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THE ROAD TO EMPOWERMENT: Facilitating the Participation of Parents of Children with Special Needs in Malaysia

A thesis

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of the requirements

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ABSTRACT

This study involves the design, development and evaluation of a parent training curriculum for parents of mildren with special needs in Malaysia. The objective of this programme was to empower parents through meaningful participation in the process of content identification, implementation and evaluation of the entire programme. The study was conducted at Bethany Home, a centre for children and adults with special needs, situated in a rural town of West Malaysia with an estimated population of 40,000 people mostly of a lower socio economic status. The study was prompted by a need for active parent participation. The researcher is a former director of the centre.

The analysis of the data suggests that information sharing through participation is the road to empowerment for parents of children with special needs in a rural setting. As a result of the programme, teacher-parent interaction has improved and the setting up of a network for parents is imminent.

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I dedicate this thesis to Bethany Home and all the parents of children with special needs who participated in this project. I sincerely appreciate the assistance and guidance provided by my supervisor Prof.Dr.Overton and my friends, which made it possible for me to complete this thesis on time. Special thanks are due to to Peter Young and Dignity and Services, Jeyasingh and maniam for their contribution to this project. Last but not least, I would like to acknowledge my family, Kay, Tim, Jacob and Emma for their patience, love and support throughout this period.

Your attitude should be the same as that of Christ Jesus: Who being in very nature God did not consider equality with God something to be grasped, but made Himself nothing, taking the very nature of a servant being made in human likeness.

Philippians 2:5-7

CHAPTER I

INTRODUCTION

We are parents who are either intimidated by professionals or angry with them, or both; parents who are unreasonably awed by them; parents who intuitively know that we know our children better than the experts of any discipline and yet we persistently assume that the professionals know best; parents who carry so much attitudinal and emotional baggage around with us that we are unable to engage in any real dialogue with professionals-teachers, principals, physicians, or psychologists-about our children. (Gorham, 1975:521).

We rob the experience, the integrity, the pride from oppressed people when we fail to publicly value their importance. Silence is a powerful ally of the dominant culture.... (Warren, 1989:4)

Introduction

Disability in a family can be devastating. Families with a disabled child can become disabled families. Parents of children with special needs have in the past been criticised and made to feel powerless by professionals in the field. They have become devalued and have lost confidence in the face of experts (Cunningham, 1983) and they no longer trust their own judgements but instead look to others who are seen as specialists (Bledstein, 1976). In recent times a professional-parent partnership model has surfaced to replace the professional based model (Cheah, 1995). Many professionals believe that active participation of families is the key to the delivery of appropriate services to meet the functional needs of the family member with special needs (Shearer & Shearer, 1977). However in practice the partnership model does not seem to be working (Mittler, 1992). This is because parents who have in the past been sidelined need to be empowered to participate actively. This study looks at a parent empowerment model. It looks at a process of empowering parents of children with special needs through parent participation in the development of a curriculum for parent education.

The professional based model

The world is made up of people with a whole range of physical and mental strengths and weaknesses but with the progress of social, cultural and especially technological advances, many societies have begun to pay more attention to specific human abilities. Disability of any kind places a stigma on the family. Attention is often focused on deficits and little or no attention is paid to the disabled child's abilities. This makes parents feel labelled and stigmatised just like their child. Therefore a disabled child can also mean a disabled family. According to Cummings (1976) it is an ongoing stress that threatens the viability of the family. Parents have often been analysed, criticised and blamed for their handicapped child. They have often been made to feel guilty by being told by the professionals that they are the cause of their child's disability. Professionals armed with so called 'expert knowledge' often ask parents to trust them and not to question their judgements (Gorham, 1975). They use mystifying language and techniques and create an aura of mystery around their work (Tomlinson, 1986). This 'professional omniscience omnipotence', as Roos (1963) calls it, is still evident in developing countries especially in rural areas where parents are vulnerable. Malaysia prior to the Second World War, the families took the responsibility for providing care for those in need. There were no community expectations of authorities and hence lesser dependence on professionals (Sushama, 1985:214). Social change that came as a result of modernisation eroded the traditional lifestyles and systems of social welfare. It undermined the role of parents and disintegrated their informal network of support that existed (Clifford, 1966). Many parents became devalued and lost confidence in themselves. Voluntary agencies have often abused their power in this context and treated parents poorly. To many rural parents the words of the professional are sacred and unquestionable and it is unfortunate that this myth is perpetrated not only by professionals but by parents as well (Roos, 1963).

The disempowered family

Parents of handicapped children have great responsibilities laid on them when in fact they may feel relatively powerless (Graham, 1982). As a result, parents of children with disabilities report stress in more areas of their lives than parents of children without disabilities (Mahoney et al, 1991) and there are several other problems such as increased financial burden and extraordinary time demands that families with a disabled child have to face to a greater extent than those without disabled children (Mallory, 1981). However most families despite the higher levels of stress respond with resilience and adaptive functioning (Dyson, 1991). It is with such resilience that families of children with special needs have for many years maintained a silent struggle in the face of criticism (Roos, 1963:14-15).

The parent-professional partnership model

Recently, however, the importance of the family has become the focus of many studies (Turnbull, 1983:19). Parents are no longer seen as passive recipients but active participants. 'The greatest resource in a developing country for helping the disabled lead lives which are as fulfilling and productive as possible is a well advised and supported family' (Arnold 1986:115) and according to Collins and Collins (1976) parents are 'twenty four hour professionals'. More recently Mittler (1992) mentions that intervention projects throughout the world which have involved parents and families have consistently achieved better outcomes for children. The participation of parents is so essential that in some countries participation of families in the special education process is no longer just a good educational practice but rather a right that is protected, respected and achieved in accordance with standards established and regulated by litigation and legislation (Turnbull, 1983).

Need for a parent empowerment model

The importance of parents as principal carers has stimulated a shift away from the traditional one-sided relationship between professional and client towards a greater emphasis on participation and partnership. Many professionals now believe that active participation of families in the planning and delivery of services will result in more appropriate services and greater functional achievement by the family member with special needs (Shearer and Shearer, 1977). Although there has been this call for universal commitment to the principles of partnership with parents, in practice this is rarely evident (Mittler, 1992:119). Partnership should be on a basis of equality with each side acknowledging the knowledge and skills of the other (Mittler, 1978:247). In a sense, according to McConachie (1986), professionals tend to miss the point that parents are already teachers. Parents by virtue of their role have a wealth of experience to offer but there are several barriers that impede their involvement and professionals are not always sensitive to these barriers that obstruct family involvement (McCallion & Toseland, 1993). According to Moxley, Raider and Cohen (1989) these barriers are resource barriers such as time and finance, training and skill barriers such as the knowledge and skills needed to participate effectively, and communication barriers such as the failure of families and professionals to understand each other's experience and expectations.

Parents generally tend to speak from experience and experience is important as it serves as the most direct basis for all knowledge or skill (Gass, 1992:7). Dewey argues that 'an ounce of experience is better than a ton of theory simply because it is only in experience that any theory has vital and verifiable significance' (1915:144). It is important therefore that parents are recognised as a source of valuable information. According to Dunst and Paget (1991) the family must be viewed positively with the belief that they can develop and build on strengths and

competencies in order to manage their lives. In the same token the practitioner must work with the family to prioritise needs and promote behaviour that will maximise their competence. Schuftan (1996:261) describes this as capacity building. According to him 'it is the approach to community development that raises people's knowledge, awareness, and skills to use their own capacity and that from available support systems, to resolve the more underlying causes of maldevelopment; it helps them better understand the decision-making process; it helps them to communicate more effectively at different levels; and to make decisions, eventually instilling in them a sense of confidence to manage their own destinies'.

Families with a disabled child are disadvantaged in many ways and encounter a wide range of problems. These problems are further intensified by lack of understanding and cooperation from professionals. Recent studies, however, show of a growing awareness of the need for partnership and participation between parents and professionals (Cheah, 1995) but unfortunately there are several barriers to meaningful participation. The top down approach to development often adopted has denied the participation of the target population. It has to give way to a bottom up strategy involving the target population in all stages of the project cycle. The professional based model has given way to a professional-parent partnership model. However parents who have been sidelined for too long need to be empowered to participate meaningfully. This study looks at a parent empowerment model. It focuses on the participation of parents in developing a curriculum for parent education and the role of the professional as the facilitator to guide and to motivate the target population so as to enhance and instill confidence in them and awaken the spirit of self reliance.

Rationale for the Study

The lack of parent participation in Bethany Home, a rural based programme for persons with special needs in Malaysia prompted the author to undertake this study. Bethany Home is typical of most charities in Malaysia that have for years subscribed to a top-down model of delivery of services to marginalised groups of people. Bethany Home underwent revolutionary changes under the directorship of the author who served as the Home director between 1981 and 1992. During this time the Home went through a transitional change from an institution to a community based programme. In all its endeavours the Home overlooked the participation of parents and as a result the parents remain disempowered and out of the mainstream of development. The previous lack of participation has been due to a number of reasons:

- The traditional approach to development in Malaysia has been from above. Participation of the target population is not encouraged and the paternalistic attitude of charities reinforces the cycle of dependency.
- Parents have little or no knowledge of the scientific approach to teaching and managing behaviour. This has created a widening gap between parents and teachers resulting in a lack of confidence among parents.
- 3. The lack of facilitators with a genuine concern and commitment to the process of empowering parents of children with special needs.

Purpose of the Study

The purpose of this study was to develop a strategy to empower

parents of children with special needs at Bethany Home so that they would meaningfully participate in the activities of the Home.

The study examines three major areas :

- The extent of parents' participation in the development process.
- 2. Parents' acquisition of skills through parent education
- 3. The facilitation process

The objective of the study is to determine if a parent education programme designed and developed through parent participation can empower parents.

Structure of the Study

This study involves the design, development and evaluation of a parent training programme for parents of children with special needs. The study has been prompted by a lack of parental participation in Bethany Home, a rural based charity providing services to an estimated population of 80000 people in Teluk Intan, a rural township of Malaysia.

This study comprises seven chapters and a number of appendices including the course material that was designed and developed specifically for the target group of parents. The appendices appear as follows.

- 1. The Parent Education Course Material
- 2. Family Information Needs Survey
- 3. Parents' Course Evaluation PCE1 and PCE2
- 4. Recording Forms and Test Sheets
- 5. Certificate of Attendance

Chapter Two, the literature review, provides the contextual framework for the study. It briefly examines the social and political context for the study. Malaysia with its booming economy is headed towards its vision 2020' to attain the status of a developed nation. Its 'caring society' concept further relinquishes the responsibility of the state towards welfare of the disadvantaged or marginalised and encourages community care through voluntarism. However the top down approach of the traditional charities is paternalistic and demeaning to the service recipients. It lacks the participation of the target population and tends to reinforce the cycle of dependency. Voluntary agencies have to break this cycle of dependency and help build a partnership with service recipients through participation. The only way to achieve this is for development projects to have people participation in all phases of the project cycle. Voluntary agencies and charities must act as facilitators rather than as 'experts'. Education can be used as a tool to help liberate people to participation. Parent education programmes have been used widely to empower parents of children with special needs.

Chapter Three provides the background information to the field study. It describes Bethany Home and its role in a rural district in Malaysia. Bethany Home is an example of a traditional charity that is breaking away from its original mould to foster community involvement and is keen to empower parents of children with special needs. Chapter Four introduces the methodology used for the study while Chapter Five presents the findings and Chapter Six the discussion. Chapter seven presents the summary and conclusion of the study.

¹ This is the vision of the Prime Minister Dr.Mahatir Mohamad or the nation to be an industrialised nation by the year 2020. It as become a policy statement.

² This concept was launched in October 1990 by Mr. Kandiah of he Ministry of Welfare Services. It includes the following bjectives:

to create self reliance

to equalise opportunities for the less fortunate

to instill 'ikram' or service and respect in all of society

CHAPTER II

LITERATURE REVIEW

Introduction

Before proceeding it is necessary to set the context for the study. Here the literature on three important aspects will be examined. They are the welfare services in Malaysia, the general ideas of participation and empowerment, and parent education. Section one of this chapter briefly examines Malaysia's concept of a 'caring society' in a free market This concept places the responsibility of welfare of the disadvantaged and the marginalised into the hands of voluntary agencies. The paternalistic attitude of the charities has in the past reinforced the cycle of dependency and devalued the individual. In a market oriented economy it is imperative for the charitable organisations to relinquish this top down attitude and adopt a 'bottom up approach' to encourage meaningful participation. Participation is a fairly new concept for traditional charities and there is a need for professionals in this sector to understand the principles of empowerment and participation in development. Section two focuses on the concept of another model of development - 'development from below' - and what participation entails. Development must inform and involve people. Section Three looks at parent education which has been used widely and successfully as a means to empower parents of children with special needs in Europe and the West. This section examines the background of parental involvement and parent education as a tool for empowerment.

Malaysia and the Caring Society

The role of charity

Before World War Two, families took the primary responsibility for providing care for those in need in Malaysia. There were no community expectations about government-provided welfare services. Indeed, there was no involvement outside the immediate family in times of difficulties (Sushama, 1985:214). The dominant economic system for many years was based on colonial capitalism and the very notion of welfare was seen as unproductive capital involvement. It was only after the Japanese Occupation at the end of the Second World War that the British changed their attitude. The Department of Social Welfare was set up in 1946 and its principal duty was 'the care of the crippled, blind and feeble minded' (Annual Report Dept of Social Welfare, 1946:11). One of its earliest projects was the establishment of the Jubilee Home in 1953. This was an institution catering for mentally, physically and multiple handicapped children. In the same year the Central Welfare Council was established 'to foster voluntary effort on the part of local welfare and charitable organisations and to achieve some coordination of effort' (ibid:7). Voluntary involvement in social welfare however began very early in 1911 with the setting up of the Home for Handicapped by the Sisters of the Infant Jesus Order. This was followed by the establishment of the St. Nicholas Home for the Blind in 1926 by the Anglican Medical missionaries. The government soon recognised that all needs could not be met solely through statutory involvement and therefore continued to encourage voluntary effort. In response more voluntary organisations such as the Malaysian Association for the Blind (in 1951), Spastic Centre (in 1960), Cheshire Home (in 1964), and Bethany Home for Epileptic Children (in 1966) were established. As a result there was wider community involvement in the lives of the disabled and their families. There was also an increase in charity and goodwill among the public and this led to further provision of institutional or custodial care for individuals or groups of disabled people.

Since independence in 1957, state responsibility for social welfare has increased. However although the total budget allocation for welfare has increased more than three fold between 1974-1984, this was still only 0.23 per cent of the total federal budget (Jacob, 1989:51). Currently the family, the state and the voluntary sector continue to share responsibility for social welfare needs in Malaysia. With the state playing a relatively residual role, charity continues to be the popular approach to meeting the needs of the marginalised. Charity however has created a state of dependency for the disadvantaged. It tends to respond to crisis and is temporary. Charity does not tackle the root problem but stands in the way of self help and self reliance. It has a paternalistic orientation and creates a subsidy and dependency mentality (Jayasooria, 1992).

Pitfalls of a Caring Society concept

Today Malaysia is headed down the path of intensive industrialisation and free market policies. The Malaysian economy is now much more subjected to the discipline and rigour of market forces with the aim of widely dispersed ownership of property and capital. This strategy is pursued by the Malaysian government as a more effective way of creating wealth than state ownership or state control. It is argued that the industrialisation process will have profound consequences on social welfare (Wilensky and Lebeaux, 1958). Jayasooria (1992) also cautions that the rapid economic growth and generation of wealth in Malaysia will create undesirable outcomes affecting the poor, disadvantaged and the marginalised. The Prime Minister's vision for a fully developed society also calls for a 'fully caring society' (K.S.Cho, M.S. Ismail, 1990).

This however does not imply heavy state expenditure on social welfare but on the contrary the call is directed towards voluntary agencies to assume greater responsibility for the welfare of the poor, disadvantaged and marginalised.

Unfortunately one undesirable outcome of market system is economic self interest. There is growing tension between self interest and common good. Muzaffar cautions us saying 'given the experience of other Newly Industrialising Economies (NIEs), it is possible that economic and social disparities will become more pronounced. What this means is that while the poorer strata of society will certainly benefit to some extent from economic development, it is the richer segment of society which will gain most from rapid economic expansion' (1991:1). In the open market system minority communities can be neglected and marginalised because of unequal conditions and opportunities. The fruits of production cannot bring about welfare of all unless there is an effective institutional mechanism for distributive justice (Nagamine, 1981).

The need for participation

The Ministry of Welfare Services has adopted a three-fold means to promote safety and security in society. The new National Welfare Policy advocates a strategy of developing a spirit of self determination and self reliance in individuals and communities (Kandiah, 1990). However with the absence of an institutional mechanism for just distribution of economic wealth and legal safeguards to guard the interests of minority groups, charities will continue to assume responsibility for the poor and marginalised in society. The caring society concept has further enhanced the role of voluntary agencies. The paternalistic attitude of these agencies instead of inculcating the spirit of self reliance in the target population has increased their dependency syndrome (Yap, 1994). In recent times a new, human centred approach is gathering momentum where the target

population is called to participate fully in the project. The challenge is for voluntary organisations to make it their 'primary goal and focus to equip and strengthen the family so as to provide a conducive environment for development' (Jayasooria, 1993:10).

Conclusion

In summary it can be seen that Malaysia's path of intensive industrialisation and free market policies will have profound consequences on social welfare. While there is a call for community care, this model has a paternalistic orientation and creates dependence and inhibits self reliance. The challenge is for voluntary agencies to help break this cycle of dependency by relinquishing their top-down approach and adopting a participatory approach to empower the target population. The challenge is for an alternative vision of development from below - development which is people centred. Giving of services to those in need can become a prestigious preoccupation for voluntary agencies. The call is to give up this attitude and foster participation in development.

Development from Below

Introduction

Conventional development practices have often failed to achieve desired goals and have sometimes created problems instead of finding solutions. However projects continue to be the cutting edge of development. In fact 'projects are the visible fingers and palms that get to people and real situations' (Amersinghe, 1988). Development from below is development determined from within by the people of a society based on their own resources - human, physical and institutional. According to Hettne (1990:153) development from below focuses on the content of development rather than the form. In this approach there is no universal

path to development and every society must find its own strategy in accordance with its own needs. Each strategy is therefore unique to that particular society. However, development must not be confined to economic growth alone. It should also benefit the environment, strengthen or consolidate the role of women and other disadvantaged groups in society, emphasise and encourage community involvement and public participation.

Development is Participation

Development from below is the development 'of people', 'by people', and as such the participation of the target population in all aspects of the project cycle is a key prerequisite for a successful project. According to Drake (1992:271) the three preconditions for effective participation are 'the capacity to exercise power, being in roles in which power can be exercised and for those roles to be in networks such that the exercise of power is effective'. However we must be aware that participation can be manipulated as well as spontaneous (Rahnema, 1992; Pretty, 1995) and activists who strongly favour participatory development have proposed the term 'popular participation' to distinguish spontaneous from manipulated participation. Popular participation gives power in the hands of people. Empowerment on the other hand is not the giving of power to a powerless group of people, but rather, through motivation, to liberate the intrinsic energy and dynamics of a society or community and particularly to liberate people from conditions of distress and powerlessness (Rahnema, 1992). Empowerment is defined as a process aimed reducing the powerlessness stemming from discrimination or stigmatisation (Kam, 1996). Empowerment activities are specifically aimed at counteracting negative valuations (Solomon, 1976). People can be empowered through a process of self help, and 'support from professionals does make a positive difference to self help groups' (Unell, 1987:57). However according to Adams (1990:33) empowerment through self help is underdeveloped and the term is often used loosely to mean enablement. The balance of power between helpers and helped, professionals and self helpers needs to be shifted in favour of the helped and the self helpers (Ungerson, 1987). Adams (1990) uses the analogy of driving to distinguish between integral self help, facilitated self help and autonomous self help. In the case of integral self help, the professional is in the driving seat while in the facilitated situation the professional accompanies the self helper who takes the wheel. In the autonomous situation the self helper owns the car and drives it independently of professional help.

Development is Endogenous

Participation enhances human dignity through equal rights and self reliance. For people to be self reliant and to have self esteem we need to recognise the diversity of starting points. According to Cardoso (1977:35) the roads to equality, to participatory democracy and to self reliance follow completely different routes for each country.

