out the socialising of the handicapped child, with particular reference to the manner in which they deal with the problem of ascribing age-appropriate roles to such a child. Again the emphasis will be on producing ordered descriptive data, but this part will be organised around the dimension of the amount of socialising pressure which the various families exert in order to wean the child from complete dependence to ever-increasing independence.

At the level of the individual we shall ask how far the conditions of the social environment, as laid down by the nature of the family group, permit the amount of personality growth that can optimally take place within the limits set by the handicap of the cerebral palsied child. This problem will be discussed around the dimension referring to the relative social maturity of the child, and thus some of the personality traits to be found in these children will be described.

Our aim throughout is therefore two-fold: to study the variability that may be found in the research sample on any one of the dimensions discussed, and to determine whether these dimensions are associated in meaningful patterns, i.e. to find out to what extent it is feasible to relate aspects of the interaction process and of the individual child's personality to the social structure within which they occur. Though lip-service has for long been paid to the fact that the family is the fundamental agency for the cultural conditioning of the child, the details of this process have generally been analysed only in terms of the parental socialising techniques and not been associated with the

characteristics of the family as a total group. We shall therefore make use of the present research setting in order to throw light on the existence and nature of this association by examining the extent to which the variation in family organisation to be found in our sample is related to differences at the other two levels of study. In this way the interdependence of the child and the family environment may be investigated.

At all points of the report an attempt has been made to keep in mind the need for carefully documented series of observation on individual cases. The manifestations of the various dimensions will therefore be illustrated by presenting detailed descriptive accounts, in order to show what kinds of behaviour patterns occur in families where one member is a cerebral palsied child. Such descriptive accounts are, we believe, essential if social measures are to be taken to help this type of family, and it is thus a primary aim of this study to furnish knowledge about the "life-pattern" of these families and to gain understanding "from the inside" of each individual case.

Some general methodological considerations.

At the end of our review of the literature on families under stress, we concluded that the variation of response as shown by different families to such a situation constitutes one of the main points of interest in this area, and that it would therefore appear to be less useful to investigate the differences between an experimental group of families under stress and a control group of families not thus affected, than it is to study the fluctuations within the former group in its own right. An internal analysis of the research sample is thus indicated, and this is further reinforced by our aim to investigate the association between various dimensions within the sample. The emphasis in this project will therefore be on the extent to which families with cerebral palsied children differ amongst each other with respect to the various phenomena isolated for study and on the relationship between these phenomena. External

comparisons are not called for by these aims: this is not an attempt to demonstrate that certain responses are unique to cerebral palsy, for such a claim would be an unlikely one to make, and to show that these responses occur more frequently in association with cerebral palsy than with other conditions or in unaffected groups is considered to be less useful than an analysis of individual differences within the cerebral palsy sample itself.

A research design involving the comparative study between the experimental group and other groups was consequently not undertaken. The same considerations also apply to another possibility, namely a "before-after" type of design, in which the experimental subjects served as their own controls and were studied both before and after the arrival of the cerebral palsied child. Such a study would, moreover, introduce additional complications, in that access before the event is generally impossible and a retrospective point of view is an unsatisfactory one: reliance would have to be placed on the memory of the subjects themselves, their accounts referring to events taking place many years previously, and as the retrospective data could not be gathered independently of the present-day data, spurious correlations may easily result. As, moreover, certain phenomena like the roles of the conjugal pair change anyway with the birth of a child, we must re-affirm our conclusion reached at the end of Chapter 3, namely that an a-historical approach is to be preferred to a comparison of temporally successive conditions, some of which are not directly accessible to the investigator.

A further methodological consideration refers to the scale of the investigation: whether this is to involve the intensive study of a relatively small number of subjects, or whether it is to take place on a more macroscopic level and be based on large numbers. Were our aim a normative one, i.e. to demonstrate the extent to which certain phenomena exist generally amongst the cerebral palsied, the latter would clearly be the necessary course. But this is not our intention, and

no attempt was therefore made to obtain a large, representative sample. Instead, the emphasis has been placed upon the richness and validity of the data obtained, and in this we follow the example of Bott (1957), an examination of whose report suggests clearly that the crucial factor lies in the type of contact made with the subjects. Information in our chosen field of enquiry has usually to be obtained, in one form or another, from the verbal, voluntary reports of the subjects studied, and if this information is to possess any validity, the relationship between interviewer and interviewee is absolutely crucial. In the large-scale investigations quoted above this point has been neglected, for the contacts there tended to be limited and impersonal, and there appears to be little insight into the meaning of this situation for the interviewee. The contacts made by Bott, however, do take this factor into account and thus extended over a much greater number of interviews. As a result, considerable confidence may be placed in her findings, even though they were obtained at the cost of a standardised approach to all cases, and even though the expenditure of time per case necessitated the use of only a small sample. In an exploratory study such as the present one this method is believed to be the more useful one and has accordingly been adopted.

The research setting.

We are now in a position to turn to the details of this investigation and describe the manner in which it was carried out. The whole project was based on an outpatient service run by the Scottish Council for the Care of Spastics, which provides for the screening and assessment of children with cerebral palsy and, wherever possible, for treatment facilities. Cases are referred by general practitioners, school medical officers, infant welfare doctors, and paediatricians, and though generally the diagnosis of cerebral palsy has already been made, some of the children are referred in order to have this diagnosis confirmed. Most of the children, however, are sent either in the hope of having

them admitted to the residential school run in conjunction with the outpatient centre, or for treatment (mostly physiotherapy) to be carried out on an outpatient basis, or for advice on medical, educational, and social matters consequent to the handicap. Referrals come from the whole of the West of Scotland, and though all ages are covered the majority of children tend to fall into the pre-school group.

As a first step in the screening process the family is usually visited by a social worker, who makes an over-all assessment of the home, the problem, and the individuals involved, and explains the screening procedure to the parents. Some time later the parents are then requested to bring the child to the Centre, and here the three consultants involved carry out their examinations. The consultants are a paediatrician, an orthopaedic surgeon, and a psychologist (the writer), and after their individual examinations are completed a conference is held at which a decision is reached as to what help and advice can be offered in the particular case.

Thus the purpose of the screening procedure is to make certain practical recommendations. The parents know this beforehand, and their expectations are therefore geared to these various possible courses. One such recommendation, for instance, might be that the child should be admitted to the residential school. During the course of this investigation, however, all places in the school were filled, and though suitable children were put on a waiting list for admission at some future time, it had to be explained to the parents that this might be delayed a number of years and that no firm promises could be made. Nevertheless, the hope for eventual admission, and for the intensive treatment programme and specific educational procedures entailed thereby, remain with many of the parents. In other cases provision can be made for outpatient treatment, which, depending on the distance, is provided either at the Centre itself or in the patient's home by a mobile physiotherapy service. In still other

cases the child is referred to other agencies for services which only they provide, and finally in some cases no help can be offered beyond advice to the parents on the daily management of the child.

It was against this clinical background that the research project was carried out. The author's task, as psychologist member of the screening team, was to assess the child's emotional, social, and intellectual potentials, to determine to what extent any behaviour problems might interfere with placement or treatment plans, to make suggestions as to educational possibilities, and to examine the parent-child relationship in order to find out whether there are any factors present which might prevent optimal development of the child. Ideally, the total amount of information to be gathered for such purposes would be considerable and would entail a prolonged contact with the child and his parents. In practice, the actual time available at the screening session is limited, and only a brief, over-all assessment of the child could therefore be attempted. Because it was felt, however, that more information was needed, and because the child was often too upset and negative at the first contact with a stranger in new surroundings to make it possible to administer tests or to observe him at play, the child was usually seen again in his own home, where it was possible to observe him and to obtain information from the parents under rather more relaxed conditions. In this way the place of enquiry was shifted from the Centre to the home. Permission to make the home visit was always first sought from the parents, most of whom were only too willing to have the writer call and see the child in his natural habitat. Here they were generally able to talk more freely, and it was also easier to observe their interaction with the child.

The sample.

30 children and their families (137 individuals in all) form the research sample. They are the first 30 cases to be referred to the Centre after the project was begun, where the following criteria

were applicable:

- a) The family was to be intact, in that both parents and the cerebral palsied child were to be living together under the same roof. In so far as the focus of the study was on the family, this was clearly an essential requirement. It ruled out all children in institutions, residential schools (including that attached to the Centre), and living with relatives or people other than their own parents. Although no requirement was made as to the presence of all siblings in the home, no case was actually encountered where this was not the case.
- b) The age of the child at the time of referral was not to be more than 6 years. A largely pre-school sample was thus gathered together, for it was felt that it is mainly in the early years that the family is called upon to make the greatest adjustment, and that it is largely during this period that the greatest problems of socialising are encountered.
- c) The family was to live within a specified geographical area, encompassing the four counties of Dunbartonshire, Lanarkshire, Renfrewshire, and Ayrshire. This was a practical requirement, designed to make the homes of the families reasonably accessible to regular visits.
- d) The socio-economic status of the family was to fall within the Registrar-General's social classes III and IV (clerical and skilled manual and semi-skilled manual respectively). This selection was done in order to eliminate, as far as possible, the influence of extraneous factors on family functioning due to differences in social class. To what extent such differences are a real factor for the particular area studied is, in fact, not known, as we lack the necessary norms on which to base judgment. Nevertheless, in view of Willmott and Young's (1960) findings, it was felt that the chances of increasing the homogeneity of the sample were probably increased by this requirement.
- e) For the same reason only families living in urban districts were selected, as the pattern of family life is believed to differ in many respects in rural areas (though again definite evidence for the area in which this investigation took place is lacking).

There were 16 boys and 14 girls in the sample, and the median age of the 30 children was 3 years 9 months at the time of the initial contact with the family, i.e., at the screening session. The range is illustrated by Table 1, the youngest child at the time being 15 months old and the oldest 71 months.

Table 1.
Age of Children at First Contact

<u>12-23</u> <u>Months</u>	<u>24-35</u> <u>Months</u>	<u>35-47</u> <u>Months</u>	<u>48-59</u> <u>Months</u>	<u>60-71</u> <u>Months</u>
8	4	5	4	9

After the initial contact had been made, the child and his family were kept under observation through repeated home visits. In some instances contacts were also made at the Centre if the child attended there for physiotherapy. The median length of the total observation period for the group was 22 months, the range being 16 to 32 months, and the distribution being as in Table 2.

Table 2.
Length of Observation Period

<u>12-17</u> <u>Months</u>	<u>18-23</u> <u>Months</u>	<u>24-29</u> <u>Months</u>	<u>30-35</u> <u>Months</u>
2	14	12	2

Details of the number and kind of contacts made during this time will be given below. The age of the child at the end of the observation period, i.e., at the final contact made with the family for the purposes of this research, showed a group median of 5 years 7 months. The distribution is shown in Table 3, the range extending from 36 months for the youngest to 95 months for the oldest.

Table 3.
Age of Children at Final Contact

<u>36-47</u> <u>Months</u>	<u>48-59</u> <u>Months</u>	<u>60-71</u> <u>Months</u>	<u>72-83</u> <u>Months</u>	<u>84-95</u> <u>Months</u>
6	6	5	4	9

All children were given a diagnosis of cerebral palsy, but the type and severity of the condition, as well as the number and kind of associated handicaps, differed considerably. Classification into types is presented in Table 4.

Table 4.
Types of Cerebral Palsy

<u>Spastic</u> <u>Hemi-</u> <u>plegia</u>	<u>Spastic</u> <u>Para-</u> <u>plegia</u>	<u>Spastic</u> <u>Quadri-</u> <u>plegia</u>	<u>Athetosis</u>
3	6	17	4

Although some mixed types were present, each child is classified under the major diagnosis made.

The relatively high incidence of spastic quadriplegia suggests that the extent of involvement found in this sample is rather great. This probably reflects the fact that this kind of child tends to be referred more frequently to the Centre than the mildly affected child, whose condition gives rise to less anxiety and for whom local facilities are more easily available. On the other hand, the severity of the condition can only be appreciated if one also takes into account the various handicaps associated with, but, according to the definition, not a necessary part of cerebral palsy. Of these, the main groups to be mentioned are sensory defects, epilepsy, and mental defect. Their incidence is recorded in the following table.

Table 5.
Incidence of Associated Handicaps

<u>Handicap</u>	<u>Number</u> <u>Affected</u>
Visual Defects	4
Auditory Defects	2
Epilepsy	5
Mental Defect	20

Mental deficiency is shown by this table to be by far the most common associated handicap. Further details of intelligence findings are given in Table 6. All children were tested (generally with the Terman-Merrill test, though other tests were also sometimes used), but in a number of cases the results obtained were considered to reflect more the severity of motor handicaps than the child's actual intellectual capacity. Under these circumstances it was often considered inadvisable to assign an exact I.Q. to the child, and instead an approximation was arrived at which permitted him to be placed into one of the groups in the following table.

Table 6.
Distribution of I.Q.'s

<u>I. Q.</u>	<u>Number of</u> <u>Children</u>
40 - 49	4
50 - 59	4
60 - 69	12
70 - 79	5
80 - 89	2
90 - 99	3

We are now in a position to consider the range of severity of the total handicap, as given by all the major symptoms which are the direct consequence of the cerebral damage. Apart from Schonell's (1956) vague and unspecified classification, no method of quantifying severity has been reported, and for this reason a Severity Index was developed, details of which are given in Appendix I. It is based on the major functions with which cerebral palsy may interfere, namely locomotion, manipulation, speech, intelligence, and sensation, and also takes into account the presence of epilepsy. No claim is made that the organically determined pathology is thereby exhausted, but the list does include the main systems generally affected. A note of caution must, however, be added, for in so far as it has been necessary to assign equal weights to all the various handicaps, a certain arbitrary element has been introduced. This procedure might be questioned, as many may

argue that mental handicap is worse than physical handicap, or that inability to speak is a greater handicap than inability to walk. Yet, as each person is likely to have his own set of priorities, an arbitrary judgment on weighting is inevitable, and it is felt that the present scheme does enable one to order the subjects according to the severity of their condition. It must also be pointed out that no account is taken by the index of age, in that it might, for instance, be said that inability to walk at the age of 8 is a greater handicap than inability to walk at the age of 4. This, however, neglects the fact that, from the point of view of society, the four-year old is as much a deviant as the eight-year old, for the former as much as the latter has been unable to reach the norm for his particular age group. It does mean, though, that the index can only be used for children of an age where normally the developmental milestones referred to in the schedule should have been reached.

The distribution of the Severity Index for this sample is set out in Table 7.

Table 7.

Distribution of Severity Index

<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>	<u>6</u>	<u>7</u>	<u>8</u>	<u>9</u>	<u>10</u>	<u>11</u>	<u>12</u>	<u>13</u>	<u>14</u>	<u>15</u>	<u>16</u>	<u>17</u>	<u>18</u>	<u>+</u>
0	1	2	5	1	2	2	5	1	2	2	2	1	1	1	1	1	0	

Although the possible maximum for the Index is 24, the highest score obtained was 17. This is largely due to the fact that those children who suffered from seizures and sensory defects happened, in this particular sample, to be those who were not too severely affected in other respects. Otherwise, however, the range is considerable. Thus the child who obtained a Severity Index of 17 was a girl who had a spastic quadriplegia, and at the age of 4 was still incapable of moving independently in any way, could just grasp objects but not actually handle them, had no speech at all, was considered to be severely mentally handicapped, and also suffered from some degree of visual impairment. The boy who obtained a score of 2, on the other hand, had

been diagnosed as having a spastic hemiplegia, which interfered only to a slight extent in the use of one arm and one leg but did not affect speech, intelligence, or any other function.

The medical and educational provisions made for these children are as follows:

Table 8.

Medical and Educational Provisions

Children receiving education and physiotherapy	12
Children receiving physiotherapy alone	17
Children receiving education alone	1
Children receiving neither	0

All but one of the 30 children received physiotherapy. In 15 cases this was given in their own homes by a mobile physiotherapy service run in conjunction with the Centre, while the remaining 14 children lived near enough a clinic (mostly the Centre itself) to attend there as out-patients. In many cases physiotherapy was given twice a week, and in no case was it given less than once a month. 19 of the children reached school age at some point during the investigation, and for all but six educational provision was made in some form. In 10 cases this entailed attendance at a special school, in one case a home tutor was made available and in two cases normal schooling was possible.

Turning now to a description of the families to whom these children belong, we may note that this was a predominantly working-class group (in accordance with the requirement to select only those from social classes III and IV). Although spread over a fairly large geographical area encompassing four counties, the families lived in mainly industrial districts, and most of the fathers worked in industry. Their occupations are given below.

Table 9.

Fathers' Occupations

Sheet Metal Worker ...	1
Machine Operator	2
Welder	3
Crane Driver	1

Table 9 (Continued)

Motor mechanic	1
Shopkeeper	1
Shop assistant	1
Engineer	5
Plumber	1
Boilermaker	1
Clerk	1
Fitter	3
Coalman	1
Railway worker	3
Fireman	1
Driver	2
Joiner	1
Storekeeper	1

Two of these men were unemployed for the major part of the observation period, while two other men experienced rather shorter spells of unemployment.

All lived in urban areas, generally rather densely populated districts within easy reach of factories, docks or railways. Some of the families were still in near-slum property, waiting for re-housing and often having to use the child's handicap as a means to get priority treatment from the authorities. Other families lived in more modern tenement blocks or terraced houses in the centre of towns, and quite a number had obtained accommodation in one of the new housing estates that had sprung up all over this area since the war. Though somewhat further from work, shopping centres, and places of entertainment, these latter families all had their own houses and gardens - in some cases for the first time, as previously they had shared accommodation with relatives. In the whole sample there was only one family which lived during the whole period of this investigation with relatives, while one further family obtained its own accommodation in the course of the project. In all other instances the nuclear family lived by itself under its own roof, for though in many cases relatives (particularly the child's grandparents) lived close by, in none had a relative actually joined the family in order to live with it. This means that the investigation concerned relatively clear-cut family units.

The composition of the family included in all cases both of the parents and the cerebral palsied child. . . . As set out in Table 10, in four cases the cerebral palsied child was the only child in the family, though in a further 13 families he was the youngest.

Table 10.
Number of Siblings

<u>None</u>	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>
4	13	7	3	2	1

Thus 26 of the families had also at least one child other than the cerebral palsied. In one family, with three children altogether, one of the siblings had also a congenital handicap, but in all other instances the cerebral palsied child was the only member of the family afflicted with a chronic disorder of any kind.

The contact with the research families.

In Table 2 attention was drawn to the fact that the contact with the research families entailed a longitudinal follow-up for periods ranging between 16 and 32 months. There are two reasons why it was decided to establish this lengthy contact with 30 families rather than make a more superficial contact with a greater number.

In the first place, experience of interviewing has shown that the validity of the information obtained is a function of the type of relationship established between interviewer and interviewee. This applies especially when emotionally laden areas are discussed, and indeed the anxiety and ill-ease displayed by many parents at the initial screening interview was such that it was often more advisable to obtain only certain concrete facts and dates referring to the child than to range further and explore family relationships. In general, the focus had to be shifted only gradually from the child himself to the family as a whole or to other individual members. It was not until the anxieties and uncertainties of the parents had been allayed to some degree that they were free enough to permit discussion of issues not

uppermost in their minds, and though the amount of anxiety varied a great deal as between different sets of parents, the need for information about possible aetiology, about prognosis, about problems of day-to-day management, and about the availability of treatment or educational provision had to be dealt with in every case before the parents could be expected to turn their minds to less immediate aspects of the child's handicap. As, moreover, some of the parents from this particular social level were in any case not at ease with authority figures, some basis of trust had to be established first. This was especially the case where (as was found fairly frequently in this sample) such areas as the parental socialising techniques showed a pattern that was highly deviant compared with the norm - and known by the parents to be so. Thus it was not until the fourth interview that the mother of one boy (six years old at the time) could bring herself to relate the fact that every evening she went to bed at the same time as the boy and that the two of them always slept in the same bed. It is therefore not surprising that information obtained in a later interview sometimes directly contradicted information obtained earlier on, and it appeared of little use to begin the enquiry before the relationship with the informants had reached the stage where the initial anxieties both about the child and about the interviewer had been dealt with to some extent.

Several contacts were thus inevitable. In addition, however, it was felt that most could be learned about the families by observing them over a certain span of their lives and describing their reactions to the various minor and major crises that they were called upon to meet: the child's failure to reach certain milestones, his rejection by schools or the necessity to have him admitted to a special school, the birth of another child, and the inability of the cerebral palsied child to keep up even with his younger siblings. Similarly, reactions to hoped for events could be observed: the child at last taking his first step or saying his first word, or the provision of treatment or educational facilities. In this way a fuller picture of the family was obtained than a cross-section at one particular point would have provided.

The spacing of interviews was arranged to fit in with this plan. The initial contact at the Centre for screening purposes was generally followed within two weeks by a further interview, this time at the family's home. Sometimes two or three contacts quickly succeeded each other at this stage, depending on the ease with which the parents were able to establish a relationship with the writer and the amount of information (test results, for instance) that had to be gathered at this point. In other cases the first two contacts made were sufficient to carry the relationship over until the next follow-up visit paid. This generally occurred three to six months later, and all contacts throughout the observation period succeeded each other at intervals not exceeding six months and often taking place rather more frequently. The range in the number of contacts made is shown in Table 11, the median for the group being seven.

Table 11.

Number of Contacts with Family

<u>5</u>	<u>6</u>	<u>7</u>	<u>8</u>	<u>9</u>	<u>10</u>
6	8	6	4	4	2

The main person with whom contact was generally made in the family was, of course, the mother. A point was, however, made of seeing each family member at least once. Fathers were always encouraged to attend the initial screening interview, and home visits were later on occasionally paid at a time when father would be at home. As will be shown later on, the readiness with which a father allowed himself to be involved in these contacts is a highly significant feature. Some fathers would even stay off work in order to be present when visits were made, while in other cases it was rather more difficult to establish contact with them at all. In only one case, however, was there a downright refusal on father's part to be involved in any way, and he was therefore the only family member in this sample who was never seen.

The role which the research worker played in relation to the parents

was very much affected by the clinical context in which the investigation took place. In practice this meant that there was on the part of the parents always some expectation of help, and it was on this basis that access was initially obtained to the families. They came to the Centre in the belief that something could be provided for the child, and they welcomed the writer because he played a part in this procedure. In so far as problems of educability arose (as they did in nearly all cases), the writer was indeed able to give a clinical service through assessment and advice. Otherwise he was able to benefit from being associated with the Centre, which in all but seven of the cases provided physiotherapy and sometimes also speech therapy and occupational therapy.

It is doubtful whether access could have been gained so easily and the relationship established on such generally sound terms if the approach had been solely on the basis of the investigator's research needs. To have asked for information without offering anything in return, at any rate in such an emotionally charged area, might have mitigated against the validity of the information obtained. Nevertheless, it would be a mistake to think that the relationship remained based throughout the observation period on the parents' demands for help. Early on (generally after the second contact) it was explained to the parents that the writer also wanted something from them, that he was trying to learn not only about the personality characteristics of children with cerebral palsy, but also about the problems of management that they had come up against and the way the family as a whole coped when a handicapped child was one of its members. Great care was taken, however, not to make it appear that the writer's clinical help was conditional on the parents' co-operation in the research project, and indeed the provision of treatment and educational facilities was generally dealt with before the research aspect was broached. It was felt that this approach not only provided the parents with the correct mental set, but also put the relationship on a co-operative rather than a one-sided basis.

The research data to be obtained referred mainly to such tangible phenomena as the social activities of family members and the kinds of interaction taking place between them. No effort was made to open up

deeper levels and to enquire after feelings and attitudes involved in having a child with a congenital handicap. Yet the therapeutic element in the relationship could not altogether be avoided. Feelings and attitudes were at times voiced overtly, help and reassurance sought, and even dream and phantasy material related by some. This occurred, no doubt, because care had been taken to establish a permissive atmosphere in the interviews where the question of right and wrong was not raised, and where as far as possible a largely non-authoritarian role was adopted. (though advice and information, when explicitly asked for, were always offered). When material emerged which concerned the deeper aspects of relationships it was accepted and, if necessary, reassurance was given, but no active attempt was made to elicit such data and to work at this level. This decision was taken, partly because the nature of the project did not call for such material, partly because a far more intensive type of contact would have been necessary, and partly because the writer did not feel himself equipped and trained to carry out such work. The need for such a service with these families was, however, striking.

Sources of data.

The information needed for this project came from various sources, but by far the most important and fertile was the series of interviews which were held with the parents.

We have already mentioned the number of interviews held, the period of time during which they took place, their spacing, and the role adopted by the interviewer, and we shall now turn to the actual form which each interview took. For research purposes an interview may take many forms (cf. the discussion by Maccoby and Maccoby, 1954), but the most fundamental respect in which they may differ concerns the degree of structure imposed by the interviewer. This may range from a completely informal, unguided discussion to a previously prepared series of questions identical for all interviewees. It was decided, on the basis of some preliminary work, that the latter alternative gave too artificial a tone to the contacts in the present setting, that it provided too little opportunity for spontaneous information which the parents wanted to offer

and that, far from making it possible to confront each interviewee with the identical stimulus situation, it introduced too much heterogeneity through the varying meanings attached to questions and the different intellectual and other qualities of the interviewees. On the other hand, a completely unstructured discussion would not have produced sufficient material that could have enabled one to make ordered comparisons between different families, and some degree of uniformity was therefore clearly called for.

The form of interview adopted was that which Merton and Kendall (1946) have labelled the "focused" type of interview. This is a semi-standardised procedure, which is guided by a memorised interview schedule containing objectives and topics, as well as suggested questions, but giving the interviewer considerable latitude as to how and when the various topics are raised. Notes were taken at the time, but in order not to prevent the spontaneity of the contact the interview was not fully written up until after it had taken place. Only the initial interview, that at the screening session, was more formal, for this was mainly concerned with the obtaining of facts and dates, mostly about the developmental history of the child and his present range of behaviour. This type of interview fitted in better with the concurrently held examinations by medical colleagues, where physical data were sought on which the medical diagnosis, prognosis, and treatment plan were to be based. During subsequent interviews, held generally at the family's home, flexibility of approach was considered to be essential to the relationships which the writer was attempting to build up with the research families, and for this purpose the "focused" interview lent itself well. It enabled the interviewer to guide the conversation to certain topics and to ask specific questions without forcing it into unnatural channels. Thus the mode of approach could be altered to the individuals concerned, without necessarily detracting from the comparability of the information obtained.

The topics to be covered and the questions to be asked are given in the Interview Guide, Appendix 2. This Guide was never produced during the interview, and the writer therefore had to have clearly in his mind the sort of information which was required. Relying in this way on his

memory meant that there were instances when he might forget to ask certain questions, when some topics were omitted, and when information was therefore lacking about certain aspects. Yet this did not occur frequently enough to invalidate the whole procedure, and was thought to be a relatively small price to pay for the elimination of artificiality from the interview. In any case, opportunities occurred at subsequent contacts to make good the omission.

Interviews generally took between one and two hours, though particularly the first interview at the family's home might take longer. The information sought in the various follow-up interviews was always the same as in the first, so that a series of cross-sectional views were obtained from each family. The condition of the child, with particular reference to his locomotor development, generally formed the starting point of the discussion, and from there it led mostly to other areas of the child's behaviour and to the changes which had taken place in them since the last visit. Sometimes following these topics, but more frequently interlinked with them, discussion took place of the parental child rearing practices. It was, for instance, fairly easy to follow an account of the child's feeding difficulties with the question: "And what have you found to be the easiest way of dealing with this?" The third of the main groups of topics, that of the family and its organisation and activities, was often the last to be covered, as to the parents it seemed of least immediate urgency. Yet the logic of the order in which all the various topics are arranged in the Interview Guide was often neglected by the flow of the conversation, and though it was easier for the writer to remember all subjects and questions if the order was adhered to, no effort was made to force the discussion into this mould.

In order to obtain accurate information, an attempt was always made to gear questions to specific behavioural tendencies occurring in defined situations. "What kind of activities do the various members of the family carry out, both inside the home and outside it" was the question uppermost in the investigator's mind during each interview, and to obtain useful answers it seemed better to ask what activities had actually been carried out rather than what activities were usually carried out. A mother who was asked how often members of the family

had visited relatives during the preceding week was likely to produce a much more helpful answer than if she had been asked "Do any of you ever visit your relatives?" (though the latter question might be used to introduce the former). In this way a more detailed account of the various activities could be obtained - of the individuals involved in them, the circumstances under which they took place, the qualitative features inherent in their performance, and of their frequency (the latter often providing a useful quantitative index). Thus, although the conversation might range fairly widely all around a topic, an effort was always made to introduce specific questions which would anchor the information to defined circumstances.

During a visit that might take up to three hours there was generally some opportunity to carry out direct observation of various relevant aspects. This applied particularly to the behaviour of the child, but also the interaction of the various members of the household (though again with particular reference to the child) could be studied during this time. Once the family became more relaxed in the interviewer's presence and their behaviour more spontaneous, situations would arise which had a direct bearing on the data sought during the interview. Yet the material obtained in this way had only strictly limited uses. One could not judge how representative isolated items of behaviour were without enquiring of the parents: some children, for instance, became so excited by a visitor's presence that their handicap showed itself in an exaggerated form and they were unable to carry out activities of which they were capable under more relaxed conditions, and the fact that an instance of physical punishment was witnessed during a visit still did not tell one about the frequency of this kind of discipline. Taken together with the fact that large areas of the family's behaviour were inaccessible to observation during visits, observational material had to play a strictly subsidiary part in the enquiry. It might in some respects supplement interview data, but more often its use lay in providing stepping-off points for discussion. Thus the parents' attention could be drawn to some item of behaviour occurring at the time, and enquiry could then be made about the frequency with which it occurred, under what circumstances it was usually manifested, how the parents deal

with it, whether it represented an improvement on earlier stages, etc. The interview thus remained the main source of the enquiry.

Although psychological tests were used during the project, the data which they provided had little direct bearing on the research. The tests were all cognitive and were used to establish the child's intellectual level, but apart from helping to define the nature of the sample and the severity of the total handicap, the tests had little to contribute (though they did provide the opportunity for more observations of behaviour taken in the course of the procedure). Personality tests for a group as young and as handicapped as the present were found to be inapplicable, and the psychological assessment of these children could therefore not be undertaken by these means.

A more useful source of information about the children's personalities was found in reports from other professional persons. This applies particularly to the physiotherapists, who were in regular contact with the children, seeing many of them once or even twice a week throughout the course of this project. Their periodic reports were therefore invaluable. How this information was used will be detailed when the findings about the children's personalities are described. In addition, most children were re-assessed periodically by the orthopaedic surgeon who had taken part in the original screening session, and in this way progress reports on medical aspects were also made available.

Treatment of data.

In an area as rich and complex as the one chosen for this investigation, it is felt that a primary consideration of exploratory research must be to do justice to the complexity of the material, and the best way of achieving this is by descriptive means. Thus the emphasis in this project is not on sophisticated measurement, but on obtaining descriptive material of a valid nature and in an ordered form. In so far as quantification helps in ordering the data it has been used, but with numbers as small as those studied here tests of statistical significance, even of the non-parametric kind, have limited use and are therefore employed only sparingly, such as for the comparison of the four major dimensions around which the data are organised. Wherever possible, information has been

summarised in tabular form, but this has been done to ease presentation rather than to demonstrate quantitative precision.

CHAPTER 6

THE FAMILY: ASSESSMENT OF DIMENSIONS

In this chapter we shall be concerned with the first of the three levels of study, namely that of the family group. The data have been organised around the two dimensions of cohesiveness and community participation, and we shall now turn to the assessment of these dimensions and the results obtained from ordering the families along them.

Assessment of cohesiveness.

In our previous discussion of cohesiveness we drew attention to the difficulties involved in finding a suitable operational criterion for such a complex phenomenon. The criticism of Gross and Martin (1952), that the use of one or even several of the determinants of cohesiveness as a measure is unjustified, suggests the need for a wider, more embracing means of assessment; and one possibility can be found in the scales which have been used in some of the sociological studies of the family. The two best known examples are the Cavan Scale for Family Integration (in Burgess and Locke, 1950) and Jansen's (1952) Family Solidarity Scale. Both take certain characteristics of the family which they consider to be pertinent to its cohesiveness and rate families on each characteristic. The sum total of these ratings represents the cohesiveness score. Unfortunately the characteristics (chosen on a priori grounds) are mostly so vague that difficulties occur in translating them into actual family behaviour. There is, moreover, considerable overlap between some of the characteristics. Thus, included in the Cavan Scale, are degree of affection, mutual co-operation, joint activities, esprit de corps, amount of tensions, and economic interdependence. In Jansen's scale the sub-scales refer to agreement with each other, co-operation, concern for each other's welfare, enjoyment of association, affection, esteem, interest, and confidence in each other.

Gross and Martin's suggestion, that one should measure the resultant directly by simply asking the group members to indicate how attractive they find the group, is clearly too naive a procedure for the purpose of measuring cohesiveness in a family. A less direct measure is needed,

which assesses the attractiveness of the family group according to the behaviour and activities of the members rather than their expressed attitudes. In his work on the cohesiveness of experimental groups Libo (1953) developed a "locomotion criterion" for measuring this phenomenon, i.e., members were able either to leave the group or to stay with it. For our purposes a rather more subtle criterion is needed, as our original requirement, that the family should at least nominally be together, eliminates the groups which are completely disrupted by the departure of one or more members and focuses attention on more intermediate grades of cohesiveness.

The criterion for family cohesiveness which, it is suggested, furnishes us with the most suitable operational definition, refers to the degree of "togetherness" of the family. Cohesiveness, it may be argued, is marked by the extent to which group members are willing to participate in group activities, wherever they are carried out and whatever their nature may be. The feeling of attraction experienced by the members for the group is thus expressed in the ratio of their joint to their individual activities. The more attractive a group, the more activities are carried out in conjunction with other members, and the less attractive it is the more will members "opt out" and act as individuals or join other social groups. A highly cohesive family will thus be marked by the fact that its members like doing things together and are frequently to be found in close association, while in a family of low cohesiveness members tend to avoid each other and to participate in few joint activities. By ranging families along a continuum representing the degree of habitual togetherness, an indication of the degree of cohesiveness may be found.

There are several advantages to approaching the assessment of cohesiveness in this way. For one thing, it is based not on a single narrow index, but on a whole range of the family members' activities. For another, the aspect of these activities with which it is concerned is relatively easily defined and does not refer to vague characteristics. And finally, it takes cognizance of another point which arose from our

previous theoretical discussion of cohesiveness, namely the distinction between cohesiveness as seen from the individual point of view and cohesiveness as a group phenomenon: the index is based on the activities of all the individual members of a group, yet the phenomenon to which they give rise, namely "togetherness", is a group characteristic and as such truly comparable to cohesiveness.

To obtain this measure, questions were asked at each interview as to the extent to which the family had been together in the preceding seven days. "Togetherness", for this purpose, entailed physical proximity, i.e., family members did not all have to be jointly engaged in the same activity, as long as they were in each other's company. If, for instance, mother was washing up, father was reading a paper, one child was doing home work and another child playing, they were all considered to be together under the same roof and pursuing activities within the family circle. "Togetherness" scores were not, of course, confined to home activities, but also took account of family visits and outings. Thus the measure was applied irrespective of place or nature of activity.

In so far as some degree of separateness is almost universally necessitated by attendance at work and at school, note was taken for the present purpose only of the time when the family could potentially have been together, i.e., the period between father's return from work (or a child's return from school, if this occurred later) and the parents' bedtime (if father voluntarily stayed on at work in order to do overtime, or if he stopped on the way home for a drink or to visit a relative, a deduction was made from the "togetherness" score). For the weekend, all the time that father did not have to be at work was taken into account.

The "togetherness" score represents the percentage of days within all the seven-day periods preceding the interviews on which the family had been together in the sense defined above. If, for example, enquiries had been made at six interviews as to the activities of family members in the previous week, the total number of days on which a "togetherness" score could have been obtained is 42, and if a family had in fact been together on 21 of these days, the percentage score for this family would be 50.

Assessment of community participation.

The operational definition of this phenomenon does not give rise to the same theoretical problems as those encountered in the case of cohesiveness, yet the literature yields only one instance of an attempt to measure community participation. Townsend (1957), while attempting to assess the degree of social isolation experienced by old people, developed a measure based on the number of contacts per week that the individual had with others. A contact he defined as "a meeting with another person, usually prearranged or customary at home or outside, which involves more than a casual exchange of greetings between, say, two neighbours in the street." Meetings with relatives, friends, doctors, etc., were each given a score of one, while other social activities received an arbitrarily chosen score (a weekly visit to a club, cinema, or church was given a score of 2, for instance; a full-time occupation was given a weekly score of 20; and a part-time occupation was given a score of 10). Townsend admits that there are difficulties in applying this method, and it is indeed difficult to see why a visit to a cinema should merit double the score assigned to a visit to a relative. Nevertheless, he does feel that this method is at least feasible, and one must sympathise with his difficulties in extracting a single quantitative index from a rather complex situation.

The measure used here is a modified version of Townsend's. Defining "contact" in the way suggested by him, we shall again consider the total number of days within all the weekly periods preceding each interview, and express the score as the percentage of days on which contact with people outside the family occurred. No account is taken of "compulsory" contacts at work and at school, so that only an individual's voluntary activities are considered. A day is scored as having included a social contact irrespective of the number of contacts or their length, the place where they occurred (at home or outside, with whom they were made and for what reason, or how many family members participated in each. Without doubt this is also a somewhat arbitrary procedure, and with a sample less extreme in its social habits it might well have been less successful in discriminating cases to any useful degree. Yet in this

particular case it is doubtful whether a more microscopic analysis would have produced substantially different results, and the present procedure is therefore employed as a sufficient means of demonstrating the range of behaviour found here.

Results

In table 12 the results are presented which were obtained from the methods of scoring outlined above. The families are also ranked in order on each of the two dimensions.

Table 12.
Scores and Ranking on the Two Family Dimensions

<u>Name</u>	<u>Cohesiveness</u>		<u>Community Participation</u>	
	<u>Score</u>	<u>Rank</u>	<u>Score</u>	<u>Rank</u>
Watson	91.6	1	14.0	30
Baker	90.0	2	24.5	25
Johnson	85.7	3	18.8	27
Sawyer	82.2	4	28.4	22.5
Strang	80.0	5	25.7	24
Vallance	77.6	6	22.3	26
McBain	76.8	7	16.0	28
McNeil	75.0	8	53.7	15
Anderson	73.3	9	14.3	29
Lane	71.4	10	32.5	18
Hooper	69.9	11	28.6	21
Newland	68.6	12	31.2	19.5
Stewart	68.1	13	28.4	22.5
Sinclair	67.5	14	33.2	17
Cairns	64.3	15	59.5	13
Napier	62.7	16	62.7	16
Cunningham	57.1	17	60.2	12
Parkinson	51.6	18	63.0	10
Burgess	51.1	19	59.2	14
Purdon	48.6	20	31.2	19.5
Fisher	45.3	21	62.1	11
Kelley	40.5	22	83.6	5
Phillips	40.0	23	65.8	8
Fletcher	34.8	24	94.2	3
McGuire	32.0	25	64.4	9
Richardson	21.4	26	100.0	1
Donaldson	20.0	27	86.0	4
Murphy	19.0	28	97.7	2
Jackson	17.1	29	80.0	6
Robertson	14.3	30	71.6	7

Two features of this table deserve comment. In the first place, perhaps the most striking fact which emerges relates to the wide range of scores covered by the sample on both dimensions. With regard to cohesiveness, we have at one extreme a family who obtained a percentage score of 91.6 because, of the 35 days covered by the enquiry periods, all members of the family had been together during their spare time on 32 of these days. At the other extreme, however, a family is found which, out of a possible total number of 28 days, had spent only 4 of these together as a family group, thus obtaining a percentage score of 14.3. The same diversity of scores applies to community participation: at one end of the range we find a family in which outside contacts were made only on 5 out of 35 days (giving a percentage score of 14.0) and at the other end a family reported such contacts occurring on every one of 42 days and obtaining in this way a percentage score of 100. One conclusion can therefore already be stated: cerebral palsied children are not all found in families of homogeneous characteristics, at any rate as given by the two dimensions investigated here. Even in such a relatively small sample a very wide range is covered, from families that show a very high degree of "togetherness" to families that show this characteristic to a very low degree, and from families where the amount of community participation is very great to families that appear relatively isolated socially.

The other point to which attention must be drawn refers to the relationship between the two dimensions. As will become readily apparent from an inspection of the table, the two phenomena are related together to quite a marked degree, and both scores and ranks indicate the extent of this association. The correlation is a negative one: those families showing a high degree of cohesiveness participate to only a limited extent in the outside community, and those with low cohesiveness are characterised by a considerable amount of community participation. The strength of this association is expressed by a product-moment correlation coefficient of -0.89 as based on the scores, or by a rank-difference correlation coefficient of -0.91 .

