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GUILT; ANXIETY REACTION OF PARENTS IN HAVING AN

INTELLECTUALLY HANDICAPPED CHILD

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ABSTRACT

Chronic Guilt: Parents emotional attitude response to having a mentally defective child.

The aim of this project is two-fold

- (1) To propose that most parents who have a mentally defective child suffer from a pervasive psychological reaction, chronic guilt, and that it is not always recognized by the professional personnel - physicians, psychologists, and social workers, who attempt to help them
- (2) To suggest some of the implications of the phenomenon of chronic guilt for parent counselling processes.

Chronic guilt is a complex emotional attitude of long term duration and generally involving emotional conflict, grief, fear, love, anxiety, anger, hatred, protection, sympathy and defensive elements, and arising out of real or imagined contravention of moral and social standards in act or thought.

Most, if not all, of these parents suffer from chronic guilt throughout their lives regardless of whether the child is kept at home or 'put away'. The intensity of this guilt varies from time to time for the same person, from situation to situation, and from one family to another. Chronic guilt may be more intense for one parent than the other in the same family. Many factors such as parents personality, ethnic origin, religion and social class can influence the intensity of this feeling. Although chronic guilt may be felt by some parents of minimally retarded children, the phenomenon is almost universal among parents of severely or moderately retarded children, that is those children who would be regarded as retarded in any society or group.

The reality faced by the parents of severely retarded children is such as to justify the chronic guilt. When a parent is asked to accept mental deficiency it is not clear just what he is asked to do. The stress placed on acceptance may suggest to the parent that he is expected to see his or her child from the point of view of the professional. This expectancy can make the parent both resentful and resistant.

The first part of this study reviews some of the important literature published during the past twenty years, and suggests that trait factor analysis could be a basis for the chronic guilt syndrome.

The second part of the study is a field investigation of Wolfensberger's theory that guilt can be a positive attribute. From a small New Zealand sample of parents of handicapped children, who were referred or visited over one month (Kimberley Hospital) and asked to complete the 16 PF, four trait factors were extracted to support the contention and underline the complexity of the chronic guilt.

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INTRODUCTION

The American Association for Mental Deficiency defines mental deficiency as below average general intellectual functioning, originating in the developmental period, associated with impairment of adaptive behavior, (Clarke and Clarke 197). According to the World Health Organisation's definition (1974) mental subnormality consists of two categories,

- (1) That due to environmental causes with no CNS impairment (mental retardation) and
- (2) That due to CNS disorders (mental deficiency)

Statistically 16% of individuals will have IQ's below 85 IQ points and 2% below 70 IQ points. Mental retardation may be classified according to IQ, developmental characteristics, potential for education or social and vocational adequacy. (Table II)(Appendix I)

There is no valid way of measuring social adaptability, but it is a far more reliable indication of a child's eventual outcome as an adult, than his IQ (Solomon and Patch, 1974). Many children with low IQ's fit in well into community setting as adults because of their good social adjustment, whereas others with higher IQ's end up in institutions because of their deviant behavior. Classifications have been based primarily on intelligence testing, but in assessing the potential for socially adequate adjustments in individual cases, the physicians, social workers, teachers, and psychologists, observations and judgments are as important as the objective ratings by IQ scores; this is assuming empathic acceptance of the handicapped child and not rejection in toto.

The effective support of parents in their care, acceptance, love and rearing of their handicapped child is very dependent on the empathic understanding of the support services, which can make or break the relationship, it is suggested. Much has been written on the care, education, and services available for the handicapped child, (Johnson and Myklebust, 1967; Peter, 1965; Wolfensberger, 1967; Deutsch, 1967; Gunzburg 1968; etc.), but little is written on the needs for understanding and support that the parents need throughout their care, placement, whether in schools or training facilities and later work or vocational and residential settings for their dependent offspring.

As is the case with normal children, the upbringing of the retarded child is primarily the task of the parents, then the day care centres, schools or training centres. Specialists can only assist the child, his parents, and his teachers to solve problems they have been unable to manage. Periods of crises when families may need additional help include

- (1) the first suspicion of the diagnosis and this may be divided into two categories
 - (a) from birth to twelve to eighteen months of age, and
 - (b) from four to six years or older
- (2) the period when diagnostic studies are being made
- (3) enrolment at school or training centre
- (4) adjustment problems with peers and siblings
- (5) family crises
- (6) vocational placement whether in sheltered workshop (SIH); sheltered employment, or institution.

Placement requires the parents to make a decision and having made the decision it does seem that the regret phase which follows emphasises the feelings of guilt and self-accusation which have lain dormant for some time and there is a need for further support and working through the anxiety of having a handicapped sibling.

Guilt may be defined as 'the emotional feeling associated with the realisation that one has violated an important social, moral or ethical regulation.' According to the psychoanalysts, guilt need not be conscious, and some guilt may be imaginary; and in the latter case it is assumed that the imagined guilt is symbolic of real repressed guilt; (Chaplin, 1970). Drever (1969) defines guilt as a 'sense of wrongdoing, as an emotional attitude generally involving emotional conflict, arising out of real or imagined contravention of moral or social standards in act or thought.' Throughout this paper the theme of guilt which evolves into chronic guilt in parents of handicapped children, Drever's definition in which he emphasises the emotional attitude and emotional conflict whether real or imagined, is accepted as the meaning for chronic guilt.

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CHAPTER IAnxiety Reaction of Parents

Management of the parents' reaction and potential guilt feelings should begin when the diagnosis of mental retardation must be conveyed to them. This is the first period of maximum stress and a lot more must be done than just reporting the facts; parents must be given help with their feelings as the anxiety caused by the diagnosis of mental retardation or mental handicap results in a period of emotional disintegration. Areas of concern involve the marital relationship, mother's emotional health (greater post natal) and personality characteristics in stress situations, father's emotional health and reactions; siblings attitudes and due regard to grandparents' acceptance or rejection influencing the parents. (Carr, 1975).

J. Winterburn (1958) refers to four stages that parents go through in their reactions to the discovery; firstly, the stage of shock, followed by a stage of disbelief; then comes the stage of fear and frustration and then hopefully the final stage of intelligent inquiry, coupled with acceptance of the fact and adjustment to the situation. Solomon and Patch (1974) group the period of shock, disbelief, fear and frustration into a period of emotional disintegration; and the period in which parents learn to accept the diagnosis and resolve to help their child, they call the period of reintegration. Further they accept there are residual feelings which can hamper the parents' efforts to rear the child in the most acceptable way and it is suggested that it is the residual feelings which are possibly the most significant in the 'pathological reactions' which occur in their relationship with the handicapped child.

Solomon and Patch (1974), refer to a later phase as the period of mature adaptation in which the parents learn to ultimately accept and love the retarded child and deal with him constructively without significant emotional stress. It is further suggested that where a severely or profoundly handicapped child has been placed in the first few weeks of life because of rejection and emotional disintegration of the parents or parent, the period of working through for both parents may take years, but still needs to be done, on three counts:-

- (1) Parents' emotional health, and the marital relationship;
- (2) Needs of the child over his life span;
- (3) Lack of adequate facilities for placement so that the

parent will periodically be faced with decisions as to where to turn next for a placement for their child.

The question then arises, when does a parent leave off interest and a feeling of responsibility for his or her child; and conversely, when does a child lose interest in his or her parents? It does seem that some parents feel the "ache in their arms" even after the death of a young child (comments made by mothers after many years when their sons or daughters have died within the first five to ten years of life (Personal experience 1970-1977)).

Table 1 Classification of Mental Retardation (Solomon and Patch 1974).

American Psychiatric Association		World Health Organisation		American Association of Mental Deficiency	
I.Q.	Terminology	I.Q.	Terminology	I.Q.	Terminology
70-85	Mild Mental Deficiency	50-69	Mild Subnormality	70-84	Borderline
				55-69	Mild
50-70	Moderate	20-49	Moderate	40-54	Moderate
0-50	Severe	0-19	Severe	20-39	Severe
				0-19	Profound

During the early period of soul searching by the parents and the questions that are asked as to why this traumatic event happened to them and their child, personal and marital relations can become strained and help is needed to work through the pathological reactions of blame, whether self or spouse, guilt, sorrow and grief. It is suggested that the parent of the mentally defective child 'suffers' from chronic guilt. By this it is meant that the emotional attitude involving emotional conflict, arising out of moral or social standards in act or thought and reinforced by apparent social and professional contacts whether real or imagined is a natural response to a tragic event. If the professional worker accepts chronic guilt as a natural, rather than a neurotic response over time, he or she can be more effective in helping the parents achieve the goal of increased comfort in living with and managing a handicapped child.

Repond (1955) investigated the reactions of parents to their subnormal

children and found that invariably whether the situation was realised at birth or later the most serious problems are aroused by parental guilt at having produced such a child. Parents return again and again to the question - what was it in us that produced this? Repond found too that stable couples bound together with mutual love and understanding and, it is suggested, by religious bonds, are brought closer together by the experience. The danger is that the parents will form a close defensive triangle with their baby so that even their other children may tend to be excluded. On the other hand if the marriage bonds are weak or strained, a seriously subnormal baby can have a disrupting effect, as each parent will blame the other, dissension will increase, and each may deny further children to the other. Marriage can break down.

Main Types of Parental Reaction

Adams (1960) suggests that there are three main types of parental reaction to the birth of a subnormal baby; acceptance; rejection; and over-compensation, and it is further suggested that one of the reactions of over-compensation is hyperpaedophilia; or the excessive love of a handicapped child by parent or parents. Throughout all counselling and support the aim to be worked for with parents is acceptance and adjustment to reality. The more mature and emotionally secure parents will have the necessary insight to react positively and such people need to be given all the factual information about their problem over time as they are able to assimilate.

Parents of the child who are apparently able to accept the diagnosis emotionally may react with a period of depression, i.e. mourning for what might have been, Lewis (1934) considered depressive states as a paradigm of adaptive reaction of the organism to an intolerable situation. This interpretation seems well suited to explain certain reactive depressive states and can perhaps be applied to depression following the severe traumatic effect of the birth of the handicapped child. It appears that during this period of depression the parents incongruence evoking experience which has been sudden and intense, if at the birth they are confronted with the knowledge, or slow and fraught with frustration as in the case of later knowledge such as at school enrolment, produces extreme incongruence and high anxiety in which the defences are unable to operate and the result is disorganised

behaviour which is resolved by denial of the self concept or an altered self concept. The Humanistic perspective of which Carl Rogers (1963) is perhaps the best known adherent, maintains that the person may adopt certain defensive behaviour as a way to cope with his or her vulnerability. This defensive behaviour serves to distort the view of the experience and is thus an attempt to restore congruence between self and the experience. This concept relies heavily on conditions of worth as the predisposing factor and it is the concept of self worth which is under extreme pressure at the birth or discovery of a handicapped child.