The concept of indigenisation is popular because it recognises the uniqueness of culture and the right to self-determination. Development that is indigenous is attainable and offers practical solutions. There are however, problems associated with our definition of the term indigenous. Our knowledge systems carry values and biases that have been born during particular economic or developmental periods and can be prejudiced. As Agrawal (1995:433) argues, there is no distinction between indigenous and western knowledge - 'the same knowledge can be classified one way or the other depending on the interests it serves, the purpose for which it is harnessed or the manner in which it is generated.' Indigenous in the context of development means appropriate. Community development was based on the principle that local people should participate actively in projects which were designed to promote their welfare (Pitt, 1976). Although there is a strong belief that community development should be carried through on the initiative and hard work of the community itself

and should not be organised from outside it is not workable. As Midgley (1981) argues rural people don't always know what their 'felt needs' are and community development workers instructed in the techniques of persuasion attempt to motivate supposedly reluctant villagers to participate in development. People must be informed and made aware of what is available. An educational approach leads to awareness of the social realities and the needs to change and transform it. Education and training are essential if the community is to develop (Dunn, 1979). In fact according to Ghai (1977:42) education provides the tools for participation and is a basic need per se. Through education you can strengthen the positive values inherent in that society. Freire's (1972) concept of conscientisation revolutionised conventional methods of adult education and attempted to stimulate an awareness of broader political and social issues. It gave insights so that people could change their circumstances.

Development is facilitation

The development practitioner's role becomes one of either facilitating group action or being involved in encouraging the development of individuals, helping them to become more skilled, challenging their assumptions and widening their horizons. Community development workers were seen as change agents to 'awaken rural communities from their traditional slumbers and help them to become dynamic, independent and alive to their own potential' (Midgley,1981:140). Cardoso (1977:33) emphasises the need 'to struggle shoulder to shoulder with the people and not to act as an agency defending models to be imposed culturally on the people'. Development from below also requires certain external inputs and some assistance from central decision making units (Stohr and Taylor, 1981). According to Justad (1990), the important role for the community worker is in providing a link between the community and the powers that be. While there are different models of rural community work, direct

community work according to Henderson and Thomas (1987) involves a close and protracted working relationship between the worker and the community. This approach seeks to empower people who otherwise are excluded from participating in the decision making process.

The opportunities for the worker or development practitioner through direct community work (is enormous provided he or she is empathetic to the values and culture of the community. He or she does not provide answers, but has questions which stimulate insight. She or he does not carry the burden of responsibility for organising and action in the community, but provides encouragement and support for those who do (Ross and Lappin, 1967). Pitt (1976) argues that one of the consequences of a fragmented and divided approach to development is experts who are remote from the object of their studies. According to Haswell (1975:213), it is the fear of involvement that keeps some away from what might be unpleasant and personally demanding. Chambers (1983) also raises some very pertinent issues confronting the development practitioner. According to Chambers (1983:1), the rural poor suffer because of the attitude 'what the eye does not see, the heart does not grieve about' among development practitioners. However Chambers (1983:3) is quick to point out that 'there are some exceptions: they include those who live with, work with and learn with the poorer rural people'. It is a choice most of us manage to evade.

Development is flexibility

Development from below argues for flexibility and is as much an ideology as a strategy. As Stohr and Taylor (1981:458) add, 'it is a way of looking at development rather than a rigid set of policies and ideas.' In practice there will be many responses to it over both time and space. A realistic project plan provides flexibility within changing circumstances and is continuously monitored and evaluated (Rondinelli 1983). Development from below proponents must not fall into the trap of

defending the purity of their ideas despite the realities of the situation. This is one of the reasons why Boisier says that 'the creation of new institutions will require new technicians who are uninfluenced by centre down strategies' (Boisier, 1981). Project design should therefore incorporate sufficient flexibility to enable changes during implementation.

Development is 'awakening to new truth'

There are different interpretations of basic human needs. Some of these needs are quantifiable while others are qualitative and partly fall in the realm of philosophy and religion (Hettne, 1990:169). As Rist points out 'It is not enough to answer that one must eat, it is also necessary to take into account what this person will eat, how he will eat and with whom he will eat.'

According to Rahnema (1992) the discovery of a spiritual awakening in people has helped mobilise their creative energy more efficiently than any other conventional form of mass mobilisation. She argues that this dimension has served 'as a most powerful instrument in reviving the old ideals of a livelihood based on love, conviviality and simplicity and also in helping people to resist the disruptive effects of economisation. We may call it spirituality, commitment, dedication, social will, love or whatever. It is this unseen and often unaccounted for force in people that motivates some, as Chambers (1983) says, to make the choice to live with, work with, learn with and participate with the core of society to help change circumstances for the better.

Conclusion

Development in the final analysis is about people, not places. The ultimate of a development from below strategy is an improvement in both a quantitative and qualitative lifestyles of all members of society (Goulet 1978a). Development must start where people are in terms of their

perception of the situation and needs. 'In the ultimate sense development is a reflection of personal values conditioned by the societal framework in which one lives. An outside view of a society's development may be very different from an assessment made by that society itself' (Stohr and Taylor, 1981). A development project has to respond to the heart beat of the community or society - it involves them, it informs them, it guides them, it identifies with them, it is not afraid to change and it perpetuates the seed of common good in people rather than selfishness. In short it becomes humanised, it becomes a friend to those in need - a practical, down to earth, grassroots friend in deed!

Parent Empowerment Through Education

Introduction

Parents of children with special needs have for years been alienated from the process of development. They have always been passive recipients of services that have been delivered from top down. Parents can feel confused and hopeless without information (Wolfensberger,1967; Cunnigham, 1979; Long and Moore,1979). Parents need to derive confidence and self esteem from what they know. One way of achieving this is through education or information sharing. According to Freire (1972) education can be either liberating or domesticating and it is the process by which we educate that shapes whether the experience will be empowering for the parents.

Historical overview of parent participation

Institutional care for intellectually handicapped people has been seen by many as the best treatment under the professional based model. It was seen as offering specialist training, care and employment for intellectually handicapped people (McConachie, 1986). In the 1960s however, these policy ideas were challenged partly in response to

increased awareness of the true nature of institutional care and increased knowledge of the real needs of families (Tizard and Grad, 1961; Carnegie UK Trust, 1964). In England several events such as the White paper ' Better Services for the Mentally Handicapped ' in 1971, the Education Act of 1970 and the Plowden Report (1966) brought changes to the education Parents soon became aware of their rights and became more actively involved in schools. In the United States of America between the 1930s and the 1950s, parents began to organise themselves as pressure groups because of the inadequate public and professional responses to their children's educational needs and their own needs for emotional support. Then from the 1950s to the 1960s these parent organisations began to help develop services for their children. They helped organise classes in community buildings and church basements. The Headstart programme which was federally funded, involved parents to address the needs of the educationally disadvantaged (Consortium on Developmental Continuity, 1977; Lazar and Darlington, 1979). It was the beginning of many other home based programmes.

Major advances in the education and training of intellectually handicapped people came with early intervention (Bowlby, 1952) and the development of behaviour modification programmes. These led to a successful approach to teaching intellectually handicapped people. Parental involvement became necessary and soon parents were acknowledged as trainers

Behaviour Management

Behaviour management techniques have become very popular in clinical and educational settings in the last 25-30 years. A survey conducted by Bernel and North (1978) even then shows that there were 26 commercially available information manuals on behaviour management making it a popular training topic. The basic principle involves defining a behaviour, observing its occurrence then modifying or introducing

reinforcement procedures. What all behavioural programmes have in common is the belief in positive reinforcement as the answer to behaviour management. However, in order to modify the child's behaviour, the parents have to change their behaviour. Therefore behaviour management programmes are used to change parent-child relationships by modifying parent and child behaviours alike. Parents are shown the principles that help increase positive behaviour and decrease negative behaviour. According to 0'Dell (1974), the advantages of using behaviour modification approaches are that -

- they are easy to learn
- 2. the majority of children's behaviours can be changed by the systematic application of behavioural principles.
- 3. it can be applied in the natural environment

A behaviour management programme also helps decrease parent-child conflict, increase positive communication, increase children's progress in social and self help skills and increase parent competence as a disciplinarian. Studies show that parents are able to learn and apply the principles of behaviour modification to change their children's behaviour and teach them new skills (Berkowitz and Graziano, 1972; Johnson and Katz, 1973; O'Dell, 1974).

The Rationale for Parent Education

The rationale for 'parent training' came from the professionals rather than from the parents (Shearer and Shearer, 1972). Parent education was based on the premise that parents can be effective in changing their children's behaviour and increasing their skills (Johnson & Katz, 1973). Studies and intervention programmes show that parents when properly trained are extremely effective teachers (Berkowit & Graziano, 1972; O'Dell, 1974). Using a behavioural approach parents of the handicapped have been trained to successfully modify a wide range of behaviours (Wahler, 1968; Graziano, 1971). Studies have also shown that

knowledgeable parents can be the strongest advocates for programme continuation and extension (Karnes, Zehrbach, & Teska,1972). Parents of a handicapped child need parenting and teaching skills above and beyond those needed by parents of a normal child as they will have to be responsible for their child longer than parents of a normal child (Shearer & Shearer 1972). Parents who have the skills are also able to provide some form of continuity in their children's lives and handle future problems more successfully (Altman & Mira,1983). Involvement of parents in the education process can have a positive effect on other siblings in the family. They are able to generalise the skills they learn and use them with the other siblings as well as help their disabled child to generalise the skills into different settings (Marholin, Siegal, & Phillips, 1975; Stokes and Baer, 1978).

Short term studies which have measured parents' teaching skills following short courses tend to show that parents can successfully acquire skills (Mash and Terdal, 1973; Tavormina, 1975; Sandler, Goren and Thurman, 1983). Parent education has long been accepted as a legitimate form of support for families (Tavormina, 1974). However the term 'parent education' is a misnomer. Parents do not need to be 'educated' on how to parent their child but rather what parent education here really means is to empower parents through participatory learning. Through this process of learning the positive experiences and attempts of parents can be validated as legitimate processes, hence giving parents the confidence to openly discuss with professionals. Again, through the very same process of learning, they can have the opportunity to refine their skills and techniques and acquire new ones. By creating a supportive atmosphere we can enable parents to learn new skills and gain confidence through talking

³ The terms parent education, parent training and information aring are used interchangeably in this context to mean active ansmission of knowledge and skills between professionals and rents and between parents and other parents.

with professionals and other parents (Hornby & Murray, 1983).

An ultimate aim of parent education programmes is to develop parents' confidence in dealing with other professionals on their own (Bromwich 1981). In recent times several efforts have emerged that focus on teacher participation in the development of curricular and teaching improvement. However, parent empowerment has focused on ways of forcing educators to be directly accountable to the desires of parents (Hess, Parental involvement in teaching has apparently become a successful and widely supported intervention strategy in helping parents (McConachie, 1986). Studies show that education provides the tools for participation (Ghai, 1977:42) and parent education has been effectively used as a tool to empower parents of children with special needs to participate in the decision making process. However, the highly structured formats of workshops and the top down style of delivery of parent education programmes have been a drawback to effective parent participation (Turnbull and Turnbull, 1982).

Parent Education Format

According to Fine (1980:5-6) parent education refers to a systematic and conceptually based programme intended to impart information and awareness or skills to the participants on aspects of parenting. It applies to organised programmes rather than to informal get togethers. It allows for mutual support between parents, opportunities to discuss with the professionals and to receive help to carry out teaching programmes at home (Mash and Terdal, 1973; Attwood, 1978; Firth, 1982). The format usually includes the presentation of specific ideas, some group discussion, sharing or processing of ideas and experiences and some skill building activities. Some programmes may use many audio visual activities (for example films, slides, videos, audiotapes etc) whereas others may have lectures, discussion and sharing of personal experience. Homework or

home task is an important aspect of most programmes. Some parent training workshops are accompanied by occasional home visits to help parents apply their learning and also to find out the practical problems that may pose as barriers (Gardner, 1983). Some workshops have manuals of instructions to accompany (Perkins, Taylor and Capie, 1980) while others invite parents to a intensive workshop where parents progress from one set of skills to another at their own pace (O'Dell, Blackwell, Larsen and Hogan, 1977). Some have used video taped instructional units (e.g.Coleman, Ganong and Brown, 1981; McConkey et al., 1982; McConkey and O'Connor, 1982).

Boucher (1981) and Gardner (1983) discovered that a workshop based at the child's school helped parents and teachers to work on the school curriculum together. Some programmes are offered without charge while payment is required in others. In some cases as a moral incentive child care was provided, transport was provided or cost reimbursed, lottery tickets were given for attendance and completion of homework or diplomas were given for the completion of programme (Baker, 1983). Turnbull and Turnbull (1982) argue that programmes and services are often based more on what some advocates and policy makers think parents ought to be and do than on parental preferences for participation. According to McConachie (1986:9), 'packaged' approaches may not be relevant to working with parents.

However, models for parental involvement have widened from a very clinical and formally structured approach to that involving more diverse options. These options are consistent with parents' preferences on ways they want them delivered, taking into consideration their schedules, time availability and responsibilities. The family systems perspective has influenced a philosophical shift from viewing parents as students of professionals to one of partners and along with this change has come a shift in terminology from 'parent training' to parent support, family

support or providing information to families. The family systems approach involves sharing information not only with the parents but with the broader family as well. This approach also enables the members of the family to voice their own priorities not just the disabled child's alone. The professionals in this context function as facilitators.

Conclusion

Although parent education programmes have been successful they are time limited and the time structure limits the support the parent educator can offer parents. In a workshop situation the parent educator will have an agenda to pursue and will not dwell extensively on any one person's situation. There is a need for flexibility and facilitation and meaningful participation of the parents in the design and development of the parent education programme.

Summary of chapter

Malaysia's concept of a 'caring society' can have profound consequences on social welfare in a free market economy. In the absence of an effective institutional mechanism for distributive justice, the traditional model of charity continues to be the popular approach. It is imperative for the charitable organisations, which in the past have adopted a 'top down approach' in their mode of service delivery, to adopt a 'bottom up approach' to encourage meaningful partnership through participation. The aim should be to enable and enhance the potential within people and to help them determine their own future (Croft and Beresford, 1992). Voluntary organisations must set as their primary goal the empowerment of people or service users. They must offer opportunities and provide the structure and mechanism for the involvement of service

users in assessment, planning, recording, action and review. The service provider becomes the reflective worker, resource worker, mobiliser, organiser and facilitator. This is the key to empowerment - to help the vulnerable break the cycle of dependency. Parents of children with disabilities need to derive confidence and self esteem from what they know. One way of achieving this is through education or information sharing. Parent education has been used as a tool for empowering parents of children with special needs. It is the process by which we educate that shapes whether the experience will be empowering for the parents. Through a process of participatory learning the positive experiences and attempts of parents can be validated as legitimate processes, hence giving parents the confidence to openly discuss matters with professionals. A supportive atmosphere enables parents to learn new skills and gain confidence through talking with professionals and other parents.

This study has been prompted by a lack of parental participation in Bethany Home, a rural based voluntary centre. The study involves the design, development and evaluation of a parent training programme for parents of children with special needs. Its objective is to empower parents through meaningful participation in the process of content identification, implementation and evaluation of the entire training programme.

Some key concepts that appear in the study need to be defined and these can now be addressed following the discussion in the above chapter. Development as it appears in the study refers to community development, more particularly the development of the parents of children with special needs. The community development approach adopted here looks at capacity building which is characterised as 'raising people's knowledge, awareness and skills to use their own capacity and that from available support systems (Schuftan, 1996). It will help them to communicate more

effectively and eventually instill in them a sense of confidence to manage their own destinies. Participation here means being in the capacity to exercise power, being in roles in which power can be exercised and for those roles to be in networks such that the exercise of power is effective (Drake,1992). Empowerment here is seen as a process that enables people to understand and use their capacity to gain power over their own lives (Schuftan, 1996).

CHAPTER III

BETHANY HOME

Introduction

Bethany Home is a non government institution for children with epilepsy. It underwent a voluntary transformation from a institutionally based system to a community based system. Bethany Home's approach was unusual in that it was not a planned and coordinated move to deinstitutionalise. Instead, evaluation of Bethany's services conducted by the direct care staff and the director resulted in a change in attitude and a shift in focus. As a result of a participatory approach being adopted, new services offered by the Home reflected the needs of the local community and began to draw much support. However the single most important drawback was the lack of participation of parents of children with special needs.

Location

Bethany Home is located in Simpang Empat which is a fast-growing village approximately 130 kilometres north-west of Kuala Lumpur and 17 kilometres south of Teluk Intan. The district of Hilir Perak is one of nine districts in the State of Perak. It consists of nine mukims (sub-districts) with an area of 659.75 square miles and a population of approximately 260,000. Bethany Home currently serves three sub districts with a total population of approximately 80,000 people. The population comprises of Malays, Chinese and Indians. About 75% of the population live in the rural areas and mostly represent the lower socio- economic segment of the population. The district of Hilir Perak is low-lying and riverine with the population mainly involved in agriculture and fishing. The crops cultivated include padi, oil palm, coconuts and cocoa.

Origins

In 1965, the Evangelical Lutheran Church of Malaysia purchased a piece of land in Simpang Empat, Teluk Intan, to set up a building for the They acquired 1.3 hectares of land at a low cost of local church. MS7,000. The Church had plans to utilise the area for a social ministry as well as for a church. At that period in time, Dr. Asirdas, a medical doctor, who was closely associated with the church, suggested that there was a need for a residential centre for children with epilepsy. limited range of drugs available for the control of epilepsy meant that many children with epilepsy were referred to psychiatric hospitals where children were treated with adult psychiatric patients. Bishop Bertil Envall of the Evangelical Lutheran Church acted upon this suggestion and in 1966 Bethany Home was established as the first centre for children with epilepsy in South East Asia. Mr. and Mrs. Sorberg, a missionary couple from Sweden came to pioneer the work. The Home operated along the lines of a hospital with a registered nurse, a voluntary doctor and six ward assistants. The children were on a strict routine with regular medication and monitoring of epileptic seizures.

The Home provided residential care for twenty five children with epilepsy and other associated disabilities. Most often the parents abandoned their children and as a result many of these children became permanent 'wards' or 'inmates' of the Home. Bethany Home remained isolated from the local community because of its fully residential status.

New Beginnings

The year 1981, being declared the 'Year of the Disabled', saw a tremendous change in the rehabilitation scene with greater public awareness. Europe and the West began to move away from institutional care towards community-based care. Many parents of children with special needs in Malaysia became aware of the need for education and training for their

disabled children. At this point in time the Sorbergs transferred over the directorship of Bethany Home to the author. The author had little knowledge of disability and came from a background in telecommunications. In 1982, the director and the staff of Bethany Home on their own accord. carried out an evaluation to assess the effectiveness of the Home's service and programmes as a residential centre. Results of the evaluation showed that the service was not meeting the needs of the target population, the local community. Therefore it was unanimously agreed that a concerted effort was needed for changes to take place. participation at this stage was minimal and confined to direct care of residents. Like all charities Bethany operated on a stringent budget and had no regular source of income apart from an annual grant of M\$ 8400 from the State Social Welfare Services which was equivalent to fifteen percent of the annual budget. The low salaries offered by the Home attracted very few workers with good academic background. However the Home had a core group of workers who, due to their Christian commitment, were dedicated to the cause of helping the disabled. This group of staff were highly motivated and wanted to be involved in all the planning and decision making processes of the Home. The Management Committee comprised several influential people who were based in the city and met once a month alternatively in Kuala Lumpur and Bethany Home. The distance made it impractical for most of them to be actively involved in the day to day affairs of the Home. The staff and director were based in the centre and were living there on a 24 hour basis.

The stigma of disability, the low wages, the lack of specialised care and the isolation of the institution from the community gave the staff the impetus to do something to break away from this vicious cycle of dependency. A proposal was made to the management committee of the Home for increased staff participation in all matters pertaining to the running of the Home. This included programme planning, fund raising and even a

staff salary review. The management committee, after much persuasion, allowed the Home to operate on a participatory basis for a trial period. As a result many changes were introduced with immediate effect. All employees of the Home assumed roles as 'teachers' in line with the shift in focus on education. Every disabled child in the centre was expected to learn some skills from every able-bodied person in the centre and teaching was not be confined to the classroom. The children were called residents or students.

It was decided that parental involvement was vital to meet the emotional needs of the children. Visits were organised to the home of every child and ties were reestablished with the families where possible. As a start to a holistic approach in rehabilitation, the Home began to operate as any normal boarding school where the children returned to their homes during term holidays and for long weekends where possible. Parents were encouraged to visit their children as often as possible (at least once in two months). A salary review was conducted by the director and staff of the home.