These high coefficients show that in the present sample the two facets of family organisation which we have examined are closely related to one another. Thus the two characteristics jointly define the type of organisation to be found in any given family, and in this way it becomes possible to range our families along a continuum according to their joint standing on the two dimensions. For the sake of clarity of presentation in the chapters which are to follow we shall, however, make certain arbitrary breaks in the continuum and describe the families in terms of three contrasting types. These types are obtained by, in the first place, diving the possible range of scores (0 - 100) into three equal parts, as has been done in Table 13.

Table 13.
Number of Cases in Three Divisions of Scales

	<u>S c o r e s</u>		
	<u>0 - 33.3</u>	<u>33.3 - 66.6</u>	<u>66.6 - 100</u>
Cohesiveness ...	6	10	14
Community Participation .	14	9	7

The two dimensions may then be combined and the typology be derived from this combination by taking all those cases falling into the lowest of the three grades of cohesiveness (those with scores between 0 and 33.3) which also fall into the highest of the three grades of community participation (those with scores between 66.6 and 100). Similarly, at the other extreme, the group will be made up of all those cases whose scores fall into the highest grade of cohesiveness (above 66.6) as well as into the lowest grade of community participation (below 33.3). This leaves an intermediate group, whose scores fall into the middle range of the scale for either one or both of the dimensions.

In the following chapters these three types of families will be described and contrasted. From this descriptive material we shall attempt to show that in this sample the two dimensions which we have examined in fact reflect one and the same characteristic, namely, the extent to which the organisation of the family centers on the handicapped child. Thus at

one extreme we find the kind of family in which all activities are oriented towards the handicapped child to such a marked degree and where the members are all so "absorbed" in him that their preoccupation will result, on the one hand, in a high degree of "togetherness", and on the other hand in a small amount of community participation. This type of family will be referred to as the "child-centric" type, and in the present sample there are 13 families who were classified as such according to the above criteria. At the other extreme we find a type of family whose functioning shows just the opposite tendency, namely where at least one of the members undertakes a great many activities away from the child and is involved with him to only a very limited extent - thus producing low scores on "togetherness" but high scores on community participation. This type of family will be labelled here as "child-fugio", and 5 of the research families were classified in this way. In between these extremes we have the "intermediate" type of family, i.e., those families who according to the above criteria tended to produce scores in the middle range of at least one of the two dimensions. There were altogether 12 such families in this sample.

CHAPTER 7

THE FAMILY: DESCRIPTION OF TYPES

The two dimensions of cohesiveness and community participation and the family types which were derived from them have provided us with a framework around which we can now assemble the descriptive data. These will be reviewed under headings referring to the various areas in which family life takes place. Generally speaking, the activities of the family can be grouped according to whether they take place within the home or outside it. Amongst the former, child care and household activities can be considered as the most important functions performed by the members, whilst among the latter leisure activities, work, and contact with relatives, neighbours, and with official agencies may be singled out. A family's cohesiveness can potentially manifest itself in all these areas, but the evidence relating to community participation will, of course, emerge only from the latter group of activities.

By presenting the information gained from the interviews with the families under the above headings, and by comparing and contrasting the three types of families in their performance of these activities, it is intended to clarify the manner in which the varying degrees of cohesiveness and community participation manifest themselves. In this way an impression will be gained of the roles played by the various family members, both in relation to each other and in the external community, and of the part which the cerebral palsied child plays in each of the family types. From a detailed analysis of the descriptive material available on the various aspects of family functioning the "life-pattern" of the three family types will emerge and it will thus become possible to reach certain conclusions regarding the forces from the social environment which impinge on the handicapped child.

Child care activities.

In this section we shall be concerned with the part child care activities play in the lives of the research families, with particular

reference to the care devoted to the handicapped child. The quality of these activities will not be examined until we turn to the socialising practices of the parents in a subsequent chapter: here we shall interest ourselves in the manner different families cope with this task, what division of labour exists in this respect, and how much of the family's time is spent on this activity. For the purpose of this analysis we shall define child care activities as the performing by another person of actions aimed at relieving in the child a need perceived by that other person.

A handicapped child, particularly if he is severely affected, clearly requires rather more care, supervision, and help than other children of his age. A normal child, if he is hungry, can explain his need to his mother, can be told to go to the kitchen and fetch some item of food, and can then feed himself with it. Many cerebral palsied children can do none of these things: even the interpretation of the child's need may have to be undertaken by others. During infancy this state of affairs can be observed in all children, but with the handicapped child it tends to be prolonged well beyond the usual period. Thus the demands made on parents are often considerable, and we must now enquire how the families in this sample dealt with this situation.

Traditionally, child care activities are primarily the mother's responsibility, and there was in fact no instance in this sample where the mother did not play a greater part in child care than any other single individual. Within these limits, however, there was considerable variation in the manner in which different mothers interpreted their task, and perhaps the most striking feature which emerges from the descriptions of their daily life refers to the extent to which they felt themselves able to leave the child's physical presence and hand him over for the occasional hour or two to the care of others. Table 14 helps to illustrate these differences. It is based on the information sought from the mother at each visit as to the number of days within the previous week on which she had left the cerebral palsied child for

a period of at least half an hour in the care of another person. "Compulsory" separations, such as those occasioned through attendance at school or treatment centers, were disregarded. From the answers obtained at different visits an average figure was calculated for each family, and it is these figures that determine the frequency category in the table to which the family is allocated. The results are analysed according to family type, and, using the table as guide, the relevant behaviour patterns will be described below in the form of case extracts.

Table 14.

Handicapped Child left by Mother
in the care of others
during previous week

	<u>Child- centric Families</u>	<u>Inter- mediate Families</u>	<u>Child- fugio Families</u>
Occurred on 0 - 1 Days	10	1	4
Occurred on 2 - 4 Days	3	9	0
Occurred on 5 - 7 Days	0	2	1
Total	13	12	5

Turning first to the child-centric group of families, we find that in the majority of these cases the mothers were extremely closely bound to the handicapped child, were reluctant to let him out of sight, and became quite upset if he had to be away from them for even a short time. The nature of this involvement with the child can best be appreciated from the following examples, selected as representative of the ten families in this group where mother rarely if ever reported leaving the child:

Bryan Strang, 6 - 4 years, athetosis, S.I. 11.* In his early years Bryan used to cling so much to his mother that she rarely found it possible to leave the room without him bursting into tears. This gradually improved, yet for a long time mother continued to behave as though he were still making the same demands for her presence. For years she made a point of never leaving him, taking him around with her everywhere, and at nights having his cot right next to her bed in case he should need her. Friendly neighbours have offered to look after him so that she could have a chance to go out, but she has always refused - at first because the child would be too upset and later, when this clearly could not be held any more, because she would be too worried when away from him. When he began to attend school, mother confessed that for the first week or two she was "worried out of her wits", wondering how he could manage on his own with complete strangers. She felt quite lost during this time, not knowing what to do with herself. Yet gradually she began reorganising her life, and later, with considerable insight, was able to say: "I now realise that before he went away to school I was always completely preoccupied with him - almost unconsciously so, for I did not realise it at the time. I was always rushing through the work to get back to him, and even when I was just in the next room I was wondering what he was doing and if he was all right."

* All case illustrations will be preceded by the name of the child, his age at the end of the observation period, his diagnostic category, and his score on the severity index (S.I.). Considerable care has been taken to preserve the anonymity of the families by changing names and other details which make it possible to identify them.

Christine Anderson, 5 - 5 years, spastic quadriplegia, S.I. 7. Although mother admits that the constant strain of being with with child is almost too much at times, she never leaves her with anyone except, very occasionally, father or an older sibling. At one time she used to leave Christine with the mother of another cerebral palsied child for an hour or two once a week while she went shopping, but this arrangement was short-lived. Though several sets of friendly neighbours are willing to have the child and so give mother an opportunity to have an occasional outing on her own, she always refuses - because, as she puts it, "these people would have no idea of how to pick her up properly or how to put her down, and they might so easily hurt her by putting her in an uncomfortable position." Sometimes, however, when father comes back from work, mother feels she simply has to get out of the way for a while, and she then goes upstairs and lies on her bed for half an hour or so. When Christine started attending school, mother was so worried about her that she was unable to get on with her housework during her absence, and often stood waiting at the window a whole hour before the bus was due to bring her back. Gradually she began to relax, however, and she now makes use of the child's absence to get her work done, so that she can devote all her time to Christine on her return.

Betty Johnson, 6 - 0 years, athetosis, S.I. 12. At one time Betty refused to stay with people other than her father or her mother, and ever since, when father is not at home, mother is continuously with her. Neither she nor the father ever go out in the evening without Betty, although they have potential babysitters available. Mother admitted that she does not want her looked after by anyone else, as she would not know what to do without her. The only time she is away from the child is on a

Saturday afternoon, when she goes shopping for an hour or two while father stays with Betty. When Betty is out in the garden mother is continually at the window to keep an eye on her. The child spends every evening with the parents, not going to bed till they do, and then shares the bed with them, sleeping right between them. When at the age of five the child was hospitalised for 3 weeks mother was in a highly agitated state throughout this time, although she knew that nothing serious was involved in the hospitalisation. She agreed that having to keep an eye on the girl all the time made her extremely nervous and was also very tiring, as she had to be continually on the go.

Donald Baker, 7 - 0 years, spastic paraplegia, S.I. 12. This mother found it difficult to remember when she was last away from her child for more than a few minutes. The parents never go out alone but always take Donald with them. During the day mother is continually with the boy, and though she is glad to have some neighbours' children calling to play with him, she does not want him to go out to play in their house. When at 6½ years of age the boy began to go once a week to the local school for a "playhour", mother was very agitated at first, and insisted on spending the whole time peering through a glass partition where she could see the child and he could see her. Shortly after he began there he was hospitalised on account of a major epileptic fit, and this was such a dreadful experience for mother that she was later quite unable to talk about it. Following this, she used to creep up to the child's bedroom several times every evening, to make sure he was all right.

These case illustrations show that mothers in the child-centric families tend to foster an extremely close contact with the handicapped

child, that they find it sometimes extraordinarily painful to tolerate the everyday separations which tend to occur in the lives of all mothers and children, and that to them child care means the supervision of the child's every moment. In three of the child-centric families the mothers, according to Table 14, have somewhat more freedom, but in these cases the fathers were always available to step into the mothers' place.

The mothers in the intermediate group, on the other hand, showed greater independence. In no case were they quite as unable to leave the cerebral palsied child or as upset by the prospect of having to do so as the child-centric mothers. Even when the child was rather clinging or when it was difficult for practical reasons to have him looked after by other people while mother went out, some sort of arrangement could usually be found. Child care for these mothers did not entail a continuous and unbroken contact with the child: they were able to leave the child at times to his own devices and did not feel the necessity of being always near him and interacting with him. The child-centric mothers could not usually stay away even when their husbands or some other trusted figure was with the child, whereas the women in this group liked to use such people in order occasionally to get right away and relax:

Michael Purdon, 7 - 0 years, spastic quadriplegia, S.I. 8. In the summer mother encourages the boy to get out into the garden or street as much as possible and play there with other children, so that she can get on with her work in peace. He is then often out of sight for hours on end, but mother, having impressed on the other children the need to look after Michael because of his handicap, feels no cause for concern. In the winter, however, mother and child are often stuck together all day because of bad weather, and then, mother admits, she could sometimes at the end of the day "cheerfully sell him for twopence." What she does instead is to hand him over to his father as soon as he returns from work, or, if father is working late, the oldest brother and his girl friend are sometimes asked to take care of him while she goes to the cinema.

Samuel Napier, 7 - 7 years, athetosis, S.I. 11. Mother freely admits that she and the boy sometimes get on each others' nerves through being together such a lot, and that this happens particularly on rainy days when they cannot get out. She therefore encourages him to go out on his bicycle as much as possible, and though for a long time she had to ask him to stay near the house as he was not very safe on his own, she related with pride how one day he disappeared round the corner, circled the block on his own, and came back triumphantly and quite safe. Since then mother has let him go as far as he likes on his bicycle as long as he does not cross any streets. She is pleased that he has formed several friendships with other children nearby and that he is often invited to play in their houses for an afternoon. Once a week she sends him to Sunday school, and though at first she used to take him and even stay with him, now she lets an older child in the neighbourhood take him and bring him back.

Charles Burgess, 5 - 6 years, spastic paraplegia, S.I. 3. For a long time this family lived together in one small room, where it was difficult to get away from one another. Mother said it often made her extremely bad tempered at the end of the day, and she was most grateful that father was willing to take Charles out for a while after his return from work. "I like my children," said this mother, "but I also like a bit of freedom, and I find I usually like them better if I can get away from them from time to time." Thus the child is encouraged to play outside or to visit his grandmother next door during the day, and at the week-end father sometimes takes him out in the car while mother stays at home to get on with the work or even to have a nap. Once a week the parents visit the cinema, and mother values this opportunity to go out very much. She looked forward to Charles beginning school, and when he did so found life very much easier

and more relaxing. The first day at school she had been rather worried and kept wondering how he was taking it all, "but the moment I saw his face when he came out I knew all was well and that I need not worry any more."

The two mothers in this group who were separated from their children most frequently were both able to do so because of their close ties with members of the extended family, who frequently took the child for lengthy periods:

Doris Fletcher, 6 - 2 years, spastic paraplegia, S.I. 3. Ever since the birth of another handicapped child the paternal grandmother helped mother to look after Doris. Thus, since the age of 3, Doris is sent by mother every morning over to her granny, so that mother can more easily manage her work. After lunch, however, mother takes her other children along to the grandmother's house, and all of them spend the afternoon together there.

Kenneth McGuire, 3 - 3 years, spastic quadriplegia, S.I. 4. Mother sees a great deal of her own mother and also of one of her sisters, and both these women often have Kenneth staying with them for a whole day. Mother feels that this is good for the boy and is grateful for the opportunity not to have him too dependent on herself. At times Kenneth has even spent whole weekends away from home. For the rest of the time, however, mother is with him all day, except on those occasions when she asks a neighbour to look after him while she goes out shopping.

In the child-fugic group we find a rather more heterogeneous selection of cases. Four of these follow the child-centric pattern, in that mother is rarely if at all separated from the child:

Gladys Murphy, 8 - 0 years, spastic quadriplegia, S.I. 6. Mother is always with this child, for though she spends most of

the day with the maternal grandparents, she never takes the opportunity of leaving her there in order to pursue some independent activity. She becomes uneasy when Gladys goes out to play, and is then constantly at the window to make sure that she is still all right. When the child was hospitalised for a lengthy time in order to be given intensive physiotherapy, mother was completely distraught and so much at a loss that she had to take a part-time job. This she did again when Gladys started at school at the age of 7, as even with her own parents mother found herself "terribly lonely." When the child returns from school in the afternoons, mother often tries to stop her from going out to play in the street, telling her that she should rest at home or bribing her with sweets and toys. She plays a lot with her, and gets very upset when Gladys becomes bored and depressed by staying in so much.

Muriel Donaldson, 5 - 11 years, spastic hemiplegia, S.I. 10. The child's frequent though minor epileptic fits are given by mother as the reason for her constant supervision of the girl. Muriel is very keen to play outside in the street, and though mother cannot prevent her she suffers agonies and is continually at the window to keep an eye on her. Mother always goes to bed with Muriel, so that she can make sure even then that she is safe. Yet occasionally mother suddenly feels that she must get away, and then insists on leaving her with whatever other member of the family happens to be at home.

The one exception in this group is a mother whose constant theme was to get "a break from the child", and whose activities in relation to the child clearly reflect this need:

David Richardson, 4 - 0 years, athetosis, S.I. 14. Not only is the child often left with other people (father, neighbours, relatives, friends), but even when he is with mother he is usually kept at a distance, for mother finds his demands for attention

often irksome. When he cries because he is left outside a shop, she refuses to take note. When he demands to be picked up or wants to be in the same room as mother she gets exasperated and smacks him. He has never been fed on her knee, as mother does not want to foster physical contact in case he gets "spoiled". If he cries during the night, father has to attend to him as mother never hears him. When going out in the car, mother finds him too restless to hold on her knee, and so always leaves him lying on the backseat while she sits in the front with father. Yet the first time he was left with the grandmother while the parents went for what was to be a week's holiday, mother got so worried about him that she had to return after 2 days. Similarly, after having smacked him and put him to bed for some misdeemeanour, she had to keep going to his bed to make sure he was still all right and had not had a fit (which he has never had).

One must conclude that the responsibilities which the mothers shoulder in relation to the care of their handicapped child tend to vary as between the three groups of families. Amongst the child-centric families most mothers foster a very intense contact with the child, are obliged to keep him under constant supervision, and are unable to withdraw even when other responsible people are available to take care of the child. There has taken place, one may interpret, an exaggeration of the parental role on the part of the mother. Amongst the intermediate families, on the other hand, no evidence for such a tight bond between mother and child was found, and the total amount of time devoted to child care activities was not as great as with the child-centric families. In the child-fugic group, finally, the two extremes are shown, in that on the one hand we find some mothers who show the same pattern as that described for the child-centric group, and on the other hand we find a family in which the mother appears to be withdrawing from her maternal responsibilities. In the former four cases it was father, as we shall presently see, who gave the family its "child-fugic" character, so that in the whole sample we can find only one

mother whose pattern of activities suggests a rejection of her maternal role vis a vis the handicapped child.

What of father's participation in child care activities? It may be thought that in those cases where mother spent so much time with the child, father would tend to be crowded out and play only a minor role in this respect. This, however, was not found to be so, for one of the most striking characteristics of the child-centric families was the extent to which father as well as mother devoted his time to the handicapped child. To obtain an index of his involvement with the child, questions were asked at each visit about the number of days within the previous week on which father had devoted all the time that he was not actually at work to being with the child and on how many days he had pursued activities away from him. The answers thus obtained at different times were averaged for each family, which was then allocated to the appropriate frequency category as given in Table 15.

Table 15.

Number of Days in Previous Week
on which Father had spent all his non-working time
with Handicapped Child

	<u>Child- Centric Families</u>	<u>Inter- mediate Families</u>	<u>Child- Fugic Families</u>
0 - 1 Day ...	0	0	4
2 - 4 Days ..	0	10	1
5 - 7 Days ..	13	2	0
Total	13	12	5

These figures suggest that, for the child-centric group, father's participation in child care activities was considerable. This will best emerge from the following examples:

Mary Sawyer, 4 - 9 years, spastic quadriplegia, S.I. 8. For the major part of the period of observation father was unemployed and therefore almost constantly available. Indeed, he made few efforts to find another job, preferring to spend his time with Mary. Most of his day is spent in playing with her or in taking her out for walks. He takes part in all the routine child care activities, helping to bath her and put her to bed, and he also gives her the exercises which he had devised himself in order to help her limbs. The child has become very clinging to him, is upset when he goes out without her and refuses to go to bed alone. As a result father goes to bed with her at 8 o'clock every evening, sleeping with her in the same bed.

Catherine Newland, 4 - 6 years, spastic quadriplegia, S.I. 7. "Wherever Catherine is you are sure to find her father." That, according to the parents, is what the neighbours laughingly say about them. And indeed, father spends all his spare time with the child, helping with feeding, bathing, and putting her to bed. But most of his time is spent in taking Catherine for long walks, for father's main concern is to "strengthen her limbs." This has been very much less in evidence since the girl became mobile, whereas previously father used to take her out for 2 hours every evening after his return from work.

Christine Anderson, 5 - 5 years, spastic quadriplegia, S.I. 7. Father had himself put on nightshift so that he might have more time to help mother to look after the child. He will play a lot with the girl during this time, and will often undertake all the routine feeding and toileting activities, as mother is too exhausted from the broken nights which the girl's considerable sleep disturbance produces. Father also helps in bathing Christine, as her weight and handicap make this a two-man job. He always accompanies mother and child on their frequent outings to doctors, hospitals, and other official agencies, so that he can help to carry the child.

Norah Sinclair, 5 - 5 years, spastic quadriplegic, S.I. 8.

Information about this child was nearly always supplied by father, for, as mother readily admitted, he is such a lot with Norah that he knows as much if not more about her ways as she does. He is continually playing with her, taking her out for rides in the car, or providing other forms of amusement. Yet the routine child care activities (feeding, bathing, etc.) are mainly mother's domain - father is quite willing to undertake them if mother is very tired or is ill, but he considers that this is really women's work and that it would not be "manly" to do such things regularly.

Thus the fathers in the child-centric group of families are also found to have increased their parental responsibilities, spending a great deal of their time simply being with the handicapped child and participating to a considerable extent in child care activities during the time not spent at work. Some of these men, one felt, were quite obsessed by their handicapped children, and their intense involvement, being culturally more deviant than a mother's, was therefore much more noticeable. Thus the exaggeration of the parental role described for the mother in this type of family is also evidenced by father.

Amongst the twelve families of the intermediate type this phenomenon was seen in only two instances. In the majority there was little doubt as to the manner in which responsibility for the care of the cerebral palsied child was shared, for mother undertook by far the larger share of this task and father was rarely involved in anything but a subsidiary role. These men were generally willing to lend a hand, and at times of mother's illness might even take over the children completely, but in the discussions with these families it became quite clear that, however interested father was in his child, he considered his upbringing to fall within mother's domain and to concern him to only a limited and at times strictly defined extent. The following case illustrations have been selected as typical of this pattern:

Joan Kelley, 3 - 3 years, spastic quadriplegia, S.I. 9. The total amount of child care to be undertaken in this family is considerable, for not only is Joan a young and fairly badly affected child, but there is also a brother only a year older. Father is on shift work and is thus often at home during the day, yet it is mother who for the most part looks after the children. She is thus very much on the go, but she has the necessary energy and believes that this arrangement is only right. Father does take the children out at times, and will also partake in disciplining them, but most of the training is left to mother. When he returns from work father generally prefers to read the paper, garden, or watch T.V. Playing with the children he would rather do when he is not tired, as otherwise they tend rather to get on his nerves. He does help mother at bedtime whenever he is not at work, but even then feels that there are certain jobs which are exclusively women's, e.g., when mother bathes the child he will dry and hold Joan, but never actually wash her.

Cecilia Parkinson, 6 - 0 years, spastic quadriplegia, S.I. 8. Father feels he spends on the whole more time with this girl than he used to with her older sister when she was at the same age, and mentions how he plays with Cecilia after supper every evening and at the weekend often takes her out. He will also help, if asked to do so by mother, in putting her to bed or supervising her feeding, but if he is not asked he will automatically assume that mother will perform these tasks alone. He has never bathed the child in his life, and would be quite at a loss if he had to do so. If he is watching anything of interest on T.V., the child has to wait before he will play with her.

Marilyn Phillips, 3 - 11 years, spastic quadriplegia, S.I. 17. This is a very helpless little girl, who needs quite a lot of attention and care. Fortunately the other children in the family are old enough to be fairly independent, and mother can therefore devote most of her time to Marilyn. Father's part is a peripheral

one: he frequently works overtime for the sake of the extra money and does not get home then until the child is about to be put to bed. At weekends, however, he will play with her, take her to the park or carry her to the local shops for an icecream, and, if mother is very busy in the kitchen, he will, if necessary, change the child's nappy. He will also put her to bed, but only when mother goes out for the evening. Occasionally he will feed her, but he readily admits that he soon loses patience because of Marilyn's slowness and will then hand her back to mother.

Thus in most of the intermediate families, mothers tended to assume responsibility for the rearing of their handicapped child in a much more exclusive manner than is found in the child-centric families. Fathers played a more peripheral part in this area of family life, and, though generally willing to help if need be, they tended to have fairly definite ideas about the point where the line should be drawn between a father's and a mother's responsibilities. A division of labour existed here which was not found among the child-centric families, and as a result father's role tended to be more sharply delineated from that of the mother. The interaction between these men and their handicapped children tended to be less intense, they never felt it necessary to devote all their spare time to them, and in discussions about the child they rarely were able to give as much information about them as their wives.

In the child-fugic families this trend was carried a great deal further. The distance between father and child was generally such that the paternal role could hardly be said to exist in most of these cases. As will be seen from Table 15, four of the child-fugic families provide the only instances in the sample where father took hardly any part at all in this sphere of family life:

Albert Jackson, 3 - 0 years, spastic quadriplegia, S.I. 4. Mother usually does everything, for father is away from home a great deal. When he is at home he generally has little to do with the child. Very occasionally he will pick him up and play with him for a while,

and once or twice in the past he has had him on his knee during a meal and fed him. This, however, is the sum total of his direct interaction with the boy, for he never takes him out or joins mother when she does so, and the only occasion when mother left him to look after the boy for the evening he became so annoyed by his crying that he refuses to be left with him again.

Sally Robertson, 3 - 1 years, spastic quadriplegia, S.I. 6.

Although father is often unemployed, he rarely spends his time at home, and even when he does he refuses to be involved in helping with the child. Apart from occasionally playing with her (usually some rough play like boxing), he rarely interacts with her in any way. Sally is thus exclusively looked after by her mother and all routine tasks in child care are performed by her. Father has never in his life fed her, bathed her, or put her to bed, and though he has occasionally taken her to the cinema, he always insists that mother should come too in order to look after her.

Muriel Donaldson, 5 - 11 years, spastic hemiplegia, S.I. 10.

This father was the only one in the sample who could not be interviewed. He tends to dissociate himself as far as possible from anything to do with the child, for he finds himself quite baffled by her and gets very ill at ease when asked to look after her. Mother believes that it is really Muriel's frequent epileptic attacks which frighten him, though he will not admit it. Despite the fact that mother has become extremely nervous through the strain of looking after the girl, father prefers to spend his time away from home to the risk of having to help with Muriel.

Gladys Murphy, 8 - 0 years, spastic quadriplegia, S.I. 6. As mother spends every possible day with Gladys over at the house of her parents, and as father hardly ever joins them on these visits,

the maternal grandparents have far more to do with the girl's upbringing than her father. Father feels that mother fusses the child far too much and does not give her enough freedom, while she resents the fact that he does not play more with the girl. He does occasionally take her out on his bicycle, but otherwise his only interest is in getting her to walk, and the daily exercises he gives her are the only regular times when he interacts with her. He rarely shares in the routine child care activities and knows little about the girl's eating or sleeping habits. When Gladys was hospitalised for a number of weeks, he visited her only once.

The only case in this group where father did participate to a somewhat greater extent in the care of the cerebral palsied child was in the family where mother provided the only clear-out example of overt rejection of the maternal role:

David Richardson, 4 - 0 years, athetosis, S.I. 14. Father has to partake a fair amount in the rearing of the child, for mother very often "downs tools" when he comes back from work, hands the boy over to his care, and goes out in order "to get a break." Father then looks after him for the evening, feeds him and puts him to bed. He also attends to him, if necessary, at night. There is, however, no intense involvement with the child on his part either, and by frequently handing over to relatives for part of the day or even for several days on end, father as well as mother shows his reluctance to assume the parental role.

The role of the father in this sphere of family functioning, i.e., the extent to which he will participate in the care of the handicapped child, is, in this sample, one of the most crucial factors in determining the nature of the family's organisation. There are considerable individual differences to be found amongst the thirty families, ranging from intense

involvement of father with child (as found in the child-centric group) to the evasion of parental tasks (as seen in most of the child-fugic families). That more fathers than mothers showed the latter pattern of behaviour is hardly surprising, for in our society rejection of the maternal role is disapproved to a far greater extent than rejection of the paternal role. It is therefore all the more surprising to see how many fathers showed in their activities an extraordinarily intense preoccupation with the handicapped child - frequently, as we shall see, at the cost of all other activities.

The picture of father's part in child care activities so far drawn must, however, be modified to some extent by taking into account the nature of the tasks in this area which the fathers assumed. Our emphasis so far has been mainly on the amount of time spent by them with the child, and it may be thought that a father's very high participation necessarily involves him in assuming a maternal role and carrying out tasks usually associated with mothers. Yet, as some of the case extracts have already indicated, even amongst child-centric families some fathers insisted on a strict division of responsibilities. This is borne out by Table 16, which presents the types of child care activities customarily undertaken by the fathers of the three groups.

Table 16.
Types of Child Care Activities
undertaken by Fathers

	<u>Child- Centric Families</u>	<u>Inter- mediate Families</u>	<u>Child- Fugic Families</u>
All Types of Activities ..	8	6	1
Routine Activities only ..	0	0	0
Play Only	4	6	0
Exercises Only	1	0	1
No Participation	0	0	3
Total	13	12	5

From this table one can see that even amongst the child-centric families there were five fathers who, despite the considerable amount of time spent by them with the child, were not willing to undertake such routine tasks as washing, feeding, toileting, etc. In four cases their activities were confined to playing with the child, taking him out, and providing other forms of amusement, and in one further case the father devoted almost his entire spare time to the correction of the child's handicap, by giving her exercises, taking her for long walks, and attempting to teach her reading, writing, and other intellectual skills. Routine activities in these five families were undertaken by the mothers. Even in the eight cases in this group where father did participate in routine activities he did not do so to the exclusion of the mother, but acted as a helper, albeit often a very active one. Thus the emphasis on father's parental role does not necessarily entail a feminisation of that role: cultural traditions clearly still play some part in limiting the range of permissible activities.

Fathers in the intermediate group do not differ a great deal in this respect from the fathers in the child-centric group. Half of these men also did not under normal circumstances participate in routine child care activities. The other half had somewhat less strong views on the male-female division of labour, but again tended to play a distinctly subsidiary role to mother when they did take part in bathing, feeding, etc. Finally in the child-fugic group one father participated in all types of activities, whereas the other fathers had little to do with their children at all, though one of them did make regular attempts to correct the child's handicap.

It has become apparent that the bond between parents and child is far tighter in some families than it is in others, and that this varies as between the three types of families which we have suggested. As this is one of the main features distinguishing the nature of family organisation found in the three types, we shall illustrate it by one further piece of evidence. This emerged when the possibility of residential schooling was raised with the parents. As one of the purposes of the initial screening interview was to determine whether the child might not best be

helped by admitting him to a residential centre for the cerebral palsied, the attitudes of the parents to such a possibility was always determined. Table 17 summarises the reactions of both mothers and fathers in the three groups.

Table 17.
Parents' Attitudes to Residential Placement

	<u>Child-Centric</u> <u>Families</u>		<u>Intermediate</u> <u>Families</u>		<u>Child-Fugic</u> <u>Families</u>	
	<u>Mother</u>	<u>Father</u>	<u>Mother</u>	<u>Father</u>	<u>Mother</u>	<u>Father</u>
Definitely Refuse ...	9	8	1	1	2	0
Accept, but Reluctantly	4	5	6	6	2	0
Definitely Accept ...	0	0	5	5	1	5
Total	13	13	12	12	5	5

The figures show that a majority of the parents in the child-centric group would not countenance such a proposal - despite the fact that they would have had to bear no financial responsibility, and despite the eagerness of all to obtain the intensive treatment and educational facilities which would have resulted from such a course. There was one disagreement between married partners: one father said he would accept, though reluctantly, any offer made, whereas his wife was definitely against such a notion. In the intermediate families no disagreements occurred, and here most parents expressed their willingness to accept any opportunity that might arise for residential placement, though often rather reluctantly. In the child-fugic group, however, it is of interest to note that all the fathers expressed themselves definitely willing to accept residential placement, yet in only one family a similar attitude was shown by the mother.

So far we have examined child care activities as they are performed by the parents of the handicapped child. We must now proceed by also examining the part siblings play in this sphere. That in general siblings

may be very much affected by the presence of a handicapped child in the family has been stressed by a number of studies, and a separate section might easily have been devoted to them. Here, however, we are not so much concerned with the siblings per se, with their individual personalities and adjustment and their relationships to parents, as with the part they play in the family group as a whole, and this may best be illustrated by describing the extent to which they too are involved in the care of the handicapped child.

The potential participation of a sibling in the care of a handicapped child will vary to a great extent with age. A baby of twelve months can hardly be expected to help in the routine care of his four-year old handicapped sibling, whereas a twelve-year old sister might well act as a second mother in this respect. Yet even the very youngest may be affected by being called upon to render "services" on behalf of the handicapped child, and though such services may not be voluntary, they nevertheless reflect the extent to which the siblings are drawn into the care of the handicapped child. Whether a sibling offers to take part in feeding or dressing, or whether he is told to give up a toy to the cerebral palsied child is immaterial from this point of view: in both cases he is (according to our definition of child care) relieving a need in the handicapped child as that need is perceived either by himself or by the parent, and he is thus participating directly in his care.

As in four cases the cerebral palsied child was the only child in the family, our analysis will concern only 26 of the 30 research families. In all these 26 families the parents showed at least some intellectual awareness of the danger of "making use" of siblings and of asking them to perform so many services on behalf of the handicapped child that their own needs and individuality became neglected. Yet the extent to which parents were able to avoid this situation varied a great deal: in some families it was sometimes quite difficult to elicit information about the interests and private activities of the siblings at all, so much were they regarded merely an adjunct to the needs of the cerebral palsied child; whereas in other families considerable care was taken to treat each sibling as an individual in his own right and not to interfere with his usual life and freedom.

For this particular aspect of family life it proved difficult to obtain a simple quantitative index which could easily illustrate the differences between the three family types. The wide range in age of the siblings in the sample as a whole, and consequently the roles and activities that one might normally expect from them, as well as the fact that in any given family different children might show different degrees of involvement with their handicapped brother or sister, made it inevitable that a rather looser classification was employed than those found in other tables of this chapter. In Table 18 the families have therefore been grouped according to a three-point rating system, and though the allocation was necessarily carried out according to subjective estimate, it is hoped that the following case material will illustrate and justify the method of classification.

Table 18.
Participation of Siblings in Child Care Activities

	<u>Child- Centric Families</u>	<u>Inter- mediate Families</u>	<u>Child- Fugio- Families</u>
Considerable	6	0	1
Occasional	5	8	1
Infrequent	0	3	2
Total	11	11	4

We shall first turn to those child-centric families in which siblings were found to be participating to a considerable extent in the care of the handicapped child:

Christine Anderson, 5 - 5 years, spastic quadriplegia, S.I. 7. A ten-year old brother, according to the mother, is "just like a big sloppy sister with Christine." He likes nothing better than to play with her, and so much of his time is spent in this way that he will often refuse to go out with his pals in order to remain with Christine. He frequently buys her sweets out of his

pocket money, often used to feed her when she was still unable to do so herself, and, as Christine is reluctant to go to bed alone, he sometimes goes to lie down with her, even though it may be two hours before his customary bedtime. At one time, whenever mother had to go out and was reluctant to leave the child with neighbours, she used to keep the brother off school in order to look after her.

Bryan Strang, 6 - 4 years, athetosis, S.I. 11. Bryan's sister, eight years older than he is, has for years devoted practically all her spare time to her handicapped brother. Her pre-occupation with him was such that her school work became neglected, and only at this point did the parents become aware that her intense involvement with Bryan paralleled their own concern and that she should be encouraged to spend more time on outside interests. Yet she still rushes to Bryan the moment she returns from school, plays with him, takes him round the garden for walks, and helps in feeding or washing him. She is extremely worried about his handicap, and frequently attempts to give him exercises. The parents have observed her standing him on his feet, presumably in the hope that he might suddenly have gained control over them.

Michael Vallance, 7 - 11 years, spastic quadriplegia, S.I. 15. Michael's older sister frequently asks her mother to allow her to help in looking after him. She takes part in all the routine activities of feedings, washing, and putting to bed whenever she is at home, and twice a week takes him by herself to the local school clinic for his physiotherapy. She has decided that when she leaves school she too will become a physiotherapist, and that she will then make sure that Michael gets far more treatment than he does now.

These instances all refer to older siblings, and in all cases participation in child care activities was voluntary. The following

examples, also from the child-centric families which were characterised by a considerable amount of participation in child care on the part of siblings, illustrate how some parents actively enforced the rendering of services by the siblings:

Walter Lane, 7 - 3 years, spastic paraplegia, S.I.10 This is an extremely egocentric child, who cannot tolerate frustration and whom the parents are always appeasing in order to avoid his terrific temper tantrums. Walter's younger brother is continually warned to give way to all requests made by Walter, and mother will in all their quarrels automatically side with the handicapped child irrespective of the rights and wrongs of the matter. She even smacks the brother if he resists Walter's attempts to take a toy away from him. He is frequently told to pass things which are out of Walter's reach. Mother is aware of the problem, but confesses: "Somehow he never was my baby, he always seemed second best to Walter."

Helen McBain, 7 - 11 years, spastic paraplegia, S.I. 8. This is a large family, in which all siblings are expected to give way to Helen's demands and not provoke her quite considerable temper. The parents have pointed out to them that they cannot expect Helen to be treated the same way as they are treated (she is the only one, for instance, who never received physical punishment), for she is handicapped and they are not. It is the youngest sibling, however, who is most affected, for he is the only one who is also not at school and is therefore with Helen all day. As mother finds it difficult to take Helen out, the younger brother also has to stay in all day. There are lots of quarrels between the two of them, and mother then regularly persuades the sibling to give in to Helen.

In the other child-centric families, where fewer services were performed by siblings, the problem was less acute or, as in the following

example, did not affect all siblings:

William Hooper, 4 - 3 years, spastic quadriplegia, S. I. 16. There are two older and one younger sibling in this family. The two older, both girls, very much lead their own life, with plenty of interest centered around school and neighbourhood friends, with whom they spend a great deal of their time. They are very close in age, and are always together. Occasionally they play with William or take him out, but are never asked to do so by mother. On the other hand, the younger sibling's birth in itself was a "service" to William, for mother was sure that another child would somehow "bring William on". Yet when she saw the baby rapidly overtaking William in his development she began to concentrate on William as she had not done before, and the baby tended to some extent to suffer from this. Thus mother finds she cannot take both children to the shops, so leaves the baby and takes William, as the latter "needs the extra stimulation." When William objects to mother feeding the baby, she gives the baby to father to hold and takes William on her knee. When William cries because the baby has a toy, mother takes it from the baby and gives it to William (though she does try to console the baby with something else).

In the intermediate group, mothers agreed that they sometimes asked a sibling to help in looking after the handicapped child, but this was kept strictly within limits and did not generally take place at the cost of the sibling's own needs and interests:

Michael Purdon, 7 - 0 years, spastic quadriplegia, S.I. 8. A brother, seven years older, is encouraged by mother to hit back if Michael starts a fight: "Handicapped or not, Michael is not going to get away with it at John's expense." John tends to lead his own life and is out most evenings with his friends, but occasionally he is asked to stay in and babysit for the parents. He also helps mother to lift Michael out of his bath when father

is not at home at the time.

Martin Fisher, 5 - 10 years, spastic quadriplegia, S. I. 4. Although Martin's brother is 15 months younger, he is as tall and already more capable than Martin, and the two are often mistaken as twins. Because he can get around more efficiently, mother expects more of him in such matters as clearing up toys. Also, if both children want a biscuit, it is the brother who is sent to fetch the tin. When the two accompany mother and the baby to the shops it is Martin who gets a ride on the pram while the brother has to walk. Yet mother never sticks up for any one of them in a quarrel, she believes in fair shares when it comes to giving treats (sweets, presents, outings, etc.), and she is careful to assign certain "duties" to Martin as well as to the sibling.

In the three cases in this group where siblings were said to be involved in the handicapped child's care to only a very limited extent, the siblings all had strong outside interests (school, clubs, sport, etc.), and the parents made a point of encouraging these activities and not expecting them to be sacrificed on behalf of the handicapped child. These children all played occasionally with their cerebral palsied sibling, but they did so as much for their own amusement as for the handicapped child's benefit.

In the child-fugic group no clear-cut picture emerges. One family was classified as demanding a lot of "services" from the sibling - one reason being that mother found it difficult to take the handicapped child out and that the young sibling was therefore also kept in a great deal. The sibling in the family that was classified in the middle category was still a young baby and it was consequently somewhat difficult to make a firm judgment as to his involvement in the care of the handicapped child. He was, however, frequently left with neighbours while mother took the handicapped child out (to therapy sessions, etc.), and in this way he did have to render occasional services to his sibling.

The remaining two cases, both in the lowest category, were there for somewhat different reasons. In one, the sibling (also a young baby) received considerably more attention from the mother than the cerebral palsied child and services were thus rendered by the latter rather than by the former. In the other family both siblings were very much older than the handicapped child (by ten and twelve years respectively) and were too involved with friends and other outside interests to be much at home. The only service rendered here was when mother insisted that one or the other should stay at home to look after the child while she went out for the evening.

The performance of child care tasks is, from our point of view, clearly a crucial area of family functioning, and its analysis has indicated the different part it plays in the three family types. The extent to which it is necessary to perform child care tasks is defined by each individual parent, and where some parents will restrict themselves to purely routine activities, mothers may consider it necessary to be constantly with the child and supervise him at every point of his waking life. Where all members adopt this latter attitude a child-centric type of organisation is indicated. The parents from this group will not share child care responsibilities by handing the child over to each other and then taking the opportunity to relax or perform other tasks: instead they will cluster simultaneously around the handicapped child and thus impose a duty on themselves which involves the major part of their daily life. It appeared that many of these mothers were virtually never away from the child, and that (perhaps even more remarkably) the fathers' only absence was occasioned by the necessity to earn a living. Such intense involvement is bound to affect other children in the family, and, as we have seen, these too tended to be drawn into this tight group either by their spontaneous concern or on the insistence of the parents.