Psychoanalytical Viewpoint

Fenichel (1946) from the psychoanalytic point of view states "the loss of self esteem is so complete that any hope of regaining it is abandoned. The ego sees itself deserted by its superego and lets itself die. To have the desire to live evidently means to feel a certain self-esteem, to feel supported by the protective forces of the superego." (pp 400-01). It is suggested that most mothers and some fathers during the phase of depression do feel a tendency to suicide during the early years of the child's life and this appears to be associated with thoughts of infanticide. The suggestion then is that the depressive phase is recurrent over several years and is associated with the period of mourning or chronic grief (Olshansky 1962). Though few parents will actually admit to these feelings until much later, even years later, it is a period in the depressive phase which must have cognizance and awareness of the supporting services. It does seem from comments made by parents over some seven years (Personal Experience; K.H. & T.S. 1970-77) that the underlying feelings of frustration, despair and the loss of their self concept, as well as the grief felt, contributes to their thoughts of suicide and infanticide. If these feelings are not taken cognizance of and the parents encouraged to face the reality of their deep feelings then the chronic guilt felt by parents will deepen and become or remain pathological. The guilt feelings then have complex origins and many factors contribute to the establishment of chronic guilt.

The Phenomenon of Guilt

Early Parent Reactions

Dally (1976) writes of the three stages of mothering. The first stage of enclosure and its physical counterpart is pregnancy but it

starts and ends later. Further Dally maintains that the period of enclosure begins with the first awareness of pregnancy and continues throughout infancy. It does seem that a few mothers during the third trimester feel that something is wrong with their baby and will seek counsel of their doctor; and in the years 1973-76 four parents mentioned this when interviewed for placement of their profoundly handicapped child into Kimberley Hospital and Training School (Personal Experience; K.H. & T.S. 1970-77) within the first seven years of age. The stage of enclosure is when the child is physically dependant on the mother and it is usually intensive until the child is two or three years of age. However, with the severely or moderately retarded child this period may last for five to twelve years or for the handicapped person's lifetime. It is instinctive and can be disrupted easily by adverse conditions either within the mother or outside. It does seem that the long period of enclosure that occurs with the mentally retarded child of the lesser abilities that this period can be a contributing factor to the chronic guilt of the parental response; i.e. the dependency phase of the child can become an onerous burden for parents who have many demands placed upon their time by social, family, and marital responsibilities, and though they love their handicapped child the demands on their energy and/or tolerance level to frustration, etc., reaches crisis levels and they feel guilty at apparently reducing the amount of care and attention they feel their handicapped child should have.

The second psychological stage is the stage of extension which corresponds to the physical stage of infancy when dependence is at first total and diminishes slowly over two to three years. It is the stage at which the mother becomes aware of the child as an extension of herself. It is during this period that the child goes through the stages of trust, mistrust, autonomy, etc. (Erikson 1968) but with the severely and moderately handicapped child these developmental milestones are delayed and with some children may never be reached. This, it is maintained, adds to the concern of parents and the burden of continual care, and dependency, creates reactions in which rejection and/or over-compensation are the end products of the slow and insidious onset of realisation that though the child may grow physically his achievements are small and slow.

The third stage is the stage of separation and Dally states that this represents the stage in which mother and child are separate people and

usually occurs near the age of 12-14 years and in which both adolescent and mother recognise and respect each other as separate people. This would not occur except in the institutionalisation of the profoundly and severely handicapped child and then it is an abnormal separation, but if counselling is available for the parents, this period can be worked through to ease the feelings of grief, rejection, and guilt at the feeling of relief and remorse that are felt by parents when the decision to place the child is made. With the mild mental retardate the parents come to this stage later and though it is important for the adolescent who is mildly retarded to be able to lead his or her own individual life, the problems of over-compensation and rejection on the part of some parents need the supporting services to relieve the family crises that ensue when the adolescent or young adult seeks the support and social interaction of his or her peer group.

Reaction to Trauma

It is during this first stage of enclosure and though the boundary lines between first and second stage are not clearly defined but may merge into one another, that the birth of a mentally handicapped child is a traumatic event for the mother and father and possibly more so for the mother. The initial reaction of shock can be associated with grief and rejection if the baby is obviously deformed and the diagnosis is positive at birth. It is suggested that in this initial phase of response to the birth of the mentally handicapped child that the first feelings of guilt occur when the parents question their own contribution to the defect or blame the other partner in the marriage.

Following the initial shock the reactions which follow vary in intensity from parent to parent as many factors such as personality, religion, social class, ethnic group and closeness of the marital partnership influence the intensity of the reaction which varies from grief, fear, frustration, and rejection to withdrawal and disbelief (Carr 1975).

Parents of the retarded child who do accept the diagnosis emotionally may then react with a period of depression, anger, and guilt, Anger at the medical profession, or fate, or God who has allowed them to have this child. This period may be one of learning how to love and protect the handicapped child or a period in which the parents seek a cure or placement for the retarded infant. Individual reactions of parents vary and depend on the closeness of the marital relationship. If the marital relationship is fragile (Adams, 1960; Younghusband, et. al. 1970)

it could be that this will mean the separation of the parents with one parent accepting the child, and though their reasons are suspect and include guilt and over-compensation, or self-punitive reaction in which the visitation of the handicapped child is regarded as retribution or punishment for past wrong doing, the solo parent endeavours to care for the retarded child. Fenechal (1946) states 'sometimes the ego seems willing to take punishments, acts of expiation, and even ... to an astonishing degree,' (pp 292). The ego's 'need for punishment' is in general subordinated to a 'need for forgiveness', punishment in the form of the handicapped child being accepted as a necessary means for removing the pressure of the superego.

Pathological reactions are frequently seen, and parents sometimes refuse to accept the diagnosis in the face of irrefutable evidence (Adams 1960; Solomon and Patch 1974). The denial by parents may allow them to accept the child into the family and continue a normal family pattern and relationship with the infant but this can expose the child to inordinate expectations and interfere with the parents' ability to deal effectively with their child's problems of development and adjustment and can lead to over-protection in later years as well as emotional problems in the handicapped child.

Solomon and Patch (1974) refer to the parental reaction of transferring their guilt feelings to others in the community such as the doctor, nursing staff, etc., as projection. Some parents are able to project onto other individuals their chronic guilt feelings and in this sense can ease the stress situation for long periods of time but eventually need to face their own share of responsibility when they have to make decisions as to ongoing care and support of their handicapped child even not making a decision it is suggested is a decision in itself. In moments of family crises then, the blame is recalled and bitterness and anger are projected onto the individual who is considered the cause of their grief, sorrow and guilt.

Parents may also displace their emotional needs onto the community, becoming active in the movements such as S.I.H. or Crippled Children Society, to promote understanding of the handicapped child; or they may become involved in other community activities as a means of denial of their handicapped child and this aids them in the placement decision, often supported by professional people in their contribution to society

as being more productive than caring for their mentally retarded sibling. Often baffled by their deviant child parents cannot call upon their own childhood experiences in deciding how to handle him, and this uncertainty may be reflected in over-protection or in unrealistic demands in performance. Each new stage in development leads to exacerbation of parental anxiety that may require counselling and support.

Other areas of concern

During the early years of the child's life, parents often encounter or feel they encounter, criticism and stares of the people they meet or come in contact with in their sojourns into the community. This period is often exacerbated by the toddlers or child's reaction to the stimuli, noise, and crowds of people around and most of the children do become cross and fretful or very demanding of mothers attention in these situations for some time. Mothers frequently state that they feel hurt by the stares of people and the voiced and non vocal criticisms they feel sure people are making of their handling of their child. It is suggested that most children do go through a stage of fretfulness when confronted by the many and varied stimuli in the towns and cities, how much more fear provoking it is for the handicapped child who needs the time to adjust and absorb what is going on around him?

As time passes and the needs of the child become more complex, often mothers feel inferior or are made to feel over-anxious when they want to know why; or what else can be done for their child; or is it possible for their child to be seen by other specialists. Too often professional staff react adversely and consider that a mother is complaining or over-anxious when, in her reality, she is only seeking reassurance that all the parents' care, concern, and anxiety for their child is respected and that they have the support and empathy of those whose role it is to support, advise and aid them in their care of their handicapped sibling. It is also the role of the supporting services to make sure the parents are wisely counselled as some parents will so cushion a child's life so as to provide a satisfactory life even for the profoundly handicapped child and though these parents are in the minority, self-sacrifice of money and resources would be expended at the expense of most of those things that make family and marriage worthwhile.

However, most families require practical assistance in the care of their child, either in the form of physical aids and/or financial assistance for those extra financial commitments that occur in their ongoing care of their child, e.g. modifications to the house and property in the way of fences, safe play areas, and privacy for other members of the family, particularly those siblings who are studying for examinations or doing their homework. This is also an important factor for both parents as they too need their privacy from the unremitting attention a demanding and very active child needs.

Problems of Training and/or Education

The dilemma faced by parents when a child, for social and practical reasons, is not fit for school by the age of five, and over-age placements in day care facilities or kindergartens is a God-send at this point in time. Some parents may need the services of institutions to facilitate a child's progress and/or to aid the parents over the stressful crises that can result when confronted with the knowledge that their child is not ready for school. In this situation the facilities provided by some of the S.I.H. branches make a very useful contribution, as the placement of a child in an institution is a very difficult and traumatic decision for parents to make. The stigma associated with the State institutions is far-reaching and the siblings in the family often meet rejection and peer group frustration if their sister or brother is placed in one of the few Hospital Board institutions. This adds to the guilt feelings of the parents and initiates a crisis in which the handicapped child is often rejected from family life.

The big advantage of the community facilities for short stay and parent relief or even long term placement away from the family is the community acceptance. The stigma associated with placement in Hospital Board institutions, though not as obvious as some five or six years ago, is still evident and parents and siblings can be confronted with peer projection i.e. a young child may be rejected by his or her peer group and no longer allowed to play with her or his friends because of their handicapped or 'mental brother or sister'.

Another area of concern for parents is the non-verbal communication of the handicapped child who finds the family life too constricting or too stressful. It does appear that some of the children who have short stays away from the family do eventually want to stay where the life

style is geared to their achievement and ability level. Often a child will indicate by his deviant behaviour on his return home that he wants to return to the Hostel or the institution and it is a very difficult time for the parents. Guilt feelings which have lain dormant for some time are again to the fore and mothers often comment that it is their fault and they are just not able to cope or look after their child any more. It is at this time that supporting services must be able to cope with the parents' grief, guilt and feelings of inadequacy and be able to help the parents to understand what the child is trying to tell them, as well as aid and assist them in finding a suitable placement for their child.