Various salary scales adopted by major companies and the plantation sector in the district were used as a basis for comparison and a proposal was made to the management committee to revise the existing salaries and make them comparable to wages paid elsewhere. This was conditionally accepted by the management committee provided the 'income' of the Home was sufficient to meet the increased expenditure as a result.

New Programmes

A building extension planned in 1980 to increase hostel facilities to accommodate 50 residents was finally completed in early 1986. Although the building was designed and built according to the original plans ie. to function as a residential institution for 50 'inmates', it was decided to abandon the original ideas and utilise the building as classrooms for day training purposes for children and adults with special needs in the vicinity. All the residential children who came from within the Teluk Intan and Bagon Datoh areas (ie. within a radius of twenty kilometres) became day students with the exception of some were severely disabled and needed some nursing care. This arrangement made available respite care places for others in need.

Bethany Home provided transport for day students to be brought to the centre at nine a.m. and sent back at three p.m. This was deliberately planned to suit the needs of most parents who were employed in the plantations and worked between those hours. With the introduction of a mini bus, received as a donation towards the end of 1987, the number of children and adults attending the day programmes increased to forty five. In 1989 the centre engaged the services of a local school bus so that as of August 1990 over 80 children and adults were attending the day programmes. The school bus further enhanced the role of Bethany Home as a educational centre and travelling in a regular school bus made social integration easier.

Children under five years of age were not receiving any help at this stage and so the Home began an Early Intervention Programme to meet this need. This was followed by the setting up of a Toy Library to enable parents to borrow appropriate toys and educational equipment for their children. To best meet the needs of students with disabilities it was important to prepare them for gainful employment. Bethany Home initiated programmes to develop the work and behavioural skills necessary for success in a working environment. Emphasis was placed on workshop practice and pre-employment skills for young adults. The workskills programme provides the bridge for young adults in transition from class

room to sheltered or open employment.

When Bethany Home began its day school programme, student numbers soared and there was a need for classroom space. The residential students were at this stage housed in the centre's new building. It was decided that the residents be moved out into the community so that they could experience a 'normal life' like their peers in school. There was a need for these young people to live in the community and feel the difference between home and school. In February 1987, a double-storey terraced house was rented in a middle-class housing estate situated about half a kilometre from Bethany Home. It was decided that the number of residents in this group home should be consistent with the number of members in an average family.

A group of six male and female mildly intellectually disabled young adults were selected for the programme. Their ages ranged from seventeen to twenty eight years. To provide an experience of a working life for the residents, who were adults, the Home initiated an employment programme in the form of a second-hand goods shop. The first 'Kedai Bethany' (or Bethany Shop) is one of four shops in a block situated 500 metres from the Home along the main road to Teluk Intan. It sells used clothes and goods received through public donations. Some of the older students manage the shop and help to sort, iron and display the clothes and articles. They are paid weekly wages. In February 1989, a second shop was established in the town of Teluk Intan to accommodate the increasing number of adults in the programme.

Income generated from both shops help to meet the cost of maintaining the shops and group homes, and paying the wages for staff and students employed at the shops. In 1992 through a capital grant received from the Swedish International Development Agency, Bethany Home constructed five modern shops along the main road to Teluk Intan. They

comprise of a bakery outlet selling cakes and bread supplied by a local bakery, a fast food outlet, a curry and rice shop, a drinks outlet and a mini market selling sundry products and Bethany Home's products. The shops employ both able bodied and disabled people. The Home's next venture was the construction of a community playground. Since there were no safe childrens' playgrounds for use by the community, it was decided that a community playground in Bethany Home's ground adjacent to Bethany's food outlets would enhance the position of the shops and promote integration between able bodied and disabled. The playground was the donation of the Australian High Commission and its construction was completed in December 1992. With the completion of the playground Bethany Home became a landmark in the district.

Conclusion

Bethany Home was transformed from being a residential institution with 24 inmates to a comprehensive pioneering programme providing a wide range of services from early intervention to open employment and group homes in the community for more than 185 children and young adults with special needs. The rapid changes brought positive outcomes. The stigma of disability generally associated with poverty, uncleanliness and hopelessness was replaced with pride as the Home became well known for its innovative changes and contribution to society. Bethany Home has pioneered several programmes in the country and is recognised by the state as a fore runner in the field of special education. In 1995 it was recognised by the Matsushita Corporation of Japan as the best voluntary organisation in terms of its contributions to society. Bethany Home's fast food shops were also judged the cleanest by the district council in 1994. Bethany Home is presently the centre for staff training for teachers from special schools from all over the country. The course is conducted by the Christchurch College of Education.

Yet in spite of its successful record Bethany Home lacks meaningful parent participation. In a sense many of Bethany Homes new programmes, though sensitive to the needs of the population, were delivered in a top down manner. In the enthusiasm to see changes the importance of parental participation in planning and development of services was sadly overlooked. The paternalistic approach adopted to help the families resulted in the families surrendering control and autonomy to the 'experts'. It undermined their self confidence. The existing focus of power needs to change from a controlling to a supportive role. This study has been initiated to redress this imbalance of power and empower parents to meaningful participation.

CHAPTER IV

RESEARCH METHODOLOGY

Introduction

The aim of this study is to determine if a parent training programme designed and developed through parent participation will empower parents. This forms the basic hypothesis for the study. My own interest in this area and my long standing association with the Home and parents prompted me to carry out this research. Currently there are no parent training programmes for parents of children with special needs in Malaysia.

The methodology used in this study has combined elements of action research methodologies as well as qualitative and quantitative methods of data collection. This chapter is divided into seven sections:

- 1. Methodological rationale
- 2. Research methods
- 3. Population and Sampling
- 4. Instruments
- 5. Pilot Study
- 6. Data Collection
- 7. Limitation of the study

Methodological Rationale

This piece of research was initiated because of the lack of parental participation in Bethany Home. I was part of the social system that needed change. Since I was engaging in applied social research and as a researcher in a development framework I was expected to develop the project on the basis of my professional expertise as a trainer. Being aware of strategies that might be applicable to influence a positive change in the parents and also being personally committed to the empowerment of parents of children with special needs, I had to be both originator and evaluator of the programme.

Research Methods

While action research forms the major part of this study, both qualitative and quantitative methods have been employed to support the findings.

Action Research

The two central concerns of action research are the improvement in practice and increase in knowledge and understanding (Kemmis et al, 1986). According to Lewin (1946) these two concerns can be linked into an integrated cycle of activities in which each phase learns from the previous one and shapes the next. 'In action research "theories" are not validated independently and then applied to practice. They are validated through practice' (Elliott, 1991:1). Action research is systematic (Stenhouse, 1980). The method of action research involves a self-reflective spiral of planning, acting, observing, reflecting and replanning. People in this field of action research are typically busy not only theorizing and describing problems but contributing to finding solutions. One is not only a researcher and responsible for the research

process but is at the same time a participant and jointly responsible for the change process. The social basis of action research is involvement and the educational basis is improvement (McNiff, 1988). Action research calls for a collaborative change of the system and the people who are involved in the system. According to McNiff (1988:3) ' the action of action research, whether on a small or large scale, implies change in people's lives, and therefore in the system in which they live'.

A participatory procedure can be much more effective in solving human interrelationships than an imposed structured process as we had practiced in Bethany Home in the past. Action research highlights the need for democratic participation. 'The best or most rational solution will probably be achieved in open discussions in which all participants are viewed as having equal rights' (Karlsen, 1991:147). However this does not imply that the participants and researcher should have the same type of expertise or take part in every stage of the research. All who participate in an action process have the need to reflect on and understand the process in which they have participated but the researcher is responsible for collating of data and making it available to the research community. The researcher is not a permanent part of the field and as soon as the research is completed he or she may leave. Therefore there is a distinction both in proximity and in responsibility.

Action research is becoming increasingly popular in the field of education. A recent survey of the field (Saeterdal & Asmerik, 1986) concluded that action research represents a fruitful form of applied social science relevant to a broad area of reform but the double challenge of action and research creates difficulty in meeting scientific standards. The use of multiple methods has been argued to have definite advantages for the validity of the data (Denzin, 1978). Traditionally the participant observer role has called for the researcher to exercise a nonobtrusive

research style but I had to conduct my study by actively participating in the system I was studying for several reasons. The use of an ecological framework requires me as the observer or intervener to make my role explicit. Although the ecological approach does call into question the tenets of value free, objective and scientific method, according to Lewin (1948) it is not possible to understand a social system without changing it. The passive observer cannot learn much about the inner dynamics and conditions of the system without becoming a member of the system and making observations over a long period of time.

Participant Observation

This particular method of research tries to depict the social world as it exists for those being researched (Hughes, 1976). As an active participant observer I was able to collect data of all sorts. Perhaps the major disadvantage of being in such a data-rich situation was to be overwhelmed by too much data. It is hard to imagine that the richness of this methodology could have been duplicated by traditional methods. Any researcher conducting some form of participant observation research faces the question of how to present himself or herself to the research subjects. Whyte (1984:30) suggests three approaches: overt, semiovert and covert. I chose a semiovert approach so as to avoid influencing the social situation and access to data. I explained initially my role as researcher to the subjects but did not dwell extensively on the issue. Because I behaved in most ways as a friend it was difficult for the parents to think of me as a researcher. Moreover most parents were quite alienated from the field of academia and were more interested in how the project would benefit them as individuals and as a group. In many ways my participant observation approach allowed me to use some of the traditional research methods too, such as interviews and surveys.

Population

The population for this study was the 145 families of children with special needs who attend the programmes at Bethany Home and are resident in the district. Two samples of the same population were taken for this study.

Study Sample One

The sample population for the Family Information Needs Survey was taken from the 145 families of the children and young adults who attend Bethany Home. A stratified random sample of 35 families incorporated a wide range of families from different ethnic backgrounds with children representing different age groups and a wide range of disabilities. The families were also from different socio-economic status groups. The children were categorised into various strata according to independent variables such as race, type of disability and socio economic status. These information were obtained from students' personal records at Bethany Home. A random sampling was then carried out by the Home's Director and the Deputy Director in consultation with me.

Study Sample Two

The participants of the parent education programme were respondents from the 145 families. All 145 families were given an equal opportunity through written invitations to participate in the planning of the training programme. 87 parents attended the promotional introductory meeting and out of that group fifteen parents volunteered to participate in the Parent Training Programme.

Instruments

A wide range of instruments were used to measure outcomes. The

instrument (Family Information Needs Survey) used in phase one was solely used to identify the training needs and course structure desired by the target population. The main instrument, the parent education manual, was constructed based on the findings of the Family Information Needs Survey. The other instruments were used to monitor and test the outcomes of the parent education programme and measure:

- The extent of parents' participation in the development process.
- 2. Parents' acquisition of skills through parent education
- The facilitation process

Construction of the Family Information Needs Survey

The Family Information Needs Survey Questionnaire (FINS) was adapted from the Turnbull and Turnbull Family Needs Inventory (1982). It is a closed questionnaire. The items were simplified and categorised into five categories (Behaviour Management, Teaching Skills, How to Record, Course Format and Interest in Macro Issues) to form an index of each category.

Likert Type Scale

A Likert type scale was used for the questionnaires. The scale has a rating of one to ten where one means a definite 'no' and ten means a definite 'yes'. The reason for opting for such a wide range is that it allows the participants a wider range of expression. From past experience in working with parents (particularly of Indian origin) in a rural area, we discovered that parents found it difficult to say 'no' assertively but prefer to express 'no' in milder forms. For example, a question such as 'Do you like it?' might elicit a response such as 'Well, this is O.K. but the other one is better'. The absence of a mid point ensures that participants made either a 'yes' or 'no' choice. Any number from one to five would indicate 'no' and six to ten would be a 'yes'.

Administration of the Family Information Needs Survey

The questionnaire was hand delivered to the participants and followed up by telephone or visits where possible. This method was employed so as to give the parents the space and time to think through and not be pressurised to respond immediately. The deputy director was briefed on the survey form and given the sole responsibility of answering queries and giving clarification where necessary. She maintained regular contact with the families to ensure the survey forms were returned promptly.

Construction of the Parent Education Programme Manual

A lot of time went into the construction and development of the parent education programme manual. A participatory approach was adopted from the onset to ensure the relevance of the material to the target population. The material was constantly revised to suit the needs of the participants. Initially the findings of the Family Information Needs Survey were used to design the manual for parent training. consultation and discussion with the parents the course was designed for six sessions. The parents verified the course content. It had three components, namely Behaviour Management, Teaching Skills, and How to Collect and Record data. The course was designed to teach the principles of behaviour management and teaching. Studies show that teaching parents the principles helped them to generalise the teaching to other tasks (Cunningham and Jeffree, 1975). Its contents contained many everyday examples, simple exercises and practicums that were developed through consultation with the participants. The material contained simple everyday language and sometimes Malay terms were used to give the material an indigenous flavour and make it more acceptable eg. 'bagus' for 'good' and 'pandai' for 'well done'. Behavioural terms and jargon such as antecedent, behaviour and consequence, were replaced with simple terms like 'before behaviour', 'behaviour' and 'after behaviour'. Lots of everyday examples were again used to illustrate concepts such as time out, praise, punishment etc. The examples used were culturally sensitive so that they would be acceptable to the three racial groups (eg, using a dipper to have a bath). The course material was interactive in nature so that parents can actively participate. The material was also translated into the Malay language.

Field Notes

Actual observations and conversations were recorded by the researcher. The parents' session was also described and recorded in note form. The field notes will indicate attitudinal and behavioural changes in the participants.

Systematic Observation of the Frequency of a Specific Behaviour

An unobtrusive measure of the number of positive and negative statements that parents made about their child or themselves throughout the six sessions was recorded. This is an observable and repeatable behaviour. A higher count of positive statements would indicate a positive attitude of the parents. Kogan (1980) in his controlled study used frequency of certain behaviours (eg. smiling, ignoring, negative voice) to measure change. An operational definition of 'positive' is any statements or words that indicated that the parents were seeing strengths in their child or themselves (eg. is better, can learn, has improved, really tries, has a lovely smile, eats well, is loving, feel confident, feel good etc). 'Negative' would be statements or words that indicated that the parents were negative about their child or themselves (eg. lazy, very difficult, won't change, stubborn, doesn't try, given up, don't know what to do, no hope etc). An operational definition of a statement is 'a

⁴ Very few homes have a showers or a bath. The common way to ke a bath is to collect water with a dipper (which is a container th a handle) from a tub filled with water and pour it over your ad.

group of words lasting for less than ten seconds '.

Systematic Observation of the Duration of a Specific behaviour

This involved an unobtrusive measure of parent engagement time during each session. The operational definition of parent engagement time in this context is the amount of time the parents were involved in active discussion in each session. This is taken as an indication of active participation. The parent engagement time was only measured by observable parent discussion. It ceased when the parents stopped talking for longer than ten seconds. The operational definition of allotted time in this context was the total time each session lasted. Two observers recorded the occurrences of this specific behaviour and both were non-parents participants. This measure was only used for the English speaking group as the other two groups comprised of much smaller numbers (three and four).

Performance Indicators

Each parent carried out practical exercises that were in the course material (Appendix 1). Each parent had to complete a 'reinforcer survey', an 'ABC format', a 'frequency and duration record' (See Appendix 4). Those parents who could not write were examined orally on an individual basis.

Case Studies of Parent Participants

According to Perrone (1981) norm referenced tests and standardised achievement tests reduce the relevance and validity for particular local programmes and more accurate evaluation results can be produced through developing case histories. The parents in the course were taught basic principles of behaviour management. They applied some of these principles at home with their children. The treatment of each child could be considered a continuous case study. However, here they are presented as illustrations of the behavioural approach. The graphs have been created

by the author based on the data collected by the parents. Some of the dialogue is presented in verbatim for the benefit of the reader to gain first hand experience of the process of problem sharing and identifying intervention strategies within the group.

The Standardised Schedule (a structured questionnaire)

The pre intervention and post intervention questionnaire was designed to gauge the participant's current knowledge in behaviour management strategies and teaching skills. A questionnaire was designed to find out how parents currently managed their children's behaviour, their understanding of praise and punishment and how they currently taught new skills to their child with special needs. The questions were based on real examples of everyday problems that parents could easily relate to and was presented in everyday language. The participants were individually asked questions from the questionnaire and the answers were written down without making any comments. The objective was to let the participant feel that whatever was said was accepted as legitimate answers. These results then formed the baseline data for the study.

There were 25 questions in all. Participants were allowed to write their own answers. Parents who needed help to write dictated the answers while a non parent observer wrote them down. Parents retained their answer sheets. At the end of the last session of the course parents were administered the same test and asked to look at their original answer sheets and decide whether they wanted to make changes to their original answers. The number of changes that each parent made was recorded. The number of changes divided by 25 (total number of questions) and multiplied by 100 gave the percentage change. This indicated gain in knowledge.

Parent Course Evaluation Questionnaire (PCE1)

The questionnaire has 23 items categorised into four categories to determine attitudinal change, validity of course, suitability of time and place and interest in macro issues. Several statements were aimed at essentially the same attitude and here these statements were categorised and the results combined to form an index of the attitude. In the category for self esteem were statements that elicited information pertaining to change in knowledge, changes in attitudes, change in behaviour and skills acquisition.

Parent Course Evaluation Two (PCE2)

A further evaluation was conducted to check reliability of PCE 1 using PCE 2. In PCE 2 similar items were repeated in different forms as check phrases/words 'to check the participants consistency and reliability' (Williams, 1995:30). Out of a total of 64 items (phrases/words), eighteen represented self esteem, nineteen represented course validity, seven represented interest in future training while twenty were negative comments. Parents were asked to tick any words or statements that reflected how they felt about the course. Throughout the evaluation anonymity was maintained. Each phrase or word was read out in sequence and the meaning explained where necessary by a participant observer. Parents were asked to tick any phrase or word that they could relate to or which reflected their feeling as a result of the course.

Systematic Observation of a Specific Behaviour

Teachers of four of the children (of participants) selected at random were asked to record the children's observable behaviour in three areas namely how settled or unsettled the child was, how happy or unhappy the child was, how compliant or non-compliant to task the child was. This record was subjective and judgement based. The results would indicate if there was a correlation between change in the parent's attitude and the

overall attitude of child. The teachers were to indicate where they thought the child was in a ten point Likert-type scale between happy-unhappy, compliant-non compliant, settled-unsettled. They recorded their observations on the week prior to the training programme and compared it with their observation on the last week of the training programme. The mean of the first week's data was used as baseline data and the mean of the final week's data was used as data after intervention. These were than tabulated and compared

Qualitative Data through Informal Interviews

In order to understand the richness of the group relationship I tried to immerse myself in all aspects of the situation by using all available sources of information such as informal talks with members of the group and other teachers and key personnel of Bethany Home and by passively observing and listening to the group and making home visits. This method of research provides me as a 'participant observer' with some sort of role in the group rather than maintaining a distance between the observer and the observed. In fact the 'less the subjects notice the process of observing and measuring the less they are likely to be influenced by it' (Simon, 1978:334). This data added some valuable information to the study.

Constructed Response

Often behaviour is described in unclear, fuzzy terms (eg. he is stubborn, she is manipulative, he is hyperactive). This information is perceived differently by different people, especially by the teachers because it does not describe overt behaviour. To be able to change a behaviour we must be able to define behaviour in observable terms. Parents were asked to write or describe their child's problem behaviour at the beginning of the course. The parents were asked to do the same at the end of the course. The statements were compared for change.

Observation Data at the Graduation Ceremony

The graduates received their certificates and gave a short speech which was recorded on video tape. Excerpts of some speeches which indicate change in attitude are used in this study.

Pilot Study

This phase involved testing and validating the draft parent education manual for simplicity of language and content. The decision to test the material with a group of new teachers at Bethany Home was consciously taken for several reasons. 'Teachers' at Bethany Home are not college trained but rather in service trained. This manual developed through parent participation could be eventually used for training new teachers at Bethany Home.

Research shows that training novice professionals/students simultaneously will boost parents' confidence (Topping, 1986:311). Very few professional staff receive direct training in working with parents of intellectually handicapped children (Atkin and Bastiani, 1984). A foundation course designed for training parents and teachers will use common terminology and intervention strategies that will help narrow the gap between parents and teachers. Studies show that because teachers lack training in working with parents there is the possibility that they may find it difficult to encourage parents to answer each others queries rather than 'be the expert' (Cunningham and Jeffree, 1975; Karnes and Teska,1980). Courses designed and developed through parent participation for use in training new teachers will be sensitive to parents' needs and priorities. Broad based training material have only recently begun to be available (McConkey, 1985).

