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THE DEVELOPMENTAL CLINIC

PALMERSTON NORTH

1977-78

A thesis presented in partial fulfilment of the requirements
for the degree of Master of Arts in Education
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SUMMARY

This thesis presents an exploration of the Developmental Clinic which operates in Palmerston North. The present psychologist has worked there for two years, the period of time the clinic has been administered by the Department of Education Psychological Service in this area. Little information was available about the clinic, its operation, its philosophy and its programme when she began so this study has been firstly a means of providing that information as a basic resource that clinic staff and others can refer to locally. As the clinic continues this information can be added, the thesis serving as an introduction.

Some effort has been made to evaluate the clinic informally and highlight problems that exist as well as conveying the very positive feelings clinic staff and others have towards the clinic. Already some of these problems are being considered and action taken to remedy them. Because the clinic is a very flexible and evolving organisation one action leads very quickly to another, and comments made at one point become outdated shortly afterwards.

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This was also provided by the staff of the Psychological Service in Palmerston North and by a number of teachers in local schools who became aware of the reasons for my frequent absence from their schools. I am very grateful for this.

During the period I was writing this thesis I was assisted by local paediatricians, the visiting therapist, and the clinic staff who were prepared to give their time to consider questions posed. Their interest in the clinic is demonstrated by their efforts to change existing situations to conform with what seems a more desirable approach to the problem of handicap. Often changes occurred as a result of an interview. It is very rewarding working alongside people such as these. Particular thanks goes too to the parents who answered questions, put forward ideas and often rang several weeks later with a new thought. Their interest was very supporting.

Special thanks go to Marie Goss for typing this thesis. Her experience is invaluable.

Finally I must commend my family for their patience. As my daughter has stated, I will now be able to teach her to knit, a skill she has done without for two years while her mother has pursued other interests.

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CHAPTER ONE

THE DEVELOPMENTAL CLINIC: AN EARLY INTERVENTION PROJECT FOR INFANTS WITH A POTENTIAL HANDICAP

SECTION ONE: INTRODUCTION

The Palmerston North Development Clinic, also called the Dawn-Start Clinic, operates on Thursday afternoons between 1 o'clock and 4 o'clock. It is staffed by three people; a psychologist employed by the Psychological Service, Department of Education, Palmerston North, a physiotherapist and a speech therapist both employed on a part-time basis by the Palmerston North Hospital Board. The clinic meets in the playroom at the hospital. Children up to a developmental age of approximately 18 months are the main group catered for but older children up to about age 3 are also assessed and occasionally worked with over a period of time. All children attend with at least one parent. It is usual for six families to attend in one afternoon, their appointments lasting one hour.

Parents of these children demonstrated a need to meet each other and share experiences so a Parents' Group exists which meets one evening a month at Terrace End School which has offered its staff room for this purpose. This is a parent-organised group which is informally structured and includes as its members parents of children who have graduated from the clinic as well as parents in families that still attend.

A variety of agencies and persons, both professional and voluntary, liaise in a loose manner with the clinic

and with one another. Prominent among these are the paediatricians who are involved with all the children attending the clinic, and the visiting therapists. Previously known as visiting cerebral palsy therapists, the latter are trained in aspects of physiotherapy and occupational therapy. They liaise between hospital agencies and specialists and families who have a child with a handicap that is expressed physically. As well, they assess the handicap in physical and functional terms providing a programme that will help organise as near to normal development as possible. Aids and appliances are made available when necessary.

Occasionally liaison exists between a hospital-employed social worker and the other agencies. This tends to occur when a child is hospitalised. The paediatric social worker learns about that child and endeavours to ensure that everything possible is being done for it.

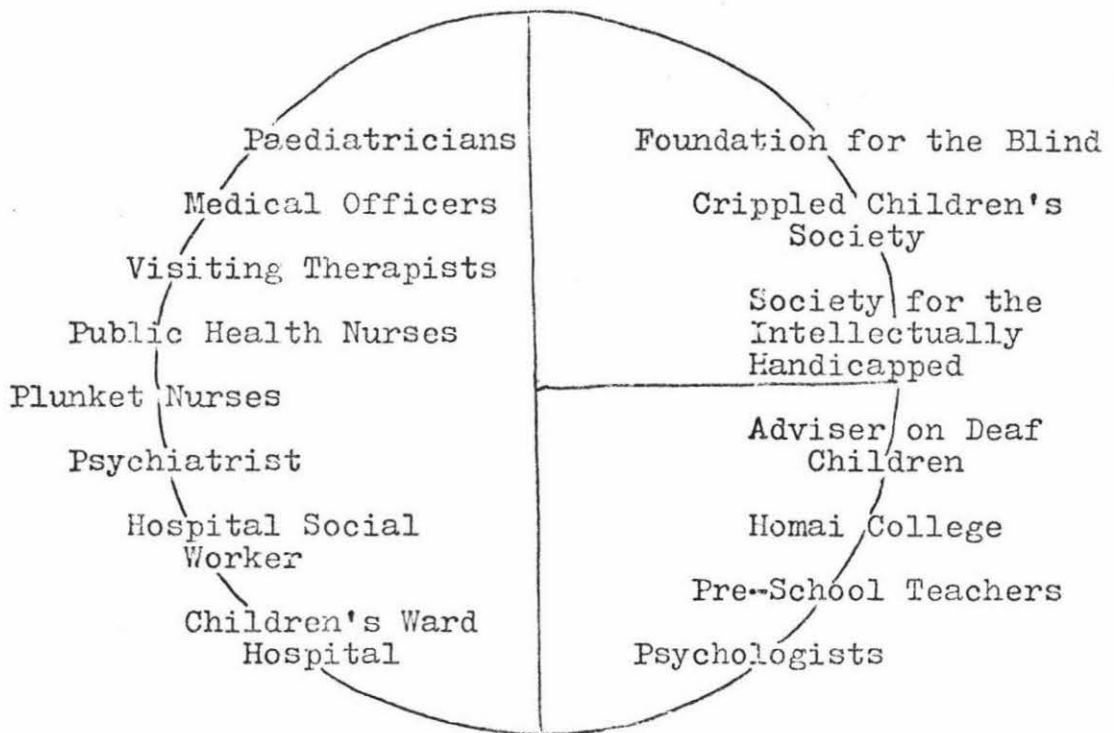
All agencies may be involved with children who have been hospitalised but they do not usually contact nurses within the ward. Only the hospital-based groups (including the clinic) make this contact to gain information about the child or to request specific action. In the clinic's case action requested has been to ask for observation or stimulation of a child.

Field workers from the Crippled Children's Society (CCS), Society for the Intellectually Handicapped (SIH), and the Foundation for the Blind, have children registered with them at an early age. This appears an indiscriminate procedure because it is voluntary, but families can receive assistance once their child is registered. These

officers liaise with all other agencies concerned with the child and are generally popular with families.

Occasionally Plunket Nurses and Public Health Department Nurses will become part of the circle of agencies concerned with a family if they feel particular concern for a child. Usually, however, they tend to remain separated confining their contact with the family to normal routine checks on progress. In the clinic's experience two Public Health Nurses and one Plunket Nurse have involved themselves with the clinic programme reinforcing clinic teaching with parents who have shown a tendency to overlook its importance.

Department of Educational personnel - Adviser on Deaf Children, Psychologists, or Pre-School Teachers - liaise mainly with clinic staff although once they are closely involved with a family they will become involved with the wider circle of agencies. The pre-school teacher from Homai College (for the Blind), Auckland, is in contact with clinic staff and the visiting therapist. Once yearly she visits children with visual impairments in the Manawatu area.



This diagram illustrates the agencies involved with the clinic and their source. The domination of the medical agencies is apparent. Liaison exists between all groups although this is not always effectively organised. The only agency which takes referrals but which does not communicate with the others is the psychiatrist.

From all appearances the clinic has close medical ties and it would be easy to assume that this is a medically-based project which happens to be assisted by educational personnel. The fact that the psychologist is considered by many to be hospital-employed reinforces this. In reality the clinic is an educational project which uses medical expertise where this is necessary and appropriate, e.g. if a social worker is required the clinic is obliged to use a hospital social worker because the Department of Education does not employ social workers. The hospital-employed speech therapist is also used because of the considerable case loads carried by Department of Education speech

therapists. It is realistic that such a sharing of facilities is possible but the effects of this must be realised.

Surrounded by so many medically-based agencies the clinic could easily feel dominated by their medical orientation. It is most important however that the clinic maintains its educational basis because it is only through this that the positive attitude so intrinsic to its philosophy can be maintained. The speech therapist provided a useful illustration of the differing approaches from her observations of a recent meeting of the Pre-School Assessment and Coordination Panel. This panel is made up of paediatricians, medical officers, visiting therapists, speech therapists, psychologists and the Adviser on Deaf Children. It meets monthly to coordinate action on particular pre-school children all agencies are involved with. Two little girls were discussed, S whose development is considerably delayed, and T who has rubella syndrome. In a general conversation about these children an interesting contrast of attitudes was shown. One medical representative in discussing T and techniques available which could have prevented her condition described her as a "write-off." The psychologist followed by reporting on a conversation she had had with the itinerant pre-school teacher from Homai who considered T to have potential and to be superior to other children in the Deaf-Blind section of the school. S's case was more confusing. The medical representative concluded that he could not find any reason for her handicap but semi-seriously suggested "bad stock." The speech therapist followed this with an account of the

child's progress, describing her as "delightful." The medical orientation appears concerned with description of the causes and expression of a problem and is therefore inclined to be static; the educational orientation as far as the clinic is concerned is intended to bring change so must focus on what the child can do. This allows a positive approach. Such a conflict of attitudes although demonstrated in this example in a very minimal sense can alienate those with a handicap as different agencies set different goals requiring different expectations of the person. This creates a meaningless existence for those concerned as their genuineness is always a doubt. (Safilios-Rothschild, 1970). Because the clinic is concerned with other people's expectations of a child with a handicap the differences between agencies' attitudes is an important factor to clinic effectiveness. If facilities are to be shared by more than one agency a common basis must be sought. The clinic with its closely considered strategy and supporting theories offers a basis from which unified action can be constructed.

It could be suggested that the Developmental Clinic is isolated in this medical environment and that this isolation could be destructive in that it could diminish the clinic's positive goals. Recently, however, the Department of Education has included infant intervention as part of its policy. Considerable support to the clinic will eventuate once a network of early intervention clinics is established in New Zealand; which is hopefully what will happen. Although this will give the clinic security it will not diminish its important role in working

with a medical team. The clinic should see itself as having two roles: an internal one concerned with a child and its family, and an external one concerned with creating an awareness of that child and family among others.

One of the major conclusions that can be drawn from this thesis is that the clinic has in general terms been successful in carrying out its internal role so that it is now in the position to focus on the wider environment of the child and family.

SECTION TWO: HISTORY

Liz Straton, Lecturer in Special Education at Massey University up until the end of 1976, was the instigator and organiser of the Palmerston North Developmental Clinic, the first project of this particular nature in New Zealand. Her interest was the result of experience in working with pre-school children with a handicap. She reasoned that if these children were to be helped to achieve the ability to learn then such help must be offered within the first year of life. Her reading supported her argument.

In 1974, with the support of other members of her department, she began working towards the establishment of the clinic. At first it was necessary to gain the cooperation and interest of other services and agencies already working in this area. All expressed support.

A physiotherapist, Joan McComas, was to be involved. Negotiations with the visiting cerebral therapist, Hospital Superintendent and paediatrician enabled her to be employed by the Palmerston North Hospital Board as Assistant Visiting Cerebral Palsy Therapist, a position

allowing for greater scope than if she were employed as a physiotherapist because she would receive a travelling allowance if necessary.

Initially the clinic was based at Massey University. Transporting problems, difficulties in finding car parks and storage problems however led to a change. With hospital permission the clinic was then transferred to the more accessible Hospital Playroom where equipment could be stored, papers and toys, in two cupboards in the playroom while larger equipment stacked outside the playroom door which leads to the main corridor of the hospital.

Equipment was either donated or loaned but \$50 was given by the Education Department at Massey University, and later \$100 donated by the Crippled Children's Society, which enabled some to be bought. This equipment has remained with the clinic but some is now in need of replacement. The Department of Education has offered finance for this.

At first six, then eight, children were involved in the project and their progress was sufficient to interest observers and enable the clinic to become a permanent facility.

In 1976 Liz Straton left Palmerston North for Wellington where she has set up further clinics in both Wellington and Porirua. Her appointment with the Department of Education as a part-time psychologist was for this purpose. Before she left Palmerston North, as a result of discussions with the Psychological Service of the Department of Education, operating the clinic in this city became a function of the Department which allowed one psychologist the required time to do this.

From discussions with Mrs Straton it is established that the philosophy of the Palmerston North Clinic has not changed but the organisation has altered. A speech therapist has become involved and the liaison with visiting therapists has extended. In contrast with the Wellington clinics, all staff of the Palmerston North clinic have become involved in additional home visits and counselling where necessary and possible. In Wellington a social worker is employed to do this. A speech therapist, although considered desirable, is not available to the Wellington clinics. The effectiveness of each clinic has developed individually, and is determined by local needs and the availability of local resources. That this could be a weakness is admitted, e.g. speech therapists may not be automatically available, but it also allows a flexibility which enables possibilities to be explored. This must be considered now these projects are to be departmentally-based as those working for government departments are only too aware that logical extensions to projects can be illogically blocked, and appointments and changes brought about according to whim instead of reasoned discussion with those who may be involved. The purposes expressed in clinic philosophy could be impeded by bureaucracy.

While it has been said that the Palmerston North clinic is the first of its kind in New Zealand, when considering the historical context, mention should be made of other early intervention measures that have occurred. Prominent amongst these is the guidance given to the parents of young deaf children through the advisory service established by the Department of Education. This is

restricted in its content in comparison with the broad strategy adopted by the Development Clinic but is organised around the same ideal of using parents as teachers of their children to help each child become integrated into family life and ordinary society. As with the clinic prevention is the main objective. This same approach has been adopted by visiting therapists and speech therapists who have also been anxious to have children referred as soon as their needs can be presumed or identified.

Although it seems certain that the Developmental Clinic will extend its organisation through New Zealand, its format may be challenged by a similar project financed largely by the Department of Education through a research contract with the University of Waikato. PATH - Parents as Teachers of the Handicapped - has similar aims to the Developmental Clinic but makes extensive use of videotapes and tape-slide programmes to convey ideas. This immediately indicates that the amount of financial support required in contrast to the Developmental Clinic would be greater while the use of audiovisual equipment has been commented on by a lecturer in pre-school education, who has observed both projects, as being a little "cold".

The important factor with both projects is the willingness of the Department of Education to become involved through its Psychological Service despite the considerable case loads already handled by this Service. In so doing this Service has given official recognition to the importance of infancy and to the principles involved in infant education even though this recognition is addressed to a very small proportion of infants, those with a potential handicap.

CHAPTER TWO

THE CLINIC'S ROLE, PHILOSOPHY AND THEORY

SECTION ONE: THE NEED TO RECONCILE THE MEDICAL APPROACH
WITH THE EDUCATIONAL APPROACH

The Developmental Clinic has a strong educational orientation supported by theory which is reflected through its aims and methods. This has certain implications which can be summarised as:

1. the need for a consistent overall approach to working with the child with a handicap and the family; and,
2. the need for the approach to emphasise the normality of the child putting this before the handicap.

The clinic has taken this orientation into an area of work which has traditionally been dominated by a medical approach. There is no conflict, as both disciplines have accepted the need for each other because the approach to handicap requires coordination of services if the unfortunate effects are to be ameliorated. The problem is that medical personnel appear involved with the nature of handicap itself rather than the child while the clinic's aims are directed towards the child's development. Each has a line of attack which is not completely understood by the other. That of the clinic is a new approach and must stand alongside what is traditional.

While both approaches can be complementary, it is obvious that certain parts of the medical approach cannot co-exist with the educational principles involved. A basic

example of this disharmony is the medical aim of treating a patient in contrast to the educational aim of working with a client. The doctor-patient relationship tends to be one in which the aim is to restore the status quo, i.e. bring a person back to health; the educator-client relationship tends to be one intended to improve on the status quo through the provision of opportunity. There is however a basic interdependence between medicine and education. The clinic's understanding of the pathological nature of a handicap comes from medical personnel. In return the clinic expects to be able to educate those personnel about its own approach because it sees this education as an intrinsic part of the amelioration of the effects of a handicap. Although the clinic has the specific role of providing parent-training programmes it must logically examine any action which may intrude upon its effectiveness. The doctor-patient technique if applied to children with a handicap in the traditional way can have a negative effect. The white coat of a doctor in itself may create a barrier between the medical practitioner and the family of the child. Safilios-Rothschild (1970) considers such situations as contradicting the rehabilitating concept that is ideally the approach to handicap. She mentions the doctor-patient attitude as one which inhibits the autonomy and initiative of those receiving treatment and goes further to comment on subtle behaviours that reinforce this attitude.

Mrs Rn was critical of the eye specialist who examined her child. She respected the fact that he was direct in stating the facts as he saw them and felt that his examination demonstrated his competence. She noted however that he did not speak to Rn and at the finish pushed him away as if he was of no consequence. This hurt her feelings.

That such education is needed is apparent from interviews with the various medical personnel closely involved with the clinic, whose comments demonstrated a lack of full understanding of clinic aims and theories. Clinic staff and the visiting therapist had made efforts to explore the clinic's rationale, while paediatricians expressed a wish for "informative material".

The visiting therapist supported by a paediatrician has suggested an education group be established to help overcome the problems in communication that appear to exist between personnel of the various fields involved. She made this decision when she recognised the difficulties clinic staff were facing in their efforts to achieve ideals. The first section of this thesis is to be considered as an explanation of the clinic's aims and supporting theories, i.e. the internal role of the clinic. It is directed towards those without specialist educational knowledge and it is hoped that it will initiate further discussion and thus understanding of the wider implications of working with children with a handicap already mentioned.

SECTION TWO: THE CLINIC'S PHILOSOPHY

A child with a handicap faces limitations of a pathological nature, intellectual, physical or sensory, which have long been viewed with various shades of conservatism. The limitations have tended to have effects considered inevitable. The Developmental Clinic questions this inevitability. It does not dispute the essential features of the handicap if in fact these can be established but rather, through its methods, it encourages a simple and economic definition of these features. The comparison of

two children serves as an illustration:

1. Rd is 2 years old. He functions at the level of a 10-11 month old. He has possibly 5% vision. Rd appears well adjusted. He carries out tasks consistent with his developmental level with the degree of reticence we could expect because he cannot see. His parents show signs of acceptance and enjoy playing with him because of his response.
2. L came to the clinic at 18 months. She appeared to be functioning at an 8-9 month level except in large body skills which were at the 12-18 month level. She is partially sighted, a distractible, restless child, who rocks repeatedly and demonstrates little responsiveness to people or objects. Her mother has refused assistance from those prepared to offer support and L attended the clinic on two occasions only. A friend commented on Mrs L's lack of acceptance of L.

The major difference between Rd and L lies in their adjustment and that of their parents. This is demonstrated in their behaviour. Rd behaves in a way we can expect of a 10-11 month old. He interacts with his general environment including the people within that environment. The behaviour of L however is a problem because interaction is prevented, stimulation difficult to give and so she does not learn. The essential features of her handicap have been obscured by her behaviour. Even though these essential features may have been unavoidable, behaviour is learned. In L's case the social and emotional consequences of this which both she and her family are experiencing give support to Sheridan's often quoted phrase that for every child with a handicap there is a handicapped family (1965). The clinic challenges the notion that handicap should always be of such a complex extensive nature. In so doing it adheres closely to Sheridan's conclusions concerning the needs of children with a handicap.

Children have a basic need to learn and require assistance to do this effectively. A child with a handicap needs often a vastly increased amount of assistance. It is common practice however to ignore this need until the child enter pre-school. The suggestion is that the nature of a handicap becomes exaggerated unless there is some form of intervention the timing of which is considered crucial. If it is too late the handicap can extend into a pattern that is entrenched by the time the child reaches pre-school, at times straining the resources of that pre-school. This creates further problems for the child and family as the child and the pre-school fail to cope with each other. Assistance given at this stage cannot prevent what has already happened, while remedial assistance is often less satisfactory. In working with infants the clinic aims at prevention. As a side issue it points out that this requires a lesser slice of educational funds. In this it adheres closely to other early intervention approaches such as that adopted by the Wolfson Centre with children with spina bidifa (K.S. Holt, 1975).

