A study of sixty-six handicapped children and their parents

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by

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INTRODUCTION

The parent-child relationship has received increasing recognition in psychological literature, interest being shown in the quality of the relationship and attempts have been made at quantification of some mother-child interactions. Systematic studies of families in which there is a young cerebral palsied child are sparse. An enquiry, therefore, into some aspects of the parent-young handicapped child was undertaken in order to investigate the impact on parental behaviour and attitudes of such an event as the birth of a cerebral palsied child especially with regard to its possible biasing effect on parental assessment of the child's physical, social, emotional and intellectual status.

A. THE SETTING

Thanks to Mr. D. Graham of the Department of Psychology, University of Durham, the writer was introduced to the Percy Hedley Centre for Spastics, Newcastle-upon-Tyne in October, 1965. This is a voluntary organisation whose origins go back to a parent-founding in 1949. Its early development is thus a pattern of other such parent-sponsored organisations of that period. The Percy Hedley School, with Ministry of Education aid, was opened in 1953 to cater for 32 "children whose physical disabilities were so severe that they were unable to attend any other school in the area and who yet had sufficient intelligence to profit from formal education", (Ellis, 1960). A clinic was established, to which parents could bring their children for assessment and advice. Doctor Ellis, the Medical Director, on appointment as co-ordinator of the medical and educational activities of the new establishment had made a survey of children suffering from cerebral palsy in the area served by the Newcastle Regional Hospital Board, which includes Northumberland, Durham, Cumberland, North Westmoreland and part of the North Riding of Yorkshire. As a result of this survey and of those of the Ministry of Education and the Local Education Authorities, the school was extended to cope with at first 70 children and latterly, for "90, half of whom are resident", (Johnston, 1966), and whose age range is 3-17 years. The advisory service, a feature from the beginning, was expanded into a treatment service in 1954, to cater for local outpatients. This was further developed by offering residential accommodation to parents living at a distance, who are admitted with their handicapped child from Monday to Friday and who are, in some instances, accompanied by other children and - on occasion - by grandmothers. The child and mother are seen by the Medical Director, therapists, psychologist and Headmaster; and they also attend the assessment group sessions of which there are four in the week, catering in all for about 60 pre school children. The age matched groups are run by Nursery School teachers with physiotherapists and speech therapists in attendance and the Medical Director and visiting psychologist are able to see these children for continuous assessment. The groups are kept deliberately small, the atmosphere informal and apparently permissive belies the carefully planned and flawlessly integrated structure of these sessions. By school age, an assessment of each child's motor, language, social and intellectual abilities and disabilities has been made and after careful discussion, his educational future decided upon.

It was the parents and children who attended these groups from October, 1965 who were to serve as subjects for the proposed study. It was decided that separate interviews with mothers and fathers should be requested, the mother's interview to take place in the Clinic, the father's in the home. The study would be largely descriptive; but one area was to be investigated rather fully - that of the parents' estimate of the present level and future achievement of the child, and a section of the proposed questionnaire would incorporate questions which, it was hoped, would elicit the realism -

or otherwise - of parental estimates. Their judgments could be compared with the child's motor, language, social and intellectual ability as seen and rated by clinic personnel, the discrepancy between parental and staff ratings being the index of bias.

The aim of the study was, in general, to investigate some parental attitudes towards the handicapped child and in particular to estimate the distortion or otherwise of parental assessments. The 66 pre-school children and their parents who attended the Percy Hedley assessment groups from October, 1965 till June, 1966 were the study population.

B. ATTRIBUTES OF THE STUDY POPULATION

A detailed description of each child is included in Appendix A. The 66 families studies came from the area served by the Newcastle Regional Hospital Board, but were mainly from the city and district, and from Northumberland and Durham. Only 3 families had difficulty in making the daily return journey and these were happy to stay over in the resident accommodation on a few occasions during the specified period.

1.	Number of families studied	66
2.	Number of mothers interviewed	66
3.	Number of fathers interviewed	55
4.	Sex of the handicapped child:	
	Boys	32
	Girls	34

5. Marital status of parents:

Married	65
Separated	1
Divorced	0

6. Mean number of years of marriage .. .. .. 8yrs. 10mths.

Range of years of marriage:

3 - 5 yrs.	6 - 9 yrs.	10 - 13 yrs.	14 - 19 yrs.
24	16	12	14

7. Mean age of mothers .. .. 30yrs. 2mths.

8. Mean age of fathers .. .. 32yrs. 4mths.

9. Age range of parents:

20 - 29 yrs.		30 - 39 yrs.		40 - 49 yrs.	
M	F	M	F	M	F
37	26	24	32	5	8

10. Education of mothers:

9 - 10 yrs.	10 - 13 yrs.	Over 13 yrs.
42	21	3

11. Education of fathers:

9 - 10 yrs.	10 - 13 yrs.	Over 13 yrs.
43	17	6

12. Classification of father's occupation according to Registrar-General's classification (1931)

Social Class I & II	9
III & IV	50
V	7

13.

Own house	Rented Council house/flat	Rented house	Rented flat	Other accommodation
25	25	5	8	3

14. Mean number of children in the family 2.5

Number of families with:

1 child	2 children	3 children	4 children	5 children	6 children	8 children
17	24	12	7	3	2	1

15. Mean age of child in study group .. .. 3yrs. 10mths.

Boy .. .. 3yrs. 8mths.

Girl .. .. 4yrs. 1mth.

Age range of children:

Boys:

1-2	2-3	3-4	4-5	5-6
1	10	6	11	4

Girls:

1-2	2-3	3-4	4-5	5-6	6-7	7-8
2	4	11	12	1	1	3

16. Ordinal position of child in study group:

Only		First Born		Intermediate		Last Born	
M	F	M	F	M	F	M	F
9	8	7	8	4	5	12	13

17. Average birth weight .. .. 5lbs. 10ozs.

18. Number of 'prematures' according to B.W. 24

19. Fathers unemployed 1

20. Mothers employed .. .. Full time 2 Part time 6

Type of Cerebral Palsy	Mild	Moderate	Severe
Athetosis	1	2	2
Spastic Quadriplegia	1	4	15
Mixed Spastic and Athetoid	-	-	1
Ataxia	1	4	1
Right Hemiplegia	5	2	1
Left Hemiplegia	2	3	2
Paraplegia	5	8	-
Percentage of total cases*	22.7%	34.8%	33.3%

Table 1. Distribution of children in the present study according to severity of physical handicap.

* An additional 6 children had a diagnosis of mental retardation.

Intellectual Rating	Mild	Moderate	Severe
Above average	1	2	-
Normal	5	1	1
Slightly Retarded	7	5	4
Moderately Retarded	-	12	5
Severely Retarded	1	4	18
Percentage of Total Cases	21.2%	36.4%	42.4%

Table 1a. Relationship of degree of physical handicap and intellectual rating in the present survey.

(After Ellis, 1955).

C. HYPOTHESES

It was hypothesised:

(1) that parental estimates of present status and future achievements should over-estimate the capacity of the child (Boles, 1959, Jensen and Kogan, 1962);

(2) that the children who were handicapped both physically and intellectually were more likely to be rated unrealistically than were less handicapped children (Ewert and Green, 1957, Zuk, 1959, Barclay and Vaught, 1964);

(3) that the younger the child, the less realistic the parental estimate and expectation (Jensen and Kogan, 1962).

The theoretical backing for these hypotheses will be discussed in Part III of the study.

D. PROCEDURE

Although controlled observation of phenomena is primarily desirable, it was not possible, in this instance, to design an experiment which would avail of exact and unambiguous responses. Admittedly, a control group could have been used to advantage; but in the circumstances, a period of observation and contact-making, to be followed by the administration of a questionnaire to the mother in the clinic and the father on a home visit (if this were acceptable) was decided upon. The disadvantages of this method were fully realised; human dynamics are not simple, uncomplicated, quantifiable phenomena; psychological barriers arise between respondent and the material we want him to bring forth due to memory failure, emotional forces, the social desirability factor. There are obstructions to communication manifested in the respondent's wish to withhold information or he tries to meet what he thinks are our expectations. Factors other than the manifest content of the presented stimuli influence response. There is the experimenter effect (Kintz et al, 1965), the "contamination problem" aggravated perhaps by the bias expected to be induced by a religious habit. Since the interview is not a series of discrete S-R events, language can play an important cue-supplying role as to what sort of person the other is, and the danger arises that respondent and experimenter speak from different experiences and frames of reference. "Language is always ambiguous as to the exact proposition which it indicates" (A.N. Whitehead in "Process and Reality" Macmillan, 1929), and informants are not always articulate, nor experimenters insightful. With these pitfalls in mind, a questionnaire was compiled and a pilot study designed to test its validity and reliability was conducted on a small sample. After some adjustments in wording and sequence of questions, the final form (Appendix B) was the instrument used in the semi-structured interview. A serious attempt was made to "translate research objectives into specific questions" (The Collection of Data by Interviewing - C.F. Cannell and R.L. Kahn in Festinger and Katz, 1953), and to prevent conditioning by previous questions or the formation of response sets. The funnel approach was used to avoid any emotional pile-up for the parent. In fact, the questions associated together from the researcher's point of view are widely separated in the questionnaire. The use of leading questions seemed unjustified, in spite of Richardson (1960) who asserts that the concern expressed that leading questions may distort the response appears exaggerated. Open-minded and closed questions have been used and an honest attempt made to construct bias-free questions - if this is ever possible.

In an effort to secure standardized conditions, the questionnaire items were committed to memory and uniform conditions of interviewing and recording verbatim were aimed for. Richardson, Dohrenwend and Klein (1965) advise the value of tape recordings - "From recorded interviews you are able to develop a systematic and detailed way of describing the verbal behaviour they contained"; but to introduce a tape-recorder seemed an intrusion, though its value as a tool is readily accepted. The same authors write: "In general, the greater the precision required, the more costly is the acquisition of the information" (1960). One can agree whole-heartedly, especially when, as in the area of parent-child interaction, controlled observation might yield the highest degree of accuracy but would be obtained at the cost of spontaneity and with, possibly, distortion. The interview and questionnaire design may lack scientific precision but a knowledge of the shortcomings can be provided for in the questionnaire construction and interview schedule.

E. CEREBRAL PALSY

Terminology

The complexity of cerebral palsy is said to make its definition difficult. Once synonymous with Little's disease, a spastic paralysis resulting from birth trauma, 'cerebral palsy' has "grown to include a diversified group of neurologic conditions whose common bond is abnormal motor function resulting from brain damage". (Denhoff, 1955b).

Bobath (1959) states: "cerebral palsy is not a single disease but a group of conditions, resulting from brain damage through factors operating in utero or in the para-natal period. The lesion is persistent and non-progressive and leads to a motor dysfunction, an impairment of the co-ordination of muscle action, frequently associated with various sensory disturbances". Minear (1956) emphasises that under the new definition approved by the American Academy for Cerebral Palsy "the patient is not accepted as cerebral palsy until a progressive nature of the etiology has been eliminated". Ellis (1955) defines cerebral palsy as "the result of abnormal brain function. It is a comprehensive term covering a large number of conditions of varying degrees of severity but characterised by the presence of abnormal muscle tone, often associated with disturbances of sensation and impairment of intelligence". This is interesting, because of its rare specific reference to "impairment of intelligence". Only Denhoff refers to "psychological dysfunction" but in his context (In "Cerebral Palsy" Cruickshank and Raus, 1955), it covers mental retardation problems as well. The importance of the 'intelligence' reference lies in the cognisance of repercussions other than motor, neurological, or orthopedic, which were hitherto stressed.

Classification

Classification is made easier by the different manifestations of disability. Phelps (1949) bases his classification mainly upon motor functions and disturbances. Balf and Ingram (1955) list 6 major types, while Bice (1950) uses a five-type classification - athetosis, spasticity, rigidity, ataxia, tremor. Spasticity contained the largest number, 46.5%. Hopkins et al (1954) found their analysis of 1,406 cases (1936-1951)

45.9% cases of spasticity
23.7% cases of athetosis
10.8% cases of ataxia

Dunsdon (1952) found that spasticity occurred approximately eight times as frequently as athetosis, as did Asher and Schonell (1950). Dunsdon (1960) speaking of the English estimates and the relative difference from that found in other countries (e.g. the U.S.) says: "There has been general agreement in all the main surveys in this country that spasticity accounts for the large majority of cases, with relative incidence of from 67% to 86% athetosis and other forms accounting respectively for from 8% to 21% and from 1% to 25% of all". Ellis (1955) in his survey, found in 133 cases:

Type of cerebral palsy	No. of cases	Percentage
Athetosis	10	7
Symmetrical Spastic Quadriplegia	25	19
Asymmetrical Spastic Quadriplegia	13	10
Mixed Spastic and Athetoid	3	2
Ataxia	5	4
Right Hemiplegia	27	20
Left Hemiplegia	21	16
Paraplegia	29	22
TOTAL	133	100

Source: Ellis (1955)

TABLE 2. The incidence of the different types of cerebral palsy.

Ellis (1955) found, in his survey, that many cases for under 5 years had probably been missed, so that he concludes: ".....the age group 0 to 5 years contained such a small number of cases that the results obtained for this age group could not be considered as representative of the cerebral palsy population as a whole". This has relevance, in that in the years since the Survey, from this same area have come pre-school children to P.H.C. of which the study group is an example.

Study	Date	Percentages			
		Athetoid	Spastics	Mixed Athetoid & spastic	Ataxia rigidity etc.
Brockway (U.S.A.)	1936	8		92	
McIntire (U.S.A.)	1938	36	36	5	23
Phelps (U.S.A.)	1940	40	40	3	17
Phelps (U.S.A.)	1942	40	40		20
Phelps (U.S.A.)	1942	45	40		15
Dunsdon (England and Wales)					
a. Diagnostic Selection	1952	13		81	6
b. Special inq. areas	1952	7.8		82.7	9.5

Source: Stephen (1964) in "Mental Deficiency, the changing outlook".

TABLE 3. Distribution of cerebral palsy by type.

Incidence

Phelps in his 1940 New Jersey survey gives the incidence figure of 4 per 1,000 total population. The Illinois Commission in 1943 (quoted by Dunsdon, 1952) estimated the incidence to be 2 - 2.5 per 1,000 child population, half of that given by the New Jersey survey. Perlstein's survey in Schenectady, New York in 1949 revealed a prevalence of 5.9 per 1,000 total child population. British figures show considerable variation but generally show a smaller figure of incidence. The Asher and Schonell (1950) survey of 4 Midland cities estimate of 1.0 per 1,000 cases. Dunsdon (1952) gives an average of incidence of 0.9 per 1,000 child population for county areas, and 1.3 for County Boroughs, with an average of 1.3 for the 10 sample areas. An incidence of between 2 and 2.5 cases of cerebral palsy per 1,000 children in Edinburgh was reported by Ingram (1955). More recent studies, Hansen, Denmark (1960) and Henderson in eastern Scotland (1961), give prevalence rates which agree with Dunsdon's rate for school children. However, the Isle of Wight survey produced a 2.9 per 1,000 figure, (Rutter et al, 1967). Discrepancies are due to different populations, to insufficient data in some instances, to different stages of infant survival and also to difficulties in defining the borderline cases. An incidence of from 1 to 2 per thousand children of school age is now generally accepted.

	Athetoid	Spastic	Mixed Athetoid & spastic	Other
Asher & Schonell (1950) 349 cases of congenital cerebral palsy in children	10%	83%	5%	1.9%
New Jersey Survey, Hopkins Bice & Colton (1951), 1,406 cases	23.6%	45.1%	3.4%	26.9%
Hansen (1960) Denmark 2621 patients	9.3%	78.5%	4.6%	7.6%
Henderson, Eastern Scotland (1961) 240 cases	11.7%	77.1%	9.6%	1.6%
Crothers & Paine (1959) 406 cases		64.6%	13.1%	22%

Source: Stephen (1964) in "Mental Deficiency, the changing outlook".

TABLE 4. Incidence of cerebral palsy by type.

Etiology

According to Denhoff (1959)

"Approximately 10% of all cases are genetically determined
18% of all cases are of prenatal origin
35% of all cases are due to causes in the paranatal period
18% of all cases may be found in the postnatal period.

In 20% - 40% of specific cases, the cause may be unknown".

Mitchell (Henderson, 1961), Ingram (1955) and Ellis (1955) give full analyses of the etiological factors found in their samples. Asher and Schonell (1950) found that with their sample of children, Athetosis is usually the result of birth injury, asphyxia or neonatal jaundice. Cruickshank and Raus (1955) give information on possible etiological factors with regard to the 1951 New Jersey survey (Hopkins et al, 1954). Dunsdon (1952) found that some 20% of the cases of cerebral palsy may be due to rhesus incompatibility. Multiple pregnancies seem to contribute disproportionately to the incidence of cerebral palsy (Asher and Schonell, 1950; Illingworth, 1958). A high incidence of prematurity has been found in many investigations (Asher and Schonell, 1950; Dunsdon, 1952; Illingworth, 1958; Polani, 1958, Drillien, 1961). In the Ellis (1955) survey, 41 cases (38%) had birth weight of 5½lbs. or less and he found prematurity "about 6 times as great as in the general population". All but two of the 41 cases were spastic. First pregnancies tend to be associated with birth injury but although 66% of Dunsdon's group (1952) were first born, in only 14% was there a history of birth injury. Ellis reports (1955) 56.5% first born and reports: "I have found a high incidence of abnormalities occurring at the time of delivery which might be expected to increase the liability of the infant to injury". Abnormal labour is frequently noted in cerebral palsy cases (Lilienfeld and Pasamanick, 1955, postulate a continuum of reproductive casualty), as well as oxygen deficit, (Stechler, 1964; Corah et al, 1965) and delivery difficulties (Davids et al 1961; Prechtl, 1963) with consequent traumatic effects. Postnatally, meningitis and encephalitis figure frequently as contributory factors (Illingworth, 1958).

These predisposing and causative factors entail associated handicaps (Lilienfield and Pasamanick, 1955, 1956; Stott, 1957) such as mental retardation, speech, hearing, visual and perception disorders. Some authors (Pasamanick, Rogers and Lilienfeld, 1956, Stott, 1957, Drillien, 1963) attribute behaviour disorders and emotional disturbance to somatic-neural impairments of the pre-birth and birth period, but whether this holds for cerebral-palsied children, is not clear.

Intelligence Evaluation

Differences of opinion as to the mental abilities and potentialities of children with cerebral palsy has for long been discussed in the literature. From the"feeble-mindedness" condition in the earliest medical literature, the pendulum swung to the assumption that most of the children with cerebral palsy were of average or superior intelligence. This was probably due to McIntyre's early New Jersey surveys and Phelps's interpretation of the findings. More recent studies of intelligence ratings of children with cerebral palsy have reversed these earlier findings.

Illingworth (1958) has summarised six of the best-known studies (Table 5).

Intelligence Evaluation.

Illingworth (1958) has summarised six of the best known studies. (TABLE 5).

Normal Population (Asher & Schonell)		Asher & Schonell (Total 354)		Dunsdon (Total 916)		Floyer (Total 168)	Hohman (Total 600)		Miller and Rosenfeld (Total 330)		Herlitz and Redin (Total 96)	
IQ	%	IQ	%	IQ	%		IQ	%	IQ	%	IQ	%
130 or over	1	130 or over	0.6	130 or over	0.5							
110 - 129	24	110 - 129	3.4	115 - 129	2.0	3.1			110 or over	4.5	less than 70	57
90 - 109	46	90 - 109	20.1	100 - 114	6.2	7.3	90 or over	12	90 - 109	23.0		
70 - 89	24	70 - 89	26.8	85 - 99	15.5	14.1	70 - 89	25	70 - 80	22.5		
Below 70	3	50 - 69	22.9	70 - 84	17.2	29.2	50 - 70	23	less than 70	50.0		
		25 - 49	10.7	55 - 69	23.6	17.1	Below 50	40				
		Below 25	11.6	Under 55	35.0	29.2						
		Not assessable	3.9									

Source: Illingworth (1958).

Table 5: Distribution of Intelligence Quotient in Cerebral Palsy.

55% of the 2,480 children involved are found to have an I.Q. of less than 70. Taking the figures of Dunsdon, Floyer, Asher and Schonell and Miller and Rosenfeld, he calculated that 3% of 1,768 children with cerebral palsy had an I.Q. of 110 - 115 and over, compared with the figure of 25% for the population as a whole. Illingworth (1958) says: "The percentage of spastic children found by Woods, Dunsdon and Hohman to have an I.Q. of less than 70 to 75 was 49, 43, and 61 respectively; the corresponding figures for Athetoid children were 34, 50 and 67. This would support the finding of Asher and Schonell that there is little difference between the mean I.Q. of athetoid and spastic children of the spastic types, the children with quadriplegia have the lowest mean I.Q....It seems likely that there is no material difference in the intelligence of children with right and left hemiplegia".

Asher and Schonell (1950), Dunsdon (1952) found that there is a positive correlation between I.Q. and extent of handicap; and it would appear that I.Q. tends to be much lower in children with convulsions than those without. Illingworth (1958) estimated that about one-third of all cases have seizures at some time or other. Figures quoted show that over one-half of all cerebral palsied children are intellectually subnormal and at least 25% below 50 I.Q. "Educability" is not a matter of I.Q. alone but is influenced by the degree of physical handicap, sensory defects, perceptual and spatial disabilities, social competence, personality stability.