In families of the intermediate type, on the other hand, there is far less joint participation in this task. Responsibility for child care rests almost solely with the traditional child-minder, i.e. the

mother, and both father and siblings play only peripheral parts. Despite this fact, however, the total amount of time spent by the mothers on this task is considerably less than that found for mothers of the child-centric group, for their involvement with the handicapped child is less intense and does not therefore compel them to devote all their time to him. All members of the family are thus very much freer to pursue other activities.

The child-fugic group provides the least clear-cut results, for not only is it small, but it has also been shown to be rather heterogeneous. Its common feature is that there is no joint participation in child care activities, that these are either completely left to one of the family members or else farmed out to whatever individuals outside the family are available. Much depends here on whether it is father or mother or both who provide the "fugic" element.

Our analysis, it is believed, is demonstrating the continuum which we have suggested, at the one extreme of which can be found the family where the handicapped child provides the focus for a great deal of intense activity, and at the other extreme of which one finds the family where the activities of at least some of its members are characterised by being oriented away from the child. The degree of "togetherness" of these families is thus largely influenced by the involvement of the various members with the cerebral palsied child. Where all are simultaneously engaged in interaction with this child for the major part of their daily life, the amount of joint participation will be high. If, on the other hand, one or more members attempt to avoid such interaction, joint participation will be low and the family will be found together on only infrequent occasions.

Household Activities

In the previous section we saw how the three types of families use different methods in organising their child care activities. In this section we shall enquire how far these different types of organisation are paralleled in the carrying out of household activities. More

specifically, we shall be concerned with the division of labour and roles adopted in respect of household tasks and with the part that they play in each of the family types.

Traditionally, the performance of household tasks is primarily the responsibility of the wife. It is she who assumes the role of "home-maker", and the extent to which other family members participate in this area will depend in part on individual personalities and in part on practical considerations. With respect to the latter, it may be argued that the presence of a handicapped child will make the carrying out of household activities more difficult for the mother and that she will then have to rely more on the help of others. This, one may argue, is likely to apply particularly to those families (mainly in the child-centric group) where it was considered necessary to spend a great deal of time on child care activities. These mothers can be expected to have less time available for household tasks and therefore to be in greater need of help from others.

At each interview questions were asked as to how much help mother had received with household tasks in the seven days preceding the interview, and who the main person was who had given such help. Turning first to the latter point, it can be seen from Table 19 that in every instance somebody was mentioned as having given mother at least some help, and that in most cases this came from her husband.

Table 19.

Main Person from whom Mother received
help with household tasks

	<u>Child- Centric Families</u>	<u>Inter- mediate Families</u>	<u>Child- Fugic Families</u>
Husband	13	8	2
Relatives	0	3	2
Others	0	1	1
None	0	0	0
Total	13	12	5

While in the child-centric group the exclusive nature of the family is emphasised by the fact that the housewife did not usually turn to outsiders for help, in the intermediate families too the husband was the most frequently mentioned helper, and only in the child-fugic group was there a tendency to turn more to other people. Yet when we turn to the actual amount of help received, irrespective of who gave it, we find that for the majority of cases this was comparatively little and that, despite having also to look after a handicapped child, mothers were still considered to be almost solely responsible for running the household. Table 20 illustrates this. In it an attempt has been made to distinguish those families where mother received daily help for household routines (where, for instance, father always helps with washing up after the evening meal and always fetches in the coal), those families where mother receives help on a less than daily basis (father helping only at the weekend, or a neighbour occasionally doing some shopping), and finally those families where no help is ever reported.

Table 20.

Amount of Help received by Mother
with household tasks

	<u>Child- Centric Families</u>	<u>Inter- mediate Families</u>	<u>Child- Fugic Families</u>
No Help	0	0	0
Occasional Help	10	12	5
Daily Help	3	0	0
Total	13	12	5

This table presents a very different picture from that obtained from our analysis of child care activities, for a remarkably similar pattern appears to exist for all three types. In all 30 families mother was able to obtain some help from others, but in only three cases did this help amount to more than the occasional service rendered. How the mothers coped will emerge from the following case illustrations, the

first of which are taken from the group of 10 child-centric families where occasional help was received by mother:

Margaret Watson, 7 - 9 years, spastic hemiplegia, S.I. 4.

"Since we found out about Margaret's handicap there just has not been any time to do much about housework. While she is at school I am out working, trying to earn the extra money for her private tuition and therapy, and when she is at home I seem to spend most of my time with her. The house has just had to take second place." In this way mother expressed her lack of interest and involvement in housework, making it clear that the amount of time spent by her on such activities was not great. Father will do the heavy jobs around the house, help with decorating, and on a Saturday do some shopping, but as he too spends most of his spare time with Margaret and as in any case he feels that a man cannot be of much use around the house, the total amount of help he gives is somewhat limited.

Walter Lane, 7 - 3 years, spastic paraplegia, S.I. 10. Though father will always help in looking after Walter, he does not believe in doing "women's work" around the house. He fetches in coal, gardens, and does repair jobs when necessary, but all else is left to mother. The only way that she can get even the essentials done is to get up at 6.30 every morning, for she insists on having all her tasks finished by mid-day, so as to be free for Walter for the rest of the day. One effect, amongst others, is that she now rarely makes anything herself (like cakes) that she can buy ready made in the shops.

Catherine Newland, 4 - 6 years, spastic quadriplegia, S.I. 7. Mother has become increasingly agitated and nervous, and often finds it difficult to remain in the house. She cannot then concentrate on her work, but feels that she and the child must

get out. They go for long walks, only to return to a house which, according to mother, "is often a disgrace." Father is willing to help, will make mother cups of tea, even lay the table or wash up. Yet mother feels it is not right to ask him to start on the housework when he comes home tired from doing his own job, and in any case he is usually employed in the evenings with Catherine.

In all ten of these cases housework always took second place to child care activities. When a choice had to be made between these two types of task, it was always housework that was put off to a later time. Some of the mothers remained houseproud and, because of the increased demands made on their time by activities connected with the child, found they had to work very much harder and for longer hours (as in the second example mentioned above), while other mothers (as in the other two examples) were unable to maintain their standards of housework and begun to cut out the less essential tasks. In all cases, however, the role of mother had priority over the role of housewife.

Although mothers in the intermediate group also had to undertake household activities with only limited help, they did not encounter the same difficulties that the mothers of the child-centric group had met. Their problem in this respect tended to be confined to such practical issues as resulted, for instance, from having to go shopping with a child unable to walk, or having to do a great deal of washing because the child could only get about by crawling. As has already been pointed out, these mothers were very much freer from their children, and as a result had no difficulty in leaving them to their own devices while they attended to other things. Thus their actual need for help from others was less, although the fathers in this group were also less bound to the children and therefore more available:

Cecilia Parkinson, 6 - 0 years, spastic quadriplegia, S.I. 8. Mother is very houseproud, and much of her time is spent in cleaning and polishing. She does not find the child any

hindrance in this respect, for she can be put out in the street or the garden for long periods, and even when she is inside the house she will amuse herself, so that mother can carry on with her work in peace. Mother does practically everything, for father undertakes tasks like washing up or making beds only in an emergency. He prefers to spend his time making furniture and gadgets for the house.

Edward Cunningham, 3 - 6 year, spastic hemiplegia, S.I. 2. Both mother and father expressed surprise when asked whether the latter participated in household activities. For a man to undertake this seemed "ridiculous" to both of them, and though father does in fact fetch coal and carries out skilled repair jobs, mother undertakes all else. She is keen on cleanliness and spends a great deal of time in making the house look nice, insisting, moreover, that the children keep it so. Though shopping, she agrees, is rather difficult with a child who cannot walk properly, she never asks father to do it for her, and instead asks him to stay at home on a Saturday to look after Edward, while she goes into the town to buy the bulk of the week's supplies.

Marilyn Phillips, 3 - 11 years, spastic quadriplegia, S.I. 17. Despite having four children, one of whom is severely handicapped, mother copes with the housework largely on her own. As father works long hours he does little during the week in this respect, but at the weekend will often go shopping for mother and help with tasks inside the house. This mother also finds shopping to present the greatest problem with a handicapped child, but solves it partly with father's help and partly by often leaving the child with a neighbour and going to the local shops by herself.

In the child-fugic group all five mothers also received only occasional help, but in other respects appear to be somewhat more

heterogeneous. Four of the families resemble the afore-mentioned child-centric families, in that priority is given to child-care activities, which take up a great deal of time, while household work must fit in as best as it can - as in the following examples:

Gladys Murphy, 8 - 0 years, spastic quadriplegia, S.I. 6.

Although the only help given by father in this case concerns repair jobs and redecorating, mother is too busy devoting her time to the child to spend much on the household. Before Gladys started attending school mother always got up early in order to get as much done as possible before the girl got up. Once at school, however, mother did agree that she had a lot more leisure to get things done in Gladys's absence, but she always made a point of having all her work finished by the time the girl came home, so that she could spend the rest of the day with her.

Sally Robertson, 3 - 1 years, spastic quadriplegia, S.I. 6.

Father never did anything in the house other than odd repair jobs. Paternal grandmother, however, was usually available and it was she who did all the shopping. Mother found it too difficult to get out with Sally, her sibling, and a pram, and return with a heap of shopping in addition. On the other hand, she did not want to leave Sally with anyone else while she went by herself to the shops, so paternal grandmother's help in this respect was most welcome.

In the fifth of the child-fugic families, however, mother's priorities seem to be the reverse of those found amongst the child-centric families:

David Richardson, 4 - 0 years, athetosis, S.I. 14. Mother

is very proud of her nice home, and has spent considerable time and money on her furniture, ornaments, clothes, etc.

When she does her housework she wants to do it in peace, and

will therefore put David firmly into another room and not give in to his demands to join her. As shopping is difficult with such a handicapped child, she tries to leave him with neighbours whenever possible. Also father is often asked to look after him so that mother can attend to the house in peace.

We must turn finally to the only three families (all from the child-centric group) where mother received rather more help from others in running the household. The help she received was always from father, and in all three instances the reason for his high participation was mother's nervous condition which prevented her from coping with the housework in a resourceful manner. Again, in all three cases mother tended to give priority to looking after the child:

Bryan Strang, 6 - 4 years, athetosis, S.I. 11. Mother found it very difficult to get things done in the house, partly because (as she realised later when the child began school and the tie had therefore become looser) she was always so pre-occupied with him that she rushed through the work to get back to him, and partly because of her tiredness and nervousness resulting from the considerable sleep upset which Bryan had in his early years. Father therefore used to help to a considerable extent in the house, often taking over everything from mother on his return from work and even doing some of the cooking. He always gave mother breakfast in bed, but he too did not have the energy left to keep the house in the decorative condition they both would have liked.

Betty Johnson, 6 - 0 years, athetosis, S.I. 12. Although furnished well and tastefully, the house is beginning to show a great deal of wear and tear, for Betty is inclined to be somewhat destructive, and she will often drive her tricycle or pedal car hard into the furniture. Neither mother nor father ever check her for this. Mother spends a lot of time keeping an eye on Betty, and when the child is outside in the garden or

street is unable to get on with cleaning or cooking, but must stand by the window to make sure she is all right. By the time father comes home from work she is often quite exhausted, emotionally as well as physically, and father therefore has to help in preparing the evening meal, washing up, etc. At weekends he will sometimes even do all the cooking. When mother finally had a nervous breakdown, he took complete charge of everything and did all the housework.

Helen McBain, 7 - 11 years, spastic paraplegia, S.I. 8. Partly because this is a large family and there is therefore a lot to do, partly because of the child's incessant demands, and partly because she is tired and depressed, mother can only barely keep up with the housework. She relies a lot on father to help, and many of the day's chores do not get done until he returns home. He will often do the shopping on his way home, and at the weekend will help mother with the cleaning and cooking.

These three families are exceptional, in that in them father plays a role which he does not play in any of the other families. In general, the participation of fathers in household tasks is not high, and though the majority were quite prepared to help as much as possible in an emergency like mother's illness, most tended to confine themselves to "manly" jobs around the house, like decorating or doing repair jobs. It is particularly interesting to note that this applies also to most of the fathers from the child-centric group. There is, in other words, no evidence of "feminisation" in their role, for in the three instances where father's participation in housework was rather high he was forced to take this role by mother's extreme need for help. Joint participation therefore concerned the care of the child and not other tasks in the home: a conclusion further reinforced by the fact that even in child-centric families siblings were rarely called upon to help with the housework. Similarly, the fathers of the child-fugic group in no instance "opted out" with regard to household tasks as completely as some of them did in relation to child-care. Although their participation in household

tasks was not great, they nevertheless showed no evidence of having rejected their role of householder in the same way as they had rejected their role of father. Also the one mother whose behaviour in relation to the child care activities provided the only example suggesting maternal rejection gave no evidence of having retreated from her role of housewife.

A surprising homogeneity is thus found in this sample. This contrasts strongly with Bott's (1957) findings, for in her sample of twenty families the range of variability with regard to father's participation in housework was far greater. It may well be that the difference is largely due to the much narrower socio-economic range from which the present sample was drawn, though regional differences may also have played their part. Whatever the reason, mother's traditional role of chief home-maker is in this sample not affected by the presence of a handicapped child. Not only did the fathers remain wary of undertaking "women's work", but surprisingly few instances were found of routine help being given by relatives and other outsiders. This is probably due to the fact that in those families where such help was needed most, namely in the child-centric families, the social isolation typical of this group prevented help from being available. Being thus almost entirely thrown back on their own resources, these mothers had either to work very much harder or cease to be houseproud. The extent to which mother's household activities were therefore affected varied with the degree of her involvement in the child and thus with the type of family group; whereas the division of labour and the participation of other family members showed little difference in this respect as between the three groups.

Employment.

Just as the mother's role is traditionally that of homemaker and child rearer, so father's main contribution in our society is to provide economic support, thus enabling the family to survive. The nature of his occupation, moreover, determines more than any other single factor the family's social status, so that both from an economic

and a social point of view father's job and the efforts he makes to improve himself are of vital importance to the family. Unlike the previous two areas which we have discussed, this sphere of activity generally involves only one family member and, taking place outside the home, thus removes him from the orbit of the family. How far is it nevertheless affected by the presence of a cerebral palsied child in the family?

All the fathers in this sample except two had full-time employment. The two exceptions were unemployed for the major part of the period of observation, and it is interesting to note the contrasting way in which they made use of their time:

Mary Sawyer, 4 - 9 years, spastic quadriplegia, S.I. 8. Father had been a storekeeper in a large factory, and lost his job in a temporary recession. Asked whether he did not find the enforced idleness irksome, he replied that he was by no means idle: "There are lots of things to be done with Mary." This is indeed borne out by his daily activities, for throughout the day he spends his time in close contact with her, playing with her and taking her for walks morning and afternoon. It soon became apparent that he is making few efforts to seek employment and that he appears to prefer staying at home in order to be with the child.

Sally Robertson, 3 - 1 years, spastic quadriplegia, S.I. 6. Father is a semi-skilled machine operator, but has been unemployed a lengthy time. He is, however, rarely to be found at home, for he spends most of his time with friends at the street corner, the pub, or at football matches. His interaction with Sally is minimal despite the greater opportunities he has for being with her.

The first mentioned father came, of course, from a child-centric family, while the second came from a child-fugic family.

Two of the mothers held jobs during the period of observation, though

in both cases their employment was part-time and lasted only a few months. In one case mother's motive was to earn more money, as the parents were spending a great deal on private tuition and therapy for their handicapped child. This was a child-centric family, while the other case involved a child-fugic family where, however, mother's tie with the child was also very close. When the child had to go into hospital for a period of weeks, and again later when she began attending school, mother was so lost that she took on a part-time job in order, as she put it, "to stop myself from thinking about her all the time."

In discussing father's involvement with the cerebral palsied child, it soon became apparent that his role as worker was by no means necessarily immune. In certain cases quite major effects were reported which could be directly related to the handicapped child. In this category may be put all those cases where a father either had to change his job because of the child's condition or was prevented by it from doing so, or where the actual nature of his job became drastically affected. As seen from Table 21, all the fathers who were thus classified came from child-centric families, and the following case extracts will illustrate this category:

Table 21.

Effects of Handicapped Child
on Father's Employment

	<u>Child- Centric Families</u>	<u>Inter- mediate Families</u>	<u>Child- Fugic Families</u>
Effects are of a Major Nature	7	0	0
Effects are of a Minor Nature	4	5	0
No effects reported ...	2	7	5
Total	13	12	5

Donald Baker, 7 - 0 years, spastic paraplegia, S.I. 12. Father had been a clerk in a small business, but shortly before Donald's birth the parents emigrated to East Africa, where father obtained a very much better position as manager in an export and import

business. Donald was born out there, and it was there that his condition was diagnosed. It was impossible to obtain treatment facilities locally, and when the parents learned that educational provisions would also not be available, they decided to return to Britain. There father had to return once more to the lower occupational level of his previous post.

Bryan Strang, 6 - 4 years, athetosis, S.I. 11. Father is a shop assistant, and some years ago was offered promotion to the post of shop manager. This would, however, have entailed a move to another part of Scotland, and as at that time the parents had just managed to obtain regular treatment sessions for Bryan (which would not have been so easily available in the small town to which they would have had to move), father turned down the offer and remained in his previous post.

Margaret Watson, 7 - 9 years, spastic hemiplegia, S. I. 4. The parents had been worried about educational prospects for this child, and became convinced that she was not getting sufficient stimulation for the development of her mental faculties in the small village where they were living. They finally decided to move to a town, and as a result father, a joiner by trade, had to change jobs. He was, in fact, unemployed for two weeks before finding something else.

Catherine Newland, 4 - 6 years, spastic quadriplegia, S.I. 7. Father is a welder, but after an accident changed his job and for a time worked as lorry driver instead. This job entailed such long hours, however, that he rarely got an opportunity to continue his previous intense contact with Catherine. As a result he finally decided to give up this post and obtained another, despite the poorer pay.

Of the other three cases in this category, one refers to the father

(already mentioned) who remained unemployed in order to stay with his child. The other two concern fathers who volunteered for permanent nightshift, despite the fact that they disliked working under such conditions. They thought it important for the sake of the child, however, to be available during the day. When one of these children began attending school and was thus out for a large part of the day, the father changed back to ordinary working hours. It is significant, moreover, that three of the seven fathers in this category refused opportunities for overtime work (and therefore increased earnings) because of the longer absence from home that this would entail.

Making sacrifices for the sake of the child which affected father's employment was also apparent in the time that some of these men took off work in order to attend screening sessions, medical check-ups, and other consultations with professional people. They did so despite the fact that they would lose financially in this way and that in any case mother was already accompanying the child. This applied to all the seven fathers from the child-centric group just mentioned, and also to the four fathers from this group who were classified as being affected to a minor degree in their employment. This indeed was the reason for these four men being put into this category, as apart from such occasional absences no other effects could be traced. The remaining two men from this group rarely took time off for such purposes.

In the intermediate group five of the fathers also stayed off work from time to time in order to attend official consultations with the child, whereas the remaining seven did so only when especially asked. No other effects on father's role as worker could be found here.

Three of the fathers from this group changed their jobs during the period of observation, but they did so for very different reasons than those motivating the child-centric fathers' changes:

Brenda McNeil, 4 - 9 years, spastic paraplegia, S.I. 4. Father is a crane driver, who had been with the same firm of builders for a number of years. His dislike of a new supervisor caused him to change his job, however, and he found employment in a

similar capacity with another firm. He is very much happier there, despite the longer journey which means being away from home for an additional hour every day.

Charles Burgess, 5 - 6 years, spastic paraplegia, S.I. 3. Father is a sheet-metal worker, and is ambitious to get on. For a long time he has been looking for an opportunity to advance himself, and when at last it came he had no hesitation in taking it. Though keen to get extra money for his family, he was also motivated by his considerable interest in his job.

Marilyn Phillips, 3 - 11 years, spastic quadriplegia, S.I. 17. Father works as a fitter, but complained that the particular work he was doing was too monotonous. He finally became so bored that he applied for another job, again as fitter, and was taken on to do work which he enjoys far more.

These changes had nothing to do with the presence of a handicapped child in the family. They took place for extraneous reasons, and there is no evidence that father's parental role encroached on his role as worker. This division of spheres of activity is even more rigidly adhered to in the child-fugic group, where the fathers hardly ever participated in visits to clinics and doctors during working hours and where other effects on father's job could also not be observed. The one father from this group who changed his job during the period of observation had not liked being on shiftwork and therefore obtained a post with regular working hours. As he also worked overtime there he saw a lot less of his handicapped child than previously.

We must conclude that father's role as wage-earner is by no means necessarily immune. This sphere too is part of the total family organisation and reflects the forces prevailing within it. Amongst the child-centric families, in the same way that mother tended to assign less importance to her role as housewife than to her maternal role, so father was generally willing to sacrifice his role as worker to his parental

role. In the intermediate families the intrusion of the child on father's work was far less marked, for though most of these men would occasionally be prepared to make some sacrifice (financial or otherwise) on behalf of the child, their decisions regarding their occupations were generally unaffected by their parental role. This applies even more to the fathers of the child-fugio group, most of whom did not interrupt their career at all with activities affecting the handicapped child. Thus the varying degrees of "togetherness" in the families of the three types are to be observed once again, ranging from families in whom the fathers showed reluctance to devote too much time to their jobs and thus be separated from the child for long periods every day to families where no such reluctance could be seen.

Contact with kin.

Amongst extra-familial roles, those involving membership in larger kinship groups are of particular importance. Other studies have stressed the close link found in certain families with the extended family (especially with maternal grandmother) and the opportunity for help and support at times of crisis that these contacts afford. In this section we shall therefore enquire as to the extent to which such contacts are used when a cerebral palsied child is a member of the family, and what differences there are in this respect among the three types of families.

In order to ascertain how much contact with kinfolk the various families habitually have, the informants were asked to describe at each interview the visits they had made to or received from relatives during the past seven days. The information required referred to the frequency of such contacts, with whom they were made, what members of the family were involved, and where they took place. In discussion an attempt was also made to elicit the reason for the contact (need for help or emotional support, duty, companionship, etc.), and what difficulties the family tended to encounter in this respect. Table 22 is based on the average number of days per weekly enquiry period on which there were contacts with relatives, and with its help we can examine the case material and determine the nature and pattern of interaction with relatives as found in the three family types.

Table 21.

Contact with Relatives in Previous Week

	<u>Child- Centric Families</u>	<u>Inter- mediate Families</u>	<u>Child- Fugio Families</u>
Occurred on 0 - 1 Days ..	7	1	0
Occurred on 2 - 4 Days ..	4	4	1
Occurred on 5 - 7 Days ..	2	7	4
Total	13	12	5

Amongst the child-centric families, the over-all frequency of contacts with kin is clearly rather less than is found in the other two types. In seven of these families there was hardly any contact with kin:

Christine Anderson, 5 - 5 years, spastic quadriplegia, S.I. 7. Mother says that she has completely lost touch with her relatives, that she never sees any of them now except perhaps at Christmas or some other anniversary, and that even her own mother has not been seen for two years or more. Her mother is somewhat infirm and finds the half-hour's bus journey too much, while Mrs. Anderson, for her part, is usually too exhausted to stir from the house any more than is necessary for shopping purposes. As for other relatives, mother never turns to them for help: "We prefer to keep everything in the family, and what Dad and I cannot do, the children will do for us."

Betty Johnson, 6 - 0 years, athetosis, S.I. 12. Father's relatives all live in another part of the country, and even during holidays there is no mutual visiting. "We have somehow grown apart," said father, "and in any case we have too much on our hands to be bothered with entertaining." This policy appears to apply also to mother's relatives, who are much more readily accessible. Again there is little mutual visiting,

and mother, when asked whether she could turn to them for help, commented that they did not understand her problems with Betty and spent their time criticising her way of life. "So we just keep to ourselves and take no notice of their opinions."

From the four families in the child-centric group where slightly more frequent contacts with relatives were reported, the following cases may be quoted:

Helen McBain, 7 - 11 years, spastic paraplegia, S.I. 8. Mother's closest relative is her sister, and about once a week she brings her children over to play with Helen and her siblings. With father's family there is little contact, despite the fact that they all live in the same neighbourhood. Paternal grandmother has to look after two young grandchildren and, according to mother, is too interested in them to have any time over for anyone else. Father's brother and his family occasionally call, but mother says she rarely feels like going out to other people's houses and thus does not usually return their visits.

William Hooper, 4 - 3 years, spastic quadriplegia, S.I. 16. At one time very few contacts indeed were made with any of the parents' numerous relatives. Mother said they looked at William all the time as though they were sorry for him and she could not stand that. Paternal grandmother had even suggested at one time that the boy ought to be put away in an institution, and for about two years after that mother had refused to see her. The only person mother felt she could rely on for help was her sister-in-law (father's sister), and with her a certain amount of visiting still continued. More often than not the sister-in-law visited the Hoopers, but if a return visit was paid it was usually at the week-end, when father could also come.

None of the families in these two categories has much investment in relationships with kin. What contacts are made occur mostly in the family's own home, and rarely is there any expectation of help or emotional support. The phrase which repeatedly recurs in discussions with these families is "We like to keep to ourselves." In only two of the child-centric families was much more frequent contact reported:

Mary Sawyer, 4 - 9 years, spastic quadriplegia, S.I. 8.

Father's sister and her family live just round the corner from the Sawyers, and they see each other almost daily at either house. She is the only one whom the family calls in for help, as she is always willing to perform such services as babysitting, calling the doctor, etc. Maternal grandmother is rarely visited, for Mary's travel sickness makes any outing a major undertaking involving both parents. As a result they have rather lost touch with her, for the parents are rarely inclined to make visits alone.

Walter Lane, 7 - 3 years, spastic paraplegia, S.I.10.

Maternal grandmother lives about 15 minutes walk away, and about twice a week she comes over to the Lanes' house. After Walter started at school mother was so despondent at first, that she spent every day at maternal grandmother's home, taking Walter's younger sibling with her. At the weekend the whole family has for years always either visited or been visited by paternal grandparents. In addition, mother has a sister who sometimes calls after returning from work, and who has often offered to babysit while the parents go out - an offer that they have, however, never accepted.

Certain reality factors may have to be taken into consideration when one evaluates these descriptive accounts, such as the accessibility of relatives, the nature of the child's handicap, and the relatives' own mobility. One or two of the informants expressed feelings of hostility

and animosity towards kinfolk, centering around the handicapped child or the parents' concern with him, yet this was found surprisingly little. But whatever real difficulties there were in keeping up social contacts, the child-centric families showed far less inclination to overcome them than was found amongst families of the intermediate group.

Amongst the latter, there was only one family which had practically no contacts with relatives. The parents had moved from another town to a district where none of their relatives lived, and though they had many social contacts with friends and neighbours, the distance from their former home town precluded anything but the most infrequent visits. As for the other families, the following examples may be taken as typical of this group (the first two come from the middle category of Table 22, while the others illustrate the third category):

Joan Kelley, 3 - 3 years, spastic quadriplegia, S.I. 9.
Once a week Mrs. Kelley takes her two children to see maternal grandmother, although the journey involves a longish bus journey. With two small children, one of whom has to be carried, this is not easy, but mother welcomes the opportunity of a change, and as she has always paid these visits she sees no reason to alter her ways now. As these visits usually take place during the week, father is rarely involved in them. Occasionally the older sibling stays with maternal grandmother for the weekend, and this is considered by all a great treat. Every weekend a visit is also paid to or by paternal grandmother - again a lengthy bus journey is involved. Father participates in this contact whenever he is not on duty at the weekend. In addition, various sets of other relatives are visited or received by the Kelleys, but rather more infrequently. At Christmas or New Year, however, they all make a point of having a great family get-together, and the Kelleys take their turn of holding it at their house. Mother does not mind the hard work these gatherings involve, "for it is all great fun."

Marilyn Phillips, 3 - 11 years, spastic quadriplegia, S.I. 17. A number of relatives live nearby, including three grandparents. During the week maternal grandmother calls several times, and every Sunday evening mother goes to her while father looks after the children. Father will sometimes call on his own mother on his way home from work, and at the weekend either mother or father will wheel Marilyn's pram over to the paternal grandparents' house (a distance of about two miles), while the other parent takes the rest of the children by bus. Help between relatives is mutual - for instance, father's brother always lends them his caravan for holidays, while mother had no hesitation in looking after her sister's young son when his mother was having another baby.

Henry Cairns - 4 - 3 years, spastic quadriplegia, S.I. 13. Maternal grandmother has a part-time job, but after work will always call in at her daughter's house and have a cup of tea there. Mother's younger sister, who works in a factory in the neighbourhood, also calls in every day and gets her lunch from mother. Paternal grandmother is seen rather less frequently by mother, as Henry for some reason took a strong dislike to her, but father makes a point of looking in on her at least once a week.

Edward Cunningham, 3 - 6 years, spastic hemiplegia, S.I. 2. As the family live on the outskirts of the town at some distance from their relatives, the latter usually come to the Cunningham's house, while return visits are paid rather more rarely. Both sets of grandparents are seen regularly once a week, and in the same way contact is kept up with mother's two sisters and their families. This usually takes place while father is at work, but as paternal grandmother lives near to his place of work he calls in there daily and is given his midday meal. The various sets of relatives also regularly go on holiday together.

In none of these cases did the child's handicap play a major part in determining the nature or the amount of contact with relatives. It did make travelling on public transport more difficult, but as these parents (unlike those of the child-centric group) were prepared to leave the child with somebody else occasionally, they were still able to keep up these contacts, though they were made alone. Help between relatives was much more readily available, but was mutual, for despite the work entailed in looking after a handicapped child these mothers were still able to shoulder extra tasks.

Amongst the child-fugio families, finally, there is generally a great deal of contact with kin:

Gladys Murphy, 8 - 0 years, spastic quadriplegia, S.I. 6.
Every single day, before Gladys began attending school, mother used to wheel her over to the maternal grandparents' home, a walk of about half an hour. She spent most of the day there, even when father was home, and was thus far more at her parents' house than her own. Father very rarely participated in these visits. Mother and Gladys even go on holiday with maternal grandparents, while father stays at home. His own family live nearby, and while he sees them frequently (particularly his brother, with whom he goes to football matches, pubs, etc.), mother has little to do with them. Paternal grandmother occasionally calls in order to see Gladys, but mother rarely returns these visits.

Albert Jackson, 3 - 0 years, spastic quadriplegia, S.I. 4.
Maternal grandmother calls several times a week, and about once a week mother returns the visit with Albert and the younger sibling. Father never joins in these contacts, for he and his in-laws do not get on together. Mother is very dependant on maternal grandmother and shares all her troubles with her. Paternal grandparents are seen about once a month or so by mother, as she feels she should let them see her children from

time to time. Father's contact with his parents is somewhat more regular, for they live nearby and he sometimes spends the evening with them.

The outstanding feature of the child-fugic cases is perhaps not so much the actual amount of contacts with relatives, as the lack of "togetherness" amongst family members in making them. It is, moreover, striking that in the child-fugic families contacts with relatives tended to be based on the need for help to a far greater extent than occurred in either of the other two groups. In four of the families the help required appeared to be mainly a matter of emotional support, for which the mother went with her handicapped child to her own family of origin. In these cases the lack of "togetherness" as between husband and wife suggests that the married couple could not provide such support for each other and that the mother, who was left with the child, had to go elsewhere in search of it. In the fifth case the lack of "togetherness" involved mainly the mother on the one hand and the child on the other, and the help required here referred to mother's constant need for child-minders.

Contact with neighbours*

Unlike relatives, neighbours are always physically available, and one can therefore enquire whether the families who have little contact with relatives are likely to compensate by having a lot of contacts with neighbours, or whether social isolation has spread to this area too. Similarly, one will want to determine whether those families

* Enquiry was also made as to contacts with friends. There were, however, extraordinarily few individuals in this sample who claimed to have friends, and where these were mentioned (especially in the case of women) they had usually been chosen from amongst neighbours. No special section is therefore devoted to contact with friends (Paucity of friendships has also been noted by Mogey (1956) in his investigation of two contrasting housing areas in Oxford).

with close ties to relatives have no need for social contacts with neighbours, or whether their sociability is of a more general kind.

The information asked for in order to answer these questions was obtained in a similar way to that referring to contact with kin. At each visit questions were asked about the frequency of contacts with neighbours during the preceding week, about the members of the family who made these contacts, with whom they were made, and the nature they assumed. Membership of formal neighbourhood organisations was not considered here, as interest centered more on personal, face-to-face contacts. Greetings or remarks made only in passing were not included, for these occurred with great frequency in the whole sample. There was not one family where members were not on terms of at least nodding acquaintance with several sets of neighbours: nowhere did one get the impression of a family being regarded or regarding itself as social outcasts in the neighbourhood. On the other hand, the contacts were often only very superficial, and it is for this reason that attention is here focussed on rather closer contacts. The average number of days per weekly period on which these took place is analysed according to family type in Table 23.

Table 23.

Contact with Neighbours in Previous Week

	<u>Child- Centric Families</u>	<u>Inter- mediate Families</u>	<u>Child- Fugic Families</u>
Occurred on 0 - 1 Days ..	6	0	1
Occurred on 2 - 4 Days ..	7	6	2
Occurred on 5 - 7 Days ..	0	6	2
Total	<u>13</u>	<u>12</u>	<u>5</u>

The figures in Table 23 help to answer the questions posed above. By largely duplicating the trends shown in Table 22, the present table suggests that the child-centric families, where rather fewer contacts

were found with relatives, are also less sociable with their neighbours than the intermediate families. Some of the child-centric families have indeed very little to do with their neighbours:

Christine Anderson, 5 - 5 years, spastic quadriplegia, S.I. 7. Mother finds the neighbours nice and always willing to help. They stop and talk to Christine when she is playing outside, and have offered to look after her and give mother the opportunity to go out by herself. But mother has never accepted these offers, and would rather keep the oldest sibling off school to look after Christine than leave her with the neighbours. The only reason she could give was that she preferred not to bother them, and that in any case they would not know how to pick her up or the correct way of putting her down on the floor. As for social activities with them, she has no time, for she would much rather play with the child than "go in for all the gossiping over the garden wall that all the rest of them around here seem to be doing all the time."

William Hooper, 4 - 3 years, spastic quadriplegia, S.I. 16. This family moved to another district when William was about 2 years old. In their old home they had known a number of neighbours quite well, but now mother does not like to have too much to do with any of the people living nearby. She agreed that most of them were very friendly and always willing to stop for chats, yet she preferred to stay away from them. She found it difficult to explain why this was so, though she did express resentment against some people who appeared to think that William must necessarily be mentally defective because he is spastic. The only service that she and her nearest neighbour perform for each other is for one to take in coal, groceries, and laundry when the other one is out.

Six of the child-centric families were altogether relatively isolated in this manner, while amongst the remaining seven there tended

to be rather more contact with neighbours:

Walter Lane, 7 - 3 years, spastic paraplegia, S.I.10. Mother knows the names of all the neighbours living around her, and they all greet each other in the street and pass remarks about the weather or similar conventional topics. Yet she is on closer terms with only one neighbour. This is a woman whom she got to know through having to use her telephone to summon a doctor for Walter, and ever since they have from time to time cups of tea with each other. But in general mother prefers to turn to maternal grandmother for help and rarely makes use of her neighbours in any way. She also says that she does not like the idea of inviting their children into her house, as she would then never get rid of them. This seems to be also her attitude towards their parents.

Catherine Newland, 4 - 6 years, spastic quadriplegia, S.I. 7. There are quite a lot of casual contacts with neighbours, generally confined to a few words exchanged in the street, but hardly any mutual visiting. The next-door neighbour, however, has become very attached to Catherine, and would like to take her out frequently. She often calls, but mother confesses that she is not keen on her taking the child, and sometimes pretends not to be in. Yet mother is also rather pleased that everyone in the neighbourhood is always asking after Catherine, and that even the man who sweeps the streets takes an interest in her.

Six of the intermediate families also had a certain amount of contact with their neighbours without being particularly close to them. In no case, however, was any desire expressed to avoid such contacts:

Henry Cairns, 4 - 3 years, spastic quadriplegia, S.I. 13. For a long time contacts with others in the street had been only formal and casual, but towards the end of the period of observa-

tion the parents became friendly with two couples living nearby, and particularly so with one of these. This was a child-less couple, who became attached to Henry, often had him in their house, and sometimes babysat for the parents. The women called each other by their Christian names, and sometimes did shopping for one another.

Samuel Napier, 7 - 7 years, athetosis, S.I. 11. Mother finds all her neighbours helpful, and when they enquire after the child mother believes they are really interested in a friendly fashion and not just "nosey". Most of these contacts are in the street or at the local shops, but with one neighbour mother has rather more frequent contacts. They are in each others houses from time to time chatting or watching T.V., and mother can always leave Sam there if she wants to go out alone for one reason or another.

In the remaining six intermediate families contact with neighbours was a great deal more frequent:

Kenneth McGuire, 3 - 3 years, spastic quadriplegia, S.I. 4. Mother is on nodding acquaintance with most of her neighbours, but with one, who lives immediately next-door, she is on very close terms. They are in and out of each others houses all day, their children play with each other, they borrow household articles from one another, and mother can always rely on this woman to help with babysitting and similar services.

Joan Kelley, 3 - 3 years, spastic quadriplegia, S.I. 9. Father being a fireman, the family live in a residential block attached to the fire station and thus form part of a small and close community of firemen and their families. They all know each other, the children play together, the men often go out in a bunch to the pub, and the women never lack companionship. There

is never any difficulty about getting help with babysitting, shopping, or taking the children out for walks.

Marilyn Phillips, 3 - 11 years, spastic quadriplegia, S.I. 17. Though mother finds most of the neighbours friendly, she has in the past suspected a few of being rather condescending and pitying in their attitude towards the child. But mother does see a great deal of her next-door neighbour - an elderly woman with a grown-up family, who spends hours every day in the Phillips' house. The attraction appears to be Marilyn, for she likes nothing better than to play with her and to look after her while mother carries on with the housework. She also accompanies mother to consultations with doctors and to other official contacts. Mother and child go to her house rather less frequently, and though she is a great help to mother, it appears that it is the neighbour who is attracted to the Phillips' family (particularly to Marilyn) rather than that mother is dependent on her for help.

Thus the intermediate families were on the whole not only able to keep up contact with their relatives, but could also participate in a certain amount of social activities with their neighbours. The one by no means precluded the other. Amongst the child-fugio families the picture is rather more ambiguous, for again a lot of divergence is found in this group. The following examples, one from each category in Table 23, will make this clear:

Gladys Murphy, 8 - 0 years, spastic quadriplegia, S.I. 6. "With a handicapped child one does rather keep to oneself." This was mother's comment when asked about her contacts with neighbours. She is in any case rarely at home, spending most of her time with her own parents, but apart from friendly greetings she has always kept herself apart from the people living around her. She said rather emphatically in one interview that she has no wish to become dependent on them, and would never consider leaving the child with them for any length of time.

Albert Jackson, 3 - 0 years, spastic quadriplegia, S.I. 4.

This mother does have some contacts with neighbours, though they are not very frequent. Some of the neighbours know that her husband is rarely in and gives her little help, and they often volunteer to look after the children or help her with the shopping. Mother is rather self-conscious about this, but admits that sheer necessity sometimes drives her to accept their offers. Yet none of the neighbours are on mutual visiting terms with her, and all their transactions take place at the front door.

David Richardson, 4 - 0 years, athetosis, S.I. 14. Mother knows several of her neighbours well, and often chats with them over the garden wall or invites them into her house for cups of tea. This applies particularly to her next-door neighbour, of whom she sees a great deal during the day, and whom she frequently asks to look after David while she goes out shopping or to social functions in the evening. Though the neighbour has offered to do the shopping for her and let her look after the boy, mother prefers it the other way round, so that she can get a chance of going out and "having a break." Mother admits that she often calls on her neighbours "just to get away from the daily routine."

It must be concluded that sociability in relation to neighbours tends to parallel sociability with kin. In the child-centric group one again finds a reluctance to assume extra-familial roles and to participate as member of the neighbourhood community. "Keeping to oneself" is the leit-motif which again and again emerges from the analysis of the social activities of these families, and though, by and large, they all agree that their neighbours are friendly and helpful, they are inclined to reject their overtures and move only within the family circle. In only a few cases did the informants voice hostility towards outsiders, based on slighting remarks concerning the handicapped child. Whatever the justification for this feeling, it occurred surprisingly rarely - not only in this group of families, but also in the other two groups. It appears that the social exile of the child-centric families is voluntary rather

than enforced by outside pressures.

Of the intermediate families all had at least some contacts with neighbours. The mothers in this group generally went further than the exchange of passing remarks, and though the total amount of contacts was often not very great, the theme of "keeping to oneself" did not occur here. The role of neighbour was never actively avoided. In the child-fugic group, however, generalisations are difficult and one is struck once more by the heterogeneity of this group. Despite the small number of cases they stretch from one extreme of the continuum to the other - from avoidance of involvement in neighbourly activities to considerable interaction. While the standing of the other two groups on the dimension of community participation emerges clearly, that of the child-fugic group is less apparent in this area. The isolation from neighbours in some of these families is, however, compensated for by intense contacts with relatives, and it was on this basis that they scored so highly on this dimension.

Contact with official agencies.