Normalisation is the need of those with a handicap but so often handicap is equated with the abnormal. This is because it can be an impeding factor in development, distorting or retarding the pattern of growth. To allow this to extend into a pattern too opposed to the norm reinforces the attitude that the handicapped child is abnormal. The clinic's preventive techniques emphasise the normality of the child. It is reasoned that all children go through the normal stages of development. Normal development is ongoing with a structured organisation

allowing continuous advance. This is very noticeable in infancy when few skills are emerging and being practised before they become integrated with others to form more complex skills. In those with a handicap if the skills are assisted at this early stage to emerge in as normal a manner as possible, the handicap can be prevented from affecting development more than it might do.

To achieve this it is necessary to understand the importance of factors which interact with the child allowing normal and adequate development to occur. Without this understanding it is suggested that the clinic would lose effectiveness.

Of key significance to this whole strategy is an understanding of the nature and importance of the relationship existing between parent(s) and child. From birth the infant is in control of himself in relation to his environment but he has obvious limitations and is therefore dependent on his parents' correct interpretation of and response to his activity. Their response to his stimulation provides him with the opportunity he needs to interact with the wider environment and thus the latter returns the stimulation reinforcing a satisfying cycle. The clinic aims at assisting the establishment of such a positive relationship between parent and child recognising that this must be done early in the child's life because family patterns are established from the beginning. A handicap may cause the delay of, distort or inhibit the appearance of developmental stages creating confusion in the parent preventing adequate attachment from occurring with the child. If this continues the parent can react with a

helplessness which increasingly concentrates on care rather than the provision of experience. When this happens holiday placement and institutions are soon turned to to help alleviate the pressure felt.

The notion of handicap exists because those who are handicapped require assistance to interact with their environment, they do not always have the physical or intellectual capacity to do this alone. Because of their interdependence with another person that person (initially the parent) also needs assistance to correctly interpret the needs of the person with the handicap. With infants this can be done by educating the parent about normal development so as she or he can recognise, promote and reinforce with experience, developmental stages as they begin to appear in their child.

Programmes have been designed which indicate the various skills an infant achieves in language and motor development. The parent is trained to become aware of these, through discussion, observation, occasional reading and the teaching of play techniques. This enables each parent to understand the direction in which development travels and to correctly apply this understanding to the child's rate of development. With such understanding, skills can be promoted in an ordered manner, creating for the child an organised pattern of behaviour which enables that child to achieve at his optimal level. Such learning is in itself a motivating force to progress. As this occurs the essential features of the handicap become more clearly demonstrated. The clinic therefore participates in diagnosis by defining the handicap, e.g. how the cerebral

palsy is expressed or an estimation of what the child with a visual impairment is able to see.

The role of the clinic then is to encourage the adjustment of parent and child to each other through the establishment of realistic expectations that are mutually held. Handicap is confined to its pathological status when adjustment exists. Unrealistic expectations either way upset the balanced nature of adjustment creating conditions that extend the pattern of handicap. Through its programmes the clinic concentrates on the individuality of the child. His development becomes a demonstration of where he stands and his parent is able to understand him more clearly, thus adopting realistic expectations of him. When the relationship between parent and child is competent the social and emotional consequences are positive. The child's resulting "normality" is a reflection of the family's "normality" in that "normality" can extend its effects as much as handicap.

Through this contact the clinic is giving support to parents helping them to come to terms with the emotional reactions they may have towards their child. It is also able to provide for them information and an opportunity to meet others with similar problems. The Developmental Clinic then incorporates in its overall strategy a number of the ingredients considered necessary to successful early intervention in that the assessment and diagnosis of children with handicaps is followed by a programme designed to ameliorate a potentially handicapping environment. (Beasley, 1977).

SECTION THREE: THEORY

Theory provides a means by which behaviour can be interpreted and action can be determined. This lends to consistency and order. Meier (1976) in his discussion of intervention programmes, suggests that those are the most effective, and have a broad theoretical basis to support their practical aims. Reynell (1973) points out that intervention programmes are concerned with the intellectual processes and that these are given meaning when a developmental approach is adopted. She states that any programme concerned with children under five years must be related to developmental patterns and progressions and that these should be applicable to children with or without a handicap.

A programme that can be simply described in these terms is that carried out by the Bobaths (1963) with children who have cerebral palsy. Their direct aim is to inhibit abnormal function and facilitate normal function in its proper developmental sequence. Indirectly they aim at preventing unnecessary retardation. Movement is considered to relate to learning, so the brain, a passive organ, is activated. Their approach is therefore not confined to function alone but attached to a theory of intellectual development.

The Developmental Clinic has a similar structure rejecting much of what is traditional theory and adopting instead the interactionist viewpoints described by Gordon (1975) as being typical of Hunt and Piaget. This requires a concern with the role of infancy in development, the importance of experience and how the environment can be structured to offer this, the nature of development and of

intelligence. In doing this the clinic has followed trends elsewhere which demonstrate how markedly developmental psychology has swung from the maturational viewpoints of those such as Gesell (1934) to a viewpoint which considers the developing child in his environment from which he elicits information. This is seen as particularly relevant to the child with a handicap who, it is believed, is so dependent on the quality of his environment if he is to develop without failure becoming a common feature of his life. It has also been considered an appropriate means for approaching the educational needs of disadvantaged infants in that the nature of disadvantage requires a focus on the environment. Gordon refers to Levenstein (1975) who adopts a home visit approach in an effort to create an effective learning centre in an infant's home.

The theories which have influenced the clinic's design are also those which support the concept of early intervention as they demonstrate the special needs of a child with a handicap.

Gordon (1975) states that holding a developmental viewpoint requires the belief that there are long-term effects of early experience and that the individual's pattern of behaviour over this time is a relevant factor throughout its life span. A.D.B., and Ann Clarke (1973) would perhaps dispute the paying of undue emphasis on this early period pointing out that a child can compensate at a later stage but they do not consider this sufficient argument to bypass this period. If as Gordon states (*ibid.*) infancy is considered significant as the clinic also believes, then the notions that intelligence is fixed and

that adult intelligence is predetermined by heredity are to be rejected. Instead intelligence is defined more as a multi-dimensional technique, a complex of skills that organise experience, solve problems, store information and understand relationships between acts and consequences. It could be described as an energy or a force. Intelligence and development appear to be of an interrelated nature demonstrated through adjustment. The clinic interprets development as an integrating force in which all factors interact with one another and with environmental factors.

Concern is with the activation of this energy or the developmental thrust. To understand this is to require an understanding of motivation which is intrinsic to developing competence. Motivation and intelligence are not separate entities as was once held but aspects of the same dynamic force that interplay with each other (Yarrow and Pedersen, 1976). Hunt and Piaget are described by Rowland and McGuire (1971) as suggesting that novelty in the environment causes and imbalance in the active organism which has sought its stimulation. The organism as a result of understanding restores stability. This gradual learning results in a competence which is satisfying because the environment has been coped with. In itself this is an argument for the provision of novel experience for all infants in contrast to the traditionally held and still adhered to view that infants should be protected from stimulation because they cannot cope with it. Straton (1977), in outlining her strategy for the clinic, points to the developmental age of eight months as crucial for intervention if it is to be truly effective because this is a decisive point in infant

development. Earlier acquired skills are now integrated to a level where the infant is able to explore novelty. Burton-White (1973) also supports the point of view that this is an ideal time because the earlier comparative helplessness of the infant is now replaced by a more independent challenge. The quality of learning opportunities and the infant's success will either stimulate or depress motivation affecting development accordingly. The child with a handicap is someone who cannot always interact with novelty and learn from that interaction without assistance. Assistance must be timed to capture the developmental thrust and direct it.

Hunt (1961) has dealt extensively with the importance of the experience that environment offers and the manner in which the organism's activity is modified by this stimuli. The greater the stimulation the more the activity is triggered into making the adjustment that is the essential component of development. Meier (1976) illustrates this by referring to the variety of research, e.g. Korner and Grobstein (1967) which demonstrates a relationship between the development of early visual-motor schemata and parent handling. Hunt (ibid.) adds that for experience to have such a result it must match the organism's capacity to interact with it otherwise imbalance remains and there is no satisfaction. This is critical to clinic work where the correct match brings about the desired response reinforcing parent attention and encouraging them to keep working with their child. It is the task of clinic staff to indicate the match and this is most easily identified in infancy because the sensori-motor learning of infancy is of a more

simplistic nature.

Competence is expressed through skills. Gordon (1975) refers to Piaget as believing that the mere possession of a skill is motivation sufficient to use it. This can be seen in play when a child delights in using the skills he has mastered, practising them as well as achieving new goals. The exercise of skills is governed by intention and feedback implying that skills are generative in nature (Bruner, 1974). Skills therefore create opportunities. The child with a handicap who has minimal skills has therefore fewer opportunities. Opportunity is an expression of adequate development. Possessing a skill implies understanding which comes with practise and is impetus sufficient to extend action. The child with a handicap is often deprived of possession because he does not have the same opportunity to practise. Failure is a feature of his life. This should be prevented from occurring from the beginning when skills are emerging.

Piaget is concerned with how the organism processes information that results from environmental experience. His developmental theory is based on the evolution of abstract thought. It is what the child is thinking rather than what he is doing that is essential. Piaget has provided a groundwork of rules to explain his theory. The clinic has organised its skills teaching programme around these emphasising that it is insufficient to teach skills in isolation as the latter can result in slower or disorganised development. Piaget's theory is an organised one where each stage depends on the previous stage. As Hunt (1961) points out even more vividly, each stage has its

roots in earlier learned skills which may appear quite different. This highlights the need to work at infant level. Because development is considered cumulative it is difficult to isolate one influential factor from another except when they are occurring.

Because Piaget is concerned with an individual child's behaviour, providing a means of estimating where that child stands developmentally and therefore what is likely to happen next, he is seen by many as offering a means of understanding mental retardation. The concept of retardation is related to the child's rate of development. Piaget's theory deals with the nature of development and not the rate in contrast to maturation theory. Klein and Safford (1977) discuss this and the small area of research which appears to support it, pointing out that it allows for a positive orientation increasing the chances for the child's normality to be recognised.

Educationally then Hunt and Piaget have much to offer those involved in preventive work with children who have a handicap. Their view that development is continuous infers a starting point. It is easier to work at beginnings to prevent situations from occurring than to attempt to patch up later on. Infant experience is considered important to development as later opportunities are dependent on what has occurred at the beginning. Hunt has applied this reasoning to the child from the poor home where once the initial environment has been explored and understood, experiences become unvaried thereby restricting the developmental thrust. This can be applied to the child with a handicap as well, disadvantaged not in terms of what is available but in terms of what he can obtain to organise

into a learning opportunity. Brinkworth (1973) describes the child with Down's Syndrome as immature and therefore unprepared for his environment. Lack of preparation for what the environment offers is a consequence of handicap implying that there is no match between the infant and the environment. Logically then development is impeded and because its nature is cumulative then the impediment's effects are cumulative. This is presumably what "at risk" means. Many such children can be identified during their early months but identification is without a purpose unless a programme exists which attempts to eliminate or reduce what is at risk in their existence.

The clinic's aims acknowledge that its programme of ameliorating handicapping effects depends on the adjustment of parent and child to each other. Straton refers specifically to Sharp (1974) who emphasises the importance of the quality of the mother-infant bond for the development of social responsiveness, a crucial factor in determining the amount and type of stimulation a child will receive. The infant with a handicap is often unable to respond adequately. This together with his mother's anxiety and possible feelings of inadequacy, can often prevent adequate bonding from taking place. The nature of the bond as two-way communication, is discussed further by Straton (1976) in a paper presented to the Speech Therapist's Conference. In this she discusses the child's need to have some awareness of the world apart from himself if he is to be able to participate in that world. The beginnings of this awareness are established in the sensori-motor period as skills are being learned when the parents make realistic demands

on their child to achieve a response.

The importance of the parent-child relationship to development is also stressed by A.D.B., and Ann Clarke (1976) who argue for the idea of resilience which appears to be a factor resulting from adequate bonding. This enables the child to make compensatory changes during development so reducing its dependence on the early years. The Clarkes refute the concept of continuity in development and therefore the overriding importance of the early years. They exclude the child with a handicap from their theory however highlighting perhaps the special needs of that child who, because of inadequate bonding, can fail to develop resilience and therefore is unable to make compensatory changes at a later date.

Bronfenbrenner (1976) states that if early intervention programmes are to be successful they must aim at parent-child intervention. He bases this statement on a variety of research comparing various kinds of programmes and concludes that intervention programmes must be family-centred to enforce training while it is in progress and sustain it once it has ended. As well as this the conditions in which the family functions should be considered, relieving pressures and enabling that family to exercise its role in child rearing as fully as possible.

Successful intervention programmes are based on this thinking. The Brookline Early Education Project (BEEP), operating since 1972 in Massachusetts, (Pines, 1975), offers parent-teachers who visit the home of all infants whose parents are interested in receiving ideas and support in their role as parents. In Australia, a parent guidance

programme is offered by the Monnington Early Childhood Development and Research Centre (Hewitt, 1977). Directed towards children with a handicap, it emphasises the needs of the child as a member of a family unit providing individual programmes for parents to train their children. Both these projects acknowledge the importance of the parent-child relationship in that the parents are encouraged to create an environment in which learning can take place. It is of interest to the clinic that the Monnington project goes further in that it looks at its professional staffing first before it considers the education of the child acknowledging that the programme must be designed from the point of view of the child and not to service the needs of clinical assessment and educational expectation.

THE RATIONALE FOR INTERVENTION

The theoretical viewpoints outlined provide justification for intervention programmes. They consider infant experience significant to later development because development is continuous and cumulative. Their orientation highlights the special needs of the child with a handicap who needs assistance to interact with his or her environment in order to gain experience and they point to the importance of the parent-child relationship if the assistance given is going to be effective. This relationship must be created as early as possible so as handicapping effects are better prevented than patched up. Meier (1976) claims on the basis of an examination of many intervention programmes that few take such a preventive approach. An examination of special education in New Zealand illustrates this as both Ross (1972)

and Barney (1978), in their discussions on this subject, refer to early intervention as taking place at the pre-school level as if existing structures dictate the timing for this rather than the needs of the child. Secondary features to handicap once they have appeared are difficult to eradicate when the child is functioning in a wider environment. Behaviour patterns are often reinforced by parents who find it difficult to understand that their child is achieving nothing from these when he appears to do little else. The fact that handicap can extend in such a complex pattern is well documented. Hewett (1970), for example, has described the problems of modifying over-protectiveness with and dependence in those with physical handicaps who are unable to be physically independent. These problems cannot wait until the child can be fitted into the education system.

Where preventive programmes do exist they do not necessarily inspire others because little data is available to support the efficacy of their procedures although comments by parents etc., are available. The expression of each handicap is unique and it is therefore difficult to evaluate any programme used to ameliorate the effects of that handicap. Cornell and Gottfried (1976) have looked at this problem in their review of literature dealing with the effects of intervention on the development of premature infants. They conclude that programmes are effective particularly in the areas of muscle tone and motor development but point out that these results are weakened by the methodological differences among studies particularly associated with a lack of knowledge concerning the ecology

of the infant. Gordon (1975) points out that the organisation of the programme and the personalities of and relationships between those communicating it must also be an influence to be estimated. If research is to focus on the long-term effects of a programme it requires a long-term basis. Controls would not be easily available while it would be considered unethical to refrain from helping a child because of research.

This problem of evaluation which encourages a cautious approach to intervention is incidental because it overlooks the true purpose of intervention which is a concern with the present and the prevention of problems occurring instead of with ultimate limits. Reynell (1976) believes that the failure of educators to become involved in intervention procedures lies with the nature of the education system which is traditionally future-orientated. The child's potential is estimated and he is categorised according to his predicted rate of development. She suggests that if concern was with allowing the child's present development to be expressed as fully as possible then the need to predict what would happen if there were no intervention would not be the important consideration.

In an effort to justify the existence of intervention programmes they are often described as therapeutic and supplying parent support. The Developmental Clinic has been thus described. This is misleading although such therapy and support should be available as part of the intervention procedures. Pugh and Russell (1977) state that parents can feel let down if their child is diagnosed as having a handicap and therefore needing special education, and then

they have to wait until the child is at pre-school or school before this is available. This tendency to make parents alone responsible for any early education has been described by Dybwad (1973) as indicative of prejudice, particularly professional prejudice towards their children. In part this seems to be prejudice concerning the educability of the child based on the traditional view that the severely subnormal lack capacity to learn. That the medical orientation given to handicap has reinforced this is unquestioned but it does not excuse the slowness of educators to recognise their responsibilities in this field. Such recognition may have prevented the following:

X a child with Down's Syndrome and a heart defect was not expected to live. She is now nearly six years old. Apart from medical care, enrolment at the Day Care Centre and referral to the Psychological Service at $4\frac{1}{2}$ years little was done for this child educationally. She was seen at the clinic at $4\frac{1}{2}$. A large non-verbal, immobile child she did little but indulge in head-banging causing considerable bruising across her forehead. Naturally her mother would attempt to prevent this but her actions brought attention to the child and reinforced her behaviour. One wonders how the pair spent their day. Recently Mrs X had a breakdown and the child is now in an institution.

This case illustrates the "wait and see" policy criticised by Straton (1975) as the typical response to handicap. Such a policy gives scant recognition to the concept of equal educational opportunity. Only too often it seems it is necessary to make a special case for the child with a handicap or to campaign for resources. What such a child receives then is motivated by compassion and charity and not a recognition of his equal rights alongside others. To give him recognition requires the adjustment of structures and attitudes. It is possible that the clinic is

going to provide the challenge necessary to cause this as parents realise their competence and confidently demand what they consider are their rights.

CHAPTER THREE

THE ADMINISTRATION AND STRUCTURE OF THE CLINIC

SECTION ONE: STRUCTURE

The Developmental Clinic is a creative venture basing its aims on research and theory. When it was first planned, structure and administration were concerns only insofar as they were necessary and convenient for functioning. The implication was that aims could be achieved within this simple framework and it was considered more important to get the venture off the ground than to wait for the ideal situation to appear. Generally the clinic is a local creation built around local facilities.

Those working in the clinic now would disagree with the idea that aims can be achieved as fully as is desired under the present structure. The feeling amongst staff and major referring agencies is that the clinic's failure to coordinate adequately with other facilities and to communicate its aims have meant that its effectiveness is weakened. The same criticism could be made of course of the other agencies working alongside the clinic. It is interesting that those who work most closely to the clinic, e.g. visiting therapists and paediatricians, experience the same frustrations, as they also can envisage an ideal but cannot achieve it. One stated:

"The lack of coordination is hopeless - a big problem in Palmerston North . . . there must be the closest integration of all services for anything to be achieved."

This same paediatrician has resigned from his position because of his inability to obtain the coordinated support

he required for research.

While there is criticism of the clinic's organisation, its creation around local facilities has been to its advantage. This has stimulated community awareness and interest. Professionals may be uncertain about its aims and theories but to local pre-schools, parents' groups, and community agencies, the clinic makes sense. They appear to have recognised it as their facility, listing it as a community venture, offering assistance in various forms and inviting staff to talk about its purpose and general implications. The enthusiasm with which it has been received is illustrated best by the offer made by one Head Teacher from a kindergarten to allow a $2\frac{1}{2}$ year old child with cerebral palsy whose development is generally delayed, to attend her kindergarten on an informal basis when the average age of entry is $3\frac{1}{2}$ years.

It is suggested that it would have been difficult to achieve the advantage of coordinating with the wider community at the same time as coping with the problem of coordinating with professionals. The latter are inclined to question specific details, e.g. the standardisation of assessment techniques which require time-consuming replies. In reality the clinic has become a community venture before it has been absorbed by the broad professional group who may be involved. Perhaps in doing this, like many community ventures it has not caused a problem in its failure to adequately coordinate with the professional group but highlighted one that already existed. Now its purpose is to press for change.

The section which follows describes the clinic's structure and relationship to other agencies. It has been

based on the combined thoughts of its staff (psychologist, physiotherapist, and speech therapist), those of the referring paediatricians and visiting therapists and a small group of parents who are very familiar with the clinic.

It is the stance of the clinic staff that any intervention programmes designed for handicapped children must be based on a structure or organisation which is sensitive to those children and their families. This stance is supported by Sheridan (1965), Straton (1977), McKeith (1973), Bobath and Finnie (1970), based on their experience working with such families.

THE PLAYROOM

Traditionally paediatricians and other specialists have provided clinical assessments of children which answer one question: what is wrong with the child? Increasingly this negatively framed inquiry is becoming more positive: what is the child's potential? how can I help? So, as Sheridan (1975) points out, assessments are becoming more functional in nature in keeping with the modern aims of normalising conditions for the child with a handicap. Children are most likely to demonstrate their abilities in a play situation so the assessment time must offer an atmosphere conducive to play. For this reason a playroom is considered an essential environment for assessment. This recognises too that parents are more inclined to relax in such an atmosphere and take advantage of the opportunity they have to learn how to handle their child and provide the best experiences.