Questions of Long Term Guardianship

Fear for their handicapped child is part of the chronic guilt syndrome in that all parents wonder who will look after their child should anything happen to them. This is possibly one of the basic fears for all parents and they do need reassurance. Often the knowledge that their child's name is on a waiting list or that they are enrolled for Hostel accommodation is sufficient for parents of children of severely or moderately retarded children. There is a big gap in the facilities available to parents of children who do require some form of oversight but who can live a productive and relatively self-supporting life within the community, for example those who are mildly retarded but because of ability levels are unable to manage their own affairs. At this point in time there is no statutory or voluntary agency which accepts guardianship of the mental retardate for the entire life span as is the case in Sweden, Norway, etc. It is understood that this area is under consideration but it will take some two or three years before New Zealand Laws move in this direction. This move has been instigated by Mr Justice Beattie (1976) and it is hoped that this gap in society will be closed by 1980, with provision for the State to appoint a guardian for every mentally retarded child. Whether or not it is to be a parent, relative or other individual will depend on the individual child's circumstances, needs, and level of ability.

Reactions of Siblings of a Retarded Child

Solomon and Patch (1974) maintain that well-integrated and functioning families can almost always adapt to a retarded child, and state that "this is easier for families in the lower socioeconomic levels of society than for middle class families with social or professional

aspirations." However, as stated earlier it appears that the acceptance or otherwise by other siblings does depend very much on the mother and father's attitude, and where there is a stable marital situation in which the parents are secure in their relationships this is reflected in their siblings attitude. However, it is important that each sibling is not under pressure to care for their handicapped brother or sister as over time this causes resentment, particularly as the teenagers develop other interests and contacts outside the family circle. (Adams 1960; Winterburn, 1958, Younghusband, et. al. 1970)

The emotional impact of seeing a retarded child's deviant behaviour can cause anxiety reactions in the younger siblings and they may wonder if they will be as their handicapped older brother or sister when they reach their age. The other reaction which is common among the adolescent 'normal' siblings is to wonder if they too will have handicapped children when they marry and in turn have children. If the mother transfers the responsibility and care of the retarded child onto the oldest daughter, this too can cause resentment and guilt.

Often too the other sibs in the family resent the care a mother has to give to a demanding moderately and severely retarded child, as the excessive demands on her energy and time often leave her feeling inadequate, and with little patience to deal with the normal siblings. This too adds to her feeling of guilt that she is unable to give as much as she would like or as she feels is expected of her to all the members of her family. Fathers, too, in this situation feel guilty if they do not share the care and attention of their handicapped child and some fathers go to great lengths to take over the responsibility of their inadequate child when they are at home, often bathing, feeding and bedding the child to save their wives a little of the very onerous burden. Winterburn (1958) maintains that while the 'normal' children may have to give up something, they should not be expected to make big sacrifices. This is possibly the hardest area for the supporting services as too often one finds one of the siblings giving up more than can reasonably be expected, for the 'normal' children have ahead of them socially useful and fruitful lives. To make the intellectually handicapped child the centre of the family life style is an error which too often occurs and the family revolves round the demands and apparent needs of the dependent sibling. This creates its own problems and though it is easy for the supporting services to encourage families to

lead a balanced life style it is very difficult to achieve, but a few do, to the social advantage of the handicapped child.

Sharing Information

Three other factors call for comment

- (1) The other children in the family should be told frankly according to their level of understanding about their brother or sister's handicap so that they grow up accepting the 'normality' of people who need and require special assistance in the way of education, living conditions, and eventually placement according to their needs and wishes even though these may be assumed from non-verbal communication or for reasons of stress and tension engendered by the onerous care of a very dependent child or adult.
- (2) This attitude - of acceptance or rejection or frustration - will be largely determined by the parents attitudes. This is one reason why it is necessary for the parents to avoid over-compensation, over-emotionalism in the way of chronic grief and guilt, and a disproportionate interest in the handicapped member of their family.
- (3) If the handicapped infant is the first child in the family, parents are usually advised to have other children. This, to the writer, is inappropriate unless adequate safeguards for the parents have been undertaken - too often are parents advised to have another child without adequate safeguards. The reason advanced by Winterburn et al (1958) is that the parents face a very real danger that their lives may become so intensely wrapped up with their handicapped offspring and this is not good for any one of the three people involved. However, it is suggested that this occurs infrequently (see Table 4) and the more important field of supporting services is to ensure that parents face future pregnancies with the knowledge that they have covered the present fields of knowledge and that they are reasonably sure that they can produce a 'normal' child.

CHAPTER 2Guilt as a Personality Trait

It is assumed in the trait attribution of guilt proneness of personality traits of parents with handicapped children that the ordinary language provides convenient basis for discriminations of profound personal and social significance. To describe a parent as guilt prone is to communicate an enormous amount of essential information in a very efficient manner. Norman (1963) maintained that concern was not with the ordinary language system in its entirety but rather with that subset of descriptive predicates that refers to perceptible variations in human attributes. Feigl (1949) emphasized that the ordinary personality language system must not be thought equivalent to a scientific language system. It is contended that the utilizing of ordinary language in the trait of guilt or chronic guilt is for social prediction and control and understanding by related professional disciplines and in so doing it is the belief that greater help for parents will be available.

An implicit theory of personality may be thought of as relatively stable scheme of expectations and anticipations concerning the relations among traits of others that a rater brings to any trait-inference situation (Hays 1958). Vernon (1964) views trait ratings 'not so much as summaries of objectively observed behaviour, as rationalisations abstracted from the raters overall picture (his homunculus) of the subject' (p59); Lay and Jackson (1969) on the other hand view implicit theories as veridical in the sense that inferential networks are acquired on the basis of experience and hence bear a close resemblance to the manner in which people are actually put together. Further they suggest that raters who rely on implicit theories in predicting behaviour of others will tend to be relatively accurate, a point that is related to "stereotype accuracy".

Kelly (1955) suggests that each man views life through a system of personal constructs that are a unique product of his own life experiences and that are not directly translatable into the different personal construct systems of other persons. This position is akin to that of Gordon Allport (1961) who held that personal dispositions are unique to each individual and that the so called common traits refer to relatively arbitrary dimensions that are imposed on others. Although there is merit in both these views it can be noted that even in studies carefully

designed to uncover individual differences in the meaning relationships of personality trait descriptors (e.g. Walters and Jackson 1966), commonalities in trait meanings are more striking than individual differences.

The choice of the trait unit as the primary attribute of behaviour in personality study has recently been criticised. The question was raised in the context of the clinical diagnosis of behaviour pathology, and during the past decade it has become increasingly apparent that psychiatric treatment procedures based on social learning principles are more effective in the amelioration of certain classes of psychiatric symptoms (e.g. phobias, etc. and Braemar Hospital in Nelson has used desensitization or counter conditioning therapy for parents who have their intellectually handicapped child referred for admission with significant positive results for parents in the way of fear, and guilt reduction.) than are treatments procedures based on psycho-dynamic principles (Bandura 1969; Franks 1969; Krasner and Ullman 1965; Ullmann and Krasner 1969). It has also become evident on both theoretical (Bandura 1969) and empirical (Paul 1969a, 1969c) grounds that traditional trait measurements are of little value in forecasting the outcomes of behaviourally orientated treatment procedures.

Radically new conceptions of the nature of clinical diagnosis and treatment have emerged both with respect to criteria classifications (Kanfer and Saslow 1965) and the assessment procedures employed for classification and prediction (Mischel 1968; Peterson 1968) and extrapolating from this the approach to parents of handicapped children has changed over the past decade to one in which support and counselling is now made available to parents who are faced with the knowledge of the birth of a handicapped child. This has occurred for three main reasons,

- (a) the upsurge of interest and the formation of the Society for Intellectually Handicapped people in New Zealand, and their development of community resources; the community resources have increased rapidly over the past five years and there are now some 48 branches of the Society (March 1976) within New Zealand, and most now have hostel, workshop, day care and supporting services in the larger towns and cities
- (b) the change in policy of Government and its related departments. Education Board developed special class facilities for mental retardates of IQ range 50-75 and accepted responsibility for

special schools with an IQ range 30-50 or those children who are classified as moderately retarded.

- (c) the transfer of psychopaedic facilities to Hospital Board control effective from 1 April 1977, placing the onus of responsibility for help for those children of severe, profound and some of the moderately retarded children who cannot be catered for with community facilities because of deviant behaviour problems. In many ways this has alleviated the problems parents face in the community in the way of stigma and guilt as the community has become more aware of the needs of the subnormal population and the cares and concerns of the parents.

Environmental Contribution

To the extent that traits may be viewed as 'inner causes', significant environmental relationships may be overlooked. The emphasis on what a person has may divert attention from significant aspects of his environment that are controlling and maintaining his or her help seeking behaviour. For the social behaviourist explanation consists of a specification of those factors in the social environment which bring about and maintain the behaviour of interest. Cattell (1966c) has developed elaborate procedures for studying the stability and fluctuations of traits across different occasions and views behaviour as primarily determined by individual differences in motives and traits which in turn are modulated by environmental factors (Cattell 1963). Social behaviourists, on the other hand, have adopted a strongly situationist stance (Wiggins 1973) to explain the dynamics of behaviour. It does seem that a trait factor of guilt proneness in an individual as antecedent to chronic guilt felt over the years by the parents of intellectually handicapped children, and the degree of the importance of environmental and social factors will vary according to the experiences of the individual. The interactions between the environmental and social factors with the trait of guilt proneness e.g. a supportive environment, empathic and non-judgmental, would help the parents and reduce anxiety but where the environmental factors are critical and non-supportive the parents face stigma and social criticism which can produce high anxiety factors which could lead to 'flight or fight', (Tofflers, 1970, Future Shock is also applicable here); are significant variables as throughout their life span the various family crises will exacerbate dormant guilt feelings.

An increase in the intensity of the guilt feelings at certain periods of the child's development, as mentioned earlier (p6) and how the families cope with the situations, depends to a large degree upon the basic emotional health of the family, the strength of the marital relationships, the value and esteem that each member places on the rights and aspirations and needs of each family member. This is an important and basic concept as the decisions and plans the families must make are often difficult, profound, and at times terrifying. The anxiety and guilt that these situations provoke and the defence mechanisms of projection, over-compensation, and over-protection that parents use are difficult conditions to cope with; " ... that parents who have achieved a relatively satisfying adjustment are likely to be able to bear the pain of having a defective child without prolonged personality disturbance. On the other hand, parents who have not achieved a satisfying adjustment in their previous years tend to react with severe personality disorders." (Mandel and Wheeler 1960 p.364).

"Modus Vivendi"

In all casework with the families of the intellectually handicapped child and, it is emphasised, the parents in particular, counselling agencies need to be aware of the social problems and the caseworker hopefully aids the family to work through to a resolution but it is considered necessary that problems be handled until a 'modus vivendi' with a chronic problem is worked out. The problem of chronic guilt in the parents of the intellectually handicapped child doesn't really ever end, it reaches plateaux, for the problem is not the guilt condition itself but rather learning how to cope with it; and it must be coped with by the parents and families in every critical period of their lives; in terms of every critical relationship - self, spouse, siblings, in-laws, friends, neighbours, boss, etc. This is to say nothing of the countless professional people that must be coped with too - therapists, doctors, educators, psychologists, social workers, and specialists in all walks of life.