Teachers participating in the pilot study were to receive a common

certificate at the graduation ceremony together with the parents. To test the course material for content and simplicity of language the course was administered to a group of eight new teachers of Bethany Home. These teachers had no prior training in special education and out of the eight teachers, three had School Certificate qualifications while the rest had fourth form qualifications. They had all been working in Bethany Home for less than a year. Together with this group of eight teachers, seven other experienced teachers (senior teachers) were assigned to attend the course so that they could understudy me and conduct similar courses for new teachers in the future. They would also be aware of the course content and hence be able to work alongside parents. The teachers were all randomly selected by the director of the Home. All the teachers who attended the course completed an evaluation form at the end of the course to help validate the course.

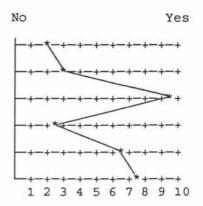
Scores

The maximum a subject could score under each category of items is equivalent to the number of items in that category multiplied by ten which is the maximum score for each item on the Likert scale. The minimum a subject could score under each category of items is equivalent to the number of items in that category multiplied by one which is the minimum score for each item on the Likert scale. Therefore the maximum score for self esteem is 70 while the minimum score is seven. The maximum score for course validity is 60 while the minimum score is six. The maximum score for suitability of time and place is 20 while the minimum score is two. The individual scores of the fifteen subjects are tabulated below. Self Esteem is represented by SE, Course Validity by CV and Suitability of Time and Place by ST. Numbers one to fifteen on the top represent the subjects. Number one to eight represent the new teachers while numbers nine to fifteen represent the senior teachers.

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
SE	69	70	63	64	67	69	70	65	63	62	55	54	52	59	55
cv	28	30	21	33	20	25	19	32	49	26	41	43	30	32	39
ST	15	14	18	18	10	19	20	17	15	15	15	20	14	20	11

A content analysis of the Course Validity category gave the following mean scores for the individual items.

- 8. The language is simple enough
 (mean is 2.1)
- 9. There were enough examples.
 (mean is 3.1)
- 10. The lectures were interesting
 (mean is 9.6)
- 11. There were enough practical sessions
 (mean is 2.4)
- 12. There was enough time for questions
 (mean is 6.7)
- 13. The next training should be conducted in the same way (mean is 7.3)



Modification to Course Material

As a result of the pilot study the language was further simplified. More everyday examples were used and more practical exercises were included.

Data Collection

The study involved collection of data through the Family Information Needs Survey Questionnaire, the Course Evaluation Questionnaires, participant observation methods, pretest and post-test questionnaires, field notes and criterion referenced tests relating to baseline comparisons.

Validity

The validity of data interpretations was confirmed through constant comparison against other findings. Denzin (1978) has called this kind of

analysis "within method triangulation" and "across method triangulation". Within one method data was triangulated to analyse the same unit of study. For example the questionnaire contained some questions that were essentially the same but were worded differently or presented in a different format to test congruence.

"Across method triangulation" is the process of comparing and justifying data from one source against that from another. By using more than one observation technique we are able to check the congruence of the results. A final point to validation rests in the reactions of the parents. This is captured on video at the graduation ceremony.

Reliability

For reliability the point by point agreement method (Kadzin, 1982) was used. An agreement is defined as both observers recording the occurrence or non occurrence of a response in a category during a prescribed period or interval. The percentage agreement formula was then used to calculate agreement for occurrences and non occurrences respectively.

Limitation of the Study

This study lacks the scientific rigour of a traditional research nevertheless the outcome confirms the usefulness of the approach taken. The small sample used and the indigenous nature of the study makes it unsuitable for external validity although according to Patton (1987) 'it is worth remembering that some of the major breakthroughs in knowledge have come from studies with small sample sizes'. Wilker (1981) records a low response rate in his own experiment where only a third responded. The diversity of the group in terms of race, language and education did pose some constraints in recording data and evaluating.

Conclusion

The study employs elements of action research methodologies as well as qualitative and quantitative methods of data collection. Many of the instruments use behaviour change as a basis for measurement. A wide range of instruments are used to consolidate the findings.

The field study is conducted in four phases.

June 1995 <u>Phase One</u> The first phase involves the construction and administration of the Family Information Needs Survey.

Nov. 1995 Phase Two The second phase involves the design of the course material in accordance with the findings of the survey; the identification of the participants and the development of the course material in consultation with the participants.

Dec. 1996 Phase Three The third phase is a Pilot Study conducted with an identified group of teachers at Bethany to test and validate the course material and format.

Jan 1996 Phase Four The final phase includes formulating the agenda for the course and administering the course whilst adhering to a participatory model of development. The parents participated in a Course Evaluation exercise to evaluate the course.

CHAPTER V

FINDINGS

Introduction

This chapter presents the findings of the study based on the data collected from the methods outlined in the previous chapter. The objective of the study is to determine if an education programme designed and developed through parent participation can empower parents. The study examines three major areas :

- The extent of parents' participation in the development process.
- 2. Parents' acquisition of skills through parent education
- 3. The facilitation process

The findings are presented in the order the instruments were administered.

- 1. Demographic characteristics of participants
- 2. Family Information Needs Survey
- 3. Field Notes of Parent Training Sessions
- 4. Systematic Observation of the Frequency of a Specific Behaviour
- 5. Systematic Observation of the Duration of a Specific Behaviour
- 6. Performance Indicators
- 7. Case Studies
- 8. Parents' Course Evaluation Questionnaire One
- 9. Parents' Course Evaluation Questionnaire Two
- 10. Systematic Observation of a Specific Behaviour
- 11. Qualitative Data through Participant Observation
- 12. The Standardised Schedule (a structured questionnaire)
- 13. Constructed Response

14. Observation Data

Results of the Instruments

Demographic Characteristics of parent participants

	MALAY	CHINESE	INDIAN	MEN	WOMEN	socio LOW	MEDIUM	HIGH
SURVEY	10	6	5	7	14	15	5	1
INVITAT	26	22	39	28	59	53	28	6
RESPONSE	4	4	11	8	11	11	6	2
% RES	15.3	18.1	28.2	28.5	18.6	20.7	21.4	33.3
FINAL	4	4	7	5	10	8	5	2
% FINAL	15.3	18.1	17.9	17.8	16.9	15	17.8	33.3

SURVEY - sample population (n=21)

INVITAT - respondents to promotional introductory meeting (n=87)

RESPONSE - respondents to the invitation to participate (n=19)

FINAL - course participants (n=15)

% = % of the 87 parents who attended the introductory meeting.

The final group was representative of the different racial groups, social class, educational background and gender class. Information on socio-economic and educational backgrounds were obtained from records kept at Bethany Home. The % FINAL box is a comparison box which compares the course participants to the respondents to the promotional introductory meeting. The % FINAL box indicates a constant percentage of between 15 % and 18 % of each racial and gender groups when compared to the initial group of 87 parents who attended the first meeting. The high percentage of participants from the high socio economic status group is, however, attributed to the participation of a married couple who are both professionals.

The findings show that a cross section of participants from different racial, gender and socio-economic backgrounds chose to participate. There was no criteria for selection of participants. Anyone who was interested

had the opportunity to participate in the programme.

Family Information Needs Survey

The Family Information Needs Survey Questionnaire (FINS) is a closed questionnaire with five categories (Behaviour Management, Teaching Skills, How to Record, Course Format and Interest in Macro Issues).

Results of this survey will indicate the parents' preference for course content and format. This will form the initial guide to development of the course material.

The findings were as follows.

- i) Part One of the questionnaire (course content)
- 88.5 % of the respondents wanted information on Behaviour Management.
- 80.9 % of the respondents wanted information on How to Record.
- 60.3 % of the respondents wanted information on Teaching Skills.

Parents were keen to gain information namely in the three main areas of behaviour management, teaching skills and observation and recording of data.

ii) Part Two of the questionnaire (course format)
The respondents indicated their preferences for course format, days,
duration and group size as follows:

Days

62% of the respondents preferred a weekend course while 29% preferred weekday course.

Duration of course

38% of the respondents preferred a two day course. Another 38% preferred a six day course while 9% of the respondents preferred a four day course.

Duration of sessions

38% of the respondents preferred two hour sessions while 29% of the respondents preferred four hour sessions. 19% of the respondents opted for three hour sessions.

Course format

100% of the respondents requested videos; 90% preferred lectures; 85% requested time for discussion; 75% wanted practicums included.

Group Size

33% of the respondents preferred a group of six while 19% of the respondents preferred a group of five and a further 19% wanted a group of ten. 14% indicated preference for a group of three. 15% requested individualised sessions.

Certificates

75% of the respondents requested for certificates to be given at the end of the course.

The results of the Family Information Needs Survey show that the respondents generally preferred weekdays to weekends and there was an equal preference for a course with a duration of two or six days.

Respondents also preferred long sessions lasting between two and four hours. Preference was for learning in group sessions rather than through individual sessions. 85 % of the total responses indicated interest in group sessions. Lectures, videos, practicums and time for discussion received high responses for mode of course delivery. Based on these results the course content and format were determined.

Consultative meetings (mesyuarat)

A promotional introductory meeting was initially held on the 17th. December 1995 to motivate parents to participate. At the end of the meeting an invitation was extended to all parents to participate in a parent training programme. A response form was handed out and a deadline given for reply. Details of the form were clearly explained in all the relevant languages so that parents understood how to respond. parents responded immediately indicating that they were keen to participate in the training programme. By the deadline, which was the 31st December, we received six more forms bringing the total number of responses to seventeen. These seventeen parents responded voluntarily. The respondents were invited to a consultative meeting (mesyuarat) to discuss and plan for the course. Ten parents attended the meeting held on the 7th. January 1996. We received three apologies from parents who could not be present due to work commitments. At this meeting we also had a parent who had not previously signed up for the meeting. The agenda was left open for parents to speak freely on their views and expectations from the training programme. We began by asking each parent to express why they were here and to say what they expected out of the course. Parent M⁵, a community worker, said 'I want my daughter [Mm, 19 years old with Downs Syndrome] to learn how to sew and cook and such things. I also like to learn sign language so that I can communicate with her.' Parent L, a policeman, who has a child who is severely physically disabled (cerebral palsy) said 'I want to know what to do when he cries for no reason'. Another parent K, a postman, said 'Me and my wife want to know how to motivate our son'. Five other parents highlighted behaviour problems and how to manage them as priorities and one parent was keen to learn teaching strategies. Parent B, a teacher said 'I want to know how to manage my daughter's behaviour [Bb is 21 years old and intellectually handicapped].

⁵ To maintain confidentially alphabets were used instead of es eg. M represents the parent and Mm represents the child.

She refuses to listen (comply) to our instructions.'

The problems were written on the white board and categorised. We unanimously agreed that the two main areas of concern were behaviour management and how to teach new skills. This was consistent with the findings of the Family Information Needs survey. A decision had to be made about days and time for the programme. Since this exercise was a new experience for the parents who in the past had always been told what to do, there was hesitation. Once they got going it became difficult to agree on a time that was suitable to all. Part of this difficulty was due to the fact that we were approaching two major festivals for the Chinese and the Malays, namely Chinese New Year and Hari Raya Puasa, and everyone was busy making preparations. To add to the difficulty, Hari Raya was preceded by a month of fasting and so the Malays would find it difficult to concentrate during the course. Different times and days of worship for the different communities made it extra hard on finding suitable times.

I asked them what they preferred as the medium of instruction. A couple of parents suggested that it should be conducted in Malay. Three other parents confessed that they were only conversant in Tamil. Parent B then suggested that the course be conducted in all three languages and be held in two different locations and at times suited to the groups. He offered his home as a venue for those living in Teluk Intan (a town situated 16 km from Bethany). The group unanimously agreed to this suggestion. It was decided that there would be three language groups. The English group would meet at B's house and the Malay and Tamil groups would meet in Bethany Home. The days and time for the first meeting for each group were agreed upon but the duration of the course was to be decided according to the progress of each group.

Field Notes - Parent Training Sessions

The field notes will indicate attitudinal and behavioural changes in the participants. Actual observations and conversations were recorded. The illustrations given here are only segments of the field notes to help the reader gain some understanding of the behaviour patterns that emerged during the sessions. Some editing has been carried out to protect the confidentiality of the participants and to correct some grammatical structure of sentences (only where necessary so as to retain the indigenous flavour). The extracts here are only from the English speaking group of parents. Here we have a first hand experience of how the group operates. The emotions that are expressed are difficult to record but they are so much a part of the action in the research.

The first meeting of the English speaking group was scheduled to be held on Tuesday 16th. January at 8 pm. However during the course of the week, A, who had signed up for the course but was unable to be present at the planning session telephoned me to say that he had consulted the others in the English group and had offered his clinic to be used as the venue for the meetings. They had made the change because they felt that they did not want to cause any intrusion into B's family and also they wanted some privacy and felt that the clinic would be more conducive.

The clinic is situated on the first floor of an old building. The landing of the staircase which was used as our lecture room was an open floor area with basic chairs and benches. There were no teaching aids like white board or video or television. The place was dimly lit with two fluorescent tube lights and had a ceiling fan. The walls had a couple of posters of pharmaceutical products. The first meeting of the English speaking group was attended by ten parents. There were two new parents (a Tamil school teacher and a land agent) who were both not present at the consultative meeting. They both expressed interest but unfortunately due to work commitments and health reasons both dropped out after two sessions. The sessions carried on with the core group of eight parents.

In the group we also had a couple of Chinese speaking mothers who both needed Chinese translation and this was provided by Marg (not her real name), a work placement officer from Bethany Home who was also a friend of one of the Chinese speaking mothers. We introduced ourselves on a first name basis. I explained to the parents that this whole exercise was a learning process for all of us, especially me, and I encouraged each one of them to contribute actively. I also explained my present role as researcher and parent advocate under the organisation Dignity and Services (an advocacy group based in Kuala Lumpur who seconded me to Bethany Home). I emphasised the fact that this was the first such course ever conducted in the country and hopefully this would be the beginning for many more. Everyone seemed quite relaxed in the environment. We began with the pretest and followed on with the course material. Parent G (a parent of a 20 year old intellectually disabled man) interrupted during a discussion on how to observe behaviour.

- G: 'Why does my son always beat me? I take such good care of him. He is ungrateful. His father doesn't care yet he does not beat his father.'
- I: 'What do you do when he beats you?'
- G: 'I tell him please Gg don't beat me, paining! (hurts!). Why you beat me? Mummy loves you .'

G was very emotional and went on for a while relating her problems to the others while they listened sympathetically and intercepted her with questions. This lasted for approximately fifteen minutes and then G stopped speaking and remained silent for the rest of the session.

Session 2

Parent A raised some questions about the reinforcer survey that he did for

his child Aa as part of the exercise.

- A: 'You know, Aa doesn't like anything very much. There are no objects that she likes. She likes cycling but it is unsuitable because of the dangers of traffic.'
 - B: 'But isn't that something she likes...?'
 - A: 'Yes!...so you mean it can be a good reinforcer. "She also likes to lie on the floor and this is unhealthy from a medical perspective. She also likes food and never stops to say enough. She also loves canned drinks and can drink a lot'.

Parents B, B1, and D agreed that perhaps canned drinks could be used as a reinforcer.

Parent A also questioned the practicality of using a token economy programme⁶ especially when both parents are in full-time employment and busy.

- B1: 'We will have to involve the siblings. Everyone can work together.'
- J: 'if we praise the child all the time for what she does won't the child have problems coping in the real world where the child may not get much praise.'
- A: 'I grew up without any praise and now I find it difficult to give praise. I received a lot of criticism from my father and I had to study hard to prove him wrong and I did it. Now I find it very difficult to praise my children. Looks like this course may change my ways and I may be able to praise my children more easily!

⁶ A reinforcer program where the child collects tokens or ticks good behaviour and is able to exchange it for a reward later

- A1: 'I'm glad he came for the course. At least now we can work together. I feel both parents must be involved'.
- G: 'I am seeing changes in Gg since I tried applying a softer approach with lots of reinforcement. Gg's 'hitting me' behaviour has decreased.

Parent A urged parent G to pursue with the programme and never give up. All the other parents praised her for persevering.

- A: 'How is Gg doing with his self feeding programme?'
- G: 'Still difficult'
- A: 'You must break it into small steps'. Parent A then went on to demonstrate how to do it.
- I: 'Well done A! You are ahead of us now. We were meant to learn how to break each activity into small steps next week but you seem to know it already and explaining it quite well. Well done!'

Parent B1 told the group of the problem they were facing with Bb.

B1: 'We find it embarrassing to take her out because she misbehaves in public. She pretends to be severely disabled and gets a lot of attention and puts parents in an embarrassing situation.'

Parent A immediately told them that they should continue to persist and take her everywhere and not to worry about the embarrassment. He related how they had a baby sitter for Aa till she was three and all the baby sitter did was put Aa to bed often.

A: 'Aa couldn't walk, was not stimulated and just stayed in the cot.

When one fine day the baby sitter packed and left we realised that we had to take care of Aa by ourselves. This was a blessing in disguise. Al had to take her to her clinic daily and it was here that Aa began to receive a lot of stimulation from the nurses and soon was responding very well and in fact began to take her first few steps. Since then the family has taken her everywhere and Aa has more friends than any one of us.'

Everyone in the room laughed.

Parent A then emphasised the importance of taking children with special needs out into the community.

Parent B said that Bb's epilepsy tends to play up sometime when they are out and perhaps it is for this reason that Bb is quite hesitant to go out. B1 cited crowded places as a possible cause for Bb's epileptic turns.

- A: 'Maybe you should begin with going out to the local sundry shop for a start before going on to supermarkets.'
- B1 'Bb would then insist that we bought her sweets.'
- A: 'Why not use that as a reinforcer for good behaviour. If she behaves well then reward her.'

Parent D then raised the problem that she faces with her son. When it's bath time and she calls him he always waits for her to come and get him. She often gets angry and slaps him before giving him a bath.

The parents were immediately reminded of an example in the study material.

- Al: 'Does Dd love baths ?'.
- D: 'yes'.

Al: 'Then you must ignore his problem behaviour. He will come on his own.'

I then asked if the parents had some more suggestions.

Parent B suggested that a favourite toy in the bath may be a way of drawing the child to perform the task. Another suggestion was that parent D should be close to Dd and without much warning give the instruction while at the same time holding his hand and walking him to the bathroom. This will prevent Dd from running away and turning it into a game.

The mother agreed to try these suggestions.

The parents were keen to keep sharing ideas and so the meeting lasted till about 10.30 p.m.

Session 3

On the Wed 24th. January the group met promptly at 8 p.m. again and before I could convene the session parent A began.

A: 'Yesterday I talked about the importance of going out into the community and the importance of exposure. I am glad that we did what we did. However there is one thing that I feel Aa missed out on and it is the early intervention programme. As a medical doctor I can see how valuable the first three years are. We are glad that we have Bethany Home here and that they came to us instead of we going to them. It made such a big difference for Aa. The exposure to the integration programme in the Methodist Girl's School also helped her with her social interaction skills.'

'I'm sorry for taking your time' (looking in my direction).

I reminded him that this was not my time but theirs (the parents) and I was happy for the discussion to continue.

Parent B1 raised another problem that she faces with Bb and asked for suggestions from the others.

- B1: 'Bb does not know how to walk on the side of the road' she said.

 'She often drifts to the middle of the road especially when she starts talking to herself.'
- F: 'Maybe you should walk alongside on the outside while Bb walks on the inside.'
- A: 'Let Bb learn to walk on a small stretch between two people before she progresses to the next stage'.
- B: 'Her problem is not just walking but it is her talking to self that causes her to loose concentration and drift away.'
- Al: 'Perhaps chewing gum may keep her from talking.'

Parent B got excited with the suggestion.

B: 'I think I'll try it out.'

Session 4

G: 'I'm so glad I have attended this course and learnt so much. Thank you all. I have already begun to see some changes in myself. I am a lot calmer in my approach now. My son is also much better. He listens to me and doesn't hit me as much. When he feeds at home I play his favourite music and he is very happy. Really thank you all very much.'

Parent G then raised a concern about Gg's walking behaviour. According to her Gg wants her to hold his hand while walking but in school he walks independently.

G: 'the floor at Bethany is cemented and smooth and makes it easy to walk whereas the road to my place is rough and shingly'.

A: 'I think you should try walking Gg on grass surfaces and other surfaces in stages so that he gradually gets his balance.'