The playroom in the Palmerston North Hospital is a large sunny room, well equipped with an extensive range of

toys, books, etc., because it caters for a wide age range. This was provided for the Hospital by the Brevet Club to be used as a playcentre. Because it is used mornings only, the Hospital has made it available to the clinic on Thursday afternoons.

This room provides a suitable environment for functional assessments which, to one paediatrician is the clinic's role, supplementing the clinical assessment he feels it is more in his training to give. He pointed out that in New Zealand such indepth assessments are rarely given because paediatric training has only recently incorporated developmental work, so that although change is occurring most paediatricians can only be generalists and must rely on other specialist services such as Education to extend their information on a child. The paediatrician recognising his need to involve other specialists and agencies, adopts the role of coordinator of the services available.

The playroom has many advantages pertinent to the clinic's aims of stimulation and to the paediatricians' aims of functional assessment. One parent described it as a "many-functioned room" meaning that its structure achieved many aims for the clinic without the clinic staff having to deliberately organise for them.

1. The setting is psychologically appropriate in that it is a playroom. The physiotherapist stated that the clinic's purpose is to help the child play so that it can learn.

2. Staff observations suggest that its atmosphere does help parents relax and involve themselves in play.

This allows ideas to be experimented with and includes the parents' ideas because they are involved. Professionals are therefore not seen as experts removed from the family but as part of a combined effort to assist the child.

3. Although the clinic has its own equipment its opportunities are extended by the wider range of equipment which belongs to the playroom. Many children with a handicap require specially designed toys but these cannot be constructed until they are observed playing with those already available. All parents attending the clinic with a child who has a physical handicap found buying toys for their child a problem. This aspect of clinic assistance is therefore important. Other parents considered that the equipment available gave them ideas for play.

4. A number of family groups attended the clinic (Table 1). Siblings are kept occupied and enjoy coming. Only one mother felt a need to place her child elsewhere when she had a clinic appointment. This has allowed staff to observe family members interacting, providing insight into parents' handling techniques and knowledge of play.

B, with cerebral palsy, seemed tense and easily withdrew from play opportunities. His older sister was as tearful as he was despite her "normality." Observations suggested that their mother's handling techniques were the major problem with this family and not necessarily B's handicap. The latter however was aggravated by this. Clinic staff therefore divided their time between B and his sister involving their mother with both. The sister was also discussed with her kindergarten teacher.

5. In a relaxed atmosphere, other children can be involved in the teaching programme. The physiotherapist used her son in this way.

M was close to crawling but proving cautious. She spotted an attractive toy but made no move towards it until the physiotherapist's son began to crawl towards it. Immediately M crawled anxious to obtain the toy first.

Situations such as this can make other children in the family feel important. The tendency for siblings to feel left out because of the time parents must devote to the child with the handicap is a problem recognised by most but infrequently dealt with. The Boston Evaluation Clinic works closely and deliberately with the brothers and sisters of children with Down's Syndrome for this reason. (Murphy et al., 1976). Parents of these children commented favourably on this programme while some children volunteered assistance at its conclusion. In a limited way the Developmental Clinic can do the same thing using the opportunities the playroom has offered. Obviously, however, it can only involve pre-school children. Two parents mentioned difficulties with teenage siblings related to their anxiety for the child with the handicap. Ideally the clinic should cater for these family members as well.

6. The playroom offers room to move. The physio-therapist has the task of examining why the child moves in the way he does but children will not move freely unless they have space. Out of 36 infants and toddlers attending the clinic during 1977-78, thirteen were mobile but required either stimulation to achieve mobility or their pattern of movement required correction.

7. The room opens outside to a grassed area which extends the opportunities for experience the child has. Concern was expressed by the visiting therapist that children receive as much sensory experience as possible.

She considers a lack of such experience a consequence of many physical handicaps. The psychologist observed that a number of children attending the clinic are kept inside their homes because it is more convenient. Parents need reminding that they must extend their children's horizons. The outdoor area attached to the playroom provides the reminder. Mrs Rd, the mother of a child with a severe visual impairment, is particularly conscious of this need for "the stimulus of outdoors" and felt the clinic should invest in a play sheet and some umbrellas. She pointed out that this would create a greater casualness which she considered desirable.

8. A private driveway leads from the road to the playroom and parents may park their cars in this driveway. A ramp leads into the playroom. The problem of carrying or pushing a weighty non-mobile child is overcome by this. Facilities without a structure that recognises what is most convenient for parents simply adds to the burden of having a child with a handicap.

The playroom also has disadvantages:

1. One parent commented that the room was "clearly not ours - and therefore not as convenient." She identified a frustration clinic staff feel. Because the clinic functions in someone else's facility it lacks the freedom to extend its hours and build up its equipment. Conflict exists between clinic staff and playcentre staff. The former do not clean up to the latter's satisfaction while children attending the playcentre have found clinic equipment and occasionally lost or broken it. Because of this the psychologist now carries four cartons of toys and

two test kits to and from the clinic every Thursday. Confidential files used by all staff cannot remain in the room and must also be carried to and from the clinic.

3. There is no carpeted area. Two mothers considered this a fault of the clinic suggesting that children often relax more when in greater comfort.

4. All clinic staff and most parents interviewed considered the room noisy and at times over-populated. They felt this spoilt concentration. Reynell (1976) points out that many children with handicaps have poor attention skills. The playroom is aggravating this and the speech therapist especially finds it occasionally impossible to work on listening skills with a child. One parent observed that the clinic staff were also distracted by the activity in the room. Screens, separate rooms, oneway mirrors were all suggestions made to overcome this difficulty although two mothers felt flexibility was called for in using these so as families could meet and children see other children.

THE HOSPITAL BASE

The attitude that a hospital base gives a negative impression to families visiting the clinic is considered a "hang-up of professionals" by the visiting therapist. Those working within the clinic certainly feel it is the least of their problems. Two parents criticised its siting, one because her child had had unpleasant hospital experiences and appeared to recognise the hospital "smell", the other because she did not want to be seen by others going into a place that might suggest there was something wrong with her child. Two other parents considered the siting as convenient, handy to other specialists they might have to

visit. Possibly the siting of the playroom alleviates difficulties with its separate entrance. Generally those within the hospital structure do not know of the clinic's existence and white-coated personnel are rarely present. Ideally, however, in keeping with its aims of normalisation the clinic should not be attached to a medically based structure which focuses on abnormality and illness. Only one parent identified this difficulty although she did not consider it a personal problem.

At this stage in its development the fact that the clinic is not part of a well-organised multi-disciplinary approach means that its hospital siting is important because it offers accessibility. Difficulties in communication can therefore be overcome.

Pl was admitted to the hospital for observation. The paediatrician concerned requested clinic assessment before discharge. Clinic staff soon realised that Pl's mother was confused about her child's condition. The paediatrician was therefore called and asked to discuss his conclusions with her and the clinic staff so as her understanding could be ensured. Parents cannot be expected to work towards the amelioration of handicapping effects if they are not adequately informed about the nature of the handicap.

Just as medical assistance is close at hand so are medical notes.

Children admitted to hospital can often continue appointments. Four out of five children listed in Table 2 as having been hospitalised have done this. Parents of children in hospital have often brought them to the clinic without appointments seemingly looking for people they know who are interested in their child's progress.

In a city where the very different approaches of psychological medicine and educational psychology are

offered there is some confusion because the Hospital Base and title "Clinic" tends to imply that educational psychology is moving into an area that is the right of others. A demarkation dispute has resulted which was only resolved when one group realised that the clinic was not Hospital "property" and that Hospital psychologists had therefore not been overlooked in its staffing. Misconceptions could be avoided by moving from the Hospital Base.

Where else the clinic could be sited is a problem. Professionals involved are attracted by the idea of a separate facility. Two parents also put this idea forward. This would be appropriate if the clinic was to be seen as contributing to a broad aim of providing infant education. In this context a community base is most desirable placing infant education alongside pre-schools suggesting the latter are natural extensions of the former.

STAFF INVOLVED IN THE CLINIC

There are three permanent staff:

Physiotherapist

Speech Therapist

Psychologist

All come to the clinic with little or no experience in infant education although all have been parents of children. New staff feel like "fish out of water" and it takes considerable time to learn techniques especially as the only information given each one has been how the clinic functions and the children's files. That all have enjoyed their experience is perhaps a compliment to work of Ms Straton in establishing the venture.

The Physiotherapist

The orientation of the physiotherapist is one which fits the educational and developmental approach of the clinic. She is trained according to the principles of the Bobaths which consider the total child and the need for early intervention to prevent motor handicaps from having a retarding effect on the mental development of the child. (Bobath and Bobath, 1963). Her attitude that the possession of a skill with its motivating influence is essential is basic to clinic aims as is her focus on the abilities of the child.

Most comprehensive approaches operating developmental programmes with young children use the expertise of a physiotherapist because of their ability to integrate their knowledge of motor development with observations of a particular child. Their role is never considered the static one of assessment but rather an educational one as they demonstrate a child's motor ability and teach his parents how to encourage progression through as near to normal stages of development as possible. (Moore, 1973; Appleyard and Baird, 1975). So many children with a handicap show some form of physical difficulty or delay and need this extra assistance. Mycklebust (1954) for example considers that there is an affiliation between auditory disorders in young children and the pattern of motor activity they demonstrate. In the same way children with visual impairments are often reticent in learning large motor skills (Adelson and Fraiberg, 1974), and require the assistance of a physiotherapist who can shape these skills and illustrate to parents how best they can

be encouraged in the child. The physiotherapist is not therefore preoccupied with those obviously physically handicapped such as those with cerebral palsy or spina bifida (Table 8).

It is suggested that some confusion exists between the role of the physiotherapist and the relationship between the clinic and the visiting therapist who has a very similar function. Originally the relationship with the visiting therapist was slight but because of her interest and because of the recognition of both services that co-ordination is essential when both have had 16 children in common, this has changed. When interviewed, both physiotherapist and visiting therapist considered their role in the clinic was supportive to the other's role.

"It's very nice to have someone to go and say 'what do you think of this kid?'"

Both considered their roles essential to a common purpose. The physiotherapist was obviously working with a number of children who were not seen by the visiting therapist, while the visiting therapist felt she offered assistance on a wider basis, e.g. feeding, bathing, home visits, etc. She also provides aids such as special chairs that will aid posture and correct movement and bathing equipment.

When the clinic first began the physiotherapist offered her services voluntarily. The importance of her work was eventually recognised when arrangements were made to pay her. Three physiotherapists have now worked in the clinic and their appointments have been made through the visiting therapist using an unofficial grapevine. This has helped prevent personality clashes and all appointments have been most appropriate. The danger is that if the

visiting therapist is not fully informed about clinic aims appointments could be inappropriate. The clinic must retain the right to make decisions about appointments but this should be done in conjunction with the visiting therapist who has the appropriate contacts and knowledge of physiotherapy.

The Speech Therapist

Ms Straton has stated (personal communication, 1978) that the clinic's handling of the development of language and speech is the least satisfactory aspect of its programme. This view is endorsed by the present psychologist, who found it impossible to handle the very specialised area of promoting language production. As a result in 1977 five infants were referred to speech therapists attached to Palmerston North schools. All were children at a developmental level of 10-12 months and referrals were made because the psychologist felt the need for this additional support in dealing with children who appeared to have special needs in the language area. Speech therapists while welcoming the opportunity to be involved at such an early level were concerned that their heavy caseloads would not give them the opportunity to adequately support the clinic.

In 1978 a speech therapist working part-time at the hospital introduced herself to the clinic having an interest in early intervention programmes. She is available for the duration of 1978 only but is endeavouring to find a replacement when she leaves. Once again the clinic has been given relative control over who is employed. Mrs Howitt felt she had a place in the clinic although she had

to create and define her role herself having not previously worked with infants. She has coordinated her work with the school-based speech therapists.

The fact that the Developmental Clinic did not have a speech therapist from the beginning was a weakness. Mittler (1973) has pointed out that language difficulties are almost invariably found in the mentally handicapped. Reference to Table 6 will illustrate the complexity of the difficulties encountered in the clinic. This table does not include the broad need of language experience by so many children attending the clinic. Such experience brings specific advantages. Children with physical handicaps can use speech as a conditioned stimulus to guide movement as is demonstrated through the Peto method (Esther Cotton, 1970) of interest in a modified form to clinic staff. The mother-child relationship is a significant factor in the teaching of language but Moerk (1975) describes this as a closed system which can be influenced only if the mother is trained. Once again this highlights the need for early intervention to counteract any difficulties a handicap may cause. This can most successfully be done by a speech therapist.

The Psychologist

Most developmental programmes for infants use either a developmental psychologist, teacher or occupational therapist to carry out programming. Usually the psychologist and occupational therapist are considered part of a medical team involved with the family and their theoretical orientations, if any, are not disclosed. The Developmental Clinic uses a psychologist from the Department of Education Psychological Service. The theoretical basis of the clinic

is one popular with educationalists while the programmes require abilities in teaching and assessment.

REFERRALS

If infant education was considered a natural process for all infants, then children with special needs would be easily identified as they are in the BEEP programme (Maya Pines, 1975). Sheridan (1975) also considers that the ideal would be to screen the entire infant population although acknowledging that time and expenditure make this impractical. Obviously if early intervention procedures are to be effective children must be identified as soon as possible (Evans and Sparrow, 1974). This is a significant factor to the clinic which holds to Sheridan's thinking (1965) that there is an optimum period of sensitivity, a phase in the physical maturation of the central nervous system, when experience is most readily assimilated leading to development. Straton (1977) gives emphasis to the period around 7-9 months as being particularly important if the integrated learning essential to language development is to occur. Referrals beyond this age could be described as "late". If the developing relationship between parent and child is considered significant however referrals should be as early as possible.

Developmental clinic staff and the visiting therapists feel that present procedures are not identifying children as early as possible. This gives concern. Tables 3, 4 and 5 illustrate this problem but two case studies further highlight the issue:

Case 1: C has cerebral palsy. He was identified as having a potential handicap at 9 months in the Observation Clinic and referred to the visiting therapist who referred him to the clinic at 11

months. His mother's nursing experience, knowledge of normal development and determination meant that this child had made excellent progress. The question remained however as to why C was not identified earlier. A chance conversation between the sister in the neo-natal unit and the clinic physiotherapist revealed that neo-natal staff expected a handicap. "This was the sickest child they'd had in a long time." Following discharge from the unit the sister occasionally inquired after C and was always surprised that he was described as progressing nicely. Somebody must have seen this child between discharge from hospital and 9 months of age. The cerebral palsy must have been apparent before this age.

Case 2: Ky was referred to the clinic at 12 months by the visiting therapist whose district extends into many country areas. The Plunket Nurse in one such area thought she might be interested in an 11 month old child who was mentally retarded and under the Society for the Intellectually Handicapped. On seeing him the visiting therapist immediately noticed that he had a severe physical handicap which no-one had identified. Clinic staff feel Ky has been referred too late and is very difficult to work with. This difficulty is expressed in a complex form. The physiotherapist commented "Ky can't bend his arms. If he had been encouraged to move his arms earlier it would have been better but now they (his family) say that he's never moved his arms so he won't move them now. They would get a thrill if he did move." Not only is Ky difficult to work with but so is his family.

It is accepted that some conditions are not easily identified during the early months, a lot is still unknown about specific conditions, and that some families may prefer not to come to the clinic but this does not seem to adequately account for the large number of "late" referrals especially when the nature of their handicaps involved is considered. (Table 4). The problem of early identification appears to arise whenever early intervention programmes come into existence. This problem is discussed by Meier (1976) who refers to 1968 statistics in the United States which indicate that 97% of developmentally handicapped children are not detected in their first year. This figure

would include presumably the more obscure learning disorders which may be missed until the child is school age. Clinic experience suggests some learning disorders can be identified in infancy:

- a) M1 whose development is apparently normal but restricted cannot imitate either visible or invisible actions easily.
- b) D demonstrates clumsy fine motor control and has difficulty putting a simple jigsaw together. Yet he appears a competent child with a delightful ability to converse.

The information clinic staff gain in dealing with such children can be of use to general identification procedures. Medical personnel have recognised this possibility but problems of coordinating information have so far prevented this usefulness from having effect.

In Palmerston North an "at risk" register operates. Children entered on this are seen six weeks from discharge from Hospital, unless there is some cause for concern before this time. The Observation Clinic used to screen all these children at age 9 months. This has been discontinued however because for the amount of time put into it only the same number of children with special needs were identified as were discovered before the Observation Clinic existed. The ages of 4 or 6 weeks, 9 months and $2\frac{1}{2}$ years appear to be the standard times that "at risk" infants are screened unless of course a problem is identified (Evans and Sparrow, 1974), but Sheridan (1965) believes that for a register to be effective it must be kept "live" or "active". By this she means that one person should ensure that these children are known to other agencies such as family doctors who would be likely to see them. Table 3 indicates the

agencies referring children to the clinic and it is noticeable that general practitioners, public health nurses and plunket nurses play little part in referring children. This could be because they are not aware of the clinic but it would seem that these children are not referred to paediatricians either. The cases of both Ky and C illustrate this. More curious are D1 (16 months) who "simply appeared" (medical officer's comments, 1978) and has a severe physical handicap, and M1 (16 months) whom the paediatrician spotted on a ward round as "strange-looking" and referred following examination. He demonstrates difficulties in learning.

It is impossible at this stage to establish exactly why the bulk of referrals are "late" but one paediatrician blamed the lack of coordination of services at the earliest level. The maximum recording of all information from birth (including behavioural assessments) could uncover more warning signs. Apart from this it was felt that the community-based medical agencies were not educated about the clinic. To achieve this the clinic depends on the paediatricians who feel they must take responsibility for this because general practitioners are conservative and are more likely to follow their suggestions than the clinic's. To do this effectively paediatricians must fully understand clinic aims.

APPOINTMENTS

Originally weekly for each child the system of appointment was revised because "it was only making us feel more secure" (Straton - personal communication, 1977). Children's appointments are now fortnightly, three weekly

or monthly depending on their need.

Failure to keep regular appointments is not common and is always investigated. Liaison with the Field Officer from the Society for the Intellectually Handicapped, the visiting therapist, the public health nurse or plunket nurse involved always helps in this and saves some time for clinic staff.

Appointments are made for one hour but timing is flexible. Some children become upset, tiny babies fall asleep and siblings can grow restless. There are many reasons to make adjustments. None of the families interviewed considered the hour too long because they recognised that it was flexible. Flexibility helps clinic staff as well because it is possible to work with a child more than once during the hour. This is particularly important with the older, mobile children who prefer to play in what to them is an exciting room than to cooperate with set tasks.

Lack of transport does effect the attendance of some families. Table 2 indicates families who have transport problems although one family can catch a bus. It is interesting to note that a number of these families are involved with a variety of services. The clinic is grateful to the Plunket Society, Society for the Intellectually Handicapped, Hospital Social Workers and Public Health Department, as well as the various grandparents and neighbours for the transport they have offered. Many families with or without transport travel a lengthy distance to the clinic for each appointment:

Feilding	-	5 families (2 without own transport)
Rongotea	-	1 family (father takes time off work to provide transport)

Newbury	-	1 family
Marton	-	1 family
Ashhurst	-	3 families
Foxton	-	2 families (1 without own transport)
Levin	-	3 families
Dannevirke	-	2 families (1 without own transport)
Ormondville	-	1 family
Pahiatua	-	1 family
Stratford	-	1 family

In only one case was the clinic able to arrange a financial assistance from the Social Welfare Department (Stratford). Recently, however, (October, 1978) a benefit became available to families with a handicapped child receiving special care of \$8 weekly although this must be agreed to by the Medical Officer. Not intended generally for infants this benefit is available to families who attend the Developmental Clinic to assist with transport and extra equipment.

EQUIPMENT

This was carefully chosen by Ms Straton and Ms McComas when the clinic was first organised. It includes physiotherapists equipment such as a mirror, rug, and Bobath ball and various toys which enable a child to learn the intellectual concepts appropriate to each developmental level. The speech therapist has donated a few extras to assist with her work such as straws and particular books.

Parents are encouraged to join the Manawatu Toy Library where they may borrow toys which will enable them to help their child practice skills at home. In August 1977, the usefulness of the Toy Library was examined by Pamela Benson. She noted that 21 out of 28 families were referred by the Developmental Clinic and visiting therapist. Those referred

by the clinic were considered clearly aware of their children's abilities and some demonstrated a considerable growth of confidence in choosing toys.