The choice of the trait unit in forecasting outcomes over time for parents of handicapped children would appear to be of little value if the consistency of traits is more apparent than real (Wiggins 1973, p378) but as a basis for understanding the guilt phenomenon of parents and selecting the most appropriate form of guidance, counselling and/or

treatment would seem to be effective, it can be argued however that the attribute is viewed not as a disposition but as a capability and the probability of occurrence in criterion situations are determined by environmental factors. To the extent that the functional relationship between the response class and situational factors are justifiable, the problems of stability and generality then become the major focus, and treatment, or counselling and/or guidance takes cognisance of the environmental conditions which may potentially control the behaviour reaction of the parents and/or family, e.g. antecedent events such as inadequate or non-supportive counselling, guidance and help etc., and (2) the consequent events; e.g. whether the parents meet stigma, or criticism, or rejection by family, in-laws, or professional personnel, etc., and (3) contingency-related conditions, e.g. marital relationships at risk because of the fear of further pregnancy; or developmental problems of the handicapped youngster and the lack of relevant experiences on the part of the parents to cope with the behaviour problems etc., and (4) the biological condition of the various people, e.g. age of the parents, and/or biological changes in the handicapped child. The environmental conditions which may be considered as systems which include potential variables that affect the parents may be psychological, biological, economic, and social events.

The processes whereby the environmental conditions that elicit and maintain guilt reaction are the major focus of the ongoing guidance and counselling casework; and the relationships between the environmental variables and the parents reaction changes with the different family crises as well as the developmental variables of the intellectually handicapped child. In most crisis situations in families with moderately to profoundly handicapped children it may be wiser to have the child sent to a hostel or institution for short stay relief, e.g. one to two months away from the immediate family, and this allows for the high tension to be worked through and some measure of relief for both parents and child so that the instigating factors, whether family, social or environmental, have time to alter and change; often the intervention of parent relief can resolve the immediate problem but it may be that the ripple effect has more far reaching effects and may include

- (1) the ongoing need for short stay placement for the child at least two or three times a year to allow for separation to occur without trauma;

- (2) or the short stay relief becomes long stay placement as the family cannot face having the child back into the family;
- (3) stage of enclosure and extension in which the parents claim back their child and refuse all future offers of help as they fear their child will die away from them. This infrequently occurs but is the result of unfortunate experiences with hospitalisation in a very few of the cases.

CHAPTER 3Counselling

Over the past decade research accumulated has shown that the severely subnormal children brought up in their own homes are more forward in their development than those brought up in institutions (Tizard 1960; Lyle 1960; Centerwall and Centerwall 1960; Stedman and Eichorn 1964; Shipe and Shotwell 1965; Bayley et al. 1960; Carr 1970). Partly as a result of these findings as well as the curtailment of building programmes for institutions the parents have been encouraged to keep their intellectually handicapped children at home for as long as is reasonably possible; and the question then arises as to the effect this has on the child's family, parents and siblings, but the effect on the extended family has hardly been considered, i.e. the effect on the extended family kinship group, grandparents, aunts and uncles, etc. However, it is suggested that where there is support for the parents from extended family members in the way of baby sitting for evenings, or weekends or moral support in a positive way this can alleviate the parents fear of allowing their child to be a 'burden' to other family members.

Sampson (1947) was one of the first professionals to propose that it was time that parents' feelings, sensibilities, and the impact of diagnosis on them, should have consideration and this was later followed by an upsurge of interest and papers concerning parents' feelings (Wolfensberger 1967). Kelman (1964) discussed the limitations of the more recent studies in which writers have compared the effects on families of a retarded child brought up in an institution or at home, and of children with different types of handicap and though studies suffer from population bias in that the populations used are based on users of services or are members of parent sponsored organisations (e.g. Society for the Intellectually Handicapped, New Zealand). Another limitation common to many studies is that of a limited time perspective; "Clinical contacts are office-bound, sporadic and short term virtually absent from the existing literature are longitudinal prospective family studies." Both Wolfensberger and Kelman emphasize that to recognize the shortcomings of these studies is not to say that they have no value, but that it is essential to recognise their biases if their contribution to our

knowledge of the situation for parents of retarded children is to be adequately assessed.

How Parents are Told

Initial counselling is generally regarded, by parents as well as professionals as of crucial importance. Raech (1966) the father of a retarded child himself - "Of particular importance, in my view, is the initial counselling experience. Usually this is given by a medical person untrained for the task. Yet, this interview is likely to be the source of the parents greatest single emotional trauma in what is commonly a life-long struggle," (p 813). It is important therefore that this interview be handled as skilfully as possible (Table 3; Table 4).

Perhaps the four major aspects of this initial interview are its timing what is told, and how it is told, and the supporting services available to the parents during the initial stress situation as well as ongoing support. Many forms of retardation do not become apparent at any particular period of the child's life; J. Carr (1970) maintains that the parents reactions are best studied in relation to mongols, whose handicap is discoverable at birth. Table 3 summarizes the findings from five studies as to when the mothers were told and how many were satisfied with the time of telling

Table 3. Times at which mothers were told their children were mongols, and whether they were satisfied with the time of telling in five studies

Authors	Date of Study	N.	Mongols Born Between	Time of telling		Satis- fied		Told by	
				1 mth %	1 year %	1 mth %	1 year %		
Tizard & Grad	1961	80	1951-55	-	55				
Drillien and Wilkinson	1964	71	1950-60	25	72	78		31	
Berg et al	1969	(1) 44 (2) 51	1929-48 1949-68	16	68	84		33	
Hutton	1966	44	1950-62	66					
Carr	1970	46	1963-64	60	96	68		33	

Parents want to be told their child's condition early and they also want to hear the truth, as Reach (1966) states, "The truth must be expressed. No purpose can possibly be served by concealing the truth and indeed a great deal of damage may be done in not stating facts clearly yet gently." (p 814). Nearly half the mothers in two studies (Drillien and Wilkinson, 1964; Carr 1970) suspected before being told that there was something wrong with their child, and other studies too have noted the bitterness that mothers (and in the writer's experience, fathers) experience when they feel that they have been fobbed off with reassurances, or that information that they urgently asked for was withheld, or they were told lies (Tizard and Grad, 1961; Hutton 1966). 'The fact that it was hidden did us more harm than the fact of her condition,' and 'They should have told me when I was asking,' were (and are) typical comments (Carr, 1970, p 814). In general, professional people accept that parents must be told the truth (Kanner; 1962; Wolfensberger, 1967) but the future prospects or ability level the child will reach over time is not possible to stipulate in the early stages of a child's life. This is possibly one of the major questions that concern parents throughout the developmental stages of their child's life; too often it seems that parents have been told that their handicapped child would not live very long and could die by seven or eight years of age. Cowie (1967) suggests that the doctors' own anxiety "may subconsciously make him defer telling the parents, contenting himself with the rationalisation that the delay is to their advantage, for the time is not ripe." (p 814). It could be that the stating of a life expectancy for handicapped children is also part of the rationalisation, as well as the statistical results of the past life expectancy for intellectually handicapped as well as physically handicapped people. However, with the advances in medical care both within the institutions and the community, the life expectancy of handicapped children and adults is increasing and the institutions within New Zealand are now developing geriatric accommodation for this aging population. The New Zealand Society for Handicapped people is also planning accommodation and leisure facilities for the 'elderly' handicapped adult (personal communication 1977). By 'elderly' it is not the chronological age which is the pertinent factor but rather the ability and physical level of the individual.

After the initial shock of hearing that their child is retarded, most parents want detailed information and advice on the possible prognosis, the expectations they can have for their child, and how to handle him.

Many doctors feel that this cannot be handled at the first interview and parents are encouraged to return later for further discussions. In a few of the main centres in New Zealand the S.I.H. hold regular clinics for parents registered with the Society, and the consulting paediatrician will see all parents and children brought forward by the Society. This has proved of benefit to many parents as they feel the medical contact does encourage their efforts in developing the small gains the child makes during the early years.

Who Tells the Parents ?

Much has been made of who should tell the parents, especially in relation to the view that the parents will feel resentful towards the doctor who tells the (Cowie, 1966). These fears seem unfounded (Carr 1970) and most parents feel that they prefer their own doctor to tell them the truth. Of far greater importance is how the parents are told. All the studies have stated that the doctor should take time and trouble over the telling, be empathetic toward the parents (Carr, 1970) and further also in sympathy with the field of the handicapped, as a professional person who is unable to accept the handicapped individual totally would find it difficult to support parents in their distress. Resentment does arise when the informant is unfeeling (cf Tizard and Grad) or informs the parents briefly or abruptly - what Raech calls the 'get-it-over-with' school.

Questions need to be answered fully but it is important for those parents who are unable to formulate questions that the doctor or counsellor give as much information as possible during the initial visits; for all parents the ongoing support and counselling of professional people, it is maintained, should be freely available, particularly in the first five or six years. Where prognosis is concerned doctors are warned against raising false hopes but in some cases they can go too far the other way and be unnecessarily discouraging (Tizard and Grad, 1961; Dembo 1964; Raech, 1966; Berg et al 1969).

Genetic Counselling

Genetic counselling for parents of handicapped children (Illingworth, 1966; Hutchison, 1966) as in other areas, awareness of need outstrips the provision made for it. Only one third of the mothers in Tizard and Grads study had had medical advice about the risks to further children;

45 per cent of the mothers in Hewett's and in Carr's studies had discussed with a doctor the question as to further children. In spite of the paucity of genetic advice it has seemed to some writers (Holt 1958b; Tins et al 1963) that parents have tended to limit their families after the birth of a retarded child, though these findings have not always been confirmed (Sigler et al., 1967; Fraser and Latour, 1968). It does seem that some parents may be put off having further children by the birth of a handicapped child but this effect may not be as important as the age of the mother, the size of her family and whether it is a first or second child or later child who is retarded, whether or not she had hoped to have further children, and the mother and fathers attitude to birth control and/or children.

Table 4. Times at which parents were told their children were handicapped and whether they were satisfied with the way they were told and the time of being told (1976 Pop. ref. for admission K.H. & T.S.)

	<u>N</u>	<u>By F/D</u>	<u>By Spec.D.</u>	<u>Satisfied</u>	<u>Not Satisfied</u>
At Birth	13		13	0	13
By 6/12	30	2	28	0	30
By 1 year	29	6	23	3	26
By 5 years	36	15	21	18	18

It is important in genetic counselling that both parents are seen, investigated and helped, regrettably in the New Zealand scene, specialist clinics are in the main centres which can place added strain on the family budget; as well as the economical factor for families is the time factor between investigation and results being made available. Ongoing counselling and support is not always available for those parents at risk and though there is little evidence to support the contention it is suggested that the knowledge that one or other of the parents carries a recessive gene can add to the marital stress as well as the guilt factor for the parent involved.