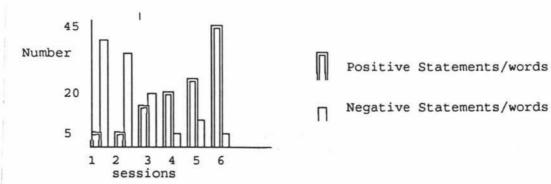
The qualitative data from the field notes indicate positive changes in the parents' attitude and behaviour. It shows an increase in parental participation and self help.

Systematic Observation of the Frequency of a Specific Behaviour

Data from this measure is used to determine attitudinal change in the participants. This is an unobtrusive measure of the number of positive and negative statements that parents made about their child or themselves throughout the six sessions. It is an observable and repeatable behaviour. A higher count of positive statements would indicate a positive attitude of the parents.

Results

Although the three groups produced different results the general trend was the same. Therefore the results were combined together to present the overall change in relation to the sessions.



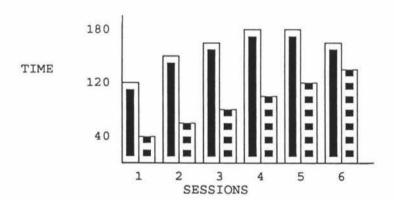
SESSIONS	1	2	3	4	5	6
POSITIVE	6	5	17	21	36	45
NEGATIVE	39	32	19	6	10	6

The results show that parents' positive statements increased from 13% to 88%. It indicates a positive change in the attitude of the parents.

Systematic Observation of the Duration of a Specific Behaviour

This involved an unobtrusive measure of parent engagement time during each session. It indicates the amount of time the parents were involved in active discussion during the session.

Results



Allotted	l Time
Engaged	Time

SESSIONS	1	2	3	4	5	6
ALLOTTED TIME (m)	120	150	180	190	185	180
ENGAGED TIME (min)	40	55	80	100	120	135

Parent engaged time increased from 25% to 43%.

Performance Indicators

These are practical exercises that were part of the course material (Appendix 1). They were used to measure skills acquisition. Ten parents completed the exercises, four parents completed more than 50 per cent of the given tasks and one parent completed less than 50 percent of given tasks.

Case Studies of Two Children of Parents in the Programme.

The parents were taught basic principles of behaviour management. Some parents applied these principles successfully at home with their children. These are presented as case studies. Some of the dialogue is presented in verbatim for the benefit of the reader to gain first hand experience of the process of problem sharing and identifying intervention strategies within the group.

Case Study One

Aa is the second child in a family of 3 children. Both her parents are professionals in private practice. Aa was diagnosed as having Downs Syndrome at birth. She is now 14 years old and is in Level 4 at Bethany. She was in an integrated programme for three years in a regular school where she had the opportunity to interact with 'normal' children during English, moral, music and physical education lessons but due to her problem behaviour her parents decided to re enrol her in Bethany Day School, a special school for children with a learning disability. Aa comes from a very loving family environment. Aa is described as mildly intellectually handicapped in her medical records.

Her teacher describes Aa as 'able to read and write standard one level, able to communicate Bahasa Malaysia very well and able to read ten word sentences very well. She is able to count the number 1 to 100 clearly and do simple addition and subtraction'.

Socially Aa interacts well with her peers. She can fry eggs and make a

drink of milo for herself. According to her teacher Aa is capable of doing household chores such as mopping, sweeping, washing dishes, watering plants and weeding the garden.

Aa is fond of incessantly making statements such as 'I want to pull your hair' or 'I give you a slap' and recently, 'I don't like you'.

Both parents are embarrassed by her behaviour. 'We have tried telling her nicely that people won't like her if she says such things. We even scolded her many times but the problem is the same, 'they said.

During the training sessions the parents discussed this problem openly with the other parents. Parents B and B1 (who have a daughter with Downs Syndrome) asked them if they had tried any other strategies. The parents of Aa replied 'We have tried saying the same thing back to her but that did not work either. We tried saying "Thank you" every time she said "I don't like you" but it only made her say more.'

'You were rewarding' exclaimed parent B. Parent B then asked parent A and A1 if they tried ignoring the behaviour.

'Yes I tried that' replied parent Al.

'Maybe you were not consistent. Maybe she is being intermittently reinforced,' said parent B.

Parents A and Al decided to collect some data on how frequently the behaviour occurs and the antecedent and consequences of the behaviour.

The parents took a frequency count of the behaviour without intervention for a baseline measure. They took that for three days. On the first day there were eight incidents. On the second day there were twelve incidents and on the third day ten incidents.

The ABC record shows no specific antecedent for the behaviour but the consequence was always attention from mum and dad even if it was negative, such as scolding or warnings.

Intervention Strategy 1: Ignoring

The parents used ignoring as a strategy and kept collecting data. The

number of incidents rose sharply initially to eighteen and then for the next two days it remained at ten and twelve respectively. According to parent A 'Aa knew I was ignoring and kept coming closer to me and saying it loudly till I had to leave her.' She added 'I know that she does not like to be ignored and it will work eventually but I can't take it.' Parent A abandoned this strategy as a result.

At the following training session the problem was discussed and parent B said 'You mustn't give up.'

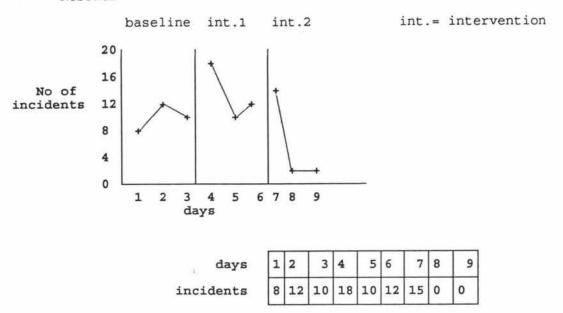
I did not have any immediate solution either but I remembered Aa's parents mentioning that they had said to Aa the same 'I don't like you' statements but it didn't make any change. There is a technique called 'flooding', I said 'which is similar to yours and it was used in a hospital in England where they literally "flooded" a person who had an obsession for blankets with blankets till he stopped asking for them.' 'That may work', said parent A: 'if all of us agreed to say "I don't like you" to her she may stop. We must all agree to work together'.

Intervention Strategy 2: Flooding Technique

The A family decided to tell the 'I don't like you' statement to Aa every time they saw her. According to Aa's parents 'it initially became a game and Aa seemed to enjoy it. The number of times she said it was initially high, about fifteen but in the evening when her younger brother (whom she loves very much) said 'I don't like you' to her she broke down in tears and came running to me saying How can V say "I don't like you?".'

Parent A recalls 'I than told Aa that perhaps he will stop saying if she did too. This really stopped her and we have not heard it since' (for two days).

Results



The number of incidents decreased to zero on day 8 and day 9.

Case Study Two

Gg is a 20 year old intellectually handicapped young man who is also physically disabled. Gg comes from a low socio economic background. His mother is the primary care giver while his father takes very little interest in his welfare. The mother finds this very demanding and often goes through depressive spells. Gg comes from a family of six children where he is the fourth. He lives at home with his parents and a little sister aged twelve.

Gg is toilet trained but needs help in all other self help skills. Gg is presently on a feeding programme to teach him to feed independently. He has difficulty in walking and often loses his balance and falls down after a few steps. He has also been diagnosed as having epilepsy and is on medication.

Gg has limited academic skills. He is able to match three colours and some pictures. He communicates through sounds and at times by gesture and eye pointing. Gg often hits his mother G whenever he is upset. This

hurts G badly and is causing her to loose all confidence in handling Gg. As a result of the parent training programme, G decided to work out an intervention programme based on what she had learnt. She decided to do an ABC of the behaviour.

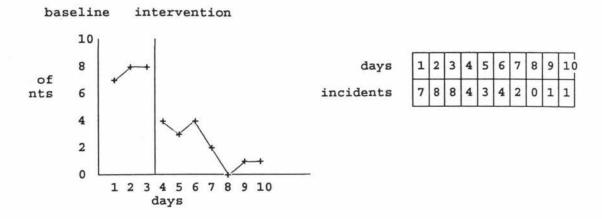
Her results showed that Gg hit her especially when she demanded a new behaviour from him, such as when she wanted him to board the bus, eat his meal, walk etc. Her record showed that the antecedent (ie what happened before the behaviour) was a strong command from her. The consequence of the behaviour was always a plea not to hit her: 'Gg please don't hit me, pain (hurts), poor mummy'...but Gg continues to hit till G moves away. Parent G took a frequency count of the hits from Gg. She obtained the following score from three consecutive incidents.- 7, 8, 8 hits.

Intervention

Through the help and advice she obtained from the other parents and also from the course material, parent G decided to change the antecedent. She decided to use a softer approach when dealing with Gg and reward him appropriately whenever he behaves well. She decided not to 'nag' him much and leave him for a while if he gets aggressive.

Results

Data collected after intervention showed that Gg's hitting behaviour reduced significantly from seven on the first day to one in day nine and ten.



Both case studies indicate positive changes in the childrens' behaviour.

Parents Course Evaluation Questionnaire (PCE1)

This questionnaire comprised of several categories designed to measure the validity of course and also parents' attitudinal change as a result of the course. It was also used to gauge parents' interest in macro issues such as future training and involvement.

Scores

The maximum a subject could score under each category of items is equivalent to the number of items in that category multiplied by ten which is the maximum score for each item on the Likert scale. The minimum a subject could score under each category of items is equivalent to the number of items in that category multiplied by one which is the minimum score for each item on the Likert scale. Therefore the maximum score for self esteem is 110 while the minimum score is eleven. The maximum score for course validity is 70 while the minimum score is seven. The maximum score for suitability of time and place is twenty while the minimum score is two

The individual scores of the fifteen subjects are tabulated below.

Self Esteem is represented by SE, Course Validity by CV and Suitability of Time and Place by ST.

Numbers one to fifteen on the top line represent the participants.

Results

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
SE	96	83	100	87	110	102	110	98	99	100	110	100	110	104	108
cv	53	58	68	47	70	55	68	55	64	70	70	70	65	66	70
ST	20	15	20	14	20	20	20	20	20	20	20	18	15	20	20
MI	30	28	28	24	30	30	30	30	25	30	30	30	23	30	30

SE - SELF ESTEEM

CV - COURSE VALIDITY

ST - SUITABILITY OF TIME AND PLACE

MI - INTEREST IN MACRO ISSUES

Stem and Leaf Display

Stem and Leaf display is a technique proposed by Tukey (1977) for original data to be read readily. It clearly shows the distribution of the scores and where the concentration lies. For example the first set of scores on self esteem given below shows that ten participants scored 100 and more. This method of display also shows the range of scores easily eg. in self esteem the range was between 83 and 110 while for course validity the range extended from 47 to 70.

Stem and Leaf Display of Scores for Self Esteem

Highest possible score is 110 and lowest possible score is eleven. All
the fifteen participants scored very high in this category with a mean
score of 101.1 indicating very high self esteem.

Malay/Tamil Groups English Group

Stem and Leaf Display of Scores for Course Validity The highest possible score is 70 and the lowest possible score is 7. Again all the participants scored very high in this category with a mean score of 63.3. This shows that the participants highly valued the course.

Malay/Tamil Groups

English Group

Stem and Leaf Display of Scores Suitability of Time and Place Highest possible score in this category is 20 and lowest possible score is two. The mean score of 18.8 is very high indicating participants' satisfaction with time and place.

Malay/Tamil Groups English Group

Stem and Leaf Display of Scores on Interest in Macro Issues
Highest possible score is 30 and lowest possible score is 3.

The mean score is 28.5. This indicates participants positive interest in future and involvement.

Malay/Tamil Groups English Group

Parents' Course Evaluation Two (PCE 2)

A further evaluation was conducted to check reliability of PCE 1 using PCE 2. In PCE 2 similar items were repeated in different forms as check phrases/words 'to check the participants consistency and reliability' (Williams, 1995:30). Each phrase or word was read out in sequence and the meaning explained where necessary by a participant observer. Parents were asked to tick any phrase or word that they could relate to or which reflected their feeling as a result of the course.

The numbers that appear in the column on the right indicate the total number of responses (refer to tables on pp.77-78).

SELF ESTEEM	
more confident	7
better relationship with my children/wife/husband	6
enjoyed the meetings	6
managed to put into practice	3
eager to learn more	4
I can become a trainer	4
feel I know as much as the teachers	2
feel I know more than the teachers	
I can be a good teacher	4
has changed my behaviour	5
I feel more in control of my anger	5
teaching is easier now	2
I praise more now	3
enjoyed meeting other parents	6
I shout less now	
should have more courses for parents	5
keen to see other parents go for courses	4
want to change the attitudes of our community	3
COURSE VALIDITY	
got what I expected	2
lectures interesting	4
learnt from the lectures	4
learnt from other parents	2
very helpful	3
notes were good	2
notes are interesting	2
interesting to read	3
enjoyed discussion times	1.
question time was interesting	5
I can do a reinforcer survey	3
I know about ABC	7
I can measure behaviour	4
I can do task analysis	6
This is the best course I have attended	3
I learnt a lot	3
course well organised	4
seating arrangement was good	1.0
homework was easy	-

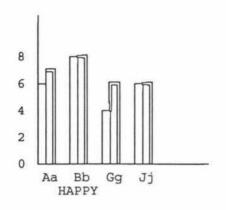
NTEREST IN FUTURE TRAINING	
Invite more specialists	3
want more courses in epilepsy/ downs syndrome/ physical handicap/ autism/	
others	7
print the notes into books	3
print the notes in Malay	2
should have videos	4
should have practical sessions with children	2
there are not enough examples	4
NEGATIVE COMMENTS	
homework was difficult	3
course not well organised	-
lectures made me sleepy	(-
notes are difficult to read	
boring to read	-
too dull to read	-
my questions not answered	-
no chance to speak	1
some answers not suitable	-
meetings too late	-
things have got worse at home	-
boring	-
too simple	
waste of time	-
less confident	
no change in myself	-
will not change my ways	-
I believe that caning is the only way	
I dont think that the course has changed my ways in managing behaviour	

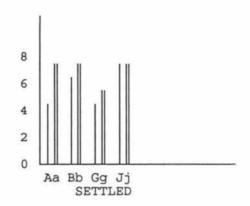
There were a total of 155 responses in the form of ticks or underlining and of this total 69 responses indicated Self Esteem, 57 verified Course Validity, 25 showed interest in Future Training. Only 4 were Negative Comments. These results correspond with the results obtained in PCE 1 confirming the reliability of that instrument.

Systematic Observation of a Specific Behaviour

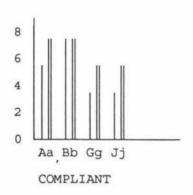
The behaviour of four randomly selected children of the participants were monitored by the class teachers to see if there were any observable change that corresponds with the change in their parents' attitude.

Results





— I



Subjects —	1 2	A	1	3	1	2	D		
happy	6	7	8	8	4	6	6	6	
settled	5	8	7	8	5	6	8	8	
compliant	6	8	8	8	4	6	4	6	
	F	L	F	I.	F	L	F	L	

F - mean of first 5 days L - mean of last 5 days

The four students recorded unchanged or higher readings for being happy, settled and compliant.

Qualitative Data Through Informal Interviews

The following data add some valuable information to the study.

Here are poignant statements made by the parents during informal conversations with them. I have categorised these as personal sacrifices parents had to make to attend the course regularly.

'My husband does not like me to go and always nags when I get home.'

'Transport is a problem so I have to get a ride from some one.'

'Had to close my clinic early today'

- 'Have to rush to Kuala Lumpur every weekend to see my father. Very tired'
- 'Have to get up early and prepare meals for the family.'
- 'My child not well today. My husband is at home taking care of the baby.'
- 'I do my home task in my work place.'
- 'Told my son to wait for me after his Karate lessons. I will fetch him after the course.'
- 'We (Muslims) are fasting today. Feel a little tired.'
- 'Had to do some late shopping for the festival (Chinese New Year).'
- 'Having visitors at our place'
- 'Not feeling well. Couldn't sleep last night but don't want to miss our meeting'
- 'Took some time off work. Must go to work after this meeting.'

The Standardised Schedule (a structured questionnaire)
Results

ENGLISH										TAMIL			MALAY		
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
CHANGE IN ANSWERS	9	8	10	4	5	5	7	8	17	14	17	10	7	8	8
%CHANGE	36	32	40	16	20	20	28	32	68	56	68	40	28	32	32

The results show a mean change of 36.6% which indicates new knowledge gained.

Constructed Response

Here are four before and after examples as recorded by parents (G,B,A,A1) in the programme.

Before indicates at the beginning of the training programme and After indicates at the end of the programme.

Results

Parent G

Before

'When angry he always beats me and is out of control in public, in school and at home. At times stubborn.'

After

'When angry he beats me. This happens when I tell him to do something he doesn't like e.g. to walk, to sit'.

Parent B

Before

'Always likes to stay in her room, listen to radio. Refuse to do exercise. Cannot get in a crowd, might get fits.'

After

'When she gets home from school she gets into her room and stays there till it's dinner time. When I ask her to come and do exercises she refuses. She had fits on 3 occasions in crowded places. I don't feel confident to take her out.

Parent A

Before

'she is adamant and persistently obstinate.'

After

'She refuses to take her bath or eat her meal when told to.'

Parent Al

Before

'She never shares and never accommodates.'

After

'She takes items that belong to her elder sister and younger brother but hits the younger brother whenever he takes anything that belongs to her.'

Observation Data at the Graduation Ceremony

The certificate presentation ceremony was held on the 14th March at the Bethany Home school hall at 5 p.m. The hall was decorated and the tables were laid out with a variety of Malaysian food. The teachers and parents who had completed the course were present together with other invited guests. There was much mingling in the crowd as people helped themselves to the food. There was a lot of interaction between parents and teachers. The presentation ceremony began at 6 p.m with the arrival of the Chairman of the Bethany Home Management Committee. Prior to receiving the certificates, teachers and parents were invited to say a few words about the Training programme.

Here are some salient points extracted from the video recording.

Teacher representative :

- 'We enjoyed the course so much we didn't realise how quickly time has gone by.'
- 'It was one of the best courses'
- 'Three languages, was very easy to understand and to put to practice.'
- 'We can see improvement in our classes.'
- 'We have new teachers who have gained a lot.'
- 'Although we are experienced teachers we learnt new ideas.'
- 'Some children have really changed through application of the behaviour principles.'

Malay parent representative :

'Thanks for the course. We now know how to teach. We deal with our children each day and so it is of great use to us. If ever there are any more courses we are ready to attend. We will inform other parents to attend as well.'

English Group Representative :

'Thank you for the opportunity to attend. We gained a lot of knowledge. We had lots of discussion and questions. We had long sessions but we enjoyed them. We can see the change in ourselves and the children.'

Parent H :

'I have learnt a lot and I can use it for all the children. I have changed now. I used to feel so useless. I didn't know how to deal with my daughter. Now I am confident and I see changes. She used to always ask me to buy this and that but now I only buy for her when she does some work for me first. I used to be afraid of her but now I know how to handle her.'

Parent C:

'I am so happy I don't know what to say (pause...wipes tears). I have never spoken in a crowd like this. I never realised that I could do a course like this. I feel like crying.' (..covers face with hands...)

Everyone applauds.

'Now I can even help my neighbour's children.'

Parent G:

'My son was a burden and a frustration but now it is very easy and simple if you know how. I like to help other children. We must try and try till we find a solution.'

Conclusion

Results of the instruments positively indicate changes in parental attitude. There is an increase in parent participation and involvement. Parents are more positive and demonstrate confidence in managing their childrens' behaviour. The data from the various measures are congruent

with this finding. The use of more than one method confirm the congruence of the results. Participants' evaluation of the course indicate increase in self esteem and skill acquisition. The data also indicates the diminishing role of the facilitator as the parents begin to help each other. A final point to validation is in the reactions of the parents and this is demonstrated in the field notes and is also captured vividly on video at the graduation ceremony.

CHAPTER VI

DISCUSSION

Introduction

Methodologies used in this study have depended on descriptive data, parental change and child change. The instrumentation used allowed direct indication of the value of the activities to the participants and although such information is hard to validate on an objective basis, according to Adams (1990:100), it is a paramount source of data on group effectiveness. The analysis delivered ample evidence of an attitudinal change in the Barnes (1992) argues that 'unlike quantitative methods, qualitative research techniques are especially suited to small scale studies where the researcher gets to know the social world being studied first hand. A qualitative approach to data analysis has given an in-depth account of the group dynamics. It has captured the feelings within the group and given a glimpse of the character development that accompanied the learning in a stimulating environment. Participation of the target population in the development of parent education programme has generated self esteem and confidence in the parents. The facilitation process allowed the participation to be meaningful for the parents. This chapter presents the discussion of findings to draw conclusions for the study.