ON GRADUATION

At a certain stage children demonstrate that they are no longer suited to the formal structured programme offered by the clinic. They show a need to socialise and to enjoy more free play opportunities. Most are too young to attend a pre-school. At the same time any possible dependence parents may feel on the clinic must be dealt with and families gradually introduced to community organisations. This is in keeping with the clinic's aim of normalisation.

To clinic staff, meeting these needs is a problem because of a lack of facilities. There are several possibilities:

1. Some few children remain at the clinic because of the delay in their development and the lack of facilities in their home area. These are rural children. The tendency to allow these children to remain arose because some children on graduation became "lost" in that caseloads prevented psychologists and others from maintaining more than infrequent contact with them.

2. Some children remain for a longer than usual period at the clinic while attending a local pre-school because they are some distance from Palmerston North and lack access to specialist services. Foxton children without transport are unable to receive speech therapy in Levin which is their area for this assistance. They can, however, catch the Foxton bus which comes through to the Hospital and receive assistance in the clinic.

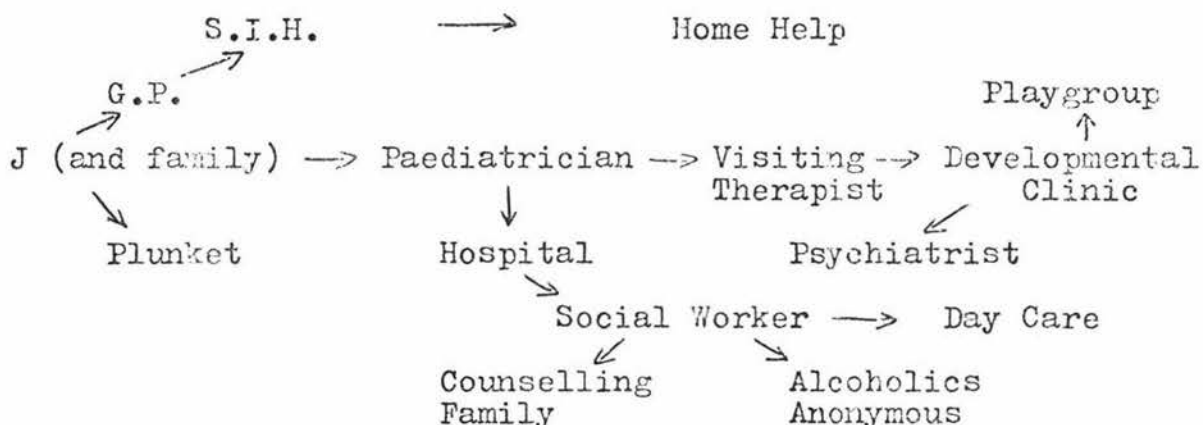
3. Where possible children are integrated with the informal toddlers' playgroups that tend to be part of the playcentre system. Some children attending the clinic are also encouraged to attend these. Such groups are very popular with parents. Liaison between playgroup supervisors, clinic staff and the visiting therapist is beginning to occur because of this. Unfortunately playgroups do not exist in every area.

4. The Correspondence School offers Home Training to pre-school children with special needs. It is possible to enrol graduates with this school.

It is most important that adequate assistance is given during the period between graduation and pre-school. A.D.B. and Ann Clarke (1973) point out that intervention procedures are wasted unless they are long-term.

SECTION TWO: COORDINATION OF FACILITIES

One of the inevitable consequences of handicap is that the family of the child concerned becomes surrounded by outsiders, professional or voluntary who offer some form of assistance in an effort to ameliorate the effects of the handicap. In Palmerston North it would seem that while the support given and the goodwill expressed is unquestioned the failure to coordinate action implies that each group exists for itself and not for the families concerned. The plight of J is an obvious example as the direction of referral to agencies is traced:



Mrs J has commented: "I don't want home help"; "I don't know how S.I.H. arrived"; "I don't want J at Day Care". She is a shy polite woman who does not like to offend people so she allows everyone to intrude on her life. No one willingly offered to withdraw as they must have cases to justify their existence. As one visiting therapist commented cynically, "trouble is there aren't enough handicapped children to go round".

Handicap can have wide implications. As Appleyard and Baird (1975) point out, multiple handicaps are more common than single ones, automatically requiring the attention of a greater number of people. Families of handicapped children

are vulnerable and therefore anxious to do the best for their child. None of those attending the Developmental Clinic have refused any of the assistance offered by any service. In Tables 2 and 7 the families receiving long-term assistance at the clinic are listed. The children's handicaps are presented in Table 7 and Table 2 illustrates the personnel involved with each family.

The Developmental Clinic must be seen in the same context as the other services offered each family. It does after all cause similar pressure in that it requires families to keep appointments which are frequent, the implications of which are that parents will return home to carry out recommended tasks. Although its staff is aware of the activities of other personnel involved with the family the preoccupation within the clinic, as with others, is with the family and its handicapped child. It is suspected, however, that focussing on the family causes the responsibility for carrying out procedures to be the family's. In other words it is up to the family to ameliorate handicapping effects. If they fail, it is their fault, e.g. faulty handling or lack of acceptance of their child.

Outside services or agencies including the clinic cannot afford to have such a detached role because what they do and say to the family is intimately tied to the family's success or lack of success in handling their child. In the early stages of infancy when the parents of such a child are still adjusting their relationship to that child the situation is very delicate. Sensitive understanding is therefore more important than enthusiastic therapy (Holt, 1975). Despite goodwill the latter can so easily aggravate

the nature of the handicap extending its pattern.

Case 1: It seemed to staff that J's progress depended greatly on his mother's handling of him. She was therefore given the programmes normally kept by staff, shown how to apply them, and staff adopted the role of reinforcing her progress. Progress did occur. The Home Help arrived and commented that Mrs J ignored her child preferring to watch T.V. The Home Help took over the job of stimulating the child. J has stopped showing signs of progress. Mrs J is again worried and anxious.

Case 2: Kn had attended clinic for 8 months. Each time, independently, staff repeated the same ideas to her mother. Kn made no progress. She attended Day Care during the week so the centre was visited and programming provided. Later conversation revealed that the centre had difficulty understanding requests and were still reinforcing the behaviour they had been asked not to reinforce. Kn caught chicken pox and was home for a length of time. On her following visit to the clinic each staff member independently noticed improvement.

These cases are useful illustrations of what can possibly occur. Unfortunately the various services, fully aware that the child is a member of a family, care for the family but forget that the family must become a member of their "team" as well. If a "team" of assistance does not exist then much of the work done must be ineffective.

It would seem that in part the confusion which does exist relates to societal changes. As a greater awareness develops of the needs of various people, helping services appear, establish their roles and disregard the areas where they overlap with others if in fact they become aware of them. Traditionally the paediatrician has been the person first involved with the child with a handicap and referral has been his role. The more recent emergence of the visiting therapist and of the Developmental Clinic have taken over some aspects of this role as both have considered it their job to refer. Currently it is realised

that none of the three groups has made any adjustment to the others.

If reference is made again to Table 2 it is possible to see the number of services available to each parent and which ones they are using. Whether or not each is necessary to that family is another issue. These families as previously stated are vulnerable and tend to use all that is offered. It has been fairly stated that very little has been done to coordinate these services. A certain amount of communication exists between members but this is always self-initiated serving a specific purpose, e.g. the psychologist has contacted the Field Officer from the Society for the Intellectually Handicapped to ask about a child who was failing to keep clinic appointments. Perhaps the most effectively coordinated area is between clinic staff, paediatricians and visiting therapist because the latter has taken it upon herself to liaise between the two. She does not consider this as her role however. It occurs because her job is based on mobility while the clinic and the paediatricians have a specific base.

The failure to coordinate action overall is serious and has disturbing effects:

J has an unidentified condition. Clinic staff suspect much of its nature is emotionally based. Focus is therefore on attitudes the family holds, with the aim of showing them their child can achieve. The appearance of the Field Officer from the Society for the Intellectually Handicapped with this family provided a label that indicated his lack of ability.

One paediatrician has stated:

"Referral cannot be taken lightly because of its labelling effects."

In the same way as lack of coordination between services

can aggravate handicap so can the failure to communicate information:

B has cerebral palsy. This condition relies on careful handling if functioning is to improve. B's mother is impatient and tends to punish failure with the result that B becomes tense. It was felt that home management problems were in part because Mrs B did not understand the true nature of her child's handicap. The paediatrician reserves the right to present the medical diagnosis to the parent but this was not done in this case so Mrs B did not know her child had a physical handicap. The paediatrician concerned knew of the problem but was called away when appointments occurred leaving paediatric registrars to handle the medical check. They were not fully aware of the difficulties involved so information was never conveyed.

Numerous research exists suggesting the effects of this lack of coordination and communication on the families of the child involved (McAndrew, 1975; Sheridan, 1965; Holt, 1975; Bobath and Pinnie, 1970). McAndrew (1975) points out that the physical strain on the family is considerable because of the time involved and the varied needs of the child. This pressure is increased by the frightening and confusing impact of clinics and the failure of various services to communicate adequately. David and Donovan (1975-6) describe these families as isolated and showed how the behaviour of medical staff appeared to be in "collusion" as they seemingly increased the isolation by ascribing no responsibility to the family.

This problem is a serious one to the clinic which approaches its work with a very specialised orientation that requires wide understanding if it is to be effective. Its orientation requires for example an understanding of its purpose, i.e. stimulation rather than assessment and the importance of early referrals. The visiting therapist commented:

"The paediatricians are frightened of giving a label and a referral to the clinic may do that. What we have to do is focus their view to the enrichment nature of our work."

COMPREHENSIVE APPROACH

The present lack of coordination which prevents adequate communication is dissatisfying to many involved with families in the early stages. Several have attempted to overcome this with meetings of all personnel involved with a child. If they wait until a need arises however it is most likely they will be unsuccessful. All agencies are inadequately staffed with big caseloads and cannot easily fit a spontaneous meeting into their schedules. The visiting therapist attempted to coordinate such meetings on a regular basis. She never succeeded in getting everyone there which may suggest that people were uncertain as to why they needed to come. One of the difficulties appears to be that they do not understand the implications of early intervention. They accept a need to coordinate action but see no urgency. All those interviewed in connection with the Developmental Clinic thought its purpose was twofold, one of assessment and support. Urgency is not attached to either of these static aims whereas intervention to stimulate suggests time is significant.

In the pre-school area assessment clinics have become popular throughout the world. These adopt a team approach, formulating one therapeutic plan which involves various members of the team. Evans and Sparrow (1974) have described these trends in Britain suggesting that they are stimulating research on more adequate assessment techniques, on programming, and the exact nature of many handicaps. One

such clinic is the Exeter Child Assessment Clinic at which the present speech therapist in the Developmental Clinic has worked. Although it has its own buildings and involves more people, it resembles very much the Pre-School Coordination and Assessment Panel in Palmerston North which meets monthly to coordinate action based on assessment for individual children. Those attending find it worthwhile but it tends to meet professional needs only, overlooking family involvement.

The tendency is for these clinics to be departmentally-based although this may involve several departments. This gives the impression of a reversed pyramid organisation with a broad spread of professionals and others across the top with a family sitting underneath them at the bottom waiting to be told what the experts have decided about their child. That this description does not disclose sympathy which exists is admitted but it is felt that this organisation does not differ from the top-down authoritarian organisation that has traditionally dominated the medical approach. (Hunter, 1973).

The "medical model" has dominated the approach to handicap in the past and in Palmerston North still does so up until about age 3 when referral to educational personnel is usual. That children have not been referred to the educational field earlier is not however the fault of medical personnel but is very likely because educationists have tended to consider early intervention as something that could occur at the pre-school level when formal structures are available. Traditionally they have not intervened in a defined sense at an earlier age. Because of the pathological nature of handicap it is obvious that

the child should be under medical care but the fact that handicap can have the secondary features of retardation and behavioural difficulties is not a medical problem but requires the recognition of others such as educators if these are to be dealt with. As long as the medical model dominates and the education system delays its participation these secondary features will appear creating very difficult children with whom to work. Other early intervention programmes recognise this, e.g. the Parent Education Centre in Indianapolis (Green and Durocher, 1965). Without such assistance parents concerned at their children's bizarre behaviour or failure to progress will resort to expensive and time consuming programmes such as the Doman-Delcato programme. (Andrews, 1976).

Recently the psychologist working in the clinic was approached by a family living in another part of New Zealand. They had a $3\frac{1}{2}$ year old son with cerebral palsy. At an earlier age he had been assessed by a medical specialist at a centre concerned with physical handicaps. His conclusions were that the condition was severe and that a "wait and see" approach was necessary. The child would probably need institutionalisation. This left the parents shocked, without any hope. In a small area what could they do? Nothing was offered that solved this problem for them, so they travelled to Philadelphia to train at the Doman School. This cost \$520 (travelling expenses only). Training was given free of charge. On their return the medical specialist refused to have anything to do with them and the family feels generally rejected by medical personnel with exception of two

physiotherapists who have expressed personal interest in the Doman method.

Hunter (1973) suggests that the "medical model" has a negative impact which is perpetuated by others who are influenced by the authority implicit in the top-down organisation on which medicine is based. It is this organisation that exists in Palmerston North although the assessment panel spreads the responsibility but an authoritarian attitude remains. In this way the community catches the implications about the handicapped which tends to be negative. Brattgard (1974) demonstrates how this occurs through the medical system's treatment programme which tends to concentrate on those functions that are diminished or lost. This focus on disabilities often prevents the person with the handicap from recognising his abilities thus discouraging him from taking his share of responsibility in the community. Adjustment is required by both community and individual but the orientation of professionals must shift to the positive if this is to occur within the traditional system.

The Developmental Clinic aims at assisting families to adjust by helping them adopt realistic expectations of their child. But community expectations can invite conflict as was illustrated when Mrs Rd was upset when Rd was not invited to a cousin's birthday presumably because of his handicap. Hunter (1973) suggests that the sources of deviant behaviour are not always to be found in the individual but in the institutionally-expected. He suggests society cherishes these expectancies expressing them through the charity and compassion shown the handicapped. McAndrew (1975) points out that community thoughtlessness

increases the stigma of handicap.

Such stigma can be reduced if an informed and coordinated programme is presented to the child and his family early enough but it must include coordinated action from all others involved while families should be included as part of a "team" approach. This respects parents' rights and also shares responsibility. Obviously when such an approach occurs there is no hierarchy or authority. Instead it is an organisation that spreads outwards from the family in the centre. This is the grassroots approach which is gaining popularity elsewhere. It requires a community involvement but still allows for the "total push" method that is necessary if the child with the handicap is to be able to operate within society. The Monnington project (1977) gives the impression of having achieved this type of structure matching staff with families and allowing community participation. Yet the project retains an air of professional competence that must increase all round confidence.

Palmerston North paediatricians are interested in adopting a similar approach. One said:

"I'm interested in community medicine. This is better done outside in the community. The personnel involved would manage."

Recently this paediatrician made himself available to talk to the Parents Group which meets in the evenings. Reactions were enthusiastic and all parents who discussed the evening with the psychologist remarked on his sense of humour.

The visiting therapist saw no problems at all with a community orientation:

"We are a community service and only have an office base at the Hospital."

Families too like this approach:

Js' family shifted to another district where Js was enrolled with a voluntary society that had an old informally furnished house with a playroom. The paediatrician visited the family at the house, played with the child on the floor and discussed his progress with his mother. She was delighted by the informality and felt relaxed with the paediatrician.

It is felt the Developmental Clinic could stimulate such an approach. Already it has achieved some semblance of this. The use of first names by all including children, home visits, occasional assistance with transport, have all contributed to informality. The visiting therapist is part of this friendliness. That parents enjoy this is inferred by Mrs Rd's statement that she had seen her paediatrician so often that "anyone would think we had been on first name terms but we aren't." The clinic has an advantage because it operates in a playroom without desks and white uniforms. Appointments here must contrast sharply with those the visiting therapist attends with families:

"The doctor and registrars sit on one side of the desk and the mums sit on the other side. I sit with the mother. I feel I have to give her a bit of support against all that."

The clinic feels its atmosphere is to its advantage. It is concerned that once its programme becomes departmental policy it will lose the autonomy that at this stage allows it to move close to the community.

It is interesting that the clinic is looking at how its base can be broadened at the same time as paediatricians are looking at ways in which they can change their traditional image. The danger is that unless both groups

recognise each other's aims and create a purpose in common
then the problems they both wish to ameliorate will remain.

CHAPTER FOUR

PROGRAMMES

The teaching programme is an integral part of the clinic strategy. It must be seen as interrelated with other aspects of this strategy and not as standing alone if clinic aims are to be achieved. Clinic staff must examine their interaction with families and other agencies in its totality rather than confining their vision to the programme.

It forms the framework for the broad and at times very specialised approach required in working with children with a handicap. Because the individuality of these children is accentuated by their handicap the teaching must make appropriate adjustments or expansions for each child.

This section examines the basic programme from the points of view of problems that have arisen during the time the present staff have worked in the clinic. These problems or questions are considered significant because not only have they stimulated clinic staff to examine some of their procedures but they have also been the basis of many questions asked by observers particularly those who are in the Psychological Service in other areas and are considering establishing their own clinics. This section also attempts to be informative by describing the theoretical orientation of the programme.

SECTION ONE: THE WHOLE CHILD

Infant intelligence is sensori-motor, that is, concerned with perceptions and movements. The infant must

be thought of as a whole. Although its development can be described in areas, e.g. language or social, this can only be done insofar as it is convenient. Kamii (1974) is especially critical of the growing tendency to compartmentalise objectives in programming for children. She considers that this overlooks the nature of intelligence which is an organised whole. If intelligence is considered to be interrelated with development the same applies. The clinic programme then must be aimed at the total child who is considered indivisible. The visiting therapist has criticised the programme however as being fragmented. To meet this criticism it is necessary to look closely at the programme's structure.

Commonly-held developmental principles are followed. These are:

1. Development is continuous.
2. The sequence of development is the same for all children. The rate of development varies. Areas of development can be defined which have their own sequence.
3. There is an intimate relationship between development and maturation and between development and environmental experience.
4. Generalised mass activity becomes gradually replaced by specific individual activity.
5. Development follows a direction from the head downwards.

On the basis of these principles the programme was organised to fit into four schedules:

1. Large Motor Skills (with an associated guide on mobility).
2. Visual and Fine Motor Skills.

3. Language.

4. The teaching of the Concept of Object Permanence.

Each schedule is a checklist of skills or appropriate activities arranged sequentially as far as possible. There is an overlap between schedules. The major impression given is that the schedules relating to large and fine motor skills resemble the Bayley Scales of Infant Development, but these are thoroughly standardised scales which have been influenced in turn by the normal developmental features listed by Gesell (1934). It is felt that the important consideration is not what scales the schedules resemble but their effectiveness in working with children.

Superimposed upon each schedule are the Piagetian stages which demonstrate how the intellectual processes develop. With the exception of the Language Schedule each schedule is divided into six parts which represent these stages:

Stage 1:(from 0-1 month): This is a period of reflex behaviour. Reflexes are not simple isolated experiences but can be seen as a differentiation of the total activity of the infant. They are the points of departure for the development of the schemata.

Stage 2: (from 1-4 months): At this stage there is a development of the ability to repeat interesting actions voluntarily. These could be described as habits. An end is achieved as a result of certain actions but that end is not predetermined.

Stage 3A: (from 4-6 months): Horizons broaden as the environment is recognised and actions are beginning to be coordinated for purposeful activity. These are

the primary circular reactions where an end is achieved as a result of a certain activity but that end is defined beforehand. The infant learns that the same actions will obtain other ends.

Stage 3B: (from 6-10 months): The secondary circular reactions are developing which allow interesting events discovered accidentally in the environment to be reproduced. Increased mobility can assist this. Interest is now in the result the child aims at.

Stage 4: (from 10-12 months): The secondary circular actions are coordinated. The infant may use one action as a means of attaining an end for which he uses another action, e.g. bringing a desired object closer by pulling an attached string.

Stage 5: (from 12-18 months): The tertiary circular reactions develop. The infant is curious about objects and what can be done with them. He uses internalised combinations as well as external groping in order to gain insight into their nature. To achieve this the infant concentrates on achieving bi-pedal locomotor skills and balance.

Stage 6: (from 18-30 months): At this stage the beginning of thought can be seen as the child thinks out solutions to simple problems. Gradually he extends his locomotor skills and begins to use complex co-ordinated motor activity to achieve his ends. This child understands that objects are permanent. This gradual learning has been linked to his growing spatial awareness and his increased coordination of action that orders his approach to problem solving.

He appreciates the relationship between objects and what has to be done to achieve results. Reality is logical and involves the infant and his environment in interaction. This is the result of sensori-motor intelligence. (Piaget and Inhelder, 1966).