Parents Counselling

Many writers have taken as self-evident the fact that parents of retarded children feel guilty, reject their child and/or over-protect them, Walker (1949) "Probably every woman bearing a retarded child

develops some sense of guilt ... which may be very openly expressed by such statements as the child is her 'cross to bear' ... or projected toward the institution (or community facilities) in a spirit of fault finding solicitation for the child's welfare ... ". Holt (1958^(p828)) considers that in 201 mothers he visited the emotions of guilt and shame were very noticeable. Two mothers showed open guilt reaction, regarding the child's condition 'as a punishment for past transgressions', others showed the guilt as over-anxiety and over-protection and devotion to the child. Others (Hutchison 1966; Illingworth, 1966) also speak of pathological attachment of the mother as a source of damage to the family, but Wright (1960) believes that in some cases over-protection may be the result of real love and concern for the child, and advises the parents to do whatever they feel will benefit the child as no matter what they do they will be criticised.

Wolfensberger (1967) takes a novel approach to the role of guilt, and suggests firstly that guilt may not be inappropriate (he quotes no evidence that this often or indeed ever happens) and secondly that guilt can be beneficial: "Perhaps a bit of guilt may go a long way in motivating parents to provide the extra attention, effort, and even love a retarded child may need."

At one time the diagnostic session contained all the counselling that parents were likely to get; increasingly it has been realised that parents cannot absorb in one interview all they need to know, or indeed what may be relevant over the child's life span. Many writers (Schumacher, 1945; Yates and Lederer, 1961; Richards, 1964; Wolfensberger, 1967; Pinkerton, 1970) have stressed the need for repeated interviews with the parents, to allow them to assimilate information, express their feelings and adjust as far as is possible to the situation. During the early phases of the child's life, i.e. in the first five years, the ongoing regular annual checks with the paediatrician are an important and respected, though sometimes feared contact with specialist services. Caldwell et al., (1961) found that the more contact that parents had with a clinic, the higher was their expressed satisfaction, while Drillien and Wilkinson (1964) stated that mothers were more satisfied with the way they had been told if they were encouraged to return to their family doctor or paediatrician

with any further questions or problems. Hewett's (1970) and Carr's (1975) studies found that mothers were critical of their hospital visits finding the long wait for a short interview and lack of discussion or advice as well as the often perfunctory attitude of the doctor, frustrating. (Table 3, Table 4). Other criticisms noted over the past five years by parents applying for institutional placement for short or long term at Levin have included

- (1) some mothers felt they were out of place at the interview as the doctor and social worker discussed their child without referring to the one most concerned, i.e. the mother or father or both
- (2) Parents felt they were being over-protective and anxious, and on several occasions had actually been told so by the specialist or doctor and/or the psychologist
- (3) Had been advised to put their severely retarded child 'away' and forget they have got him
- (4) Were embarrassed by the behaviour of their child
- (5) Were embarrassed by the specialists discussing their child in front of the child (particularly with the three to five year olds who appear to understand a certain amount, i.e. the moderately and mildly subnormal.

"The parents are often viewed as being problem-ridden, anxious and maladjusted," (Wolfensberger, 1967)^(p821) and he further maintains that there is a certain psychiatric orientation which views parents as patients and that sees the source of their problems as residing within them. Feelings of frustration and irritation have been noted by some parents who have been offered psychotherapy when all they have been asking for is information and/or advice in dealing with their problem child. (cf Yates and Lederer, 1961; Cummings and Stock, 1962). As Wolfensberger (1967) states, "The parents, as is apparent over and over, want counsel on the child management and facts about retardation. The professionals want to give them therapy." (p822).

Relationships as the Basis of Help

As stated earlier the initial interview is crucial and during the early years the counsellor and/or social worker works within the medical model, where the doctor is seen by the parent as an authority person who diagnoses and where necessary prescribes, and it is usually on the doctors advice that the counsellor or social worker is called in.

During the early phases of the relationship it is important that the counsellor or social worker aims to support the parents during the stressful period of denial, grief, fear, frustration and rejection, etc., and though the goal of the initial visit is to establish an informal contract with the parents it is imperative that no pressure be applied for a firm commitment but rather the establishment of contact and the offer of support and help is the important first step.

Who Does the Counselling and/or Support

Initially the Paediatrician or Doctor who makes the diagnosis and gives the parents the information and possible prognosis in the first contact. Over the past decade in the New Zealand context increases in community supporting services in the way of experienced personnel and related facilities; e.g.

- 1) Social Workers in the Society for the Handicapped, Day Care; Hostel: Workshop facilities;
- 2) Increase in Social Workers and Child Psychiatrists in Child Health Clinics
- 3) Increase in Psychologists in Education Department Psychological Services;

have increased the avenues available to parents for advice and support in their search for information and help in caring for their child. However, it does seem that early referral to Voluntary or Statutory agencies would assist the parents and possibly alleviate a lot of the dissatisfaction (Table 4) felt as the helper support could include early contact with parents who also have handicapped children. It is recognised that the early contact with other parents does help to alleviate the feelings of distress, isolation, and fear, (Youngusband et al 1970; Forrest, Ritson, Zeally, 1973).

Helper Support (Counsellor and/or Social Worker)

It is suggested that the role of the Helper lies in supportive counselling. The parents are making painful adjustments during the early stages and are in need of and seek support. The Helper being aware of the family's distress, conveys by his or her openness, accurate empathy, nonpossessive warmth, genuineness and non-judgmental approach that the parents have the inherent strength to cope with their problems and can reach a way of life which will be full and satisfying.

Schwartz (1961) describes worker interventions in terms of five major tasks in the helping process and emphasises the spontaneous interactions in the here and now which determine specific helper actions. Through the demand for work implied by the very contact with families of handicapped people, the helper responds on a 'human, reciprocal, intuitive basis, using the terms of his contract as his general guide,' (pp 39). The five tasks he presents as broad categories of activity and seem applicable to the long term counselling and support needed by parents as they allow for the helper and parents to engage in solving the various problems as the need arises.

The Five Tasks of the Helper

The first task entails, 'searching out the common ground between the clients perception of his own needs and the aspects of social demand, with which he is faced,' (Schwartz, 1961, p 157). This task rests on the symbiotic relationship between man and his society. The helper enables family members to look beyond themselves and weigh their obligations to the family unit. The helper aids them in defining their own needs, in understanding the needs of others, and in negotiating acceptable 'terms'. Friction between family members may be resolved, for example, as they more clearly perceive that their mutual needs for love and support far outweigh any differences.

The second task the helper engages in with the family over time is "detecting and challenging the obstacles which obscure the common ground and frustrate the efforts of the family members to identify their own self-interest with that of 'significant others' " (Schwartz, 1961, p 157). Obstacles to 'modus vivendi' may appear in many forms, but they always represent a struggle between family members and their present way of life. For example, parents may become too involved with their handicapped child and tend to exclude their other children from the tight relationship, or one parent may become too involved with the child and tend to exclude the other spouse and children, thus forming two subgroups. Whenever this occurs the family is not acting in its own self-interest and is failing to achieve a 'modus vivendi'. Although the obstacles may be complex and inter-related, the helper does not need to deal with causal factors but has rather three functions to perform (Schwartz 1967). Firstly he can alert the family to the present obstacle but must not condemn members for

it, he helps the family deal with the obstacle through an examination and understanding of it, and most important he prevents the family's preoccupation with analysing the problem to the exclusion of the overall 'modus vivendi'.

The third task involves the helper in "contributing data - ideas, facts, and value-concepts which are not available to the family and which may prove useful to them in attempting to cope with that part of social reality which is involved in the problems on which he or she is working" (Schwartz 1967, p 157). In giving information to the parents and family, the helper shares himself - his impressions, his ideas, his knowledge, his feelings, his values. Further his or her behaviour tends to serve as a model to other family members for freely exchanging information and for investing in the work of the family unit. However, he must be careful not to impose his own standards on the family, and whatever he offers must be pertinent to the concerns of the family, and is offered as only one of many possible views of the social reality (Table 3).

The fourth task requires "'Lending a vision' to the family, in which the helper both reveals himself as one whose own hopes and aspirations are strongly invested in the interaction between people and society and projects a deep feeling or that which represents individual well-being and the social good" (Schwartz, 1967, p 157). In performing this task which pervades all facets of the family unit the helper displays his enthusiasm for and his faith in, his encouragement of, and his caring for the members of the unit and the tasks and goals they have selected. When the family or its members are experiencing difficulty, this task can be vital, for example - Father may be working long hours, mother has the onerous task of caring for a severely handicapped child, other children are needing her attention and help with homework and or a quiet room in which to study, and financial problems are increasing, social stigma from neighbours and extended family members (Table 5). It is imperative that the helper is available for ongoing support and he or she is able to obtain the services of other agencies to assist the family in distress.

Lastly, the helper is involved in "defining the requirements and limits" of the situation in which the client and worker system is set. These rules and boundaries establish the context for the 'working contract' which binds the client and agency to each other and creates

the conditions under which both client and worker assume their respective functions" (Schwartz, 1967, p 158). The family members, the helper and the agency have reciprocal responsibilities and specific rules should be established early governing these relationships in the contract. For example, parents have the responsibility for the final decision concerning their handicapped child and though he may be placed in an institution or into the care of the Society's Hostel accommodation and related facilities, he is still their child at this point in time - although this position could change during the next few years if the Act pertaining to guardianship is formulated and accepted by Government (Beattie, 1976).

Schwartz indicates that the major factor governing the use of these five tasks must be the enhancement of the work of the group namely the family. The type and degree of helper activity will vary with the work each family needs and the choice of tasks is left to the intuition and skill of the helper. It is only as the helper interacts with the family in a particular situation that he can be sensitive to the form and timing the tasks should take.

The Waiting Time

In the words of Dr R. Wilson (1946) sometimes it is wise to wait and "it is harder to stand and wait than to move in and attempt to do something which would only aggravate the condition." (Lecture New Plymouth Hospital). It does seem in the long supporting counselling situation with parents and families of handicapped people that there is a time when the stress within the family is better left to simmer and find its own solution. Solomon and Patch (1974) emphasise the aspects of non-intervention when the stress situation for a person can be too much for the individual to handle, for example, the parent of a severely handicapped child denies the child belongs to his or her family and over time builds up his or her defences and makes a reasonable life style but in the event of trauma or crisis situation the defence mechanisms may crumble and a pathological condition arise which requires intervention.