Testing a child with a sensory deficit and/or language difficulty may prompt self-questioning, if not sometimes parental criticism, of the validity of the measuring instrument. Early assessment should help in the management of the child, for marking out "the significance of different areas of development" (Gibbs, 1968) and not in the mere furnishing of a developmental figure. But the predictive value of early infant tests, weighted with purely sensorimotor behaviour has not been established. Hindley (1961) is critical of their predictive powers, though Illingworth (1966) claims to be able to diagnose severe subnormality within the first year. He disagrees with the Schonell (1958) statement that "most assessment scales such as those of Gesell and Griffiths especially designed for babies and very young children, are of the developmental type and hence are not suitable for those with cerebral palsy, many of whom, irrespective of intelligence, tend to be retarded in physical and social development". Illingworth adds: "I consider that the Gesell tests are entirely suitable for assessing these children, though of course the difficulties in prediction in severe cases can be very great". Illingworth's (1962) advice is to use the scales to judge a child's development in various areas in comparison with that of normal children. These scales, including motor skills and responses to social training are not strictly measures of "intelligence". Yet how much of infant behaviour and infant intelligence is composed of these sensorimotor functions in the Piagetian sense.?

Pre-school testing is a complex process. Schonell (1956) realising the limitations of the Terman-Merrill Revision for testing cerebrally palsied children, found it the most suitable - ".....under favourable circumstances the Scale probably gives a more useful estimate than would an instrument - if such could be devised - which allowed for the cumulative effects of handicap on mental development". She would exclude the very young and the very severely handicapped from that statement. Dunsdon (1952) defends the use of the standard intelligence tests. But Gibbs (1968) found that the Stanford-Binet's great drawback, being a non-linear scale like the Merrill-Palmer (which is largely performance), "the resulting I.Q. obtained at different ages may be made up of qualitatively very different tasks" (Gibbs, 1968). Another criticism of these scales is that they have been standardised on non-cerebral palsied populations. But the cerebral palsied are not a homogeneous population and the person with cerebral palsy has to live and compete in a non-cerebral palsied world. Perhaps the solution lies in our redefining, or sharpening what we mean by "educability" in terms of multiple handicapping conditions; and in our viewing assessment as a continuing process, recommended by Sheridan (1965) and Rabinowitz (1968) and practised in the Percy Hedley Centre. Francis Williams (1966) reiterates that Illingworth (1962) said: "The difficulties in assessment are great and prolonged observation is necessary".

The validity of intelligence tests has thus been questioned with regard to physically handicapped children because of these children's frequent language difficulties, sensory impairments, experimental deprivation. Accordingly, the Vineland Social Maturity Scale (Doll, 1947) is often used as a measure of adaptive behaviour, Doll (1953) noting a high correlation between Social Age (SA) and Mental Age (MA) - $r = .856$.

The information is supplied by a reliable informant and the 117 items of the scale relate to self help, self direction, communication, socialisation, locomotion, occupation. The Scale provides a quantitative measure of social competence rather than the subjective, qualitative judgments commonly made in diagnosis; but because of Doll's small samples, the standard deviations of the Vineland scale are not well established, nor are the later age ranges adequately covered. Kellmer-Pringle (1966) has made an intensive study of the Scale and applied it to 250 English children of

6-8 years. Kellmer-Pringle found that "the relationship between intelligence and social growth may not be a linear one ....It is possible, therefore, that the true regression of S.Q. on I.Q. is curvilinear. Because of the nature of the sampling, our data are insufficient to determine this with certainty; but if it were so, it would be in accordance with a theory that looks on social maturity as a composite function of many influences, both personal and environmental".

The VSMS was administered in respect of each child in the study.

Therapy

A perusal of the relevant literature would seem to reveal that we have moved away from a purely mechanical approach to disability. Human lives are involved - the family, society as well as the child with spastic quadriplegia. Cerebral palsy is a community and social issue today and the parents form an integral part of the treatment campaign. "Handicapped children should not be considered in isolation. Children have parents and it is important that their parents, particularly the parents of handicapped children, should not be ignored - important because the reaction of his parents to his disability may be the most significant factor in the life of a handicapped child". (Ellis, 1955). For these parents of handicapped and retarded children, much is being done in the provision - especially in America - of therapeutic counselling facilities - Beck (1959, 1962); Sheimo (1957); Begab (1956); Cummings and Stock (1962); Doll (1953); Coleman (1953); Mahoney (1958); Reid (1958); Weingold and Hermuth (1953); Zwerling (1954); Ruzicka (1958); Kelman (1957); Popp et al (1954); Rankin (1957); Giannini and Goodman (1963); Laycock (1952);

Unger (1954); Bice and Holden (1949); Doob et al (1955); Barsch (1961), the last named paper being relevant to the "brain injured child", and the previous three specifically about parents of cerebral palsied children. Dunsdon (1952) emphasises the need for parent guidance to prevent both over and under expectations and this is borne out by Boles (1959), Zuk (1959), Barclay and Vaught (1964), Jensen and Kogan (1962) investigations of the attitudes and emotional reactions of parents of cerebral palsied children.

Needs of cerebral palsied children

As regards treatment, this is based upon fulfilling as far as possible and as early as possible, the physical intellectual, social and emotional needs of these children. Particular therapists look after the physical treatment of which there are many varieties; and treated early, Ellis (1965) says children "will usually reach the point of maximum treatment by the time they reach late childhood". However, "physical maintenance and physical education will continue throughout the rest of the child's life".

The child's intellectual needs are met primarily in the home, nursery school with its emphasis on optimum stimulation, and if necessary, the special school giving the most normal life experience possible. Early part-time developmental training to "reduce some of the handicapped child's immaturity and (which) can fill in some of the gaps in his experience" is suggested by Wigglesworth (1966). Cashdan (1966) emphasises the now well-known need for practical experiences and encounters with the environment which Clarke (1958) has reiterated. Cashdan (1966) pleads for "more sophisticated but realistic hypotheses and good experimental techniques to test them "so that we may know which features of the parent-child relationship are crucial and which not. Test results will have helped the educationist (particularly if the Illinois Test of Psycholinguistic abilities or the Marianne Frostig have been used) to exploit the child's strengths and to ignore his weaknesses, and to give him opportunities for social interaction and enjoyment of adult interest in him. Piaget's findings, basically developmental, and replication work of these by Woodward (1959) for example, would seem to have implications for the education of cerebral palsied children. Knowing what stages in intellectual growth a child has mastered is potentially a more effective instrument than an I.Q. figure which may measure ability or capacity. Opportunities for secondary and even tertiary education for older cerebral palsied children and for vocational training are a feature of the educational picture today. Dunsdon's (1952) list of criteria for an adequate selection policy is valuable. She takes I.Q. 85 as minimum admission level, a figure at which some might quibble.

Kellmer-Pringle (1965) lists four needs of handicapped children:

1. The need for love and security
2. The need for new experiences
3. The need for recognition and achievement
4. The need for responsibility.

These are the needs of all of us - and it is valuable to be reminded that cerebral palsied children are primarily - children with the fundamental human needs. Research has revealed that emotional disorders of different kinds and degrees may be associated with cerebral palsy. Dunsdon (1952) found that of 16 children in a special school with I.Q.s below 70, only two seemed reasonably stable: of 50 with I.Q.s above 70, instability was noted in 38%. Dunsdon remarks that this incidence is about 10 times that of the general population. There is the question here, of course, of how stable is "stable"? Floyer (1955) found 42% of cerebral palsied children showed excessive emotionality i.e. distractibility, lack of drive, disinhibition; and stated that there seemed greater vulnerability to personality deviations with a cerebral palsy population than with an ordinary school population. Schonell (1956), however, found no innate limitations, on the temperamental side, among the special school children she investigated. But she does say - "it was on the acquired side of personality that there was need for help". The necessity for longitudinal studies seems indicated here, which would provide information about personality changes in children, especially in cerebral palsied children. Cruickshank and Raus (1955) comment on the necessity for controlled experiments on the personality of cerebral palsied individuals and draw attention to the fact that Phelps' (1948) statement of fundamental psychological attributes pertaining to different types of cerebral palsy is nowhere corroborated by controlled research. They quote the Shere (1954) twin-studies which reveal that personality characteristics are more related to relationship with parents than to intrinsic factors. The weight of evidence, on the whole, would appear to be against the view that the person with cerebral palsy is a maladjusted person. Barker et al (1953) would say that physique was only one factor! But there is often a related immaturity and this would apply especially to adolescents.

Gibbs (1958) cautions against unrealistic thinking. "It is important.....to realize two points about needs: one is that all the basic needs found in normal children and adults cannot usually be met if the cerebral palsy is more than very mild; the other is that the affected child may have needs which do not exist and which therefore do not have to be met, in physically normal people.....Of course we should think of and treat an affected child as if he were like other children - but only as far as he is like other children. It is important to distinguish between reality and phantasy in the matter of goals, without setting our sights too low".

This seems to summarise realistically, yet sympathetically, what our attitudes might be.

So far, cerebral palsy has been discussed with regard to terminology and classification, incidence, etiology, associated handicaps, intelligence evaluation, therapy, needs. But the child with cerebral palsy is a member of a family, who has siblings, who lives in a particular geographical area within a certain culture. The family is faced with the impact of this crisis. The question of institutionalisation may arise for various reasons (Jolly, 1953); Ellis, 1963; Kershaw, 1963; Milano-Comparetti, 1963); What to do? Francis Williams (1966) quotes Sir John Charles, who in the preface to Mary Sheridan's "Developmental Progress of Infants and Young Children", 1960, wrote:- "The handicapped baby above all others, needs affectionate individual care and the opportunity to develop at his own tempo in the security of his home until he has passed the critical years of early childhood". Ellis has made arrangements at his Clinic for parents to be taught to treat their own child, and only on occasion, when living at a distance, to have to stay overnight at the Clinic. He says: "In the past 9 years, 1,007 cases have been referred to the Clinic at the centre. Of these 501 were under the age of 5 years. A small number of these young children had to be admitted for social reasons, either temporarily or permanently to hospitals, residential nurseries of foster homes but none of these young children had to be removed from their families for treatment" (1963). Jolly (1953) reflects this attitude, "It is usually better to have the parents work out their emotional conflicts gradually, while caring for the child at home, during the first years of life. Under the guidance of a physician who will take time to explain the possible causes of the defect, give an honest prognosis, and emphasize the positive features of institutional life, the parents will come to accept their misfortune and see the logic of separation. The request for institutionalisation will then come from the parents themselves". Milani (1963) visualises the child, for treatment's sake, having to be institutionalized, but would not wish him to be removed permanently from his home. Kershaw states, quite emphatically: "There is only one absolute and universally valid indication for residential treatment of a brain-damaged child, namely, that the child in question has no home!" (1963).

Other problems cannot be solved quite so comfortingly. The handicapped child reacts affectively on his parents, siblings, extended family, neighbours, and they, to a greater or less degree, interact with him. The question of family limitation arises, coping defences break down, expectations crash bitterly. However, all this happens, usually, in the family situation, and the principles of family functioning are the same whether the child is normal or handicapped. For this reason, the cerebral palsied child has been viewed as a member of a family in Part III and the relevant literature is reviewed in Part II.

II. REVIEW OF THE LITERATURE

Theory

Interest in parent-child research is not new. But what is new is "the attempt to conceptualize various aspects of the relationship in terms of antecedent, consequent and intervening variables" (Sears, Maccoby and Levin, 1957; Sigel, 1956; Crandall, 1960). There is an emphasis on the manifest content of parent-child and child-parent interaction (Smith, 1958; Sigel, 1960), a plea for the reorganising of designs (McCandless and Spiker, 1956) for the experimental approach to the treatment and upbringing of handicapped children (Tizard, 1966). But, however much one would wish to analyze relationships in terms of a few and relatively simple variables, the multiplicity and complexity of the factors in the parent-child relationship, apart altogether from the lack of precision in defining these same variables and the unsuitability of the laboratory - experimental set-up makes difficult the use of a simple S-R model. Terrell (1958) contends that "the likelihood of variables which are known to apply at a simple behavioural level to be relevant also at a more complex level is greater than the probability that variables suggested as relevant in complicated, poorly controlled studies are in fact relevant at that level".

When one turns to parent-handicapped child relationships in the literature, there is a dearth of controlled, quantitative observation and evaluation. In spite of hopes expressed by some writers (Gibbs, 1964; Cashdan, 1966) in the field, for more experimentally biased reports, the material continues for the most part, to be predominantly clinical in character. As with normal family relationships, it is not easy to impose the controls necessary for effective research into the influence of the parent on the handicapped child and vice versa, manipulation of variables being usually limited to the institutional setting. Nor is it easy to tease out certain areas for scientific observation from the whole emotionally-tinged pattern of living.

The Family

A handicapped child is first of all a child and parents of a handicapped child are ordinary people, members of a family, living in society, not over-protecting nor rejecting stereotypes living in isolation, with periodical sorties for counselling. It is for this reason that the cerebral palsied child is now to be seen against research literature dealing with the normal family as far as possible. This family is the first agency of socialization with which most children have any contact and its influence is paramount. The language they will use, their moral values and loyalties, their abilities, the basis of all their future growing they will have learned at home.
For Hess and Handel (1959) the family is a psycho-social organisation and they maintain that it remains, ina sense, a bounded universe however wide the ramifications of the wider community. "Members of a family - parents and their young children - inhabit a world of their own, making a community of feeling and fantasy, action and precept". Some writers see the family as an emotional organisation their attitudes deriving from an interest in personality disturbance e.g. Ackerman (1961), who

emphasises the complexity of interpersonal involvements within the family. The sociologists, Burgess and Cottrell began, in the late 1940's,their critical - evaluative studies of family behaviour. Cottrell concentrated on limited areas of behaviour e.g. reproduction, socialization and personality patterning; Burgess on follow-up studies of engaged couples, marital roles and marital satisfaction. Later, Parsons and Bales (1955) analysed family interaction from the social system point of view, the family being viewed as a small group, the members of whom are in dynamic interchange with one another and accordingly, playing a crucial role in personality formation. Brim (1957) saw the mother-child relation as a separate social system embedded in the more general system of the family and acting upon it and being acted upon. Bell and Vogel (1960) emphasise this interactive process as important for tension management in the family as well. They refer to family "coping mechanisms" which operate to maintain the family solidarity but which occur in response to "crises such as illness or disaster". This is all very relevant to families in which there is a cerebral palsied child. This emphasis on family-child interaction is in contrast to the intensive psychological studies of the Mother-Child interactional patterns which constitute a large part of the literature, Ribble (1943), Escalona (1953), Brody (1956). The adequacy of the cause-effect model of mother influencing child has been questioned by Ackerman (1958) - though this was the result of innovations in psychiatric concepts rather than due to research findings; and the individual is now more often seen from the orientation of "The family as a unit of interacting personalities", Burgess's formulation of as long ago as 1926. This title seems to call in question the cause-effect model which attributes independent variables to the parents and dependent variables exclusively to the child. The idea of each child in a family having a unique ordinal position has special relevance for the handicapped member and his siblings within the family matrix. Sears (1950), Koch (1958), Lasko (1954), Barker and Wright (1955) have investigated this area, the latter named from the ecological viewpoint.

The idea that groups have a distinctive psychological character was implied by Lewin, Lippitt and White's (1939) classic work; and Josselyn (1953) says that analysis of each family member's interpersonal relationships "only partially reveal the significance of the family. The intermeshing of these multiple relationships creates a structure that has meaning over and above the meaning of its parts". A "superpersonality" - in Burgess's term. Parsons and Bales (1955) analyse the family interaction in terms of the sociological concept of social role and the family is seen as a system of roles. This concept has been availed of when viewing the families in the study. Spiegel (1957) uses this frame of reference and it is helpful when parents of the handicapped view their roles incompatibly; but Bott (1957), in her study of family roles and norms in London had to revert to a more psychological and family-centred view. Even for the child, there appear to be various stages in a person's role expectations. As a small child - and especially as a small handicapped child, his roles are ascribed to him. As an older child peer group expectations may cut across parental expectations. As a young adult, he may have his own scheme of expectations as guides to interaction.

With regard to special family problems and stressful situations, Angell (1936), Cavan (1938), Koos (1946), Hill (1949) and Waller (1951, revised by Hill) portray the classic reactions of families to crises of dismemberment and demoralisation; Waller and Hill dealt with adjustments to the war-born crises of separation and reunion, finding family integration, first identified by Angell and scaled by Cavan and family adaptability - omnibus of several factors - highly significant. This was the prelude to works in the late 1950's and early 1960's in which the impact of a handicapped member on the family is investigated. Many of these works are descriptive, few having a theoretical framework: Westlund and Palumbo (1946), Denhoff and Holden (1954), Korkes (1956), Holt (1958, 1958a), Miller with cerebral palsied children (1958), Schonell and Watts (1956), Schonell and Rorke (1960) and Farber (1959, 1960, 1960a), this latter with great expertise and a sound sociological framework. The usual pattern is to study the repercussions of the handicap on family life, on siblings and marital happiness. Boles (1959) in one of the few cerebral palsy studies, with controls, investigated the attitudes and emotional reactions of parents, especially the mother's personality change. He found the only significant difference between the two groups apart from age of child or religion, to be that mothers of cerebral palsied children were more overprotective and had more marital conflicts than mothers of controls. Caldwell and Guze (1960) attempted a whole family approach in their study of the parents' and siblings' adjustment to institutionalized and non-institutionalized retarded children. Cockburn (Henderson, 1961) in the Dundee survey studies the homes of her cerebral palsied patients finding that "acceptance of the handicap bore little relation to the intellectual status of the home or to the age or the degree of the handicap of the cerebral palsied person". 3 studies, each of 200 families, make up the report - "Handicapped Children and their Families" (Dunfermline, 1964). The aim was "to obtain information about the needs of children with different handicaps and at different stages of growth, the family circumstances.....the impact of the handicapped child on the family, the need of the family for outside help.....". A most comprehensive task and the needs were found to be enormous and that these needs were inadequately met. The fact of multiple handicap and of a bewildering number of visits to hospitals and social agencies comes across. Parental isolation and lack of understanding of their children's handicap also emerge. Leeson (1961) studied in England 6 families with a mentally handicapped child. The mothers were in poor health and upset at the diagnosis. Difficulties were largely those arising from the poor achievement habits and health of the backward children, complicated in some instances by the presence of younger children. Leeson stressed the need for guidance for such parents. Clarke and Davis (1963), guided by a disorder theory of mental retardation, compared the mothers of 17 speech retarded children and those of 16 generally retarded children and investigated as well the mother's attitudes to marriage and child bearing, to spouse kin relationships and home conditions. It was found that the generally retarded children tended to be detached from and the speech retarded to cling to their mothers. Tizard and Grad (1961) in a sample of 250 severely subnormal children and adults, partly living at home and partly in institutions refer to how "family life became abnormal or disorganised". They emphasise the difficulty of management which parents of severely handicapped cerebral palsied defective patients have to cope with - a quarter of the retarded children living at home were reported as restless and over active, and a further 20% were considered uncontrollable or helpless. Shere, in one of the very few studies involving twins, one of which was cerebral palsied, investigated family conditions in the lives of 30 pairs of twins, one of whom was diagnosed as cerebral palsied. The behaviour of the cerebral palsied child was considered more desirable than that of the non-cerebral palsied twin, and this is probably accounted for by having received more attention and acceptance, more being expected of the non-handicapped child. Sykes (1958) studies the family backgrounds of a group of 31 special school going children with cerebral palsy and found that the general family problem is many sided - "There is the problem of the handicapped child himself, and his own needs, that of the parents separately and together, that of brothers and sisters, and that of the family as a whole". She found that many parents deliberately chose to restrict the family unit, in an effort to reduce the impact, but of course, resulting in an intensification of the problem. The problem for the child when he must realise his condition was dreaded by all parents. Hall (1963) investigated the association between severity of cerebral palsy and a young child and the severity of family stress. Marital, parent-child, and sib relationships as well as family solidarity were explored in interview and a global judgment made. Financial strains, psychological reactions to the birth of the child, parental feelings of guilt seemed more intense in the early period. Though some families were found to be functioning well, the majority were suffering serious stress which demanded a reorientation of family relationships and family goals. Families with psychiatric problems, Lidz (1949), Ackerman (1958), Schaffer (1964) have been more studied than normal families (Harris, 1959, for example) or even families with a handicapped member, largely because they are more available in therapy.

The Parents

Families exist prior to crises involving the birth of a handicapped child. In fact, Denhoff and Holden (1954) made an intensive study of parents of handicapped children, showing how their family backgrounds and social class membership have repercussions on the child and establish their reactions to the crisis of handicap (Zuk, 1959, 1961). Stone (1948) found that the handicapped child seemed to become unconsciously "the pawn in the battle between marital partners". Some attitudes may precipitate crisis e.g. Moncur (1952) and Pavenstedt (1961), the latter studying immature mothers in an effort to counteract the effect of these immature traits on the child, Thankfully, the normal infant is often very resilient (Anderson, 1948) and survives the bungling of new parents.

All parents face a variety of problems, of which the most researched upon is undoubtedly that of child-rearing and its experiences for the development of later personality and in some cases of psychopathology. The child's personality is generally viewed as the dependent variable and it seems to be commonly assumed that parental personality is a fixed factor exerting a one-way influence, regardless of the change-inducing factor of time. It has already been noted that to see the child as an interactor in the whole family situation is a more realistic way of viewing the organism. The mother has been the family member most intensively explored in studies of child development. She is the prime socialiser in view of her cultural status and great theoretical importance is ascribed to her role. She is also more accessible than the father. It would be interesting to enquire deeper into her motives for being often, so readily available for study! However important her role, father, siblings and extended family play contributory roles in the socialization process. Gradually, as in psychiatric treatment where only the patient used to be treated, the focus is growing to include a whole constellation of influences.