In this section we shall be concerned with the contacts made by the research families with various official agencies and individuals. The following will be considered here: medical agencies (general practitioners, specialists, infant welfare clinics, and hospital out-patients' departments), educational agencies (schools, school medical officers, educational psychologists, and departments of education), welfare organisations (voluntary and state social agencies, including associations for parents of handicapped children), and religious bodies. Not included in this section are all those bodies which are essentially leisure time organisations, such as clubs concerned with sports or hobbies. These will be considered later: here we shall look at the contacts made with those organisations and their individual representatives who are, potentially at least, able to render services to the family.

A chronic handicap like cerebral palsy, with its manifold physical, psychological, educational and social implications, can easily make great demands on the relevant social services. Yet the last two sections have

shown that the readiness with which families in this sample make contact with others in the community tends to vary greatly. In this section we shall therefore describe the amount of contacts made with official agencies, in order to determine whether the same variation between the three contrasting family types exists also in this area.

In the following table we present the number of families in each of the three types who fall into the frequency categories indicated. As usual, the information obtained at all the interviews held with each family was used in order to allocate that family to one of these categories.

Table 24.
Contact with Official Agencies in Previous Week

	<u>Child- Centric Families</u>	<u>Inter- mediate Families</u>	<u>Child- Fugic Families</u>
No Contact	2	1	1
Contact occurred once weekly	2	4	2
Contact occurred more than once weekly	9	7	2
Total	13	12	5

The figures in this table differ in one important respect from those in most previous tables: they do not show a difference in their distribution as between the three types of families. With one or two exceptions in each group, these families all had frequent contact with official agencies, and this applies as much to the child-centric families (who in other respects had been characterised by a relative degree of social isolation) as to the rest.

The frequency of contacts with official agencies is very largely influenced by the number of regular contacts with physiotherapists characterising this particular sample. All but one of the children received physiotherapy for at least part of the period of observation, and this generally involved one or two visits per week either to a clinic or from a mobile physiotherapy unit. The four cases in the first line

of Table 24 included the one child who did not receive physiotherapy at all, while the other three received it only at long intervals, or, for one reason or another, did not receive physiotherapy for a major part of the period of observation. All the other families, however, did not only attend regular physiotherapy sessions but were also continually in touch with a great many other agencies. It should be pointed out, though, that for nearly all cases the number of contacts immediately preceding and following the original diagnosis tended to be rather greater than subsequently. Before a diagnosis was firmly established parents generally had to attend a number of consultations in quick succession, and once the diagnosis had been made there were often many more contacts in order to investigate the implications of the diagnosis in terms of remedy and treatment and also (only too often!) in order to find someone who could explain the mysterious terms in which the experts had presented the diagnosis to the parents. In so far as our period of observation generally began after this first hectic stage had passed, the number of contacts for some of the families are less than they might have been earlier on.

Turning to the descriptive material, the following cases illustrate the contacts made by the child-centric families. The first is of a family who had hardly any contact with official agencies at the time, the second of one with rather more numerous contacts, and the other two of families who were classified in the third line of the table:

Mary Sawyer, 4 - 9 years, spastic quadriplegia, S.I. 8. Between twelve and eighteen months of age this girl was seen by a number of experts in quick succession when contact with the family had not yet begun. The Health Visitor had sent the parents to the Infant Welfare Clinic, but there they were told that the child was just a bit slow. They had then gone to the general practitioner, and he had sent them to a paediatrician, who had seen the child a number of times and then given the diagnosis. From there they were referred to an orthopaedic surgeon, who had arranged for the screening at the Centre. At that point the period of observation for the purpose of the present research project was begun. For

practical reasons it was not possible to offer the parents physiotherapy for the child at that time, and so for a while all contact with official agencies abruptly ceased. Although the reasons for not offering treatment had been explained to the parents, they did not accept them and expressed a good deal of aggression in this respect. Eighteen months later the child did begin physiotherapy at a local clinic, though the parents did not consider his once monthly attendance sufficient.

Helen McBain, 7 - 11 years, spastic paraplegia, S.I. 8. Once a week (but with frequent breaks because of illness) Helen goes to physiotherapy. Father, who is self-employed, always makes a point of being available at those times and takes mother and child in his lorry to the clinic. But both parents are rather frightened of officials and authority figures, and apart from those contacts which were arranged for them they have always preferred to keep away from doctors, organisations, etc. Thus, despite their worry about the child, she was already 18 months old and still not walking before they took her for the first time to be examined. Also, although the local Parents' Association holds its meetings only a short distance away from their home, they do not belong to it and have never attended any of its meetings.

Donald Baker, 7 - 0 years, spastic paraplegia, S.I.12. Since the early months of this boy's life the parents have gone from one expert to another. Initially their search for help involved the child's physical condition, and, having returned from abroad because not enough facilities were available there, they visited numerous specialists in the firm belief that one of them would be able to suggest a cure. During this time the boy was also in hospital on two occasions. He was given physiotherapy at a hospital out-patient department twice a week, but the parents were not satisfied with his progress and therefore arranged for further consultations with other specialists and finally were able to have

him treated at home by a mobile physiotherapy service. Later the parents' worries centered around Donald's educational prospects, and again approaches were made by them to a number of different experts and authorities. For a period of nine months father phoned the local school medical officer once every week in order to remind him of a promise that schooling would eventually be arranged for Donald. During this time, in addition to the physiotherapist's twice weekly visit, a home tutor also called at the house twice a week. The parents still frequently express resentment that not more help is forthcoming. In addition to all these contacts, mother has had to attend her doctor on her own behalf in order to obtain sedatives for her "nerves".

William Hooper, 4 - 3 years, spastic quadriplegia, S.I. 16. "If somebody suggested it, I would go to Land's End to get another opinion," said this mother, and again: "One is always hoping that every new doctor will have something optimistic to say about him." She and father have indeed tried everything. When the family doctor rejected mother's early suspicions that something was amiss, she went to the Infant Welfare Clinic, and there insisted that the doctor should refer her to a paediatrician. The latter made the diagnosis and arranged for physiotherapy at a children's hospital, but mother was dissatisfied with its infrequency and brevity, got herself referred to an orthopaedic surgeon and from him managed to obtain thrice weekly physiotherapy, being always fetched in an ambulance and later in a W.V.S. car. The whole family attend church regularly, and it was to the priest that mother turned when the diagnosis was originally made - both for explanation of the condition and for emotional support. She has been trying to take William to Lourdes, but for financial reasons was not able to do so. Instead she took him to a local "holy man", and though he was unable to cure the boy, mother found herself considerably uplifted. Father made spontaneous enquiries about the local Parents' Association, and he and mother initially

attended regularly. They ceased going, however, as they did not find the meetings of help. Although at first the parents were always full of gratitude for all professional help, after the birth of the next child and its rapid development in comparison with William they began to get somewhat resentful that "the so-called experts" were not able to do more for him.

Amongst the intermediate families the pattern of contacts with official agencies was very similar in many respects to that described for the child-centric families. The first of the examples to follow comes from the middle category of Table 24, while the other two come from the third category:

Brenda McNeil, 4 - 9 years, spastic paraplegia, S.I. 4. Brenda goes once a week to a clinic for physiotherapy, and the parents are extremely grateful for this service. This is now the only regular contact the family has with official agencies, except that mother occasionally attends meetings of the local Parents' Association. In the first year of Brenda's life they had many more such contacts: first with the family doctor (whom the parents found most sympathetic and of whose continuing interest they speak most warmly), then with a specialist (who told them not to worry as there was nothing wrong with the child), then with a second specialist (who told them that the sooner they put the child into an institution and forgot about her the better), and then finally with still another consultant, who was able to give them a more realistic appraisal and arrange the physiotherapy sessions.

Joan Kelley, 3 - 3 years, spastic quadriplegia, S.I. 9. Twice every week a physiotherapist calls at the house and gives Joan her exercises, and once a fortnight she is taken to a speech therapist. In addition, the child's eyes have needed a great deal of attention from an ophthalmic surgeon, to whom the child was taken for a time at regular intervals, culminating in a week's period of hospitalisation. Initially the parents had made the usual round of Infant

Welfare Clinic, family doctor, paediatrician, and orthopaedic surgeon while the diagnosis was being established. Mother then found out about the local Parents' Association, and came back from its first meeting full of enthusiasm: "It was wonderful walking into a room where you knew everybody was the same, that they all shared your trouble and knew just how you felt." Ever since she has been a keen worker on their behalf, attending all meetings (usually alone, as father is either at work or only just back from it) and helping to raise funds for them.

Samuel Napier, 7 - 7 years, athetosis, S.I. 11. Apart from twice weekly physiotherapy and once weekly speech therapy (the former at home, the latter at a clinic), there have been a good many contacts with school medical officers, educational psychologists, and others involved in arranging Samuel's education. After the boy had been declared ineducable, mother had done her best to reverse this decision and at one time had been in frequent touch with officials from the local education department. "There is always someone calling at the house because of Sam," she said during one visit. Right from the start mother has been chasing up specialists and other experts. The consultant who had made the original diagnosis had seen the boy at 3-monthly intervals for a time, but then dismissed the case and said that nothing more could be done for him. The parents consulted another specialist (privately this time, in order to get better service), and were then referred to the Centre and thus obtained physiotherapy and speech therapy. Mother is now an active member of the Parents' Association, serving as one of its local officers. Father participates in these contacts only infrequently, for he is somewhat ill-at-ease with authority figures.

Finally, three examples are taken from the child-fugic type, one from each of the categories in Table 24:

Muriel Donaldson, 5 - 11 years, spastic hemiplegia, S.I. 10. This child has been hospitalised on four occasions because of epilepsy, and ever since is seen from time to time as an out-patient. Mother is rather annoyed that no physiotherapy had been offered to the girl, and even more so that she was not admitted to school. She finds herself at a loss as to what she should do about the situation, and is, as she admitted, "just waiting around until a magical solution presents itself."

Albert Jackson, 3 - 0 years, spastic quadriplegia, S.I. 4. This mother has seen rather fewer experts than most of the others, for her doctor referred her straight to the Centre, where she has been attending ever since for weekly physiotherapy sessions. She also occasionally attends the local Parents' Association meetings, but does so alone, as father refuses to be involved.

Gladys Murphy, 8 - 0 years, spastic quadriplegia, S.I. 6. "I wish six physiotherapists could work on her every day," was mother's attitude, and she has accordingly taken the child to a great many hospitals and clinics in the hope of getting more and more intensive treatment for her. The girl was in fact admitted to hospital on two occasions for lengthy periods just for this purpose. But mother is still dissatisfied and often showed her resentment against the doctors who, according to her, refused to take the child's condition seriously. Though father has also insisted on some of these referrals, he never accompanies mother and child to them.

The amount of contacts with agencies is, we must conclude, equally great in all three groups of families. This is clearly not a form of community participation which is avoided by those families who are in other respects socially somewhat isolated. The need for social services of one kind or another is in general very high in all these families, for

the nature of the child's handicap is such that prolonged and varied contacts with agencies is often called for. It is worth pointing out that all informants were asked for details not only of those contacts centering around the child's condition, but also of all other occasions on which members of the family sought professional services of one kind or another. Yet the latter were rarely mentioned and clearly occurred far less frequently than the former.

The family types differ, however, in one respect, namely in the joint participation of the parents in making official contacts. This did not apply so much to routine physiotherapy sessions which took place in most instances during the husband's working hours. The difference is mainly found in those consultations with doctors and others which were more than routine. This point has already been established in a previous section in relation to father's attendance at consultations during working hours. It was found there that fathers from child-centric families were much more ready to attend such consultations than fathers from intermediate families, while the fathers from the child-fugic families tended to stay away from these contacts altogether. The differences between the three family types in "togetherness" is therefore apparent, even though in this particular respect the differences on amount of community participation do not emerge.

Leisure activities.

In this section the part played by leisure activities in the lives of the research families will be examined. For this purpose informants were asked at each visit to describe their leisure activities, with particular reference to their nature, their frequency, the place where they had occurred, and the members of the family who participated in them.

The overriding impression gained from these accounts was one of poverty of interest and hobbies amongst the families of this sample. There were comparatively few who actively organized their leisure life and participated in a variety of recreational activities. In many instances the spare time of family members was spent mainly in such purely passive activities as watching television or reading magazines and fiction.

In Table 25 the nature of the various leisure activities found in the sample are given, together with the number of families who habitually engaged in them.

Table 25.
Number of Families Engaging in Leisure Activities

Watching television	28
Reading books and magazines	26
Visits to cinema or theatre	13
Attending football matches	11
Visiting public houses or cafes	11
Attending horse and dog races	11
Trips to the country or seaside	10
Gardening	10
Listening to records	6
Motor repairs	5
Woodwork	4
Card playing	2
Making clothes	2
Dancing	2
Golf	2
Tennis	1
Watching ice hockey	1
Attending Women's Institute	1

The first two of these activities, watching television and reading, were mentioned by nearly all informants at nearly all visits, irrespective of the type of family being interviewed. Television in particular appeared to take up a large part of the spare time of family members, though in one or two cases a set was said to have been specially bought for the sake of the handicapped child. Because of their almost universal occurrence in this sample, these two activities are excluded from the following table and attention is given only to the frequency with which the remaining, more active leisure pursuits occur amongst the three types of families. Again all interviews held with each family were taken into account in constructing this table, which thus refers to the average number of days in the previous weekly periods on which any member of the family engaged in leisure activities.

Table 26.

Pursuit of Leisure Activities in Previous Week

	<u>Child- Centric Families</u>	<u>Inter- mediate Families</u>	<u>Child- Fugic Families</u>
Occurred on 0 - 1 Day	6	0	0
Occurred on 2 - 4 Days ...	7	7	1
Occurred on 5 - 7 Days ...	0	5	4
Total	13	12	5

This table indicates a definite trend. Amongst child-centric families leisure pursuits are undertaken with far less frequency than amongst intermediate families, while in child-fugic families such activities tend to occur rather more frequently than either of the other types. As in other sections, this table will be used to guide the following case illustrations. First we shall turn to the child-centric families who rarely reported leisure pursuits:

Margaret Watson, 7 - 9 years, spastic hemiplegia, S.I. 4. Father says that he gave up all his outside interests long ago. He used to attend football matches regularly, have a drink occasionally at the pub on a Saturday evening, and was also rather keen on cycling. "You can't do these things," he says, "and be as busy as we are in trying to bring Margaret on." Mother has been to the cinema once in four years, and otherwise never gets further than the television set in what spare time she has. The family have not been on holiday for several years, as they have no money to spare after paying for the child's private treatment and tuition sessions.

Mary Sawyer, 4 - 9 years, spastic quadriplegia, S.I. 8. "We are in a rut," both parents agreed when first asked about their leisure activities. The main trouble, according to them, is

that Mary clings to them so much that they can never get out anywhere without her, and to take her along is too difficult for them in view of her walking disability. Moreover, father always has to go to bed with her, which makes it virtually impossible for the parents ever to undertake anything in the evening.

Bryan Strang, 6 - 4 years, athetosis, S.I. 11. These parents found it quite impossible to remember when they had last been to the cinema or had last taken a trip to the country. They remembered doing so when they had only the one child, but after Bryan's birth the only outings they ever had were to meetings of the Parents' Association, and the only thing they ever did at home was to turn over the pages of magazines or watch T.V. Even when Bryan went into a convalescent home for a few weeks the parents found themselves unable to do anything but sit at home. It is quite exceptional for mother even to get into town to look at the shops, and the one occasion when, during father's holidays one year, she was able to attend a fashion show, stands out as a most unusual experience for her.

The next two case illustrations come from child-centric families who did report some leisure activities:

Walter Lane, 7 - 3 years, spastic paraplegia, S.I. 10. The parents are reluctant to leave the child with anyone else, although babysitters are available, and as a result they never go out together. They used to spend their evenings playing cards, but since Walter began to insist on staying up with them, and on going to bed at the same time, they found the only thing that would keep him quiet is for all to watch T.V. together. When Walter began to walk at 5 years of age mother started going out to the cinema again once a week, leaving father to look after Walter, while father for his part resumed his former habit of going to the pub for a drink every Saturday evening. Yet after Walter had a major

convulsion at 6½ years of age, the parents again ceased these independent activities and once more spent all their time at home.

Catherine Newland, 4 - 6 years, spastic quadriplegia, S.I. 7. During the summer the whole family sometimes take the bus to the seaside and spend the day there. Occasionally they will also all go to town, do some window shopping, and then go to a cafe and have ice cream. Once or twice they have all gone to the cinema together. Father has no interests or hobbies of his own, and television and looking at magazines are their only occupations when at home.

Many of the intermediate families showed no more leisure pursuits than the last category of child-centric families, yet one striking difference emerges from the descriptions: whereas the leisure activities just described for the child-centric families nearly always involve the "togetherness" of the whole family, in the intermediate families one finds rather more individual interests and hobbies:

Doris Fletcher, 6 - 2 years, spastic paraplegia, S.I. 3. On Saturday afternoons during the winter father always goes to football matches. Also mother and he occasionally go to the cinema while a relative looks after the children. Otherwise they spend their spare time at home watching T.V. They never go on holiday because of the cost, but gladly let paternal grandmother take Doris with her to the seaside for a fortnight.

Charles Burgess, 5 - 6 years, spastic paraplegia, S.I. 3. Every Friday evening the parents go to the cinema, while an aunt babysits. Mother also has a passion for reading novels, in which she often indulges during the evening. Father has bought an old motor car, and spends his Sunday mornings tinkering with it. They do not go away for holidays as a rule, as they cannot afford it, but occasionally the whole family will go for a ride in the

car either to the seaside or for a picnic in the country.

Michael Purdon, 7 - 8 years, spastic quadriplegia, S.I. 8. Mother goes regularly once a week to a neighbour's house for a card playing session in which apparently quite a lot of money changes hands. Father's main interest is gardening, and he often spends the weekend in this activity. Otherwise, however, they have few interests and usually just watch T.V. in the evening.

This tendency is even more in evidence amongst the remaining intermediate families, where the frequency with which leisure pursuits were undertaken was rather greater:

Martin Fisher, 5 - 10 years, spastic quadriplegia, S.I. 4. The parents are very keen on ice hockey, and once or twice weekly go to watch it, while paternal grandmother looks after the children. Occasionally they also go to the cinema, but on the whole prefer to stay at home and watch T.V. instead. Father has a second-hand car, and often tinkers with it. The family go for rides in it occasionally, and it also enables them during the summer to go frequently to a caravan which they have at the seaside.

Marilyn Phillips, 3 - 11 years, spastic quadriplegia, S.I. 17. About once a fortnight mother goes out to the cinema - usually by herself, as father prefers to relax at home, where he spends his time in the garden. Sometimes father goes to watch a football match or greyhound racing, and on a Saturday afternoon the whole family often go into town, do some shopping together, and then split up: mother and the children to a cafe, father to the pub.

Henry Cairns, 4 - 3 years, spastic quadriplegia, S.I. 13. Father is an enthusiastic gardener, and will often spend his spare time thus occupied. He is also good at joinery, has built a garden shed and various cupboards, and sometimes does little jobs for

neighbours in order to supplement his income. Once a week the parents go to the cinema, leaving Henry in the care of a relative, and also once a week mother goes to the Women's Institute.

Most of the child-fugio families show a great deal of interest in leisure activities, and amongst them the extent to which these are carried out separately by family members is taken a lot further than amongst intermediate families:

David Richardson, 4 - 0 years, athetosis, S.I. 14. Both parents lead a very active life in their spare time, and this applies particularly so to mother. She is very keen on fashions, likes making clothes and is always on the look-out for a fashion show which she can attend. She is also interested in sports, and twice a week during the summer goes to play tennis at a local club. Father spends every Saturday morning golfing with friends. During the winter the parents often go to dances together, leaving the child in a neighbour's care. Mother also goes to the cinema at times with a girl friend. They regularly go away for holidays, sometimes twice a year, and will then often leave David with relatives.

Gladys Murphy, 8 - 0 years, spastic quadriplegia, S.I. 6. Father spends a lot of his time away from home, often at a pub or with friends, at football matches or attending race meetings. He also goes out on his motor bicycle quite frequently. Mother and Gladys spend nearly all their spare time listening to records or watching T.V. Even holidays are spent apart, at any rate on the one occasion when they went away: mother and Gladys joined the maternal grandparents and went with them to the seaside, while father worked on during this time and took his holidays later on in the year.

Thus the difference in "togetherness" amongst the research families

in their recreational activities is striking. Amongst the child-centric families few independent interests are found, while at the other extreme the child-fugic families show little joint participation of all family members in this respect. Once again the tight bond with the handicapped child manifests itself amongst the former group, and once again the absence of this bond in the latter type of family between the child and at least one parent emerges from the descriptions. One can thus contrast these two extremes in their emphasis on the parental role: in the one type of family the parental role takes precedence over all else and tends to exclude all incompatible activities; whereas at the other extreme activities not concerned with child-care play a far larger part in the life of the family. This means that in child-centric families the number of leisure pursuits is a great deal less than in the child-fugic families. For one thing, the preoccupation with the child allows less time for other activities, and for another the value placed on "togetherness" prevents members taking up those interests that could only be pursued individually. The number of extra-familial roles played by members of child-centric families is therefore far less than those played by members of child-fugic families (and, to a lesser extent, of intermediate families): membership of tennis clubs or Women's Institutes would entail separation from the child, and this, as has previously been shown, is intolerable to some parents. The amount of community participation is thus affected and differs as between the three types of families in a similar way to that already described in some of the preceding sections.

Summary of Family Types.

Three family types were established in the last chapter on the basis of their joint standing on the dimensions of degree of cohesiveness and amount of community participation. It was suggested there that the three types were to be characterised respectively as "child-centric", "intermediate", and "child-fugic". The present chapter has attempted to justify this characterisation by analysing the various functions of the family and by describing the contrasting ways in which the three types of families

organise their activities. A detailed picture of each family type has thus emerged.

The child-centric family is marked, on the one hand, by a high degree of cohesiveness (as given by the operational criterion of "togetherness"), and on the other hand by relatively little community participation. Both characteristics stem from the family's preoccupation with the cerebral palsied child, and can be said to represent the opposite sides of the same coin. In these families there is considerable emphasis on the care of the handicapped child, in that activities connected with the child not only take up far more of the family's time but also take precedence over all other activities. Particularly noteworthy is the fact that it is not only the mother who is deeply involved in this way, but that father too and even the siblings of the handicapped child are similarly affected. Thus the cohesiveness of the family is achieved through the intense interaction of all members with the cerebral palsied child: it is he who acts as the cement of the group and it is on his account that such high scores on "togetherness" are obtained by the child-centric families. The members of these families are rarely able to hand the child over to other people for short periods or even to each other: it is as though a magnet attracts them and they must all cluster around simultaneously. As a result other activities tend to suffer, for participation in them would be incompatible with the high precedence given to the parental role. This applies not only to other home activities, but also affects the part parents play in the outside community in such areas as work, leisure, relationships with kin and contacts with neighbours. The only exception concerns contacts with official agencies, for these are almost solely made on behalf of the child. In all other respects community participation is rarely possible for child-centric families.

In the intermediate type of family members appear to have rather greater individual freedom. The cerebral palsied child does not exert the same compelling power over the group, and in consequence there is less joint participation in activities concerned with his care. Mother is almost solely responsible for this family function, father playing the more traditional secondary role. Because the bond with the child is not

as tight as amongst the child-centric families, the parents and siblings in this group can more easily pursue other activities: mothers show more involvement in housework, fathers more in their jobs, and both more in leisure activities and contacts with other individuals and groups. No need is felt to be constantly together with the child, and members can therefore undertake activities as individuals in their own right, assuming roles other than the parental one. Nevertheless, the parental role is given its due and family responsibilities are by no means avoided.

In the child-fugic families, however, there is evidence that some of the members wish to "opt out" of their parental role. In four of the five cases this applies mainly to father, in the remaining case more to mother. Though in some respects this is a rather heterogeneous group, the striking characteristic shared by all these families is the lack of cohesiveness as evidenced by the considerable degree of individuality manifested in the activities of the members. These families are together far less than either of the other two types, and though in some of the cases the mother-child relationship assumes the tight form typical of child-centric families, the family group as such tends to be an extremely loose one. In consequence the amount of community participation is high: mother may more or less join her family of origin again, father may find substitute satisfactions in leisure activities. The nuclear family has ceased to be attractive to some of the members, and in this respect shows just the opposite phenomenon from that found at the other extreme, among the child-centric families, where the individuals' "attraction-to-group" is so high that all other activities tend to become crowded out.

CHAPTER 8

THE PARENTAL SOCIALISING TECHNIQUES

Having identified certain types of family organisation and described their characteristics, we shall in this chapter turn to the second level selected for study and ask how the three family types differ with regard to the contents of the interaction process between parents and cerebral palsied child. Specifically, we shall examine the parental socialising techniques in order to find out how parents deal with the problem of assigning age-appropriate roles to a handicapped child, i.e. to what extent they exert pressures to socialise the child and thus help him to develop from a state of complete dependence towards whatever degree of independence his handicap makes feasible. From the many aspects of the parental socialising techniques that could be studied we shall therefore select the severity with which such techniques are applied in order to make demands for independence. Descriptions will be presented to illustrate the various degrees of socialising pressures used by the parents of this sample, and these will be analysed in relation to three family types in order to determine whether a particular type of family organisation tends to be associated with a particular mode of exerting socialising pressures on the child.

The assessment of socialising severity.

From the descriptions given by the parents of the manner in which they attempted to help their children to achieve mastery over their environment, it soon became apparent that a wide range existed in the severity of their demands. There were, on the one hand, parents who appeared to make hardly any such demands, who adopted a laissez-faire attitude towards child rearing, showed extreme permissiveness and indulgence, and tended to adapt to the wishes of the child without ever expecting him to adapt to their own demands. At the other extreme there were parents who used a highly rigid, punitive technique in their socialising practices, who exerted considerable pressure towards achievement and thus tended to force a fast pace of development. To distinguish

between the various degrees of socialising severity, enquiries were made at each interview as to parental behaviour in relation to the main areas which were considered to be the foci of socialising efforts with young handicapped children. Six such areas were distinguished, namely locomotor development, speech, the acquisition of formal knowledge, feeding, sleeping, and toileting. The enquiries referred to the nature of the parental demands in relation to each of one of these areas, their frequency, and the sanctions used to enforce them. Again the interview followed no formal, pre-determined course, but parents were given full scope to describe their practices and problems in managing the child, so that as full an account as possible could be obtained of their behaviour in relation to each area. In order, however, to anchor the information to concrete situations, questions were mostly geared to happenings in the last 24 hours. Although parents were free, and were even encouraged, to range wider and bring up any material they considered relevant, they were always asked to detail in particular the demands they had made of the child in the specified time period. This enabled one to obtain a very much more vivid picture, rooted in actual happenings, and also made easier comparison between different sets of parents.

Three grades of socialising severity were distinguished:

- (a) The handicapped child has not, within the last 24 hours, been subjected to any demands from the parents designed to foster his independence with regard to the function under consideration (the "no pressures" category).
- (b) Demands have been made by the parents of the handicapped child in order to foster his independence with regard to the function under consideration, but failure to comply was not generally followed by punitive measures (the "mild pressures" category).
- (c) Demands have been made by the parents of the handicapped child in order to foster his independence with regard to the function under consideration, and failure to comply was generally followed by punitive measures (the "severe pressures" category).

These categories give some means, it is suggested, of distinguishing three steps of severity, ranging from complete failure on the part of the parents to channelise the child's behaviour and direct it towards certain goals set by them to the forcible expression of parental expectations backed by the imposition of sanctions. For the latter category punishment does not necessarily always refer to physical punishment, but includes all measures which Sears, Maccoby, and Levin (1957) have labelled as "negative sanctions", e.g. deprivation of privileges, isolation, withholding of love, threats, etc.

The information on socialising practices obtained from all interviews was given to an independent judge (a psychologist), who was asked to rate each family separately for each of the six areas of child behaviour previously indicated by allocation to one of the three severity categories. (The judge had no access to any of the other material collected, pertaining to the family group and the child's personality). In the following discussion we shall compare the three family types by using this system of classification for our illustrative tables. As in the last chapter, the different categories will then be described by means of detailed case extracts.

Locomotor development.

Under normal circumstances motor functions like walking, sitting and manipulation are thought to develop mainly as the result of maturation, and the part played by parents in their development is considered to be limited. For cerebral palsied children, on the other hand, the situation is rather different. In such a child an organic injury prevents, delays, or impairs the progress expected of him, as a result of which he will, to a greater or less extent, remain unable to assume the independence consequent to the mastery of the basic motor skills. Under these circumstances the parents have to determine how far they are to play a much more active part than is customary in teaching the child what maturation will not bring about. In so far as physiotherapy is being carried out, such teaching is already in progress, but at best this takes up only an hour or so a week. For all the remaining time the parents are confronted

with the dilemma of what demands they are to make of the child with regard to motor functions and to what extent he should be expected to overcome his handicap. Different parents are likely to solve this problem in different ways, and both Table 27 and the following descriptive accounts will illustrate how far these differences are related to family type.

Table 27.

Severity of Socialising Pressures: Locomotor Functions

	<u>Child- Centric Families</u>	<u>Inter- mediate Families</u>	<u>Child- Fugic Families</u>
No pressures	7	1	1
Mild pressures	4	10	1
Severe pressures ..	2	1	3
Total	13	12	5

Amongst the child-centric families a majority of the parents did virtually nothing to bring about any change in the child's motor habits. The following three cases will illustrate this pattern of behaviour in greater detail:

Betty Johnson, 6 - 0 years, athetosis, S.I. 12. These parents find it advisable not to make any effort to influence the child's movement patterns, for Betty is much too self-willed to make this possible. She will not tolerate any interference with her own ways of sitting, getting about, or manipulating objects, and rather than evoke one of her violent temper tantrums the parents allow her to choose her own modes of behaviour. They are convinced that she will one day achieve the necessary mastery over motor skills, but only "when she feels like it." They do rely on outside help from physiotherapists, however, but are not surprised when Betty refuses to co-operate with them. In the meantime everything is done for her that she either cannot or does not

wish to do for herself: thus she is not only pushed around in a pushchair on walks, carried upstairs, or given help with other skills which are realistically judged to be beyond her, but is also never asked to help in washing and dressing and feeding, despite the fact that she might easily carry out at least parts of these functions, and in fact at times does carry them out. Similarly, when something is out of her reach while playing on the floor, it is immediately passed to her. If, for instance, Betty finds that she requires a toy that is on the other side of the room, she points to it and shouts, whereupon mother will at once leave all else and go to fetch it for her - knowing that the child is in fact sufficiently mobile to go for it herself.

Donald Baker, 7 - 0 years, spastic paraplegia, S.I. 12. The parents are prepared to go to a lot of trouble to arrange help from others to ameliorate the child's handicap, yet themselves never make any attempts in this direction. Though shown some exercises by a physiotherapist and asked to carry these out at home, they have never done so. Both parents are extremely concerned about the child's inability to walk, yet they never make any effort to try him out on his feet, to change his posture in any way, or to persuade him to fetch things for himself. Moreover, although manipulation is unaffected by the injury, mother always washes and dresses him and cuts up his food for him - though admitting that he could probably do all these things himself.

Malcolm Stewart, 7 - 7 years, spastic quadriplegia, S.I. 5. When this boy began attending school, mother was astonished to find that within a week he was able to wash and dress himself. It had never occurred to her that he might do these things for himself. Yet even then she continued to do all this for the boy, until the latter decided on his own initiative to take over. Despite the fact that no physiotherapy was for a time available,

the parents never gave Malcolm exercises themselves, nor attempted in any other way to change his handicap, which did, however, give them a great deal of concern. When he finally began to walk he was not allowed out to play, in case he got knocked over by rough children. Advised to buy various constructional toys to develop his finer hand co-ordination, the parents did so, but on finding the boy mishandling them and playing with them in a most unconstructional manner, no effort was made by them to persuade him to use them properly.

The next two examples come from those child-centric families where parents in some way did take a hand in the child's motor development, but without undue severity or harshness:

Christine Anderson, 5 - 5 years, spastic quadriplegia, S.I. 7.

During the first three years this child simply lay on a couch all day, and the parents did everything for her - feeding her, putting toys into her hand, and carrying her around the house. Once she became mobile, however, the parents became much less despondent and also much less passive in their attitude. They encouraged her to move around the floor instead of lying on the couch, and occasionally mother also persuaded her to help with feeding and dressing. All members of the family were still, however, inclined to jump up the moment they saw her reach for an object and get it for her, even at times actually open her hand and put the object into it. At the age of five Christine still relied in many respects on others to do things well within the range of her abilities, but mother then called a family council and they decided that too much had been done for her in the past and that in future help for the child should be strictly rationed.

William Hooper, 4 - 3 years, spastic quadriplegia, S.I. 16. This mother is convinced that a miracle will happen and that the child (who is severely handicapped) will one day be able to play football, dance, and go swimming. At present mother does put some

pressure on the boy's motor development: she religiously carries out the daily exercises which have been suggested to her, she asks him from time to time to hold his head up or to put his tongue in, and she puts pieces of chocolate in front of him in order to get him to pick them up and put them into his mouth. Pressures are thus exerted, but the idea of punishing his failures is quite strange to this mother. Father, on the other hand, is rather inclined to infantilise the child. He never insists that William should pick up an object, but always does the job for him by putting it straight into his hand or, if edible, into his mouth.

The two cases from the child-centric group that fall into the third category, where the pressure exerted on motor functions is severe, present a very different picture from the cases described above:

Margaret Watson, 7 - 9 years, spastic hemiplegia, S. I. 4. This is a very mildly handicapped child, and her developmental progress showed only a little delay. Nevertheless, everything that could possibly be done to rectify the handicap has been done by these parents. From an early age on she has been sent to physiotherapy sessions (which the parents had to arrange privately, as at the local hospital the child was thought not to require such treatment), to kindergarten drill classes, and even to country dance classes. "Everything I could think of to help her walking was done by us," was mother's comment, and towards the same end Margaret has been given skipping ropes, skates, cycles, and scooters. To the parents these are not toys, but means of developing the child's motor abilities, and on frequent occasions mother orders her to use them. Both parents continually remind the child to walk properly, to keep her heels down, not to stumble, etc., and many scenes occur in the course of each day when the child is severely reprimanded for not taking sufficient care over her movements, slapped, or threatened that she will never walk

properly if she does not obey the parental demands.

Catherine Newland, 4 - 6 years, spastic quadriplegia, S.I. 7. The concentration on the child's handicap comes mainly from father. Every day he makes a point of taking Catherine out walking for two hours in order to strengthen her limbs, even though she has to hold on to him or to a pram which they take with them. He also frequently makes her walk round the garden fence, and has in the past given her some quite severe "leatherings" for refusing to do so. Every day before bedtime he gives her some exercises of his own devising. When professionally advised to keep the girl off her feet for some time, as she was developing faulty walking habits, the parents were able to obey these instructions for only a short time, and then had to give in to the strain which this imposed. They feared that in this way the girl would become too much "like one of those completely immobile and inert spastics," and they therefore resumed the previous pressure. Mother did admit that at one time she used to do too much for Catherine, carrying her and fetching things for her, but that father had insisted on her stopping all this. Yet all the concentration is on locomotion and not on manipulation, which is only minimally affected. Mother still dresses and washes the child, although these things could easily be carried out by Catherine herself.

Apart from the last two cases, the passivity of the parents in the child-centric group is marked. Not only are few attempts made to see if the child can climb further up the developmental ladder towards greater independence in motor functions, but the skills which he is known to have already mastered are frequently not exploited. These parents are extremely concerned about their child's condition and would go to a great deal of trouble to get professional help in putting it right, yet in their own handling of the child they reveal a disinclination to make demands - even those which could be regarded as reasonable in terms of the child's capacities. They have few expectations of him, and in

failing to make use of those skills which do lie within his range they treat him as even more handicapped than he is. This certainly applies to all those families classified in the first category of the table, and to a lesser extent it may also be seen in the four families belonging to the middle category. Here, however, the tendency is not so marked, either because it applies to only one of the parents, or because it applies to only one period of the child's life, or because (as in one case) the pressure was exerted in only one respect, namely by taking the child for long walks but infantilising him in all other respects. The two cases in the third category, on the other hand, reveal tendencies at just the opposite extreme. The pressure applied to further the child's motor development is very intense, setting a level of aspiration well beyond his reach. Thus in the child-centric group as a whole parental sensitivity to the child's true capacities is rarely to be seen in this area: demands and expectations are either not sufficient or else too harsh.

In the intermediate group, only one family was found in which no pressure of any kind was put on the child's motor development. This was a child whose handicap was not at all severe and who gave rise to very little anxiety in his parents. The parents felt that the child could get around so efficiently despite the handicap that, apart from taking her to physiotherapy sessions, no special measures were necessary to help her on any faster. Amongst most of the other families in this group, however, such measures were considered necessary:

Joan Kelley, 3 - 3 years, spastic quadriplegia, S.I. 9. As this child's right hand is more severely affected than the left, mother often tries to stimulate the former by holding the left one down and getting her to grasp objects with the right hand. Before physiotherapy was started the parents frequently stood Joan on her feet in the hope that this might provide sufficient sensation in the legs for her to begin using them. When they were advised not to do so as it would only cause harm, they found the instructions rather hard to follow at first, yet managed to obey them faithfully. Having also been advised not to let the

child move around the floor by backward thrust, they encouraged her to roll instead. All this is done in a fairly tolerant manner, however, and when, for instance, the girl does occasionally use the backward thrust mother does not always stop her and scold her for it, as she realises that this is Joan's most effective way of getting around and that it would be too frustrating for her having always to roll. Exercises are left to the physiotherapist, but otherwise a fair amount of attention is paid to the child's movements and how they can best be modified.

Kenneth McGuire, 3 - 3 years, spastic quadriplegia, S.I. 4. Before regular physiotherapy was started, the parents used to take Kenneth out "walking" every evening "until he got fed up." Now they leave exercises to the physiotherapist, but they encourage the boy's motor development by giving him suitable toys like a rocking horse, a tricycle, and a swing ("so that he has to bend his knees when on it"). He is never forced to use them, however, and can play with them when he likes. He is always expected to fetch his own toys, and mother makes a point of not carrying him from room to room, even when she is in a hurry, in order to give him plenty of opportunity for crawling.

Henry Cairns, 4 - 3 years, spastic quadriplegia, S.I. 13. From time to time mother reminds the boy to hold his head up or to keep his tongue in, but such demands are not unreasonable or excessive. At first Henry was always kept on a couch, and mother was initially somewhat reluctant to let him lie on the floor as suggested by the physiotherapist. But now she is glad the child is able to roll around the floor a little and often leaves toys purposely at a distance so that he has to go for them. If he gets stuck in trying to roll, mother first attempts to get him to help himself, and only when she sees that this is not possible will she take a hand. Father is generally rather more indulgent and makes fewer demands, but mother insists that he too should not always pass

things to the boy but should let him try to get them for himself.

The final example from the intermediate type comes from the one family in whom a rather more intense concentration on the motor disability was found:

Brenda McNeil, 4 - 9 years, spastic paraplegia, S.I. 4. Most of the pressure here comes from father, who takes an intense interest in the child's condition and during visits would often invite the writer to inspect the child's legs ("they are getting much fatter at the bottom, but at the top are still awfully thin" was the kind of comment he would then make). He was one of the few parents in the sample who was not grateful for the physiotherapy sessions provided for his child - "it is only twice a week, but what about all the rest of the time? She just forgets." Every night he gives Brenda exercises of his own devising after her bath, and in his spare time he will often take her out for long walks holding on to a pram. Mother applies rather less pressure: she repeatedly tells Brenda to keep her heel down, but never expects her to help in dressing.

This last case illustrates a pattern that closely resembles that of the two-child centric families in the same category. It may be significant that this family scored very highly on cohesiveness and that the amount of time father spent together with the child was considerable. They earned their classification as intermediate, however, on the basis of their score on community participation. As for the other cases of the intermediate type, a contrast is provided with those of the child-centric type in their willingness to make fullest use of whatever capacities the child does have and their attempts to help him on to the next stage. These parents have not ceased having expectations, they do not rely entirely on the help of outsiders, but are willing to make demands on the child which they feel to be appropriate. They are able to exert themselves via a via the handicapped child and to put pressures on him without losing their sensitivity to the limits beyond which it is useless to go.

In the child-fugic group we find, as on several previous occasions, considerable heterogeneity. In three cases a good deal of pressure was exerted on the child's motor development, while in the other two little if any was manifested, as seen in the following case excerpts:

Sally Robertson, 3 - 1 years, spastic quadriplegia, S.I. 6. Father takes no part in the rearing of the child, and a tight bond exists between mother and Sally. The child is rather indulged by mother - she was shown some exercises, for instance, that she could carry out, but has never tried them; she never attempted to find out whether the child could feed herself and was surprised when Sally did so on her own initiative; and as she is afraid the child might get hurt when put out in the garden Sally is generally kept in the rather confined space of the two rooms where they live.