Similarly where the implied or felt guilt of family prohibits intervention and help in caring for the handicapped child, e.g. a Maori family in hill country feel that any help given to their daughter in the way of hospitalization or parent relief will endanger their daughter's life and yet she requires full nursing care with no prospects of attaining any self-care skills. This family blame them-

selves for their daughter's condition as she was on a tractor driven by her father when there was an accident and the family were persuaded to send their daughter to hospital where she developed meningitis (personal experience, 1974).

Undiscussed Anxieties

As the relationship between helper and family grows it is sometimes helpful if parents are encouraged to write down questions that they want to ask no matter how apparently trivial it may appear. I agree that some professional people may think that this encourages obsessional people, but how often do people stand outside a clinic or agency or even after a helper has left a house and say, "God, I forgot to ask the most important question, you know, will my child be deaf or blind and that sort of thing." Sometimes it is not as related to the ability level of the handicapped person but rather to the effects on the siblings, i.e. "My daughter wants to know if she will have a handicapped child," or "Does my son need to see anyone about the possibility of having a handicapped child when he gets married?"

Sometimes in the early stages the parents get angry and they blame God but also then they are very angry with a person. Often the doctor who makes the diagnosis is the scapegoat, but where it does do a lot of damage, I feel, is the blame and anger that is put onto the spouse, the wife blaming the husband and the husband blaming the wife (Blackburn, 1974). The direction of anger, blame and frustration within the family is destructive and if this can be alleviated and directed outside the family prior to coming to grips with the fear and guilt engendered with the birth of a handicapped child, will ease the burden. However, some parents fear the disability is due to some action of their own, and as well as the parents, the grandparents and the aunts and uncles may think so too. If the parents think that some action of their own could be suspect they may feel very guilty about it but be unable to bring it up for a very long time. Sometimes the reason is associated with medieval thinking, the visitation of the Gods and their wrath upon the parent because he or she thinks they have done something wrong in their past (Blackburn, 1974). Sometimes this is associated with premarital sexual relationships or conception, at others it may be associated with sexual intercourse following pregnancy, and though there is no basis in actual fact for their reasoning this can cause a lot of heartsearching for the

parents and they do need to discuss their fears and feelings of guilt with an empathic and non-judgmental professional person.

Other causes for concern which mothers are usually blamed for are associated with medication. Ever since the thalidomide disaster, whenever a woman who has had a handicapped child she has wondered whether it was because she had taken an aspirin, etc. when she was five months pregnant. Dr Blackburn (1974) thinks that it will be some years yet before the fear associated with this will be alleviated. It does seem that rather than the woman taking the responsibility for avoiding dangerous drugs such as tranquillisers, etc. it should be left to the medical profession.

After Birth

The next thing parents think may have caused their child to be handicapped is possibly something that happens in the first year of life in the way of infections, falls and so on. Sometimes a parent will state, "Oh, Doctor, I haven't told anyone this but once he rolled over and fell about eighteen inches onto the floor when I wasn't watching properly." Dr Blackburn (1974) feels that this is a fairly common occurrence for children but where a mother of a handicapped child is concerned and blames herself then this should be refuted when the diagnosis is obvious but even more so when there is doubt about the causal factor of the diagnosis.

The next cause of terrific guilt, particularly following the recent revelations, is smoking during pregnancy and the effect on the unborn child. The Perinatal Trust survey has found from its long term survey that babies of mothers who smoke are just less good at reading, less well-behaved, and less successful than their contemporaries (Blackburn 1974).

Finally the marriage between relatives. This may be cousins or second cousins and if they have a handicapped child the guilt felt is extremely heavy. It does seem that the only thing that can be done in this instance is for adequate premarital counselling of the prospective parents. They don't feel guilty if they don't have handicapped children but if they do, then the feelings of guilt are indeed traumatic.

Other areas requiring support and counselling include negative and destructive criticisms by extended family members, i.e. grandparents, aunts and uncles, etc. Family adjustments to the demands made by the care of a very dependent child over a long period of time and this includes the curtailment of family outings because the handicapped child's behaviour precludes enjoyment by the whole family e.g. the stimulation and/or the strangeness of the outing may be too fear-producing for the child and his or her screaming behaviour then becomes upsetting, and it is wiser to leave the child at home with 'Mum'; criticism or implied criticism by social contacts when the mother takes her child into town for shopping, and because of her sensitivity to people looking at her child she feels very upset and angry if the contacts make disparaging remarks about her child and his behaviour (Goffman, 1970); all common enough problems in the main but where parents are sensitive to the added demands of their handicapped child, these do tend to aggravate the feelings of guilt, fear, rejection and/or overcompensation.

Specialist Services

The Helper in his or her role of supporting the family and as friend and confidant does need to be also a co-ordinator of specialist services for the family. Paediatricians and Child Psychiatrists are available through Child Health clinics or Hospital clinics, and their role in supporting and helping the family is as varied as the family needs themselves. It may be that intensive help is needed for a period, e.g. a child with hyperactivity may require intensive play therapy and the parents can have help with their problems of management and/or anxiety; or, it may be that the annual or bi-annual visit to the paediatrician for their child's developmental oversight is sufficient for the parents, while other agencies help and support the parents in their care of their child.

Psychological Services offer counselling and programme development for children with special problems, e.g. temper tantrums, toilet training, etc., but as mentioned (p 1) specialists can only assist the parents or teachers to solve problems they have been unable to manage. The role of the helper in these situations is again supportive and

and often the parents feel the need to ask questions and seek support from the one person they know well and feel is more a friend than a professional.

Advice and therapy is available through the Child Health Clinics but as these are only in the main centres within the New Zealand context it leaves those parents in outlying small towns or country with the problems of transport, finance and availability of time when faced with the need for specialist help and advice. However, the Public Health Nurses and Medical Officers of Health do and will help parents in outlying areas whenever a family is in need. Most of the helpers such as S.I.H. Social Workers, and Statutory social workers are available by telephone to help parents faced with a crisis situation but the ongoing help from specialist services is limited in this country due to the dearth of personnel, and their services are stretched beyond the limits of possibility it would appear, i.e. Wellington Child Health Clinic had one and a half child psychiatrists, vacancies for one social worker; five vacancies for psychologists in the Education Department, for a population of 417,300 (Est.1975) covering the Wellington, Hutt Valley, Porirua and servicing the Wairarapa and Horowhenua areas.

Table 5

<u>Effect on Extended Family</u>						
118 cases	No.	Support	Rejection	Allowed	Not Allowed	
Paternal Grandparents	50	11 22%	14 28%	9 18%	16 32%	
Maternal Grandparents	52	20 36.46%	10 19.23%	12 23.08%	10 19.23%	
Paternal Uncles	21	7 33.3%	6 28.57%	5 21.33%	3 14.28%	
Paternal Aunts	19	7 36.84%	5 26.34%	4 21.1%	3 15.8%	
Maternal Uncles	23	8 34.8%	7 30.43%	4 17.4%	4 17.4%	
Maternal Aunts	21	8 38.1%	5 23.3%	6 28.57%	3 14.3%	
<u>Population of referred cases to Levin Hospital, 1 Jan.1976 - 1 May 1977</u>						

Extended Family Effects

In a survey of 118 cases referred for admission or waiting list inclusion at Kimberley Hospital between 1 January 1976 and 1 May 1977 22% of paternal grandparents offered support, 28% rejected the handicapped child, 18% were allowed to offer and give help, and 32% were actively discouraged and not allowed to assist the parents.

Some of the reasons include:

- 1) They spoil the child and won't make him do as he is told, they let him do anything he likes
- 2) They are always saying, "Oh, poor Jimmy. What a shame he is handicapped ... " and they tend to aggravate the parents particularly the mother, by implied criticism of the way she is bringing up her child
- 3) Premarital discord between paternal grandparents and parents; i.e. mother feels she was rejected by her husband's parents, etc.
- 4) Grandparents' age. "They are too old and can't look after Johnny. He is too hard to handle."

38.46% of maternal grandparents offered support, 19.23% rejected the child, 23.08% were allowed to help and 19.23% were not allowed to support or help.

The effects of the retarded child on parents, brothers and sisters, the highest percentage offered support and were allowed to.

It does appear that where support is offered and accepted by the extended family members parents feel able to seek a baby sitter from within their own family members and their children seem to benefit from the extended family concern.

Within the counselling or supporting situation pertinent information can be explored over time in the area of the extended family and the parents perceived effect on their relationships; the objective here is to determine the extent to which the parents agree concerning the feelings and attitudes concerning their in-laws. Where there is support parents are able to take advantage of their close contact with their extended family and when making decisions concerning placement the extended family support appears to lessen the guilt, fear, and anxiety for the parents. Pressure from the extended family to reject or 'put the child away' adds to the feelings of guilt and inadequacy and can have a detrimental affect on family as well as marital relationships it would seem.

Home or Institutional Care

Many studies have focused on the family's decision on whether or not a child should be institutionalised. One early study bore the title "When should the severely retarded infant be institutionalised?" (Jolly, 1953, p 810). Others discussed the need for the case worker to help parents overcome their reluctance to place the child, and once in the institution, forget they had had him (Wardell 1947; Walker, 1949). It was accepted practice for the advisor to "emphasise the positive features of institutional life so parents will come to ... see the logic of separation" (Jolly, 1953, p 810). Parents were subjected to pressure from their family as well as the professional advisors.

With the advance of community facilities and the care and concern of the Society for the Intellectually Handicapped, the parents have felt better able to care for their child within the family situation. Most parents state that they are well satisfied with the help received from the Society, and of 118 families referred to Kimberley Hospital (1976-77) for admission or inclusion onto the waiting list, 90 families stated that they appreciated the help received and thought that the Society had given wonderful help, 10 families were not registered with the Society as they felt their child was not catered for by the Society, and 5 parents complained that they did not receive the help that they should, and 13 parents stated that they were helped but the Society did not have sufficient Hostel accommodation and they felt that this was a barrier which needed to be overcome.

The impression gained from talking with parents is that they want their child at home but between the ages of 9 years and 13 years they would like to have boarding facilities available for their child so that he is not deprived from outings and companionship, particularly when there are older siblings in the household. Parents feel under some stress from the older siblings when they refuse to bring their friends home, or if they do they are worried about the handicapped child's reaction to the social situation. It is suggested too that the handicapped child also feels the need to escape from the increasing social stress and to this end the case worker needs to be aware of the non-verbal communication of the handicapped, e.g.

Case 1 - (Personal Experience, 1970-77)

Miles, aged 11 years, the second son in a family of two boys and one girl. Miles had been away for a prolonged short stay for behaviour modification and drug therapy review. He had returned home on the 4th February and for three days had been very good. Then his sleep pattern was disturbed and he was up and about for most of the night. Toileting regressed and he became incontinent, or rather did not go to the toilet though he was capable. He was disruptive at school so spent most of his time there on the trampoline. When the caseworker visited Miles spent most of his time close to her and initiated the contact. In discussing the situation with the parents they felt they were not coping and did not know what to do.