The Newsons explored this constellation of roles in Nottingham families who had a handicapped child. "Parents bring up their children; but there is a very real sense in which children also bring up their parents; and if this is true for normal children, it probably has even more relevance in the case of handicapped children". (Newson and Newson, 196

The Mother

Behrens (1954) suggests the term "Total Mother Person", probably to describe those components of maternal behaviour which impinge on the growth of children. Certainly, she plays the most crucial part in mediating the family's attitude. Though all the members of a family react to a handicapped child in terms of their own life experience and the values and attitudes of their immediate environment. Barsch (1961) suggests that the siblings of a "brain-injured child" imitate their mothers' attitudes towards him and explain his condition in parentally-used terms. Brody (1956) points out that "the infant may re-arouse tensions" in the mother or "may reawaken conflicts or may precipitate the appearance of new ones". If this is so in the case of the normal infant, how much more emotionally involved will the mother be if the child is defective? The intensity of the reaction will be a function of her total background, her living experience, her relationship with her own mother and with her husband, her pregnancy (Stott, 1959) and paranatal condition (Davids et al, 1961). Bibring et al (1961) see child birth as a crisis and mother not ready for "the demands which this reality places on her". Rose (1958) reminds us that "social and psychic readiness for pregnancy are not direct functions of physical readiness. Some women are ready for pregnancy but not for child care". Few, indeed, are ready to cope both with the new role of mother and with the added vulnerability of being the mother of a handicapped child. Whately (1962) on this point, describes the incredible shock that is sometimes associated with the birth of such a child. "It is useful to consider, not only what the birth of a physically handicapped child does to parents, but also what it does to us as professional people. Even though we (doctors, nurses, almoners, psychologists, social workers) are trained in a field where distress and tragedy are part of our daily work, the birth of a very abnormal baby gives us a severe shock, whether we are conscious of it or not. Gross deformities such as absence of limbs or a large meningo mye locoele, may evolve the most primitive reactions. We cannot believe it, such a thing should never have happened. It is a threat to the natural order of things". Rose (1958) refers to how a child can produce disturbed feelings in any adult - "various states of child development not only disturb significant adults but are actually able to influence the maturational progress of those individuals in constant contact with the child". The mother's handling of her other children may be affected. The effect of the handicapped child on the siblings will be considered later.

In general, maternal influence on her child's development has been predominantly emphasised in the literature, but with a corresponding dearth of unequivocal studies. Orlansky (1949) is much quoted for his conclusion "that evidence for a relationship between maternal practices and personality development is unconvincing. Probably it is the atmosphere in which these practices are carried out that is important and not the isolated experiences (Sewell 1952). The classic Harvard and Chicago studies on social class and child rearing have more than a period of interest; the Sears et al, 1957, (The Pattern study), a thorough investigation of middle class techniques of socialization but sharing the disadvantage of being based on interviews rather than on observation, has been of value in the present study. Permissiveness (seen by Sears et al 1957, as running through most child-rearing activities) and dependency, with its overtones of parental protectiveness interest the research worker involved in handicapped child investigation. Incidentally, Lynn and Gordon (1961) found similar results to those of the Pattern study in that British middle class mothers were more permissive and less punitive towards their children's unsocialized behaviour, but that as a whole, British mothers are less permissive, more punitive than American mothers.

Investigations of feeding and weaning experiences (Sewell and Mussen 1952) are more complex than were once thought and have the shortcomings of being based on anamnestic reports (McGraw and Molloy, 1941; Wenar and Coulter (1962); Wenar 1961, 1963, Mednick and Shaffer 1963, Yarrow et al 1964). Yarrow is very critical of the data in family research - "more directly of the <u>methods</u> of family research". Undoubtedly, it is tempting to translate findings as relationships between parental behaviour and child characteristics and dangerous when data contributing to findings has been subject to the well-known unreliability of memory and the varying reliability of different informants. For this reason, papers like Merrill's (1946) and Bishop's (1951), reporting methods of studying the mother-child interaction under live-controlled conditions, Marschak's study of interaction (1960) and Antonovsky's (1959) findings regarding discrepancies of data obtained through interviews and observation are of great value. Rheingold's

(1960) measurement of maternal care has the advantage of observational method, without reliance on contrived techniques. Donnelly (1960) in London made home visits to observe families of psychotic children and Brody (1956) observed mother and child in the home in connection with laboratory observations. However, lack of standardisation is a weakness for naturalistic observations, all adding to the complexity of assessment of the parent-child relationship.

The Father

In our culturally determined matricentric concept of child care, the significance of any psychological response of fatherliness in men is minimised. Often a paper with "parent" incorporated in the title has been said to bear only reference to the mother (Nowlis, 1952). Josselyn (1952) remarked on society's failure to attribute any deep roots of fatherliness to its men. Fathers are admittedly less accessible than mothers are but even to Bowlby (1951) the father is "of no direct importance to the young child but is of indirect value as an economic support and in his emotional support of the mother". Nash (1965) remarks that most of the data about the father "are confined to his occupation or education and he consequently appears as a kind of statistical appendage to the family". Later in the child's life, the father plays a more prominent part - in the studies of identification (Sears et al, 1957) and in behaviour problem studies as in the Glueck's famous studies of delinquents and in Andry (1960). Aberle and Naegele

(1952) is one of the few studies which is deliberately one-sided, dealing almost entirely with fathers and high lighting "other aspects of the socialisation process at the expense of such matters as feeding practices, toilet training and sex training". But the fathers studied are exclusively middle class. Sears et al (1957) is one of the studies of the family that has acknowledged the existence of fathers and gives some information on their role in child rearing. Earlier, Mead (1949) had described the changing American scene in which "the danger that delight in parenthood may prove equally seductive to young men" (than to the mother). The Newsons (1963) found in Nottingham that 52% of fathers were"highly participant" in looking after the baby and 27% "moderately participant", and refer to "this massive change in the masculine role". Musgrove (1966) found the willingness of fathers to look after their young children to be "a very distinctive feature of modern family life in England". However, Holt's (1958) fathers played little part in rearing children and 29 of the mothers were reported as under severe physical and mental strain. The father of the schizophrenic patient is portrayed as weak, immature, uninvolved in family life (Lidz et al, 1957). The questions of father 'participation' will be referred to later with regard to the population studied by the writer.

The Child

Madoff's paper (1959) showed mothers of disturbed children showing a different pattern of attitudes from mothers of healthy children and it has been suggested in the literature that child behaviour is one of the chief factors influencing parents' attitudes (Klebanoff, 1959; Margolis, 1961; Guertin, 1961). The Klebanoff paper is interesting in that mothers of schizophrenic children showed fewer, not more, pathological attitudes than did mothers of brain-damaged and retarded children. A further comparison revealed that the mothers of the 2 groups of "ill" children manifested more pathological attitudes than did mothers of normal children. If attitudes reflect maternal behaviour (and only a careful observational study could reveal the relationship between responses on a questionnaire and actual parent practices) and if such maternal behaviour influences the child's personality development, then these maternal attitudes would be an important intervening variable affecting the adjustment of handicapped children. Granted that other environmental forces will operate but for the first few years at least, the mother is the cue stimulus for the large majority of handicapped children. Rose (1958) puts forward the reward value of the child - "The ability of a child to reward and satisfy a mother seems to arise partly from what he is as a real creature and partly from the values engendered by imagination and creative perception". If this be so, then the reality of a defective child is a factor of acute importance in parental perception and acceptance. To be a parent, as Zuk (1962) says is a good thing ("traditional" in Duvall's (1946) terminology); but expectation is of normal offspring. Zuk speaks of the cultural dilemma resulting, wherein the production of a handicapped child becomes a bad thing. This threat to the parent's self-image in many cases becomes crystallised when the child tends to frustrate the parent's needs and the consequent defence against engendered guilt spills over into over-protection or rejection or both. Since personality is conceived of as the product of interaction between heredity and environmental factors, such inconsistent parental attitudes can have a marked effect on the development of a child, handicapped or normal. But then, what difference to this child's personality is attributable to restricted sensory input? From the earliest days, his reactive tendencies influence both his responses to the environment and how significant individuals in that environment respond to him. The Anderson (1948) view of the baby as an active energy system, seeking stimulation, able to withstand many stresses, with self-repairing and adjusting mechanisms has redressed the view of a passively impressionable victim of stimuli and impulses. This applies, to some degree, to a handicapped baby too, and there seems little danger of the over-stimulation visualised for normal infants by Escalona (1953), nor of irreversible damage caused by meeting "frustration or privation for these factors immediately cause exaggerated tension and stimulate latent defense attitudes" (Ribble, 1943). However, organic factors distort perception of self and others, environmental lack of stimulation reacts in the sensory and intellectual sphere and with consequent feed back effect on the parent. Sociocultural factors are at work to decry dependency. Festinger's theory of cognitive dissonance (1957) helps us understand the need for self-consistency in the handicapped, in the role and self-image of whom are often the two components of dependence and a sense of misfortune and in whom, also, grow a system of defences by which they protect their ego and self-esteem.

How the child perceives his parents (Itkin, 1955; Kagan, 1956; Hawkes, Burchinal and Gardner, 1957), his environment and his handicap (Richardson et al, 1964; Cruickshank, 1951) is crucial to his behaviour and adjustment. Richardson (1963) found in a study of 10 year olds, half of them normal, half crippled, that the handicapped had a low self-estimate, had a better relationship with their mother than with their father or siblings and he considered the handicap to have a blunting effect. In a later study, (Richardson et al, 1964), it was found that the 10 year old handicapped children were aware of their physical restriction and evidenced less social experiences than did normal children. Cruickshank's (1951) study of 264 physically handicapped children noted that these children saw themselves as having more fears and more guilt feelings than do children of normal physical characteristics ; and he concludes that this fact affects "the less satisfactory social adjustment which the handicapped children feel that they are making" and which he reported later in 1952. Previously, Cruickshank and Dolphin (1949) had indicated that the emotional characteristics of physically handicapped children "do not differ greatly on a quantitative basis from children who are physically normal and of the same age and general socioeconomic background". Baldwin (1948) writing of "socialization and the parent-child relationship" has normal children in mind but what he says applies also to the handicapped. "The predominant effect of parent behaviour upon the socialization of the preschool child is to raise or lower his willingness and ability to behave actively toward his environment ..... Freedom alone does not, however, actively encourage the development of spontaneity;

a high level of interaction between the parent and child is required to push the child into activity, particularly of the interpersonal variety".

With regard to the school adjustment of cerebral palsied children, a measure of life success after all, Denhoff and Holden (1954) by follow up study, have found that even though good medical and psychological treatment is necessary, nevertheless the key to "good" school adjustment is family understanding and acceptance. A two-way process, no doubt.

"The handicapped family"

"It is no exaggeration to say that in the background of every individual handicapped child, there is always a handicapped family" (Sheridan, 1965). Earlier in the same work she had defined a handicapped child as "one who suffers from any continuing disability of the body, intellect or personality which is likely to interfere with his normal growth, development and capacity to learn." How does the normal family become a "handicapped" one? The concept of and reaction to crisis (Farber, 1960, 1960a; Dow, 1965) may determine not only how a handicapped child is perceived and reared and finally accepted, but also account for a family becoming "handicapped". Kirkpatrick (1955) saw family disorganisation as the reaction to an atypical or premature event for which adequate coping devices were not devised. Hill (1958) viewed disequilibrium of the social order as the result of crisis and suggested that an event becomes a crisis when the family is unable to cope. Farber (1960) defines a family crisis as "the breakdown of patterns of conduct and values which had been developed to guide activities of family members through the family's life-cycle". Thus, crisis has been variously defined according to the manner in which the family group is conceptualised, mostly seeing it, however, as a situation in which there is wide divergence between role expectations and role performance and necessitating reorganisation of the family as a social system. Lindemann (1944) and Caplan (1961a) postulated that for each major type of acute situational disorder, there is a set of psychological tasks to be accomplished before the problem is successfully worked through - which they call the "grief work", after Freud. Solnit and Stark (1961), Tisza (1962), Olshansky (1962) saw parental reaction to the birth of a defective child as mourning the loss of an expected perfect baby, and a period of detachment as necessary for some parents so that they can find adaptational techniques for coping. Thurston (1960) in his study of the parents of 373 institutionalized cerebral palsied retarded patients found, that for some parents, the period of mourning never ends. On the average, he found considerable emotional upset remaining after 10 years had elapsed.

Le Masters (1957) found that 38 of his 46 couples reported marked difficulty in adjustment to their first (normal) child, and almost all of these marriages were rated well adjusted. The fact that parenthood is normal does not eliminate crisis. Every couple is faced with working out a mode of family living which will fulfil mutual and often latent needs. Present research findings indicate that personality characteristics of individuals are related to their degree of marital adjustment (Burgess and Wallin, 1953), and the relationship between marital adjustment and parental acceptance of children has been demonstrated by Locke (1951). But Hawkes et al (1956) used the Porter scale to measure acceptance of their children by parents, yet found no significant relationship between the parental satisfaction scores of the mothers and their acceptance scores. Weisman (1963) had similar findings, that child functioning and relationships were not significantly related to marital functioning in general, or to the degree of conflict or satisfaction the parents experienced in the marriage (instances of this were found in the present study). However, parental functioning was found to be related to child functioning, which finding supports the belief in the relationship between parental performance and child behaviour. Weisman admits to "the primitive level of the techniques available". Farber (1962) had explored the extent to which marital relations are associated with parent-child interaction in families with a mentally retarded child and found that in some ways "high marital integration may be dysfunctional to socialization of the children". In 1959, Farber found in his study of 240 families having a severely retarded child that those families which had had high integration scores before the birth of the retarded child fared better than those whose prospects were poor. Dow (1965) in an analysis of 58 families, describes family reaction to a crisis event, physical disability of a family member, and found that reaction was a function of family structure: "a structure founded on a contracted network of interactions and obligations will be associated with an extreme or dysfunctional response while one containing an extended network will prove functional in coping with the same crisis". It would appear that the "affective interpersonal intrafamily crisis" is better coped with by the larger family structure. The resources of the family and its previous experience with crisis are important as well as the size of the family, the large family usually having had to learn to make adjustments to all sorts of changes in status, responsibilities, role.

Religion was found by Zuk (1959, 1959a, 1962) to be a support to the mother's feelings of guilt and unworthiness: Catholic mothers did not appear to blame themselves for bearing retarded children. He found Catholic mothers more "acceptant" than non-Catholic mothers. However, Boles (1959) found that Catholic mothers of cerebral palsied children were more guilty, anxious, socially withdrawn than Jewish mothers. Baum (1961) expressed the parents' feelings to a defective child ; "The baby is not perfect, therefore I must be bad". According to Coughlin (1947) guilt is one of the deep-seated feelings brought to the surface upon the birth of a handicapped child. Klebanoff (1957) reported "more pathological attitudes" in Catholic mothers of brain-injured children. According to Farber, Jenne and Toigo (1960) Catholic parents' marital integration is at the same level whether their retarded boy is at home or not. Non-Catholic parents had a lower degree of marital integration when their retarded boy was at home. The Farber (1959) study supported the idea that religion lends support to Catholic parents ".....non-Catholic families seem more affected than Catholics in a crisis situation". However, there are many contradictory findings on the role that religion plays in the acceptance or otherwise of a defective child. Catholic mothers' verbalisations might cover guilt, or be the desired response in view of Catholic teaching on suffering. Murray (1959) spoke of the theological conflicts which confront the parent of a mentally retarded child, resolved sometimes in bitterness, sometimes in acceptance.

Johnson and Medinnus (1965) ask: "Does parenthood require a certain kind of person? Perhaps to some extent it does." We might ask what parental variables may be expected to determine the healthy psychological atmosphere in a home? Certainly, parents cannot rely on "built-in" responses. As we have already seen, marriage integration, and religion may affect attitudes. Socialization, broader in nature than specific practices, social class and education mediate these attitudes (Sears et al, 1957; Gildea et al, 1961; Zuk, 1962; Kagan and Moss, 1962). Families of higher socioeconomic level tend to take into account the opinions of others and the careers of the other children especially when the question of institutionalization comes up for consideration (Farber, Jenne and Toigo, 1960; Downey, 1963). Socioeconomic status seems to affect the definition of the problem through variations placed on different aims in child rearing by different classes. There is often a conflict in the families of higher socioeconomic status where the child presents more-than-normal personal frustration but where the parent also feels it his duty to continue caring for the child (Farber, 1964). Gildea et al (1960) used two sorts of instruments to approach attitudes and identified a number of class biases. The measurement of parental variables goes back to Champney (1941) who devised a series of parent behaviour attitude scales, affect, democracy, child centredness in the home for example, of considerable sensitivity, and whose use is described by Baldwin, Kalhorn and Breese (1945). The consistency of parent's behaviour was emphasised. Later, Schaefer and Bell (1958) developed a measure of parental attitudes towards child rearing and family life, a paper and pencil test and consisting of 23 five-item scales. Studies conducted with the PARI suggest the importance of the maternal role. A stable PARI factor is that identified as the Authoritarian - control factor. Schaefer's (1959) circumplex model identifies the two axes as Autonomy-Control and Hostility-Love. Klebanoff (1959) and Jordan (1961) used the PARI in their research with parents of the handicapped. However, the relationship between maternal attitudes and consequent child behaviour is still largely hypothetical, paternal behaviour being merely speculative.

A cluster of variables to emerge from the Fels studies (1945) was labelled acceptance of the child and included rapport, approach, childcentredness of the home, acceptant, rejectant, casual homes. A scale in the Sears et al (1957) study was labelled "mother's rejection of the child". These proved of value in the present study, but did not elicit the factors which render the home "handicapped". Bell (1964) found that the Scale Intrusiveness (Schaefer and Bell, 1958) showed higher means in mothers of congenitally handicapped children in several studies. He used "intrusiveness" to refer to "an effort on the part of the mother to enter the private world of the child". He found it related to domination of the child, excessive vigilance, restriction of movements and freedom. If such a pattern generalises, then it is possible that the psychological atmosphere of the home becomes maladaptive, pathological, handicapped.

But the most powerful factor perhaps, in contributing to disruptive effects on a family group is the concept of physical disability which its members hold. Schaffer (1964) found that stress due to the presence of their cerebral palsied children in the 30 families of his study led to the development of pathological parental attitudes. In 13 of these "too cohesive" families, there was intense preoccupation with the handicapped child and its dependency - this spilled over on to the other children - a reduction in the "amount of community participation", a growing apart from relatives. 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 organization. Psychologists, for the most part, have been more concerned with the evaluation of disability in physical and intellectual areas than with the psychological effect of disability. Wright (1959) in 'A New Look at Overprotection and Dependency' asks us to reconsider "the emotional bias of our culture toward independence" especially with regard to early childhood training where we might be in danger of forgetting dependency needs. She refers to Shere's (1956) criteria of over-protective parents and remarks ; "in any case, what is the evidence that over-protection leads to undesirable behaviour in children?" Levy's (1943) 20 subjects she calls "cases of pure over-protection" and says findings in that study must be viewed as child guidance clinic cases and already selected for behaviour difficulties. Wright suggests that some children during "special phases of their development" needs more physical contact, proximity, attention. This might well be the case with cerebral palsied children, providing of course that the "predominant effort of the parent, consciously and subconsciously is geared toward the child's needs, not the parent's". Parents are often influenced by cultural pressures to push their handicapped child too fast. A well-meaning barrage of advice urges them to provide a stimulating environment for their experientially deprived child. By limiting "over protection" and expecting him to become confident and independent in areas not affected by his physical disability, parents will motivate a handicapped child effectively and thereby relieve stress on siblings and themselves. In 'Physical Disability - A Psychological Approach', Wright (1960) differentiates between disability and handicap disability being "more particularly a medical condition", a handicap more nearly referring to a somatop~~h~~sychological relationship between the individual and his potential. "In the individual case, a physical disability may or may not be a physical handicap.....moreover a physical attribute may become handicapping not because it is physically limiting but because it adversely affects social relationships." There are instances of this in most clinic populations.