Albert Jackson, 3 - 0 years, spastic quadriplegia, S.I. 4. This mother is also closely involved with her child, while father plays little part in his upbringing. The only thing he does is to give him some "exercises" occasionally, or to hold him up to see if he can support his weight on his feet yet. Mother makes no demands on the child at all, believing that such things should be left to the experts.

The cases where considerable pressure was found are illustrated by the following example:

David Richardson, 4 - 0 years, athetosis, S.I. 14. Within his physical limits this is a rather active boy, and mother finds this most exasperating. She finds she cannot hold him on her knee for this reason, and often admonishes him to keep still. Frequently she also attempts to modify his behaviour in other respects, telling him, for instance, to hold his head up, put his tongue in, or get his legs uncrossed. She agrees that David probably cannot hold

his head up, yet behaves as though he purposely refuses to do so, smacking him for his failure to comply and shouting "I will cut your head off" or making such comments as "I suppose your head is as much of a nuisance to you as it is to me." She is amazed that he is not making progress more quickly, and will at times roll him along the floor so that he can at least experience the sensation of this movement.

The descriptive material presented in this section shows that there exist widely divergent ways in which parents define their task of helping the child to overcome his motor handicap. They range from one extreme to the other, from the parents who are unable to make any demands on the child whatever and treat him as even more helpless than he actually is, to the parents whose expectations are far too high. Both these patterns are found mainly in the child-centric and the child-fugic groups, whereas in the intermediate type the majority of parents relate to their children in very much more appropriate ways and show greater sensitivity to what the children are capable of doing. We will now turn to the other areas of child development and attempt to ascertain how far these patterns exist there too.

Speech development.

Speech is another function which in non-handicapped children tends to develop with only minimal interference on the part of others. Given a certain maturational stage, the child will naturally begin to imitate the sounds made by those around him, and the part played by actual teaching is limited. What pressure is put on children in this respect is designed to hurry them along in the number of words known to them, in sentence formation, or in "speaking nicely". In general, however, there is always the expectation that some time in the second year of life the child will spontaneously become capable of verbally communicating with others.

When cerebral injury is present, speech is frequently affected. This can either be due to the lesion implicating the speech area in the brain,

or to secondary results from spasticity, deafness, or mental defect. Whatever the cause, and whatever the nature of the defect, it poses the same problem to the parents as that posed by motor handicap, namely the extent to which they should take an active hand in furthering the child's developmental progress.

In this sample there were altogether seven children who even at the end of the period of observation had no speech at all. A further nineteen children had speech that was retarded or unclear in comparison with norms for the respective age, leaving only four children whose speech showed no handicap. What pressures the parents of these children exerted in order to further their speech development is summarised in the following table.

Table 28.
Severity of Socialising Pressures: Speech

	<u>Child- Centric Families</u>	<u>Inter- mediate Families</u>	<u>Child- Fugic Families</u>
No pressures	9	3	4
Mild pressures ..	3	8	0
Severe pressures .	1	1	1
Total ...	13	12	5

As usual the table will serve as a basis for the case presentation, and for this purpose the child-centric families will be examined first. The figures in the table, it will be noted, show the same trend as those in Table 27: the majority of the child-centric families again fall into the first category, in that they customarily never exerted any kind of pressure on the child's speech functions:

Betty Johnson, 6 - 0 years, athetosis, S.I. 12. Betty is unable to speak at all, but the parents now never make any demands on her to repeat sounds after them, as they feel she just would not listen. A speech therapist had advised the mother to pretend

not to understand the child's gestures and noises, but mother believes this is nonsense, as Betty would simply fly into a temper if her parents did not at once comply with her demands. Mother finds it easier to manage the child if she can always anticipate her wants, and she therefore attempts to arrange the situation in such a way that the child really has little need for any speech. Thus mother puts out her toys in the morning, gives her the right food at the right time, fetches for her whatever she is pointing to, always keeps the doors open so that Betty never has to demand having them opened, etc. At the same time there is always hope that outsiders might be able to help her speech development, and to this end speech therapists have been approached. Moreover, when the parents found that Betty was apparently imitating the dog in crawling around and thus becoming mobile for the first time, they at once bought a budgerigar in the hope that her speech would similarly profit.

Michael Vallance, 7 - 11 years, spastic quadriplegia, S.I. 15. This boy cannot speak at all, being unable to make any but incoherent sounds. He has a few gestures, but even so the possibility of communicating with others is limited. Yet mother says she can "read him like a book," that she can often not only interpret but even foretell his needs. She agrees that she probably understands him too well, and admits that she has now got into the habit of never expecting him to make any meaningful noises. At one time she used to say "ta" whenever giving Michael something, or point to things and name them. Now neither she nor father do any of these things.

Norah Sinclair, 5 - 5 years, spastic quadriplegia, S.I. 8. This child's speech is very unclear and infantile sounding. The parents, however, understand her perfectly well most of the time, and do not consider it necessary to correct her in any way: "We are too thankful for what speech she has got and too worried about her not walking to start nagging her to speak better." Thus they

let Norah speak as she likes, not attempting to correct the lisp she has got, not making any effort to teach her new words, and never asking her to repeat words she has pronounced badly or showing her how they should be pronounced.

These cases illustrate the marked passivity characterising the majority of parents in the child-centric group. There were some exceptions, however, and the two following examples are taken from each of the other two categories, where pressures were found of a mild and of a severe degree respectively:

William Hooper, 4 - 3 years, spastic quadriplegia, S.I. 16. This is another child who cannot speak at all, and though mother is able to interpret his needs from minimal cues, she does her best to teach the child to communicate in some way. She would like him to learn to speak so that one can then see just how intelligent he really is. She has taught him to point, and now often speaks to him, asking him questions, always hoping that he might somehow manage to indicate his answer. When she gives him something she usually names it, and she has also taught him the names of objects around the house. He still cannot say these himself, but when mother wants to show off how intelligent he is she will ask him where one of them is and he will thereupon look at it.

Margaret Watson, 7 - 9 years, spastic hemiplegia, S.I. 4. Though Margaret's speech is now quite comprehensible, it was rather late in developing, and the parents ever since have done everything to further it. They sent her to private speech therapy, gave her "lessons" at home, and every week-end father used to take her out on his bicycle pointing things out to her, naming them, and asking her to repeat the names. Now the parents are still rather dissatisfied with her speech, make her repeat words not properly spoken, and at a time when the other children are allowed out to play she will be kept in and made to read aloud in order to improve

her diction.

Some variability does exist therefore among the child-centric type, ranging from complete passivity to highly active intervention on the part of the parents. Yet most parents of this group, as we have seen, believe for one reason or another that it is useless to put any pressure on the child's speaking ability. They rarely offer him any incentive to attempt speech-like noises, but always understand him even in the absence of speech. They foretell his wants before he has to communicate them, thus not arousing his need to speak. The situation is essentially the same for those children who do have some speech: even when this is imperfect the parents do not make any demands on the child to better it, and though several were glad enough to have speech therapy arranged, they themselves never interfered with the child's natural mode of expression.

The passive pattern predominant among the child-centric group is seen in only three cases in the intermediate group, and in two of these the child's speech was in fact unaffected and perfectly normal. In the third case the child did speak, but was very retarded in this sphere. Nonetheless, the parents made no efforts to further it, having no ambitions in this respect nor any anxieties. The majority of the parents in this group, however, fall into the second category, i.e., they did make some attempts to further the child's speech development, though without ever doing this particularly forcibly:

Brenda McNeil, 4 - 3 years, spastic paraplegia, S.I. 4. Brenda's speech development has been somewhat delayed, and when during her second year this first became noticeable father bought a book on making speech sounds and attempted to teach her from it. He soon found this to be quite useless, however, and threw the book away. As at the same time Brenda's speech began to make considerable progress, the parents were no longer anxious about it. Now they still correct her speech from time to time to make it clearer to others (they can understand it perfectly well), but do so merely in passing and without any undue fuss.

Martin Fisher, 5 - 10 years, spastic quadriplegia, S.I. 4.

Martin can still say only a few words, and can rarely put these together into phrases or sentences. But mother feels that his speech is just on the verge of developing, and that he needs help. She therefore has done her best to teach him the names of household objects, asks him to say them from time to time, and when he points at something he wants she refuses to take notice until he says or at least attempts to say the necessary word. There is, however, never any punishment for failure to do so.

Joan Kelly, 3 - 3 years, spastic quadriplegia, S.I. 9. At the beginning of the period of observation Joan was unable to speak at all, and only right at the end of it did she begin to say a few simple words. But mother has always attempted to persuade her to repeat words after her, pointing to members of the family and saying their names, saying "ta" before giving her a toy or some food, "bye bye" when going out, and singing nursery rhymes to her in the hope that she might pick up words in this way. After some words did appear she redoubled her efforts, asking the child to repeat the words correctly though never insisting if she sees this to be beyond her capacities.

The parents here were clearly determined to make the utmost of what capacities the child did have, making definite demands on him and expecting him to meet these demands. Their pressures were exerted rather more forcibly in the one instance in this group where the parents were allocated to the third category. This child was rather slow in learning to speak, as a result of which the mother often got annoyed at his habit of still talking in a babyish way, and enforced her demands to change his habits with the help of threats of becoming a "cissy" or by reprimands.

None of the child-fugic group is found in the middle category of Table 28. One was classified as showing the more severe socialisation

pressure, while the remaining four are all in the "no pressure" category. The following two cases come from this latter group:

Sally Robertson, 3 - 1 years, spastic quadriplegia, S.I. 6. Speech development has been very slow, yet mother never does anything to hurry it along. She believes it will come all right on its own, and compares Sally to her sister, who was also somewhat slow. She allows the child to use whatever other methods of communication she chooses - pointing, gesturing, etc., and has taken no special measure to increase Sally's very limited vocabulary of single words. Yet she has also expressed resentment that speech therapy has not been recommended for Sally, believing that she could well benefit from it.

Albert Jackson, 3 - 0 years, spastic quadriplegia, S.I. 4. Apart from a slight delay in development, speech appears to be unaffected by the handicap. Mother never makes any attempts to interfere in this function, believing it is not "fair on a handicapped child to make a lot of demands on him and so put him under strain." She is thankful Albert can talk at all, would rather leave his development well alone, and prefers to "read" him to find out what he wants.

The final case illustration is provided by the only family among the child-fugic group classified in the most severe of the socialisation categories:

David Richardson, 4 - 0 years, athetosis, S.I. 14. Mother frequently tries to teach David to talk, sitting down in front of him and trying to get him to repeat words after her. For a time she gave this up in exasperation as being useless, but then resumed again when a few words appeared naturally. She gives him "exercises" from time to time, i.e. making him say words which she knows he can say, and will punish him if he does not comply. On one occasion, when the writer was leaving at the

end of a visit, she smacked David hard because he refused to say "bye bye" - one of the words he can say.

Parental pressures on speech development, we may conclude, show the same wide range in this sample as was found for locomotor development, extending from a complete absence of pressure to fairly severe pressures. Yet these modes of parental behaviour are not distributed in an entirely haphazard fashion among the research families, for in our comparison of the three family types the same associations are found which were described for motor functions. Thus the child-centric type is characterised by a tendency towards passivity in socialising practices: these parents make no demands on the child's speech development, they indulge him in that they set no goals beyond his present stage of functioning, and in general a policy of non-intervention may be said to distinguish the majority of this type. This is also the pattern characterising most of the child-fugic families, though in both types one case was found which showed just the opposite behaviour on the part of the parents, namely a very severe application of pressures on speech attainments. Both these extreme family types may be contrasted with the intermediate type, where the majority of parents did make demands on their children's verbal capacities, but not in a severe fashion. For the sample as a whole, however, it may be noted that the pressure on speech functions is rather less than the pressure exerted on motor functions. A comparison of Table 27 and Table 28 will show that the totals for the three categories in Table 27 amount to 9, 15, and 6, while for Table 28 they amount to 16, 11, and 3. This indicates that parental socialising pressures are not exerted equally on all functions - a point to be taken up again later.

Acquisition of formal knowledge.

In the course of development a great deal of knowledge has to be acquired by the child which will help him to adjust to the ways of the world, make it possible for him to communicate meaningfully with others, enable him to acquire certain "intellectual" skills, and equip him eventually to take his place independently in the society of adults. The acquisition of such knowledge is a complicated process, for it is

embedded in the child's total experience and depends as much on purely informal learning acquired in the course of day-to-day living as on the deliberate instilling of formal knowledge on the part of adults.

Although no hard and fast line can be drawn between these two kinds of experience, we shall concentrate in this section mainly on the latter, as it is here that the part played by the parents can be most easily observed.

This type of learning is commonly associated with attendance at school, for this institution is specifically designed to serve such a purpose. Yet long before children begin attending school the process of instilling some formal knowledge into them has generally begun. Thus the parents will teach them the names of animals, how to distinguish colours, how to count, what their own name and age is, the value of certain coins, the material from which certain household articles are made - the list may be continued at great length, as reference to most intelligence tests for the pre-school group will show. With cerebral palsied children the acquisition of such formal knowledge often has a particular interest, for development in this respect is generally used as an indication of intelligence, and in so far as intellectual functioning may be impaired as a result of the cerebral injury socialising practices in this area are likely to deviate from the norm. This may apply even to those cases where intelligence has not been affected: fear of the association of mental with physical handicap is so wide-spread, that from an early age, as soon as the physical handicap has been diagnosed, the child may be watched anxiously by the parents as to his ability to acquire formal knowledge. In this section we shall therefore describe the manner in which the parents of the research sample dealt with this problem, and the pressures that were exerted on the development of intellectual capacities.

Some of the children under consideration are still very young, and the acquisition of formal knowledge does not therefore play as large a part in their development as it tends to do later on. It is usually in the fifth year, when the child approaches school age, that parents are found to become particularly concerned about this function. Nevertheless, for the sake of comparison with the pressures exerted on other

functions, all children have been included in the following analysis, though special consideration must be given to the ages of the children when evaluating the descriptive material. We shall follow the usual procedure of first presenting the results in tabular form, and then illustrating the figures with case descriptions.

Table 29.

Severity of Socialising Pressures:
Intellectual Functions

	<u>Child- Centric Families</u>	<u>Inter- mediate Families</u>	<u>Child- Furic Families</u>
No pressures	8	3	5
Mild pressures	4	9	0
Severe pressures	1	0	0
Total	13	12	5

A glance at this table confirms that the trends noted for the functions already reviewed exist also in relation to the present function: on the one hand the sample as a whole is by no means homogeneous in its child rearing practices in this area, and on the other hand the variability found is associated with family type. The following examples illustrate the majority trend among the child-centric type:

Donald Baker, 7 - 0 years, spastic paraplegia, S.I. 12. When at the age of five years no educational provision could be laid on for Donald, the parents became extremely concerned, and for a time were in constant touch with the education authorities in their search for help. Yet all along they have relied entirely on outsiders to undertake teaching. They felt it would be better not to carry out such things themselves, as others would do it much better and Donald would only get confused if different people taught him by different methods. In any case, they added, Donald

would probably not obey them, as he would simply have a temper tantrum if they tried to make him do something he did not want to do. Thus, despite their oft-repeated assertion that Donald was ready for learning, they themselves did nothing to remedy the situation. They gave him books but did not encourage him to look at them; they gave him pencils and paper and merely hoped that he would want to learn to write. But when he demanded that they should read the books to him they always complied with his request without ever showing him that he too could undertake such a task, and when he merely scribbled with the pencils they never persuaded him to use them more constructively.

Malcolm Stewart, 7 - 7 years, spastic quadriplegia, S.I. 5. When this boy began school at the age of six, he was still unable to name colours or to count, despite the fact that he could speak and that he was educable. The parents were extremely pleased with the progress he made at school, but felt it would have been useless to have taught him themselves, as he would never listen to them. They had actually bought a blackboard for him and supplied him with chalks, but never used this as an opportunity for teaching. Now that the child's interest has been aroused at school he will sometimes spontaneously ask for information and this is always supplied, but the parents will never on their own initiative try to impart knowledge to him.

Catherine Newland, 4 - 6 years, spastic quadriplegia, S.I. 7. No effort has ever been made by the parents to teach Catherine anything, despite the fact that father has been only too ready to put pressure on locomotor functions. Mother has always insisted that Catherine (who is in fact feeble-minded) is really quite intelligent - "just a bit slower than others." She believes there is no point in telling her such things as the names of colours or teaching her to count: "She will pick these things up by herself when she is older."

These cases illustrate the by now familiar passivity in child rearing that characterises so many of these parents in the child-centric group. There were some, however, who did show some ambition to make use of whatever intellectual abilities the child had and who therefore did exert a certain amount of pressure, as shown by the following case:

William Hooper, 4 - 5 years, spastic quadriplegia, S.I. 16.

Mother has always been very keen to give William appropriate toys to help him to distinguish shapes, colours, and sizes. She sometimes asks him to point out the bigger of two objects, or to pass her one of a certain colour. She also makes a point of taking him out as much as possible in order to "bring him on a bit." Things are then pointed out to him and named, and when she wants to show him off to others she asks him to indicate where various things are. She is very relieved that he is so responsive to his surroundings, feels that this shows him to be intelligent (he is in fact very retarded indeed), and no longer worries in case his "brain" might be affected.

The one case that is found in the third severity category has already been quoted for similar behaviour with respect to motor and speech function:

Margaret Watson, 7 - 9 years, spastic hemiplegia, S.I. 4. "We could open a shop with all the writing material, books, and educational toys in the house," was mother's own comment. And again: "We get through miles of paper every week working away at her reading and writing." Everything is done to "bring the child on", including sending Margaret to private coaching and to a museum club every weekend, furnishing her with educational toys such as clocks and wooden alphabets, and every night sitting down with her and going over her lessons and homework and giving her additional exercises to do. Both parents take part in this, and unless the child does well such treats as sweets or bedtime stories are withheld.

Turning now to the intermediate group, three cases are found where no pressures on intellectual functions were reported. Closer inspection shows that in all three instances the children were on the one hand still very young (among the youngest in the sample even at the end of the period of observation) and on the other hand all very severely physically handicapped (including complete lack of speech). None of the three mothers felt that it was at all appropriate to exert any pressure in this respect, as the acquisition of even the simplest formal knowledge was quite beyond the present capacities of the children.

All other parents in this group did expect their children to make some effort in the intellectual field, though in no case did they back up their demands with predominantly punitive methods:

Charles Durgess, 5 - 6 years, spastic paraplegia, S.I. 3. At the time of diagnosis the parents had been told that their child would turn out mentally defective, "like most other spastics." "But I proved them wrong," was mother's triumphant comment, and Charles is indeed of normal intelligence and going to an ordinary school. For a short time after the original diagnosis the parents had tried to give the boy as much stimulation as possible "to bring him on", but very soon had found this unnecessary as he was clearly developing at a normal rate. They then also learned that many cerebral palsied children are of normal intelligence, and at one point even asserted that "some things can be done better by them than by others just because they are spastic." Before beginning school the parents had helped Charles to learn to count and to distinguish the letters of the alphabet, but this was always done in play. Now that he is at school they play with him at sums, writing, etc., but this is nearly always on the child's own initiative.

Cecilia Parkinson, 6 - 0 years, spastic quadriplegia, S.I. 8. Up to the fifth year of the child's life little pressure had been exerted on her with regard to intellectual achievement. Then mother became worried about educational prospects, and this

intensified when Cecilia was not admitted to a school at the usual age. Mother is now trying to teach her at home, having bought a book on the subject and attempting to give her exercises from it. She has, however, tried to dress this procedure up as a treat for Cecilia's benefit, telling her that she is lucky to get her lessons at home without having to bother to go somewhere else for them.

Samuel Napier, 7 - 7 years, athetosis, S.I. 11. The mother often plays with Sam at school, and has even bought him a desk for this purpose. There he often sits and does his "writing", for which purpose the parents supply pencils, crayons, paper, etc. They have tried to teach him the letters of the alphabet, but gave this up fairly quickly when they saw that this was still quite beyond him. They now praise him for simply producing scribbles, but have managed to teach him things like counting and colour names.

None of the five children in the child-fugic group were found to have pressure exerted on them in this area. In three cases, however, the children were still very young and also quite badly handicapped, and the mothers (rightly) considered it inappropriate to make demands on them for intellectual achievement. The remaining two, on the other hand, were older and more capable:

Muriel Donaldson, 5 - 11 years, spastic hemiplegia, S.I. 10. Mother is very keen to get Muriel to school, but confessed at one point that this was to a great extent in order to get a rest from her. In the meantime she makes no effort to get any kind of formal knowledge across to the child, preferring to leave all this to school teachers. She thinks it would be too much of a battle to try to make the child learn anything at all, and would rather someone else took on this task.

Gladys Murphy, 8 - 0 years, spastic quadriplegia, S.I. 6.

Mother has always been most concerned to prove that Gladys is of normal intelligence (her I.Q. is in fact 65), and has often rather vehemently asserted that the child's memory, her general interest in her surroundings, and her ability to sing innumerable popular tunes show how bright she is. Because of the child's fondness for music, mother has been wondering whether she might not become a concert pianist (despite the fact that Gladys's hands are affected by the injury!). Nevertheless, even before she began school, Gladys was never actually expected to prove her intellectual abilities. Mother had at one time tried to teach her to count and found this impossible, and since then has been asserting that such things had better be left to other people.

It appears that in this area too differences exist between, on the one hand, the child-centric and the child-fugio families, and on the other hand the intermediate families. The latter reveal a sensitivity in their expectations of the child which is seen but rarely in the other two family types. They make attempts to use whatever capacity the child has for intellectual achievement, yet do not put their demands in a rigid, punitive manner. They may assert that the child is bright when he is in fact retarded, but their expectations show no lack of realism. Amongst the other two types the previously described inhibited attitude in child rearing is commonly found, according to which the child is treated as an infant of even lower abilities than those he does have. It is of interest to see, however, that the opposite extreme of this attitude, where a great deal of pressure is put on the child, is found in only one instance in the whole sample.

Feeding.

Locomotor, speech, and intellectual functions are the areas generally regarded as most directly affected in cerebral palsy. Yet in other areas too the brain injury may produce both direct and indirect effects. Thus in the case of feeding many parents report a history of

difficulties in early infancy, when the child was found to be a poor feeder, having difficulty in sucking and often taking very long in finishing feeds. Later on there may be difficulties about swallowing solids, so that all food must be specially strained and mashed. Also, when manipulation is impaired, the child will be unable to feed himself and thus be dependent on others in this respect.

Such factors tend to increase the difficulties parents have in socialising the feeding habits of their cerebral palsied children. Yet it is widely accepted that it is one of the tasks of parents, particularly in the early years of the child's life, to bring about changes in infantile feeding patterns and instill in him habits culturally regarded as appropriate to his particular age. Pressures are therefore brought to bear on the child to conform with these expectations and to give up modes of behaviour which may have been permissible at an earlier age, but which society now no longer considers appropriate. Giving up breast or bottle is one of the first of such major demands, and though the question of weaning and its effects has probably received more attention in the psychological literature than any other aspect of feeding behaviour, it is only the first in a chain and is followed, inter alia, by such requests as to eat certain kinds of food which adults consider right for the child, to eat at certain set times laid down by adults, to become gradually independent in feeding and not have to rely on others to do so, and to eat "nicely" according to the adults' definition of good manners. In this section we shall consider how the parents in the research sample, given the physical handicap of their children, met the demands of society to socialise the children in this way.

In Table 30 figures are given of the number of families in which parents resorted to the modes of socialising their children's feeding habits by means of the three techniques previously distinguished.

Table 30.

Severity of Socializing Pressures: Feeding

	<u>Child- Centric Families</u>	<u>Inter- mediate Families</u>	<u>Child- fused Families</u>
No pressures	10	1	1
Mild pressures	2	11	2
Severe pressures	1	0	2
Total	13	12	5

The three family types will now be discussed in greater detail, beginning with the child-centric type. Here the figures show that again the majority of parents in this group carried out no active socialising of their children:

Michael Vallance, 7 - 11 years, spastic quadriplegia, S.I. 15. When mother feeds this boy she hold him on her knee and has him tucked against her just like a baby. Mother does not want to give him a spoon to help with feeding, as she believes that with his jerky movements he would only hurt his mouth in this way. Michael is very fussy about food, but mother allows him to have his own way entirely in this respect: "There is after all so little that one can do for such a child." This means that his "crases", which he gets periodically, are all indulged: he will eat nothing but a certain kind of food for days on end, till finally he quite suddenly refuses to eat any more of it and will not touch it again for months.

Helen McBain, 7 - 11 years, spastic paraplegia, S.I. 8. Mother complains that the child eats little at mealtimes, yet the reason is that throughout the day the child asks almost continually for sweets, biscuits, cake, etc., and mother never refuses to supply these things. Helen thus eats more or less when and

what she likes. Although the child can use both hands, mother had made no effort to teach her to feed herself until urged to do so by the physiotherapist. Even then Helen would frequently give up half way through the meal and ask her parents or even her siblings to feed her - a request never refused.

Betty Johnson, 6 - 0 years, athetosis, S.I. 12. At the age of six this child is still on the bottle. If it is not produced as soon as Betty asks for it, she has such tantrums that mother has never felt like withholding it altogether. When Betty had to go into hospital for some weeks she was immediately weaned there from the bottle, yet on return home mother spontaneously offered it to her again. In other respects the child is also very much indulged. She can, for instance, feed herself, yet prefers mother to do so and the latter inevitably does this in order to avoid the child's temper tantrums should she refuse. Betty also has many strong dislikes as far as food is concerned (tea, meat, vegetables, etc.), and mother makes no attempt to persuade her to eat these, as she fears more tantrums.

Most of the child-centric mothers produce evidence such as that detailed above of infantilising their children and not helping them to progress developmentally with their feeding habits. In two cases a rather more assertive manner characterised the parental attitudes towards feeding, of which the following is an example:

Norah Sinclair, 5 - 5 years, spastic quadriplegia, S.I. 8. Feeding has never been a problem area with this child. She was weaned from the bottle at 10 months, and is now given exactly the same food as the rest of the family has. Things like sweets and ice cream between meals are rationed, so that her appetite for other things is not spoiled. She had to be fed by the mother for a long time because of defective hand control, but the parents

were keen to have her independent and father therefore made her some specially shaped cutlery with which she was taught to feed herself.

The final case in this group is that of the child (Margaret Watson) who has been quoted as consistently falling into the third category of socialising severity. This applies also to feeding, due to the strict attention the parents paid to her manipulative skills in feeding herself and the punishment (withdrawal of sweets and other favourite foods) given for undue clumsiness.

In the intermediate group only one case was found which follows the majority pattern of the child-centric in its extreme permissiveness in feeding habits. All other members of this group fall into the second category, in that mild pressures on feeding behaviour were reported:

Joan Kelley, 3 - 3 years, spastic quadriplegia, S.I. 9. Joan was given the bottle until the age of 18 months (the older sibling had also kept it until then). At this point, however, mother decided that it was ridiculous that a child of this age should still have the bottle, and she firmly made up her mind to remove it (only to be agreeably surprised that the child gave it up quite easily). Although Joan's hands are affected by the injury, mother had from an early age on given her biscuits to hold, even though at first she was quite unable to get them into her mouth. When later on Joan gained more control over her hands mother gave her a spoon to hold during meals to encourage her to help in feeding, but later replaced it with a fork as spearing food was easier for Joan than scooping it up.

Cecilia Parkinson, 6 - 0 years, spastic quadriplegia, S.I. 8. This child had been a very poor feeder as an infant, but there was no difficulty in weaning at around 6 to 9 months. Since then mother has been keen to encourage her independence in feeding herself, as soon as her motor development would allow this.

Now Cecillia always feeds herself, having even been taught to use a knife despite somewhat defective hand control. Mother is anxious that the child should have good table manners and will at times check her for this. Yet there is no undue pressure and she is, for instance, allowed to leave part of a meal that she feels she cannot finish.

Marilyn Phillips, 3 - 11 years, spastic quadriplegia, S.I. 17. At one time Marilyn was inclined to be very fussy about food, rejecting a lot of things and eating only a few. But mother persevered and finally "persuaded" her out of this habit, never forcing and yet insisting. The child still chokes easily, but mother feels that she must learn to eat solids, and so gives her small lumps as well as the mashed food that she can manage more easily. "If she does choke I can just put my finger down her throat and get the food out again," was mother's attitude. She used to feed Marilyn on her knee, firmly tucked against herself, but then decided that in this way the child could never get hold of the spoon should she feel like doing so, and thus fed her on a chair instead. Also, whereas previously Marilyn fed before the rest of the family had their meal, she thought it would give the girl a better chance to learn correct feeding habits if she joined the others at table, and she therefore began feeding her with the rest.

The child-fugic group, as can be seen from the figures in Table 30, is again rather heterogeneous. The cases are distributed over all three categories, and the following three cases represent an example from each of these:

Sally Robertson, 3 - 1 years, spastic quadriplegia, S.I. 6. Sally is still allowed her nightly bottle, mother making no attempt to remove it. She is also completely permissive with regard to the child's fussiness, although this involves things

like milk, fruit, and porridge. Sally is feeding herself, but only because father insisted on this, mother having been convinced at the time that Sally would not be able to do so. The child is still, however, sat in a baby's high chair at every meal.

Albert Jackson, 3 - 0 years, spastic quadriplegia, S.I. 4. Albert has always been a poor feeder. Mother has to coax him at every meal, and though she never forces she will not let him eat as little as he would want to. She distracts him, plays with him, even lets him watch T.V. while feeding, but always perseveres. She still allows him a bottle at night, as this is one of the few things he takes greedily.

David Richardson, 4 - 0 years, athetosis, S.I. 14. There are often big scenes at mealtimes, for mother gets very impatient with David's slowness. She also insists that he eats everything she gives him. When he refuses to swallow and even spits the food out, mother frequently sticks it in again. As the child is quite incapable of feeding himself (despite mother's repeated efforts) she has to do all the feeding, but never holds him on her knee for this purpose, having found it easier to prop him up in a chair.

Feeding, like the previous areas reviewed, is thus shown to reveal differences in parental socialising practices between the three groups of families. It is admittedly not easy to make generalisations about the child-fugic group: they are again too heterogeneous and too few in number to make this possible. The other two groups stand in clear contrast, however, for on the one hand we have the passivity, indulgence, extreme permissiveness and infantilising which characterises the parental socialising practices of the child-centric group, and on the other hand we have the assertiveness tempered by sensitivity which distinguishes the intermediate group. Three cases show the harsher type of

socialisation this time, and of these one comes from the child-centric group while both the remaining two are from the child-fagic group.

Sleeping.

Although sleep is not an area to which much attention is generally given in discussions of socialising practices, this function is, like the others discussed here, also subject to parental demands for conformity. Thus children are expected both to go to bed and to get up at certain times laid down by adults, to sleep in a definite place allotted to them, and (unless overcrowding and poverty make this an impossible requirement) to sleep on their own. Only in infancy are such requirements not found: then the baby is to a considerable extent allowed to follow his own sleeping needs and set his own pattern, and his mother is more likely to keep his cot close to her own bed so that she may always be ready to attend to his needs. At later stages of development, however, such indulgence does not usually occur, and, according to the age of the child, certain demands with regard to time and place are made on his sleeping habits.

Amongst those with cerebral palsy, sleep may be interfered with by such factors as the child's muscular inability to turn over by himself, but in general sleep is rarely mentioned as directly affected by the lesion. Yet it is interesting to note in passing that in this particular sample there were four children who showed a very distinctive sleep upset suggestive of an organic basis. The disturbance started in early infancy, usually in the first few weeks of life, and was characterised by a very low total requirement of sleep. As a result the child rarely slept for more than two or three hours and then woke up, crying and demanding attention. No form of treatment tried was effective: various drugs, punishment, leaving the child or taking him to the parents' bed were all equally useless in mitigating the disorder, which continued for the first two to four years of the child's life and only then gradually abated. In view of recent neurophysiological work on the subcortical basis of sleep it would appear highly likely that the cerebral injury

was directly responsible for this upset and thus presented the parents with one more difficulty (and to them an exceptionally wearing one) of rearing their handicapped child. As far as the present enquiry is concerned, however, this problem appeared only in the developmental history given by the parents, as in all four cases the disturbance had either already completely abated by the time the first contact was made with the family or was rapidly waning then and only in evidence to a rather mild extent.

On the basis of the parental reports, socialising pressures as applied to sleeping habits were classified by the independent judge in the three categories of severity previously used. The results appear in the following table.

Table 31.
Severity of Socialising Pressures: Sleeping

	<u>Child-</u> <u>centric</u> <u>Families</u>	<u>Inter-</u> <u>mediate</u> <u>Families</u>	<u>Child-</u> <u>fugic</u> <u>Families</u>
No pressures	8	1	1
Mild pressures	5	11	4
Severe pressures ...	0	0	0
Total	13	12	5

One point becomes at once apparent from these figures, namely that there was no instance in the whole sample where sleeping habits were habitually subjected to the more severe kinds of socialising pressures. Here we have an area in which parents did not consider it appropriate to use punishment to enforce their demands, and though occasionally a parent did report giving a slap to a child for refusal to go to bed at the customary time, this occurred rarely and was never regarded as a necessary and usual manner of shaping the child's sleep behaviour.

For the child-centric group the table confirms the previously indicated trend, in that again the majority of families report an extremely indulgent mode of child rearing for this particular area:

Mary Sawyer, 4 - 9 years, spastic quadriplegia, S.I. 8.

Every night father has to go to bed with this child, for she refuses to go up alone. As they are generally out for long walks during the day, Mary is too tired to be kept up late, and father thus also has to go to bed very early. Past attempts to get the child to sleep on her own have failed and not been repeated, and indeed the parents now dislike leaving Mary on her own in case she has a seizure, these having always come at night. Father cannot leave her once she is asleep and return downstairs, for she wakes too easily. "At least I get plenty of sleep," was his comment on this situation.

Michael Vallance, 7 - 11 years, spastic quadriplegia, S.I. 15.

For years mother has always gone to bed with this boy and shared a bed with him. She is afraid that he might fall out of bed if alone, yet admits that this is now more a habit on her part and that the boy might very easily go alone to bed. She has, however, made no attempts to enforce this, and instead keeps him up late every night but allowing him to sleep late next morning. During that time she can attend to the other children and get them off to school without being interrupted by Michael's demands.

Betty Johnson, 6 - 0 years, athetosis, S.I. 12. Although Betty's sibling is put to bed at a normal time, Betty herself refuses to go until the parents' bedtime. Thus she stays up with them every evening, and as any attempt to put her to bed earlier immediately evokes a temper tantrum, the parents give way and allow her to stay with them. They say that nobody can cope with Betty when she is in one of these tantrums, and that the whole neighbourhood would be aroused if they really tried to persevere. When they go upstairs to bed Betty is permitted to sleep between the parents in their bed, and though attempts have been made in the past to move her to her own bed when

asleep, these are usually unsuccessful, as Betty tends to waken up sooner or later and creep back to the parental bed. Mother admits that she now finds it difficult to sleep without feeling Betty right up against her, and when at one point the girl did begin sleeping by herself (on her own initiative), mother took her back into her bed as Betty had a cold and mother was afraid she might choke.

There are altogether eight children in the child-centric group who are indulged in this manner. The other five, however, are subject to some parental pressure, as illustrated by the following two cases:

William Hooper, 4 - 3 years, spastic quadriplegia, S.I. 16.

At first William's cot was always kept in the parents' room, so that mother could attend to him if necessary. But when another baby was born in William's third year mother moved him to the older siblings' room, as she felt he was old enough to be on his own, while the baby needed her presence more. William is always put to bed around seven o'clock, although this means that he is on his own then.

Norah Sinclair, 5 - 5 years, spastic quadriplegia, S.I. 8.

At one time this child had refused to sleep on her own and mother had always gone up with her to bed, while father slept with the sibling. But finally mother determined to change this, as she felt that Norah was far too old for such dependence. She finally told the child that in future she would have to go up on her own and sleep in her own bed, and with this demand she persisted, despite the child's temper tantrums. Now Norah goes to bed when told to, even though this is earlier than the bedtime for her older sibling.

In the intermediate group all but one case belongs to the second category of socialising severity. The exception refers to a family

where the child insisted on having father accompany him to bed and stay with him till asleep. Father fell in with these demands without ever attempting to resist them, and though mother regarded this as a ridiculous arrangement she did not interfere in any way. In all other families, however, a definite routine was imposed on the child and he was expected to comply with parental demands:

Joan Kelley, 3 - 4 years, spastic quadriplegia, S.I. 9. Until her second year Joan was kept in a cot in her parents' room. Then, however, mother thought she was big enough to be away from her, and accordingly put her into a separate room, where she shared a double bed with the older sibling. The two children are always put to bed early. After a period of hospitalisation Joan was rather upset at nights, and mother then took her into bed with her for a while. She was anxious not to start a habit, however, and at the earliest possible moment put her back into her own bed.

Martin Fisher, 5 - 10 years, spastic quadriplegia, S.I. 4. Martin shares a room with his sibling, and the two always go together to bed. For a time, however, Martin went through a phase of sleep disturbances, and during this time mother had occasionally to take him into the parents' bed to soothe him. She did this only as a last resort, for father objected to being disturbed by the child in their bed, and she herself felt it was more advisable to have Martin "independent and coping on his own, without needing his mother day and night."

Marilyn Phillips, 3 - 11 years, spastic quadriplegia, S.I. 17. During the second year of Marilyn's life mother had to give in to the child's demands to go upstairs to bed with her and stay until she fell asleep. All along, however, mother has attempted to get her out of this habit, trying to distract her and then slipping out of the room, or at least accepting father instead as a companion at that time. She has never resorted to keeping her up with the rest of the family, although she thought

that this would probably be the easiest way of pacifying Marilyn. Instead, being the youngest of the family, she is always put to bed the first in a room shared with the siblings.

In the child-fugio group, finally, we find one case that illustrates the absence of socialising pressures on sleep habits, while the other four belong to the second category of socialising severity. The former is described in the first case illustration below, the remainder being represented by the other two cases:

Muriel Donaldson, 5 - 11 years, spastic hemiplegia, S.I. 10. Muriel always demands that mother goes upstairs with her and stays there until asleep. Though mother has once or twice tried not to go, the child generally refuses point blank to go by herself, and as mother is in any case worried about Muriel's fits she complies fairly readily with the child's wishes. She can slip out again once the child is asleep, but has Muriel's bed close to her own so that she can keep an eye on her at night.

Gladys Murphy, 8 - 0 years, spastic quadriplegia, S.I. 6. As father is often out in the evening, mother likes to keep Gladys up with her for the sake of company. They go to bed at the same time, but though Gladys would like to sleep with mother, the latter does not allow this and insists on the child going to her own room. She does, however, allow her to keep a light on.

David Richardson, 4 - 0 years, athetosis, S. I. 14. David is put to bed early, so that mother can get a "break". Though the boy sleeps in a cot next to mother's bed, she never hears him at night when he cries and it is father who then has to attend to him. Mother does not consider sleep to be a problem with David: "He has always been told to go to bed at a time

that I think is right, and he has never objected." She regards the idea of taking him into her bed when she is unwell as "disgusting".

Two themes emerge from these cases. One is the degree to which parents are prepared to assert themselves vis a vis their children, to rear them according to patterns generally regarded as suitable for children's sleep habits, and to put pressures on them aimed at enforcing conformity. The rarity with which punitive measures are reported shows that this area does not usually provide the battlefield that some of the other areas of child behaviour provide. On the other hand, it will have become apparent from some of the above case illustrations that there are some parents who go to the opposite extreme, who permit the child to determine his own sleep habits and who are prepared to gratify all his wishes in this respect rather than impose their own on him. The child is allowed to stay up as long as he likes, his demands for company when going to bed are complied with and only rarely resisted, and he may even be allowed to share the parental bed and not have to sleep on his own. Such a highly indulgent pattern is again found to typify the majority of the child-centric families, occurring only rarely in the other two groups. There the parents tend to be far more prepared to resist the child's wishes and to require him to give up needs which they consider inappropriate to his age. Thus most parents kept the child close to their bed at night during his early infancy, but while many of the child-centric families continued this practice (at the child's request), the other parents considered it more suitable for an older child to be on his own and accordingly moved him if space permitted this. Similarly, many of the children had at one time or another shown their dependency needs on their parents by requesting their company when going up to bed, but while some parents (mainly in the child-centric group) made few efforts to change this habit even when the child reached later developmental stages, other parents (mainly in the other two groups) tried to strike a balance between satisfying a genuine need in the child and helping him to grow beyond this need. Thus our findings for the functions previously reviewed here are echoed

once more: the majority of parents belonging to child-centric families are characterised by passivity in their socialising practices, in contrast to the intermediate families where pressures are mostly evidenced. In this case, the child-fugic group tends mainly to follow the pattern of the intermediate group.

The other theme which emerges from the above case illustrations leads us back to our previous discussion on "togetherness". We can see once again from the above descriptions how some parents foster a close tie with the child, not only encouraging his dependency needs but actively discouraging any sign of independence. From this point of view, the parental socialising techniques as applied to sleeping habits reflect the different needs parents have to foster the child's dependence and to keep in close physical proximity to him even during the hours of the night.

Toileting.