The study examines three major areas :

- 1. The extent of parents' participation in the development process.
- 2. Parents' acquisition of skills through parent education
- 3. The facilitation process

The discussion of the findings in this chapter revolves around these three major areas. It is difficult to compartmentalise each area as they are closely interrelated and complementary to each other. Participatory learning takes place in a conducive environment that is actively facilitated. When people participate in the process of development they feel empowered. 'Empowerment is the psychological energy that activates

us' (Clutterbuck, 1994:13). The findings of this study are used to challenge the traditional concept of a top down mode of development and offer as an alternative, a people centred development approach to empowering parents of children with special needs in Malaysia.

The study demonstrates that parents played an active part in the needs identification process, the initial stage of the project cycle. practitioner should start where the family wants to start. the family's needs and validating and affirming thoughts and feelings can be therapeutic and empowering (McCallion & Toseland, 1993). By involving parents in the first stage of the project cycle the research confirms that the findings of the survey are consistent with other research findings that behaviour management is a favourite topic among parents (McConachie, The material designed for parent education through parent participation was used for teachers in the pilot study. The course material was appreciated by the teachers and validated for use for future teacher training. This helped boost parent confidence and is confirmed by other studies (Topping, 1986:311). The course designed through parent participation used simple and common terminology to help narrow the gap between parents and teachers. Stone (1992) highlights that existence of too much jargon in literature is an obstacle to information sharing. Parent involvement in the design and development of training programmes for use by teachers will also help destroy the myth that the teacher is an expert which several studies highlight (Cunningham and Jeffree, 1975; Karnes and Teska, 1980).

Courses designed and developed through parent participation for use in training new teachers will be sensitive to parents' needs and priorities. Parent participation in designing courses for teachers can have an empowering effect on parents. The process of identifying the parent participants was a free exercise giving parents the choice to

participate. 'For more often than not people are asked or dragged into partaking in operations of no interest to them in the name of participation' (Rahnema, 1992:116). The consultative meetings (mesyuarat) conducted in traditional style followed an indigenous format having no agenda hence giving the parents the freedom to reaffirm their needs and decide on the venue, medium of instruction and structure.

The parent sessions clearly demonstrate that parents exercised their power, for example their control over time and topic. Parents were confident and took over the sessions operating on a self help mode to discover solutions to their problems. These sessions operated beyond socio-economic class distinctions and educational level and parents related freely with each other. According to Adams (1990), the centrality of mutual aid is to encourage all to participate irrespective of their social or professionals positions. The increase in the duration of parent interaction for each session is an indication of active parent participation. The sessions uncovered the release of some intrinsic energy within the group that tended to gain momentum. It is the kind of energy that Rahnema (1990) and Clutterbuck (1994) talk about. Parent A who had never actively participated in the past was a keen contributor in all the sessions.

The flexibility of time and the absence of a rigid workshop structure to conform to, helped the parents to participate freely and enjoy the sessions. In the course of time they opened up a lot to each other and there was a honesty in sharing thoughts and there was empathy for each other's problems. They entrusted each other to find solutions for their problems. The case studies further testify that through participatory learning the parents have been empowered to obtain solutions for their problems. An interesting observation was the knowledge that each one had to contribute to the group (for example A breaking down the

activity into steps).

Data also indicate that a mean change of 36.5% was attained corresponding to a gain in knowledge acquired through the programme. The result also proves that the information presented was not all new to the parents who in their natural roles as parents have constantly applied or have been aware of the principles involved. This is consistent with other findings where parents' existing teaching interactions with their children were examined and found that many were already successfully using teaching strategies (Cheseldine and McConkey, 1979; Beveridge et al, 1982). The parents were very much in control of the sessions. The flexibility allowed parents to feel free to interrupt and divert from what was being discussed. Throughout the discussion I, as the facilitator, maintained a low profile and provided facilitation by asking questions or giving suggestions to encourage discussion.

The facilitation process involved flexibility, appropriateness of course material and the ready transfer of power to the parents. Parents recorded a high number of positive statements towards the end of the course indicating a positive change in parental attitude. The teachers also saw an improvement in the children of the participants. This positive correlation indicates that a change in parents' attitude corresponds with a change in the child's attitude and vice versa. Parents enjoyment of their children is an important guiding principle for facilitation of parents' confidence in themselves (Bromwich, 1981). There is ample research associating parental involvement to child achievement although not specifically in the area of special education (Irvine et al, 1979; Herman & Yeh, 1980; Benas, 1980, Grothberg and Deloria, 1983).

Parents are often reluctant to speak in the presence of the professional especially on issues pertaining to training. It clearly

demonstrates that parents can be empowered to share information in an unthreatening, uninhibited environment and this is very much dependent on the facilitative process. Adhering to a structure without flexibility tends to put the professional or course organiser in a controlling situation. This undermines parental power instead of enhancing it. The time taken up by parent discussion was at the expense of lecture time but what was evident was that the lecture time was compensated by parents reading the material at home. Parents found time to do their home tasks despite their family and work commitments. The data gave an indication of the group performance: 66.6 percent of the parents completed the hometasks; 26.6 percent completed more than 50 percent of the hometasks; and 6.66 percent completed less than 50 percent of hometasks. This demonstrates that parents took the responsibility upon themselves without any coercion. The contribution of ideas from other parents and the sincerity in criticism (e.g. 'maybe you are not consistent') and the use of behavioural terminology (eg. reinforcer, consistent, ignore etc.) suggest a positive learning outcome in problem solving. The parents had a more realistic approach to dealing with the problem behaviours. When Al realised that ignoring was too difficult for her she confessed to the group and was willing to try something that suited her.

So often strategies that are suggested by professionals may not be suitable in practice due to so many hidden reasons and this is why unless the parents feel comfortable with the intervention procedure it should not be imposed upon them. G applied the principles of behaviour management and saw changes in her son. She was well supported by the group and encouraged all the way. The results clearly boosted her confidence and the confidence of the other parents. Al similarly applied a strategy that worked and saw the change in her daughter's behaviour. In both cases the results are consistent with research findings that parents are able to learn and apply the principles of behaviour modification to change their

children's behaviour and teach them new skills (Berkowitz and Graziano, 1972; Johnson and Katz, 1973; O'Dell, 1974). The findings of both case studies are also consistent with Sandler's findings of record keeping and the results suggest that record keeping may have heightened mothers' awareness of the quality of childrens' responses (Sandler et al, 1983).

The data collected through informal interviews also show that many parents attended the course at a personal cost. Comments like 'My husband does not like me to go and always nags when I get home,' 'Have to get up early and prepare meals for the family', 'I do my home task in my work place', all suggest that the parents exercised their will and power to overcome these barriers so that they could participate. The initiative to do so demonstrates a degree of empowerment. The parents chose to complete the programme in spite of these barriers without any external pressure.

Results at the end of the programme also show that parents learnt to be more descriptive of their childrens' overt behaviour rather than interpreting the behaviour. The change in the style of description indicates a learned approach which will be useful in fostering teacher-parent interaction.

The final evaluation by the parent participants themselves confirms the empowering effect of the participatory approach. The high mean score of 101.1 out of a maximum 110 for self esteem indicates that the parents were very motivated by the course. Participants scored a mean of 63.3 out of 70 for course validity. This confirms that the course was simple enough and relevant to the participants' needs because they helped develop it. The participants recorded a mean of 28.5 for the category 'interest in macro issues' indicating a desire to help with future training. The results show that parents are keen to teach other parents.

Other studies agree that parents can be recruited as instructors to

work alongside professionals (Bell, Coyne, Jarvis and Pease, 1984). At an informal dinner organised by the parent participants the parents indicated their interest in forming a network and having ongoing courses. The parents requested the Home director to facilitate regular meetings on an informal basis till the parents can organise their own meetings. This clearly indicates that the participatory learning had helped forge a common bond among the participants and is certainly moving them away from the dependency syndrome.

The Certificate presentation was the culmination of the course and it was an empowering moment for the parents to walk side by side with the teachers to receive a common certificate of attendance. Comments like 'I never realised that I could do a course like this. I feel like crying', and 'Now I am confident and I see changes', bear testimony to the empowering effect of participation. The parents had been involved in all aspects of the development even in deciding on the certification. The comments of the parents at the graduation ceremony are positive and indicate a change in their attitudes. The confidence with which the parents came up to express their views is in the opinion of the director and chairman of Bethany Home, a demonstration of empowered parents.

Conclusion

The results of the initial survey were consistent with research findings on course content for parent education programmes. Behaviour management remains a popular topic. All the results clearly indicate a positive change in behaviour and attitude of the participants. Analysis of the field notes indicate a process of empowerment through active participation. The course evaluations confirm parental increase in self esteem. The results of the various measures complement each other and indicate a consistent positive change in attitude. The findings of the study are conclusive that participation of parents in the development of

the parent education programme and the facilitation process are major contributive factors to empowering parents of children with special needs.

CHAPTER VII

SUMMARY AND CONCLUSIONS

The professional based model has created a chasm between the professional and the parent. It subscribes to a top down model of development. Unfortunately this model of development is perpetrated by charities in most developing countries. It has disempowered the target population and enhanced the dependency syndrome. In recent times a new model, the parent-professional partnership model has surfaced. It calls for participation through equality. However many of the parents with their poor past experiences in terms of being patronised lack enthusiasm for participation (McGrath & Grant, 1993). They need to be empowered to participate meaningfully. This study examined three major areas.

- 1. The extent of parents' participation in the development process.
- 2. Parents' acquisition of skills through parent education
- 3. The facilitation process

The study conclusively demonstrates that parents' participation in the development process, their acquisition of skills through parent education and the process of facilitation were clearly the major elements involved and proposes that a parent empowerment model should comprise of those elements. As Yap(1994) puts it, what is transferred is not precepts but principles, not messages but methods, not a package of practices but a basket of choices from which to select. The facilitation process involves the provision of the necessary stimulus, the occasion and incentive for meetings and discussions.

Oliver points out that empowerment is not something that can be given but something that people must take for themselves. According to him, researchers must learn how to put their knowledge and skills at the disposal of their research subjects 'for them to use in whatever ways they

choose' (1990:13-14). The process of participation in a sense leads to the instilling of a positive feeling or attitude. It is a creative process that is intrinsic in nature however the fruits of empowerment can be seen in the observable behaviour and its effects.

Empowerment activities are specifically aimed at counteracting negative valuations (Solomon, 1976). Powerlessness can stem from an experience of discrimination or stigmatisation (Kam, 1996). The role of the professional is to engage in activities aimed at reducing this powerlessness. The objective to involve parents actively means that the facilitator has to exercise trust in their wisdom and go at a pace set by the parents. To empower is to seek the opportunity to respond appropriately according to the desire of the target group thereby enabling them to take over the reins.

According to Lather (1987) the methodology of research should be built upon trust and respect and in participation and reciprocity. The process of empowering relies on the parents having power and exercising it. The process of empowerment calls for the practitioner or facilitator to become less apparent thereby helping generate inertia from within the group and allowing the group to gain momentum from within. 'The facilitator should be compassionate, have empathy for the plight of the target population, have the ability to guide and motivate not in a paternalistic and authoritarian way but in a manner to enhance their confidence and awaken the spirit of self reliance in them' (Yap, 1994:2).

The process of empowerment calls for information to be made available when needed. It should be relevant to the lives of the participants. The validity of any research can be supported by evidence that the participants who have a vested interest in the research view it

as relevant to their needs. It calls for a change in people's perception of their potentials to forge a new reality. It calls for raising people's consciousness to legitimise their claims (Schuftan, 1996).

Occasionally there is the need to feed ideas to prevent stagnation within the group. Appropriate information fed at the appropriate times can help extend the group to attain new heights. According to Drake (1992:271) the three preconditions for effective participation are 'the capacity to exercise power, being in roles in which power can be exercised and for those roles to be in networks such that the exercise of power is effective'.

As McConachie (1986:205) sums up 'professional workers have to understand more fully what they are suggesting parents undertake, and to be guided by them as much as vice versa'. Research must demonstrate relevance to real-world questions (Kadzin, 1982). A participatory approach empowers the target population to have a greater control over their social environment. Participation helps build trust and confidence within the group and enhances their capabilities.

Implications for future practice

Development projects should involve the grassroots population in all stages of the project cycle. The participation of the target population will help break the dependency syndrome. Development practitioners must be genuine in their efforts to facilitate participation. A participatory approach to development will lead to sustainable development through empowering the target population.

As Topping (1986:199) says, 'there is no longer any doubt about the durability of gains accruing from parent training programmes, which has been satisfactorily demonstrated over long periods as well as short' and

as Allan & Hudd (1987:134) point out 'a considerable amount of knowledge' is necessary for parents to be able to exercise their rights fully.

However what the study shows is that simply participating in parent group meetings or attending meetings does not imply that the parent is actively participating. This is a myth, according to Bennet (1985). It is the manner in which information is shared that holds the key to the issue of empowerment. Parents should be allowed to actively participate in curricular development of any programme that involves them. Programmes must be flexible and relevant to the target population. Flexibility must be a crucial characteristic or personality trait for an effective development practitioner. It involves the participation of the facilitator but he or she should not dominate the meetings.

The study has demonstrated that the process of information sharing through participation is a road to empowerment of parents of children with special needs. The study reveals three important aspects. The process of empowerment calls for grassroots participation. It calls for information sharing to motivate people and the progression from passivity to activity is a guided process in the hands of the facilitator.

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APPENDIX 1

PARENT EDUCATION COURSE MATERIAL

Behaviour Management

What is behaviour

Behaviour is an action or a reaction to something. Some behaviours can be seen while others cannot. For example behaviours such as shouting, talking, smiling, clapping can all be seen but behaviours such as thinking, dreaming or mental addition cannot be seen. Behaviour is a means of communication.

							v.				
Give	some	examples	of	behaviours	that	cannot	be	seen	?		

What causes behaviour ?

Anything within us or in the environment around us can cause us to behave differently. For example when you touch something hot you may cry out or jump OR when you think of something sad you may want to cry. When you see food you become hungry. When your boss is around you work hard.

Look	at your	examples	above and	think of	some possible	causes	for those
behav	iours.						
		-				-	
-		.40					
-				_			

What causes us to repeat some behaviours and not others ?

Let's see a few examples !

Ahmad went to school for the first time and some boys bullied him in school. Will Ahmad like going to school again ? Why ?

Rani has a beautiful voice and whenever she sings people praise her ? Will Rani continue to sing in front of people ? Why ?

Ah Meng bought some durians from Ah Kow's stall. When he opened them he found that they were all rotten. Will Ah Meng buy durians from Ah Kow again ? Why?

3
In all those examples what do you think changed their behaviours?
75
Siti cries whenever the ice cream seller comes and the only way to stop her
crying is to buy her an ice cream cone. Will Siti continue to cry whenever the
ice cream man comes ? Why ?
Research shows us that almost all of our behaviours are learned as a result of
our interaction with the environment.
What happens immediately after our behaviour will determine whether that
behaviour will repeat itself or not.
LOOK AT THE EVANDIES ASAIN
LOOK AT THE EXAMPLES AGAIN
What happened when Ahmad went to school
Will Ahmad like going to school ? YES / NO

Will this behaviour repeat itself ?

What	happened when Rani sang ?
Will	Rani sing again ? YES / NO
Will	this behaviour repeat itself ?
What	happened when Ah Meng bought durians from Ah Kow ?
	×
Will	Ah Meng buy durians from Ah Kow again ? YES /NO
Will	this behaviour repeat itself ?
What	happened when Siti cried
Will	Siti continue to cry when she sees the Ice cream seller \ensuremath{YES} / \ensuremath{NO}
Will	this behaviour increase or decrease
1.	BEHAVIOUR IS LEARNT THROUGH OUR INTERACTION WITH THE ENVIRONMENT.

BEHAVIOUR CAN BE CHANGED BY CHANGING THE CONSEQUENCE OR CHANGING WHAT

2.

HAPPENS AFTER THE BEHAVIOUR.

POINT TO REMEMBER

 A behavioural approach involves making the home and family environment to produce a pleasant outcome for the child's appropriate behaviour.

IF THE CONSEQUENCE IS REWARDING THAN THE BEHAVIOUR WILL REPEAT ITSELF REMEMBER! SEE THE CONSEQUENCE FROM THE CHILD'S POINT OF VIEW.

DO BAD OR INAPPROPRIATE BEHAVIOURS REPEAT THEMSELVES BECAUSE THEY ARE REWARDED

YES ! BAD BEHAVIOURS REPEAT THEMSELVES BECAUSE THEY ARE REWARDED

LET'S LOOK AT SOME EXAMPLES

When the naughty student in class does something funny the TEACHER SCOLDS HIM OR SENDS HIM OUT OF THE CLASS.

WHAT IS HIS REWARD ?

There can be a few possible REWARDS eg. he gets the teacher's attention (which he usually may not get for good work), he escapes from the subject which he hates or may not be good at, his classmates may think he is 'hero' to stand up to the teacher, he doesn't like the teacher so he gets to stand outside the class and see what is happening outside......CAN YOU THINK OF ANYMORE!

Let's look at other examples.

In a hospital ward every time the nurse pushes the food trolley into the ward Abu shouts and cries for food so the nurse scolds him but always gives him the food first to stop him making noise. So Abu's bad behaviour has been well rewarded.

Will Abu continue to make noise ? Why ?

What can the nurse do to change his bad behaviour.

When a child screams at the supermarket and asks for chocolate in front of people the mother WILL GIVE THE CHILD what she asks for to avoid embarrassment. The child's screaming behaviour in the supermarket is rewarded.

While the family is watching T.V. the child screams and demands for something so the parents usually give in to what she wants so that they can watch the show peacefully. Again the child gets the reward.

The child takes her own sweet time to finish her meal although she can eat quickly. She gets a lot of scolding when she eats slowly and enjoys the attention and so repeats that behaviour.

To stop her daughter crying the mother gives her a sweet. The child stops crying. For the mother the sweet stops the crying so she continues to give sweets whenever the daughter cries. For the daughter crying is a way of getting sweets and so her crying behaviour is rewarded.

Whenever it is time for a bath Selvi struggles and runs and waits for her mother to chase her. The mother finds this difficult. She gets angry at the daughter, scolds her and occasionally hits her before giving her the bath.

Sometimes she gives up and the child comes on her own accord after a while.

Annie is a sweet little girl but she has a big mouth. She talks back all the time and must always have the last word. This irritates her family and she constantly gets told off by every one in the family. She occasionally gets smacked and when she cries her mother feels sorry and so comforts her.

AS PARENTS WE SOMETIMES FIND THE EASY OPTION OR SOLUTION TO THE PROBLEM AND ALTHOUGH IT SEEMS TO HAVE SOLVED THE PROBLEM FOR THE MOMENT WE FAIL TO REALISE THAT WE STRENGTHEN THE CHILD'S PROBLEM BEHAVIOUR. THE CHILD EVENTUALLY GETS WHAT HE WANTS.

IF BEHAVIOURS ARE REWARDED THEY ARE MOST LIKELY TO HAPPEN AGAIN, EVEN BAD BEHAVIOURS!

SO WHAT IS A REWARD ?

IT IS SOMETHING THAT WE LIKE AND APPRECIATE. IT IS DIFFERENT FOR DIFFERENT PERSONS. SOMETIMES WHAT IS A PUNISHMENT FOR ONE PERSON CAN BE A REWARD FOR ANOTHER PERSON. eg. I like cheese but Mary (the cook at Bethany) hates cheese. Cheese is a reward for me BUT it is a punishment for Mary.

CAN	YOU	NAME	SOME	FOODS	THAT	YOU	LIKE	AND	DISLIKE.
• • •						• • • •			
•••		• • • • •	• • • • •	• • • • • •	• • • • •	• • • •			

COMPARE with your friends and see if they are the same .

POINT TO REMEMBER

FOOD IS A POPULAR REWARD FOR CHILDREN BUT DAILY MEALS SHOULD NOT BE TREATED AS REWARDS FOR LEARNING. FOOD IS A BASIC REQUIREMENT AND EVERY PERSON IS ENTITLED TO HIS/HER DAILY PORTIONS.