The over-protective parent, the overly-indulgent parent would seem to be both accepting and rejecting (Levy, 1943). The dissonance of parent-child relations in such instances may well be a contributory factor to a breakdown in family adjustment and functioning, over-protection may be a consequence of "spread". Wright (1960) says that the physical disability is often"perceived as spreading to other physical aspects of the person". Pertinent research findings were made by Mussen and Barker (1944), Ray (1946, unpublished, quoted by Wright) and Richardson (1961) in which college students, high school students and children were asked to rate cripples. Richardson found an unexpectedly uniform reaction in children to the physical disabilities of other children. Apparently there is cultural evidence of a "depreciatory evaluation of physically handicapped persons"; and evidence that a person's physical characteristics strongly influence the reaction and judgment of those who perceive him (Barker et al, 1953). In fact Rose (1961) found disorganisation in the infant as a reaction to the mother's distorted perception of his abnormalities and this inappropriate mothering in turn hindered the child's development. Something similar happens when parents see their child as "different". Heider (1958) attributes the threatening aspect of unfamiliarity to its being unstructured cognitively; "the strange is experienced as not fitting the structure of the matrix of the life space". Several parents in the present study population confessed to fear of 'spastic', 'athetoid', till the diagnosis was explained. Wright (1960) quotes Hebb's neurophysiological theory to account for this fear response to the "strange". Parents are often very vulnerable to the phenomenal aspect of handicap, its impact and significance for others especially in this status age when physical wholeness is so highly prized. This is but one of many emotionally painful adjustments which the family of a physically handicapped child must make. Parental grief, anger and denial are the usual first and often catastrophic reactive processes that one finds in the literature (Bowlby, 1958, 1961; Mandelbaum and Wheeler, 1960; Zwerling, 1954; Olshansky, 1965; Baum, 1962; Thurston, 1960). Later comes guilt, ambivalent feelings, the conflict, the almost universal feeling of inadequacy. Then anxiety, with the realisation of the impact on the usual adaptive patterns, the 'shopping around' for more hopeful medical opinions, and much later, the adjustments to the new patterns of living. Most of the relevant literature is American and the result of work with mentally handicapped children for whose parents the shock seems to be even more severe than for those of cerebral palsied children. There have been but few studies of the latter. Boles (1959) matched 60 mothers of cerebral palsied children with 60 mothers of nonhandicapped children on 10 variables. On the basis of the self-administered attitude questionnaires it was found that mothers of the cerebral palsied children were more over-protective and had more marital conflicts. Shere and Kastenbaum (1966) in a clinical investigation involving mother - severely cerebral palsied children interaction found that cognitive development generally was ignored by the mothers. Meerloo and Meerloo (1950), one of the earliest studies and mainly descriptive, found that "nearly every parent is neurotically affected by his paralyzed child". Wortis (1954) stresses the potential damage to the family group; Miller (1958) emphasises that disturbed parent-child relationships may be present to a greater degree with mild handicap than with a severe one. Zuk (1959) studied motor handicapped mentally retarded children and mentally retarded without physical handicap to investigate autistic distortions in their parents' evaluation, as did Barclay and Vaught (1964), Stoddard (1959), Jensen and Kogan (1962), Ewert and Green (1957), Schulman and Stern (1959), Worschel and Worschel (1961), Thurston (1959). Not all these papers deal with cerebral palsied children; they will be discussed in detail in Part III.

A study of 66 mothers of cerebral palsied children and controls did not furnish Mann (1957) with the hypothesised differences in attitudes with regard to various aspects of child rearing and child development expected. Studies by Hall (1963) and Sykes (1958) have already been referred to. Thurston (1960) evaluated "areas of significance" to parents and their institutionalized cerebral palsied children. After the passage of time, it was found that this tragedy still involved them directly. Wortis and Margolies (1955) studied a group of New York parents whose children were attending a special school for children with cerebral palsy, the age range being 4-13 years. Little data is given about the severity of the disability. Wortis and Margolies start from the premise that the burden of care for parents is a real situational one - "it is not a neurotically manufactured conflict" and they conclude the tensions and personality disturbances are the result of reality problems e.g. housing, finance. The mothers in half of the 37 families studied were physically exhausted. Holt (1958) in England found exhaustion to be part of the domestic pattern with mentally retarded children. 7 out of the 37 families "seemed able to absorb the handicapped child without undue stress." In 8 families there was sharp parental conflict. Boles (1959) also found this marital conflict in parents of cerebral palsied children more so than in parents of the normal children. Boles attributes the disturbance of marital adjustment to "anxiety, guilt, over-protection and unrealistic attitudes". Boles, Margolies and Wortis and others, all stress how the extent and totality of the problem begin to show with increasing age of the child.

In a study unpublished but reported in 1961, Jordan found that the impact of the two disabilities of mental handicap and cerebral palsy on the mother was about the same. "Phenomenally both conditions mean the same thing....It is not the biological form of a disability that counts; it is the phenomenal impact on the parents. Clearly, parents of children with various disabilities have much in common".

Accordingly a list of reports under various headings has been made. The studies referred to are mainly those of mentally retarded children and their parents but as Jordan says above: "Phenomenally both conditions mean the same thing......".

Difficulty of acceptance: Michaels and Schucman (1962); Zuk et al (1961); Rosen (1955).

Denial of retardation and search for "magic cures": Grebler (1952); Begab (1956); Michaels and Schucman (1962); Auerback (1961); Rheingold (1945); Waterman (1948); Weinfold and Hormuth (1953); Graliker et al (1959).

Guilt: Forrer (1959); Zuk (1959); Boles (1959) and guilt at not being able to love the child; Dalton and Epstein (1963).

Practical Issues (e.g. why? can we have another child? Factual questions usually but emotionally tinged). Kanner (1953); Rheinfold (1945); Roos (1963); Stone (1948); Cummings and Stock (1962).

Child seen as psychological extension of the parent: Dalton and Epstein (1963); Kelman (1953); Solnit and Stark (1961).

Negative feelings: Coleman (1953) Steimo (1951); Michaels and Schucman (1961); Murray (1959).

Overprotection/Rejection: Shere (1957); Westlund and Palumbo (1946); Thorne and Andrews (1946); Zwerling (1954); Grebler (1952).

Family limitation: Holt (1958; Tizard and Grad (1961); Carnegie Report (1961).

Change after Counselling: Stone (1948); Rosen (1955); Appell et al (1964).

Effect on siblings: Farber (1959); Peck and Stephens (1960); Graliker et al (1962); Caldwell and Guze (1960).

Restriction on social life: Tizard and Grad (1961); Holt (1958); Schonell and Watts (1956); Schonell and Rorke (1960); Peck and Stephens (1960).

Acceptance of Martyrdom: Michaels and Schucman (1962); Waterman (1948) labelled this response "a martyr or chosen people syndrome". Zwerling (1954) indicated that 25% of his respondents thought religion an important factor in accepting the retarded child. Jordan (1961) identified this martyrdom constellation too. So much for the effect on parents of the presence of a defective child. But what are the key factors in turning the family into a "handicapped one"? What other variables affect the family's toleration capacity? Dow (1965) investigated the relationship between socioeconomic status and reaction to physical disability, finding that "most parents attached little significance to physique" and found no significant class bias. It is of interest that none of the children in his sample were mentally retarded. Graliker et al (1959) found that in 67 families "rejection of the diagnosis of retardation occurred in one third of these families". The sex of the handicapped child may intensify the amount of parental and family stress. Farber (1959, 1960) found that mentally handicapped boys have more negative influence on marital integration than girls, and also, that the age of the handicapped child was negatively correlated with marital integration (1960a). Number of siblings may be a significant factor, and Farber et al (1960a) found a linear relationship among higher socioeconomic families between number of siblings and the willingness to institutionalize a severely retarded child. Farber (1960) found sex of child, religion and social status of family and marital integration of parents to be related in a complex way to the decision to institutionalize, seen sometimes as a coping strategy. This problem of institutionalization is emotionally fraught, often producing a psychosocial crisis. Evidence by Farber (1959) and Farber et al (1963) suggest that the relationship of siblings with the rest of the family suffers after the handicapped child has been "put away". Farber found that normal sisters were often helped by the decision to institutionalize as they are often forced into close contact with the retarded child. However, Caldwell and Guze (1960) report no significant difference between mother and siblings of institutionalized retarded children and non-institutionalized. This finding suggests that adolescents "who have had the experience of a retarded child in the family are generally adaptable and that they can mould their value systems in this matter to conform to the status quo".

Publication of papers on "The Indications for Residential Treatment in Early Years" by Ellis, Kershaw, Milani-Camparetti in "Developmental Medicine and Child Neurology" (1963) emphasise that young cerebrally palsied children need both family life and early treatment and they discuss sympathectically the obstacles in the way of providing them simultaneously. The Newcastle solution of avoiding separation if at all possible would appear to be the ideal. The pediatrician is a "key" man vis-a-vis this problem. In fact, his very significant role in the maintenance of psychologically healthy family attitudes will be seen when the study population is discussed in detail. It is hoped, then, that by investigating some bits of crucial behaviour, we may arrive at some knowledge of what is the final handicapping factor which precipitates the 'normal' family into which the child is born, into the 'handicapped' category predominantly seen in the literature.

III DISCUSSION

A. The Study Population

The analysis of the questionnaire replies, after interview and visit, provided some significant information.

Physical characteristics: (i) The families. Of the 66 families studied, all but two were intact, one of these being very recently legally separated; in the other case, where both husband and wife were in their forties, the husband had apparently only temporarily deserted his wife. There was a certain amount of 'father absence' in the lives of 3 families where the father had periods at sea and in 11 families where night-shift rotas and late working hours prevented evening sessions with the children. A 21 year-old father had to leave for London to seek work during the interviewing period and his 21 year-old wife was coping, uncomplainingly, with their two small children, though she was grateful for spasmodic in-law help.

(ii) Age of parents: There was a greater age spread for fathers and these were usually older than their wives. In 10 cases, the wife was older than her husband but in no case, by more than 3 years. The age factor seemed an important one in the ability to cope with the physical ramifications of having a handicapped child. The oldest mother (45 years) confessed to "often getting very worked up" with her intelligent 4 year old hemiplegic daughter with athetosis. "It's not so bad for me, being old, but it must be more difficult for a young mother- the years stretching ahead". Her husband (also 45 years) was very conscious of his lesser resilience and lack of sheer physical energy to cope with his two young children - "we just live for 10.30 p.m. to have them quiet and we can get to sleep". Two other sets of parents, in the '40-49 years' age bracket, one mother menopausal, ("My husband had a nervous breakdown because of her and I just dare not be ill") were faced with the problem of institutionalization, for, "she will get more than we can manage". These parents had had respectively 13, 15½ and 17 years of marriage: in fact, 39.4% of all the parents had 10-19 years of marriage. 24 parents or 36.4% were in the '3-5 years of marriage' category and for 10 of these, their handicapped child was their first and only one. The youngest mother in the sample was just twenty, her husband 24, and their spastic paraplegic daughter 1.11 years. This young mother, only recently left work and now taking full charge of the baby from her mother, spoke of two occasions of her great loneliness, her fears for the child, her difficulty with finances, the "stacks of washing". "But as long as I get some tabs*, I'm all right". By contrast, another 21 year-old pair, parents of a mentally retarded right hemiplegic daughter, seemed mature, but she was their third handicapped baby, the other two having died at birth and in early infancy - "I don't let her handicap get me down. I treat her as normal." The majority of the parents however, were in their late twenties and early thirties and the mean number of years of marriage was 8 years 10 months.

(iii) Composition of family. There were 17 'only' children and two families with more than one handicapped child. In one of these families the elder boy had muscular dystrophy whilst his younger sister was a severely mentally retarded spastic quadriplegic. The eldest child in

*cigarettes

the other family, a spastic boy, had been institutionalised,a normal teen-age girl was at home as was the youngest girl in whom ataxic cerebral palsy had been recently diagnosed. There was one family of 8 children and two of 6 children in all of whom the second youngest child was the handicapped one. Of the three 5 children families, the second youngest in two of the families was handicapped. In the third family, the youngest was the handicapped one. No pattern of position emerged from the study of the other families. In the seven families with 4 children each the eldest in one family, second youngest in three, and the youngest in three families was the handicapped child. For the twelve 3 children families, the 9 youngest, two middle and one eldest were handicapped. 36.4% i.e. 24 families consisted of 2 children and the handicap incidence was equally divided among the twelve younger and twelve elder children.

(iv) Accommodation. The 66 families studied were, all but two, urban dwellers. 25 families owned their comfortable homes, with garden, 25 lived in rented council houses/flats, and 3 lived with the maternal grandmother. The only permanently non-intact family of the sample was in the last category and there were no complaints about living arrangements. In fact - "My family are a great help. I couldn't work if it weren't for them" was this allegedly devoted mother's comment. Such was not the case, however, with the second family in this position of "living in", where there was said to be extreme tension and unpleasantness due to "my mother's siding with my brother against my husband." Lack of living space was said to be a contributory factor, as may also have been the fact that the husband was not the father of this child with spastic quadriplegia. There was no garden or playing space at all, and the child had only the busy street to play in. The third family appeared to have settled happily and the mildly handicapped little boy, an only child, had cousins to play with. This matter of inadequate accommodation was keenly felt by 14 parents who complained e.g. "She's on top of me all the time" and "I'm at screaming point he's so restless". 9 families had no garden and some had only a small yard. Two families had only an outside toilet. One downstairs flat had an outside toilet across a badly paved yard which the hemiplegic boy, aged 2.8 years, had difficulty in negotiating. This toilet was shared with the top flat neighbours and not unaccountably there appeared to be a certain degree of tension existing. The mother was expecting, with some trepidation, her second child and had this additional worry of inadequate housing and a rather delicate husband. 8 families lived in upstairs flats and only two of the handicapped children concerned were able to walk, and that with a certain degree of difficulty. The others had to be carried up and down, and this was a backbreaking job for all but especially so in two cases where one mother was in late pregnancy, and in the other, where the child, a severely disabled spastic paraplegic, now 6 years old and heavy, was an increasing problem to the parents as they had been told by the ambulance men who took the child daily to a Training Centre, that they "might have to consider an alternative method of conveyance". These parents were "worried sick" by the carrying problem and the dearth of alternative accommodation. Another mother of two, a paraplegic girl of 4.2 years and a normal 2 year old boy, living in an upstairs flat in a most depressing area, with no yard or garden said she was "afraid to make noise as the downstairs people are so unhelpful, I'm a nervous wreck in case he runs about - the other poor bairn can't. You'd think people would be more sympathetic with a spastic child".

(v) Extended family. But this young mother's disappointment was assuaged by the nearby presence of her "Mam". Just as in Liverpool (Kerr, 1958) and Bethnal Green (Young and Willmott, 1957), Tyneside's maternal grandmothers play a significant part in the life of their own children. "I can always go up to my Mam's when I'm lonely", a mother of two handicapped children said: "She's heartbroken for my sorrow". Another mother in the study was still mourning her mother's death of 2 years ago; "It's a big miss. I can't speak to my husband like I used to speak to my Mam". A sympathetic council housing authority had arranged that a grandmother be moved next door to her granddaughter who had spastic quadriplegia and mental retardation. It was noticeable that many of the mothers who seemed specially attached to their own mothers had the more grossly handicapped children. Socioeconomic factors and education rather than age or lesser disability or even geographical distance seemed to account for lesser dependence on the extended family. The 9 parents in Social Classes I & II made the recognised weekly visit to "Grandma" and sometimes had her baby-sit while husband and wife went out. In the main, these were also the parents with the longest period of formal education. It is noticeable that of this group two mothers were at variance with their own mother, and one had a "poor relationship" with her mother-in-law. This was causing her husband considerable upset and he confessed, with a gleam of humour, that "It is well I am emotionally stable". In both cases of mother-daughter variance the handicapped child was blamed for the tension as it was in a third case where the young mother complained that her parents gave no help at all - "They say they brought their own up and now they're letting me bring mine up". As this woman's parents had been looking after the child when she had the accident leading to her disability, "I wonder if it could have been avoided. I've lived it over a thousand times. Mother hides her feelings, so I don't know if she feels guilty". A mother, seriously disturbed by the impact of her partially sighted and mentally retarded son, berated both her own family and that of her husband for their neglect: "People are very selfish really. Everything is an ordeal now. Everything revolves round him". And the the often-heard cry - "You don't know what it is unless you have a handicapped child". There were a few such complaints but in a much lower toned key. In the main, they were no more than reactions of 5 over-tired mothers against "his" relatives.

(vi) Employment. One father was unemployed. Two (Social Class V) had just returned to labouring jobs after a long spell of unemployment. 75.7% - 50 fathers - were in Classes III and IV and of these 11 were on night-shift rotas. Three fathers had been hospitalised for a long period, two with tuberculosis, another was epileptic but all were now working normal hours. Of the mothers, one was working full-time since legal separation, leaving her 3½ year old son with spastic paraplegia in the care of his maternal grandmother with whom they now live. The elder child was of school going age. The second working mother's two children attended a nursery. 6 mothers had part-time occupations in the evening when the father had come back from work, mainly to swell the family income, though two admitted to working in order "to be in touch with life again".

Of the 6 children, two were ambulant and only mildly physically handicapped; two five year olds were severely physically handicapped; and two were severely mentally and physically handicapped, aged 3.10 years and 7 years. 6 mothers said they would return to work (part-time at first) as soon as it were physically possible. Of these, three were professional women who had decided to work, not in their own field, but in a new, if somewhat related, area. All the working mothers stated their awareness of the dangers of non-continuous mothering but that the age of their children precluded deprivation. None showed evidence of psychic guilt. From research (Yarrow et al, 1962; Maccoby, 1958; Stolz, 1960) and with non-handicapped children, the effects of the single factor, maternal employment appears to be small, if any, and these will not be the same on all children. Age, degree of disability, intellectual capacities of the child are of importance when the child is handicapped as are the parents' education and emotional stability, the size and composition of the family. Of special importance would seem to be the father's attitude to being a rearing agent, the mother's positive/negative view of her work and her methods of compensation for any alterations in the rearing environment and emotional bond. Research on the effects of maternal employment where the child is young and handicapped would be valuable in a mining area such as that covered by the existing study where due to closure of pits, more women may have to take on employment, or where, generally, mothers may want to return to work to use special skills or for self fulfilment purposes.

(vii) The children. Probably it is the quality rather than the quantity of caretaking interaction between the mother and child which is psychologically significant and here the age of the child is a variable of importance. Ellis (1967) spoke of the few young children referred to his clinic in the first year of life; "we hope that, as interest in the early diagnosis of cerebral palsy becomes more widespread children will be referred to our clinic for assessment and treatment at an increasingly early age". The youngest children in this sample were both 1.3 years, the next youngest was 1.11 years. These 3 children had been only very recently referred, as had been 4 others in the sample, and none under the first year. The age range of the children has already been diagrammed (page 4) and shows the great predominance of children in the 4-5 years group, in fact 34.8%. Table 1 shows the distribution of the children in the study group according to the severity of handicap. In a later section, the psychometric data will be discussed. The degree of disability is a significantly important variable in any measure of parental attitude so, too is the incidence of prematurity, 30.3% in this instance; there is the question of feed back effects on the parent of living with a particular child who may have been over-protected and isolated (Shirley, 1939). V.D. Mann's unpublished work (1957) - 'A study of the attitudes of mothers of cerebral palsied children toward child adjustment' - has been widely quoted. She found that a large number of significant differences found between the mothers of the children with C.P. and those in the control group pointed to the possible operation of a reactive factor in parental attitudes when measured retrospectively. Apparently the reaction of a parent to the child rearing problems posed by a handicapped child may lead to manifest attitudes resembling those which when manifested by the mother of a schizophrenic child have been assumed to indicate causal significance (Klebanoff, 1959). It has been said that children control parents more than parents control children; and the Newsons add (1963) that "how parents behave is a function of the sort of children they have". A table gives a poor picture of the children, 21 of them without speech, 9 immobile in a sample which makes no claim to be a homogeneous group. Their very unfamiliarity can be conflict-producing especially where the handicapped child is the first and/or 'only' child and where in addition to his handicap, has had to bear the brunt of the parents learning to be parents. However, many of the statements about 'only' handicapped children are unsupported by research; and Koch's research (1956) was done on normal children and their siblings. Lasko (1954) compared the behaviour of mothers towards first and second children, finding that the mothers behaved less warmly and were more restrictive with their first child than with their second. She found, too, that they tended to protect the second child more than the first, with a consequent lessening of parent-child interaction. This might well have personality repercussions with a handicapped child and influence his perception of parental acceptance. Schachter's (1959) finding of strong relationships between ordinal position in the family and the need for affiliation could also be relevant. Lasko found, also, that parents become more consistent in their child care practices as they gain experience with successive children, so that the later born handicapped in our sample may benefit from such changing patterns of attitude. From observation, one could see that some parents in spite of, or perhaps because of increasing age and experience, could handle their mildly handicapped children more positively than did younger parents with earlier born children of similar degree of handicap. However, whatever the regime, conscious attitude or birth order, in the majority of cases the handicapped child in this sample and at this stage of his life appeared to dominate the family circle.

Social characteristics. The parent - other people relationships was explored, though not in depth, by analysis of responses to Questions 38, 39 and 51.

To Question 38 ("Some parents feel isolated with a handicapped child. Do you?") the replies were:

Mother			Father	
Yes	No	Sometimes	Yes	No
27	38	1	10	45

It is of interest that only 4 mothers of severely mentally and physically handicapped children out of 17 such mothers replied "No" while 9 mothers of mildly handicapped children out of 14 such mothers complained of isolation and loneliness. One of these 'lonely' mothers was in full employment, another had part-time evening work, yet they said they felt cut off from community affairs and entertainment by the presence of their handicapped child. The husband of the former woman replied - "No - I'm not affected at all"; but as he was away from home some nights every week, his wife had not his physical support. The husband of the latter woman replied - "No. I never think of her as being handicapped anyway". Of the 10 fathers who replied "Yes", 4 were fathers of severely handicapped children both mentally and physically and 3 of their wives agreed as to the loneliness now felt. 4 of the children were moderately and 2 slightly handicapped and one father in the latter category spoke for some of the others when he said: "You're on your own, relations and neighbours are not anxious to look after and accept responsibility for such children - and she's yours anyway". With regard to the 4 mothers who replied "No" and whose children were severely mentally and physically handicapped, these emphasised family support and not neighbourly help. 3 of their husbands also replied "No", the fourth replying that he now felt "much more insular and introvert". "Our circle of friends has diminished to practically zero - not consciously but because we can't partake of normal activities and people don't visit so much with a handicapped child. Even my mother thinks my daughter is a peculiarity. My side of the family give very little tangible assistance to us - just sympathy." The wife of this intelligent and emotionally suffering man had said - "I never feel isolated because of having such good neighbours. At times of course, you feel that everything is against you".