Elimination and the acquisition of control over it form an area in which, at least in our culture, the presence of socialising influences are particularly obvious. Few parents are content to leave this matter entirely in the hands of maturation and indeed many neglect its role altogether and believe that training alone can help the child to achieve control. In most cases toilet training begins some time in the first 15 months, but within this period there are great variations as to the precise time of starting training, just as there are considerable individual differences as to methods of training. The emotional overtones attached to this area are probably more in evidence than is found with any of the other functions analysed here, with both social shame and the practical nuisance value of having an unclean child acting as motives to achieve training as soon as possible. In consequence methods of training are likely to be more forceful in relation to toileting than in relation to the other functions, and the permissiveness attached to early, infantile habits will usually give way quite soon to fairly rigorous demands for control and independence.

How far a cerebral lesion interferes with the acquisition of control over elimination is not at all easy to determine in any individual case. From the point of view of the parents this presents often a considerable puzzle: how far the general lag of development, mental and physical, also applies to toilet functions, whether inability to sit up is likely to interfere, to what extent the child can be said to suffer from a lack of sensation in bladder or bowel, and even whether inability to communicate might be blamed for slow development in this area. Thus parents tend to be confronted by a situation rather different from that confronting the parents of non-handicapped children, and under these ambiguous circumstances conventional methods of training may not necessarily be regarded as appropriate.

How the parents in this sample approached this problem will be described below. First it must be mentioned, however, that in 8 cases it was not possible to obtain the usual information about training methods, because, even at the beginning of the contact with the family, the child was already fully and reliably trained and therefore no longer subject to parental pressures. In these cases information could only be obtained from the developmental history given by the parents, but as this is of a different order from the other data, it is presented separately in brackets in Table 31. These 8 cases are also not used for the case illustrations that follow.

Table 31.

Severity of Socialising Pressures: Toileting

	<u>Child- Centric Families</u>	<u>Inter- mediate Families</u>	<u>Child- Furic Families</u>
No pressures	4	0	0
Mild pressures	3 (+5)	7 (+1)	2 (+1)
Severe pressures	0 (+1)	4	2
Total	7 (+6)	11 (+1)	4 (+1)

This table reveals for the sample as a whole a greater tendency to exert socialising pressures than was found in any of the preceding tables relating to child training methods. There are fewer cases in the first category and more in the third category than in any other table. No doubt the attitude towards toileting in the community as a whole, to which we referred above, is reflected in these figures. Even the child-centric group is affected, for though the only four cases in the sample which were classified as showing no socialising pressures on toileting are found in this group, this number is less than is seen in the corresponding cell of any of the preceding tables. On the other hand, in view of the prevailing social attitude on this matter, it may be considered that these four cases are all the more significant as standing out against the general trend. The following two cases serve as examples:

Catherine Newland, 4 - 6 years, spastic quadriplegia, S.I. 7. At 4½ the child is still unreliable day and night. Mother puts her in nappies during the night and special pants during the day, and maintains that she would not know what to do if she suddenly had no more nappies to wash. She believes that the child just cannot help wetting herself, and that it would be useless to attempt training her. She had done this at one time, but when Catherine developed temper tantrums every time she saw the pot being produced and tried to kick it away, she dropped all efforts at training and has not attempted to resume them systematically. From time to time she asks Catherine whether she needs to eliminate, but these are rather feeble attempts, and she does not pursue the matter if Catherine (as she usually does) simply does not reply. "When she has an accident I feel I should be cross, so I look at her and she looks at me, and then we both burst out laughing - so what is the use?" This is the attitude that mother has now adopted for the last 2½ years.

Helen McBain, 7 - 11 years, spastic paraplegia, S.I. 8. No

No regular attempts to toilet train have been undertaken since Helen's second year. At that time she would not perform on the pot and began objecting to it, and ever since mother has kept her in nappies and given up all regular attempts at training. She is allowed to wet and soil herself without correction and discipline. Mother sometimes calls her "bad girl" on such occasions, but in such a tone that it certainly cannot be regarded as showing disapproval. Even when the parents were told that Helen could not be admitted to any kind of school until she was reliably trained, no further efforts were made by the mother towards this end.

The following two cases illustrate these child-centric families in which some attempts to train were reported:

Christine Anderson, 5-5 years, spastic quadriplegia, S.I. 7. For a long time mother felt that it was a more or less empty ceremony to take Christine at all to the lavatory, that she just did not have the necessary sensation for control and that one could therefore not have any real expectations. She nevertheless persisted in taking her every 2 hours, and for any success praised her and even gave her sweets, until at the age of 5 she finally decided she could risk leaving off the child's nappies - impressing the child at that time that she could now do without as she was clever enough to tell mother when she needed to go to the toilet.

Bryan Strang, 6 - 4 years, athetosis, S.I. 11. In the first four years training had been somewhat inconsistent - mother at times making fairly rigid and impatient demands, at other times feeling too exhausted to do anything but more or less mechanically changing the child every few hours. After that, however, mother began rather more systematically to train Bryan, pottting him regularly, calling him a "clever boy" for successes, and

finally teaching him to ask by means of special gestures, but at the same time assuring him that it did not matter at all if he did not then perform.

In the intermediate group, in which all children were subjected to some form of toileting pressure, the majority of cases resemble the last two illustrations from the child-centric group. The following two cases show this:

Henry Cairns, 4 - 3 years, spastic quadriplegia, S.I. 13. Mother began toilet training in the first month of Henry's life, and despite the fact that he is still quite unreliable she has persisted ever since. She is rather fed up with the continual washing, but is convinced the boy cannot help his lack of control, and therefore pots him more in the hope of saving herself work. This she does at regular intervals, always accompanied with the admonishment to be "a good boy", and also, at one time, with the offer of a sweet if he succeeded. Failures are not, however, met with punishment, though mother admits that she does not find it easy to hide her exasperation at times.

Marilyn Phillips, 3 - 11 years, spastic quadriplegia, S.I. 17. Training began soon after birth, and mother now believes she can tell from the child's face when she needs to eliminate. Marilyn is still unreliable, however, and though mother never punishes her for failures, she indicates clearly by gestures and words what she expects of the child. She has been trying to teach her to point to the pot when in need of it (Marilyn cannot speak at all), and therefore keeps the pot under a settee in the sitting room.

In four cases in this group rather more vigorous action was taken by the parents in attempting to get the child trained as illustrated below:

Cecilia Parkinson, 6 - 0 years, spastic quadriplegia. S.I. 8

Before she succeeded in training Cecilia in her fifth year, mother used to leave out a pot for the child to crawl to, so that she could be independent as soon as possible. At set intervals the child was told to use it, and if she refused she was simply picked up and put on it. From the second year on mother was cross about accidents, and though she rarely used physical punishment she at times deprived Cecilia of sweets or called her mockingly a baby. Thus there were always definite expectations held out. As soon as the child began to exercise some control over elimination mother left off her nappies. During the night she always picks her up in order to pot her, at one time doing this twice a night.

Edward Cunningham, 3 - 6 years, spastic hemiplegia, S.I. 2. Mother is very keen on cleanliness, and rather ashamed that in the boy's third year he was still not quite reliable. She asked him frequently whether he wanted to go to the bathroom, and after accidents generally gave him a telling off, insisting that he should obey her instructions to tell her or to go to the bathroom by himself. He is now considered quite capable of control, and accidents are regarded as due to his "laziness" and punished with a light slap.

The child-fugio group provides no instance where pressure on toileting was completely absent. One example is taken from each of the other two categories:

Albert Jackson, 3 - 0 years, spastic quadriplegia. S.I. 4. This boy is still quite unreliable, and mother has to keep him in nappies day and night. She continues to train him by sitting him on his pot at regular intervals and showing her disapproval of failures, and has promised him a pedal car when he can manage to go a whole day without accidents.

David Richardson, 4 - 0 years, athetosis, S.I. 14. Training began in the first month, but is still quite unsuccessful. Mother smacks David for failures, and there are now a lot of battles over potting. As soon as the boy sees the pot he screams and kicks it away. For a time mother attempted to force him to sit on it. When this proved impossible, she gave up in despair and for a period did not produce the pot at all but allowed David to wet and soil his nappies. Training was then resumed, but as the boy was still very negative about the whole situation, more smacking ensued.

It must be concluded that the group differences previously mentioned are not as clearly apparent in the area of toilet training. There is still a tendency towards passivity in the socialising practices of some child-centric parents, yet even in this group the majority of parents did make attempts at training and did confront their children with definite expectations. This was also the accepted mode of behaviour on the part of parents in the other two groups, where at times the demands made on the children took a quite vigorous form. This sometimes continued for years without any sign of success, and it is astonishing that so many of the parents managed to persevere on an even course. Many expressed bewilderment as to their failure to accomplish training at the usual time, not having expected a motor handicap to be accompanied by a lag in control over elimination, yet most did their best to overcome apparent obstacles (inability to communicate, dependence on others to take them to the toilet, etc.) by various devices without making this area into a battlefield.

Overview of socialising techniques.

The six areas which have been reviewed in this chapter have given rise to mostly similar conclusions. Child-centric families tend to exert few socialising pressures on their handicapped children, and their child rearing practices appear to be characterised by indulgence of a

frequently extreme nature; intermediate families in general do exert socialising pressures but rarely in a predominantly harsh, punitive manner; and only the child-fugic group fails to reveal a characteristic pattern of its own. So far, however, these six areas have been treated separately, and we must now pull the data together and enquire as to the consistency with which each family tends to apply socialising techniques in the various areas. Had all the child-centric families, for instance, been allocated to the "no pressures" category in every one of the six tables, there would be no need to pose this problem. In fact, a certain amount of overspill into the other categories occurred in every instance, and it is therefore relevant to ask how many families in this and each of the other two types fell consistently into one or the other category and what degree of inconsistency occurred in the remainder.

The full details of the categories for each family are given in Appendix 3. Here this information has been abstracted, and from Table 33, we can ascertain how many families in each type received consistent classifications for all six areas, and in how many there were only two, three, four, or five areas in which the same parental treatment was found.

Table 33
Consistency of Socialising Techniques

	<u>Child- Centric Families</u>	<u>Inter- mediate Families</u>	<u>Child- Fugic Families</u>	<u>Total</u>
Six identical classifications	2	2	0	4
Five identical classifications	5	5	0	10
Four identical classifications	4	5	3	12
Three identical classifications	2	0	2	4
Two identical classifications	0	0	0	0
Total	13	12	5	30

Complete consistency, it will be seen, occurred in only four cases. In one of these (a child-centric family) no socialising pressure was used for any of the six areas, while in the other three cases the families were classified each time in the middle one of the severity categories. Of these three, two belonged to the intermediate type, but the third belongs to the child-centric type - a surprising exception to a general trend. Complete inconsistency, however, was also rare, for in nearly half the sample (14 cases) no more than one area was treated in a way different from the remaining five, while in nearly the whole sample (26 cases) at least four of the six areas were found to receive similar treatment. It may also be seen from the table that there is a tendency for the child-fugic group to be somewhat less consistent than the other two, though the small numbers preclude a firm judgment.

These figures mean that a certain amount of caution must be used in characterising the severity with which parents apply socialising pressures, for within any one family there may be some variation from area to area. Yet the figures also indicate that the variation is not great, that consistency, though rarely 100%, is nevertheless sufficiently great to permit generalisation. Various families do show predominant types of socialising severity, and on this basis it becomes feasible to describe these techniques as they tend to be found in each of the family types. It is true that allowance must be made for the possible existence of a "halo effect", for the classification of each area was not made independently of the other areas, but by one and the same judge. This, however, is likely to have affected the three types to a similar degree, for the judge did not know to which type each family belonged.

The difference between the three family types in the severity with which they apply socialising pressures may be expressed statistically. If the three categories of severity are given weights of 0 (for the "no pressures" category), 1 (for the "mild pressures" category), and 2 (for the "severe pressures" category), a total severity score can be obtained for each family by adding the weights obtained for the six separate areas (see details in Appendix 4). Grouping these scores according to family types, a mean severity score can then be calculated for each of the three

types. These are presented in Table 34.

Table 34.
Scores for Over-all Socialising Severity
of Three Family Types

	<u>Mean</u>	<u>Standard Deviation</u>	<u>Range</u>
Child-Centric Type	2.92	1.83	0 - 11
Intermediate Type	5.75	1.39	4 - 8
Child-Fugic Type	5.20	2.59	2 - 9

The total possible range of scores extends from 0 to 12. Thus the mean of the child-centric type is found to be very near the "no pressures" end, whereas the means of both the other groups are close to the middle of the range. The difference between the means of the child-centric group and the intermediate group is statistically highly significant, and that between the child-centric group and the child-fugic group also reaches an acceptable level of significance (at the .05 level). The difference between the intermediate and the child-fugic groups, on the other hand, is not statistically significant. Although the range of scores obtained by the child-centric group appears to be very large, its extension upwards is mainly due to one case, in which consistently high socialising pressure was found and a score of 11 obtained. Disregarding this case, the range would extend from 0 to 6, confirming the definite tendency of parents belonging to the child-centric group to be very lax and indulgent in their child rearing practices. Intermediate families, however, all have scores closely grouped around the middle of the continuum, as shown by the rather small standard deviation of the mean and by the narrow range of scores obtained. Thus they differ from the other two groups in their avoidance of extreme practices: both indulgence and the application of punitive pressures are absent from the over-all picture of their socialising

techniques. In the child-fugio type, on the other hand, these extremes can be found, for though the mean score of the group as a whole falls near that of the intermediate type in the middle of the continuum, the standard deviation is large and the range of scores extends almost from one extreme to the other. The heterogeneity of this group, so often referred to previously, is once more shown up.

This method of evaluating socialising severity quantitatively is perhaps somewhat arbitrary, for each of the six areas of child behaviour is given equal weighting, even though in any one case the amount of attention spent on one particular area may far exceed the attention spent on other areas. By averaging out the six separate scores obtained for each family a somewhat distorted picture may be given of the individual case. Yet this distortion is not likely to be serious when, as in this discussion, the analysis is centered on groups and not on particular individuals. As indicated by the means and distribution of scores presented above, the three groups of families do show up certain overall trends, and we can now turn to stating these trends in summary.

In families belonging to the child-centric type, parental socialising techniques were found to be frequently characterised by a remarkable degree of passivity and lack of assertiveness in the face of the child's own wishes and desires. However much these parents wanted to see changes brought about in the child's behaviour, and however much they were willing to obtain outside help towards this end, they themselves tended to be inhibited from undertaking this task. In these families the child himself almost entirely dictated the speed and pattern of his development, without any of the usual pressures being brought to bear on him to change in certain directions customarily considered desirable. Not only were few demands made on him to master the next developmental step, but even skills known to be already within his powers were not exploited. Handicapped as he was, he was treated as even more helpless. Dependency was thus fostered and independence kept in check: as though (one might venture to interpret) the parents wished to maintain a permanent state of infancy in the child. Infantilising appears to be indeed the main

theme running through the child rearing practices in the majority of these families - as though the parents, having come up against the difficulties imposed by the handicap, felt themselves unable to continue at all with their task of socialising and thus decided to maintain the status quo.

The note of caution against making too sweeping generalisations must, however, again be sounded. As already pointed out, only one case amongst the child-centric group showed complete consistency in the failure to apply socialising pressures to any of the six areas. Amongst all but two of the remaining families the pattern described above was the predominant one, yet in these two it did not occur at all. In one its opposite was found: the family was categorised in five of the six areas as applying socialising pressures of a severe degree, and the descriptive material illustrates the harshness with which the parents attempted to force this child towards further development and the overcoming of the (minimal) handicap. The other exception refers to the case in which almost consistently socialising pressures of a mild degree were applied, the parents thereby showing a pattern more typical of the intermediate than the child-centric group.

Despite these variations from family to family and also within each family, it is clearly justifiable to characterise the child rearing practices found in this group as being by and large based on a policy of laissez-faire. It is, for instance, significant that a majority of child-centric families never used physical punishment in any form, believing it wrong to give even a light tap to a physically handicapped child, whatever the misdeed. That they differ in this respect from the other two types of families is shown in Table 35, for only one other family in the rest of the sample took this attitude.

Table 35.

Number of Families using physical punishment

	<u>Child- Centric Families</u>	<u>Inter- mediate Families</u>	<u>Child- Fugic Families</u>
Physical Punishment used	5	11	5
Physical Punishment never used	8	1	0
Total	13	12	5

Discipline in general is but rarely in evidence amongst the child-centric families. Frequently no attempts are made to set limits to even the most outrageous demands, and the child's own inclinations are generally given free rein. Infantile omnipotence is thus fostered, conformity with adult demands not enforced, and maximum gratification with minimum frustration permitted. The role which these parents thus ascribe to the child in the family tends to emphasise both the dependence and the egocentricity of the young infant. Having found that the child cannot play his age-appropriate role, the parents no longer expect him to compete even on a lower level, but assign him to an age level at which few social pressures are enforced and where the normal give-and-take attitude in interpersonal relationships is not demanded.

Amongst parents in the intermediate group of families the predominant pattern of socialising is that represented by the second category of socialising severity used here, namely the application of mild pressures. These parents did take an active hand in furthering the child's development, they were generally not content to leave him standing at his present stage, and accordingly they attempted to direct and channelise his behaviour in directions considered by them as desirable and appropriate to his particular capacities. In so doing they often had to go counter the child's own wishes and desires, yet (unlike the previous group of parents) they were prepared to do this if need be. Faced with the obstacle to progress and independence imposed by the child's condition, they tended to seek ways round it, and in this attempt did not merely rely on outsiders but undertook this task themselves. Thus pressures were brought to bear on their children, yet on the whole the pressures were not harsh or excessive. Change was brought about by example, praise, or reward rather than by punishment. This does not mean that these parents never used punishment - all but one family in this group had occasional recourse to this method of enforcing demands. Punishment was, however, never the predominant means of inducing change in the child's behaviour.

The socialising practices show this group to be a very homogeneous one. In two cases the family was assigned to the middle category of severity for all six areas, in five cases there was just one exception

and in five further cases there were two exceptions to this method of socialising.

In this group, we can conclude, the parents are generally able to give the child support and control sufficient to help him in mastering developmental tasks. They make use of whatever skills the child has, often revealing considerable sensitivity in adjusting their demands to his real capacities, and in this way showing their willingness to help the child along towards whatever his optimal degree of dependence may be. By making demands on the child and holding out definite expectations, they stress the reciprocity of human relations, indicating that he not only has certain rights but also must meet certain obligations. Limits are set and the importance of social conformity thus stressed. Though the child may not be able to assume the role appropriate to his chronological age, he is expected to behave at least according to his functional age.

In contrast to the other two types of families, the child-fugic group provides no evidence of one characteristic pattern of socialising methods. Comparing tables 27 to 32 for the distribution of cases amongst the three categories of severity, one finds no consistent trend in this group. In the areas of speech and formal learning these families tend to adopt the pattern associated mainly with the child-centric families, i.e. they put practically no pressure on the development of these functions and leave the child to his own devices in this respect. With regard to motor functions, on the other hand, they were found to go to the opposite extreme, in that they adopted a punitive attitude and applied severe pressures to the child. In the remaining three areas of feeding, toileting, and sleep there was a tendency to follow the pattern of the intermediate group and apply pressures of a fairly mild degree.

Generalisations about the child-fugic group as a whole are therefore difficult to make, and the same applies to individual cases, for here too lack of consistency tends to be shown as between the kinds of socialising pressures applied to different areas. This was pointed out in relation to Table 33, from which it can be seen that none of the

child-fugic group received identical classifications for all six areas or even for five of these areas. One case was classified in the first category (no socialising pressures) for four areas, with two areas being given different treatment; another case was classified in the middle category of socialising severity four times, again two exceptions occurring; and a third case was assigned to the most severe category for four areas, the other two areas being given different classifications. The remaining two cases show an even more miscellaneous collection of categories, ranging from the most severe to the least severe. The fact that the mean score for over-all socialising severity (see Table 34) should fall near the middle of the continuum is therefore of little significance: it is the wide distribution around this mean that is noteworthy.

There is no doubt that the small numbers in this group tend to obscure the picture. Yet it seems likely that even with larger numbers a consistent picture would not have emerged, for it is just this inconsistency which appears to be the chief distinguishing feature of the child rearing practices of this group. In some cases this applies to the individual parent, who uses different approaches to different systems of behaviour: pressure on one, indulgence for another. But even more influential in producing inconsistency is the difference between the parents. In four of these families father interacted only infrequently with the handicapped child, yet when he did so he tended to adopt a rather harsh attitude which contrasted strongly with mother's more indulgent treatment. This may be illustrated in connection with Table 35 on the use of physical punishment, according to which all five children in this group received such punishment. In three of these cases, however, mother adopted the attitude characterising many of the child-centric families, namely that it is wrong to use physical punishment on a handicapped child and that no such disciplinary measures should be taken. Yet, because of father's conflicting view, physical punishment did occur in all these families.

Thus the role-ascribing process in this group of families varies from situation to situation, depending on the socialising agent on the

one hand and the area of child behaviour on the other. The child may therefore be subject to conflicting demands, and have to face different types of treatment at different times. Had we been able to obtain a group of "pure" child-fugic families, i.e. families in which both parents showed a considerable lack of involvement with the handicapped child, it is likely that the socialising practices of this group would have yielded a more clear-cut picture, and that this picture would have highlighted the considerable severity with which such parents make independence demands on their children.

CHAPTER 9

THE CHILD

We now turn to our third level of study, namely that of the individual cerebral palsied child. So far we have considered some of the social forces that impinge on him, and the question now arises as to the effects of these forces on his personality. Ideally one would like to determine whether the conditions of the environment, as established by the emotional atmosphere prevailing in the family, permit the optimum amount of personality growth that can take place within the limits set by the physical handicap. The cerebral palsied child has, after all, certain organically imposed difficulties in making successful adjustments to life situations, and the problem that therefore presents itself is the extent to which the various types of social setting distinguished in this report help or hinder him in making these adjustments. Such a task, however, requires a dovetailing of variables that is so infinitely fine that it is still beyond our powers with present research equipment, and only a rather more limited and modest analysis can therefore be undertaken. The purpose of this chapter will therefore be to determine whether the different family types give rise to certain characteristic personality aspects in the children, with particular reference to that capacity to assume age-appropriate roles to which we have previously referred as the social maturity of the child.

The assessment of social maturity.

In chapter 2, where we reviewed the studies that have been carried out on personality development of the cerebral palsied, attention was drawn to the considerable methodological difficulties encountered in any systematic attempt to assess such children. Authors have therefore tended to select rather unrepresentative samples composed of older children with normal intelligence and full speaking ability, to whom projective and other tests could be administered. For the present sample such tests are clearly inappropriate: these children are all still

very young, most of them are below average intelligence, and the verbal capacity of many is affected by their condition.

In the assessment of social maturity, these difficulties must be taken into account. The validity of using tests standardised on and designed for non-handicapped children has already been commented on, and it applies especially to the one test that has been constructed in order to measure this particular area, namely the Vineland Social Maturity Scale. A cerebral palsied child will be heavily penalised on this test by the specific effects of his motor handicap, with little allowance made for the manner in which he attempts to make the maximum use of whatever residual powers he does have or the way in which he attempts to circumvent his handicap. Yet, at least within the context of this research project, it is just these aspects which are of most interest, and in this chapter we shall therefore try to isolate the psychological determinants from the organic obstacles and ask how far, within the limits set by the physical condition, the individual is reaching for social maturity. We are thus not aiming to ascertain the total effect on the child's development, but are using the organic condition as a given factor in the situation in order to attempt a description of psychological functions. This means that each child must be judged in his own right, that omnibus criteria cannot be set up, but that in every case the organic limitations present must be taken into account.

In our discussion of social maturity in Chapter 4, we linked this concept to the assumption of age-appropriate roles, and it was pointed out there that this is not a unitary concept but represents an over-all judgment based on a number of different manifestations. To assess social maturity we must identify these manifestations - bearing in mind the age level of the sample (for social maturity will be indicated in different ways at different stages of development), as well as the accessibility to observation of the relevant material. The following three areas were therefore chosen, in the belief that with this particular sample they provide the most suitable approach to the problem in hand:

- a) The child's emotional dependence on his parents, as expressed in his clinging to them and his reactions to the brief every-day separations which occur in the lives of all children.
- b) The child's instrumental dependence, as indicated by the degree to which he makes full use of his developmental capacity in relation to such functions as feeding, toileting, dressing, washing, etc., as against indications that he is unduly dependent on others in these respects.
- c) The child's capacity for co-operation with other people and his ability to meet their demands, as against his inclination to follow purely egocentric modes of behaviour.

From these three areas, it is suggested, an indication may be obtained of the roles played by the children in the respective social situations, and evidence will thus be accumulated to show whether a child is functioning at a very much less mature age level than might be expected in view of his chronological and mental age and his physical handicap. The evidence required will refer to the child's actual behaviour in real-life situations, and for this purpose the reports from physiotherapists were found to be particularly valuable. Through their frequent and prolonged contact with the child the physiotherapists were in a most useful position to accumulate information about each case. They had intimate knowledge of the behaviour characteristics of the children, and moreover were well able to weigh up the influence of organic factors in producing the phenomena under consideration. Through periodic contacts with them throughout the course of the project it was possible to obtain a great deal of qualitative material about the relevant functions, which could be supplemented further by the information obtained from the parents in the course of each interview, as well as the writer's own observations.

In order to compare the personality characteristics of the children belonging to the three family types, the qualitative data had to be arranged in a way permitting such comparison. In theory a continuum exists from maturity to immaturity, and it should thus be possible to place different children at different points on this continuum. In practice, however, the data are not precise enough to permit this

procedure, and a very much cruder method had therefore to be used. This consisted of asking the physiotherapists to rate the children according to the quantitative differences in the functions under consideration (i.e. degree of emotional dependence, degree of instrumental dependence, and degree of co-operation). A 4-point rating scale was originally used, yet even with such a crude instrument the raters frequently reported difficulties in making distinctions, and it has therefore been decided to present the results only in terms of two categories, by combining the first two and the last two points of the rating scale.

Six judges were involved in making the ratings. Each had known the children they were asked to rate for periods of at least 18 months, and they were chosen because each was the professional person in closest contact with the particular child. They included five physiotherapists and one teacher (the latter for the one child in the sample who did not receive physiotherapy). One physiotherapist rated 20 children, another five, two others one child each, and the teacher also judged just one child. All saw the children at least at monthly intervals, though the majority were seen weekly or even twice weekly throughout the contact with the case. The ratings were carried out at the end of the period over which the investigation took place, and were made without knowledge of the type to which each child's family had been allocated.

Emotional dependence.

The literature on the effects of maternal deprivation has shown clearly that young children form strong emotional attachments to particular individuals (usually their parents), as a result of which they tend to seek their company, follow them around, cling to them, and attempt to avoid separation from them. Such attachment is, however, more in evidence at certain ages than at others: it first arises in the second half of the first year and almost immediately reaches full strength (Schaffer, 1958, and 1959), remains at this height during the second and third year, and from then on gradually wanes (Bowlby, 1953). It is thus common for children of 1 and 2 years to show strong attachments to their parents, to

protest at even brief separations from them, and to show negativism towards strangers. At the age of 5 or 6, on the other hand, one would no longer expect to find this pattern in its full intensity (except perhaps at times of stress and illness), for by that time a child is expected to assume greater independence and no longer to need the constant presence of his mother. Should he still show this pattern, one would be justified in regarding this as an indication of social immaturity.

It is probable that this is an area free from any direct effects of organic brain injury. Bender (1956) maintains that a child's motor dependence will in itself give rise to emotional dependence, but her arguments are open to questioning. If such an automatic association existed, all cerebral palsied children would manifest an attachment to their mothers stronger than is usually found in their normal peers, yet neither the literature nor one's own clinical experience suggests this as a universal characteristic of the cerebral palsied population. This indeed is borne out by the present sample, for (to anticipate the findings of this section) considerable variability was found in these children and by no means all showed signs of inordinately high emotional dependence on their parents.

The information which was required to make judgments about each child's behaviour in this area refers to his reactions to those occasions when he has to let his parents out of sight for any length of time. This is a situation which occurs frequently in the course of every child's day - when he is left with other people for an hour or two, when he is put to bed at night, and indeed every time that his mother leaves the room. Information such as this could be gathered from the interviews with the parents, but the physiotherapists were particularly well-placed to observe the relevant behaviour, for their procedure always necessitated the removal of the child from the mother. This was perhaps more noticeable when treatment took place at a clinic, where the mother was asked to wait outside while the child was taken to the therapy room. To a less degree, however, it applied also to treatment carried out in the child's own home, for even if the mother remained in the same room

the child had to leave her immediate presence and trust himself to the hands of a stranger. With a very young child some upset under these circumstances may be regarded as normal, yet sooner or later he may be expected to develop sufficient security and trust to react to this situation without misgivings and tears, and any child who fails to show this change, despite the frequent contacts with the physiotherapist and the opportunity thus provided for "reality testing", must be regarded as showing excessive emotional dependence.

Table 36.
Number of Children Showing Varying Degrees
of Emotional Dependence on Parents

	<u>Child-</u> <u>Centric</u> <u>Families</u>	<u>Inter-</u> <u>mediate</u> <u>Families</u>	<u>Child-</u> <u>Furic</u> <u>Families</u>
Normal emotional dependence	2	7	4
Excessive emotional dependence	11	5	1
Total	13	12	5

A trend is shown in Table 36 which parallels the trend of many of our previous tables, for again there is striking difference between the child-centric and the intermediate types. In the former by far the majority of children were found to show signs of excessive emotional dependence. Only two cases from this group were considered to fall within the normal range, one of which is described below:

Christine Anderson, 5 - 5 years, spastic quadriplegia, S.I. 7
Physiotherapy was started when Christine was three years old, and though it was carried out in her own home and in the presence of the mother, Christine at first cried bitterly every time she was approached by the physiotherapist, clinging to her mother and refusing to leave her. Yet within a few sessions she had become

much more confident and was gradually able to tolerate mother's absence at this time. In the first three years Christine had generally clung a lot to her mother, crying when left alone in a room and not wanting to be looked after by anyone else. Even with father she cried when mother first departed. She also insisted on mother accompanying her to bed. Yet after this age she gradually improved, stayed with other members of the family without protest when mother went out without her, and often demanded that she be let out to play in the street. When sent to school in her sixth year she cried for the first two days, believing she would be kept there for good, but then settled in quickly and even began to look forward to going there each morning.

In this case we see signs of the gradual loosening of the tie with mother, generally regarded as a positive sign of mental health in the growing child. However great the initial clinging, around the fourth year one can expect the child to be more secure in his relationship with the mother and thus more capable of leaving her and joining other groups. But in the majority of child-centric families this was not seen. Little indication of the child's growing emotional emancipation was found here, the period of strong attachment being extended well beyond the usual period. This is seen in the following cases:

Bryan Strang, 6 - 4 years, athetosis, S.I.11. The beginning of physiotherapy in Bryan's fourth year provided a major battle. At first in the clinic, then in his own home, Bryan used to cling desperately to his mother and sob bitterly throughout the whole session. This went on for months on end, before finally the physiotherapist was able to establish rapport with the boy. Right until his sixth year Bryan was frightened of strangers, and cried himself literally sick if ever mother left him with anyone else. He always demanded the presence of one or the other of his parents, whined the moment he saw them go towards the door, and would not go to bed alone. He was also very upset when he

started school in his seventh year, crying every morning on leaving mother for several weeks.

Norah Sinclair, 5 - 5 years, spastic quadriplegia, S.I. 8.

This child also took a long time to settle in the physiotherapy sessions, crying when taken from mother and still crying desperately when brought back again at the end of the session. She finally did settle in, but is otherwise still extremely clinging to her mother and father. She gets upset when left in her pushchair outside shops, will not go to bed alone, and still follows mother everywhere around the house. When confronted by a stranger she still becomes very frightened, even in mother's presence, and it took many visits before the writer was able to make contact with her.

Michael Vallance, 7 - 11 years, spastic quadriplegia, S.I. 15.

Though now very much less clinging than he used to be, Michael still shows considerable unease in the presence of strangers when his mother is not there. Until the age of six he never went to anyone outside his family, and it has only recently become possible to leave him with other people. Every evening his mother still accompanies him to bed. At one time he used to get upset the moment mother was out of sight, and though mother now no longer has to take him with her from room to room, he still likes to shout to her occasionally when she is working in another room to make sure she is available. Though now quite at ease with the physiotherapist, it was at first impossible to separate him from mother without causing a major scene, even though he was already five years old by then.

Mary Sawyer, 4 - 9 years, spastic quadriplegia, S.I. 8. Mary's

attachment is almost exclusively focussed on father, who, being unemployed, is at home most of the day. She cries bitterly when she sees him go out without her, and though she does leave him in order to play with other children, in their absence she

is constantly making demands for his attention, crying if ever he is not available. When at one time mother took her away on holiday she pined for father so much that the holiday had to be cut short and the child brought back. But her clinging is most in evidence at the end of the day, when she insists on father's presence, particularly at bedtime. Father must always accompany her to bed, and indeed has to settle down with her in the same bed.

These children show a pattern of behaviour that can hardly be regarded as appropriate to their age. The degree of emotional dependence shown is more typical of a child in its second or third year, whereas at the age that these children have reached considerably greater independence can generally be expected. This is seen in the majority of cases in the intermediate type of family, as illustrated below:

Cecilia Parkinson, 6 - 0 years, spastic quadriplegia, S.I. 8. When physiotherapy was begun in her third year, Cecilia was extremely ill at ease in the first few sessions, generally crying more when she saw her mother again at the end of the session than when she left her at the beginning. Yet she soon settled in and became quite attached to the physiotherapist. At one time, in her second year, she cried every time her father left for work in the morning, and in her third year she went through a phase of constantly wanting to follow mother around the house. This she does no more, but on the contrary now clamours frequently to be let out to play in the street or the garden. There is no difficulty in leaving her with others when the parents wish to go out. She is still inclined to be rather shy with strangers on first meeting them, hiding her face and retreating behind mother. Yet even on the first occasion that the writer saw this child it proved not difficult to establish rapport with her quite speedily.

Brenda McNeil, 4 - 9 years, spastic paraplegia, S.I. 4. Though

around the age of 2 Brenda went through a phase of considerable dependence on her parents (exasperated by a period of hospitalisation), she is now showing many signs of increasing independence. There is no difficulty in leaving her with relatives and other people she knows; she likes to get outside to play on her own; she does not now follow mother around the house; and when she started nursery school at 4½, she settled in very quickly. For a time she was inclined to be negative towards strangers, but this too was a passing phase and she soon became fond of her nursery school teacher. She does still object when father goes out without her at the weekend or in the evening, but the parents are not sure whether this is because she wants his company or because she thinks she may be missing a treat.

Doris Fletcher, 6 - 2 years, spastic paraplegia, S.I. 3. Until about 2½ years of age, Doris tended to cling to her mother quite a lot and could not be separated from her even for very brief periods without upset. At 6 this is no longer in evidence, and Doris now leads an active social life of her own, spending a great deal of her time with relatives and other children without seeing mother for hours on end. Although frightened of strangers in her first three years, particularly of doctors, she is now a little more confident in their presence and quickly took to her physiotherapist. When a stranger visits the house she is at first still inclined to climb up on mother's knee and seek reassurance, but it is not long before she climbs down again and starts interacting with the stranger.

Not all the children of the intermediate families follow this pattern, however, for in five cases there were signs of more than ordinary emotional dependence on the parents, as seen in these two examples:

Michael Purdon, 7 - 0 years, spastic quadriplegia, S.I. 8.

Michael is still rather inclined to cling to his parents at the age of 7. As a result he cannot be left with anyone but his older siblings, for otherwise he cries so much that his parents feel it would be unfair to ask anyone to take on the task of looking after him in their absence. In the house Michael used to try and follow mother around from room to room, getting very frustrated at his handicap which prevented him from doing so effectively. This he does no longer, and he now loves going out to play with other children. On the other hand, he frequently expresses fears of his parents going away and leaving him. He is still very shy with people outside the family, and both the physiotherapist and the speech therapist had considerable difficulty in making contact with him.

Henry Cairns, 4 - 3 years, spastic quadriplegia, S.I. 13. Henry is very attached to his parents, and at the age of 4 mother still cannot leave him outside a shop because he screams so much after her. Though he does go to bed alone and though he can be left with his grandmother for an evening, he dislikes being left by himself in a room by mother and will cry after her as soon as she goes out of the door. He is especially fond of his father, and loves nothing better than to sit on his knee and be cuddled, usually protesting strongly when father has to put him down again. With other people he is very shy, will cling to mother in their presence and become quite still and unresponsive when approached by them. Beginning physiotherapy was thus a nightmare for all involved.

Turning finally to the child-fugio families, we find that only one of these had a child showing evidence of excessive emotional attachment, while the remaining four all fell into the other category. The two examples that follow are taken from this latter group:

Gladys Murphy, 8 - 0 years, spastic quadriplegia, S.I. 6. For

some time now there has been little sign of any clinging behaviour directed at the mother. Gladys loves getting out of the house into the street to play with others, and feels resentful when mother will not let her go. At the beginning of a recent hospitalisation she did show some upset, yet this did not last long and she quickly settled in. Similarly, when she began school at 7, she was soon at home there and never showed reluctance at leaving mother. With other people she is very friendly and forthcoming.

David Richardson, 4 - 0 years, athetosis, S.I. 14. Excessive emotional dependence has never been seen in this boy - on the contrary, the tie with mother seems a somewhat tenuous one. David has phases of screaming for attention when alone in a room, yet they are not specifically directed at mother, as the company of anyone will do. Mother could on no occasion that she was interviewed recall any difficulties in leaving David with others, and though he did at one time show reluctance to be left alone in the evening after being put to bed, mother had no difficulty in discouraging such behaviour. With other people, even strangers, he makes immediate contact, and when another physiotherapist took over from the previous one he showed hardly any sign of having even noticed the change.

The final example is provided by the one case from the child-fugie group that did show excessive emotional dependence:

Muriel Donaldson, 5 - 11 years, spastic hemiplegia, S.I. 10. According to the mother, Muriel is "terribly affectionate", frequently climbing up on mother's knee and demanding cuddling and kissing. For the first four years there had been little sign of clinging, yet around 4½ she quite suddenly developed over-dependence on the mother, crying when left alone by her and following her around everywhere. Though this phase did not last very long, she has all along demanded mother's presence at bedtime, asking her to stay until she falls asleep.

These case illustrations make the same two points that have been made in connection with the dimensions previously examined, namely that the sample as a whole is by no means homogeneous but contains within it considerable variability, and that the variability is not merely haphazard but is related to family type. As for the first point, we must refer back to the argument advanced by Bender (1956), that motor dependence is bound to lead to emotional dependence. This is manifestly not the case, and as the presence of a physical handicap alone cannot account for the phenomena observed here, an association with other variables must be looked for. This brings us to the second point, namely the fact that the various family types appear to show differences in the number of children with excessive emotional dependence. The child-centric type stands out from the other two in that by far the majority of its cases were found to manifest such excessive dependence, whereas this occurred in only a minority of children in the intermediate and the child-fugic groups. In view of the emphasis on "togetherness" in child-centric families, these findings hardly come as a surprise. How far the phenomenon of "togetherness" is governed by the child's excessive clinging and how far this clinging is really stimulated by parental behaviour is a debatable point, and we shall defer consideration of it till the next chapter. Here we may note that, whatever the cause, the effect on the child is quite apparent: in the child-centric family the handicapped child shows a pattern of behaviour in his relationship to the parents that must be regarded as appropriate to a younger age level, for his clinging and his inability to let them out of sight reveal the gropings for security that typify the young toddler. In the other two types of families the majority of children are beginning to stand on their own feet - in the psychological, if not in the physical, sense. With these children dependence in social behaviour is giving way to growing independence, so that they are, on the one hand, able to tolerate ever-increasing separations from the parents and, on the other hand, can gradually gain confidence in their relationships with outsiders. This, we would argue, indicates the assumption of age-appropriate roles, which in the children from the child-centric type is not taking place. Thus social maturity, at least in this area, is found in some, and social immaturity in others.

Instrumental dependence.

The term "instrumental dependence" has been borrowed from Heathers (1955), and is used to refer to the young child's reliance on other people for the satisfaction of his bodily wants. At the beginning of life the infant is completely helpless: he needs another person to feed him, to keep him warm, clean, and out of harm's way, to move him from place to place, and to alleviate pain and discomfort. This dependence, as Heathers points out, is initially of a passive character, but as the child gets older he will actively seek help from others for the alleviation of his needs. Moreover, as the child's motor functions mature he will, under normal circumstances, become more and more capable of assuming responsibility for his bodily comfort without having to have recourse to the help given by others.