With each stage rules of learning are laid down. Just as the external features of development occur in an ordered sequential pattern, invariant order is claimed also for development of the internal processes. Uzgiris (1976) discusses the various research which substantiates this, pointing out that allowances are made for minor variations. The fact that the ages at which the Piagetian stages are said to occur are not confirmed by some research (a criticism made of the clinic) is considered by Wolinsky (1970) to be of little importance. She states that it is more important to appreciate that change occurs, that children understand things at certain times and that change is not spontaneous but gradual, built up through the experiential world of each child.

The schedules used by the clinic then list the skills that are the physical expression of development and interpret these according to Piaget's theory of development. They therefore consider development as a whole. Because it is only the skills that vary in each schedule and not the theory, there is consistency. If development is dependent on motivation or the harnessing of the developmental thrust by an alert curious child and motivation is considered as part of the same force as intelligence then it is the theoretical interpretation given the schedules that is the important thing. Kamii (1974) believes that a Piagetian

format enables attempts to be made to develop children's intelligence as an organised whole. In infancy this begins through the gaining of physical knowledge through activity. Such knowledge is interrelated with motivation and it is the latter that determines the child's future learning. That is the major aim of the programme.

That there is consistency between schedules is suggested by the physiotherapist's comment which was also made by a previous physiotherapist in the clinic:

"It's amazing how we appear to say the same things to parents at the same times and reinforce one another."

Despite this, however, the comment of the visiting therapist is an important one. It would be very easy to work from a schedule and ignore the work others were doing in the clinic. In fact wherever possible clinic staff should attempt to blend efforts.

M at 12 months would not reach. With poor body tone she was also partially sighted and had a hearing loss. She needed to learn to use her arms and hands more deliberately. Her play was limited and demonstrated only a quiet curiosity. Toys and play activities appropriate to her level were allied to the physiotherapist's indications of where and how her arms moved.

Because each staff member works separately with a child on a number of occasions, it would be possible for a parent to concentrate on only one area because she has not fully understood what has to be done in another, or because she finds it difficult to work at particular skills where her child may give only minimal response. Observation of a child's progress within the clinic will usually identify problems such as these and within the clinic's organisation there are always opportunities for a parent to talk to all the staff together. The visiting therapist has also taken

the responsibility for occasionally knitting together separate tasks when she makes a home visit and discovers a parent who is confused. One parent interviewed admitted to being confused on occasions.

On the basis of Kamii's comments it could be asked why there is a separate schedule teaching the concept of Object Permanence. This concept is significant because it enables a child to understand that objects exist even when they cannot be seen. Such knowledge gives to the object (or the person) a separate existence or construction of their own. From this the child learns that some objects are similar and some are different and so the ability to recognise and identify is extended. Once this concept is understood the infant sees himself as separate in the world and understands that by using all skills he can then explore the environment beyond the immediate surrounds. That this understanding is also linked to language development is shown by the fact that language can symbolise what cannot be seen and can also influence someone else whose behaviour is independent. In demonstrating knowledge of this concept the infant will be coordinating more than one scheme.

The importance of this concept is recognised by all scales that are concerned with the development of infant intelligence, e.g. the Uzgiris-Hunt Scales. The fact that it can be taught is suggested by Bower (1977) who discusses the acceleration of the process by giving the infant intensive practice in the various abilities related to the concept. He warns, however, that this should be related to the infant's ability to carry out place-to-place following and movement following; otherwise frustration or boredom

results. Brassell and Dunst (1978) have been concerned with the teaching of this concept to retarded children in a parent-involved intervention programme in Western Carolina. Results indicated that training led to a moderate but significant difference in performance. The Uzgiris-Hunt Scales were used to evaluate progress. Many of the skills related to this concept are presented in each schedule, e.g. the tracking skills considered by Bower (*ibid.*) to be essential, but as Kamii (1974) points out teaching and practising skills alone does not ensure that the rule is learned if the skills are treated as isolated factors. She suggests that concentrating on the teaching skills and ignoring their intellectual content is successful only because children already understand that content. The schedule on Object Permanence concentrates on the teaching of the intellectual process involved. It could be suggested that the traditional approach of physiotherapists, occupational therapists, and the visiting therapists has been through skills rather than through the intellectual process. Such an approach could be criticised but its weakness is now recognised by visiting therapists who are encouraged to broaden their approach to include an understanding of cognitive development.

The basis for the schedule's construction has been the Uzgiris-Hunt Scale, Visual Pursuit and Permanence of Objects. Kramer, Hill and Cohen (1975) consider that their use of a six task series is unnecessary as clear age differences and developmental patterns could be gained from using a shortened set. Straton has also used a lengthy series of steps to teach the concept. In teaching a child

with a handicap it may be necessary to extend the process over a wider series of steps but in practice this can be confusing to the person carrying out the teaching especially in the later stages of development. This is in part because the psychologist experiences some of the difficulties described by Kramer, Hill and Cohen (1975) involved with infant behaviour. Infants do not always attend when an object is being hidden as they can be distracted by the most minute movement or sound. They also vary in their levels of cooperation; tiredness, teething, playfulness etc., intruding on what is a formal teaching situation. At a certain stage many object to an attractive toy being hidden. With thought, tasks described by Straton can be revised, presented in a different form and still achieve the same aim. Occasionally children demonstrate their knowledge of the concept through play activities. Observation then may eliminate the need to teach the concept to some. Kramer, Hill and Cohen have provided a shortened task series as a means of assessing infant cognitive development from 5 months. This could be usefully applied in the clinic to establish a baseline. The schedule already used is too cumbersome in its detail for this kind of assessment.

In conclusion it could be said that the programmes provide an interesting blend of medical and educational knowledge. No other programmes appear to have this blend but tend to concentrate either on intellectual development, e.g. Uzgiris-Hunt Scales, or on the physical expression of development, e.g. Griffiths Scales. This feature is significant to a clinic which combines the expertise of a medically-trained physiotherapist and an educationally-

trained psychologist. Both consider the programme interesting and challenging to work with and feel it provides meaningful results. Paediatricians are not so receptive. They receive clinic reports on children dealing with programme interpretation. One claims he cannot understand the programme. The other rejects material that is not universally known, accepted or standardised. The responsibility for educating those using data produced in the clinic lies with clinic staff but it is interesting that the visiting therapist took the initiative in educating herself by enrolling in a course that would provide for her more understanding of intellectual development.

FLEXIBILITY

Reynell (1976) makes the point that a developmentally-based programme needs to be flexible enough to adapt to individual differences in place and patterns of development. This is logical when the individual nature of handicap is considered.

A psychologist visiting the clinic commented that the programme used appeared to be the basis of the work done but all staff tended to work intuitively. The physiotherapist has expanded this idea:

"I work through the basic programme but vary according to the children. I have to encourage them for example to come onto their hands and knees but it is necessary to use a different means. B has a behind thrust of his head, M flops her head forward, D1 alternates. I have a common goal with each child but can move in lots of paths to get there."

The psychologist is concerned about behaviours as well as teaching from the schedules. A child's approach to the clinic or to practising activities can be inhibited by its behaviour.

Rd appeared unnecessarily cautious. His parents handled him with gentleness and spoke in soft voices. Rhymes which invited lively play such as handclapping, or bumping on knees were suggested. This was extended to all families when it was discovered that nine out of ten families questioned never indulged in such activities with their children but handled them with a gentleness that did not seem typical of normal infant handling.

Associated with this is the problem of dealing with stereotypic behaviour. During the period when secondary circular reactions are being developed, as a means of making interesting sights last, the infant repeats motor habits that have certain effects on his or her environment. In doing this the action itself is being learned but the infant is becoming interested in its consequence. Initially only a few actions are used. As these are used with greater deliberation and new actions are incorporated, behaviour becomes more intentional. Gradually as these actions become more varied and more definitely focussed on the aim of exploring the object the infant enters the stage of tertiary circular reactions. Some infants however appear to "fix". They develop few secondary reactions and only dimly associate them with their effects so become absorbed in the action rather than the effect repeating it over and over again in a mechanical manner. Such behaviour resembles the mannerisms often described as "autistic type behaviours" or "blindisms" because they seemingly cut the child off from his world. Because they can be associated with a

developmental time this highlights the need for early referral. If the child has been indulging in self stimulating activities such as these for too long he is very difficult to work with.

Clinic staff must be constantly aware of the possibility that these behaviours can occur. They must be aware of their variety and for the need for a consistent approach in overcoming them. This requires a careful explanation for parents who show a tendency to reinforce the behaviour as "play".

In the clinic these behaviours have been observed in:

- M (persistent mouthing)
- Kn (banging and rocking)
- Rd (rocking and mouthing)
- R (rocking and banging)
- J (turning objects round)
- L (rocking)

They are not dissimilar in their effects to the distractibility that is characteristic of three children and the very active behaviour that is demonstrated by another. Depending on the manner in which the child demonstrates the behaviour concerned there are ways of dealing with it:

- a) Ignoring the behaviour and responding to what is desirable.
- b) Persistent practice of a skill in an effort to stimulate to the next stage.
- c) Making the behaviour meaningful, e.g. banging can become meaningful if good quality chime bars are used and a "conversation" developed between adult and child which causes that child to listen.

d) Distracting the child into a play activity.

e) Using flexible mediums such as sand and water which not only soothes the child but can be adapted by him to his own purpose. Through this the child learns other pleasing activities.

A problem occurs if the child is attending more than one "teaching" facility, e.g. playgroup, clinic and Day Care Centre. It has been observed that others working with the child apart from the parents also have a tendency to reinforce stereotypic behaviour as play. So far the clinic's efforts at communicating its intentions to others involved with teaching the child have been accepted but the question could be asked as to whether clinic staff can extend their authority over other agencies particularly if any are non-governmental. Yet clinic programmes are ineffective unless this occurs. Liaison must be tactfully managed.

Late referrals require a remedial approach. In those with a physical handicap such as cerebral palsy, abnormal function is marked and difficult to inhibit. The child does not readily look or listen so more normal function cannot be easily stimulated as the child shows no inclination towards this. The clinic programme is a preventive one and must therefore be adjusted when a remedial approach is required.

Adjusting to the manner in which a handicap is expressed, coping with the behaviours that may appear and providing remedial programmes are common examples of the flexible nature of clinic work. Less frequently, because the clinic is not used specifically for this purpose, older children attend the clinic and are simply played with.

They come because there is no other facility available to them. Only three children have received this assistance during 1977-78 and all lacked overall experience. Their abilities are explored and needs established. Play techniques are demonstrated for the parents who are encouraged to join in. The clinic is not designed for this type of programme but the children's progress indicates their need. It is interesting to see that in the large medically-based clinics such as the Mary Sheridan Centre a pre-school teacher is employed to cater for these children. (Appleyard and Baird, 1975). Numbers support this complex organisation and presumably transport is more likely to be available to parents. The latter is the complicating factor as far as the Palmerston North clinic is concerned.

RESOURCES

To enable skills to be taught and flexibility to be achieved guidance is provided with the checklists of skills. Suitable toys are suggested within this. As well Ms Straton and Ms McComas organised a series of Stimulation Sheets for each Piagetian stage. These contain a variety of suggestions for appropriate activities at a specified developmental level and are for parents to use. For some parents these are a useful handout and all parents are given them at appropriate times. Unfortunately the suggestions given are of a general nature only and do not consider the unique nature of each child's handicap.

Kn has a right hemiplegia and overlooks her right arm and hand in play. She must be encouraged to use them so a programme is devised which will assist her. In Kn's case it involved water play, finger games, songs with actions and the use of specific objects, e.g. two hands holding a ...

large ring. Her needs have been interpreted in far greater detail than the teaching schedules or stimulation sheets allow for.

Because it has been found that parents take more notice of written programmes than spoken suggestions these are typed and posted to each family. Ms Straton used task sheets to list the tasks to be practised at home. These are still used if the tasks are straightforward. It has been noticed however that parents do not always fill in the section provided to illustrate their progress.

Ideas for activities are gleaned from a variety of books such as those written by Ira Gordon, Dorothy Jeffree and Burton White who are currently involved in infant education. As well parents have many useful ideas and it is hoped through the parents group that some of these can be coordinated and printed as handouts to other parents.

ASSESSMENT, DIAGNOSIS AND STIMULATION

Intervention implies interference. When applied to a developing child it involves the concepts of stimulation and modification. Activity must be modified so it is as near to normal as is possible otherwise it cannot successfully meet the challenge of the child who wishes to learn. That child will not wish to learn unless it is correctly stimulated. Stimulation arouses the child creating an alert curious being, "virtues" on which intellectual development depend (Kamii, 1974). The child is only satisfied however if it can physically and sensorily cope with the challenge. The clinic's task is to solve this problem with the child who has a handicap. Its means of doing this are complex.

Others consider the clinic's aims are "multipurpose" or concerned with assessment. One paediatrician sees the clinic as supporting him by providing functional assessments. His referral letters conclude "I would be grateful for your assessment." Another paediatrician considered the clinic assessed the children and provided parent support. A paediatric registrar writes "Will you please see and assess this boy." The visiting therapist used the concept "multipurpose" in describing the clinic and showed an understanding of the complexity of the clinic's aims although she did not comment on their interrelationship when interviewed. She also considered assessment a significant part of the clinic's role.

Parents interviewed were given a confusion of reasons for their referral to the Developmental Clinic. Only one very recent referral stated that the clinic was exactly as she had expected. Two others were told that it was "a sort of playgroup," two were given no explanation and only one was told "a bit of stimulation won't do him any harm even if there's nothing wrong" suggesting that the paediatrician concerned did have some awareness of the true nature of clinic work.

Traditionally the approach to handicap has been concerned with assessment. Psychologists have played their part in this, assessing children for administrative reasons. A.D.B. and Ann Clarke (1973) point out that this has led to a preoccupation with tests in an effort to find the ones with the best predictive powers. More recently, involvement with teaching programmes particularly in a remedial capacity has required assessment techniques to aid diagnosis as well

as to predict. The Developmental Clinic however is not a remedial centre, rather it is a preventive centre and is teaching what is considered normal and yet to occur. Preoccupation is with the teaching programme. The Clarkes consider that such programmes based on a knowledge of developmental and cognitive psychology provide understanding of the ways in which an individual interacts with the environment. A flexible programme then makes the appropriate modifications to the child's behaviour or to the environment. The clinic has adopted this procedure. To approach working with children with handicaps in this way is realistic because it recognises the individual nature of the child's handicap and teaches with positive methods. In contrast an assessment has a tendency to acknowledge deficits often requiring a label to describe them so showing a tendency to highlight what is negative and abnormal. Handicap is not static while assessments and labels are. As well assessments are usually carried out by using standardised tests. These do not evaluate specific behaviours in the way that structured teaching programmes directed towards specific goals can.

Assessment still occurs within the clinic in three ways. Firstly, it provides an introduction to the child and a base line from which to work. This assessment is an estimation to provide a starting point. Secondly, assessment and diagnosis occur as byproducts of the teaching programme. At a given point clinic staff can describe the child's progress in the various schedules of skills being taught. This indicates what the child can do and therefore what it appears to understand. It can be measured alongside the approximate

age for the appearance of these abilities.

Formal test batteries are infrequently used. Infant Assessment Scales except for the very complex Uzgiris-Hunt Scales were not available for clinic use during 1977-78. At a certain point the Stanford Binet Intelligence Scale and the Reynell Tests of Receptive and Expressive Language are used. These are used at a time when and if they will indicate achievement to the mother and to clinic staff and usually coincide with the child's graduation from the clinic. Very often at this point another departmental psychologist begins working with the child and a standardised assessment can provide a familiar starting point for that person as well as a summary of the child's achievement. Recently the Bayley Infant Development Scales were made available to the psychologist. This has stimulated the need to consider more closely the place of assessment in the clinic and just what the role of the psychologist is. Reactions at this stage suggest that the Scales are a useful resource but that they are not as valuable to the child as the teaching programme. The important consideration in using formal assessment techniques is the child who requires a very flexible approach by professionals who must not allow their skills to restrict their approach.

Assessment must be seen as realistic to overall planning (Pugh and Russell, 1977) otherwise it is of no useful purpose to those with a handicap. (Mittler, 1973; A.D.B. and Ann Clarke, 1973).

REPORTS

Children are usually referred to the clinic with a request for information on their functioning. The clinic can provide this information although this is not its primary purpose. The provision of assessment information however is a means of communicating with referral agencies. In this it is valuable because it can highlight progress that was unexpected and indicate problems that may otherwise be overlooked. Further medical tests may result from the information provided as the diagnosis is narrowed down. Information is written in the form of a report.

Reports were discussed with each referring agency. For one they were not detailed enough, for another they were too detailed and difficult to understand. Two people questioned the use of assessment techniques that were not standardised. One was suspicious of intuition, the other puzzled at the clinic's failure to use the Denver Developmental Scales. Obviously once again the clinic's primary function has not been understood.

Parents are aware that copies of the reports go to the paediatrician. They expect feedback on the reports' comments. Paediatricians rarely give this often saying little more than "I've got a report from the clinic." Clinic staff suspect that information from the report is used in general discussion with parents but parents cannot identify this and are annoyed by what they consider is the paediatrician's failure to communicate. Paediatricians have never commented on reports to clinic staff nor do they convey their impressions of the child's progress to the clinic unless specifically asked. One parent has criticised

this as "unfair to leave so much to (the clinic staff)."

One of the difficulties is that parents do not always see the paediatrician at their regular appointments but see the paediatric registrars who often do know that the clinic writes reports on a child.

The clinic holds the initiative in writing the report. It is convenient to have a report to the paediatrician in time for a child's appointment but this is the clinic's choice. One paediatrician complained when a report did not arrive in time suggesting that the clinic is part of his assessment team. This illustrates the traditional authority the paediatrician has had and which the clinic is not prepared to accept.

THE RATE OF DEVELOPMENT

Although the sequence of development is the same for all children, the rate of development differs. (Illingworth, 1960). In as much as the clinic is concerned with a child's activity and thought, it is also concerned with his developmental rate. Staff must attempt over time to understand these three factors in development in an effort to define the essential features of the child's handicap. Late referrals, where there is already a pattern of retardation that appears unnecessary, are confusing for this reason. With particular handicaps a developmental rate appears to be peculiar to that handicap, e.g. Share and Veale (1974) have set out guidelines for the approximate times specific developmental milestones are achieved by children with Down's Syndrome. They point out that these apply to children who have not received a programme of stimulation.

Understanding developmental rate is important if parents are to come to terms with their child's handicap and adopt realistic expectations from it. It is also important because delays which might be quite normal for a particular type of handicap, e.g. blindness, can be misinterpreted with hazardous results.

The Problem of Blindness

Rd had encephalitis at about 6 months. He was then referred to the clinic who considered development was progressing satisfactorily. At 11 months he had a major convulsion. As a result of one or the other he became severely visually impaired. Following the convulsion he resembled a large neonate; there was very little movement or sound. As time went on it became apparent that his eyes were not functioning normally but this may have been the result of the drugs he was taking. Blindness was not confirmed for 8 months. During this time he was considered very retarded - one medical expert described him as a "vegetable". Once blindness was diagnosed however it was appreciated that he had been wrongly handled although his immaturity was such that it is doubtful that this had a significant effect. Following the diagnosis clinic staff having not dealt with any form of severe visual impairment before, as a result of research, realised that blind children could appear more retarded than they really were. The problem became - what was Rd's major handicap? The clinic believed he was seriously retarded; his parents believed blindness was the major problem. Although Mr and Mrs Rd made considerable adjustment their inability to accept that their child was considerably retarded led them to seek cures such as attending a chiropractor on a weekly basis. They have high hopes that Rd will attend Homai College but this school does not take children who are too retarded. Mr and Mrs Rd may be disappointed. Rd has made better progress than medical personnel expected. At 2 years 8 months he is close to crawling; identifies and imitates sounds, babbles, plays with simple toys. Conservative and cautious, he has a tendency to rock and to mouth and is overweight. His family, including his 4 year old sister, enjoy him and show marked ability to interpret his behaviour.

This case highlighted a problem for clinic staff in that there seemed to be a subtle but important difference between the sighted child and the child with a severe

visual impairment. Burlingham (1964) discusses this as "developmental deviations" and suggests that some result from the inability of a mother to correctly interpret her child's behaviour because it uses a different perceptual awareness. The sighted child learns to concentrate on seeing as well as hearing while the correctly handled non-sighted child learns to concentrate on hearing. Use of language is more realistic if objects etc., can be seen, but the non-sighted must have body gestures interpreted. Fraiberg (1971) endorses this. She talks of the "unique developmental patterns" of the blind child but feels many problems had applicability to other groups of infants who might be disadvantaged in some way. Her interpretation of development occurring as a result of the establishment of an adequate two-way communication between mother and child was relevant to clinic staff. Knowledge was required on where to look for responses that a mother could effectively stimulate knowing that these were essential to the awareness of her child. The conflict between how a sighted person learns and develops and how a non-sighted person does the same is marked and requires considerable adjustment on the part of those who can see. Brodey (1962) quoted by Burlingham (1964) requires his teachers to spend several hours blindfolded to encourage them to understand the children they teach at the Pilot School for Blind Children in Washington. Reynell (1974) however points out that blind children are still considerably disadvantaged in comparison to blindfolded sighted children and considers the differences should be realised if blind children are to receive adequate stimulation.