There was a discrepancy in 18 Mother-Father replies and an analysis revealed some interesting facts. 14 mothers replied "Yes" to the fathers "No" and 4 mothers replied "No" to the fathers "Yes". Of these 14 mothers, 6 were the mothers of severely mentally and physically handicapped children, one of whom for example, had been crying ceaselessly for a fortnight. In such cases, the mother being the prime caretaker is both emotionally as well as physically tied to her child. In this particular case the husband was equally worried but "It's not so bad for me being out at work. But the second bairn has done a lot for our marriage and for us. Without him we'd have been in despair". This fairly well summed up the other fathers' acceptance that "it's harder for the wife". Of the remaining 8 mothers who felt isolated whilst their husbands did not, to the same degree anyway, 5 were mothers of only slightly handicapped children, but 3 had moderately physically handicapped children who had to be carried and cared for continuously and the husband of one had been away at sea till just previous to my interview. So, as she said, "I've had to go it alone", as had the other two mothers whose husbands worked long hours.

There were 27 cases in which there was agreement on this question between the spouses; and this included the parents of the more than one handicapped child families. The parents of the two at home agreed to "feeling very isolated and alone", whilst those of the institutionalised boy, normal girl and home-based ataxic daughter were agreed that their "relatives helped a lot to prevent isolation".

From these results, it would appear that temperament and attitudes of the parents are more significant than actual degree of impairment in the child, or what is perceived as 'impairment', in determining the incidence of 'isolation' feelings. One busy mother of six determined not to let this event overwhelm her: "As soon as I realised I had a handicapped baby, I learned to drive and started to take her out because I could have been isolated - tied to the house". This was perhaps viewing isolation physically. A father, younger and less well educated, in the formal sense, than this mother seemed to sense another dimension of isolation. He replied, "Yes, I feel isolated. Because we are looked on as something different, we do get sympathy from people and understanding. But I still feel alone". (This man's wife had said: "I felt it dreadful at first when the idea sank in that he was a spastic and that he will be different. But you get used to the idea. If the neighbours weren't so good, I'd have been dreadfully lonely.") An intelligent perceptive father of two, the younger a much longed for son but also a spastic quadriplegic summed the matter up like this: "It's the temperament of people that cause isolation. It's not the primary fact - handicap. At first we got a shock - not disappointment - when we heard he was spastic. I see this as a challenge. It made us more conscious of needing everyone, an awareness of life. I know life now, rather than knowing of life".

Some families appeared to lock themselves away from others, unlike the father just quoted. An indication of this was seen in the responses to "Are your neighbours helpful?" There were 20 replies of either "No" or "I don't bother with them" from mothers and 22 "Nos"from fathers. One mother said - "I don't know the neighbours. Mam's a support and that's what I'd be lost without". This reliance on 'the family' was especially obvious with parents of the children in the 'severe' category, where none seemed to have satisfying relations with the neighbours. One father confessed - "The neighbours get on my nerves a lot because they don't understand the problems we face. They are thoughtless in telling us how much their children are doing physically. I'd never do that". The mother of a four year old girl with a left hemiplegia, said to follow head injury, told me that she felt especially isolated "when we are with other children." This mother, the only one to have domestic help, was able to go out often with her husband. Few of the other parents - 30.3% - were able to get out together, due to the lack of willing baby-sitters with whom the handicapped child could be left. This confirms the finding in the Carnegie Report, (1964). Unless they went out as a family (not always possible due to degree of handicap and lack of means of transport, only 30 families having a car or van) most of the mothers and fathers went out singly to the usual social activities of 'Keep Fit' classes, Young Wives Clubs, Bingo, Old Time Dancing, Judo, the pub. A fewwere members of organisations, some of which had church connections. 3 sets of parents went to meetings of their local Mentally Handicapped Society. Only one mother said "I never go out except to the hospital" and she was the mother of eight! One young professional woman, with no trace of self-pity remarked, "You can't live like normal people really. You look out of the window. You can't go far........".

The replies to Question 51 were to some extent an indication of the physical handicap and a belying of the "I treat him as normal" attitude. Though the majority of the children could be put in push-cars (all but the six most severely handicapped), 80% of the parents found the child to be restricting with regard to holidays and outings, but nevertheless managed to take him out at least during the fine weather. 15.1% parents spoke bitterly of people's curiosity and even rudeness when gone away from their own neighbourhood. One woman whose husband was philosophical about "looks and stares" said: "I have resented people - especially someone who said that handicapped children should not be allowed to live. We waited 11 years for our son". Her son was an extremely bright little boy, though paraplegic. Another mother of a very mildly handicapped little girl, had a reason for people's curiosity: "People enjoy being curious about a child somehow - and about seeing some people who are well off and yet having troubles. They can feel superior. It doesn't bother me - but they do keep on asking". One felt that she still minded quite a lot. Parents of a highly intelligent 4 year old hemiplegic said they didn't resent "the stares but the child does". The mother of a severely handicapped girl "resented" people: "They stare terribly - more so when you've two. The boy's in a wheel chair all the time now and my husband's getting rattled,people are so ignorant. I don't mind that much but I just couldn't take the children to a hotel or restaurant". An older mother had "learnt to live with it. I wanted to hide her at first. Not now. But I still want to protect her and people not to look too much". Admittedly these two were grossly handicapped cases, but some parents of the lesser handicapped had been put off holidaying and outings by the "nappy" problem, by the unpredictability of the child's reactions, and also, too, by people's questions. "It still annoys me when people stare - it's little things like that that get you down". There is no doubt that parents themselves contribute a great deal to the difficulties that they have with others. They are extremely sensitive and defensive in their dealings with other people. Whilst parent education might remedy this by ensuring more accepting parents, it is important to help modify those attitudes and actions of other people that are perceived as offensive by parents of handicapped children.

Emotional Characteristics. It has been said that the psychological fate of a child is determined by the emotional health of its parents. But this is to see even the most severely spastic child as too passive an organism for accuracy. The child, as a member of a primary face-to-face group, acts upon as well as is acted upon in a social-psychological scheme in a dynamic interaction. For the parents of a handicapped child this interactive process is often delayed, severely restricted, even distorted, for interpretation of the stimulus perceived is the important factor here. Nevertheless, the parents' emotional maturity seen in the resources brought to a demanding situation, in the adequacy to meet and adjust to crises, in the flexibility for role reorganisation appears to be closely related to family vulnerability, to stress and children's social and emotional maturity.

The parents of handicapped children, taken as a group, resemble fairly closely any cross section of the general population. Their personality deviations or problems often have not been obvious prior to the crisis of having a defective child. "Handicapped children belong to emotionally healthy and mature parents and to neurotic and insecure parents. Most often they belong to average parents who are able to withstand a moderate amount of stress and strain but who may develop serious problems of adjustment if the stress becomes very great. In other words, the typical parent of a handicapped child is, like most of us, a person who can take just so much and no more". (Reid, 1958). But what is this much beyond which maladjustment begins? A review of the literature reveals that being the parent of a defective child constitutes usually a severe ego threat: a variety of conscious and unconscious emotions are said to be aroused: the child's handicap is seen as the result of "sin", a punishment for wrongdoing: denial of reality as a stress reaction is coupled with an almost obsessive overprotection. Often the blame is projected upon someone else (on the midwife, on the hospital doctor or on the family doctor as in the study sample). These parents are often described as "rejecting". But most parents at one time or another are rejecting i.e. as expressing negative values. As Gallagher (1956) says - "Parents are entitled to a little negative outpouring without having their human response labelled as something psychologically revolting." If rejection is seen as the persistent holding of negative values of the child so that attitudes to the child are coloured unrealistically, then this feeling must be rare. One father in the sample, whose only son is a scaphocephalic with severe mental retardation, would appear to have accepted his rejection of this son and is now able to view, even the rejection, with detachment. "I have moments when I regret him - when I wish he'd never been born. My wife and I talk it over....If we shut it away we would never accept it..... I see his death taking away all my problems. He doesn't react to me as a father, he's just the same to any neighbour that comes in". This man's story was a success one, financially speaking, but somehow a success story that had a searing quality. Recent literature tends to categorise all parents of handicapped children as guilt-ridden, anxious, emotionally traumatized, and there is constant reiteration of such emotionally loaded words as hostility, remorse, insecurity. That such symptoms as grief, uncertainty, even despair are frequently observable is undeniable - the emotional impact of this son on his father is great, though the father believes he has "written him off" but these reactions are not universal nor do they last forever. Roith (1963) speaks of the "myth" of parental attitudes and in an attempt to investigate the impact of handicap on the emotional life of the parents in the sample, an analysis of some responses has been made. It was realised that the interview and questionnaire method is an imprecise tool, that responses may be biased when "people are interviewed directly concerning behaviour about which there is a strong expectation of social approval or disapproval and in which there is considerable ego-involvement." (Maccoby,E.E. and Maccoby, N., 1954).

To Question 43 ("Some parents are brought closer together, others estranged by an event like this. Has your relationship with your husband/ wife altered due to N's being handicapped?") the replies were:

Mother			Father			
No change	Closer	Tension "apart" "estranged"	No change	Closer	Tension "change for the worse"	"Strained but all right now"
26	19*	21	25	11	16	3

*"not wholly due to child" according to one mother.

In the case of legal separation, it was emphasised that the handicapped child had "nothing whatever to do with it". Where the father had temporarily deserted his wife - "we were divided by the child" the mother reported. With regard to discrepancies in response between husband and wife (8 cases) it was usually the mother who felt increasing tension and these mothers were only in 2 cases the mothers of moderately handicapped children. 3 fathers felt increasing strain in the marital relationship due to their severely handicapped child, the wives not registering similar tension. There were 6 cases of agreement as to worsening relations, growth of disagreement and tension. 4 of the children concerned were severe cases, two moderately handicapped. There were 6 cases of agreement the relations were closer since and due to the birth of the handicapped child.

To Question 44 ("Do you think a handicapped child can lead to more tension in a family?") the replies were:

Mother		Father	
Yes	No	Yes	No
47	19	37	18

29 parents agreed that "Tension is bound to happen. We disagree about her future, her treatment." This was a father's typical reply as was a mother's: "Our's isn't a strained relationship but we certainly haven't been brought closer together. Definitely he brings tension. Because it affects <u>everyone</u> in the family". Another, a nurse with experience, found that a handicapped child (hers was a slightly handicapped child) "definitely makes for tension. You never stop working for example. It's the worry at the back of your mind always and having the abnormal child falling a lot. And when child and mother are tired and the normal child doesn't know what the abnormal child wants, then you get bottled up to

the pitch you could scream. You sometimes get round it. It's christian faith that is bringing us through this". Her husband found handicapped children "overbearing", and that this aspect of their child provoked argument and dissensions. However, 9 sets of parents agreed that their child did not make for tension. A father, one of many such parents referred to lack of sleep (due to the child's sleeplessness) as causing a personality change early on - "We'd get irritable but there was never tension". There were only 2 severely handicapped children in this category. One of the mothers (a diabetic with a moderately physically handicapped paraplegic daughter and 7 other children) said: "There's no tension in our house. There's times I get over-tired but I make up for it when they are all abed. You need to be patient". One mother had this tribute paid to her by her husband: "I don't think a handicapped child leads to tension. But I understand her irritability when I'd come home at night. Tell the truth, I don't know how she managed to get to the shops in the winter especially when the second baby was small. And she always had my tea ready".

In the psychiatric literature, there has been particular emphasis on the "chronic sorrow" attached to a birth such as 63 of the 66 parents interviewed had experienced - three of the children have apparently developed handicap post-natally. For 30 parents their handicapped child was born in the early years of their marriage - a time when each partner has to effect an emotional separation from his own family and together, as partners, try to gain a sense of identity as a family unit. 20 children had been premature - a crisis-producing event according to Caplan (1961a) out of which may come a healing or an unhealthy outcome, depending on helpful intervention. Solnit and Stark (1961) discuss the emotional reactions of the mother who gives birth to an obviously defective child and the necessity for the period of mourning or "grief work" to be gone through. Bowlby (1960) observes that "the bereaved either makes unreasonable demands or else hardly seems to know what he wants....." But with cerebral palsy the defect is rarely obvious at birth; and the parents in this study sample have had time to adopt coping mechanisms and restitutive facilities which ease the disappointment and pain. Both parents will have their cultural criteria as to the values of the mother, father, person, parent and experience in the management of past adaptive crises, probably none of which was so emotionally shattering as this. Both parents may have already adopted the role of "parent of handicapped child" and patterns of relationship which make it easier to bear the new experience. Farber (1960) found that socioeconomic status determined a mother's acceptance of a defective child. At this 'crisis' period of the child's approaching school-going age, one could see in this sample, the cultural expectations were a factor in the generation of anxiety but no indication that education or class had an effect on the acceptance of the handicapped child. All the children were accepted - their disability, no. All the children appeared to have reward-value for their parents at this stage; but already the disadvantage of the lack of speech was commented on by two fathers, the mothers all proudly claiming that they always understood what the child was "saying". Many mothers emphasised the physical limitations of the handicap rather than the social or intellectual. "If only he/she could walk" was a constant wish, understandably so at this early stage when the physical implications of disability are very marked and where 28 children are not yet toilet trained. This emphasis on increased work was mentioned by 57.6% of the mothers who attributed their tension and irritability to its debilitating effect. An analysis of the replies to Question 59 ("what effect has a handicapped child on a family - on your family?) elicited a 96.9% agreement that the child caused tension and irritability. "There's something there, all the time", as one woman described it and she was the mother of a slightly handicapped boy. "It's quite disastrous really. It goes on day after day and you don't remember the days. I have thought I should jump off the end of the pier with him - but there's the others. I wouldn't do it really - most suicides don't intend doing it" declared the mother of a severely retarded little boy. She was, self-admittedly, "at the end of my tether". But another mother, apparently adjusting well to her "altered life" admitted: "It's never out of my mind completely, this thing. I always have it at the back of my mind. In my bath, relaxing, it looms up. It doesn't seem to affect my husband like this. I always have it at the back of my mind - why did it have to happen!" A father, whose little girl is now severely retarded, both physically and mentally, after having been "normal till she was six months old" according to her parents, admits that "It's difficult to have an appraisal of the situation when you are one of the prime participants. Initially it's a shock, and this resolves into a realisation over a period of time and an acceptance". His wife had found that "It alters the whole plan of your life....You have to consider the handicapped child first. If our first baby had been handicapped, we would have had no more". Degree of disability is a factor which influences reactions as well as age, sex, education, previous experience. For one young mother, her child was "a tremendous shock... I always used to turn my head when a handicapped person passed by". Many referred to the grief, still felt, though not so poignantly now. A father, a rather silent miner, spoke movingly: "It had a terrible effect on the wife. We are broken-hearted. It's a thing you can't do anything about. You shed a few tears now and again and just go on". The grief, the tension were there, but there was acceptance too, and the effort in the majority of families, to try to lead as normal a life as possible"for the family's sake". This upheld findings by Michaels and Schucman (1962): "Some parents are apparently able to make a reasonably successful adaptation without external assistance....." But a certain amount of "shopping around" - "the fruitless searching for a cure" referred to by Sheimo (1951) - was found in this sample in which there was evidence of a reliance on the 'magic' of surgery (3 cases) and dependence on the weekly visit to the faith healer (2 cases) and the manipulator-cum-healer, this last at considerable expense of time and money.

In reply to Question 45, about health etc. every mother said she was tired, as were the mothers in the Holt study (1958) and in the

Margolies and Wortis investigation (1956); 15% were sometimes worried, 85% were very worried about their child. All admitted to being depressed. An older mother said, "It's mother's handicap as well, you know". A much younger mother, who had already lost two babies, confessed: "I just cry in bed. He thinks I'm over-tired. But it's about her I cry". A mother had financial troubles in addition to worry over material tension and her hydrocephalic spastic quadriplegic son. Of the fathers only 3 replied - "Never depressed or worried", and one was the father of 8 children. A fourth, the father of the scaphocephalic boy said: "I'm not worried now. It doesn't profit the situation". One felt that this warm-hearted, disappointed man was almost torturing himself and that <u>his</u> emotional handicap was more serious than that of his child (Carr, 1958). The parents of the two handicapped children at home were "desperately tired". "I sleep when I sit down" said the mother. The father said, "I'm always over-tired,worried and depressed". The other set of parents, similarly afflicted were equally depressed. The father, a miner and not very articulate, told me: "I'm worried about the future. I've just sat and thought about it and then had to put it out of my head". A man who was feeling the tiredness of middle age, confronted with two young children always felt "over-tired but not particularly depressed. Life could be easier if one didn't have children. But it might have its empty moments too."

This picture of depressed parents was belied by the first meeting with them. It was after some acquaintance that they revealed their fears. But nevertheless, these were realistic fears, their anxiety was based on the real problem of handicap. The depression may have been unnecessary: the physical health in all but 5 mothers and 2 fathers was self admittedly very good, in fact, all that was possible medically and therapeutically was being done for their children. There did not appear to be any pathological denial. The "I treat her as normal" was no mere act of self-protection. It seemed a natural rather than a neurotic reaction, and it is possible that such an attitude, fairly prevalent among the parents, betokened absorption and integration of loss. The statement of the 3 fathers who were "never worried or depressed" raised questions regarding their emotional health for their children were not seriously retarded. Boles (1959) attributed the difference in meaning that the defective child had for the father and the mother to the difference in parental roles. The Parsons and Boles (1955) differentiation of roles is relevant: perhaps the father does not encounter the reality of the child's defect till the educational problem arises.

Boles (1959) in one of the very few controlled studies of parent-cerebral palsied child relationships, found religious attitudes to serve as a support and buffer against feelings of guilt, unworthiness, punishment, and Farber (1959) suggests that Catholics receive more emotional support from their religion, in a crisis, than do non-Catholics. Zuk et al (1961) show that Catholic mothers of retarded children in a clinical population tended to verbalise more accepting attitudes toward their child than did non-Catholic mothers, while Boles's Catholic mothers expressed more guilt over the child's condition than did Jewish or

Protestant mothers. The present research did not set out to investigate the religious factor in a population in which there were 6 pairs of Catholic parents, 4 Catholic mothers and one Catholic father. However, there were 7 sets of parents to whom religious practices seemed a support and one of these was Catholic: "Without faith, this would be calamitous, it would have no meaning" the mother remarked. Only one mother, of a severely retarded child, referred specifically to "punishment", though many parents echoed the question - "Why had it to happen to us?"

Boles found frequent marital tension in the 60 families, Farber (1959) also, but this latter investigation was concerned with the effect of a severe mentally retarded child on marital harmony in 240 families. The presence of a handicapped child may disrupt marital relations in many ways. There may be distortion of perception of roles, disruption of the family life cycle, severe repercussions ~~or~~ on siblings, while the threat of institutionalisation may hang over the family. Conflicting coping mechanisms may lead to tension even disintegration, especially if the child is seen as an extension of the self (Baum, 1961). Margolies and Wortis (1956) observe that the problem of cerebral palsy changes for the family and becomes more serious as the child grows older. The very young, physically handicapped children of this sample are socially and emotionally acceptable as yet, and there were only 6 cases of agreement that harmony was threatened. However, 3 of these seemed to be potentially, extremely serious, though in each case to superficial observation the parents appeared to have made a fair emotional adjustment to the crisis. One mother said she had considered divorce "if it were not for the other children". This woman was under great physical strain with her very severely mentally retarded son. Underlying failures of adjustment were not investigated and the prevailing picture seemed of a population of harmonious and successful families who were managing to cope with a demanding experience. The figures differ from Holt's (1958) in whose sample of 201 families with a severely retarded child, 12 parents were seriously quarrelling. He found, too, that although additional pregnancies were theoretically possible in 160 of the families, 101 families did not want more children and in 90 of these 101 families, the restriction was due to the presence of the severely retarded child. Tizard and Grad (1961) found a tendency to avoid having more children in their study, though in both these studies, a small number of families wanted other children to compensate for the disappointment of the defective child. In the present study of the 17 'only' children, 15 were first born and 9 mothers and 10 fathers would not consider a second child, but 8 mothers and 6 fathers would like another child. 2 of these mothers were extremely anxious for a baby, feeling "cheated", and showed none of the fear reactions of the 8 mothers who openly admitted to fear and worry for a second possibly handicapped child. Of the families where the handicapped child was younger/youngest 19 mothers and 15 fathers were adamant about "having no more", and 3 mothers and 3 fathers were willing to "chance having another baby" as one mother said. The ages of all these parents and the degree of disability were variables and it was perhaps significant that only one mother of a severely retarded child was anxious to have another baby "in spite of disturbed nights and endless nappy washing".