It is one of the many unfortunate consequences of cerebral palsy that this normal progression is interfered with by the brain injury. As a result the period of infantile instrumental dependence tends to be prolonged beyond the usual time, and a certain degree of helplessness is thus bound to characterise children so afflicted. Yet even in the most severely affected cases development is rarely at a complete standstill, for not all functions of the individual will be affected, and even in those functions which are seriously impaired some residual capacity for development, however slow and slight, can usually be found. The question therefore arises as to the extent to which the individual cerebral palsied child has been able to make use of this residual capacity, i.e. how far, within the limits of his physical handicap, he has made the maximum developmental progress possible. With this question we shall be concerned in this section, for it provides another approach to the problem of ascertaining the social maturity of the children in this sample. It is, after all, an essential ingredient of social maturity that a child should show a degree of instrumental independence appropriate to his age and not unduly rely on others for the satisfaction of bodily wants, and while a cerebral palsied child can never attain the same degree of social maturity in this respect as his non-handicapped peers, it should nevertheless be possible to ascertain what efforts, if any, he is making to use whatever abilities he does have or how far he is content to

remain unnecessarily dependent on those around him. Any judgment about the presence of excessive instrumental dependence must therefore be relative not only to the individual child's age, but also the nature and extent of the organic condition.

The precise limitations imposed by the organic condition cannot always be defined. Judgments about the degree to which a child is functioning at optimum level in one or another area may therefore be somewhat hazardous, and for this reason too fine a breakdown in terms of the various systems of behaviour (as was done in the case of socialising practices) is not possible. On the other hand, when evidence from all areas is collated and the child judged as a whole, and especially when the judgment is carried out by someone with an intimate knowledge of the child's organic condition, then it does become possible to make the kind of crude categorisation which was used in the last section. The physiotherapists generally had an excellent knowledge not only of what a child actually did, but also of what he should be doing at present, and for them it was therefore normally possible to state whether a child with certain physical and intellectual handicaps was functioning at his optimal level. Furthermore, a number of children began attending school during the course of this project, as a result of which one could see in some cases a quite sudden spurt in development (in toilet training, in independent feeding and dressing, etc.), suggesting that up to that time the child had not made full use of his capacities in these areas. In this way confirmation was often provided for the physiotherapists' judgments. These are summarised in Table 37, where they are again presented separately for the three family types.

Table 37.

Number of Children Developing
Varying Degrees of Instrumental Dependence

	<u>Child-</u> <u>Centric</u> <u>Families</u>	<u>Inter-</u> <u>mediate</u> <u>Families</u>	<u>Child-</u> <u>Fugic</u> <u>Families</u>
Normal instrumental dependence	4	11	3
Excessive instrumental dependence	9	1	2
Total	13	12	5

The figures in the above table indicate the same trend that was found in Table 36. As far as the child-centric type of family is concerned, this means an emphasis on excessive instrumental dependence. In the judgment of the physiotherapists, only a minority of the children from this group were functioning up to their capacity - in contrast to the other two groups, where most children showed a degree of instrumental dependence that was considered normal in view of their limitations. The minority of the child-centric group showing normal dependence are represented by the following two examples:

Mary Sawyer, 4 - 9 years, spastic quadriplegia, S.I. 8. Although Mary's motor co-ordination is rather poor, she is keen to use her hands as much as possible and to do things for herself. Her parents, for instance, wanted her to hold her cup with both hands because of her unsteadiness, but Mary insisted on copying other people and using only one hand. Similarly, she likes to help in feeding herself with a spoon, although her parents are quite prepared to do it all for her. She has also tried to help in dressing, but has found this still quite beyond her. She does, however, manage to cope sufficiently well with her clothes to be independent about toileting, having been reliably trained since her third year.

William Hooper, 4 - 5 years, spastic quadriplegia, S.I. 16. Mother noticed that when she bought William an ice-cream cone, he dropped it helplessly and she had to feed him with it. Yet when one of his siblings gave him one he somehow managed to get hold of it, despite defective hand control, and eat it. Mother therefore refused to help him any more and almost at once William became independent with her too. He has also made attempts to help with spoon feeding, and on his own initiative now tries at every meal, however unsuccessfully, to put the spoon in his mouth. He is almost toilet trained, for although he cannot ask or otherwise indicate his needs he often remains clean and dry throughout the day, and often at night too.

Thus, despite severe physical limitations, there are signs in these children that some desire for independence has been aroused. "He wants to do things for himself" is the phrase which repeatedly occurs in the reports of the parents, as though the child himself had decided that the ways of infancy are no longer for him. In the other category, however, no such evidence could be found:

Helen McBain, 7 - 11 years, spastic paraplegia, S.I. 8. Helen is still completely lacking in toilet training, and never shows any sign of being bothered by this. She refuses to go to the bathroom, screaming if ever any pressure is put on her to use the toilet. Yet, when in her seventh year she attended school for a short time, she became trained there within a period of weeks, only to relapse once more after having to cease attendance. One of the reasons for having to stop schooling lay in her inability to benefit from either tuition or therapy. All members of staff agreed that this was due not so much to limited intelligence or any other inherent factor, but to Helen's complete lack of drive and initiative. The same conclusion emerged in the course of intelligence testing, where the result obtained had to be regarded as inaccurate as a true measure of her intellectual capacity because of the lack of interest and desire for achievement shown. This was also manifested in other areas of the child's behaviour: thus, although she has the use of both hands, Helen did not begin feeding herself until seven years of age, and even then would often stop halfway through a meal and demand to be fed by her parents or older siblings.

Donald Baker, 7 - 0 years, spastic paraplegia, S.I. 12. Three intelligence tests carried out at different times all gave widely divergent results, and the factor considered responsible was the varying degree of motivation shown by this boy. This was also found by a home tutor and by the physiotherapist: both felt that Donald showed absolutely no interest in making progress and that learning and motor skills need not be as retarded as they were. At home his mother describes him as "lazy", for whenever Donald

wants anything, however easily he can reach it, he asks his mother to pass it to him, even though he may have to shout for her to come from another room.

Betty Johnson, 6 - 0 years, athetosis, S.I. 12. At the age of six this child is still on the bottle and resists all attempts to make her drink from a cup. She is still in nappies, appears never bothered about wetting or soiling herself, and responds with a temper tantrum if a pot is ever produced. Her hand control is good enough to carry out even fine co-ordinations, yet she shows no inclination to help with washing, dressing, or feeding herself. A speech therapist, moreover, felt that the complete absence of speech could not be explained on an organic basis, and that Betty's resistance to any attempt to carry out therapy appeared to indicate her disinterest in making any kind of developmental progress.

Walter Lane, 7 - 3 years, spastic paraplegia, S.I. 10. Though Walter has been dry at night since the age of three, he did not achieve training during the day till nearly seven years of age, and then only after starting at school. Right until this time he also held on to his bottle, throwing temper tantrums if ever it was not given to him. Though his hands are unaffected, he never dresses or washes himself but relies entirely on mother to do this for him.

In all these cases there were indications that the child did not make the developmental progress that one might have expected from him. He held on to infantile modes of behaviour and thus showed an undue dependence on his parents in dealing with his bodily needs. In the intermediate type, on the other hand, this was seen in only one case, for in all other instances there were signs that the child was not content with being fixated at a stage of helplessness:

Samuel Napier, 7 - 7 years, athetosis, S.I. 11. For some time now Samuel has shown his frustration at not being able to go school like

the other children in the neighbourhood. He likes nothing better than to play at schools, sitting at the desk his parents have bought for him and there doing what he calls his "homework". Though his accomplishments with a pencil are still very poor, he takes considerable pride in his ability to do jig-saw puzzles, having in the first instance taught himself to solve them. Having become toilet trained during the day by the time he was four, it was not till a year or so later that Samuel himself asked his mother to leave off his nappy during the night and promptly became dry then too. He did hold on to the bottle till he was four, but is now attempting to feed himself with spoon and fork.

Kenneth McGuire, 3 - 3 years, spastic quadriplegia, S.I. 4. For some time now mother has noticed that Kenneth often watches other children running around, and she feels sure that he is attempting to copy them. He certainly shows remarkable confidence in his movements, and when given a swing at one time and a rocking horse at another he at once climbed up on his own in order to try them out. He has been toilet trained since an early age, and was off the bottle at 10 months (though since the arrival of a baby has been seen taking an occasional surreptitious sip from the baby's bottle). He takes pleasure in being able to feed himself, having done so since the age of two and a half.

Brenda McNeil, 4 - 9 years, spastic paraplegia, S.I. 4. At one time Brenda was rather frightened of getting on her feet, but now she is keen to do so and often asks when she will walk and why she cannot do so now like other children. Toilet trained around $3\frac{1}{2}$, she is now quite reliable. She is keen to be independent in feeding herself, and insisted on having a knife and fork just like her parents, not the spoon which was originally given her. She resents any help being offered in undressing herself, though in dressing she still has to rely on mother.

The one exception in this group is provided by a child who was reported as rather apathetic in most areas, rarely stirring, not making full use of his manipulative powers, and at times not even swallowing solid food.

In the child-fugic group three of the cases are found in the "normal dependency" category, while the other two belong to the second category. Each of the categories contributes one of the following two examples:

Sally Robertson, 3 - 1 years, spastic quadriplegia, S.I. 6. In her general motor activity Sally is a very confident child, for despite many bumps and bruises from falls she is always actively climbing the furniture and crawling around after her older sibling. Frequently she attempts on her own initiative to stand without support, yet her lack of success has not left her with any fears connected with falling and loss of balance. She still demands a bottle every evening, yet has become reliably toilet trained in the course of her third year, and is now also able to feed herself.

Muriel Donaldson, 5 - 11 years, spastic hemiplegia, S.I. 10. One hand of this child is almost useless, and all manipulative skills have therefore to be carried out by the other hand. Yet this hand too is used relatively little for skills well within Muriel's scope: she rarely feeds herself with it but relies on mother to do so, and in dressing and washing she similarly behaves in a quite helpless and dependent fashion. As mother once put it: "It is as though the one hand had infected the other."

These results suggest strongly that amongst cerebral palsied children there are some that suffer from more than a physical handicap in the development of their bodily functions. It is well known now that such development in a child does not take place in a vacuum, that maturation alone cannot account for the changes that take place and the rate at which they occur. This has been borne out, for instance, by studies of deprived children, thus illustrating the influence of social factors on development.

Our data make the same point, for they suggest that in certain family settings children do not make full use of their developmental capacities, so that the physical handicap becomes augmented by a social handicap, and the child becomes even more of a helpless and dependent being than is necessary in view of his organic limitations. Excessive instrumental dependence is thus found in the same circumstances as excessive emotional dependence, for both are mainly associated with child-centric families, occurring rather more rarely in the other two types.

Co-operation and egocentricity.

In this section the question of social maturity will be approached from yet another direction. It will be recalled that in our discussion of this concept we referred to Newcomb's (1952) stages of role development, in which considerable emphasis was laid on a child's gradually increasing ability to perceive social relations in terms of reciprocity. Whereas in infancy other people are seen only as agents for drive-relief and the child's own perspective rules supreme, a growing awareness of the rights of others thereafter forces itself on the child. Thus he must learn that his world cannot be arranged purely in terms of his own needs, that his point of view must be integrated with others and that he has obligations as well as rights. In this way he passes from egocentricity to co-operation in his relations with others, and any sign that he is failing to make such progress may be regarded as further evidence of social immaturity.

Some degree of egocentricity is found throughout most of childhood, as Piaget (1932) has shown by examining the thought processes of children at various ages. In their social relationships, however, complete egocentricity exists only in infancy, and some degree of compliance to the wishes of others is generally found at all subsequent stages. Opportunities for observing such compliance may be found again and again in the daily life of the young child, for it represents the child's willingness to sacrifice his own mode of behaviour in favour of responses requested by others. The reports of parents thus furnish plenty of examples for the case illustrations. Again, however, this was a function which could be particularly well observed by the physiotherapists. They worked in a set situation in which

a great deal depended on the child's ability to adjust to their requests, to follow instructions, and to give up patterns of behaviour that to the child may have been more "natural" than those demanded from him. We have here, in other words, a structured socialisation situation in which the socialising agent is able to observe the effects of her demands on the child in a relatively dispassionate manner, and thus (working again within the framework of each individual's age and set of handicaps) make a judgment as to the child's ability to fit in with her framework of expectations as against his inclination to follow purely egocentric modes of behaviour.

The physiotherapists' judgements were again made by allocating the children to categories expressing the co-operation or lack of co-operation obtained from them. The results are presented in Table 38 and as before are separated according to family type. They refer to the children's behaviour in physiotherapy after they had overcome their initial fear of the situation and had stopped clinging to their mothers. In the following case illustrations, however, the material has, as before, been drawn also from the other sources of qualitative data available, namely the reports of the parents and, in this case, the observations made during intelligence testing.

Table 38.

Number of Children showing Varying Degrees
of Co-operation with Physiotherapists.

	<u>Child- Centric Families</u>	<u>Inter- mediate Families</u>	<u>Child- Fugic Families</u>
Co-operative	3	10	3
Unco-operative ...	10	2	2
Total	13	12	5

Once again we find that the children from the child-centric type of family show a pattern of behaviour in clear contrast to that shown in most of the intermediate and child-fugic types. Only three cases from the former group were regarded as reasonably co-operative, as shown by the

following example:

Christine Anderson, 5 - 5 years, spastic quadriplegia, S.I. 7. The physiotherapist has all along been very pleased with the progress made by this child, and feels that this is largely due to the excellent co-operation she has been able to obtain from her. As the physiotherapist put it: "This child 'gives' in the way you want her to, mentally at least, if not always physically." Mother is also pleased with the response she can get from Christine, for though at one time she was said to be rather negative and inclined to throw tantrums if not allowed her own way, now she is fairly obedient and able to deal much better with frustration. The same ability to fit in with the wishes of others is also seen in her play with other children, for there are rarely any difficulties about sharing toys or taking turns.

The majority of children from the child-centric group, on the other hand, show a rather different attitude in similar social situations. Taking turns, sharing, "giving", obeying, following instructions and making allowance for others are all phrases which occur but rarely in the reports on these children:

Donald Baker, spastic paraplegia, 8 - 0 years, S.I. 12. In physiotherapy Donald was at times an "infuriating" child. He is generally quite passive, absorbed in his own thoughts, showing no motivation and paying no attention, and at one time suddenly looked up half way through a session, stared blankly at the physiotherapist, and said: "I don't remember you coming." Similarly, repeated intelligence testing came up against Donald's unco-operative attitude: he showed some interest in the test material at the beginning, but as soon as the novelty had worn off he took charge of the situation, handled the material as he wanted to and not as he was asked to, did not answer questions but instead put questions to the writer, and finally just wandered off. A home tutor had come up against the same difficulties, but Donald's domineering

attitude is perhaps most in evidence in his everyday life. In his play with other children, for instance, he insists on structuring the situation, playing with whatever toy he happens to want (even if it entails taking it off another child) and deciding how and where to play. With his parents he is also very much the boss, refusing to accept food he does not fancy, always relying on mother to fetch toys or to clear them up, and on the few occasions that the parents tried to give him formal tuition, he threw a temper tantrum and refused to listen to them. If for any reason the parents do not immediately give way, he proceeds to pinch them.

Malcolm Stewart, 7 - 7 years, spastic quadriplegia, S.I. 5. The teacher who reported on this boy expressed considerable doubts about the possibility of making much progress with him - not so much on account of intellectual deficiency, but because of his tendency to take no notice of her instructions and blithely to pursue his own course. For the same reason it is difficult to get him to join in organised games with other children, as he always wants to take charge of the situation and, when this is not allowed, tends to wander off on his own. Intelligence testing proved to be a very long and arduous task, as his co-operation could be elicited only in patches. This was largely because of his over-familiar attitude towards the tester, for after an initial period of shyness he went to the opposite extreme, began boxing with him and blowing down his neck, and returned only momentarily to the task in hand when considerable firmness was used. His parents confess that he is not at all obedient, that he wants his own way in almost everything and will throw a violent temper tantrum if they do not give in to him. He switches off the television when it is time for him to go to bed and will not allow the parents to have it on again that evening. He is said to be very self-willed with his siblings, never tolerating any kind of privilege accorded to them and not to him, and constantly snatching their toys and interrupting their play activities.

Betty Johnson, 6 - 0 years, athetosis, S.I. 12. Both a physiotherapist and a speech therapist tried for many months to treat this child, and both failed. Similarly, two psychologists tried to test her on different occasions and found it an impossible task. With all these people she behaved as though they were not present, taking little notice of them, not listening to their requests, pursuing her own activities and throwing a temper tantrum if an active attempt was made to attract her away from them. Temper tantrums are indeed very readily apparent in the face of any kind of frustration. Thus attempts to take her feeding bottle away, to put her to bed on her own, to make her use the toilet or not to damage furniture all meet the same response, namely an immediate outburst of aggression directed against the source of frustration. With her parents she often behaves as though she does not hear them (although there is no organic auditory impairment). She is very domineering towards them, and will, for instance, suddenly insist that mother should sit on a different chair. She never allows her to read a book or magazine while she is in the room, snatching it away and demanding attention for herself. If she does not get her way she will often bite or throw things. With other children Betty is similarly domineering, snatching their toys away and being quite incapable of playing with them. She loves being in their presence, yet even older children are terrified of her and avoid her.

Walter Lane, 7 - 3 years, spastic paraplegia, S.I. 10. Neither of two physiotherapists found this at all an easy child to treat. Though some co-operation could be got from him at first, he quickly deteriorated in this respect with both, so that treatment did not appear to be making any progress after a while. He never shows any active objection to treatment, but generally adopts a completely passive and uninterested attitude, talking continuously about his particular activities and interests of the moment. At school he was found to pay no attention, using the material given him in his own fashion and not in the way pointed out by the teacher. He is

inclined to be self-willed with his parents, throwing temper tantrums if a forceful attempt is ever made to change his behaviour. There are lots of fights with his sibling, whom he bullies a great deal and whose toys he is continuously snatching away, and though with other children he is not aggressive, he rarely joins their games but merely watches them or turns his back on them and pursues his own activities.

The immaturity in the behaviour of these children is very striking. They show the egocentricity and intolerance to frustration that is so typical of very young children, so that even at the age of six or seven they still throw the frequent temper tantrums found in the toddler. They find it difficult to meet the expectations of others when these conflict with their own desires of the moment, and in their need to pursue purely self-centered activities they tend to adopt an intolerant and domineering attitude towards those around them. Thus it is difficult or even impossible to elicit co-operation in such set situations as physiotherapy sessions or intelligence testing, and though the degree of their lack of co-operation varied, a marked defect in social relations can be said to characterise all these children.

The majority of children in the intermediate group show no sign of such problems. The physiotherapists regarded them mainly as co-operative, and their judgements were in general borne out by the material obtained from other sources. The following cases illustrate this pattern:

Doris Fletcher, 6 - 2 years, spastic paraplegia, S.I. 3. The physiotherapist considered Doris to be an extremely co-operative child, with whom it is a pleasure to work. There is rarely any sign of negativism, and Doris seems genuinely to enjoy meeting the requests made by the physiotherapist. The mother reports her as "quite an obedient child", who grew out of the negativistic and temper tantrum phase long ago and can now normally be relied on to do what she is told - with enough exceptions to show that she does have a will of her own. She sees a great deal of other children

and gets on very well with them. There is never any difficulty here about sharing or taking turns, and though a lot of fights occur with the siblings, these are by no means excessive.

Martin Fisher, 5 - 10 years, spastic quadriplegia, S.I. 4. Not only the physiotherapist, but also the boy's teacher find him a very willing child with whom they can easily work once he had got over his initial shyness. He rather likes a set routine and tends to be upset by changes, but otherwise is regarded as a good child to deal with. At home mother found him rather different: "He never does for me what he does for other people," she complained, referring to his frequent temper tantrums when told to do something by her that he did not want to do. Yet this was at the beginning of the contact, when Martin was just over 4. Eighteen months later these tantrums, though still in evidence, were very much less frequent, and while mother often wishes he were more obedient, she does agree that he always seems to realise when he has reached a limit beyond which it is not wise to provoke her. With his younger sibling Martin tends to be rather bossy, so that a lot of fights and quarrels are always going on; on the other hand with other children, both at school and at home, he plays well and does not try to domineer the situation.

Samuel Napier, 7 - 7 years, athetosis, S.I. 11. At one time the physiotherapist reported this boy to be "almost too co-operative", in that he tended to be extremely placid and rarely showed any assertiveness, doing what he was told and only too eager to please the therapist. This was also found during intelligence testing, for Sam needed continual reassurance that he was doing just what was wanted of him - as though he were frightened of giving offence. From the reports of his mother he also emerged as a very gentle, placid child, anxious to please and rarely disobedient. He does not play a great deal with his younger sibling, for the disparity in their abilities was already too great, yet when they do interact it is always the younger child who sets the pace and tells Sam

what to do.

These three cases show that the ability to co-operate and meet the requests of others can be found in very different personality settings. Thus not only the degree of co-operation elicited but also its qualitative features and the motivation behind it vary considerably from case to case. Yet these cases do form a homogenous group in their relative absence of egocentric and domineering attitudes, so that social relationships are far more characterised by give-and-take than is seen amongst the children categorised as unco-operative. There are only two of the latter in the intermediate type, and in both the child emerged as reasonably co-operative from the remarks made by the parents, but as rather self-willed, negativistic, and disinclined to follow instructions from the physiotherapist's reports.

Once again the child-fugio group, unlike the other two groups, provides no clear-cut trends, with three cases falling into one category and two into the other. Each of the categories is illustrated by one of the following cases, the first giving details of a child categorised as co-operative and the second of an unco-operative child:

Albert Jackson, 3 - 0 years, spastic quadriplegia, S.I. 4. After the initial upset at the beginning of physiotherapy had subsided, Albert soon established a very trusting relationship with the physiotherapist, as a result of which she was able "really to get to work on him." There is now rarely any resistance to following her instructions, even when on some occasions he shows a certain amount of fear connected with balance and falling. At home he is said to be a contented child, who does have the occasional tantrum, but who more often bursts into tears when firmly told "no". Obedience is thus no problem, so that the mother hardly ever has to use punishment. During intelligence testing it was also noted that for one of his age Albert co-operated well, appearing eager to please and ready to follow the instructions given.

David Richardson, 4 - 0 years, athetosis, S.I. 14. The physio-

therapist found this in many ways an exasperating and unrewarding child to treat. He rarely gives a flicker of recognition when he sees her, and throughout the session behaves as though she were not there. He is thus quite static physically, and the physiotherapist believes this to be due to the difficulty of getting through to him. An intelligence test could also not be administered, as he tended merely to stare at the test material without taking any notice of requests to respond to it in certain ways. At home he is said to need smacking before he will do what he has been told, and even then frequently resumes the forbidden activity.

In so far as progress with socialising in general and physiotherapy in particular depends on the willingness of the child to meet the relevant demands from others, one must conclude that the children found to be unco-operative in this sample are probably advancing at a slower rate than they might. This reinforces the views expressed in the preceding section, that certain children are functioning at a level lower than their bodily equipment would allow. Moreover, the data indicate clearly the differences in social maturity found in the sample. We have, on the one hand, children whose behaviour may be regarded as inappropriate to their age: their egocentricity and inability to tolerate frustration assign them to a very much younger age level and thus reveal a degree of emotional immaturity that in some cases appears to reach pathological proportions. Yet again it must be emphasised that this is no inherent characteristic of all the cerebral palsied, for many of the children in this sample fail to show it, and greater significance must therefore be attached to the distribution of this characteristic among the three family types.

Overview of maturity findings.

We shall now follow the procedure adopted at the end of the chapter on socialising techniques, and draw together the three threads which have so far been treated separately. The fact that our search for evidence about the children's social maturity took place in only three areas entails a

rather narrower empirical basis than is desirable, but the nature of the sample makes it improbable that a more refined approach could have been chosen. Each of the three areas is, however, concerned with certain vital functions of the small child, and provides some of the most important data from which the individual's standing on the maturity-immaturity dimension can be assessed.

The first question to which we turn concerns the consistency of classification for the three areas, i.e. whether children were always assigned to the "mature" or always to the "immature" category. Full details of the classification are given in Appendix 4, but Table 39 summarises the necessary information.

Table 39.
Consistency of Maturity Classifications

	<u>Child- Centric Families</u>	<u>Inter- mediate Families</u>	<u>Child- Fugic Families</u>	<u>Total</u>
Three identical classifications	8	7	4	19
Two identical classifications	5	5	1	11
Total	13	12	5	30

The fact that only three classifications were made for each case rather hampers us in arriving at any conclusions about the extent to which individuals reach the same standing with regard to social maturity in all areas of functioning. The above table does show that the majority in this sample received identical classifications, that for most of the children in all three groups this characteristic was an all-pervading one in terms of the field of enquiry. On the other hand the remaining cases show that this is not a unitary trait, for these children were found relatively mature in one or two areas and immature in the others. As with socialising techniques, so here too we must exercise a certain amount of caution in making generalisations, for variability does exist in some individual cases. Yet the trend towards consistency seems strong enough in the sample as a

whole to make it possible to see certain predominant patterns, and we shall therefore now examine the association found between the family types and the level of maturity of the children.

For this purpose an over-all maturity score was calculated for each child by giving weights to the two categories in each of the three relevant tables (nos. 36, 37, and 38). In every case the category expressing immaturity (excessive emotional dependence, excessive instrumental dependence, and lack of co-operation) was weighted 0, while the other category, expressing maturity, was weighted 1. From these individual scores the group means were calculated, and these, together with their standard deviations and the range of scores found, are presented in Table 40.

Table 40.
Over-all Maturity Scores of Children

	<u>Mean</u>	<u>Standard Deviation</u>	<u>Range</u>
Child-centric type69	.77	0 - 3
Intermediate type	2.42	.96	0 - 3
Child-fugic type	2.00	1.41	0 - 3

As the total possible range covers only four points, it is not surprising to find that all three groups are spread from one extreme to the other. Yet the high standard deviation obtained for the mean of the child-fugic group shows that the spread of scores in this group is very much greater than for the other two, indicating again the greater heterogeneity of findings from the child-fugic type. The mean of the child-centric group differs, according to the t test, from that of the intermediate group at a statistically significant level beyond .01, and from that of the child-fugic group at a significant level beyond .05, thereby showing the very much greater tendency towards over-all social immaturity found amongst children from the child-centric families. The mean of the intermediate group, on the other hand, approaches closest to the maximum score possible, though it does not differ significantly from that of the

child-fugic type.

There is thus a definite association between family type and degree of social maturity shown by the handicapped children. Before we enlarge on this, however, we must turn to the association with the other level examined in this report, namely the socialising techniques. The following table accordingly summarises the association found between the over-all socialising severity scores and the maturity scores.

Table 41.

Association between socialising severity
and child maturity

<u>Maturity Scores</u>	<u>Severity Scores</u>		
	<u>0 - 3</u>	<u>4 - 7</u>	<u>8 - 12</u>
0 - 1	8	4	2
2 - 3	2	13	1

From this table it can be seen that there is a tendency for indulgent socialising techniques (severity scores 0 to 3) to be associated with relatively immature children (maturity scores 0 to 1), while socialising techniques of medium severity (scores 4 to 7) are mainly found in the same families that produce relatively mature children. A chi-square analysis of the table shows that the difference in distribution of severity scores allotted to the two groups of children reaches a statistically significant level (.05). For two of the three types of families, the child-centric and the intermediate, there appears therefore to be a mutual relationship between all the levels examined here: the child-centric type of family organisation uses indulgent socialising techniques and produces socially immature children, while the intermediate type of family organisation does apply definite socialising pressures (though predominantly in a flexible and realistic manner) and produces children regarded as relatively socially mature. Only the child-fugic type fails to show a characteristic pattern on the other two levels.

The child who develops within the context of the child-centric type of family is clearly the most likely to show social immaturity. The data

on emotional dependence show him to be particularly prone to intense clinging to his parents and to manifest signs of attachment which must be judged excessive for his age. The opposite side of the coin to this excessive emotional dependence is the reluctance with which he makes extra-familial contacts - as physiotherapists and teachers so often experienced to their cost. To leave the mother and accompany a stranger to an unfamiliar room may be an ordeal for most two-year olds, but to be unable to cope with such an experience at the age of six or seven is most unusual. These children are rather too firmly rooted in their families - so firmly that they find it extremely difficult to participate in any other group. Thus there are two kinds of deficiency in the role-playing behaviour: on the one hand the nature of the role played within the family is inappropriate to the child's age level, and on the other hand the total number of roles which the child is capable of playing is extremely restricted. The continual demand for the presence of mother or father makes it difficult for the child to acquire experience of other social situations. He does not want to go out into the street to join a group of children, he is reluctant to participate in a physiotherapy or classroom situation, he does not wish to be looked after by a neighbour nor to stay in a relative's house, and as a result all his affect will be centered on the family and his experience of the outside world will be limited not only by his possession of a physical handicap but even more so by the nature of his psychological equipment. There is thus a stunting of his role playing capacity, and this provides us with one of the strands of which social immaturity is woven.

A second strand refers to the instrumental dependence which is also characteristic of most of the children from child-centric families. In the view of their physiotherapists, these children show a greater helplessness in the satisfaction of their bodily needs than their organic capacities warrant. In many areas, such as feeding or toileting, the children behaved in a more infantile manner than was necessary in view of their handicap. Little evidence of any achievement drive was found here: these children showed no motivation for independence and preferred to be fed, dressed, and changed like infants when they might well have taken at least

some part in these activities. Thus, handicapped as these children were, their handicap was further exaggerated, and though it is difficult to obtain definitive evidence from these reports, it appears likely that this type of child only too often frustrates the efforts of professional workers by his own lack of motivation to progress developmentally.

This may well be further accentuated by our third strand, namely the amount of co-operation which a child is capable of giving. In a family setting where there is little frustration and where all attention is concentrated on him, the child will have had little opportunity for learning that reciprocity is an essential component of mature inter-personal relationships. In this area we find the clearest evidence for the kind of behaviour with which Newcomb (1952) characterised the earliest stages of role development: the autistic nature of the child's wants, his insistence on immediate drive relief, his lack of conformity to social custom, and his inability to take into account the perspectives of others. Meeting the demands of others when these conflict with his own desires appears to be an experience with which most of the children from the child-centric families could not cope, and the usual reaction to such demands took the form either of temper tantrums like those usually seen in a toddler or of complete passivity and withdrawal. Once again progress in physiotherapy, for example, is likely to be hindered to a considerable degree by such an attitude in the child, for it reveals an egocentricity which cannot accept limitation and channelisation of behaviour imposed by others. The child-centric family, we must conclude, tends to produce the egocentric child.

That none of these trends is an inherent part of brain damage and motor handicap is shown by their relative absence from the intermediate group of families. These children may at one time have passed through a phase of intense attachment to the parents, but after the third and fourth years this tended to decrease somewhat, so that it no longer became impossible to leave these children with other people. Their induction into the social world outside the home was therefore very much easier, and it was also easier for physiotherapists and teachers to establish contact with them. Though shy or even frightened of the stranger at first, it did not take them long to establish a relationship of trust and to leave mother

without hesitation. Thus they gradually increased the range of their social contacts, and their role playing capacity tended thereby to be correspondingly enriched.

As for their instrumental dependence, the children from the intermediate type were, of course, hampered by their organic disabilities, and to that degree had to rely on others in the daily course of their lives. Yet within the limits imposed by the handicap these children, in the view of their physiotherapists, were on the whole thought to function well and to make good use of whatever residual capacities they did have. They were not content to remain at a low level of dependence, but strove to achieve skills which would help them on towards increasing independence. In relation to others, therefore, they had to rely on outside help to no greater degree than was dictated by the nature of the cerebral palsy.

Most of the children from this group were also found to adopt a generally co-operative attitude in the course of their physiotherapy session, and evidence from such other areas as their response to socialising demands from parents, their relationships with other children, and their behaviour during intelligence testing all tended to confirm that these children were learning to fall in with the wishes of others and were no longer exclusively guided by autistic wishes. Thus their infantile egocentricity was giving way to a capacity for reciprocity in human relationships, and on this basis co-operation in learning situations tended to be fostered and true membership of social groups made possible.

Though most of the children from the child-fugic group showed consistent scores for the three areas that were investigated, the pattern of the group as a whole is again confused. One of the children was found to be immature in all three areas, while another was found immature in two of the three areas. The other three children, however, showed a consistently mature pattern in all functions considered. There are clearly too many divergent forces at work in this group to permit generalisations about their influence on the child's development. As we have seen, the nature of the child-fugic organisation and the kind of socialising techniques adopted tend to vary so much that it is hardly surprising that the personalities of the children also differ a great deal. Although in four cases mother and child formed the close unit typical of the child-centric group, the fact that the

children failed to manifest the same characteristics as those from child-centric families, may well be due to the frequent and often intense interaction with other relatives (especially maternal grandmother). No claim is, of course, made that the child's personality remained unaffected by father's "fugio" relationship with him, for only three aspects of personality development were here investigated. These three aspects, however, did not show the same profound effects as was found for the child-centric type.

C H A P T E R 10
EVALUATION OF FINDINGS

In the preceding chapters the descriptive material elicited in the course of this project has been presented. In this chapter we shall range further afield, and attempt to evaluate and interpret the data in order to arrive at some general conclusions about the social concomitants that may be found in a sample of cerebral palsied children and their families.

Theoretical implications.

As we noted in the review of the literature, there are in existence very few empirical studies of social aspects of cerebral palsy. We know little about the ways in which families cope when one of their members has a congenital physical handicap, how they interact with this member, and how the member himself develops in his particular social environment. Yet books and articles appear all the time in which advice is given to those looking after handicapped children on how they should perform this task - advice which is clearly devoid of the necessary knowledge on which it should be based. Application of knowledge cannot take place before that knowledge has come into existence, and the need for more facts in this field is certainly clear. This project was designed to supply some of these facts, and though the number of cases studied is small the focus of the investigation was a relatively intense one. We have not been concerned here with advice, with how parents should behave, but rather with facts, with how parents do behave. Such questions as whether parents should administer physical punishment to handicapped children or whether these children require more emotional support than is normally encountered have not arisen, for our only aim has been to determine the number of parents who do use physical punishment in this sample or who do foster emotional dependence, and then to relate this information to the other data obtained.

It is this latter aspect, namely the inter-relating of the various items of information, that forms the core of this project. Thus apparently quite unrelated data were found to be associated together in

Certain patterns, so that the use of physical punishment, for instance, is no longer an isolated item of information, but is found to be one constituent of a series of inter-linked behaviour patterns which contain such apparently quite distinct items as the amount of time a father spends in child-care activities, the child's co-operation in physiotherapy, the extent of a family's contact with relatives, and the readiness of the mother to let her child out of sight. The life-pattern of these families tended thus to be of one piece and to be expressed in a variety of areas in a meaningfully related manner, cutting across the lines of demarcation between such conventionally separate fields of enquiry as the development of the individual personality, the nature of group activities, and the characteristics of interpersonal relationships. Even physical progress may be regarded to some extent as forming part of the over-all pattern. The interdependence of these various types of phenomena is probably of an extremely complex form, and the links provided here are but an initial attempt to point to its existence. The exceptions to general trends which occur at all points of the enquiry clearly suggest the multi-determined nature of the phenomena under consideration. Nevertheless, some of the trends are strong enough to be indicated even with the tools and methods used here.

For the sake of convenience and ease of discussion we have grouped the patterns of phenomena into three family types. The disadvantage of such a typology lies in the impression that it may give of being more absolute than in fact it is, that the gaps between the three types are considerable, and that our descriptions refer to completely discrete groupings. This, of course, is not so, as reference back to Table 12 on page 87 will show. The family dimensions form a continuum, and the breaks made in them for the sake of constructing the typology were arbitrarily chosen. This means that there is bound to be some overlap in characteristics and that a family classified as belonging to a given type may easily show some features which have been found to be associated more commonly with one or the other type. In highlighting differences, we must not overlook similarities and overlap. It is, moreover, no part of our argument that the form of a family's social organisation necessarily remains static. Due to the longitudinal approach used in this project

we were able to observe certain changes taking place in this respect: in one family, for instance, the mother went to the cinema for the first time for years a few days after her child had at last taken her first step; in another family there was a gradual increase in social isolation at the same time as the parents became increasingly aware of the severity of the child's handicap in relation to the fast development of a younger sibling; in two further families the beginning of the child's attendance at school resulted in a considerable freeing of the parents' social life, while in yet another family the same event produced, if anything, a greater total amount of child-centered behaviour. In constructing the typology these fluctuations within the period of observation were averaged out, but it is apparent that, when attempting to understand any one family, much can be learned by observing its reactions to various life events and tracing the consequent changes in its organisation.

The relative numbers in the types are, it must be stressed, of little significance. This small sample can by no means be regarded as representative: it was not selected as such and indeed our criteria of selection specifically excluded, inter alia, families that had completely disrupted. It is nevertheless interesting to note that, within these limits, such a large proportion of our cases should fall into the child-centric type of family organisation. The description of this type draws attention, we believe, to a kind of family group that tends to be overlooked by social scientists, for it is always the disrupted group, the family completely lacking in cohesiveness, which more obviously calls for help and action and which is thus best known to the social worker. The vast literature on the "broken home" amply testifies to this statement, yet in many respects the family at the other extreme of the continuum, i.e. the family manifesting an inordinately high degree of cohesiveness, is just as much in need of help and systematic study. This kind of family is perhaps often regarded with approval, in that its members appear to have drawn together in the face of stress and are keeping their troubles to themselves. The family as such is still in existence, and it is therefore not likely to incur the criticism of society in the way that a disrupted family would incur. Yet closer study suggests that inherent in such a

group there are many pathological features, and because the child-centric family is the least known among the three types we have described, the discussion that follows will be particularly concerned with it.

Behavioural pathology may be found at various levels: at the individual level (where it may emerge in such forms as anxiety symptoms, phobias, obsessions, etc.), at the interpersonal level (as indicated by hostility, rejection, over-dependence, etc.), and at the group level. About the latter least is known: how far one can define an optimum level of group functioning, what form group "symptoms" take, or in what way a group is able to call upon defence mechanisms are all still largely unsolved problems. In our theoretical discussion we suggested two aspects of a family group's functioning which it is useful to evaluate from this point of view, namely its cohesiveness and its community participation, and from the subsequent empirical descriptions it emerged that the extremes of these two dimensions may indeed furnish evidence of group pathology. In the child-centric type of family this manifests itself in an "all-eggs-in-one-basket" policy: the intense preoccupation of family members with the cerebral palsied child crowded out all else, so that they were no longer able to play any appreciable part in the outside community and instead over-emphasised their parental role. Cohesiveness can thus be too high as well as too low and yet one of the conclusions which one must reach about the child-centric families is that their high cohesiveness is in fact an artificial and illusory one. Closer examination shows that their "togetherness" is largely the product of only one single factor, namely the preoccupation with the handicapped child. Family members are not family-centered but child-centered: all lines of communication go through the handicapped child and exist only to a minimal degree between other members. This was particularly in evidence in relation to other children in the family, who were rarely regarded as individuals in their own right but more often as adjuncts to the needs of the handicapped child. It is also suggested by the fact that father's high participation in child-care activities was generally not paralleled by a high participation in household activities. The role adopted by these fathers was dictated not so much by the needs of

the family as a whole or of the mother in particular, but by their own concern with the handicapped child. This pseudo-cohesiveness clearly creates a dangerous situation for the family, for if the child is ever removed from it the remaining members will suddenly be brought face to face with one another, and, having worked out no adaptive mechanisms for such a situation, may at that time be in danger of complete disruption. This situation was vividly illustrated by one such family, where the cerebral palsied child went for a few weeks to a convalescent home and thus gave the parents their first break away from him since he was born. As the mother put it afterwards: "We went away for our first holiday in five years, but after two days we had to come back. My husband and I were like strangers together, we did not know what to do with ourselves and seemed almost to have lost touch with each other." It may well be that the reluctance of these parents to let the child go to residential school is to some extent caused by their partial awareness of this situation. This study also shows, however, that the concept of cohesiveness is an extremely complex one. We sought to define it by using the "togetherness" criterion, but having done so it may well be argued that this gives in some respect a misleading impression. The high "togetherness" scores of the child-centric families are produced not by the members' attraction to the group as a whole but to one feature of the group (the handicapped child). In some ways this does produce a very cohesive group, for the members are all jointly engaged in one particular kind of activity (child-care), all share the same absorbing interest, and all are disinclined to participate in other groups. Many experimental studies of group cohesiveness would be satisfied with these criteria, yet the more clinically oriented might well feel that certain subtle but vital aspects are thus neglected and that a great deal more needs to be done on the successful definition for research purposes of this concept.

How far a particular kind of family group is to be regarded as pathological must be judged to some extent in relation to its success in rearing mentally healthy children. In the last chapter we stated certain associations between the three family types and some characteristics of the individual children reared in them, and here we may carry

the discussion further by asking in what manner the various patterns of social forces shape the personality of the cerebral palsied child. This can be done most clearly by comparing the child-centric with the intermediate families, for in the child-fugio type too great a diversity is found in the constellation of social forces to make generalisations possible. Moreover, as the concept of role has been found so useful in viewing individuals in their social context, we shall centre our enquiry on the different role-taking skills which the children acquire in these two kinds of environment.

In the intermediate type of family the cerebral palsied child is treated from the beginning as a member of the family group who not only has certain needs as an individual in his own right, but who must also learn to respect the individuality of other members. He is given the additional help and support which his organic condition necessitate, but beyond that he is expected to strive for independence and not to regard other people as being continually at his beck and call to perform services for him. Demands to conform to adult expectations are made on him, and though these are rarely excessive the parents have no hesitation in backing them up with disciplinary measures. As a result the child's ability to take age-appropriate roles develops and grows, and, though his handicap may prevent him from functioning at his chronological level, he is likely to make good use of whatever residual capacities he does have.