KINDS OF REWARDS

There are different kinds of rewards such as

ATTENTION

This is the most important reward you can give your child. Children love to be appreciated, praised, hugged and given lots of encouragement when they perform well. Sometimes we give too much attention to the child when the child is not doing what we want by scolding, yelling or even pleading. The child may enjoy this attention and so refuse to do the work because he is being rewarded for not doing what we want. So remember to give all the attention when the child is doing the right thing and not the wrong thing. Some other ways of giving attention is through smiles, handshakes etc.

SNACKS

Food is an immediate reward and works well for children who lack understanding of other rewards. Food must be given in small portions so that the child does not become preoccupied with eating. If you give too much of the same food too often the child may lose interest in the food. Suitable snacks are small portions of food or drink eg. keropok pieces, biscuit pieces, muruku pieces etc. Reward immediately by putting the food into the child's mouth and always accompany it with

a social reinforcer such as praise or a hug. The more immediate the reward the more easily the child associates the reward with the activity or behaviour. As the child becomes more successful in performing the behaviour or activity than gradually fade away the food reward (giving it occasionally) and replace it with the social reinforcer. Use the food reward only for new or difficult tasks. Some of you may not like using food as reward because it is not age appropriate or it is against your principle. I do not like to use it too but if food is the only motivation for the child to learn new skills or perform difficult tasks than I'll go for it.

ACTIVITIES

Activities can be good rewards for children who like them and would do anything to be allowed to participate in the activity. Games (indoor and outdoor), watching T.V, playing with toys, going on outings, playing with friends etc. can all be activities. Children who can wait for their reward can be coaxed to perform difficult or new tasks before being allowed to participate in their favourite activity. For example " you can watch your video after you have completed your homework."

TOKENS

Token is another way of prolonging the reward if your child understands the value of token. We all receive money as a token. although money is only paper we understand it's value and know that it can be exchanged for our favourite reward.

Similarly a child can collect stars or coupons and eventually exchange it for a reward he likes eg. an activity, food or objects. Some example of tokens are money, stars, stamps etc.

To introduce a child to a token system you must first build the association of the reward to the token. Initially the reward is given immediately in exchange for the token so that the value of the token is established. For example when Ali has swept the floor immediately give him a token (coupon) and say " Bagus Ali, you have swept the floor ". Then immediately ask him for the coupon and say " Now you can ride your bike " or ask him for the coupon and hand him his favourite sweet saying " Now you can have this sweet for the coupon ". As Ali builds the association between the token and the reward then gradually increase the time between giving the token and exchanging it for the reward. You must clearly specify the number of tokens the child can exchange for a particular reward. Have a range of rewards in terms of value so that the child may be motivated to earn more (hence work longer) for a particular reward.

USE THE RIGHT REWARDS AT THE RIGHT TIME

Use food when child is hungry. Use drink when child is thirsty. Use toys when child is bored.

NAME	THE KINDS	OF RE	WARDS YOU	OFTEN GET	FROM YOUR			
WORK	PLACE		•••••					
HOME.						• • • • • • • •	• • • •	
ELSEW	HERE	(EG.	CLUBS,	FRIENDS	COMPANY	Y E	ETC)

Now t	hink of yo	our ch	ild. What	does he/she	e like.			
FOOD	• • • • • • • • •			• • • • • • • • • • • • • • • • • • • •	•••			
ACTIV	ITIES							
ATTEN	TION			******	*****			
If yo	u are unce	ertain	of your	child's like	es or rewards			
i.	Ask the	child						
ii.	observe ;	your c	hild and	see what he	/she likes			
iii.	observe p	peers	and see w	hat they li	ce			
iv.				ty of thing	s (food, items	s, toys	etc.)	and see
	miac you.	. CHIL	4 13 III.E	resteu III.				
-						_		
					work that he/s	she can	do but	usually
refus	es.							

EXERCISE 1.

Tell your child to do the work or activity and tell him/her that you will give _____ when it is done.

WELL DONE FOR TRYING. YOU MAY HAVE SUCCEEDED OR YOU MAY NOT BUT IT DOESN'T MATTER AT THIS STAGE. IF THE REWARD WAS WORTH THE TASK THE CHILD WOULD HAVE DONE IT IF NOT THERE COULD BE 2 POSSIBLE REASONS

- 1. THE CHILD WAS NOT FEELING UP TO IT DUE TO HEALTH REASONS
- THE TASK WAS TOO DIFFICULT AND NEEDS TEACHING

THERE ARE A GROUP OF BEHAVIOURS CALLED PROBLEM BEHAVIOURS.

What is a Problem Behaviour ?

Problem Behaviours can be organised into 3 categories

Behaviours that interfere with learning

eg. every time Ah Hoon's mother tries to teach him to use the spoon he cries and throws the food. This is Ah Hoon's way of saying No! to learning. Some children involve in certain behaviours such as rocking, walking around, looking away or focused in some other objects.

2. Behaviours that interfere with skills already learnt

eg. Banu's mother has to stand by her constantly to urge her to put on her clothes although she has learned to dress herself. Some behaviours such as eating, taking a bath, using the toilet etc can come under this category.

Behaviours that are disruptive to the family or harmful to the child.

eg. Eswari cries and screams every night at bedtime and the whole family
is upset. Some other behaviours in this category are grabbing food from
other children, biting, making noise while family is watching T.V. etc.

The ABC of Behaviour

As we saw earlier behaviour does not just happen without reason and it's the same with problem behaviour. We saw what causes behaviour to increase or decrease and here we are going to see the context where a behaviour takes place will determine if it is a problem behaviour or not.

eg. Ahmad said Hi sayang! to a girl

This only tells us what happened but to understand whether it was an acceptable behaviour or not we need to know the context or where and/or when the behaviour took place.

Ahmad said Hi sayang ! to a girl in front of her father

Now this tells us if Ahmad's behaviour was appropriate or not. Was it appropriate? _____

hat happens next will show if this behaviour will repeat itself.

er father got angry and scolded him.

s we saw in our earlier unit what happens after a behaviour will clearly show f the behavior will repeat itself. In this case Ahmad will not say hello to the girl in front of her father but on the other hand if the girl's father smiled at Ahmad and said hello to him than Ahmad would repeat the behaviour.

It is important to know the setting for the behaviour and also what immediately took place after the behaviour.

Before behaviour

Behaviour

After behaviour

Girl with father

Ahmad said Hi! Sayang

Girl's father is

angry and scolds Ahmad.

EXERCISE 2

Now try and separate these incidents into Before Behaviour, Behaviour and After behaviour and also say if the behaviour will repeat itself or not.

- The traffic light turned red but Ah Kow continued driving and he was summoned by the police.
- Samy stopped at the hawker stall and ate roti canai but it was not tasty.

- . Sita grabs the food when visitors are around and gets away with it.
- . Ah Meng cries loudly whenever he sees his father and his father carries him immediately.
- . James fights with his elder sister whenever she is playing and as a result the sister gets told off by the mother.
- not respond to him.

We saw that some behaviours are alright in some places but not in others eg. It is wrong for Ahmad to say "Hi! sayang" to the girl in the presence of her father yet it may be alright to say that to her if there was no one else around. If you are watching a game of football in the stadium than it is alright to shout but if you are in the class, shouting is not alright.

If a behaviour is not acceptable in a place than you want to change it

There are many ways to reduce inappropriate behaviour. Below are 5 ways you can use.

- 1. Encourage a different behaviour by rewarding it. eg if the child goes and irritates the other children when they are working than give the child a different task to do.
- 2. Whenever the child is involved in an appropriate behaviour reward him

always so that he does not have time to do or think about doing something that is nor inappropriate.

- 3. If a child is involved in a behaviour that you want to remove totally give him an activity or task that makes it impossible for him to perform both activities at the same time. eg. if Ah Chai likes to hit his head with his right hand then give him an activity that involves the use of his right hand eg. holding the rubbish bag.
- 4. Change the physical setting eg. if Ah Kow always hits his sister try not to let him sit close to her or if Mohd. likes to grab food while no one is watching then try to keep the food away from him.
- 5. Change your style of instruction eg.if you usually say "If you don't eat your food I will smack you" then try changing to "If you eat up your food you may watch T.V. for 30 mins, or you may say something positive like "I like the way you are eating so fast "

We learnt that changing consequences changes behaviour.

Here are a few consequences that can reduce problem behaviours.

1. Ignore the behaviour

It is very difficult to ignore certain behaviours like destroying things or hurting someone physically or hurting oneself.

You have learnt that if a child continuously calls you while you are having a chat you tend to ignore that behaviour and it usually stops.

Also during bedtimes if the child cries you tend to ignore and the cry usually subsides. When you ignore the behaviour the simple message to the child is that he will not get any attention. You may even want to walk away from the situation or occupy yourself with some other work. if your child tries to pull your hand, clothes etc just firmly shift the child's hands away as though nothing happened and carry on with what you are doing. The child may try to scream louder or pull harder to try and get your attention but if you persist he will give in to you.

eg. Salmah cries loudly and hits her head on the floor whenever her mother leaves her with her baby sitter. The mother usually hugs her, talks to her and stays with her for a while and steals away when Salmah is not watching. The problem became worse and Salmah held on to her mother and did not let her go. The baby sitter suggested that the mother ignore the crying behaviour and Salmah will settle down. The mother carried this through for a few days and now Salmah cries only for a short while and is happier.

EXERCISE 3: Write the ABC pattern of Salmah's behaviour?

Example. Devi talked a lot of nonsense and made people laugh. Her sister used to scold her and tell her not to talk but all the more Devi talked nonsense and entertained her sister's friends. Her sister was fed up and so she told her friends to help her change Devi's behaviour. It worked!

EXERCISE 4

What do you think the sister's plan was? Write the ABC.

Take away the reward.

Sometimes when a child is given some food the child may play with the food. When this happens you can momentarily remove the food and tell the child not to play with the food then return the food to the child. If the child is not sitting quietly while watching his favourite T.V. programme than you can turn the T.V. off for a few minutes to remind the child to sit properly before turning it on again.

Example: Rajan loves colouring. Sometimes when no one is watching he colours the table top. Rajan's father whenever he sees this immediately takes the crayons away from him and says "No Colouring on table " and keeps it with him for about 1 minute then he returns the crayons and says "colour on paper". Sometimes Rajan throws a temper tantrum and rolls on the floor when the father takes away the crayon but the father ignores the behaviour and when Rajan is back on his chair he give him the crayon saying " colour on paper ". Rajan slowly got the message because his father was consistent in his management of Rajan's behaviour. His father gave a lot of attention when Rajan was doing the right thing. He patted him and said " Very good ", "Good boy"

EXERCISE 5: Write the ABC pattern of Rajan's behaviour.

3. Time out

As parents we have all told our children to go to the bedroom when they behave badly. This is a sort of time out. This procedure removes the

child from his rewarding activity and acts as a punishment. Sometimes instead of sending the child to the bedroom you may send the child to a corner where he can sit but miss out on the activity that the others are enjoying. eg. sitting in the lounge but not facing the T.V. or sitting outside and watching the others play but not allowed to join in. You may time out a child for anything from 5 - 15 minutes. Remember that time out is a punishment and the child MUST dislike it. If the child enjoys it than it is a reward and should not be used to change inappropriate behaviour.

Example. Ah Kwang loves to be in the company of people but has a bad habit of spitting whenever he is told to do something. His sisters were sick of his behaviour and so whenever he spat they took him by the hand without saying a word (as they did not want to give him any attention for the behaviour and made him sit alone in the room for 3 minutes. Ah Kwang hated this. Sometimes he was angry with his sisters and when they went to get him from time out he spat at them. They shut the door on him and let him remain for another 3 minutes before they let him out. Soon Ah Kwang realised that he was being punished for his spitting behaviour. He changed considerably.

EXERCISE 6: Write the ABC of Ah Kwang's behaviour as it was and now.

DOs AND DON'Ts about Time Out

The child must know what he is being punished for. Use few words that just tell the child "where he should go" and "for what reason".eg. "

Awak pukul, pergi ke bilik "

- 2. Be consistent ie. carry out every time the problem behaviour occurs.
- 3. Be immediate
- 4. When you take the child to time out avoid much talk, take the child firmly by hand and lead to the time out area.
- 5. Do not time out for longer than 5 mins at a time.(children may get used to Time out and it can lose it's objective)
- 6. Ignore any tantrums on the way or at the time out place. If the time out experience is not rewarding than the problem behaviour will decrease in time.
- 7. Bring the child out of time out only when he is settled or quiet
- When he is out of time out be quick to reward him for any good behaviour.

WHY NOT PHYSICAL PUNISHMENT (SMACKING/BEATING) ?

1. It is not a consistent and planned approach. You usually smack because you are angry. You may be angry because you are tired, you had a bad day or perhaps you feel that your child is doing it purposely. Just think for a moment! If your child was a 6 month old baby you may be forgiving because you would say that she is only a baby but if your 16 year old does the same thing you would say to yourself that she should act her age. But again we need to ask ourselves is it the child's problem or our

management. All I am saying is that when we look at things from the child's perspective we may be less angry with our child and our punishment may not be a response in anger but a systematic strategy to teach the child.

- 2. You model a behaviour that the child may learn
- It may build fear in the child and prevent a cordial parent/child relationship from developing.
- It can become a form of attention seeking and rewarding experience for the child.
- 5. If the behaviour does not change than the smacking technically is not a punishment because it does not reduce the behaviour. Sometimes we are tempted to increase the intensity of our smacks and these can then lead to permanent injury.

SMACKING IS GOOD FOR IMMEDIATE RESULTS IN SOME CASES HOWEVER. IT DOESN'T TEACH
THE CHILD WHAT TO DO BUT RATHER WHAT NOT TO DO. IT MAY BE USED AS A PUNISHMENT
BY A NON-ANGRY PARENT TO TEACH THE CHILD WHAT IS WRONG ONLY WHEN OTHER METHODS
DON'T WORK.

TO CHANGE A BEHAVIOUR YOU MUST BE CONSISTENT WITH WHATEVER APPROACH YOU USE.

eg. if a child is to be weaned off mother's milk he or she will persist in crying. His crying has to be ignored for the program to be successful. If the child's crying behaviour is then intermittently rewarded by a mother who sometimes give in this crying behaviour will remain.

So we see that what is a problem behaviour to us is actually the child's way of getting what he wants. If you decide to change it than he will soon learn that he has to discover another way to get what he wants. This is then the opportunity for us to teach him the appropriate behaviour by rewarding him when he performs it.

Rahim's family did not just ignore his problem behaviour but when he was sitting at table they gave him a lot of attention. Soon Rahim learnt that to get attention he has to sit at the table.

Therefore every program should have these 2 parts ie. discouraging the problem behaviour and encouraging the appropriate behaviour.

If you tell your child not to do something one day and then allow the child to do it on the next then that behaviour will not change. Similarly for good behaviours if they are intermittently rewarded those behaviours will stay or strengthen.

To change a behaviour you need to be able to describe it in clear and simple terms as you see it happen.

Look at the following descriptions of behaviours.

Ah Lim is a naughty boy.

Maniam is stubborn

Ahmad is lazy.

What do you understand by the term naughty ?

What do you understand by the term stubborn ?

What do understand by the term lazy ?

Now compare your answers

Can you see how different they are. Yet we use these terms often to describe the behaviours of our children. We use the same terms but mean different things.

If we want to change a child's behaviour than we must first be able to describe the child's problem behaviour and the behaviour that we want him to learn in clear and specific terms.

eg. instead of saying naughty we can describe his actions such as he beats his sister, he says dirty words, he does not come home in time for dinner etc.

Inste	ead	of	st	ubbo	orn	we	can	de	scribe	his	act	tions	as	"he	did	not	eat	when	Ι	told
him t	:o".	Ca	an	you	add	l or	ı a	few	more	actio	ons	that	des	scril	oe s	tubb	orn	?		

.....

and instead of lazy we could say Ahmad takes 1 hour to put on his clothes. Can you add on a few more actions that describe lazy?

The following example shows the importance of describing the behaviour exactly and clearly.

Rahim was a new boy at Bethany Home. When describing Rahim his mother said "
He is a good boy but sometimes very stubborn "

Suppose you were Rahim's teacher, what will you think is Rahim's problem? How will you improve his behaviour?

You don't know exactly what she means by 'stubborn' or 'good'!

Stubborn could mean that he does not come when called or does not read his book when told to or does not eat his meal when told to or a variety of things.

Good could mean he can dress himself, goes to the toilet without any help, does not dirty his clothes etc.

POINT TO REMEMBER

Behaviour must be described clearly and simply.

EXERCISE 7

It is always easy to look first at problem behaviours because they affect us.

Look inside this box! What do you see?

•

You are right! The Black Dot! But there is only a small dot on a big white screen. Why didn't you say a big white screen with a small dot? Yes! we tend to focus on the most obvious. That is how it is with behaviour.

For the following exercise let us try and focus on the good or appropriate behaviours of your child.

EXERCISE 8

Identify	your child'	s good or	acceptable	behaviours in	clear	specific	terms
under the	e following	categories	í.				

1.	behaviour	that	does	not	interf	ere wi	th learn	ing		
2.	behaviour	that	does	not	affect	the f	amily	_		
3	behaviour	that	does	not	affect	other	s eg.the	- community	etc	

Now identify your child's problem behaviours in clear specific terms under the following categories.

- problem behaviour that interferes with learning
- 2. problem behaviour that affects the family
- 3 problem behaviour that affects others eg.the community etc

POINT TO REMEMBER

Behaviour must be described in terms of MOVEMENT or ACTIONS THAT CAN BE SEEN.

eg. we cannot see naughty but we can see hitting, pinching, spitting etc.

If you want to change your child's behaviour than you must be able to MEASURE it. If we cannot measure it than we won't know if the behaviour is getting better or worse.

To measure the behaviour, the behaviour must have a beginning and an end.

eg. Anuar started crying at 2pm and stopped crying at 2.30 pm.

Behaviours must repeat themselves

If it happens only once it is not a problem behaviour

All behaviours that can be seen have a beginning and an end.

MEASURING simply means counting how many times the behaviour occurs OR for how long it lasts.

eg. Ah Hoon hit Lee 11 times during recess (how many times)

Siti cried for 45 minutes in bed (how long)

Jenny takes 50 mins. to dress up (how long)

Rao sat at the table for 35 minutes during lunchtime. (how long)

Billy hit his head 10 times (how many times)

Before you measure the behaviour you must decide which method to use ie. counting how many times it happens (FREQUENCY) or for how long (DURATION) The best way to do this is to check out if the behaviour you are observing is of short duration (happens for a short time ie. less than 5 secs eg. hitting, pinching, slapping, calling names etc OR of long duration (eg. crying, not sitting, dressing up etc). If it is for a short duration then it is easy to count BUT if it happens for a long time than it is better to know for how long it takes place.

Select a method that is easy for you to record!

Ask yourself the question "Will counting how many times OR how long show me that the behaviour is getting better.

Example.

- 1. If Siti takes a long time to get dressed, counting how many times Siti gets dressed will not show me that Siti is improving whereas if I measured how long Siti takes to dress than it will show me if she is improving or not.
- If Ah Meng bites others around him it maybe useful to know how often he does that rather than how long.

EXERCISE 9

Look at the following problem behaviours and decide whether a frequency or a duration count is applicable.

1. Ah Meng likes to kick the cat

- 2. Rahim cries when he comes to school
- 3. Ganesan takes a long time to eat his food

POINT TO REMEMBER

THINK OF THE PROBLEM BEHAVIOUR. ASK YOURSELF THE QUESTION " AM I WORRIED ABOUT HOW LONG THE BEHAVIOUR TAKES PLACE FOR OR HOW OFTEN IT HAPPENS. THIS WILL HELP YOU CHOOSE THE METHOD OF MEASUREMENT.

NOW READ THIS STORY ABOUT RAHIM

Rahim always jumps about during mealtimes. He goes and opens the kitchen cupboard and throws things on to the floor or wanders around. When he is told to sit down and eat his meal, he screams and shouts. RAHIM'S MOTHER WAS WORRIED THAT HE WAS NOT SITTING DOWN LONG ENOUGH TO EAT HIS MEAL.

Rahim mother wanted to find out what causes the behaviour to occur and so decided to keep a record of how long he remained seated during meals.

This is her record

	Mon	Tues	Wed
Breakfast	20m	15m	15m
Lunch	15m	20m	15m
Dinner	5m	5m	5m

Rahim's mother noticed that the record showed her that Rahim was worst during dinner times. She soon realised that during dinner Rahim's father was there back from work. The setting was different. During breakfast and lunch Rahim gets a lot of attention from his mother but during dinner his mother is busy talking to his father and so Rahim gets less attention. Therefore he does all the inappropriate behaviour to draw attention.