Another area in which a defective child can cause tension is in sibling integration in the family. Ordinal position is reputed to be less significant than family spacing in normal families, and this possibly holds for families with handicapped members. There were 4 families in the study in which the handicapped child's older sibling's school behaviour was causing anxiety. Farber (1959) suggests that the birth of a handicapped child causes a tremendous disruption in family patterns due to arrest in the family life cycle, each individual having his anticipated roles frustrated. His research involved severe mentally retarded children under 16, and his findings were not supported by Graliker, Fishler and Koch (1962) who found that the presence of a young retarded child did not have an adverse effect, particularly where parental counselling was available. Many variables must be considered - age and sex of the child and siblings, the family's adaptive competence, the mother's view of the child's dependence. Spacing, as has already been mentioned, will determine the amount of contact the sibs have and the degree of disparity in their circle of friends. In the present sample, 5 families had teen-age members, and there was a considerable "gap" in their ages and that of the defective child. Two of the parents (one a mother, the other a father) betrayed anxiety as to the future marriage prospects of the daughters in their families due to the incidence of handicap. These older children in the families helped in varying degrees of efficiency with the entertainment of the handicapped child, though in one instance of where the child was reputedly destructive and inordinately restless - "they love her but now there is resentment. She ties them down so much" - the once dreaded question of institionalisation was being re-opened - now welcomingly. Two other families, in which the chil was grossly retarded, were awaiting, with relief, the promise of a placement in a large nearby hospital for subnormals. The self-questionings, guilt, pain were subdued at the time of interviewing; but all sets of parents admitted to the ambivalence of feelings and the extreme tension prior to the final determination. But not all parents had reached this stage of equilibrium. To all other parents, even those of very severely retarded children, the thought of institutionalisation was emotionally upsetting: the thought of a residential school, even, provoked a fear reaction of forgetting and being forgotten in some parents. Two families with moderately physically handicapped children would move to the city rather than have their children in a residential special school. But a father of a severely handicapped little girl of 5 years said of her pending institionalisation: "If we lost her by death, it would be like losing a normal child - a piece out of our lives. For all that we try not to think of her, still we are attached to her. One thing I'm sure of - we'd never forget her. At work I can't bring myself to say 'my little girl is handicapped'. If she were physically handicapped, it would be different. If you say mentally handicapped, they look at you". And all the time, during the interview, the little girl cried dully and persistently through closed doors.

The impact of the mother upon the child and the general characteristics of the mother-child, even mother-cerebral palsied child relations have been emphasised. The primacy of the mother's role as a social reinforcer for the child and the importance of this in the child's formative years has been suggested. Bowlby (1952) has emphasised that should the nurturance role be abdicated, and he had the mother in mind,personal and social maladjustment may result. Farber (1960) indicated that socioeconomic status determined, to some degree, the mother's attitude to the crisis of the birth of a defective child. Mothers of all classes typically spend more time with children than do fathers (many of the fathers in this study referred to their wives' constant attendance upon their child and yet they too were "highly participant" in domestic events. Newsons, 1963). Young and Willmott's (1957) reference to mutual consideration draws attention to a facet of modern marriage in which the father's role is becoming less exclusive: "The younger husband of today does not consider that the children belong exclusively to his wife's world or that he can abandon them to her (and her mother) while he takes his comfort in the male atmosphere of the pub. He now shares responsibility for the number of children as well as for their welfare after they are born". What holds for Bethnal Green is also typical of the North-East, and not only in the working class. Many of the fathers in this study were extraordinarily perceptive and sensitive. The stress engendered by the presence of a handicapped child seems to permeate the whole emotional climate of the family and the father's role is not an easy one, mediating between the family and the outside world. Traditionally his is a somewhat passive role in the early months; but in this study population, the vast majority (89%) of the fathers had helped and were still helping the mother by their emotional support, though baulking at nappy changing and bathing (25 cases). Often, it is he to whom the diagnosis is given and it is his unenviable task to interpret this to his wife, and as Denhoff and Holden (1955) remark "when he himself is unsure of the facts". In connection with this shift of emphasis from mother to father in the consideration of the father's role in the family, and his higher degree of participation in child-rearing, some relevant questions were included in the Questionnaire.

To Question 47 ("Do you think N's handicap might have been avoided.... ...?" the replies were:

Mother			Father		
No	Yes	I don't know	No	Yes	I don't know
31	26	9	24	17	14

To Question 49 ("Would earlier diagnosis have helped in N's case?") the replies were:

Mother			Father		
No	Yes	I don't know	No	Yes	I don't know
39	22	5	34	18	2

and one "No comment" from a father.

To Question 48 ("How do you think parents should be told about their child's handicap? And when?") there was much pertinent information. The majority of parents complained of (a) lack of information; (b) delay in telling; (c) Separately told, one mother being told before medical students (10 complaints). There were also complaints about (d) "evasive" telling; (e) "never really told by our doctor" (2 cases); (f) "I was told alone and had to go home on the bus with the child"; (g) "I was told stupidly. I thought he was going to die"; (h) "I only vaguely understood what 'spastic'meant. I thought it meant he was an imbecile". 4 other parents referred to their unclear ideas about 'spastic', associating it with imbecility and not with physical handicap. One father complained "we weren't told the basic thing, how she's going to develop" and his wife said ; "I was told too much too soon". There were 14 "no complaints" from both parents - or 21.2% were satisfied at how the medical diagnosis was transmitted. One of these fathers commented on how difficult it is for the pediatrician to decide how much and when the break the news to the parent. "Perhaps it's better to let it gradually dawn on them and the shock, then, is not too great". In the Koch et al (1959) study of 105 families, hardly half of the parents were satisfied with the medical help they received. But such dissatisfaction cannot always be explained by faulty communication techniques. Breaking the news to parents about an abnormal child is extremely distressing and demands insight, human understanding, non-sentimental sympathy as well, of course, as specialist knowledge. "Parents who are worried about their child's normality deserve not unthinking reassurance, but an informed opinion about the child and informed understanding of their feelings and problems" (MacKeith, 1961a). The giving of such opinion, according to Ellis (1965) "should be left to the doctor - and (that) he should only give this explanation and advice after he has gathered the evidence from all who are involved with the child and after he himself has struggled to understand the situation in which the child and his family find themselves". This is the procedure adopted by the Percy Hedley Clinic, and its success is warranted for by the study population's praise. One mother and two fathers felt that more could be done for their children - all others were satisfied.

The child's physical, social and emotional maturity is closely related to the parents' attitudes and behaviour, their standards of child care, the emotional climate of the home. As has been seen, the physical standards of accommodation and care were, generally, fairly high, though two homes were somewhat unkempt and eleven children slept in their parents' room. This is a much higher rate of success than Cockburn (1961) found in her Scottish sample where "about one quarter of the cases studied came from homes deemed unsatisfactory or unsuitable". The child's social maturity is closely bound up with his parents' emotional maturity, their relationship with each other and with the outside world. There did not appear to be any neurotically isolated nor insulated parents, though naturally, there was a certain incidence of housebound parents. The children, in this sample, had, according to their parents, access to other children (usually cousins) where there were no siblings. A complaint by 10 mothers was that other children were too rough and this usually meant that the handicapped child "played" alone. No index of over-protection was sought as with such young and handicapped children a certain amount of extra precaution is necessary. Since parental care is one medium for the expression of care personality characteristics, the specific competences, anxieties and possible distortions probably reflect the parents' experiences and personality structure but no quantitative measure was sought. There was one case of a mother's extreme protectiveness, an almost neurotic devotion to a 3 year old severely retarded son. There was the case of the father's apparently rejecting behaviour already noted. One could explain the first case by the emotional satisfaction derived from the interaction and fail to see it as emotional exploitation or hyperpaedophilia (Ounsted, 1955). Where an only son is pitifully handicapped and culturally the child is seen as the future of the family (Roos, 1963) then one can understand the disappointed father's attempt to shut out an emotionally draining experience (Baum, 1961). These two instances apart, there were no behavioural indicationsof any of the untoward reactions often related in clinical literature, though a certain degree of tension was admitted by all parents to be present in their relationship and to be due to the presence of their handicapped child. No method of quantifying this tension was possible; but statistical procedures were adopted to discern parental estimations of intellectual potential of their cerebral palsied children. This will be discussed fully in the next two sections.

B. STATISTICAL ANALYSIS

Since the required process was generally that of correlation between characteristics of the parents or children which are numerically measurable, and the assessments of the parents which are essentially a binary idea and are thus only generally divisible into "realistic" and "non-realistic" it was decided that the coefficient of Bi-Serial Correlation was the most suitable numerical measure (McNemar, 1953). For the purposes of these calculations, over and under estimates were bracketed together as "non-realistic".

This method was used to investigate Hypothesis (3) - that the younger the child, the less realistic the parental estimate and expectation. The parents' estimates were divided as above and the ages of the children provided the numerical variable.

For p = realistic and q = non-realistic

$$r_{Bis} = \frac{A.M.p \; - \; A.M.q}{6} \times \frac{p\%.q\%}{z}$$

$$= \frac{4.088 \; - \; 3.57}{1.315} \times \frac{0.222}{0.362}$$

$$= +\,0.242$$

A further investigation was undertaken with the same data with the more probable 8 - 2 distribution in the 5+ frequency (Table 9).

This gave $r_{Bis} = 0.360$.

A similar method was employed to calculate the correlation between physical and intellectual handicaps.

In the other statistical tables, the data available was not suitable for this treatment since neither group was determined numerically or not with sufficient information or variety of numerical assessment. In these cases, percentages were calculated to illustrate and support the respective hypotheses.

C. HYPOTHESES

"Intelligence" has a high status in our culture. Nearly all parents expect their children to be above average, applying rule of thumb procedures. Even "normal" has overtones of down-grading. With physically handicapped children, it is thought that the parents might be aware of possible intellectual impairment, yet Boles (1959) found that with regard to "parental expectation", 72% of the cerebrally palsied children in his study were below average in intelligence, yet half or more of the parents believed that their children might be self-supporting, graduate from college and become professional persons. Zuk (1959) found "autistic distortion" in parents' biased estimates when they acted as Vineland informants about their retarded children who were relatively normal in motor functioning. He did not find this trend in parents whose children were also physically handicapped. Zuk posited the Freudian notion of unconscious wish fulfilment where in the case of the very mildly physically handicapped, the appearance of normalcy reinforces the unconscious desire for it. Such reinforcement is not present with the more obviously handicapped child; needs, in this instance, do not influence perception or cognitive processes. Jensen and Kogan (1962) found that parents over-rate the intelligence potential of younger cerebral palsied children to a greater extent than older children. Farber suggests that this may be because parents tend to minimise the amount of deviance of the child in his developing social roles. Rheingold (1945), Rosen (1955), and Schulman and Stern (1959) found that parents are fairly realistic in judging the I.Q. of their retarded children. Schulman and Stern, for example, found the correlation coefficient between test I.Q. and the "parent I.Q." to be +0.67. Barclay and Vaught, (1964) in their study of 40 mothers of young cerebral palsied children, found that neither age nor physical ability was related to maternal over-estimation of their children's future development and indicated that mothers' estimates are most deviant with regard to children of low intelligence. Three other studies are relevant. Ewert and Green (1957) studied a population of 100 mothers of retarded children seen as out-patients in the Mayo Clinic. These children were equally distributed as to etiology, organic and non-organic. Results indicated that approximately the same proportion of mothers of children with organic lesions and mothers of children with simple mental retardation were accurate in their estimates (i.e. estimated I.Q.'s within 15 points of actual score). The presence of a serious physical condition did not seem to be related either to accurate or erroneous estimates. These authors examined some of the factors possibly associated with this apparent tendency to over-estimate potential but did not find any significant relationship between accuracy of parental estimate and level of child's intelligence, sex, age, previous psychological testing, ordinal position or father's education or occupation nor, as has been already stated, between presence or absence of physical handicap. Rosen (1955) had found that the level of the child's intellectual rating did not seem related to the accuracy of the mother's appraisal and also had found no correlation between the mother's estimates of I.Q. and her realisation of the child's retardation. Ewert and Green found a significant relationship between the mother's educational level and the accuracy of her estimate of the child's functioning age level. In a group of children with a mean I.Q. of 61.1, Copabianco and Knox (1963) examined the effect of parental sex in parental I.Q. estimation. The 66 children in their study were mentally retarded. The mothers were found to over-estimate their children's ability by an average of 6.6 I.Q. points which was significantly different from full-scale I.Q. Fathers deviated as a group by only 0.6 I.Q. points which was not sigificantly different from full-scale I.Q. but was significantly different from the maternal estimates. Heriot and Schmickel (1967) in a study of 65 children with an average age of 94.5 months, average I.Q. of 77.32 and average Vineland quotient of 80.79, found that mothers slightly, but significantly, over-estimated their child's full-scale I.Q. and to a lesser extent, under-estimated the Vineland quotient. They report, "Our findings generally support the position taken by Schulman and Stern (1959) that there is a positive and significant relationship between parental estimate of I.Q. and measured full-scale I.Q. Both studies revealed very little difference between average maternal estimate and average I.Q.". Unlike the Ewert and Green (1957) findings, Heriot and Schmickel found that the presence of seizures was related to greater accuracy of appraisal and that I.Q. was positively related to the accuracy of maternal estimate.

The discrepancies in these findings is probably due to differences between the samples with regard to age, degree of physical and mental handicap, education and socioeconomic status of the parents, the availability of early assessment techniques and supportive counselling, and above all, of the definition by the parents of what constitutes retardation. In the present survey, one father speaking of his child who had a mild physical handicap but a severe high frequency deafness, remarked: "She's really normal, except for her hearing and speech". Perhaps a definition of normality is equally necessary. As in the Ewert and Green (1957) study, the parents manifested concern about the physical aspect of the handicap, mobility being seen as a priority. Ellis (1955) had found that, "In general most parents find it easier to accept a physical disability, such as a hemiplegia or a paraplegia because it can be seen and recognised. For a parent, who is often the last to give up hope that his child will eventually catch up with his fellows, it is a much harder task to accept a limit of intelligence, because intelligence cannot be seen". The raters in this study reported that replies to questions regarding the physical capacity of the child were relatively more accurate than those of intellectual potential. The clinical device of having the parents assign an age level to their child's development and functioning appears to be regarded as an index of the degree of acceptance by the parents of their child's condition (Ewert and Green, 1957; Rosen, 1955). However, acceptance is not the "all or nothing" process it was once thought to be, Stoddard (1959) did not find any correlation between parental awareness and acceptance. Rosen (1955) found time to be the significant factor in the gradual acceptance of a mentally handicapped child. It is probable that full scale acceptance of any child is rare. There is a balance struck in the best adjusted relationships between accepting and rejecting. Capobianco and Knox (1963) refer to the increased knowledge which parents have today of the nature of mental retardation and state that this adds to accuracy of parental appraisal and consequent acceptance of the child's condition. In the present study, there was a fair amount of initial ignorance of the nature of cerebral palsy as revealed in questionnaire responses, but in all cases, attendance at the Clinic assessment groups seems to have allayed unfounded fears. No measure of acceptance was sought. Certainly, parental attitudes are probably the most important factor in the cerebral palsied child's life. On theirrealistic appraisal of the situation will depend the child's personality growth, his self-concept, ability for self-evaluation; but to help the child, the parent has to come to terms with the deficit on the basis of a realistic realisation of the strengths. An effort was made, in this study, to determine how realistic parental appraisals are with regard to the handicapped child's physical, social, emotional status and educational potential, realising that although there has been some support in the literature for the hypothesised relationship between accuracy of parental estimation of the child's functioning and degree of acceptance of the child's condition, the kind of adaptation which the parent makes depends on a great many variables. Stone (1948) for example, thought that the mental health of the parent was the deciding factor; Worchel and Worchel (1961), Sheimo (1951) found that parental denial of mental deficiency was "an important element in their defence mechanisms." A minority of parents, 9.1% in the present study, maintained that they did not consider their child as "handicapped". Of the children in question, all but one had speech, four were only mildly physically handicapped and seven moderately physically handicapped, two with associated mental handicap; but there did not seem to be "denial" in the pathological sense. Michaels and Schucman (1962) indicate that the tendency to define the handicap as a lesser one or not at all, occurs in high socioeconomic status families. This did not appear to be the case in the present sample of parents and no trace of pathological distortion seemed evident. Parental pressures for achievment may reveal themselves later as a form of denial of abnormality but as yet, only two cases of possible over-stimulation had appeared in the sample.

To investigate, then, the accuracy of parental estimation of their child's functioning in the four areas already referred to, pertinent questions were put to each parent and the replies were independently rated by four members of the clinical team, among whom there was a very high degree of reliability. Three hypotheses were considered.

<u>Hypothesis (1)</u>: Over-estimation in parental appraisals.

MOTHERS			FATHERS		
Realistic	Non-realistic		Realistic	Non-realistic	
46 (69.7%)	20 (30.3%)		34 (61.8%)	21 (38.2%)	
	Over-estimate	Under-estimate		Over-estimate	Under-estimate
	19(28.8%)	1(1.5%)		20(36.4%)	1(1.8%)

From these results it will be seen that the majority of both parents made what were considered to be realistic appraisals of their handicapped child's present functioning in the physical, social and emotional areas and future achievement in the intellectual. These findings concur with those of Schulman and Stern (1959) and Heriot and Schmickel (1967) but are at variance with those other workers whose samples consisted of cerebral palsied children and their mothers - Boles (1959), Jensen and Kogan (1962), Barclay and Vaught (1964). With regard to the Jensen and Kogan study, a greater number of their children were in the "mild" category of physical handicap than were those in the present study but otherwise, the samples are comparable and with regard to the method used to evaluate accuracy of estimate. Barclay and Vaught (1964) using Jensen and Kogan's (1962) rating scale but test scores as the basis for judgments of progress as opposed to staff ratings, found that mothers of young cerebral palsied children over-estimated their children's potential for future achievement. In this present study, I.Q. (where available) and S.Q. of the child were used as well as staff ratings to determine over or under-estimate of the child. So too, was the parent's ability to assess present status (physically, socially and emotionally) and future potential (for education). Boles (1959) had found that the mothers of cerebral palsied children in his sample were generally realistic about their child's <u>present</u> capacity but highly unrealistic in their hopes, for <u>future</u> improvement. Zuk (1959) found unrealism in the social areas (seen as "autistic distortion" in Vineland ratings by the mother), but in the present study, raters found that most unrealism was seen to operate in the assessment of educational potential (by 10.8%) and that the area in which most accurate estimation was made was that of motor attainments.

Capobianco and Knox (1964) with a population of 66 retarded children, age range 5.2 to 17.6 years, I.Q. range 30 to 84, and a "sophisticated" set of parents who had knowledge of mental retardation and experience with counselling, found mothers over-estimating I.Q.'s of their mentally retarded children and fathers' estimates to be significantly more accurate. Ewert and Green (1957) in their population of 100 mothers of retarded children found a greater percentage of accurate raters to be younger mothers, better educated and representing higher occupational levels. No significant relationship between the accuracy of estimates and the fathers' education or occupation was found. Schafer and Bell (1958) have called attention to the crucial role of years of schooling in maternal responses on the PARI. Accordingly an enquiry was made into the possible effect of parents' age, education and socioeconomic status on the accuracy of their estimates.

(a) Mothers	Correct estimate	Over-estimate	Under-estimate	Total	Correct estimate as a % of total
20 - 29 years	28	9	1	38	74%
30 - 39 years	16	8	0	24	67%
40 - 49 years	4	1	0	5	80%

(b) Fathers	Correct estimate	Over-estimate	Under-estimate	Total	Correct estimate as a % of total
20 - 29 years	14	9	0	23	61%
30 - 39 years	16	11	0	27	59%
40 - 49 years	5	0	1	6	83%

Table 5: Realism of Estimates according to parents' age.

(a) Mothers	Correct estimate	Over-estimate	Under-estimate	Total	Correct estimate as a % of total
Minimum education 9-10 yrs.	28	13	1	42	67%
More than minimum education 10+ years	18	6	0	24	75%

(b) Fathers	Correct estimate	Over-estimate	Under-estimate	Total	Correct estimate as a % of total
Minimum education 9-10 yrs.	22	14	0	36	61%
More than minimum education 10+ years	12	6	1	19	62%

Table 6: Realism of Estimate according to parents' education.

SES	Realistic estimate	Over-estimate	Under-estimate
I	5	0	0
II	8	1	1
III	8	9	0
IV	56	19	1
V	3	10	0

Table 7: Distribution of both parents' estimate according to SES.

With regard to age, the five parents in the 40-49 age bracket were found to have the highest percentage of realism due perhaps to experience with their other children and to their age. After that, the youngest group made the more realistic assessments, one mother of a moderately physically and mentally retarded little boy making an under-estimate of his capacity. The only other underestimate was that made by a father in the 40-49 age range, of his severely physically and mentally retarded daughter. When one considers education as a variable, the Ewert and Green (1957) finding that the younger the parent and the better educated, the more reliable the estimate is supported by the present data. It is to be noted that 75% of the mothers with a longer period of education rated realistically as compared with 62% of fathers of a similar period of education. Baldwin et al (1945) reported in a study of the educational levels found in various types of homes that "democratic" (more emotionally mature) attitudes were found more often in homes where the educational level of parents was high, while in homes where the educational level was low the parents exhibited either "passive-neglectful" or actively hostile attitudes towards their children. It would seem then that parental emotional adjustment is a function of education and socio-economic status, where normal children are concerned. Murstein (1960) reported the importance of cognitive and socioeconomic factors in adjustment of parents to leukemia in their children. This may also apply to parents of the handicapped.

With regard to socioeconomic status as a factor in parental estimation, all the parents of Class I made a realistic estimate, and only one in Class II made an over-estimate. Class IV parents made a high proportion of realistic appraisals, Class V parents a high number of over-estimates. As education and SES are closely related in our culture, these results tie up, to a certain degree, with the "education" results already discussed.

Fathers, according to Copabianco and Knox (1964) made significantly more accurate estimates of the learning ability of their children. Such was not the case in the present study where, as has already been seen, 69.7% mothers made realistic estimates as compared with 61.8% fathers. This may be due to the more constant involvement of the mother with the child, seeing him in all behavioural aspects and having more contact with doctors and therapists in the often dreary round of hospitals and clinics. A large percentage of fathers in the present study, while participating in the care of the handicapped child, yet alluded to the mother as having the "hardest job" all day and every day.