The child brought up in a child-centric type of family will be exposed to very different expectations. Regarded as a pathetic creature for whom everything possible must be done, he encounters no demands to achieve things independently. He learns that other members of the family are always available and always prepared to act as his tools. Social reciprocity is thus not stressed, and as a result the child's infantile egocentricity remains unmodified. The parental socialising practices are in many respects similar to those described by Levy (1943) for his cases of maternal overprotection, and the descriptions of his children also overlaps to a very appreciable extent with those mentioned here. In this report, however, we have added one further level of study, namely that appertaining to the family group as a whole and the

importance of this from the child's point of view becomes apparent when we consider the effects of the child-centric family's social isolation on role-taking skills. The situation has been described so aptly by Parsons and Bales (1956) that we shall quote in full the relevant part of their theoretical exposition:

"A primary function and characteristic of the family is that it should be a social group in which in the earliest stages the child can "invest" all of his emotional resources, to which he can become overwhelmingly "committed" or on which he can become fully "dependent". But, at the same time, in the nature of the socialisation process, this dependency must be temporary rather than permanent. Therefore, it is very important that the socialising agents should not themselves be too completely immersed in their family ties. It is a condition equally important with facilitating dependency that a family should, in due course, help in emancipating the child from his dependence on the family. Hence the family must be a differentiated subsystem of a society, not in itself a "little society" or anything too closely approaching it. More specifically this means that the adult members must have roles other than their familial roles which occupy strategically important places in their own personalities."

This is a most pertinent statement, for it describes accurately the situation confronting the individual from the child-centric family, and it helps us to understand why such a family must be regarded as a pathogenic influence on the child. It has often been said that the family is an agent of society and that it is through the family that culture is transmitted to the child. Having learned those modes of behaviour which are culturally approved, he is ready to leave home and participate in the activities of other social groups. This means, however, that the family must be, to use Parsons and Bales' phrase, a "differentiated subsystem of society", that the members should behave in a manner acceptable not only in that particular family but also in society in

general, and that the role assigned to a child through the parental socialising practices should not deviate markedly from the role which society expects him to adopt. In general parents do not primarily ascribe roles to the child in order to fit him out for life in the outside community. They do so rather in order to fit him into their own family group, and the fact that these roles are usually found appropriate later on is only due to the mirroring of cultural conventions within the family. But when the family system differs in certain fundamental ways from culturally accepted norms, when, for instance, its child rearing methods stress different values, it will fail to provide a bridge to the community. Within the family the child's role may be perfectly well adjusted, but once he joins other groups he will come up against a completely different set of expectations and social maladjustment may then occur.

It is for this reason that the child-centric type of family must be judged as pathological. Within the family itself no social maladjustment is apparent, for the members are all perfectly adapted to one another. The parents are always ready to perform services for the child, and the child is always ready to accept them. It is only when such a child leaves the family and participates in other groups that his behaviour will be found inappropriate, for the expectations he meets there will clash with the only modes of role playing available to him. This is seen repeatedly in the case illustrations, for whenever a child from a child-centric family leaves the familiar home environment and interacts with other children in play, with physiotherapists during treatment or with a psychologist during testing, he is unable to adjust to their expectations. He has not been trained in the give-and-take of social relationships, and when he attempts to carry forward his usual domineering, egocentric modes of behaviour he is suddenly forced to realise that a very different social situation from that to which he is accustomed confronts him. Thus the child-centric family equips the child with socially unacceptable modes of behaviour, and in leaving him at an infantile level stunts his role-playing skills. Through the lack of community participation of this kind of family the child fails to come into regular contact with out-

side influences which might modify and increase his repertoire of roles, and having no opportunity to identify with others except his parents, the influence of the latter (already intense because of the high "togetherness") will be all the more powerful. Both the nature and the number of roles adopted by the child will thus be affected, resulting in the marked degree of social immaturity previously described. This means that the narrow range of stimulation entailed by the presence of a physical handicap is further reinforced by the particular type of family organisation, and in this way the peculiarities of the family set-up play right into the special characteristics of the physically handicapped child, just as the inability of these parents to set limits and impose discipline plays right into the emotional lability and impulsiveness so often found in the brain injured.

Some aetiological considerations.

In the main body of this report nothing was said about the cause and effect relationships that may exist between the various sets of phenomena described. Attention was drawn to their association, but it was not felt justified there to expound the type of association which may exist between them. In this chapter we can consider ourselves free to offer interpretations, and in the foregoing discussion of the development of the cerebral palsied child in relation to a particular kind of family organisation we did in fact make the assumption that a casual link is found here, and that the degree of social maturity of the child is due to the nature of the forces impinging upon him from his family environment. Yet many of the parents in the child-centric group clearly believed that the cause-effect sequence functioned in the opposite direction, namely that their general style of life and their particular treatment of the child was a necessary consequence of the child's handicapped condition. They pointed, for instance, to the child's intense clinging and asserted that this made it impossible for them to leave him and to engage in activities outside the family. This, however, is only a partial truth, for it neglects the fact that many parents with similarly handicapped children did not meet this problem and that it is therefore unlikely that this characteristic of the child is an inevitable

consequence of the organic condition. The more likely interpretation would seem to be that, for reasons of their own, the parents related to the child in such a way that intense emotional dependence was called forth and stimulated by their behaviour towards him, but that, once this pattern of responses was established in the child, the relation became a circular one and that the parents indeed had to respond to his need. A similar argument can be employed with regard to other interlinked phenomena, e.g. the parents' infantilising and the children's physical dependence, or the reluctance of the parents to discipline and the egocentricity of the children. In each case it may be assumed that, in these particular parents, the factor of cerebral palsy gives rise to a certain set of reactions, which is then further activated by the particular characteristic thus called into being in the child.

Are we then justified in assuming that the particular patterns of family behaviour described here are directly due to the stress of having a cerebral palsied child? Or would they have assumed that form anyway? On the basis of the present material we cannot conclusively answer this question. The project was set up in order to investigate the kinds of social reactions which occur when cerebral palsy is a given factor in the situation, and was concerned with the considerable intra-sample variability rather than with external comparisons. To determine what would have happened to a particular family if their child had not been afflicted with a congenital handicap appears an impossible question to answer, and neither a before-after type of research design nor the use of a control group can provide the solution. We can but describe the situation as it exists at present, and in this way confine ourselves to the here-and-now. Certain suggestive clues do, however, emerge from these descriptions, giving some indication of the extent to which parental patterns of behaviour are exclusive to the cerebral palsied child. These are seen most clearly in the child-centric group; it is the handicapped child who provides the focus for the family, it is around him that members tend to cluster, and it is for his sake that other activities tend to be sacrificed. This is not seen in the intermediate type, thus suggesting that the course of these families has not been deflected by the handicapped child. For the child-fugic

families the evidence is more equivocal: in at least two of these families a rift appears to have existed between the parents even before the arrival of the cerebral palsied child, but as in these cases father's lack of involvement with the child was more marked than his lack of involvement in other family activities, it may well be that the child's arrival brought about a further loosening of the family ties. It appears therefore likely that the reactions of the two extreme types are directly influenced by the factor of cerebral palsy, though no conclusive evidence on this point can be offered.

Although the project was set up to investigate the variability found within the sample rather than the reasons for such differences, it is nevertheless extremely tempting to seek an answer to the latter problem as well and at least to explore some of the more obvious possibilities. In many respects the sample is a very homogeneous one: all the families studied have as one of their members a child with congenital physical handicap; all these children are still in the early years of childhood; in all instances regular help from experts in the form of physiotherapy and/or education was received; the families are all apparently intact; they all belong to the same end of the socio-economic range; they are all drawn from one geographical area; and all form part of a largely industrial community. Nevertheless, three widely different patterns of behaviour were found under these circumstances, and certain further factors must therefore be operative and be able to account for these differences. For the purpose of such an enquiry it is worth recalling that Hill (1949) distinguished three classes of variables which determine a family's behaviour under stress: the hardship of the event itself, the resources of the family, and the definition the family makes of the event. We shall follow this schema and review possible aetiological factors under these three headings.

As for the hardship of the event itself, we must take into account what is perhaps the most obvious difference between the various families of the research sample, namely the severity of the child's handicap. To express this quantitatively the Severity Index was developed, and this enables us to ascertain whether any differences existed among the three family types in this respect. Table 42 shows the relevant figures.

Table 42.

The Severity Index in the Three Family Types

	<u>Mean</u>	<u>Standard Deviation</u>	<u>Range</u>
Child-centric type .	9.46	3.62	4 - 16
Intermediate type .	7.16	4.67	2 - 17
Child-fugic type ..	8.00	4.24	4 - 14

The intermediate group shows a mean figure lower than either of the extreme groups. This difference is, however, small, and use of the t test reveals that none of the differences between the three groups reaches an acceptable level of statistical significance (probability of .05). Each group, moreover, covers a wide range of scores and thus includes both very mildly and very severely affected cases. For instance, the child-centric family which received the most extreme scores on both the dimensions of cohesiveness and of community participation, and in which also more severe socialising pressure was found than in any other family in the sample, had the most mildly handicapped child in the child-centric group. In the intermediate group, on the other hand, we find the family with the most severely handicapped child in the whole sample, and in this group there is also the one family which had two handicapped children.

It appears therefore that the over-all severity of the child's handicap, objectively defined, cannot account for the more extreme reactions shown by some families as compared with others. This problem may, however, be investigated further, and one may enquire as to differences between the three family types in the nature of the handicap. As there were only four athetoids in the sample (two in the child-centric group and one in each of the other two groups), nothing can be concluded as to the differential influence of the two main types of cerebral palsy, spasticity and athetosis (the argument that the two conditions give rise to different personality constellations receives no support from our material). It may be argued, however, that the degree to which particular functions are affected is more important, that, for instance, interference with locomotion is the most visible aspect of cerebral palsy

and that a child's inability to walk is thus likely to be experienced as the greatest hardship. The sample was therefore divided according to ability to walk (i.e. take a number of steps without support from others) at the end of the period of observation. The results are presented in Table 43 according to family type; in the same table a division is also made between those able to speak at the end of the period of observation and those who had still not acquired any words at all.

Table 43.

Ability to Walk and to Speak
in the Three Family Types

	<u>Able</u> <u>to Walk</u>	<u>Unable</u> <u>to Walk</u>	<u>Able</u> <u>to Speak</u>	<u>Unable</u> <u>to Speak</u>
Child-centric type	5	8	9	4
Intermediate type	3	9	8	4
Child-fugic type	2	3	4	1

These figures indicate no marked differences in the three types of families. Looking next at the number of children with associated handicaps, Table 44 does reveal one interesting difference, for all the five cases with epilepsy are found in the two extreme groups, and none in the intermediate group.

Table 44.

Number of Associated Handicaps
in the Three Family Types

	<u>Visual</u> <u>Defects</u>	<u>Auditory</u> <u>Defects</u>	<u>Epilepsy</u>	<u>Total</u>
Child-centric type	2	1	4	7
Intermediate type	1	1	0	2
Child-fugic type	1	0	1	2

The other associated defects show no noteworthy differences. It may well be that the frightening features of epileptic fits did induce the parents to keep a closer eye on the child and were thus influential in producing high "togetherness". On the other hand this occurred in only a few cases and cannot therefore be regarded as playing a major part in the sample.

One aspect of cerebral palsy of which many parents expressed fear concerns the possibility of mental handicap. This, some felt, was worse than physical handicap and its diagnosis often elicited much sharper reactions than the diagnosis of the physical condition. In Table 45 we investigate whether there are any differences between the three groups in this respect. The figures are based on the I.Q.'s obtained from the children, and where an exact figure could not be stated and the child allocated only to a certain range, the middle point of this range was selected for the present purpose.

Table 45.

I. Q.'s obtained in the
Three Family Types

	<u>Mean</u>	<u>Standard Deviation</u>	<u>Range</u>
Child-centric type	61.08	10.13	40 - 75
Intermediate type	72.00	18.09	44 - 96
Child-fugic type	67.40	15.19	45 - 89

The means for the three family types show that a difference in favour of the intermediate type exists, that children from this group of families are on the average less intellectually handicapped than the children from the other two groups. The difference between the means of the child-centric type and the intermediate type is statistically significant (beyond the .01 level), but neither of the other two differences reaches a significant level. One must again, however, draw attention to the considerable range covered by all three types, particularly that covered by the intermediate type, which contained not only the most

intelligent children in the sample but also some of the least intelligent.

We conclude that a few differences do exist in the severity of the handicap which the three family types have to face. Epilepsy and mental retardation in particular appear to be more associated with the two extreme reactions. Yet our analysis bears out the contention of other writers on the behaviour of families under stress, that the degree of hardship alone cannot account for the total picture. Most of the above tables fail to reveal marked differences, and the overlap between the three groups is striking. Other determining forces are therefore present, and to these we shall now turn.

The resources of the family (Hill's second group of influences) may here be thought of in terms of "blow-softeners". However severe the stress, it may be that there are certain factors present in the family or its environment that will make it easier to adjust to the crisis. One such possibility refers to the presence of other, non-handicapped children. It may be argued that they at least give the parents the opportunity to show that they are capable of producing sound offsprings and that their parental role is therefore less damaged than that of parents who have produced only a handicapped child. In this sample only four families had no other children besides the handicapped one. Of these, two belong to the child-centric type, while one comes from each of the other two types. The great majority of families in all three types therefore did have other, non-handicapped children, and one must conclude that their presence cannot serve here as a differentiating criterion.

Another potential "blow-softener" refers to the attitude of the community in which each family lives. This, as Farber (1959) points out, may be supportive or non-supportive. If the latter, the family may be subjected to pressures which emphasise its difference from other families, and it will suffer a certain amount of ostracism. Such an argument is clearly highly relevant to our finding that the amount of community participation varied a great deal in the sample, and leads us to enquire whether the child-centric families, among whom social isolation was most marked, were more exposed to non-supportive community pressures than families in the other groups. The most satisfactory way of answering this question would be through a direct assessment of the particular com-

munity with which each family interacts. This was not done here, however, and the only pertinent material we have are the reports of the parents themselves on the attitudes met within their community. A bias is thereby introduced, in that the community is viewed through the parents' eyes, so that, if feelings of rejection are voiced, it will be difficult to disentangle reality from such subjective elements as projected hostility. However, surprisingly few parents reported such feelings, although at every interview questions were put to them about the attitudes they met in the community, with particular reference to friends, neighbours, and relatives. The few families who felt themselves at all exposed to unfavourable community pressures are drawn from all three types, with no undue preponderance of child-centric families. Of the thirteen families in this group, only three ever reported negative attitudes relating to the handicapped child, while of the twelve intermediate families two and of the five child-fugic families one family also produced such reports. Child-centric families did show a tendency to express rather more aggression towards official agencies, feeling that not enough was being done for them, but this, as we have seen, did not prevent them from continuing to make contact with them. It seems unlikely, therefore, that the kind of organisation found in each of three family types, with particular reference to the amount of community participation, can be explained on the basis of external pressures. This does not mean that the parents did not feel self-conscious in public when seen with their handicapped child, for curiosity on the part of strangers was frequently reported. Yet this occurred in all three family types, and it must be emphasised that none of the parents in this sample made any effort to hide the children from public view. All took them regularly to shops, to parks, etc., and feelings of social ostracism were rarely voiced. Where antipathy existed between child-centric families and relatives it was usually secondary to the isolation of the family rather than responsible for it. Relatives criticised the parents for their inward turned style of life, and the parents in their turn resented what they regarded as unjustified interference. It was therefore the extreme preoccupation with the child which crowded out other social contacts, and not the community which rejected the parents and forced them to remain

within their own family circle. Active role conflict does not therefore exist for the parents of the child-centric group, for their total emotional investment in the parental role was just not compatible with the carrying out of other roles. Social isolation, we must conclude, appears to be self-imposed rather than forced on the family from outside.

If community attitudes do not differ appreciably from group to group, there may nevertheless be certain practical reasons why some families find it more difficult to keep up social contacts. The sheer physical effort involved in moving a handicapped child from place to place may act as a brake to social intercourse, and this mobility factor will vary according to the handicap of the child, the proximity of other members of the family's community, and the available transport facilities.

As for the handicap of the child, we have already seen that its severity does not differ significantly from group to group. Inability to walk in particular is not found more frequently among those families whose community participation is lowest. Some families, it is true, lived a considerable distance away from their kinfolk and would therefore in any case have found it more difficult to keep up frequent contact with them. This applied mainly to those families who had moved to one of the new housing estates and whose relatives were often left behind in the old neighbourhood. Yet when the sample is arbitrarily divided according to whether the family lived within 30 minutes walking distance from the nearest member of either parent's family of origin, no striking differences emerge from Table 46.

Table 46.

	<u>Proximity of Family to Kinfolk</u>	
	<u>Within 30 Minutes Walking Distance</u>	<u>Not Within 30 Minutes Walking Distance</u>
Child-centric type ...	7	6
Intermediate type	8	4
Child-fugic type	2	3

The varying amount of contact with relatives cannot, therefore, be

explained on the basis of proximity, for many of the most isolated families lived in the same district as their kinfolk. Furthermore, we must remember that the lack of community participation applied also to contacts with neighbours, who by definition are available on the doorstep, and also to leisure activities, which the parents might well have carried out without the child.

Although a number of parents complained of the difficulties involved in the use of public transport with a handicapped child, this applied to all the three groups. The mothers of the intermediate group appeared, however, far more ready to tackle these difficulties, and if this was not possible they had none of the hesitation shown by child-centric mothers to leave the child with others and pay visits alone. It is, moreover, significant that four of the child-centric families had cars of their own and yet failed to make use of them in order to increase their community participation.

It appears that the presence of "blow-softeners" (i.e. having non-handicapped children in the family, living in a non-critical community, and having ready access to this community) does not have any appreciable influence on family type. Taken in conjunction with the findings regarding the severity of the condition, these results turn our attention to the third class of influences, namely those defining the meaning which a family attaches to such an event. Here, however, we are dealing with a very different kind of variable, for whereas previously we examined forces which were directly accessible to observation, we are now concerned with material which, in the context of this project, must be inferential in nature. This involves leaving the empirical level and proposing certain theoretical formulations which may be more controversial but which are nevertheless considered necessary as providing an essential link in any attempt at explanation. Most studies of behaviour under stress show that the objective properties of the external situation alone cannot account for an individual's reactions, that the characteristics of the individual himself must also be taken into consideration (cf. Lazarus et al., 1952, and Schaffer, 1954). Though under certain circumstances these individual characteristics may be directly accessible to study, mostly they are inferred from the observable responses to the situation

and must thus be regarded as intervening variables. It is in this light that we shall consider the following interpretation.

What does it mean, we must ask, to be given a child with a congenital handicap? Parents always expect their child to be perfect, and when for one reason or another these expectations are not met and the child is mentally or physically crippled, a severe blow is dealt to them. The congenital nature of the handicap gives rise to feelings of responsibility in the parents, for they themselves have produced the imperfect child, and when the imperfection is of a severe, permanent, and unsightly nature, their narcissism, with particular reference to their capacity as parents in its initial and most important aspect, is seriously challenged. The three family patterns of behaviour described in this report represent, we suggest, three ways in which such a challenge is met.

Taking the intermediate group first, it is not part of our argument that in families of this type the parents do not feel themselves challenged at all, that they take the handicapped child in their stride as though this were a perfectly normal, expected event which arouses no concern or anxiety. Such an attitude would signify a detachment and lack of investment in the parental role that in itself would be of a highly pathological nature. This certainly does not apply to these parents. They were concerned and anxious about the child, they did identify themselves with him and they did feel involved in his condition. Yet their behaviour patterns show that they were able to keep their feelings within bounds and not involve the child in them. On the one hand they did not feel the necessity to reject their parental role or to try and force the child out of his handicapped condition, and on the other hand they were sufficiently free to help the child towards independence and not keep a permanent and total stranglehold on him. They had, in other words, successfully met the challenge to their parental role. The child thus no longer represented to them a continual reminder of their failure, and, having resolved their feelings of involvement, they were able to treat him as an individual in his own right without making him a victim of their own needs.

In the child-centric and the child-fugic types, on the other hand,

we see two different reactions to failure to meet the challenge to the parental role. The child-fugic type provides evidence of the simplest and most direct way of dealing with such a situation, namely by avoiding the child and rejecting the parental role. The picture is confused by the fact that in most families of this type a child-fugic pattern of behaviour is adopted by only one of the parents and not by both. But where it does appear one can see the disinclination to play the parental role to such a child in the attempts made to cut down interaction with him to a minimum. These parents did not accept the situation as it was, for they could not bear to be confronted by their failure, and they found it therefore simplest to avoid it as much as was possible without actually withdrawing from the situation altogether. Their hostility to the child who was responsible for their shame and failure thus found open expression in feelings of rejection, and is also seen in the severity of their socialising techniques and disciplinary methods.

The child-centric pattern of behaviour reveals, we believe, basically the same sense of failure and feelings of hostility, but with the phenomenon of over-compensation superimposed on it. These parents cannot allow themselves to give open rein to their negative feelings towards the child, for this would arouse too much guilt in them. They thus go to the opposite extreme, and their whole life-pattern is the external realisation of their intense need to be recognised as good parents. In some respects their behaviour is almost a caricature of what a parent should do: the ordinary necessity to keep an eye on a child means to them that the child should never be let out of sight, and the task of providing support for his dependent condition entails for them an over-protection and infantilising that often assumes extreme forms. But only the indulgent aspect of the parental role is ever acted out, for these parents have to keep such a tight check on their hostile impulses that they cannot allow themselves to impose even minimal control over the child and to bring even mild socialising pressures to bear on him. It is no wonder that the idea of physical punishment is abhorrent to most of these parents.

This situation has all the elements of a neurotic conflict: an

undesirable tendency which the individual dare not acknowledge, an attempted solution by repressing this tendency, and a subsequent overt over-compensation. As in all neurotic conflicts, however, a price must be paid, and this may take various forms. The one that is found in all families of this group concerns the considerable constriction of activities. The individual is no longer free to participate in a variety of fields and to assume a number of different roles in the community: all his energy is absorbed by the parental role, which thus becomes grossly inflated and tends to crowd out all other interests. In some respects this is highly reminiscent of the psychiatric condition in children described as "school phobia", where the core of the problem involves, not a fear of going to school, but a fear of leaving the mother for whom considerable repressed hostility is felt and for whose safety the child is thus extremely concerned. In the same way the parents described here are forced into their child-centric mode of life not by external pressures, but rather by the internal pressures resulting from the repressed hostility feelings. These make it necessary for them to be constantly with the child, and indeed unrealistic fears about his safety were frequently expressed ("he might fall out of bed", "he might choke", "he might get hurt because other people don't know how to handle him", etc.). The high "togetherness" and the low community participation of these families may thus be regarded as the social consequences of the intra-psychic meaning which the handicapped child has for the parents.

Another price which some of the parents have to pay for the successful repression of the conflict is to be found in their individual psychiatric symptomatology. Of the 30 research families there were nine in which a parent developed a psychiatric condition severe enough to require medical attention. In all nine families it was the mother who was affected, but in one the father too was forced to seek help for himself. In every instance the condition developed some time after the child's birth, never having appeared before that time. It generally took the form of "nerves" (as the parents described it) - a diffuse anxiety condition with psychosomatic or depressive symptoms. In one case a short period of hospitalisation was required, during which the mother received E.C.T., while the others were treated mainly with sedatives and

and tranquillisers. Our interest, however, lies mainly in the distribution of these cases among the three family types. Only one of the cases came from the intermediate group, two from the child-fugic group, and the remaining six all came from the child-centric group. Thus nearly half the families of the latter type furnished evidence of some overt psychiatric disturbance severe enough to impel the individual to seek professional help. This appears to support our interpretation: in the intermediate group the objective situation confronting the parents was similar to that to which the child-centric group was exposed, yet it was experienced as a far greater strain by the latter and had thus clearly assumed a different meaning. It is also significant that among the child-fugic group the two cases that developed a psychiatric condition concerned mothers who both adopted a child-centric pattern of behaviour towards their children, and that no disturbance was found in any parent who gave direct outlet to his negative feelings. Further support for our interpretation can be found in the fact that in two of the child-centric cases the mothers, after their breakdown, quite suddenly adopted for a time just the opposite attitude to that previously held, insisting, for example, that the child must be sent away and, in their socialising techniques, changing from indulgent to severe and punitive methods. This illustrates well the usually hidden feelings of aggression and hostility, and makes it less puzzling that one of the child-centric families was found regularly to adopt very severe socialising methods.

Basically, therefore, parents in both the child-centric and the child-fugic groups are forced to deal with the same problem. In both cases producing a child with a congenital handicap means to the individual that his parental role has been called in question, and in both cases they are unable to meet the challenge. But while in one case avoidance techniques are employed to deal with this situation, in the other case the parents do not feel themselves able to adopt this solution, and, using an over-compensation mechanism, go to the opposite extreme and manifest a gross exaggeration of the parental role. Thus the overt reaction patterns differ from group to group, and it is these which determine the emotional atmosphere in which the child is reared and to which attention has therefore been primarily given in this report.

Practical implications.

Having presented the empirical data and some conclusions about their theoretical import, we may finally turn to the practical implications of this study and consider what social action they suggest. It may perhaps seem presumptuous to say anything at all about this aspect when such a small and unrepresentative sample forms the basis of the investigation, and it is indeed clear that further research is needed to confirm and amplify these results. Thus the ascertainment of the statistical frequency of the various types amongst families with handicapped children would form one useful line of enquiry, which could furthermore be combined with an investigation of the effects on sub-samples differing from the present in terms of socio-economic class, cultural (geographical) factors, and non-availability or very limited availability of regular professional help. The occurrence of the family types in conjunction with other forms of handicap, congenital and acquired, should provide further information as to the usefulness of the schema here proposed. But over and above these questions specifically concerned with the problem of handicap and its social concomitants it is important to follow up some of the suggestions raised about the development of particular personality constellations in particular family settings. Young and Willmott (1957) point to our ignorance regarding the association of these two areas when they remark that "personality, far from being an independent variable, is probably related to family structure. But we can at present hardly even guess which kind of family produces which kind of person ... This is the kind of question which psychologists should in time be able to illuminate, and thus add another, and vital, dimension to our understanding of kinship." Because of the widely divergent kinds of family setting the present sample has provided a useful starting point for such an enquiry. Considerable refinement of methods of assessment is, however, required before a more precise dovetailing of social structure and individual personality becomes possible, and here unfortunately cerebral palsied children, with their multiple handicaps involving means of expression, are hardly the easiest of subjects to investigate. Nevertheless (possibly by using older and less handicapped subjects) such refinement is essential for a better understanding of the social forces which impinge on and shape the growing

child's personality.

Yet even before improvement in methodology and the widening of the field of enquiry have produced more facts, the need for help of many of these families is so obvious that, bearing in mind all the limitations of size and unrepresentativeness of the present sample, some tentative suggestions are herewith included as to the kinds of social action which appear to be called for.

Two general conclusions arising from this study can be stated: that families do not by any means all behave similarly in the face of congenital handicap, and that the proportion of pathological reactions is inordinately high. As for the first point, this has formed the central theme of this report and needs no further comment. The second point is substantiated by the writings of other workers in this field and was referred to in the review of the literature, and is further borne out by the writer's clinical experience which has also confirmed the usefulness of viewing families in the light of the typology here suggested. The conclusion that follows is that psychiatric services for the handicapped and their families should be made far more readily available than they are at present, so that those who do need this form of help can be spotted and the nature of the necessary therapeutic intervention be decided on in time. The assumption, that any behaviour disorder in the cerebral palsied individual is bound to be an unalterable part of the brain injury, is far too common still and is too frequently used to neglect the mental health aspect of such a child's personality development. That this is, however, of no more academic interest but that psychotherapy with brain-injured and with mental defective subjects is feasible has been shown by Stone (1960) and by Mundy (1957).

It is essential, however, that such a service be based on the family as a whole and not merely on the individual child. This has become apparent in the course of our descriptions, which have justified our initial promise that congenital handicap is the problem not merely of the individual so afflicted but of the family as a whole. Many families do have the strength to adjust to this situation, but, as we have seen, there

are others in which the mental health and social standing of every member may suffer. This widening of focus from the study of the handicapped child to concern with the whole family must, in fact, form the starting point for any plan to further the mental health of such children (see Adams, 1960, for the exposition of the same point of view made on behalf of the mentally handicapped).

Once this has been realized, the practical measures to be taken will be influenced by the assessment of the family as a whole, and not only by the diagnostic picture presented by the child. To give but one example: from the child's point of view placement in a residential school may be most desirable in helping his physical and educational progress. Yet, should he come from a child-centric family where he has for years formed the focal point of all social activities, this sudden removal is likely to have serious disruptive effects on the balance of the family group. This may well be followed eventually by a gradual blossoming and re-emergence of true family life; on the other hand it may also be followed by complete disintegration (Cohen, 1961, has reported a case where the parents both committed suicide after the death of their spastic son, leaving a note to the effect that they now had nothing more to live for). In either case, this is clearly a situation which must be managed with caution, requiring preliminary casework with the parents, continuing contacts and support after the separation, and, wherever possible, making the break a gradual rather than a sudden one.

The kind of help that a family requires will vary from case to case, but once again generalisations may be usefully made in terms of the three types. As for the intermediate type, psychiatric intervention does not appear to be called for, and though advice and guidance on practical problems of management may often be most useful, the very fact that such families can usually benefit from such "common sense" methods gives an indication of their mental health. This is not the case amongst the other two types, where parents' resistance to advice from physiotherapists and other professional workers was frequently reported. Co-operation in treatment plans was often impossible to obtain because it demanded from the parents a relationship with the child which, for subjective and

and unconscious reasons, they were incapable of maintaining. What is therefore required is some means of dealing with these unconscious forces, i.e. the provision of psychiatric casework for the parents. The word "parents" is used advisedly, for the traditional child guidance approach of working only with the mother and rarely, if at all, seeing father, is clearly inappropriate here. The part father plays in these families, whether it assumes a "fugic" or a "centric" form, is so crucial that it is essential that he too must be involved in all efforts at modification.

The manner of providing such a service is an administrative problem beyond the scope of this report. Our concern here is to point to a need rather than to work out a detailed scheme of catering for this need. One of the essential requirements, however, which must be stated is that "family diagnosis" should take place as early as possible once the handicap has been detected. In this way preventive measures may be taken by, for instance, providing or maintaining bridges to the community for those families where social isolation is taking place. Nursery units for the handicapped are particularly valuable as far as the children are concerned, and Parents' Associations (more perhaps through their recreational than their educational activities) may serve the same purpose for the parents. But most important of all is the attempt to arrest as soon as possible the development of a pathological relationship between parents and child, so that the implications of giving birth to a handicapped child may be followed up with those parents where adjustment appears not to be taking place. To achieve early access to the family close liaison with other agencies dealing with the assessment of the handicapped is called for. Screening services for the various forms of handicap are now fairly prevalent, but are still almost solely concerned with making provisions for the child from the organic and the educational points of view. The more one can include psychiatrically oriented personnel in the screening procedure the greater will be the chance to prevent some of the social and individual pathology described in this report. In this way also the mental health aspect of each case may be borne in mind when making plans as to medical and educational provisions.

By undertaking psychiatric casework with the parents of handicapped children, an opportunity is, furthermore, offered to investigate the hypothesis stated in the last section as to the psychopathology found in parents of the three family types. Our search for possible aetiological factors led us there from a consideration of external "reality" factors to a consideration of subjective forces, and while the project had not been planned to work directly at this level, it has nevertheless been mentioned as providing an essential "missing link" to any attempt at explanation. Such an approach can at present only feasibly take place in a clinical context, and the therapeutic aspect of the above suggestions for psychiatric casework may therefore be most usefully combined with the research aspect. We still do not know why some parents are able to meet the challenge of congenital handicap and why others are bowled over by it, or what factors determine that one individual uses avoidance techniques and another uses over-compensation techniques. By adding this further level of study it should become possible to answer such vital questions.

THE SEVERITY INDEX

Procedure:

The child is classified in the appropriate category under each of the following six headings, and the sum total of the scores thus obtained represents the Severity Index.

a. Locomotion.

- Immobile - cannot walk, crawl, roll, or get about independently by any other means (4)
- Cannot walk, but is mobile through crawling or rolling (3)
- Can walk, but only by holding on to supports or by such artificial means as callipers or crutches (2)
- Can walk independently, but in a clumsy, "uneighty" manner (1)
- Locomotion unaffected (0)

b. Manipulation.

- Unable to grasp objects with either hand (4)
- Can grasp with at least one hand, but unable to carry out other co-ordinated movements (3)
- Only finer co-ordinated movements adversely affected (2)
- Use of only one hand impaired, the other unaffected (1)
- Manipulation unaffected (0)

c. Speech.

- Unable to say words at all (4)
- Can say only one or two single words (3)
- Can put words together in phrases and sentences, but vocabulary limited for age (2)
- Effective speech, though unclear (1)
- Speech unaffected (0)

d. Intelligence.

- I.Q. below 50 (4)
- I.Q. between 50 and 59 (3)
- I.Q. between 60 and 69 (2)
- I.Q. between 70 and 79 (1)
- I.Q. above 80 (0)

e. Seizures.

Frequent and severe	(4)
Infrequent, but severe	(3)
Frequent, but mild	(2)
Infrequent and minor	(1)
None	(0)

f. Sensory functions.

Total disability with regard to sight and/or hearing	(4)
Sight and/or hearing impaired sufficiently to interfere seriously with effective functioning	(3)
Sight and hearing efficient, but artificial aids (glasses, hearing aid, etc.) required	(2)
Handicap mild enough not to require artificial aids (e.g. squint, slight degree of deafness)	(1)
Sensory functions unaffected	(0)

APPENDIX 2.

INTERVIEW GUIDE

The topics indicated below form the orientation points around which each interview was structured. No attempt was made to cover the topics in any particular order nor to standardise the wording of questions. The only exception to the latter point refers to those specific questions (indicated by Q) where an attempt was made to obtain a quantitative measure of certain family activities.

A. Family Activities.

1. Child-care

- a) Performance of routine activities (feeding, washing, toileting, dressing, putting to bed, giving exercises):
 - sharing of responsibility amongst family members for such tasks;
 - amount of time spent each day on these activities.

- b) Performance of non-routine activities (playing, taking for walks and outings, general supervision):
 - sharing of responsibility amongst family members for such tasks;
 - amount of time spent each day on these activities.

Q: "On how many days in the last week did you (the mother) leave the child in someone else's care for a period of more than about half an hour?"

Q: "On how many days in the last week did father spend all the time that he was not at work together with the child?"

Q: "If a place were available for your child at a residential school for spastics, would you be willing to send him there?"

(This question was asked once only, usually during the first or second interview).

2. Household tasks.

Performance of routine household activities:

- extent to which father and siblings participated and nature of tasks for which they were responsible;
- help received from individuals outside the family (from whom and how much);
- amount of time spent on housework (daily timetable);
- extent to which mother felt housework was interfered with by the care given to the cerebral palsied child.

Q: "How often did you (the mother) receive help with household tasks in the preceding week? Every day, just occasionally, or not at all?"

3. Employment

- members of family in employment, and nature of employment;
- amount of time per day spent away from home on this account, and interruptions of working time on account of cerebral palsied child;
- other effects of cerebral palsied child on nature of employment.

4. Contact with kin

Visits paid to or received from relatives;

- frequency of contacts (Q: "On how many days in the last week did any member of the family see a relative?");
- what relatives were seen;
- the members of the family involved in these contacts;
- where the contacts took place (own home, relative's home, elsewhere);
- reason for such contacts (help, duty, companionship, emotional support);
- difficulties in the way of such contacts;
- attitudes of relatives to handicap.

5. Contact with neighbours

(other than mere greetings or passing remarks):

- frequency of contacts (Q: "On how many days in the last week did any member of the family talk to a neighbour?");
- number of neighbours with whom contact was made;
- the members of the family involved in these contacts;
- where the contacts took place (own home, neighbour's home, elsewhere);
- reason for such contacts;
- attitude of neighbours to handicap.

6. Contact with official agencies

All bodies and individuals giving professional services (medical, educational, social, welfare, religious):

- frequency of contacts (Q: "How many such contacts were there in the last week?");
- kinds of agencies and individuals seen;
- members of family participating in such contacts;
- reason for contact;
- attitude of agencies to handicap.

7. Leisure activities

- nature of leisure activities engaged in by family members;
- frequency (Q: "On how many days in the last week did any member of the family engage in some sort of leisure activity?");
- members of family participating in each activity.

B. Parental Socialising Techniques.

1. Locomotor functions

Attempts made by parents to correct the child's present manner of functioning:

- do they take place;
- how frequently;
- the form that such attempts take;
- sanctions employed to enforce parental demands.

The same topics also to be covered in respect of:

2. Speech

3. Intellectual functions

4. Feeding

5. Toileting

6. Sleeping

C. The Child

1. Nature of handicap

- its manifestations (in locomotor skills, speech, intellectual functions, sensory abilities, seizures);
- improvement since last contact.

2. Reactions to handicap

- signs of self-consciousness, frustration, denial, anxiety, depression;
- dependence on others for the performance of skills;
- attempts at self-help and circumvention;
- "holding own" with other children.

3. Reactions to training

- compliance to parental requests in each of six socialising areas (locomotor functions, speech, intellectual functions, feeding, toileting, sleeping);
- behaviour in physio- and speech therapy and in classroom (where appropriate).

SOCIALISING SEVERITY SCORES

<u>Name*</u>	<u>Loco-</u> <u>motion</u>	<u>Speech</u>	<u>Intell-</u> <u>ectual</u> <u>Func-</u> <u>tioning</u>	<u>Feed-</u> <u>ing</u>	<u>Sleep-</u> <u>ing</u>	<u>Toilet-</u> <u>ing</u>	<u>Total</u> <u>Score</u>
Anderson, a.	1	0	1	0	0	1	3
Baker, a.	0	0	0	0	1	1	2
Burgess, b.	1	0	1	1	1	1	5
Cairns, b.	1	1	0	0	1	1	4
Cunningham, b.	1	1	1	1	1	2	7
Donaldson, c.	2	0	0	2	0	2	6
Fisher, b.	1	1	1	1	1	1	6
Fletcher, b.	0	0	1	1	1	1	4
Hooper, a.	1	1	1	1	1	1	6
Jackson, c.	1	0	0	1	1	1	4
Johnson, a.	0	0	0	0	0	0	0
Kelley, b.	1	1	0	1	1	2	6
Lane, a.	1	0	0	0	0	0	1
McBain, a.	0	1	0	0	0	0	1
McGuire, b.	1	0	1	1	0	1	4
McNeil, b.	2	1	1	1	1	1	7
Murphy, c.	2	0	0	1	1	1	5
Napier, b.	1	1	1	1	1	1	6
Newland, a.	2	0	0	0	1	0	3
Parkinson, b.	1	2	1	1	1	2	8
Phillips, b.	1	1	0	1	1	1	5
Purdon, b.	1	1	1	1	1	2	7
Richardson, c.	2	2	0	2	1	2	9
Robertson	0	0	0	0	1	1	2
Sawyer, a.	0	1	0	0	0	1	2
Sinclair, a.	0	0	1	1	1	1	4
Stewart, a.	0	0	0	0	0	1	1
Strang, a.	1	0	1	0	0	1	3
Vallance, a.	0	0	0	0	0	1	1
Watson, a.	2	2	2	2	1	2	11

* a. Child-centric families
b. Intermediate families
c. Child-fugic families

APPENDIX 4.

CHILD MATURITY SCORES

<u>Name*</u>	<u>Emotional Dependence</u>	<u>Instrumental Dependence</u>	<u>Co-operation</u>	<u>Total Score</u>
Anderson, a.	1	1	1	3
Baker, a.	0	0	0	0
Burgess, b.	0	1	1	2
Cairns, b.	0	0	0	0
Cunningham, b.	1	1	1	3
Donaldson, c.	0	0	0	0
Fisher, b.	0	1	1	2
Fletcher, b.	1	1	1	3
Hooper, a.	0	1	0	1
Jackson, c.	1	1	1	3
Johnson, a.	0	0	0	0
Kelley, b.	1	1	1	3
Lane, a.	0	0	0	0
McBain, a.	0	0	0	0
McGuire, b.	1	1	1	3
McNeil, b.	1	1	1	3
Murphy, c.	1	1	1	3
Napier, b.	0	1	1	2
Newland, a.	1	0	0	1
Parkinson, b.	1	1	1	3
Phillips, b.	1	1	0	2
Purdon, b.	0	1	1	2
Richardson, c.	1	0	0	1
Robertson, c.	1	1	1	3
Sawyer, a.	0	1	0	1
Sinclair, a.	0	0	0	0
Stewart, a.	0	0	0	0
Strang, a.	0	1	1	2
Vallance, a.	0	0	0	0
Watson, a.	0	0	1	1

- * a. Child-centric family
 b. Intermediate family
 c. Child-fugic family

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