From observation over three years it was felt that Miles himself was trying to tell his parents as well as the caseworker that he wanted to return to the institution and this the parents finally decided to try.

On return to the institution Miles reverted to his usual self; his sleep pattern returned to normal; his toileting improved and he himself initiated his leaving his parents by wandering off to the courtyard and being beside his peers.

Though the parents went through a very traumatic two weeks and decided that they were the ones who were unable to cope and the grief and guilt associated with the feelings was at crisis point, they eventually accepted Miles' own decision, and acquiesced. The problems of facing a child's decision is traumatic for the parents but does need care and working through. Family and friends' support in this instance proved a positive aid for both parents and siblings.

CHAPTER 4Relaxation Therapy

Of all the methods of coping with tensions and anxieties of daily life, Relaxation Training probably offers the most direct and positive means of dealing with events that are upsetting or distressing for parents. The aim of relaxation response techniques to minimize the disturbing effects of anxiety which can be brought about by external (i.e. overt or covert criticism by family or friends) or internal (i.e. guilt, fear, grief, etc.), sources that inhibit the effective coping with real-life problems.

Relaxation is one technique for effective intervention in feelings of anxiety and may be used to deal with less obvious and often complex sources of distress. These may involve ideas, bodily sensations, or external situations. Emotional stress can occur as the result of family arguments or illness in the family. Environmental stress, such as exposure to excessive heat or cold is an entirely different phenomenon. Dr H. Selye of Montreal believes that physiological stress activates steroid hormones from the adrenal glands which are vitally important for survival of the organism and are sensitive indices of stress (Benson, 1976).

Holmes and Rahe (1967), devised a scale of stressful events that require adjustment to meet a series of life events. According to the doctors change, whether for good or bad, causes stress to a human being, leaving the individual susceptible to disease. Benson's (1976) approach is similar and he defines stress as environmental conditions that require behavioural adjustment. "For example, stressful circumstances are those associated with rapid cultural change, urbanization and migration, socioeconomic mobility, or uncertainty in the immediate environment" (Benson, 1976, pp 39-42). Life-threatening events are the most obvious environmental circumstances requiring behavioural adjustment and it is suggested that the birth of a handicapped child threatens the very way of life of husband and wife. Less dramatic but more relevant is what happens to the parents who have to adjust to the knowledge of the handicapped child and the effects on themselves as well as their other siblings and even the extended family members. Less immediate is the felt effect on friends and acquaintances. Several studies have examined how individuals are

affected when social roles break down and they are forced to establish new ones, (Benson, 1976).

Progressive Relaxation

Relaxation technique emphasizes the relaxation of voluntary skeletal muscles, i.e. the muscles over which we have conscious control. This technique seeks to achieve increased control over skeletal muscle groups such as in the arms and legs. Jacobson (1938) argues that anxiety neurosis and other related conditions are caused or aggravated by skeletal muscle contraction whereas muscular relaxation produces opposite physiological states, (Benson, 1976). In most instances people cannot limit the situations which require behavioural adjustment and people frequently find their lives thwarted by frustrating circumstances requiring adjustment, (Benson, 1976). How much more will parents of handicapped children who are anxious, guilty about "producing a handicapped child", with a secret desire to kill the child, under social pressure from ignorant neighbours or sheer physical exhaustion (Forrest Ritson and Zealley, 1973), feel thwarted and frustrated? Unlike the flight - or flight response (Selye, 1975), which is repeatedly brought forth as a response to difficult everyday situations and is elicited without conscious effort, Relaxation techniques can be evoked in the early stages of learning only if time is set aside and a conscious effort is made (Benson, 1976).

The use of tape recordings following the helpers or therapists demonstrating with the parents co-operation the contrast between tension and relaxation can be helpful. The technique can be taught to individuals or in groups and in order to utilise the relaxation techniques the helper or therapist must have a knowledge of and develop skill in three sets of operations which may be involved:-

- (1) training in deep muscle relaxation
- (2) the construction of anxiety hierarchies, and
- (3) the counterposing of relaxation and anxiety provoking stimuli from the parents own anxiety hierarchy (Carkhuff, 1969).

Braemar Hospital in Nelson has used the desensitization model for parents who have applied for admission of their handicapped child to the institution. Over the four or five years they consider that this

has helped the parents and reduced anxiety not only in their association with their handicapped child, but also has transferred to other problem areas in their daily lives with beneficial effects.

Four Basic Components

- (1) A Quiet Environment. Ideally a quiet, calm environment with as few distractions as possible contributes to the effectiveness of the learning situation and makes it easier to eliminate distracting thoughts.
- (2) A Comfortable Position. A comfortable posture is important so that there is no undue muscular tension. Some methods call for a sitting position, others use a prone position, but in lying down there is a tendency to go to sleep. Others use a cross-legged 'lotus' position of the Yogi. Essentially the position adopted allows for comfort and relaxation.
- (3) A Mental Device. To shift the mind from logical, external oriented thought there needs to be a constant stimulus, a sound, a word, or phrase repeated silently or aloud; or fixed gazing at an object. Dr Jacobson (1938) uses the stimulus words calm, serene, courage, etc., to encourage mental relaxation and combat 'mind wandering' and to break the train of distracting thoughts.
- (4) A Passive Attitude. Benson (1976) maintains that the passive attitude is perhaps the most important element in eliciting the relaxation response. Further he maintains that distracting thoughts will occur but by simply returning to the repetition of the stimulus words or phrase, the relaxation can again become deep.

Deep Muscle Relaxation

The training begins with the helper or therapist choosing a particular muscle group to demonstrate, with the client's aid, the contrast between tension and relaxation. The hand or forearm is usually chosen as a beginning point and the person is instructed to make a fist with his hand and maintain it for some seconds. While the person is performing this action the helper or therapist usually calls his attention to the feelings of tension that the person is experiencing. The Helper then instructs the person to allow his or her fist to open and rest and at the same time brings to his or her attention how

different and pleasant the sensations of relaxation.

During the training period the following muscle groups are focused upon (Carkhuff, 1969):-

A. Extensor Muscles

1. Right hand and forearm
2. Entire Right arm
3. Left arm and forearm
4. Entire left arm
5. Right thigh and calf
6. Entire right leg
7. Left thigh and calf
8. Entire left leg

B. Abdominal Muscles

1. Stomach muscles
2. Lower back muscles

C. Facial Muscles

1. Forehead
2. Eyes
3. Nose
4. Jaw

D. Upper Trunk and Neck

1. Neck
2. Shoulders
3. Chest

The training proceeds from one muscle group to another following the same format of first tension then relaxation. The therapist may focus on one muscle group per session and at the following session there is a brief review of each previous muscle group before helper and client move on to the next. Between sessions the client is instructed to practice at home what he has already learned for a period of 20 to 30 minutes per day. It appears that 5-6 sessions or up to 10 sessions are sufficient training for a client and after this it is sufficient for the helper to give general suggestions of relaxation for his or her client. Once the person has achieved a relaxed state the helper or therapist should use direct suggestion to further increase his or her relaxation, (Dr Jacobson, 1938), e.g. "You are now calm and you

are very much relaxed. However, you may become even more deeply relaxed and as I count backward from ten to one you will achieve even greater depths of relaxation ... Ten, nine ... etc."

(Carkhuff, 1969).

CHAPTER 5

Factors Associated with Parent Personality in a Small New Zealand sample

The behaviour of parents of handicapped children derives from many factors, and include cultural and social class attitudes to children in general, to handicapped people, and to teachers, social workers, doctors and medical care. But to a major degree their behaviour derives from their feelings about having a handicapped child. It has been argued (Mackie, 1974) that guilt feelings are less common than some people state (Wolfensberger, 1967). The present study takes as its starting point Wolfensberger's theory that 'guilt may not be inappropriate and that it may go a long way in motivating parents to provide the extra attention, effort and even love, a retarded child may need.' Neither Mackie nor Wolfensberger specify the particular attitudes, personality traits, and emotional reactions of parents with handicapped children in whatever category the child may be classified. As discussed above (pp 5-8), personality characteristics indicative of chronic guilt are guilt proneness, sensitivity, warmth, and anxiety.

Method

The data for this study consists of responses of 22 parents of retarded children who were asked to complete the 16PF. Within the group were two solo parents and the others were married couples. All agreed to co-operate and the questionnaires were administered within the home setting on a parent or individual basis.

Limitations of the Sample

The limitations of the sample are mainly those of small size and self selection. All parents seen or interviewed over a period of four weeks were asked to co-operate. The age range is between 20 and 48 years, and voluntary participation of these 22 parents which comprises about 7% of families referred for help in the past 12 months, does limit the generalisation from the findings, due regard to the sample bias.

Instrument Used

The Sixteen Personality Factor Questionnaire

The 16PF was chosen because the dimensions or scales are essentially independent and moreover "the experimentally obtained correlations among the sixteen scales are generally quite small so that each scale

provides some new piece of information" (Cattell and Eber, 1972). Scores on the sixteen factors being utilized as operational definitions of basic personality factors. The titles suggested as a basis for chronic guilt are, a tendency to guilt proneness, the emphasis on feelings, with a tendency toward awareness of criticism timidity or threat sensitivity, and a tendency toward increased tension. Therefore the four scales selected from the 16PF with face validity are (a) Factor O; guilt proneness; (b) Factor C; affected by feelings; (c) Factor H; shy, timid and threat sensitive; (d) Factor Q₄; high ergic tension. The critical score for the four 16PF scales are considered to include stens of 5 and 6.

Reliability

The reliability co-efficient takes three major forms for the 16PF; Consistency, Equivalence, and Stability. Dependability for the four factors range between 72 to 92, with Equivalence co-efficients ranging between 54 and 71; Stability co-efficients range between 75 and 98. The values for the 16PF are about as high as test values reach for the number of items.

Validity

Validity of the 16PF includes the concepts of construct validity, and specific clinical and industrial criterion validity. The Concept Validity has been measured in two ways, namely direct and indirect.

Direct concept validity for the four factors range between 63 and 94, and the indirect validity ranges between 84 and 95.

Results

Table 6, a,b,c,d, report the four factors extracted from the 16PF. Table 6a shows that more females than males scored above the critical score and approximately 50% of the sample scored above the critical score on guilt proneness.

On Affected by Feelings (Table 6b) females scored lower than males, while 54.5% of the sample were below the critical score.

Similar results occurred in Table 6c threat sensitivity, and Table 6d for high ergic tension.

Discussion

The summary data on the prevalence of factors associated with chronic

guilt in a small sample of parents with handicapped children has not included the chronic grief associated with chronic guilt (Olshansky 1962), yet it is suggested that the four factors do support the contention that grief is part of the chronic guilt syndrome, which may be more an emotional attitude generally involving emotional conflict, and this is supported by the tendency toward tension illustrated in Table 6d.