The possible influence of the sex of the child on like and unlike parent's estimates was next investigated. Farber, Jenne and Toigo (1960) found that stress on the parent of a mentally retarded child appeared to be sex-linked, with the mother showing greater stress if the child were a girl and the father showing more impact if the boy is retarded. This ties in with the theory of sex-role identification of Parsons and Bales (1955). Ewert and Green (1957) found no significant relationship between the accuracy of parental estimate of development and sex of the child. Results of the present study, expressed on a percentage basis show:

75% of mothers of boys were realistic)	64.6% of mothers of girls were realistic)
62.5% of fathers ___________________)	54.8% of fathers ___________________)

Mothers are thus seen to be more realistic of both sexes' development and potential. If impact of the retarded son were to lead to devaluation by the father (Aberle and Naegele, 1952), it is probable that this would be reflected in the father's assessment. This was not borne out by the figure of 62.5% of fathers who made a realistic estimate of their handicapped son's abilities.

It was thought that experience with other normal children might influence the process whereby parents make accurate assessments of their handicapped children. No parent had had experience with handicapped children till marriage and for 64 out of 66 families, this was a new experience. Accordingly, an investigation was made of the estimates of the parents where the handicapped child was an only child.

Estimates	y Realistic	x Non-realistic	x as a % of y
whole population	80	41	34%
those with one child only	13	20	60%

Table 8: Consideration of the estimates where the handicapped child is an only child.

These percentages show that only children are more likely to be unrealistically assessed than those from larger families, /Where there is a constant reminder of developmental milestones not being reached in the areas of child development and the presence of normal children must bring moments of comparison. The position of the child with reference to his siblings was investigated in each of these categories - oldest, intermediate, youngest or only child.

Position of Child	Parents' realistic estimate	Parents' unrealistic estimate
Oldest	86.2%	13.7%
Intermediate	76.9%	23%
Youngest	70.8%	29.1%
Only	39.3%	60.6%

These figures indicate that, apart from the only children, there is no significant difference found in birth order and realistic judgments made by parents. With regard to unrealistic estimates, youngest and only children are assessed with a high degree of error.

Heriot and Schmickel (1967) came to the conclusion that "mothers estimate their child's I.Q. most accurately (in this population) when the child is either seriously retarded or when the child comes relatively close to achieving full scale I.Q. quotients and Vineland quotients of 100". Barclay and Vaught (1964) indicated that estimates of the mother are "most deviant with respect to low intelligence". Miller (1958) in a study found parents of the mildly handicapped cerebral palsied children to be generally anxious, guilty and ambivalent in their feelings towards these children: "One of their big problems had to do with recognizing the condition as handicapping since the child was self-sufficient. Actually, their greatest need was to have this 'almost normal' child be normal. There was real confusion as to what to expect of the child since he seemed so variable in his capabilities........

This child was generally expected to perform beyond his capacity in all ways, possibly as a salve for the wounded parental ego". It is worthy of note that these children had been referred to a child guidance clinic with emotional problems, but nevertheless the cognitive dissonance engendered by the "almost normal" child could account for his inaccurate assessment. In the present study, 91.3% of the parents of the mildly handicapped children made realistic assessments; 8.6% made unrealistic estimates. Of these children, 10 are now attending their local primary schools, and 2 are at local E.S.N. schools. It would appear that mildly handicapped children can be adequately assessed by parents. None of these children had a S.Q. on the Vineland above 90 (the range was 76 to 90) and one only had an above-average I.Q. (I.Q. and S.Q. figures are given in Appendix A). They thus support the Heriot and Schmickel conclusion already referred to - that "mothers estimate their child's I.Q. most accurately when the child..... comes relatively close to achieving full scale I.Q. quotients and Vineland quotients of 100".

Hypothesis (2): Physically and intellectually handicapped children are more likely to be rated unrealistically. The child's intellectual and physical capacity is now to be considered as a variable in parental estimation. Tables 1 and 1a show the distribution of handicap according to severity and its relationship to intellectual rating in the population of children. The mean Vineland Social Quotient was 52.4. The range of I.Q.'s of the children was very wide, and though the intelligence tests employed were not completely comparable with each other, each was chosen to secure the most objective evaluation of level of functioning. An investigation was made of the correlation between physical and intellectual handicaps in consideration of this hypothesis (2). Since a numerical I.Q. for all the children was not available in view of the difficulty of testing the more severely handicapped, a division of the population according to the distinction "Severe and moderately severely intellectually retarded" and "above average, normal and slightly retarded", making the division at an I.Q. level of 70. This was then used with the numerical data of the S.Q. to calculate the Bi-Serial correlation coefficient given by

$$r_{Bis} = \frac{A.M.p - A.M.q}{6} \times \frac{p.q}{z}$$

where A.M.p = the mean of the group "above average etc."

A.M.q = the mean of the group "severe and mod. severe etc."

and p.q, the fractional division of the population according to the given dichotomy.

The relevant figures were

$$r = \frac{75.46 - 36.17}{29.1} \times \frac{26 \times 40}{66 \times 66} \times \frac{1}{0.386}$$

$$= +0.835$$, showing a fairly high degree of positive correlation.

Dividing the population into those with severe or moderate handicap, both intellectual and physical against the remainder, it was found that 38 children were in Category I and 28 in Category II.

	No. of children	No. of realistic estimates x	No. of unrealistic estimates y	y as a % of x
severe/mod. handicap	38	69	25	36.2%
neither sev. or mod. physical and intellectual	28	52	16	30.8%

In the severe/moderate category, 36.2% of the children were unrealistically estimated and in the second category, 30.8% were unrealistically estimated. These percentages support the initial hypothesis but the degree of difference is hardly marked. A large number of parents of moderately handicapped children were realistic in their estimates. Many of these children had associated defects, e.g. eye defects, whereas Abercrombie (1963) has pointed out, responses and perception can be influenced by the child's appearance. Dangers of stereotyping and spread (Wright, 1960) were present, yet parents were realistic. This supports Zuk's (1959) study in which he found the Freudian notion of unconscious wish fulfilment to operate with non-motor handicapped retarded children but the "realistic" process to operate when there was no perceptual ambiguity and motor impairment imposed some restriction on perceptual evaluation. Ewert and Green (1959) did not find that the presence or absence of a severe physical abnormality was related to the mother's accurate estimate. Results from this present study are somewhat inconclusive with regard to degree of physical and intellectual handicap as a factor in parental assessment.

Hypothesis (3): The younger the child, the less reliable the parental estimate and expectation.

Coughlin (1947) found with her 51 cases, none of whom was cerebrally palsied, an inclination to accept the handicapped on a level lower than his age. Three factors are said to relate most to parental over-estimation - severity of physical handicap, degree of intellectual impairment and age of the child. Severity of intellectual and physical handicap have been seen to contribute to unrealism in assessment. It is now proposed to analyse the age of the child as a factor in assessment. Jensen and Kogan (1962) found that the younger, more severely handicapped and more intellectually retarded children were more frequently over-estimated by their parents. But Barclay and Vaught (1964) found over-estimation of cerebral palsied children by parents, regardless of age or degree of physical handicap: "It would seem that the factor of intelligence seems to overshadow other handicaps at least in the eyes of the parents of this study".

A comparison of parents' estimates has been made according to the age of the child.

(a) Mothers' Estimates (66 replies)

Age of child	Realistic estimate	Over or under estimate
1+	1	2
2+	7	7
3+	14	3
4+	18	5
5+	2	3
6+	1	0
7+	3	0

(b) Fathers' Estimates (55 replies)

Age of child	Realistic estimate	Over or under estimate
1+	1	2
2+	6	6
3+	8	5
4+	14	5
5+	3	2
6+	1	0
7+	1	1

Results suggest that unreasonable estimates are more likely while the child is young. The result in (a) 5+ giving a disproportionate faulty estimate is for too small a statistical population to be significant.

To consider the correlation between the realism of the parents' estimates and the age of the child, both parents' estimates were combined into the following Table 9.

Age	x realistic estimate	y nonrealistic estimate	y as a % of (x + y)
1+	2	4	67%
2+	13	13	50%
3+	22	8	27%
4+	32	10	24%
5+	5	5	50%
6+	2	0	0%
7+	4	1	25%

From this table it can be seen that the general trend is for a higher proportion of the estimates of the younger children to be unrealistic than for those of the rather older. Only the 2+, 3+ and 4+ age groups have sufficiently large populations to illustrate the general trend. For this set of data:

> r_{Bis} = 0.242 showing fair correlation, considering the 5+ frequency, which does not follow the general trend of the % figures. In fact had the frequencies for 5+ been 8 - x, 2 - y, the equivalent value of r_{Bis} would have been 0.360.

At 2+ there seems to be a watershed and beyond 3 years the estimates are much more realistic. At 5+ the direction seems to be against the general trend. Is it that "school age" presents an element of distortion? The

The position of "handicapped" has crystallised for the 6+ and 7+ children. Had they been considered educable, they would already have been in primary or special schools, or training centres.

The previous discussion has pointed to the ability of the majority of the parents in this study to make realistic estimates of their cerebral palsied children's achievements and potential. From their replies to the questionnaire, their concerns seemed realistic as were their efforts to make reality adjustments. Grief and tension have been experienced, but many parents have already come to the realisation that not only had they been expecting normality but also perfection. The role of unfamiliarity may produce conflict and dissonance (Festinger, 1957), the power of physique generates the spread phenomenon (Wright, 1960), especially where there has been little preparation for the problem. Some of the unrealistic assessments may have been elicited by physical deviations in the child preventing a rewarding response to parental stimulation, but as there were only 2 cases of under-estimation, this may not be a significant factor. Prechtl (1963) found that the baby with brain damage and abnormality of sensory input may fail to make a satisfactory interaction with the mother. This may produce an emotional reaction in the mother not conducive to accuracy of estimate. This population, a restricted and highly selective one, has had the advantage of early medical help and guidance in management at the Percy Hedley Clinic where assessment is continuous and preparation of the parents for the next stage is carefully considered. Attendance at the assessment groups and consequent interaction with other parents, observation of other children, helps in the reality process. This has probably helped the parents to make their assessments more realistic as has the educational level reached by them.

IV. CONCLUSION

The purpose of this research was to study 66 families in which there was a young cerebral palsied child in order to investigate the effect of such a child on parental attitudes and behaviour. One area was quantatively explored, that of maternal and paternal estimates of present status and future potential of the handicapped child's physical, social, emotional and intellectual functioning.

Three hypotheses were established. Hypothesis (1) - that parental estimates of present status and future achievements should over-estimate the capacity of the child - was rejected. 69.7% of mothers and 61.8% of fathers were considered to have made realistic appraisals by independent raters among whom there was a high degree of inter-rater reliability. Educational potential was found to be least reliably appraised and motor attainments to be most accurately estimated. Education and age of the parent appear to be significant factors in realistic estimation; mothers were found to make more accurate estimates of both sexes' development than did fathers; and only children tended to be unrealistically assessed.

Hypothesis (2) - that the children who were handicapped both physically and intellectually were more likely to be rated unrealistically than were less handicapped children - was supported; but the degree of difference was hardly marked. Findings as to how interactive physical disability is with parental perceptions were inconclusive.

Hypothesis (3) - that the younger the child, the less realistic the parental estimate and expectation - was supported. This 66 families study was undertaken at a time when the majority of the children were approaching a school placement age. The period when the parents appeared more concerned with the physical rather than the intellectual concomitants of the disability was receding. Family expectations were found to increase as the child lost his babyish appearance. In fact, his place as "the baby" chronologically speaking, has been ceded in 7 cases where another baby has been born since the investigation began in 1965. 27.3% parents - 20 mothersand 13 fathers - had stated that their home was centred on the handicapped child. Only one of these mothers has had another baby since then. A marked degree of realism was found in parental estimates of children of 4+, but with this, a certain amount of over-estimation was also found. The child's future was seen to depend not only on his ability to walk, but on the achievement of personal, social, emotional and educational adjustment and achieved ideally in the local primary school setting.

About 87.9% of the children in the present study will become adults in a non-handicapped community, such as that in which their "psychologically at risk" families are living today. This study has shown that 67.2% of the fathers and 70.6% of the mothers were agreed that a handicapped child, their cerebral palsied child, caused tension in the family; but as yet, only 6 cases of agreed worsening relations and disharmony due to the child, were found. Margolies and Wortis (1956) found increasing family problems as the cerebral palsied children in their New York study grew older: it will be of interest to discover what effect time and expertise have on intrafamily relationships in these 66 English families when investigated at a later date and at another developmental level. The "tension" generally admitted does not appear to be synonymous with Boles's (1959) "marital conflict" and which he found to differentiate mothers of cerebral palsied children from mothers of non-handicapped children. The majority of the 66 parents said this "tension" began with the realisation that their child was handicapped. It would appear that in these early months - or even weeks - when the family is arriving at a healthy or maladaptive resolution of the crisis event that these "at risk" families derive most benefit from timely and perceptive medical support such as that described by Denhoff and Holden (1951). The doctor's ability to empathise without loss of perspective, his acceptance that there are some things which can never be wholly accepted by parents, his realisation that "we fail to see their sufferings through their eyes but rather through our own feelings" (Mandelbaum and Wheeler, 1960) frees him to work towards the family's optimal growth and adjustment. Ellis (1966) remarks: "From the beginning the parents have the most important part to play in the life of a child with a developmental disorder", and in the early stages, parents appear to be the major focus of treatment at his clinic. With earlier diagnosis and referral to such a clinic, it is hoped that distressful parental reactions will be minimised. Only 21.2% of the parents in this study had "no complaint" about the way in which they were told their child was handicapped, and of the remainder many were loud and bitter in their complaints about how the initial medical findings had been transmitted before their referral to Percy Hedley Clinic. This has already been discussed but the importance of these early interviews with the pediatrician cannot be over-emphasised for they play a part in the community defence programme to help those "at risk" families from becoming socially and emotionally isolate and "too cohesive" in Schaffer's (1964) term, "handicapped" in Sheridan's reference (1965). The significance of the doctor's role emerged very clearly in the findings. Questionnaire replies evidenced the parents' dependence on medical support even after the peak period of emotional vulnerability.

I.Q. findings in this study are shown alongside the Ellis (1955) figures:

2% children had an I.Q. rating	Above Average	(4.5% - 1968)
38%	Normal	(10.6% - 1968)
37%	Slightly Retarded	(24.2% - 1968)
15%	Moderately Retarded	(25.7% - 1968)
8%	Grossly Retarded	(34.8% - 1968)

Compared with the normal child population, both studies show the percentage of "above average" children with cerebral palsy to be disproportionately low. In this 1968 study, only 10.6% of children have a "Normal" rating as compared with 38% (Ellis, 1955) and 52% (normal child population); 84.7% have I.Q.'s below normal as compared with 60% (Ellis, 1955) and 25% in the normal population. A reason for disparity may be the young age of the clinic population as compared with Ellis's 5-16 years age range in 1955 and may be also due to the imprecise tools with which the I.Q. of young cerebral palsied children has to be computed. The figures for intellectually severely retarded children also show a discrepancy. 20 children in the present survey or 30.3% were untestable. Ellis (1955) refers to the fact that his findings confirm the intellectual backwardness of more than half the cerebral palsy population and adds: "Whether this backwardness is the result of poor innate intelligence or of inadequate and abnormal movement and sensation in early childhood is a question which must be left for future research to answer".

Other research possibilities emerge from the findings. The possible effects of the over-estimating parents' attitudes on the handicapped child's personality development might be a fruitful investigation, as might be a follow-up study of the 24 prematurely born children in the sample as compared with the "full-term" ones. One might profitably enquire into a later and perhaps more accurate estimate of ability by the parent due to the child's increasing age and consequent parental experience of his weaknesses and strengths. The absence of a control group in this study is regretted. An indication of the amount, if any, of a parent's over-estimation of his normal child's potential at the pre-school stage would have been helpful in the interpretation of the results of the present study in which 38.2% of fathers made an unrealistic appraisal (36.4% over-estimating) and 30.3% of mothers made an unrealistic estimate (28.5% over-estimating). Do parents of deaf children, blind children over-estimate to the same degree? An analysis of response functions of the handicapped child - he contributes to behavioural change as much as do the stimulus figures in his environment -

might be valuable in such parent-child studies as the present one in which stereotyping may have restrictive or over-evaluating effects on appraisal. The atpyicality and strangeness of the children in the sample was beginning to be noticed and conformity to the "normal" performance of the favoured majority wished for. How such parental fear of lowered status position might affect the child's later self-acceptance could be explored, preferably with psychometric and laboratory techniques.

"The healthy upbringing of children in a restricted living space by parents rendered uncertain of themselves by the great and small anxieties and difficulties of our time is rarely achieved by the simple light of nature or by the coldly scientific application of rules deduced from psychoanalysis or from child development studies" (Wall, 1955). Many of the parents in this study referred to themselves as "unsure", "uncertain" when dealing with the strangeness of a handicapped baby. "Physical disability, through social derogation does produce psychological problems", according to Wright (1960) and Allen and Pearson (1928) pointed out that the "feeling of inferiority has causes other than the physical defect, although these causes are associated with and conditioned by it". Schaffer (1964) found, in his study, that many of the marriages were close to breaking point: "the family unity turns out to be a deceptive phenomenon, a pseudo-cohesiveness". No pathological dependency seemed present in this study. There was "tension" and marital tension in six cases. But raising a normal family is difficult enough and must produce its own situational crises. ". Doing the washing and Hoovering at night -

it's a dreadful life" might have been an experience replicated by many young mothers with no handicapped child to claim their attention all day. As was also the disruption of meal-times, sleeping arrangements and restriction of social life. Many parents of normal children over-protect them and many only children are "pivots of family life" in Gibb's (1958) phrase. The young mother of a cerebral palsied child has the everyday problems of bathing, feeding, nappy-changing, but for her, there is a prolonged babyhood to cope with and the necessity of mastering special techniques in management (Culloty, 1961). And hers is a long-term commitment, during which she will no doubt be assailed by grief, hostility, anger, regression, guilt, uncertainty. Reality reinforces hostility - the child is frustrating, the community uncaring. Only later research will reveal how these 66 families will cope with such further problems of continued dependency, sibling attitudes, school failure, possible institutionalisation, all the existential difficulties their lives will bring. One would hope that Nursery School provision might offset the frequent sensory deprivation and lack of meaningful experience in the lives of these small handicapped children whose environment may be confined to some floor space, a few toys with which he does not play and an over-worked mother. Training in White's (1960) concept of competence and in social independence can be organised in centres where the children can learn with enjoyment to explore the real world and to make relationships beyond the narrow confines of family relations. Zimmerman and Jones (1965) report gains in intellectual ratings, social skills and general adaptability of pre-school cerebral palsied children who were given early training and environmental enrichment. The incidence of one cerebral palsied child per one thousand is numerically small. Could the young cerebral palsied child not be integrated into existing Nurseries, at least the less severely retarded? To do so, could surely implement the Plowden Report philosophy - "At the heart of the educational process lies the child". We might add - "the cerebral palsied child".