The clinic was surprised by the lack of satisfactory information available on the subject of development in blind children. Some valuable assistance was offered by psychologists within the Department of Education but in certain areas there was always vagueness. There were the areas most relevant to the clinic. Staff were not prepared to accept that 80% of learning before the age of 2 years was as a result of visual cues. This was frequently pointed out but seemed to imply that the blind child did not have a chance. Burlingham (1964) appears also to question this and points out that a great deal of attention is given to the function of looking but little attention is given to the function of hearing. Blind babies can be inactive because they are listening and require stillness to correctly ascertain a sound. This type of attentiveness must be recognised by parents and respected.

Clinic staff were told to expect delay in development but observations of Rd indicated that this delay was not an overall phenomenon. Adelson and Fraiberg (1974) showed that delay could be found in self-initiated mobility. It would seem that the blind child sees himself in relation to the area in which he sits. Any unintended movement from that area results in withdrawal. Intention depends on the ability to attach sounds to objects, a skill appearing towards the end of the first year. Until the child realises that he can move himself to touch an object that makes a sound he will remain immobile. Adelson and Fraiberg supply the approximate ages for mobility in blind children. In the same way as the child will not move towards a toy, it will not reach towards it until nearly one year old. The

major problem for the blind child then appears to be the establishment of a concept of object permanence. Intervention programmes must focus on uniting sound and touch.

Clinic programmes require reinterpretation for children with visual impairments because they do not identify the peculiar needs of these children. This identification appears to be crucial. Reynell (1974) points out that there are no really satisfactory developmental scales for infants and young children with visual handicaps because of what she terms the "inappropriate" concern with standardisation and prediction. Because blind children often have other handicaps together with Zinkin, Reynell has developed scales for use in developmental programmes. These do not appear to be used or available in New Zealand.

It is suspected that reinterpretation is also required wherever there is a perceptual difficulty in an effort to establish the exact nature of the difficulty and how it can be overcome. During 1977 and 1978 clinic staff have encountered the following cases that highlight this problem:

Sensory Deficits:

- | | |
|---|---------|
| 1. Hearing loss | 2 cases |
| 2. Visual impairment (varying degrees) | 9 cases |
| 3. Loss of an opportunity to touch effectively because of physical handicap | 2 cases |
| 4. Insensitive tongue | 1 case |

Learning Difficulties:

- | | |
|---|---------|
| 1. Inability to reverse actions | 1 case |
| 2. Inability to imitate (invisible) and poor body image | 1 case |
| 3. Poor visual perception (subtle) | 1 case |
| 4. Failure to look or listen | 5 cases |

Resources are not always easily available to help extend the knowledge of staff in these areas and occasional concern is felt that inexperience results in delayed recognition of the difficulty, or in faulty diagnosis.

SECTION TWO: PARENTS

INVOLVEMENT

The current popularity of infant intervention programmes emphasises parent involvement giving recognition to the fact that the infant's environmental base is his home. Very few programmes require an understanding of the home environment however although this is the environment of the handicap and will be important in determining the course of that handicap. Rayner (1978) comments on the importance of a home assessment as well as a developmental assessment of a child, the data gained overall being the baseline of information required from which to begin a programme. It would seem that few intervention programmes give recognition to this. Those that do are home-based programmes, e.g. Deep (Maya Pines, 1975). Most programmes are carried out at a centre or clinic such as in Palmerston North. Some use a social worker for home assessments but it seems that this is done once a programme has commenced and often as a result of parents signalling a need rather than for the reason Rayner suggests. The need for a home assessment before intervention begins makes sense and would contribute to clinic effectiveness. Rayner considers this the role of the psychologist, presumably because she is following a personal interest but one which also interests the psychologist and speech therapist in the Palmerston North clinic. It is felt that this would give better insight into what the parents could understand and cope with and also what adjustments would need to be made to achieve a stimulating environment.

Programmes usually involve parents in either of two ways. The Hester Adrian Centre (Evans and Sparrow, 1974) adopts a group approach. This appears to be the most widespread method of working with families where there is a handicap. It is likely to be more economic than an individual programme such as the Palmerston North one but this would be determined by the number of families catered for. Up to the end of 1978 the clinic had no difficulty catering for the numbers concerned on an individual basis.

Whether they are group-based or individual, all programmes appear to follow a similar format. Infants are observed and assessed to establish a baseline, some form of reinforcement schedule is adopted to shape behaviour and the infant's progress is continuously monitored. Within this, interaction between parent and child is observed with the intent of giving the parent expertise that will enable them to carry on when trained staff are not present. Nicholas (1977) points out that such programmes are best organised within an educational context that is within the community and behaviourally oriented, rather than within a medical context.

A flexible programme allows for parent support as well as education. Although Ms Straton has not highlighted this aspect of clinic work she shows recognition of its need in various case studies (1977) and in her use of a social worker in the Wellington clinic. Rayner (1978) considers developmental assessment and programming alone insufficient because it concentrates on the child defining its handicap and stimulating its development. She talks instead of developmental therapy aimed at the whole family. This

recognises the multitude of problems, major and minor that a family may face and allows for a realistic presentation of the more structured programme putting this into the back seat if other problems are too severe. In clinic experience, there are few families who experience major difficulties. Most are familiar, seemingly small but significant to the family concerned, e.g. coping with convolvulus in the garden. Although insignificant they are one more pressure on a family that already feels different and pressured by the presence of a child with a handicap.

Within the clinic's informal structure it is easy to recognise the sophistication of the majority of parents attending. In an area of work where so often it is a matter of the "expert" conveying information to the "non-expert" (parent), it is important to realise that the parent also has information about the child and is in fact more knowledgeable about that child as a whole than the expert. Parents are informed that it is as much their responsibility to "sell" their child to the community as it is the responsibility of the various agencies involved. For this reason they are often requested to talk to visitors, especially students, and to attend seminars. They are able to discuss their child's handicap and the most suitable methods of handling him or her. The confidence they gain from this is particularly demonstrated at the meetings of the Parent's Group where problems are shared and advice given. Although no parent is "pushed" into taking this role most are surprisingly keen to do it, one mother even taking the floor at a well-attended seminar to demonstrate how to dance with a visually impaired child. Clinic staff

are able to roughly assess their effectiveness by observing situations such as these.

ADJUSTING EXPECTATIONS

"My doctor told me to live from day to day with my child, not to look to the future." (Mrs Ly).

No doubt the doctor was requesting this parent to adopt realistic expectations of her child. Stokes (1976) points out how frequently, through their familiarity to the adviser, statements like this are made which do not mean anything to the parents. In the context of the above quotation only one question can be asked - "how?". The peculiar vulnerability of parents in this position however prevents them from asking this question. They depend on others for this kind of information. One mother interviewed described parents' needs vividly:

"Assistance should be available ... when people are facing a crisis they need things. They cannot solve their own problem. They need help immediately ... can't create their own."

Facing the diagnosis that a child has a handicap is a crisis. The child's future depends on how quickly the family can cope, and this can in turn depend on the quality of the support offered.

The advice given to Mrs Ly is in itself sensible but because it did not tell her how she could achieve such an ideal it was quite unrealistic. This mother was given nothing to hold on to and no means of adjusting to day to day living. To give parents no opportunity to have any expectations is to encourage them to lapse into the caring role which can so often lead to early institutionalisation for the child and possible abandonment. (Hood, 1976). Children with a handicap are entitled to live at home and

this must be made possible.

What then can parents expect that is realistic? To answer this it is appropriate to look at the normal child and his parents. Burton White (1975) suggests that the parents want, in early years, a well developed child who achieves the general goals associated with development within an acceptable time range. In general these goals for most parents are seen as smiling, sitting or walking. Parent focus on these goals is traditional to New Zealand society and reinforced by Plunket Nurses, Public Health Department Nurses, doctors and other parents. Even the school medical card asks for the age of the child when it walked and talked. This focus on specific goals is misleading. Trained personnel are aware that these skills are only indications of previous development and maturity but in emphasising these and in distracting parents from other equally important developments in their child they are taking an opportunity from parents of understanding and stimulating their children in simple but enjoyable ways so that those children are truly well-developed. But although it could be argued that infants generally tend to be understimulated it is probably true that most parents of the normally developing child gain sufficient satisfaction from the achievements their child makes in the broad areas of development. Their expectations are fulfilled and the effort they have put into encouraging those achievements is rewarded within the expected time. The mother of a child with a handicap has no such security and the power of our customary manner of viewing development is strong.

B who has cerebral palsy learned to bang on a surface. This skill required much effort on his part although the bang was subdued because of poor control. B was 10 months. Mrs B said as he did this, "Yes, but when will he sit?" She later told a visitor to the clinic that her neighbour's child who is the same age as B had been sitting for some time. The quality of her relationship with her child is impaired by her lack of understanding of achievement.

Meier (1976) refers to the work of Clarke-Stewart (1973) which suggests that an infant's intellectual and social development during the first two years of life is optimally facilitated if his mother or primary caretaker provides varied stimulation, shows affection and responds fairly quickly and consistently to his signals.

In a subtle way the clinic has challenged the traditional manner of viewing child development. The programmes used reduce the importance of "milestones" and bring forward other skills to equal status. Parents are trained to focus on each simple skill separately and to stimulate and reward its appearance. In looking for these simple actions which take less time to appear than the "milestones" they are able to live from day to day with their child working towards these short-term goals. It is surprising how quickly most parents become involved and are encouraged by their children. Certainly they do look towards the future but not to solve their own needs rather to solve their child's needs. They consider pre-schools, schooling, speech therapy and institutions insofar as they are interested in how a particular institution will assist them further, e.g. the parents of a blind child visited Homai College soon after his sight defect was diagnosed. Whereas these parents might consider institutions in later years it is suggested that this decision will be realistic involving an appraisal of

their own capacity to care for that child or adult and the latter's need for independence, work or social contacts. These parents have developed a relationship with their child that is rewarding to all. They can understand and watch their child's progress and they can realistically stimulate that progress. In this way their expectations are modified to what is realistic and they are the ones who have achieved that modification.

The programmes used are organised around the stages of sensori-motor development defined by Piaget. These stages are sequential. Piaget (Rowland and MacGuire, 1971) suggests a fixed order of cognitive development wherein each stage depends on the accomplishment of the previous stage. If this is followed it becomes possible to see how the child's stage of development is at issue and not his chronological age suggesting that it is the stage that becomes the milestone and not the skills incorporated in that stage (Klein and Safford, 1977). This shift in thinking is positive. It enables others to look at what the child is and what he can do rather than his deficits. Parents show little interest in the abstract nature of the Piagetian stages and are not concerned that these are the "milestones". They prefer the concrete feedback that the appearance of a skill provides for them.

Adjustment is very often demonstrated when the parents begin to use the label that would describe their child, e.g. "mentally retarded". Clinic staff avoid the use of labels until parents indicate some interest in knowing how their child would be described or until a need is demonstrated. It is surprising how naturally this will occur and often

reveals considerable thought on the part of the parent. The other surprising thing is the parent's accuracy, one mother expressing exasperation to the psychologist when her doctor described her son as severely mentally handicapped because she considered him moderately mentally handicapped. She gave reasons for her decision. No parents have used a label in the first few weeks of clinic attendance even avoiding terms such as "deafness". Their recognition of the label seems to be connected with their realisation that their child has a future but that this may require special facilities. The care taken in using labels is essential if parents are going to have realistic expectations of their children. It also indicates the long period of diagnostic teaching that is sometimes required before a label can be correctly applied. When a label is used it is noticed that clinic parents will use it descriptively always giving an explanation of how the particular handicap is expressed.

Other signs of adjustment are demonstrated when parents meet as a group when individual attitudes are challenged by others. One mother surprised by buying a bicycle and placing her child (with spina bifida) in the seat at the back. She quickly pointed out that the fact that her child had spina bifida was no reason not to have a bicycle with toddler's seat attached. Another mother was challenged when she claimed she could not go out at nights because of her child. Gradually parents come to understand their child's "normality" and begin to apply this to everyday situations. They cannot do this alone, however, and just as their children require ongoing intervention they require ongoing support.

CHAPTER FIVE

THE FAMILIES INVOLVED

SECTION ONE: FOUR CASE STUDIES

During 1977 and 1978 48 children attended the clinic.

They may be categorised as follows:

- | | | |
|---|-----|----|
| A. Children with a handicap who received long-term programming at the clinic, i.e. they attended regular appointments over a period of time. | } | 21 |
| B. Children for whom long-term programming was considered necessary but where this did not occur because: | } | 8 |
| a) Parents shifted from district | - 2 | |
| b) Parents refused to attend | - 4 | |
| c) New baby arrived | - 1 | |
| d) Distance travelled (from Stratford) | - 1 | |
| C. Children attending for assessment only but no handicap identified and programming considered unnecessary. Clinic staff did not feel secure making this decision on the basis of one appointment because they felt their knowledge of handicap in infancy was inadequate so a second check would be made 6 months later. These children had often suffered quite severe illness, e.g. meningitis. | } | 8 |
| D. Children attending for assessment whose needs would be better met through a pre-school (2) or the developmental play-group run by the Department of Education (5) | } | 7 |

- | | | |
|--|---|---|
| E. Children receiving programming at home. | } | 5 |
| These are special cases where transport | | |
| difficulties and particular needs are | | |
| considered more easily catered for in | | |
| this way. | } | |

Table 6 indicates the variety of handicaps these children exhibit although some have not been confirmed by medical tests. Tables 7, 8, 9, illustrate the specific manner in which many of these handicaps are expressed.

The types of handicap appearing, the nature of the specialised work with them and the categories of children dealt with suggest that the service given resembles fairly closely the developmental work done elsewhere. (Cowan and Brenton, 1975; K.S. Holt, 1975; Reynell, 1976).

It is planned in this section to examine some of these children in an effort to provide an evaluation of clinic work. The difficulty of providing evaluation of this kind of individualised, and often intuitive work, is recognised by others involved in this field. (Beventon, Gardner and Cocks, 1978).

CHILDREN RECEIVING LONG-TERM PROGRAMMING (CATEGORY A)

This category best illustrates the clinic's broad strategy and philosophy.

Each child and family will be examined from five viewpoints:

- a) That its handicap will influence how successful the clinic is in working with it.
- b) That its parents' expectations will play a major role in determining clinic success.
- c) That the other agencies involved will influence outcome.
- d) That the home environment (including the parents'

attitudes to their role as parents) is a significant factor to clinic success.

e) That the organisation of the clinic is in itself a factor determining success.

B referred to the clinic at 6 months.

B referred by the paediatrician who wrote:

"This baby suffered severe fetal hypoxia. ... At birth he showed limpness and required prompt and active resuscitation. ... antibiotics were given before the caesarean section and this camouflaged the development of meningitis. ... He apparently responded well to chemotherapy.

However, the mother is now worried about his developmental progress, although I could find no clinical abnormality."

Assessment over time in the clinic revealed that this was a child with a severe physical handicap which was going to affect his ability to grasp, release and manipulate objects. He was going to be deprived of the important tactile experiences that come naturally through using the hands. B was considered a challenge by clinic staff who pooled their resources to discover every possible way the child could be stimulated. He is now $2\frac{1}{2}$ years old. Development is delayed possibly unnecessarily. He is a poorly motivated child, distractible at times with an inability to persevere with tasks.

Bobath (1963) points to the high success rate of early intervention procedures with infants with cerebral palsy. Clinic staff were aware of this and had no reason to believe that they would be unsuccessful with B. The manner in which his cerebral palsy was expressed however, in that it prevented adequate use of hands, immediately placed restrictions on what could be done with him. It is suggested

that although success with children with cerebral palsy is possible, their challenge is not always an easy one to meet. They must be placed into the correct posture if they are to be able to move correctly. Despite the number of aids available to assist posture, very often playing with the child requires two people, although this is not an absolute necessity. When this is considered alongside the other tasks parents must carry out and their particular temperaments, some very obvious reasons for the failure of programmes is apparent. In this context B can be usefully compared with S, a child with Down's Syndrome who, although showing delay, was able to move freely. He still required assistance to learn but did not require the precise handling that B needed so placing fewer pressures on his parents.

Paediatricians consider a mother's observations important in assessment. (Illingworth, 1972). Mrs B is the only parent attending the clinic who initiated contact with a doctor herself because she thought something was wrong with her child. She realised that at 4 months of age B was not moving in the manner that her daughter N had. In interview she mentioned that she was not surprised something was wrong because a relation had had neo-natal meningitis and was "slow". Her expectation was that B would also be slow. Before clinic staff were aware of this background, they were more than aware that they had a problem dealing with Mrs B's expectations of her child. The first progress report on B (age 9 months) states: "... she (i.e. Mrs B) gives the impression that B's progress is something over which she has no power." The second progress report on B (age 22 months) says: "On occasions Mrs B does work with

him but we wonder if she has fully appreciated the amount of assistance B does need."

Throughout the first year of B's life it was considered that his mother had been inadequately informed as to his condition. This was realised by the visiting therapist who liaises between paediatrician and parent. The paediatrician reserves the right to present diagnosis to a patient. Clinic staff and the visiting therapist have been careful to respect this. Ms McComas in a personal communication (1977) reinforced this attitude when she described paediatric displeasure when on one occasion clinic staff took the initiative in presenting a diagnosis. In B's case the paediatrician was informed of the difficulty. Unless Mrs B understood her child's handicap she would not handle him with the relaxed handling required. Appointments were made but the paediatrician would be called away. The visiting therapist decided to inform Mrs B and described B as "physically handicapped" avoiding the closer medical description of cerebral palsy.

Mrs B has attended the clinic regularly. She feels it has helped B; "Any kid is lucky these days with all this around." She claims clinic ideas make sense and she has no difficulty carrying them out. B's progress suggests clinic ideas are not always fully applied. This view is supported by the visiting therapist. The psychologist visited the home where observation revealed the many subtle ways in which B's needs were overlooked, e.g. conversation was lacking, net curtains covered the windows preventing B from looking through them. A means of overcoming these problems was conveyed to Mrs B and she carried out the advice given.

An initial home assessment followed up by home visits by someone trained in observation with an associated knowledge of a child's requirements would probably have assisted this case but the clinic's organisation did not allow for this on a routine basis.

B attended the clinic accompanied by his older sister and his mother. All appeared to enjoy coming but B and N were inevitably reduced to tears during the hour, B because he did not do what was required of him, and his sister because she disturbed him. To create the relaxed atmosphere necessary for working with B because of his physical handicap, staff worked with both children. The importance of a tension-free atmosphere was at all times emphasised with Mrs B but it was not until N went to school that this was achieved and even then Mrs B remained a dominating force. It was felt that Mrs B's concept of mothering related to the giving of material possessions. She did not appreciate that not only must children be given a toy but they must also be shown how to play. Playthings were confined to what could be bought and these were well chosen. Sandpits, water play, dough play and exploring the cupboards were not allowed because they created mess. It became necessary for clinic staff to accept this and compromise. Stimulating materials for B had to fit a framework of what was acceptable for his mother. Because of his restricted movement this was difficult to do. His grasp reflex was primitive and little could be held on to with ease, let alone manœuvred in any way. When B was $2\frac{1}{2}$ years the psychologist visited his home. B sat in his high chair with an assortment of rattles in front of him. In no way was his increasing maturity

recognised through the objects given to him; it was easier to give him a rattle than a truck. B showed momentary interest in the toys then lapsed into a placid apathy.

The extent to which B's handicap is the cause of his difficulty is debateable. It is suspected that it is aggravated by his home environment. This can be illustrated by describing his sister. A timid insecure child, N attended the clinic regularly with her brother and eagerly played with the toys in the playroom. She responded to attention clinic staff gave her with a smile and said very little. Her tearfulness and frequent colds concerned clinic staff while the paediatrician also kept her under supervision. Contact was made with her kindergarten teacher and her particular needs for affection and unrestricted play opportunities were discussed. Eventually she began school. At a later date her kindergarten teacher commented: "We wished we could have kept N for longer, she wasn't ready for school... She would run home screaming all the time." N has a friendly but fleeting relationship with her brother. Mrs B comments: "She comes in, drops her bag and goes to play with a friend across the road. She gets lonely here: after all she can't play with B." Mr B plays little part in his family's daily life.