For the total sample more females than males were above the 6th sten 50% for females and 40% for males with a total of 50% overall for guilt proneness. Similarly the feelings trait is higher in females than males, 50% of males show greater control of feelings compared with 16.6% for females. 58.3% of the women score between the 1st and 4th sten compared with 40% of the men. Including the critical score for the sample brings the percentage to 68% approximately overall (Table 6d).

Similarly threat sensitivity is higher in women than men, more females scored lower than the critical score compared with 40% of the males (Table 6c). A greater tendency toward high ergic tension was found in this sample for both men and women, 50% of the scores were above the critical score. With the addition of the critical scores the tendency toward high ergic tension as one factor in the chronic guilt syndrome comprised 72.7%.

Perhaps the tendency for females to score higher in the four factors than the men may be related to the two hypotheses, namely females have a greater need for social approval (Meisels and Ford, 1969; Miller, 1974) and the greater impulsivity of females (Goldfried, 1963). Another factor it is suggested relates to the inclusion phase suggested by Dally, 1976. With the closer involvement of women in child-bearing it may be that the emotional overlay does affect the scoring whereas men do not go through the inclusion phase hypothesized by Dally. Rather the males, it is suggested, skip that phase and enter the extension phase at the birth of the child. This may help to explain the mens greater tendency to control.

Table 6 - 16PF, four factors, guilt proneness, Affected by Feelings, Sensitivity, and High Ergic Tension

Table 6a

Guilt Proneness

Sten	N	1 - 2	3 - 4	5 - 6	7 - 8	9 - 10
Males	10	1	3	2	4	-
Females	12	-	2	3	4	3
Total	22	1	5	5	8	3

Table 6b

Affected by Feelings

Sten	N	1 - 2	3 - 4	5 - 6	7 - 8	9 - 10
Males	10	-	4	1	4	1
Females	12	2	5	3	1	1
Total	22	2	9	4	5	2

Table 6c

Shy Timid Threat Sensitive

Sten	N	1 - 2	3 - 4	5 - 6	7 - 8	9 - 10
Males	10	2	2	4	2	-
Females	12	2	4	4	2	-
Total	22	4	6	8	4	-

Table 6d

Tense Frustrated - High Ergic Tension

Sten	N	1 - 2	3 - 4	5 - 6	7 - 8	9 - 10
Males	10	1	3	1	2	3
Females	12	-	2	4	5	1
Total	22	1	5	5	7	4

No correction for age. Norm tables used were for the general population (Reg. Manual and Handbook; Tabular Supplement No.1 to the 16PF Handbook 1967-68).

Other 16PF scales for this sample showed no significant tendencies for either males or females. The four factor scales pre-selected tended to show that females scored lower or higher than the critical score when compared with the men except for high ergic tension. Within the

context of threat sensitivity and tension parents do tend to suspect the motives of those who are trying to help. Often professional people are subjected to extended family pressure or even pressure from neighbours and friends in whom the parents have more trust and faith than in them. Perhaps here it is sometimes the fault of the professional people who too often do not take into account that the parents live with the child for 24 hours of the day in their early years and for something in the region of 16 hours when the child is at school. Most parents want to know what the future holds for their child, and why he is like he is - a question which is difficult and often impossible to answer.

It seems logical to assume that the personality modes carry over into child-rearing practices, so that some form of control and care will be related to personality (Dally, 1976). If chronic guilt is viewed as a capability rather than a disposition to enable the parents to cope with a retarded child, it may help to explain why and how parents can cope with very difficult behaviour problems for long periods of time within the home situation before seeking placement for their problem child.

Trait Factor, or Emotional Attitude

One can make assumptions from the Trait Factors extracted from the 16PF and draw some conclusions.

Firstly, guilt proneness was found in more women than men and of the total sample 72.7% of the scores were between the 5th and 10th sten. Similarly for threat sensitivity and affected by feelings. Tension for both males and females including the critical score was 72.7% of the sample.

Secondly, the combination of trait factors emphasises the complexity of chronic guilt felt by parents of handicapped children.

Chronic guilt has a basis in Personality Trait Theory and the results indicate that it is more common than Mackeith (1974) has implied for this group of people. In addition, the traits probably interact in complex ways with the environment in which the child lives. Also Trait Theory does not take into account the emotional attitudes arising

out of real or imagined contravention of moral or social standards in thought or act, (p 2). Nor does it explain what has occurred over time from the birth of the handicapped child to the present day; i.e. has the trait been accentuated or negated by the birth of the handicapped child ?

Other questions that arise are:-

1. To what degree was the trait present prior to the birth of the child ?
2. Was the trait a minor factor prior to the birth of the child or has it been accentuated or reduced because of the understanding and love the parents have given their dependent child ?
3. Is there a combination of Trait Factors which could predict when or if parents wish to place their child ?

Results of this field study tend to indicate that there is a combination of traits which can be extracted from the 16PF to illustrate the complexity of chronic guilt. Together with environmental, social and support factors which parents receive or seek, perhaps chronic guilt can aid the parents in bringing their child to his or her full potential within whatever situation is considered best for the child, whether home, institution or voluntary society hostel placement.

Acknowledgements

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Appendix 1Table 2 Classification of Mental Retardation

N.Z. Education Department Classification		N.Z. Health Department Classification	
I.Q.	Classification	I.Q.	Classification
70-85	Dull Normal or Variations in Normal Intelligence		
50-69	Mild Mental Retardation or Educable M.R.	50-70	Mild Mental Retardation
			} Special Class
35-49	Moderate Mental Retardation or Trainable	35-50	Moderate Mental Retardation. Trainable
			} Psycho- paedic
20-34	Severe Mental Retard- ation or Trainable Severely retarded	20-34	Severe Mental Retardation Trainable
			} Psycho- paedic
0-19	Profound Mental Retardation	0-19	Profound Mental Retardation
			} Psycho- paedic

In 1967 the World Health Organisation produced its Manual of the International Statistical Classification of Diseases, Injuries and Causes of Death. This was a revision carried out in 1965 of seven earlier versions. In the classification of mental retardation this report classes those with I.Qs. in the range 68-85 as 'borderline mentally retarded' as shown in category 310. On this basis 16%+ of the population would be regarded as subnormal. Thus, in 1968 an Expert Committee of the World Health Organisation recommended a revision of the classification so that 'mild retardation' was to cover the range from I.Q. 50 up to I.Q. 70 (W.H.O. 1968, Organisation of Services for the mentally retarded, 15th report of the W.H.O. Expert Committee on Mental Health. W.H.O. Tech. Rep. Serv. 392).

This viewpoint was further advanced at the 1969 W.H.O. Seminar in Washington which when making recommendations for the ninth revision of the I.C.D., recommended that the grades of mental retardation used in the 1968 report should be used, and that the category 'borderline mental retardation' be replaced by a category 'normal variations in intelligence'. In addition it recommended that the I.Q. ranges be removed from the manual and specified in a new glossary.

(See Moser J. (1971) W.H.O. activities concerning mental retardation. In, Primrose, D.A. (ed) Proc 2nd Cong. Intern. Assoc. Scient. Stud. Ment. Defic. 546-7).

This recommendation has been formally acknowledged in the 1973 revision of the Manual on Terminology and Classification in Mental Retardation of the American Association of Mental Deficiency, which no longer recognises the term 'borderline' retardation, and the upper limit of subnormality is placed at two standard deviations below the mean, that is I.Q. 70.

In terms of accepted expert opinion therefore it is now quite clear that a person with an I.Q. above 70 is regarded as a slow learner but within the normal range of intelligence.

This point of view is reflected in more recent textbooks by authors from various fields of professional interest. For example a clear statement is given in Silver, Kempe and Bruyn (Handbook of Pediatrics 10th ed. 1973)

" ... there is a large group of children whose I.Q.'s range from 70-90 in whom a diagnosis of mental deficiency should not be made but who do have a real intellectual handicap. Often this 'slowness' is not recognised until the primary grades." P.166.

Similar viewpoints are given in Eden (Mental Handicap, 1976) Forrest, Ruson and Zealley (New Perspectives in Mental Handicap, 1973) and Kenny and Clemmens (Behavioral Pediatrics and Child Development, 1975) for example.

While an I.Q. of 70 indicates an upper limit for a legitimate diagnosis of Mental Subnormality in terms of the Mental Health Act 1969, there remains a grey area as to the most appropriate placement for people whose intelligence falls within the mild range of subnormality, say above I.Q. 55.

An I.Q. score gives an indication of ability to learn new material in a mixture of formal and informal situations with respect to the time taken and the difficulty of the material involved. It does not necessarily show how sensibly or appropriately the person will use what he has learnt. Thus people with I.Q.'s above 70 can commit social offences - but are held to be fit to plead to a charge in a Court of Law, and can be dealt with in the normal facilities provided

for offenders against the law.

People with I.Q.'s below 70 can be regarded as not fit to plead to a legal charge against them, and can be dealt with in institutions covered by the Mental Health Act.

While this takes care of the legal matter of disposal it does not give an indication of the most appropriate institution in the group covered by the Mental Health Act, namely psychopaedic or psychiatric institutions.

Because of the interaction between intelligence (I.Q.) and personality factors and social experience, one person in the mild range of subnormality who has sought the protection of the Act may have been aware of the legal implications of his actions when these were being carried out - while another with the same level of ability may have been quite unaware.

0-50 I.Q. is classified as psychopaedic within the New Zealand context and is accepted as a legal definition and has received the accolade of New Zealand legislature. Within the psychopaedic category are the profoundly, severely and moderately subnormal. However, within the field of subnormality the social definition is becoming increasingly popular, in which the social quotient and maturity of the individual is taken into account with the I.Q. at any one point in time, with most of the people involved in the testing of handicapped people.

Forrest, Ritson and Zealley, (1973), state that the importance of social intelligence has been stressed by Gunzberg (1968) who regards this quality as critical in determining the future for mentally retarded people.

Gunsberg has pointed out that individuals demonstrate intelligent behaviour in three different ways - verbal, non-verbal or practical, and social intelligence. He describes social intelligence as the 'ability to establish and maintain adequate relationships with people.' The person who misjudges or cannot appreciate the rules and standards of his society will be rejected more readily than the person who lacks formal learning, but has an understanding of the social situation (Forrest, Ritson, and Zealley, 1973).

It is the individuals capacity to cope with and adapt to his or her environment which determines the extent of the real handicap. Those who are severely, or profoundly retarded will always require some degree of care and protection, but amongst the moderately and mildly retarded, independence will depend on the degree to which the person has mastered social skills. Of the main psychopaedic hospitals, Mangere Hospital does not accept people over 50 I.Q. level and has an age limit of 16 years; Templeton and Kimberley Hospitals have a much broader category and take people for training and/or care from all categories of intellectual handicap with no age limit.

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