APPENDIX A

DESCRIPTION OF THE CHILD POPULATION

	AGE	BIRTH WEIGHT		F.TERM/ PREM.	DIAGNOSIS	I.Q.	S.Q.	PLACEMENT (1968)
		lbs.	ozs.					
1	3.11	8	15	F.T.	Right hemiathetosis	122(SB)	125	Special school
2	4.11	8	8	F.T.	Bilateral athetosis. High frequency deafness	77(MP)	73	Special school
3	4.6	7	14	F.T.	Ataxia following head injury	55(MP) 64(SB)	62	Special school
4	4.7	6	12	F.T.	Right hemiplegia	Normal	87	Primary school
5	2.4	7	4	F.T.	Paraplegia	Normal	89	Primary school
6	7.4	8	3	F.T.	Spastic quadriplegia. Mental retardation. Fits.	Untestable	11.3	At home. Awaiting admission to J.T. Centre
7	7.11	7	1	F.T.	Spastic quadriplegia. Mental retardation	Untestable	10.5	J.T. centre
8	5.6	6	12	F.T.	Mental retardation	Untestable	14	Transferred
9	3.3	6	1	F.T.	Spastic quadriplegia. Mental retardation	Untestable	42	J.T. Centre
10	2.2	8	3	F.T.	Bilateral Athetosis	Slightly mentally retarded	54	Waiting list for special school
11	2.3	8	5	F.T.	Right hemiplegia	Normal	87	Primary school
12	5.9	3	8	P	Spastic quadriplegia. Mental retardation	Untestable	23.5	J.T. Centre
13	4.4	7	0	F.T.	Ataxia. Mental retardation	Untestable	30	S.C. Unit
14	3.3	2	11	P	Spastic paraplegia	81(MP) 119(SB)	68	Primary school
15	4.6	3	5	P	Spastic paraplegia. Fits.	68WISC.	90	Special school
16	2.11	5	0	F.T.	Spastic quadriplegia. Mental retardation	Moderately Mentally retarded	42	S.C. Unit

	AGE	BIRTH WEIGHT		F.TERM/ PREM.	DIAGNOSIS	I.Q.	S.Q.	PLACEMENT (1968)
		lbs.	ozs.					
17	2.8	6	12	F.T.	Right hemiplegia	Normal	90	Primary school
18	4	9	4	F.T.	Left hemiplegia. Mental retardation	50 (non-verbal IQ Minnesota Pre-School Scale)	39	J.T. Centre
19	3.5	8	9	F.T.	Athetosis	79(SB)	65	Special school
20	3.2	5	7	P	Spastic paraplegia	Normal	86	Primary school
21	3.10	-		F.T.	Spastic quadriplegia	81-77(SB)	40	Special school
22	4.9	-		F.T.	Hydrocephalus following meningitis. Spastic quadriplegia. Mental retardation	Severely Mentally retarded	14.5	Hospital for Subnormals
23	4	-		F.T.	Ataxia. Mental retardation	52(MP)	43.5	J.T.Centre
24	5.11	2	5	P	Spastic quadriplegia. Mental retardation	57(SB)	72	J.T. Centre
25	2.10	8	12	F.T.	Right hemiplegia. Mental retardation	Moderately mentally retarded	52	J.T. Centre
26	2.11	7	8	F.T.	Left hemiplegia. Dysarthria	80(MP)	82	Special school
27	4.7	8	12	F.T.	Congenital hydrocephalus. Ataxia. Mental retardation.	Untestable	40	J.T. Centre
28	4.5	5	2	F.T.	Spastic quadriplegia. Fits. Mental retardation.	Untestable	26.5	J.T. Centre
29	4	7	2	F.T.	Spastic paraplegia. Mental retardation	Untestable	29	J.T. Centre
30	4	6	2	F.T.	Spastic quadriplegia Mental retardation	Untestable	10.5	J.T. Centre

	AGE	BIRTH WEIGHT		F.TERM/ PREM.	DIAGNOSIS	I.Q.	S.Q.	PLACEMENT (1968)
		lbs.	ozs.					
31	3	9	8	F.T.	Ataxia. Mental retardation	Moderately mentally retarded	35	J.T. Centre
32	3.8	4	11	P	Spastic paraplegia	122(MP)	61	Special school
33	3.3	-		F.T.	Spastic quadriplegia. Mental retardation	Severely mentally retarded	38	At home
34	3.10	3	1	P	Spastic quadriplegia	71(MP)	46	Special school
35	2.8	2	0	P	Spastic quadriplegia. Mental retardation	Severely mentally retarded	59	J.T. Centre
36	4.7	-		F.T.	Left hemiplegia	89(SB)	90	Primary school
37	4.2	6	8	F.T.	Left hemiplegia. Dysarthria	56(MP) 69(SB)	58	Primary school
38	4.11	7	8	F.T.	Left hemiplegia following head injury. Aphasia. Mental retardation	44 (MP)	25	J.T. Centre
39	4.3	3	7	P	Spastic paraplegia	78(SB) 92(MP)	76	Special school
40	4.2	5	12	F.T.	Spastic quadriplegia. Recurrent chest infections	81(SB)	58	Special school
41	1.3	6	2	F.T.	Occipital encephalocoele. Left hemiplegia	Moderately mentally retarded	72	Assessment group
42	2.1	3	13	P	Spastic quadriplegia. Athetosis. Mental retardation	Untestable	30	J. T. Centre
43	4	8	1	F.T.	Mental retardation. Visual impairment	Untestable	39	J.T. Centre
44	1.11	3	1	P	Spastic paraplegia	Slightly mentally retarded	65	Special school
45	3.8	7	7	F.T.	Spastic quadriplegia. Mental retardation	Untestable	18	At home

	AGE	BIRTH WEIGHT		F.TERM/ PREM.	DIAGNOSIS	I.Q.	S.Q.	PLACEMENT (1968)
		lbs.ozs.						
46	4.4	5	0	F.T.	Nystagmus. Mental retardation	79(SB)	88	Nursery school
47	2.3	9	9	F.T.	Right hemiplegia. Microcephaly	Normal	87	Primary school
48	5.7	3	4	P	Spastic quadriplegia. Mental retardation	45(SB) Verbal WISC 72	29	Residential school
49	4.11	2	2	P	Spastic paraplegia Mental retardation	39-48(SB)	33	Residential school
50	4.10	3	1	P	Right hemiplegia	80(SB)	87	Primary school
51	3.9	8	4	F.T.	Spastic quadriplegia. Mental retardation. Fits	65 (MP)	69	J. T. Centre
52	2.8	9	2	F.T.	Left hemiplegia. Mental retardation	Severely mentally retarded	87	J.T. Centre
53	1.3	7	0	F.T.	Mental retardation. Ataxia	Severely mentally retarded	46	Assessment group
54	4.9	6	5	F.T.	Spastic paraplegia	86(SB)	88	Primary school
55	3	3	10	P	Spastic paraplegia	67(SB)	52	Special school
56	3.5	7	15	F.T.	Right hemiplegia	Slightly mentally retarded	78	Special school
57	3.1	6	12	F.T.	Blind, deaf. Mental retardation following maternal rubella	Untestable	functioning at 15 months level	On waiting list for Hospital for Subnormals
58	2.10	3	8	P	Congenital hydrocephalus. Spastic paraplegia	92(SB) W.I.S.C. Verbal 106 Performance 79	61	Special school
59	7.5	5	0	P	Mental retardation. Visual defect	Untestable	65	Hospital for Subnormals

	AGE	BIRTH WEIGHT lbs.ozs.	F.TERM/ PREM.	DIAGNOSIS	I.Q.	S.Q.	PLACEMENT (1968)
60	3.2	3 13	P	Right hemiplegia	Moderately mentally retarded	62	Special school
61	2.9	5 8	F.T.	Spastic paraplegia	Slightly mentally retarded	39	Transferred
62	4.7	3 15	P	Spastic paraplegia. Mental retardation	57(MP)	76	At home
63	2.3	9 6	F.T.	Bilateral athetosis	Slightly mentally retarded	91	On waiting list for special school
64	5.8	8 7	F.T.	Microcephaly. Mental retardation. Spastic quadriplegia	Untestable	1	On waiting list for hospital for subnormals
65	3.11	5 7	F.T.	Mental retardation	Untestable	.18	At home
66	6.2	3 14	P	Spastic quadriplegia	59(SB) W.I.S.C. Verbal 76 Performance 58	27	Special school

APPENDIX B

QUESTIONNAIRE

to be used in Clinic/home interviews with Mother/Father
of the handicapped child.

DATE: ____________________

ENVIRONMENTAL FACTORS:

1. Child's name: ____ D.O.B. ____________

Sex: Boy/Girl

2. Mother's age: ______________________________ Working full-time/part-time.

Number of years married: __________________ Not working/Unemployed.

3. Former occupation: ____

4. Prior experience with children? ____

5. Father's age: ______________________________ Working full-time/part-time.

Occupation: ________________________________ Shift-working

Home at night/away from home.

Unemployed.

6. Family size (indicate ordinal position and name and sex of sibs)

____

____

7. Any other adult in the house? __________ If so, who? ____________________

8. Details of extended family: ____

____

9. Accommodation: Council house, flat, room own house: ________________

____

10. Living space: how much scope for N's activity, inside and outside?

____

PARENT'S ESTIMATE OF N - physically, socially, emotionally NOW

		Slightly	Badly
11. (a) What is N's special difficulty?______________			
	R. Leg		
	L. Leg		
	R. Arm		
	L. Arm		

(b) Does he have any difficulty in getting around?______________

(c) If he does not walk, does he crawl, push himself along the floor?

____

(d) Can he get up from a lying position or does he need help to do this?_______________________________

(e) Can he roll over on to his tummy?____________________

(f) Can he stay in the sitting position without support?__________

If not, what support does he need?____________________

(g) Can he stand without help?__________For how long?__________

(h) Can he climb upstairs?____________________________

(i) Can he walk at all?_______If so, with how much support?_______

____

(j) Has N difficulty in holding his head up?__________________

(k) Is N mobile with equipment?___________________________

12. Has N any special disabilities, of sight, hearing, chewing difficulties, for example?_____________________________

Is he healthy apart from this special difficulty?______________

SOCIALIZATION

13. Are there some things N can do for himself?___________________

Can he occupy himself when you are out of the room?____________

Can he play with other children?__________________________

Follow simple instructions?________Can he drink from a cup?_______

Feed himself?_________With or without help?__________________

If he cannot feed himself, do you feed him?___________________

14. Does N have his meals with the family?____________________

How do you arrange meal times if you have other small children?

____

Do you find this a trying time?________________________

COMMUNICATION

15. Has N any difficulty with his speech?____________________

Can strangers always understand him?____________________

Do you always understand him?________________________

Do other children?______________________________

Did he speak when you expected him to?____________________

Is he quicker or slower?____________________________

16. What do other children in the family feel about N?____________

Do they play with him?____________________________

Do their friends know N?___________________________

Perhaps play with him?____________________________

17. If he is the 'only one' does he meet cousins or neighbours' children sometimes?____________________________

What is their attitude to him?________________________

18. Sometimes with a handicapped child one spends a lot of time with him and the rest of the family feel a bit jealous, have you found this?

____

If so, how do you deal with it?________________________

____

19. Do you think you are less strict with N because of his handicap?

____

20. What does your husband/wife think about this?______________

____

Does he/she expect more or less of N than you do?____________

21. Have you tried to toilet train N?______________________

Can he let you know by some clue that he needs to go to the toilet?

____

22. If dry usually, when he does have an accident, do you scold him?

________________Show him that you disapprove?______________

Or do you disregard it?____________________________________

23. Who does the 'spanking' in your house?______________________

Does your husband/wife leave it to you?______________________

Do you think a handicapped child should be corrected?__________

24. Does N take an interest in other people - other children - tys?

____

Does he seem to concentrate on you?________________________

25. Would he understand the danger attached to a boiling kettle, the fire?____

EMOTIONAL FACTORS

26. Would you say that N is very attached to you?_________________

Does he cling to you?____________Seek contact?______________

Does he draw away?____

27. Have you and N ever been separated?_________________________

If so, was he upset?___________Were you upset?_______________

Do you ever leave him for short periods with a baby sitter, a relative?____

28. Would you like to tell me how N appears to you? Is he loving, distant, spoiled, always demanding attention, independent, too babyish, shy, needs constant care?___________________________

29. In your opinion, has his difficulty had any effect on his learning ability?____

On his response to people?___________________________________

30. Do you think cuddles and kisses can lead to too much babying?

____

Does the handicapped child need extra love and protection?

____

31. Could you tell me some of your views of child-rearing?________________

____

____

What about discipline for example?________________________________

How are you bringing up N?______________________________________

Are you bringing him up as you were brought up?____________________

32. Would you ever punish N?_______________________________________

In what circumstances and how?__________________________________

33. How is N with strangers?_______________________________________

With doctors, therapists?______________________________________

With the woman next door?______________________________________

34. And with his father/mother?_____________________________________

What is the relationship?______________________________________

Very close/average/not so close as with you?______________________

35. What is his father's/mother's attitude to N?______________Resentful, dissatisfied, disappointed, accepting, indulgent?___________________

36. What amount of contact has his father with N?____________________

What does he do for him and how often?____________________________

____

37. Does your husband/wife ever resent the time you spend with N?________

Does your husband/wife worry that you must often be over-tired and would like to have time off with you but this is impossible now?____

38. Some parents feel isolated with a handicapped child. Do you?________

____

Are your neighbours helpful?______________________________________

Are your parents and in-laws a support?____________________________

Are you a member of a club or church organization of any kind?_______

____

Do you get out together often?____________________

39. Have you home help?__________Often/occasionally/seldom/never?_____

Have you a baby sitter?____________________

Often/occasionally/seldom/never?____________________

40. How do you manage the lifting of N?____________________

Are bathing times difficult?____________________

What about shopping?____________________

What about the future when N is heavier?____________________

____

41. Does your husband help with these things?____________________

42. Would you rate your home as child, parent or family centred?__________

______________________________Is this how you want and

think it should be?____________________

43. Some parents are brought closer together, others estranged by an event like this. Has your relationship with your husband/wife altered due to N's being handicapped?____________________

Are you always in agreement about his treatment?____________________

Disciplining?________________Care?____________________

Future?____________________

44. Do you think a handicapped child can lead to more tension in a family?

____

Does your husband/wife ever blame you?____________________

45. What about your health?____________________

Are you over-tired?__________Often/sometimes/never_______________

Depressed?________________Often/sometimes/never_______________

Worried?__________________Often/sometimes/never_______________

46. Did you realise early that N might be handicapped?____________________

____

47. Do you think N's handicap might have been avoided - by more efficient ante-natal care?________________By less anxiety?________________
Overwork perhaps during pregnancy?____________________________

48. How do you think parents should be told about their child's handicap?

____

And when?____

49. Would earlier diagnosis have helped in N's case?______________

50. Do you think parents should be given much information about their child's handicap?____

____

Do you feel you understand it as well as you want to?____________

____

51. About outings, holidays - does N restrict your plans, hopes?________
____________________Does he accompany you?________________

Do other parents take an interest in him?____________________

How do you feel about this NOW?____________________________

Did you always accept their interest or did you want to avoid people at first?____

52. Would you like N to go to an ordinary school, a special school, a day centre or have home teaching?____________________________

Have you any special reasons for your choice?__________________

____

53. Do you think N has average learning ability?________________

above " " " ________________

below " " " ________________

54. Do you think N will be able to go to a primary school or to a Special School or residential school?____________________________

____

55. What of the future, do you think N will be able to care for himself?

____

Or will he perhaps have to rely on others?____________________

____

56. What do you think N's greatest handicap is from N's point of view?

____

57. From your point of view?______________________________

What is hardest to cope with?___________________________

58. Do you plan for N's future?_____________________________

Does your husband/wife have similar ideas on this subject?_______

____

59. What effect has a handicapped child on a family - on your family?

____

____

60. Is there any way by which your burden could be lightened - more equipment - gadgets in the house, more discussion and advice in the clinic?_____________________________________

____

61. How would you rate your husband's/wife's behaviour to N?________

Strict, tolerant, too soft, indifferent, unconcerned___________

Has his attitude changed over the years?___________________

62. And you, how do you see yourself?______________________

Firm, honest, responsible, understanding, adjusted______________

63. Would you rate yourself as not concerned, concerned, very concerned?

____

64. Would you rate N as being not dependent, dependent, very dependent?

____

ADDITIONAL INFORMATION

Psychometric data

APPENDIX C

	Child's age	I.Q.	S.Q.	Physical Disability	Mother's age	Education	Father's age	Education	SES
1	3.11	122 (SB)	125	Moderate	45	10-13 yrs	45	10-13 yrs	II
2	4.11	77 (MP)	73	C.P. - Mild - deafness - moderate	31	9-10 yrs	33	9-10 yrs	IV
3	4.6	55 (MP) 64 (SB)	62	Severe	37	9-10 yrs	39	9-10 yrs	V
4	4.7	Normal	87	Mild	26	9-10 yrs	32	9-10 yrs	IV
5	2.4	Normal	89	Mild	25	10-13 yrs	27	10-13 yrs	III
6	7.4	Untestable	11.3	Severe	35	10-13 yrs	44	9-10 yrs	IV
7	7.11	Untestable	10.5	Severe	29	9-10 yrs	32	9-10 yrs	IV
8	5.6	Untestable	14	Severe	35	10-13 yrs	40	10-13 yrs	II
9	3.3	Untestable	42	Severe	26	9-10 yrs	33	9-10 yrs	IV
10	2.2	Slightly M.R.	54	Severe	31	9-10 yrs	30	10-13 yrs	III
11	2.3	Normal	87	Mild	26	9-10 yrs	32	9-10 yrs	IV
12	5.9	Untestable	23.5	Severe	31	10-13 yrs	32	10-13 yrs	III
13	4.4	Untestable	30	Moderate	28	9-10 yrs	29	9-10 yrs	IV
14	3.3	81 (MP) 119 (SB)	68	Mild	21	9-10 yrs	21	9-10 yrs	IV
15	4.6	68(WISC)	90	Moderate	26	10-13 yrs	27	over 13yrs	III
16	2.11	Moderately M.R.	42	Moderate	28	10-13 yrs	29	10-13 yrs	IV
17	2.8	Normal	90	Severe	22	9-10 yrs	25	10-13 yrs	IV
18	4	50 (non-verbal)	39	Moderate	28	10-13 yrs	29	10-13 yrs	IV

	Child's age	I.Q.	S.Q.	Physical Disability	Mother's age	Education	Father's age	Education	SES
19	3.5	79 (SB)	65	Moderate	26	10-13 yrs	26	9-10 yrs	IV
20	3.2	Normal	86	Mild	24	10-13 yrs	28	10-13 yrs	III
21	3.10	81 (SB) 77 (SB)	40	Severe	41	9-10 yrs	38	9-10 yrs	IV
22	4.9	Severely M.R.	14.5	Severe	26	9-10 yrs	28	9-10 yrs	V
23	4	52 (MP)	43.5	Moderate	40	9-10 yrs	41	9-10 yrs	IV
24	5.11	57 (SB)	72	Moderate	37	10-13 yrs	38	9-10 yrs	IV
25	2.10	Moderately M.R.	52	Moderate	23	9-10 yrs	26	9-10 yrs	IV
26	2.11	80 (MP)	82	Moderate	37	9-10 yrs	34	9-10 yrs	V
27	4.7	Untestable	40	Moderate	36	10-13 yrs	40	Over 13yrs	II
28	4.5	Untestable	26.5	Severe	34	9-10 yrs	38	9-10 yrs	IV
29	4	Untestable	29	Moderate	26	Over 13yrs	31	10-13 yrs	II
30	4	Untestable	10.5	Severe	29	10-13 yrs	30	10-13 yrs	III
31	3	Moderately M.R.	35	Moderate	42	9-10 yrs	41	9-10 yrs	IV
32	3.8	122 (MP)	61	Moderate	33	10-13 yrs	39	Over 13yrs	I
33	3.3	Severely M.R.	38	Severe	30	9-10 yrs	29	9-10 yrs	IV
34	3.10	71 (MP)	46	Moderate	36	9-10 yrs	39	9-10 yrs	IV
35	2.8	Severely M.R.	59	Moderate	29	9-10 yrs	32	9-10 yrs	V
36	4.7	89 (SB)	90	Mild	33	9-10 yrs	37	10-13 yrs	IV
37	4.2	56 (MP) 69 (SB)	58	Moderate	28	9-10 yrs	29	9-10 yrs	IV
38	4.11	44 (MP)	25	Severe	24	10-13 yrs	30	10-13 yrs	II

	Child's age	I.Q.	S.Q.	Physical Disability	Mother's age	Education	Father's age	Education	SES
39	4.3	78 (SB) 92 (MP)	76	Mild	32	Over 13 yrs	39	Over 13yrs	I
40	4.2	81 (SB)	58	Severe	24	10-13 yrs	27	9-10 yrs	IV
41	1.3	Moderately N.R.	72	Severe	21	9-10 yrs	21	9-10 yrs	IV
42	2.1	Untestable	.30	Severe	26	10-13 yrs	26	10-13 yrs	III
43	4	Severely M.R.	39	Severe	37	9-10 yrs	37	10-13 yrs	IV
44	1.11	Slightly M.R.	65	Moderate	20	9-10 yrs	24	9-10 yrs	IV
45	3.8	Untestable	.18	Severe	26	9-10 yrs	27	9-10 yrs	IV
46	4.4	79 (SB)	88	Moderate	35	9-10 yrs	36	9-10 yrs	IV
47	2.3	Normal	87	Mild	26	10-13 yrs	26	10-13 yrs	III
48	5.7	45 (SB) 72 (Verbal WISC)	29	Moderate	35	9-10 yrs	36	9-10 yrs	V
49	4.11	39 (SB) 48 (SB)	33	Moderate	24	10-13 yrs	23	9-10 yrs	IV
50	4.10	80 (SB)	87	Mild	28	9-10 yrs	33	9-10 yrs	IV
51	3.9	65 (MP)	69	Severe	29	9-10 yrs	33	9-10 yrs	V
52	2.8	Severely M.R.	87	Severe	26	9-10 yrs	30	9-10 yrs	V
53	1.3	Severely M.R.	46	Mild	33	9-10 yrs	36	9-10 yrs	IV
54	4.9	86 (SB)	88	Mild	24	9-10 yrs	27	9-10 yrs	IV
55	3	67 (SB)	52	Moderate	25	9-10 yrs	28	9-10 yrs	IV
56	3.5	E.S.N.	78	Mild	29	9-10 yrs	29	9-10 yrs	IV
57	3.1	Untestable	15 months	Severe	36	10-13 yrs	39	10-13 yrs	III
58	2.10	92(SB) 106verb) 79 perf) WISC	61	Moderate	27	Over 13yrs	32	Over 13yrs	I

	Child's age	I.Q.	S.Q.	Physical Disability	Mother's age	Education	Father's age	Education	SES
59	7.5	Untestable	.65	Severe	44	9-10 yrs	43	9-10 yrs	IV
60	3.2	Moderately M.R.	62	Moderate	24	9-10 yrs	25	9-10 yrs	IV
61	2.9	Slightly M.R.	39	Mild	29	9-10 yrs	28	9-10 yrs	IV
62	4.7	57 (MP)	76	Moderate	34	9-10 yrs	36	9-10 yrs	IV
63	2.3	Slightly M.R.	91	Severe	36	10-13 yrs	35	Over 13yrs	II
64	5.8	Untestable	1	Severe	39	9-10 yrs	40	9-10 yrs	IV
65	3.11	Untestable	.18	Severe	32	9-10 yrs	37	9.10 yrs	IV
66	6.2	59 (SB)	27	Severe	29	9-10 yrs	29	9-10 yrs	IV

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