Bobath (1963) points out that the relationship between a physical handicap and intelligence is not direct and that a number of variables can obscure the picture including emotional wellbeing and parent handling. It is felt B's case illustrates this problem. Clinic success is also determined by these variables which in B's case have been complex. The severity of his handicap and its particular

expression, his mother's low expectations, the failure of agencies to communicate information about his handicap and his restrictive home environment have minimised opportunities for success. In turn clinic organisation has not enabled his problem to be fully explored and attacked at the broadest possible level.

R referred to the clinic at 7 months.

This little girl is one of two adopted children of university-educated parents. At age 5 months before adoption procedures were finalised, the family doctor suggested the child had something wrong and this was confirmed a month later. R had an unknown syndrome which included extra ventricles in her brain. This was a shock to her parents who were still required to make a final decision about her adoption. Those counselling them suggested that they should not adopt R and that she "should never have been placed for adoption".

During this time, a friend who assisted in a small developmental playgroup run by the Department of Education Psychological Service, suggested that Mr and Mrs R contact the psychologist involved in the Developmental Clinic who would explore R's difficulties and provide suitable stimulation. Mrs R made the approach and an appointment was made. This is the only child to attend the clinic as a result of the parents' referral.

Notes made by the psychologist on R's first appointment indicated that she was a suitable candidate for the clinic programme:

"Strange little girl. Perseverates - really fixes on something and even though attention gradually switches to something else she cannot easily switch - almost gets stuck. Processing of information seems held up. Distractible."

She appeared to be functioning at a 6 month level although her understanding of object permanence was at a 4 month level. Her features were unusual, her head being large and almost mongoloid in appearance. As well she was unusually heavy.

Besides providing educational ideas to stimulate R, support was given to her mother who was concerned about her adoption. Finally consent papers were signed because her mother said: "I could not live with the guilt I would feel if I did not adopt her." Attendance at the clinic was regular, Mrs R admitting to the "big emotional relief" it gave her.

Although R's handicap was unknown its expression was easily catered for in the structured programme offered by the clinic. At 13 months her first progress report stated:

"Her activities have to be taught in sequence. They do not follow a natural progression, e.g. lying to the sitting position is being taught at present. ... I have noted that R must be encouraged to lift her head from the supine position. The pronounced head lag when pulled to sitting has disappeared." (Physiotherapist's comments on large body skills).

"R's development in this area has followed quite a defined growth and plateau pattern ... very much a catching up and forward moving stage so that although R appears to show delay at some periods, at others she is at least consistent with those of her chronological age ... R has demonstrated a difficulty in achieving a reverse action." (Psychologist's comments on fine body skills).

Both psychologist and physiotherapist at this stage considered R the "most fascinating" child attending the clinic. It was thought that without intervention she would

have already been showing a definite overall pattern of retardation.

Because progress was considered satisfactory R eventually began attending the clinic monthly instead of fortnightly. At age 2 years 1 month she passed all items at the Year II level of the Stanford-Binet Intelligence Scale (Form L-M). Still an unusual looking child she was walking steadily and interacting with other children with confidence.

Although features of this syndrome were considered to have a high correlation with intellectual problems, in R's case this was never stated absolutely because medical experts were indecisive about her condition. Mr and Mrs R were therefore uncertain about what to expect but were aware of the power they had over R's progress. Attempts were made to inhibit this however. Mrs R's father-in-law was an elderly retired general practitioner. He warned against taking notice of experts and suggested R's parents "let things be" and that Mrs R carry on with natural mothering. Mrs R was annoyed by this and chose to ignore him. She had studied education and human development at university level and knew of Piaget. She could therefore cope with the full complexity of clinic philosophy. It was obvious to clinic staff that R's parents worked hard with their daughter. At each appointment Mrs R made notes and discussed progress and problems with understanding. She was delighted by progress but seemed anxious to avoid setting her sights too high. Her disappointment seemed directed towards this as R's problem. "I worry that she will be self-conscious later on and that she will have trouble

finding clothes."

Parents differ in their ability to communicate with professionals and their ability to understand what they are told. Mr and Mrs R were fortunate. Without appearing demanding they asked detailed questions. This helped to create a rapport with medical specialists and the clinic staff, the only agencies with whom they had contact. In his concern for this family and their problems relating to the adoption decision, the paediatrician visited the home to discuss R's case in an informal atmosphere. Such an action, although highly desirable, rarely occurs. As well Mrs R had many friends and interests in common with the psychologist in the clinic. This could only have been to her advantage.

The clinic seemed adequate for Mrs R's needs. She soon began taking an interest in other families offering considerable support to some. Mr R became involved in the running of the Toy Library.

R belonged to a child-centred family. Although at times anxious her mother was able to organise her time around her child and was assisted by her husband and her own mother. Her older son attended playcentre giving R many incidental opportunities to be with other children and to be handled by other adults.

R appears as a fortunate child. She has been adopted into a sensitive, concerned family who are able to understand her needs. In contrast to Mr and Mrs B this family has received very supportive assistance from other agencies and clinic organisation appears satisfactory for their needs. It is felt by clinic staff that R's particular

handicap was less destructive in its effects than B's. Easier to work with, it caught the imaginations of clinic staff in that it seemed to demonstrate the unknown area of "learning difficulty". Attached expectations were vague and more easily challenged while Mrs R's response to the clinic reinforced positively the efforts of its staff.

M referred to the clinic at 8 months.

This little girl, the youngest (and only girl) of three children of a family involved in farming, was referred by the paediatrician. The referral letter read:

"This infant had a birth weight of 5lb 7oz (2407g) and gestational age 40 weeks. She had a small eye on the left side. Since then various other developments have occurred such as a general lack of muscle tone, a tendency to pick up objects with the left hand and transfer them to the right and a continual watering of the eyes. Very extensive investigations were carried out but no etiological agent was found to account for this clinical picture. The possibility of a cytomegaloverus infection during pregnancy has been raised."

M did not begin attending the clinic until 10 months. A tiny lethargic child, she gave only minimal response to toys. Her breathing was heavy and her eyes watered. Her mother mentioned a possibility of partial sight but this could not be adequately determined until she was more mature. Within minutes of her first appointment it was apparent that M was also deaf. The Adviser on Deaf Children confirmed this while the Ear, Nose and Throat specialist arranged hospitalisation so as tonsils and adenoids could be removed and tubes placed in the ears. M has a persistent conductive hearing loss adding to a possible sensori-neural problem. Hearing aids were fitted at age 20 months. M's case illustrates the importance of functional assessment in an

informal environment where the child will play. Her lethargy probably concealed her deafness during clinic assessments. Mrs M had "wondered" if there was something wrong with M's hearing. She did not mention this to others however. This is otherwise a most competent mother but M had so much wrong and pressures were initially so great on this family that the significance of the hearing loss was simply overlooked. In this context clinic programmes are most important.

With so many problems it was difficult to know how best to approach M. Her frailty and easy tiredness prevented too much activity. She required stimulation in a wide variety of ways highlighting her need for her parents' time, yet this was a busy family with both parents committed to the day-long running of a farm. M was never neglected however and her progress was apparent from her reports and the pleasure the paediatrician expressed at her development. At age 12 months she was functioning between 6-7 months in large body skills, and 10-11 in visual and fine motor skills. Four months later progress was hampered by perceptual difficulties which appeared associated with her visual and hearing difficulties. As her strength and health improved however she began to respond and throughout 1978 progress was consistent. In November 1978, at age 2 years 4 months, M passed the three non-verbal tests at the Year II level on the Stanford-Binet Intelligence Scale (Form L-M). A sociable little girl she remains frail but this is overcome by confidence and determination. M's progress was the result of her parents' efficiency. The Adviser on Deaf Children commented following a home visit:

"I'm so impressed by Mrs M. Last week she had three appointments to keep, she has the other children, visitors turning up, the farm to help with yet she had still found time to make the scrapbook I suggested. When I arrived the other morning she had just completed her baking. I don't know how she does it."

Mrs M has always shown the clinic respect, carrying out every task she is set and consulting clinic staff about general problems with her children and the neighbourhood children. The clinic appears to have earned the status usually given to the paediatrician. Perhaps this is because of the quick diagnosis of deafness it gave but it also could be because the paediatrician placed the responsibility for learning about M on the clinic's shoulders. He did not state definitely what M's problem was although he discussed his suspicions fully with her parents. Because of this M's parents were not given any idea of what to expect. They were free to establish their own expectations and appeared to feel they had hope. Mrs M said:

"If I'd been told what to expect I might have given up."

Whatever learning activities were recommended Mrs M would carry them out often surprising others with the skill and the speed with which she did this. M occasionally developed behavioural patterns which interfered with progress, e.g. persistent mouthing. Mrs M handled these objectively, ignoring or distracting when necessary.

The variety of problems M demonstrated required a variety of specialist help. Initially defensive, Mrs M soon relaxed and gradually began talking about her problems - a jealous older son, a middle child requiring speech therapy, a farming husband who worked long hours and a difficult mother-in-law. It was quickly realised by clinic staff that

this mother could be overwhelmed by appointments and because she was afraid of this, she had stopped the middle boy's speech therapy. This was explained to the paediatrician who took responsibility for keeping pressure from her. M's case demonstrates that agencies can be controlled if the family is encouraged to communicate its difficulties. As her confidence grew Mrs M began to understand how her time was taken up with her daughter and she refused to participate in extra activities that were not essential because "the boys need my time as well".

The clinic appeared adequate for Mrs M's needs. That she found it supportive was demonstrated by the occasions when she would "drop in" while her daughter was hospitalised. This is one of the few families not visited by clinic staff although one physiotherapist occasionally babysat for the family. Visiting was not considered necessary however as the visiting therapist, Adviser on Deaf Children and later the pre-school teacher from St Dominic's School for the Deaf, Feilding, were visiting routinely.

Mrs M was observed playing with her children when she brought them to the clinic and also with other children. She was patient and accepting, observant and thoughtful. Although her husband worked long hours he appeared to offer support and occasionally visited the clinic also.

As with R, M's case shows that the parents' understanding of a situation, their ability to carry out recommendations and their flexible expectations are important factors in their child's progress. The clinic is used for what assistance it can give and its staff are reinforced by the child's progress feeling no need to interfere further with the family who are confident in their approach to handicap.

J referred to the clinic at 14 months.

J was referred to the clinic by the visiting therapist. He had two presenting problems:

1. Development was considerably delayed.
2. He cried constantly.

Whether the problems were interrelated and if so which one was a consequence of which was not known. A request for medical information on this child received no response.

J was a small, delicate looking child, with blond curls and big blue eyes. Very easily these filled with tears and his bottom lip lowered. Mrs J always cuddled and soothed him to stop the crying. Two conclusions were reached in the first appointment. Firstly, J's cry was too sophisticated for a child whose development was apparently so delayed and, secondly, Mrs J never attempted to distract him from crying. Instead her actions reinforced the behaviour. Clinic staff concluded his problem was largely emotional. In this they were in conflict with all other agencies until J was 26 months.

Isolated in their conclusions, clinic staff found this case amongst the most complex they had to deal with. Many factors contributed to the family's difficulties requiring specialist assistance in themselves, e.g. Mr J had a drinking problem, the teenage daughters were considered "difficult", Mrs J was depressed, on tranquilisers and had undergone psychiatric therapy. To further complicate matters many situations occurred with this family without the clinic's knowledge often hampering assistance already being given. This occurred in part because no one held views in common concerning the nature of the child's handicap.

The determination of others to discover the handicap although a necessary thing, caused J's family to believe there was one. Clinic staff consistently said to Mrs J "there is no handicap that we can discover" but in the following paediatric appointment arrangements would be made for further tests to determine the "handicap". At home J was not played with consistently. His mother was depressed, toys supplied were inadequate. This child was seriously "at risk" and the retardation he was already showing demonstrated this. Unfortunately the retardation supplied the label for the handicap. The family doctor said to Mrs J when J was 16 months "can't you see he's mentally handicapped". When the Society for the Intellectually Handicapped became involved Mr J announced "the boy's nuts". J's immaturity was such that Mrs J constantly dressed him in white baby clothes. Whereas the clinic was prepared to concede that there might have been something pathologically wrong with the child it was not willing to accept the very low expectations that others held for J. Gradually other agencies accepted this and a concerted effort was made by all to show Mrs J that her child was growing and was able to do things. Enrolment with an informal playgroup helped with this adjustment.

The insensitivity of various agencies further aggravated the problem. A flow chart has already been presented showing the number of agencies who became involved (page 54). When the clinic and the visiting therapist realised what was happening they made an effort to reduce this number but no one withdrew. It must be stated that all agencies became involved because the family was referred to them by another

agency and they intended goodwill but did not appreciate Mrs J's predicament. The clinic of course must be included in this criticism. To illustrate:

Mrs J arrived at the clinic with J. She looked happy and appeared more self-assured than she had for a long time. In the course of conversation the following information was conveyed:

Mrs J - "I told the Field Officer (from the Society for the Intellectually Handicapped) that I did not want the Home Help. I had told her before that but she kept saying that she was available and I might as well use her services. She was a nice person but not strong. It took her ages to fasten a safety pin. I felt I was helping her."

Psychologist - "And you obviously felt you were doing the Society a service in taking her."

Mrs J - "Yes - I felt awful but I just have to do things my own way."

"Who is helping whom?" is an obvious question. During the period the Home Help was available J made no progress. Mrs J was frequently depressed and developed migraines. The change in Mrs J and J once the Home Help left was dramatic. Mrs J in one month put on weight, looked cheerful, began helping tidy up the playroom and played with the other children present. In many statements she demonstrated that she had at least understood her child, e.g. "He's started crossing his eyes -- he knows it makes me anxious so I just look the other way and tell everyone else to also."

The clinic frequently proved an unsatisfactory situation for this family. Mrs J often felt uncomfortable when visitors were present and withdrew into a reserved silence often with her head down. This worried other parents who tried to be friendly but were uncertain about her reaction. Noise and movement in the clinic distracted J who resorted to everything possible to gain attention. He knew it was easier to obtain a reaction if he were distracted than if he

carried out the task he was presented with. Appointments were reorganised in an effort to find a time when there would be no interruptions and people wanting to visit the clinic were prevented from coming when J was present but it was almost inevitable that something would happen to destroy the confidence and quietness of the room. The clinic's difficulty was that it had become one of the local educational and medical showpieces and some visitors did not always think to ask if their visit was appropriate.

At this point J must be considered a child with a handicap but it seems that much of this has been created for him. At 28 months he is crawling. He plays in a quiet distractible manner at a 12-14 month level. Babbling is becoming more spontaneous. He exhibits a number of obsessive behaviours, eye blinking, turning objects around, giving incorrect responses to tasks presented, e.g. smiling rather than examining a toy, and if he cries he does so until he vomits. The clinic does not feel equipped to deal with the complex nature of these problems. J requires a more therapeutic approach using sand, water, music and movement as well as the presentation of appropriate stimulating toys. His family require intensive counselling, but have already had a psychiatric referral and communication in this area with the clinic is non-existent.

J's future poses a problem. What the clinic has achieved poses another problem. Clinic staff can only see in his life span so far a series of events that have done anything but achieve what they were expected to.

PROBLEMS RELATING TO CLINIC "FAILURE"Failure to thrive.

Although J not B are considered children who have failed to thrive the clinic would consider this their problem. Thriving relates to the quality of the relationship existing between parent and child as demonstrated in the stimulation provided. (Coleman and Provence, 1974). J is an obvious example of this and resembles in some ways the case studies described by Coleman and Provence. Children with organically-caused handicaps however are not usually placed into the category of "failure to thrive" but B's case and the description of his sister suggest that much of their problem is environmental although aggravated by the handicap and its consequences.

When this situation occurs there is usually evidence of a disturbed mother-child relationship but disturbed does not necessarily mean an emotional problem as is demonstrated in J's case, but rather an absence of a suitable emotional atmosphere for a child to develop. Bruner (1974) in his discussion on the effects of poverty in childhood refers to the mother-child relationship in terms of power. Those who are effective are those who feel they have power over their child and set realistic goals for the child to achieve. The disadvantaged do not have this feeling of power. Adequate parental expectations set in an environment which lends to emotional well-being will enable a child to thrive whether or not the child has a handicap. In the case of handicap assistance must be given to define those expectations. This was demonstrated by Stinson (1978) in his research with the mothers of hearing-impaired children.

Coleman and Provence (ibid.) in outlining the programmes used to overcome this problem, consider the prognosis for future development as good in these cases. The correct therapeutic assistance must be available however - home assessments, family counselling, stimulation programmes, and possibly hospitalisation or foster-home placement, if the case is severe.

The problem of a failure to thrive is further complicated if there is a socio-economic difference. Three children (Category B) who could be described in this way have been referred to the clinic:

a) VK was brought to the clinic from the Children's Ward. A 16 month old girl she was tiny, not crawling and unadventurous. She screamed throughout her appointment and withdrew from all human contact. Her only response was to a small musical toy. She swayed to its rhythm. She was referred by the paediatrician because of a "failure to thrive". Her mother refused to attend the clinic and no further appointments were made.

b) T was referred by the Medical Officer. An only child she was delayed in large body skills for no apparent reason. Her mother was anxious, not wanting her to be "backward". She attended the clinic on one occasion only then refused to come again.

c) Chs was referred by the Public Health Nurse who described him as "failing to thrive". A small boy, the youngest of four children, he was considerably behind in large motor skills although coping in a quiet manner with play typical of his age group. It was considered however that if he did not begin to make more use of the space

around him the pattern of retardation he was already showing would extend its effects. The physiotherapist described him as a "cot baby" meaning that he was often confined to a cot or highchair. Chs screamed when placed on the floor in an open space. His mother attended the clinic on two occasions only. She was markedly defensive and claimed her child did everything that he very obviously could not do.

Clinic staff considered these three cases as "tragic". In all instances parents obviously cared a great deal about their children but simply lacked the power that Bruner described and the associated "know-how" to help them. That these children had a need for a stimulation programme was apparent at the time of their appointments and in two cases has been proven over time.

a) Vx was discovered by the Medical Officer at age 3 years still confined to her playpen and very retarded in overall development.

b) Chs and his older brother have been observed by the psychologist in a play setting some 18 months following the first contact made with them. They were very retarded overall looking like toddlers rather than of age $2\frac{1}{2}$ and 4 years.

The fact that they did not receive the programmes they required at the clinic is not the fault of their families or the clinic. In all three cases the mothers appeared quite unable to cope with clinic conditions, informal as they appear to clinic staff. As much as these mothers felt inadequate with the clinic staff, the latter felt inadequate with the mothers. From all appearances these were three families who were socially different with limited finances.

It is quite inappropriate to bring families such as these into a formal setting such as a hospital to attend a clinic where confident informality is required. Cowan and Brenton (1975) mention the need for community-based programmes for socially deprived underfunctioning children. This need is also recognised by Earladeen Badger (1971) in a mother's training project run by the university in Illinois which extended its efforts to other centres. In these projects mothers met in groups which followed both mother-centred and child-centred programmes, the former to encourage confidence and self-esteem, the latter to educate mothers in play techniques. Ms Straton felt it was not the clinic's purpose to solve socio-economic problems (personal communication, 1978) but clinic staff feel that if they had the extra resources and time a more appropriate community-based programme could be organised for this purpose.

Other Difficulties.

Twenty-one children attended the clinic for long-term programming. Of these clinic staff considered all but four were "successful" cases. In Category B, seven children required long-term programming but appointments were refused. Reasons for the clinic's "failure" or refusal of families to attend can be listed:

- Transport difficulties
- Late age of referral
- Marital problems
- Inability to cope with clinic structure
- Another child in the family whose handicap led to unfortunate experiences for the mother
- Leaving the district
- Psychiatric illness
- Low expectations

Birth of a baby

Poor prognosis for one child who eventually died.

In five cases - J, B, Chs, Vk and T - it is considered that the clinic contributed to the difficulties families experienced or did not extend its structure sufficiently to cope with their situation. In one case (Dl) the child was withdrawn from its long-term programme at the clinic's request. Dl's mother worked and was not able to attend clinic sessions. Dl was frequently hospitalised in either Palmerston North or Dannevirke and also spent considerable time at the Day Care Centre. It became impossible to carry out a consistent programme with this child whose attendance became most erratic. Mrs Dl became involved in the Parents Group which met in the evenings but was soon in conflict with other parents attending so withdrew and formed a voluntary group of her own.

Span of Normality.

In every case dealt with clinic staff endeavour to stimulate that child so that it achieves optimal development. Children such as R and M demonstrate satisfying progress. Apart from the facts that one wears a hearing aid and the other has unusual features these children appear quite normal. Other children such as Ly who has microcephaly and cerebral palsy have also made satisfying progress although in comparison with others of their chronological age they appear retarded. These are well-adjusted children with parents who also demonstrate adjustment. The clinic however is not future-oriented. Although its stance is that development is cumulative, handicap is something which varies in its effects and

clinic staff are aware that the "span of normality" with each child cannot be estimated. Pugh and Russell (1977) warn that those training parents to be parent educators must take responsibility for parental depression when the child reaches a plateau because parents can be deluded by stimulation techniques into thinking they can "cure" their child. This same warning applies when a child has been ill or hospitalised. Clinic experience has shown that all children in these cases have either stopped making progress or dropped back. This can have a very depressing effect on parents. If referrals are early enough and the parent and child in regular contact with the clinic so that the child's whole development is supervised, delays can be identified and discussed with parents. M was such an example. All parents show alarm at a slowing down in development and they must be well-informed of the clinic's limits in stimulation so as not to adopt false expectations.

SECTION TWO: PARENT REACTIONS TO ASSISTANCE GIVEN

Parents interviewed were generally helpful in answering questions. They appeared to feel that the clinic was still in a formative stage and that their comments could influence the direction in which it developed. This attitude is also demonstrated during meetings of the Parents' Group when clinic staff and the visiting therapist are present. Advice is often given along with thoughtfully expressed praise and criticism.

Although the clinic structure and situation was criticised, the overall impression parents gave was that they liked coming to appointments and appreciated what the clinic was trying to achieve, claiming it gave a variety of support -

"I feel quite confident"

"You believe me when I tell you things"

"The tasks make sense"

"It gets us out of home"

"I couldn't ask for any more"

"You give us time"

"Made me aware of what to do"

"We meet other people"

One mother added that she had not really thought about the clinic critically but tended to accept what was there. The visiting therapist was asked to comment on reactions she had received from parents during home visits. She stated that parents appeared to like the clinic although one (Mrs J) had complained about the visitors present.

In contrast parents' reactions to other professional agencies show a tendency to be negative although criticism is not usually directed towards those who make home visits such as the visiting therapist and various social workers. Some of this criticism is at times confused and expressed

aggressively.

Mrs Rd stormed into the clinic with a red face. She stood in the middle of the room and declared "I'm not a cabbage. I have two cousins who are doctors and an uncle who is a lawyer. I was a herd tester. Surely that means I've got some brains? Why do they treat me as if I haven't?". This tirade was directed towards a doctor but it was very difficult to discover what the doctor had done wrong yet he had obviously offended her.

Clinic staff often feel caught in the middle of other professionals and parents. The aggression with which some parents express their thoughts must lead to a certain amount of caution towards visiting the clinic on the part of medical personnel. One such visit to the clinic led to an encounter which required the psychologist to mediate so as something was achieved rather than a shaky relationship completely destroyed. When one doctor accepted the invitation to answer questions from a group of parents both visiting therapists attended with the partial aim of keeping control of the situation. The meeting was a success seemingly because at last parents had the expert there with the time to answer questions. For the first time they saw a person with a sense of humour instead of a white-coated professional.

The problem of lack of information appears to be a major cause of upset on the part of parents. Irene McAndrew (1976) noted that out of 116 families interviewed three quarters stated that they lacked information about their children yet most felt they had been given ample opportunity to discuss them. She pointed out that parents felt ill at ease at appointments, did not understand technical terms and felt the professional person was a busy person who did not want his time wasted. Clinic parents interviewed indicated similar problems. One stated:

"I get sick of people saying they're such busy people ... we're all busy. They could get away from this god on a pedestal business. It would give you girls (clinic staff) some support. But with a handicapped child parents do get a bit selfish about things. You concentrate on yourself and your child."

Lack of understanding of a child's condition can create conflict:

V has a right hemiplegia and is making good progress. She is getting all the attention she requires, positive parent handling and it seems time will take care of her difficulty. The orthopaedic surgeon said to Mrs V "We'll just watch and see what happens until she's 7-8 years old." Mrs V says "What about now? - I worry about it now." Mrs V feels left on a limb. Time given to adequately explain V's problem would probably solve her mother's.

Clinic parents ask for time from professionals. This will enable both groups to listen to one another. As it is they complain of "elusiveness". They require communication that is consistently given from one person and do not like to see the paediatrician's "offsiders", as "they never seem to know what it's about." To them, the paediatrician or specialist is a very important person because he or she has given the first diagnosis and holds a watching brief over the child. If that person can identify progress then the parent feels very rewarded. Because the medical expert is highly thought of he or she is expected to show interest in all the child does. Parents who have received home visits have been very grateful but they do not require this rather they require a clinic visit. They want to show the medical expert what their child can do. They are aware that during a medical appointment their child rarely performs at his true level.

Parents are ultimately responsible for the care of their child (Lloyd Wright, 1976). In carrying out this

responsibility they show an awareness that childhood is a short temporary phase in a person's existence. As Sheridan expresses it "it is the prologue, not the whole play." (1965). Following childhood is the main phase of life when the child will not necessarily have it parent present. In the same way as parents become concerned about wills, trusts and insurances to protect their child's future, they also wonder about job opportunities and what their child will look like. Childhood becomes an important time as they realise that what they do as parents will effect their child's future.

Lloyd Wright (1976) refers to an article written by Pearl Buck (1950) who had the experience of being the mother of a child with Down's Syndrome. Buck states that parents of a child with a handicap have two questions: "How can I recover from my sorrow?" and "What can I do for my child?". The clinic's purpose is a response to these questions. All parents interviewed stated that they come to the clinic to help their child. Most did not stop to ask what the clinic was, where it was and who ran it, but trusted the often inadequate explanations they were given by the referring agent.

Those writing about the emotional factors involved in having a child with a handicap describe a period of shock, grief, shame, guilt or anger. (Wright, 1976; Stokes, 1976; Sheridan, 1965).

Roith (1963) disputes this pointing out that his experience working in the field as a psychiatrist has shown that the parents of children with handicaps are quite ordinary normal people who do not show the emotions described. Clinic experience would agree that its parents

are ordinary people but they have expressed grief at a diagnosis, lack of realism about their child, and considerable aggression towards those who have presented the diagnosis. These feelings are not abnormal as Roith seems to be saying but acceptable reactions to the unpleasant facts of their situation.

Mrs Ly, a competent, experienced mother, was told: "She's not responsive, she can't even smile." Mrs Ly described her reaction: "He did not leave a glimmer of hope; I argued. I felt strong disbelief."

Writers suggest that those feelings are helped by time and involvement but it seems that involvement is something which comes with recovery. This suggests that just as there is a sensitive period for growth in a child necessitating carefully timed referral, there is also a sensitive period for parent involvement. If a child is referred at an early enough period the clinic staff has opportunity to become acquainted with the family and to assess their attitudes to attending the clinic before beginning clinic sessions. This need has been felt most commonly with the parents of children with Down's Syndrome who have appeared defensive about showing their children to others. In two cases of the five children with Down's Syndrome who were referred to the clinic, mothers did not go outside with their children, except for medical appointments, for some months after their child's birth. The National Society for Mentally Handicapped Children (1974) describes similar difficulties in the case of these children. This society discusses how parents are immediately exposed to other people's reactions to their children because their problem is so obvious. K's parents did not take her out. K eventually died. At the funeral a

relation stated to the psychologist, "I feel sorry for K and Mrs K but I never used to visit them - I couldn't bear seeing the baby."

Involvement is a means of restoring feelings of adequacy to a parent. Green and Durocher (1965) describe how otherwise resourceful parents seem surprisingly uncertain about the growth and development of their child. One clinic mother interviewed said:

"I needed to know more. It was an advantage to be directed by someone who knew more than me. ... recommended reading was important. It made me feel like a competent person rather than a hopeless parent."

Florence Diamond (1971) emphasises these parental needs in the centre she runs for infants with handicaps in California (Elic). A planned programme involves the mother in a learning situation which is supportive enough to enable her to relax. Through her interaction with her child she discovers her importance. Stokes (1975) points out that as the parents can identify progress in their child, acceptance becomes easier. As soon as this point is reached they become more assured of their child's future.

With involvement can come dependence. This is a problem that clinic staff has faced with three children. In two cases mothers realised their children were overly dependent. One placed her daughter in an informal playgroup in an effort to reduce this while another made arrangements for her daughter to play with a neighbour's child. This mother complained that her daughter resorted to many measures including pulling tablecloths off set tables in order to maintain her mother's attention. The third case remains a problem as the mother does not leave her child at

all even when the child attends playcentre. Hewett (1970) refers to this problem as an effect of handicap. It may be that the clinic is reinforcing dependence through its programme. A suitably structured playgroup could provide a weaning process for such cases.

PARENT'S GROUP

As parents settled into regular appointments they began to make friends with other parents always taking a great interest in their children. On observing this clinic staff decided to begin a parent's group which could meet in the evenings and provide support and information. All parents attending the clinic have the opportunity of attending meetings as there is not defined membership or format.

Meetings are held monthly in the staffroom at Terrace End School. Two out of three meetings are informative. Clinic staff, medical personnel, teachers, adults with handicaps, etc., have been asked to discuss specific problems with the group. On the third evening parents socialise without outsiders, discussing mutual problems or successful ideas. Gradually parents have formed useful contacts with each other.

Mrs Ly's daughter who has cerebral palsy was sliding around the house. Mrs Z had an older child with spina bifida who did the same so the home was organised to meet the child's needs and make life easier for her mother. Mrs Ly recalled this from a meeting so rang Mrs Z to discuss the manner in which she could best help Ly do the same.

Clinic staff and visiting therapists attend meetings regularly but control lies with the parents. It is felt that the meetings are not solving some of the specific problems a group of parents might have, e.g. facing up to

life with a child with Down's Syndrome, but it has been decided that these are special needs which can be met separately.

The clinic is grateful for the enthusiasm so many of its parents have shown because in organising the meetings they are extending the clinic's purpose and filling in the gaps the clinic cannot cover during its Thursday afternoon sessions.

CHAPTER SIX

CONCLUSION

The objectives of the Developmental Clinic have been incorporated into policy by the Department of Education. This evaluation of the clinic gives rise to certain implications which are relevant if the clinic's objectives are to be realised.

A MULTIDISCIPLINARY APPROACH

Although the clinic appears to be working with other agencies towards a common purpose in fact this is not happening. Instead agencies work in a parallel fashion and do not adequately communicate their purpose to one another. The integrated approach required with a philosophy in common therefore does not exist.

The clinic must be part of a coordinated plan of action. To achieve this it must intrude into an area which is traditionally the domain of others. Because it considers its strategy and associated philosophy essential to the handling of those with a handicap, it must also extend its ideals to others. This is no easy task and could well offend those who are already working in this area with skills that the clinic simply does not have.

A comprehensive approach is one based on shared ideas requiring information to be communicated. Ideally parents should be involved at this stage. In this way family pressures can be recognised. It is as much the behaviour of others towards families that threatens their feelings of inadequacy as it is the existence of the handicap. To encourage parent involvement with a programme or with

treatment is to share the responsibility of its outcome. Helping agencies, professional or non-professional, are there to assist. They are not there to increase handicapping effects by imposing additional effects on the family.

Who is to coordinate this approach raises a further problem. Traditionally the paediatrician has been the coordinator of treatment plans. It is suggested that the visiting therapist is now doing this in Palmerston North. Whoever does it must have the required understanding of the philosophy basic to the approach adopted. This implies that the clinic may have to consider this its role. In fact it does not matter who does this if adequate communication between the agencies exists. Within the clinic however it is the responsibility of the psychologist to ensure staff fully understand strategy and procedure to ensure a consistent approach.

A CENTRAL BASE

In part difficulties in coordination exist because the family do not have a central base to attend. Instead they attend a variety of specialists, professional voluntary, educational and medical at different bases. The family must go to the specialist in the present system rather than the system going to the family. Such a scattered organisation leads to an unreliable attendance on the part of specialists as immediately they are responsible to other sources as well as the family concerned. Appointments at a central base, removed from other interruptions would help overcome this difficulty.

It is felt that the clinic is most conveniently sited

with medical personnel but it is suggested that the ideal base (in keeping with clinic philosophy) is removed from the Hospital. A community base seems most appropriate allowing for an informality that institutions do not always achieve.

THE OVERALL CONCEPT INVOLVED

This is implied in clinic philosophy which has some natural extensions which should be given recognition. The clinic as part of a multi-disciplinary team must be linked to other educational facilities in a way that encourages ongoing structured intervention programmes. A gap appears to exist between the clinic and pre-schools. Informal playgroups are few in number and not all clinic children are suited to them. An "earlybird" playgroup such as those described by Straton (personal communication, 1977) is necessary. Children would attend as a group in contrast to the individual attention given in the clinic and teaching programmes adopted which would coordinate the skills of various therapists and provide an approach similar to the clinic's. This would enable the clinic to concentrate on the young infant and avoid having to work with the toddler whose needs are not entirely met by clinic programmes but who cannot attend another facility.

The Toy Library also has an important part to play in this total approach because it involves the parents. Ideally it should have a permanent site of its own and this would be most appropriate in a central base alongside the clinic and the playgroup.

EDUCATION

A problem exists between those agencies which adopt a

specialist approach using a variety of expertise to do this, e.g. the emphasis given to Piagetian theory by the clinic. Knowledge such as this is not necessarily shared by others but is often essential if the differing approaches are to be understood. The suggestion given by the visiting therapist for an education group where ideas can be exchanged is a useful one. Such a group could provide the stimulus for research into topics related to infant handicap. Extending the clinic's purpose in this way may provide some means of understanding the problems of early identification.

CLINIC STRUCTURE

The clinic does require a facility of its own. This must have certain features:

1. It must have access to a playroom.
2. Withdrawal facilities must be available so as distractible children and less confident parents can be catered for without interruption or embarrassment.
3. An observation room with one-way mirror would be useful for visitors although wherever practical visitors should participate.
4. The clinic must be accessible so that families do not have added pressures in attending.

TRANSPORT

As long as the Department of Education discriminates between school-age children and pre-school children in the provision of transport to special educational facilities, it is making only a token gesture to its policy on early intervention. This argument now extends to the families of infants who are without transport and have the opportunity to attend the clinic.

THE ROLE OF THE PSYCHOLOGIST

The clinic's approach questions the roles of its staff and associated agencies. The psychologist must provide a variety of expertise - teaching, counselling and assessment. Whether a psychologist should carry out all these tasks or whether a social worker or teacher should be employed to carry out one area of work needs to be considered. Immediately such a move means one more agency or person is working with the family but it also releases the psychologist so as the clinic's format can be extended, e.g. by home visits and assessments and the greater availability of counselling. At this stage the psychologist just copes with the complex role required. If the clinic extends its organisation thus lengthening the time its staff is involved, the questioning of the psychologist's role becomes more relevant.

SPEECH THERAPIST

A speech therapist has an essential place in the clinic. Whether he/she is medically or educationally based is of no consequence with regard to qualification but because the clinic is an educational project ideally the speech therapist should be employed by the Education Department.

INFANT EDUCATION

Infant education has a place in the community not directed solely towards the infant with a handicap but also towards:

a) The infant whose difficulty is environmental requiring a community-based approach which is less threatening for the mother.

b) All infants. This would provide all parents with the opportunity to enjoy their children as clinic parents appear to. There is no reason why educational information cannot be coordinated with the information that is already made available to parents through Plunket and the Public Health Department.

In conclusion it should be stated that all those who have worked in the clinic have found it rewarding and stimulating. Much of the credit for this must go to Ms Straton and those who had the foresight to support her desire to initiate this project.

TABLE 1

Indicates persons who attend the clinic with the child receiving long-term programming.

F: Frequently. O: Occasional

Child- ren	Mother	Father	Sibl- ing	Other Relation	Friend	Helping Agency
	F O	F O	F O	F O	F O	F O
Rd	x	x	x			
Ly	x	x	x			
V	x	x	x	x		
B	x		x	x		
M	x	x	x			
R	x		x			
Kn	x	x				x
S	x		x			
Cy	x	x		x		
Ky	x			x		x
J	x					x
Je	x		x	x	x	x
Mc	x	x	x		x	
C	x					
P	x		x			x
K	x	x	x			
Dl	x				x	
17	16	3	10	3	1	4

TABLE 3

Indicates the chronological age at referral
and the agency referring.

Chronological Age	Paediatrician	Visiting Th.	G.P.	Medical Off.	Public Health Nurse	Plunket Nurse	Adviser on Deaf Chldn.	Pre-School Adv. Homai	Parent	TOTAL
0-3m	2									2
4-6m	3		1							4
7-10m	4				1	1			1	7
11-14m	1	4								5
15-18m	4	2		1			1			8
(1) 19-22m	1									1
23-26m	2	1		2						5
27-30m								1		1
31-34m	1									1
(2) 34m +	2									2

(1) "Late" referrals.

(2) Children assessed only.

TABLE 4

Indicates the chronological age at referral
and the major handicap presented at referral.

Chronological Age	Down's Syndrome	Cerebral Palsy	Hydrocephaly	Vis. Impmt	Hearing L.	Microcephaly	Hemiplegia	Undiagnosed at risk from birth for various reasons	Assess. following later illness.	Delayed Development	TOTAL
0-3m	2										2
4-6m	2	1						1			4
7-10m		1				1		2		3	7
11-14m		3					2				5
(1) 15-18m			1	1	1			2	1	2	8
19-22m									1		1
23-26m				1				1		3	5
27-30m				1							1
31-34m										1	1
(2) 34m +	1									1	2
	5	5	1		1	1	2	6	2	10	

(1) Late Referrals. (2) Children assessed only.

TABLE 5

Indicates years in which referrals made
and the chronological ages of children
referred in those years.

Chronological Age	pre1977	1977	1978
0-3m		1	1
4-6m	1	2	
7-10m	2	3	3
11-14m		1	4
15-18m	1	6	1
19-22m			1
23-26m		4	1
27-30m		1	
31-34m			1
34m +			1
TOTAL	4	18	13

"Late"
Referrals

TABLE 6

Indicates the presenting broad diagnosis of children receiving long-term programming in the clinic. Asterisk identifies twins.

Children	Developmental Clinic	Vision	Hearing	Cerebral Palsy or Phys. Handicap	Hemiplegia	Down's Syndrome	Microcephaly	Organic	Hypothyroidism	Poor Body Tone	Undiagnosed	Congenital Hip Displacement	Cleft Palate
E					x								
Rd	x	x											
Ly	x			x			x						
*V	x				x								
B	x			x									
M	x	x	x							x			
R								x					
Kn	x	x			x					x			
S	x					x							
Cy	x					x							
K	x					x			x	x			
Ky	x			x						x			
J	x									x	x		
Je	x	x						x					
Ml	x										x		
C				x									
P	x					x							
Dl	x	x		x						x			
Pl	x	x		x									
*Ks	x											x	x
*Dw	x	x								x			
	18	7	1	6	3	4	1	2	1	7	2	1	1

TABLE 7

Indicates specific problems handled by the
physiotherapist during 1978 with children
receiving long-term programming.

Children	Muscle Tone Difficulties	Reflex Patterns	Hemiplegia	Head Control	Trunk Rotation	Sensory Deficit	Associated Conditions	Limitation of Joint Range
Rd	x					x		
M	x					x		
V			x					
C	x	x						x
B	x	x		x	x			x
E			x					
Kn	x		x			x		x
Pl	x	x		x	x	x		
Ks	x						x	
Dl	x			x	x			
Ky	x	x		x	x			x
J	x							x
Dw	x			x		x		
	11	4	3	5	4	5	1	5

TABLE 8

Indicates specific problems handled by
Speech Therapist, June-December 1978.

*Two children were not receiving long-term
programming.

Children	Hearing Loss	Poor Chewing Patterns	Cleft Palate	Dribbling	Coordination, e.g. Cerebral Palsy	Attention Patterns	Tonsils and Adenoids	Lack of Confidence	Specific Language Difficulties
V				x					
B		x			x	x			
C					x				
M	x	x							
K		x							
*Pa	x?						x		
W				x			x		
Ky					x				
Ml	x?					x			x
J						x		x	
Ks			x	x					
Rd								x	
	3	3	1	3	3	3	2	2	1

TABLE 9

Indicates specific problems the psychologist has dealt with during 1978 with a group of children receiving long-term programming.

Children	Behavioural Patterns	Coordination Difficulties	Perceptual Problems	Sensory Deficit	Attention Problems	Parent Handling Problems	Hemiplegia
Rd	x			x		x	
Ly		x			x	x	
V	x						x
B	x	x		x	x	x	
M	x		x	x			
R	x		x		x		
Kn	x	x		x	x	x	x
Ky	x	x				x	
D	x	x	x			x	
K						x	
J	x				x	x	
Ml	x	x	x		x	x	
C		x					
	10	7	4	4	6		2

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