If we want to change a child's behaviour than we must know what happens before the behaviour and after the behaviour. In this case Rahim's mother observed what happened before and after the behaviour. Can you guess ? (Hint : look at the underlined words)

Now can you fill in the details for Rahim's mother.

Before Behaviour Behaviour After Behaviour

What was Rahim's reward ?

WELL DONE !

The Before record

Before you try to change a behaviour you must first measure the behaviour as it is. This is called the baseline data or before record.

eg. Ahmad had a problem with smoking. He wanted to stop smoking. He kept a record for 3 days to find out how many cigarettes he smoked. This is his Before Record.

Days	Mon	Tues	Wed
No. of cigarettes	23	25	22

AHMAD WANTED TO CHANGE HIS BEHAVIOUR.

Ahmad decided that every time he took a cigarette to smoke he would roll his cigarette with a \$ 1 note and light it.

This is Ahmad's after behaviour

Days	Mon	Tues	Wed	
No. of cigarettes	8	5	2	

The Before record and After record will show the improvement in Ahmad's smoking behaviour.

Let's now look at Rahim's story again. Rahim's mother had taken a Before record of Rahim's mealtime behaviour. She wanted to know how long Rahim sat at the table.

	Mon	Tues	Wed
Breakfast	20m	15m	15m
Lunch	15m	20m	15m
Dinner	5m	5m	5m

The Before record showed that the problem occurred mostly during dinner.

ne discovered the A B C pattern of his behaviour as follows.

EFORE BEHAVIOUR BEHAVIOUR

A B C

When mother talks Rahim walks about Gets attention to father from family

Rahim's family decided to change his behaviour. Because they knew he liked attention , they decided to give him a lot of attention while he was in his seat and to completely ignore him when he was out of his seat. When Rahim was at the table, the family would all talk to him and when he leaves the table they will just pretend not to know and continue conversation among themselves. They were not sure if it would work but they decided to try and measure the behaviour.

This is the After record of Rahim's behaviour.

	Mon	Tues	Wed
Breakfast	20т	25m	20m
Lunch	22m	20m	21m
Dinner	20m	20m	30m

By having a Before and After record Rahim's parents were able to see if it worked and exactly how much Rahim had improved. They were also able to show the record to the teacher.

SYABAS ! MAK RAHIM !

.et's review the program that Rahim's mother introduced to change his pehaviour at mealtime.

- 1. She identified the problem behaviour in clear, specific terms. She did not say that Rahim was difficult or hyperactive. She described his behaviour in a way that described his actions. eg. he jumps, opens kitchen cupboard, throws things etc
- She took a Before Record of what she wanted to change ie.how long he sits at the table.
- She did an ABC pattern to find out what happened before the behaviour and after the behaviour.
- 4. She discovered that the reward he got was attention from the family. She planned to give the attention for the good behaviour which was sitting at the table and decided to ignore the bad behaviour.

FOUR POINTS TO REMEMBER

- Identify the behaviour What is the behaviour
- Identify the context Where and when does it take place
- Identify the criteria When is it a bad behaviour eg. if he talks loudly do you call it shouting
 - Identify the measurement How many times did it happen or for how long

STEP 1. Define the behaviour

i. What is the behaviour.
Can we see it
When does it start
When does it stop

STEP 2. Define the context

ii. What is the context ie. when is it happening, where is it
 happening
 What are the consequences
 Is it acceptable

STEP 3. Define the criteria

Is there too much or too little of the behaviour. If there is too little how much must you increase it to make it acceptable. If there is too much then how much must you decrease it to make it acceptable.

STEP 4. Define the measurement

iii. Does the behaviour last for less than 5 secs. Does it happen many times. If yes, than I will count the number of times it happens (Frequency count) Does the behaviour last for longer than 5 secs and fewer times. If yes, than I will count how long it occurs (duration count).

STEP 5. When to observe.

- If the behaviour occurs at odd times with no pattern to it than observe the whole day.
- ii. If it occurs frequently and at specific times than observe for a short period during that time

EXERCISE 10

Watch the video.

Sanjay is in the pool. He is `swimming 'and enjoying himself but sometimes he just stands and looks away and is not swimming. Out of the allotted time of 5 mins. we would like to know what part of the time Sanjay `swims'.

STEP 1. Define the behaviour

Sanjay is swimming. What does swimming mean to you? Does it mean that if Sanjay is in the water up to his shoulders and moving it is swimming? Would you consider him doing something active eg. jumping, turning etc. while in the water as swimming? Then we can say that Sanjay is not

swimming when he is not doing any of the above.

Once you have determined what swimming is and isn't than you can observe and record.

STEP 2. Define the context

Swimming is an acceptable behaviour in the pool and needs to be increased.

STEP 3. Define the criteria

Swimming time has to be increased to 80 % of the allotted time.

STEP 4. Define the measurement

How long. (Duration)

TEACHING SKILLS

PREPARATION

We learn a lot from the environment. This place is a sitting room. It is very quiet and ideal for me to talk to you. The chairs are arranged so that you know what to do when you arrive. Just imagine if I had all of you in the kitchen now your first thought would be that either I want to show you something in the kitchen or I want to offer you some food or drink or I want to teach you to do some work in the kitchen. If I did not have any chairs you may just stand or sit on the floor. When we teach children the environment must be prepared in such a way that they can guess what they are going to learn. For example if I want to teach Lim to feed independently than I would have set the table (of suitable height), chair and his favourite food in the place where he or the family usually have their meals. When Lim walks in he would be able to guess what the activity would be. We should not have too many distracting things around when teaching takes place.

WHAT TO TEACH

HOW TO SELECT WHAT TO TEACH

FIRST	0 - 1	bserv	e your	chil	d's ty	pical	day a	nd make	a lis	t of	some of	the	self
help	skil	ls th	at you	now	do for	him/h	ner.eg.	brushing	g his	teeth	, tying	his	shoe
lace	. Can	you	add on	to t	his li	st ?							
• • • •		• • • • •	•••••		•••••	• • • • • •		• • • • • • •	• • • • •	• • • • •	• • • • • • • •	• • • • •	••••

You may have in mind other skills that you would want him/her to learn
eg.sweeping the floor, playing games etc. List these as well !
•••••••••••••••••••••••••••••••••••••••
CAN YOU TEACH ALL THESE AT ONCE ?
SO WHICH SKILL DO YOU START WITH ?
Your child may want to learn a particular skill. Observe your child and see
eg. she may be trying to pour a drink for herself or for you, he may want to
hold a dipper and shower himself.
What does your child want to learn?
Your child may be ready to learn a particular skill. Look at the list of
skills you have made and see which ones he makes an effort to do and which
ones he can do parts of already.
List these skills as well
•••••
••••••
You may want to teach a particular skill. From the list again select the skill
that you feel is important to you and the family. Make sure that it is a
simple skill to begin with and one you feel confident with.

9
List the skills you have selected here
NOW YOU CAN BEGIN WITH THE ONE THAT YOU FEEL CONFIDENT WITH
With the second
Write it down
EVERY SKILL INVOLVES MANY STEPS YET IT MAY SEEM SIMPLE TO US BECAUSE WE HAVE
LEARNED TO DO IT AS ONE ACTION.
Let's look at some simple tasks or skills. eg. drinking from a cup, eating
with a spoon,
This could involve several steps although we tend to perform it
instantaneously.
Drinking from a cup
1. Hold the cup
2. Bring it to the mouth
3. Place the rim between the lips
4. Tilt the cup

Drink

5.

Eating with a spoon

- . Hold the spoon
- . Fill the spoon using a scooping action
- 1. Bring the spoon to the mouth
- i. Open mouth and receive food
- 5. Return spoon to the plate

EXERCISE 11

Task: Tooth Brushing

Get together in pairs. One of you will pretend to brush your teeth while the other would observe CLOSELY and record every small step of the activity.

Remember ! Some steps may seem unnecessary to us but it can be a big step for a handicapped child .

Now take another skill you have chosen and break it down into steps. Create as many steps as you possibly can.

HAVE YOU DONE IT ! GOOD ! TAKE A BREAK ! YOU DESERVE IT!

POINT TO REMEMBER

We have to break every skill into small steps that can be easily taught.

WHEN IS THE BEST TIME TO TEACH MY CHILD ?

There is no special time for teaching. It is up to you to choose a time when you can give undivided attention to your child. It can be for only 10 or 15 minutes a day. Ideally this time coincides with the activity that he/she has to perform as part of the daily routine. eg .teaching to brush teeth in the morning, teaching to put on the clothes after a shower etc.

WHERE IS THE BEST PLACE TO TEACH ?

Ideally it is the place where the activity usually takes place eg. sweeping in the hall, eating at the dining table, brushing teeth in the bathroom etc.

WHAT ARE THE THINGS I NEED TO TEACH WITH.

Use materials that are interesting and easy to use for the child. For example if you want to teach your child to button the shirt then start with large buttons before you go on to small buttons. Similarly if you want to teach how to catch a ball then it is easier for the child to catch a big ball than a small ball or to wear a shoe that has velcro straps rather than shoe laces. Always use materials that are comfortable for the child to use materials that ensure success.

HOW TO TEACH

" IF YOU TELL ME, I MAY NOT UNDERSTAND, IF YOU SHOW ME, I MAY BE ABLE TO FOLLOW YOU BUT IF YOU DO IT WITH ME IT MAKES IT EASY FOR ME. "

elling

hen we tell the child what to do we so often assume that the child nderstands our instruction when he performs well. Often the child may not nderstand our words but gets the cue to perform from the gestures that we rovide without realising. For example the mother may say to Raja, "Go and ring the chair" while pointing to the chair. If the mother said softly " Go and bring the chair" and gave no cue ie. no gestures, no facial expression, and no looking in the direction of the chair then we will know if the child understood the instruction.

Telling has to be simple and clear in few words.eg. come here, sit, eat your lunch, brush teeth, watch me, your turn etc.

Make sure that your child is listening to your instruction.

Showing

Sometimes the child may not understand what we say. In that case we need to show the child what we are requesting. Do bit by bit or step by step so that the child can observe and imitate. For example if I want to show how to pour myself a drink than I would say to the child "Look at me " as I hold the bottle and pour myself a drink. It becomes even clearer to the child when you make your actions simple and say aloud what you do at each step. Then I would say to the child "now your turn." Let the child look at what you do and imitate. Use the child's favourite drink so that the activity becomes rewarding.

Physical help

Sometimes the child is unable to follow the directions or imitate actions. In

such cases you have to physically guide the child to perform. Many children have learned to become helpless by being 'SERVED' by their parents. Parents tend to know the child's every need and so even before they can ask, everything is often done for them. The child does not learn because there is no need or expectation from the parents.

Physical help means to place your hand upon the child's hand and make the child 'do' the activity. As you physically guide the child's hand he/she becomes accustomed to using his hand. As the child becomes confident gradually relax the hold. In stages if necessary move your hand to the wrist, elbow and eventually just "shadow the hand" before completely fading away that help. Always accompany every step by telling what you are doing. This will help the child to associate every step with an instruction.

Every step or approximate step of a behaviour that the child successfully learns must be rewarded. This will keep the child motivated to learn.

'SLOW AND STEADY WINS THE RACE.'

Before a child can learn new skills, he/she must possess some basic learning skills.

What are these basic learning skills ?

The child must be able to identify objects, be able to follow directions and be able to imitate simple actions.

What this simply means is that the child must able to look, understand what we say, and do it.

Many children do not have these skills and need to be taught.

Example 1.

Teaching Halim to look when called

Position

Put your Halim in a chair in front of you close enough so that you are nearly touching Halim's knees with your knees. If you think that Halim may run away from the position, then back his chair against a corner as shown in the illustration.

Materials

Keep a reward (something Halim loves eg.pieces of chocolate or biscuits or keropok)

Teaching Method

- 1. Hold the reward in front of your face and say "(Halim ", Look at me!.
 If he looks at you than immediately put the piece of reward into his mouth while saying " Pandai! or Bagus! ".
- 2. Wait for a few secs till Halim looks away then repeat the above.

If Halim does not respond at all, than carry out the following steps.

1. Hold the reward in front of your face with one hand and with your other hand, physically turn Halim's face to face you while saying "Halim", Look at me!

Wait till you gain eye contact, then reward him immediately by putting the piece of reward into his mouth while saying " Pandai! or Bagus! ".

. Once he is able to do step 1. then repeat step 1. but instead of physically guiding his face to face you, gently touch his chin so that he looks at you.

Wait till you gain eye contact, then reward him immediately by putting the piece of reward into his mouth while saying " Pandai! or Bagus! ".

3. Once he is able to do step 2. then repeat step 2, but instead of gently touching his chin so that he looks at you, just say "Halim ,, Look at me ! . .

Wait till you gain eye contact, then reward him immediately by putting the piece of reward into his mouth while saying " Pandai! or Bagus! ".

- 4. Once he is able to do step 3. then repeat step 3. but this time when he looks at you and you have gained eye contact, count 1 to 5 silently and then reward him by putting the piece of reward into his mouth while saying "Pandai! or Bagus! ".
- Once he is able to do step 4. then repeat step 4. but this time hold the reward out of his sight and when he looks at you and you have gained eye contact, count 1 to 5 silently and then reward him by putting the piece of reward into his mouth while saying "Pandai! or Bagus! ".

Example 2.

Teaching Ah Leng to come when called

Before you can carry out this program your child must be able to physically

move from one place to another.

Materials

Keep a reward (pieces of chocolate or biscuits or keropok)

Teaching method

- Stand 2 steps away from Ah Leng. Say to Ah Leng "Ah Leng, Look at me."
 When Ah Leng looks at you ,put your hand on Ah Leng's shoulder and gently draw Ah Leng towards you while saying "Ah Leng, Come here." Then when he responds appropriately, reward him immediately by putting the piece of reward into his mouth while saying "Pandai! or Bagus! ".
- When Ah Leng is able to perform step 1, repeat step 1 but instead of putting your hand on child's shoulder, motion to child with hand (as illustrated) saying " Ah Leng ", Come here." Then reward him immediately by putting the piece of reward into his mouth while saying "Pandai! or Bagus! ".
- 3. When child is able to perform step 2, repeat step 2 but instead of putting your hand on child's shoulder, motion to child with hand (as illustrated) saying " Ah Leng " , Come here." Then reward him immediately by putting the piece of reward into his mouth while saying " Pandai! or Bagus! ".
- 4. Once your child is able to perform the above then stand 2 steps away from your child. Say to child "Ah Leng ", Look at me. "When child looks at you, then say "Come here" When he comes reward him immediately by putting the piece of reward into his mouth while saying "

Pandai! or Bagus! ".

5. Now that your child will come to you when called from 2 steps, begin calling him progressively from 3 steps, 5 steps, 7 steps, 10 steps away and reward appropriately.

Remember it may take time and you have got to keep working consistently. Don't be discouraged if the program seems to be going fine and all of sudden it doesn't work. It could mean that you are moving too fast or you may have to change the reward.

Make sure that each session ends with success.

Example 3.

To Teach Rani to Identify and Name Objects and items.

Preparation

Take an object or item that you would like to teach your child to name. Begin with a toy or item that your child will use often.

eg. Rani uses the spoon for eating.

Position

Sit facing your child at a table (preferably a small table). Have nothing on the table except the object that you want to teach her to identify and name. eg. To identify spoon and name spoon

Materials

Have a variety of spoons so that Rani knows that spoons can be made of metal or plastic, they can be different colours and different sizes. Have 3 other items that Rani can identify and name. eg. book, doll, hat

Method

- Place a spoon on the table in front of your child, point and say "This
 is a spoon". Then ask "What is this" ? Wait for child to respond " spoon
 ". Say "Pandai!" and reward immediately with a piece of biscuit.
 - 1. Continue this procedure with each spoon till she is able to name spoon.
 - Keep the spoons and other items hidden and present each, one at a time in the order spoon, spoon, spoon, book, spoon, doll, spoon, spoon, hat, spoon.
 - Ask the question "What is this?" and wait for answer. If she makes a mistake, tell her the correct answer and continue till she gets all right.
 - Once Rani can identify and name spoon then you can mix it up with other items she can already name and test her as above.

xample 4.

'o Teach John to identify the colour red and name it.

'osition

Sit facing your child at a table (preferably a small table). Have nothing on the table except the object that you want to teach her to identify and name.

Materials

Have a variety of items that are different in shape, size and texture BUT are all red.

Method

Follow the steps set out for teaching "spoon". One the child knows the colour red then use red with different colours to test.

EXERCISE 12

Teach your friend to identify and name a jawi, tamil, or chinese character.

Example 5

Teaching Hari to imitate eg. clap hands, stand up, sit, jump, touch nose. lie down etc

Preparation

This teaching can be carried out in a quiet place in the house.

Position

Sit on the floor or on a chair facing the child.

Materials

No materials are needed except pieces of reward (Hari's favourites).

Teaching Method

- Say "Hari look at me". When he looks at you, say " Good Boy ". Then say "Hari, clap your hands" while clapping your hands
- If Hari does not clap, hold Hari's hands and clap them for him while saying "Hari, clap hands".
- 3. Say "Good clapping Hari" and reward him.
- 4. Continue repeating step 2 and when you feel that Hari is beginning to put some effort into it, then slowly release your hold on his hands and

gently fade out the help.

- 5. Reward him for every attempt he makes.
- 6. Now repeat step 1 and wait for Hari to respond. If Hari does not respond, then prompt him by just touching his hands and saying "Hari, clap hands".. If he still does not respond then go back to step 2 and follow through.

Once Hari is able to imitate clap hands go on to teaching him simple actions such as stand up, jump, touch toes etc.

Follow the teaching program as above but remember the rules.

- 1. Pick one simple direction to teach
- 2. Model ie. show how to do
- 3. Physically guide him to do.
- 4. Reward him
- 5. Gradually fade out the physical help.

To teach Maria to remain longer on a task or work.

Problem behaviour :

Maria's mother is concerned that Maria does not stay long enough on any work that she is given. Maria is able to sweep the floor but she refuses to do it for longer than 3 minutes. Maria's mother wants her to sweep the floor and

complete the job. This may take Maria 10 minutes to do so.

Maria's mother decided that since Maria liked asam very much, she would go every 2 minutes to Maria and say "Good sweeping, Maria "and put a piece of asam into her mouth.

Since Maria was rewarded every 2 minutes (ie. before she got tired of sweeping) she continued to remain on task. The reward kept Maria motivated.

Maria's mother intends to gradually increase the reward time from 2 minutes to 3, 4, or 5 minutes and eventually fade out the food reward and give more social praise. Maria's mother may allow Maria to watch T.V. (which she loves) after she has completed her work.

Teaching how to push, pull, turn, hold and release

These skills are basic fine motor skills that your child needs before he/she can perform other difficult tasks such as dressing, brushing, feeding, opening doors etc. Children generally learn these skills in a play situation and for those who have not these skills have to be specifically taught.

To teach to pull

Activities

- 1. Let child pull toys on wheels with a string attached
- 2. Attach a piece of string to one end of a favourite toy. Sit with the child on one end of the table and lower the toy on the other end. Help child to slowly pull the toy making it appear suddenly. Slowly fade out the physical guidance and allow child to pull independently.

3. Pull pillow case out of pillow.

To teach to turn

Activities

- 1. Turn on taps
- 2. Cause effect toys with turning function.eg. musical toys
- 3. Screwing and unscrewing the tops of bottles, tooth paste etc.

Holding and releasing objects

Materials

Several different objects and an empty box

Activity

Begin with objects that are fairly small and easy to hold.

Method.

 Place your hand on child's hand and guide child's hand to pick any object the child wants to. If child is not cooperative than hold child's wrist in an upward position as illustrated to increase the grip on object.

- 2. Slowly move child's hand with object to box and say "Open hand" and to make it easier (if child is uncooperative) hold child's wrist downwards as illustrated. Let object drop. Say" Pandai " and reward child if activity itself is not rewarding.
- 3. Repeat steps 1 and 2 but gradually fade out the physically guidance till child is able to pick and release independently.
- 4. Reward every effort.

Water Play

Materials

Plastic containers, plastic bottles, plastic cups, empty cans etc.

Activity

Fill one container half full with coloured water. Help child to pour water from one container into another. Begin with full assistance and gradually fade out allowing child to pour independently.

This skill will help with attention and coordination and also prepare child for future skills such as pouring a drink into a glass.

RULES

- 1. Pick a simple direction eg. give,
- Gain child's attention
- 3. Tell your child clearly and simply
 Use words that your child can understand.
 Use short sentences for instruction

eg. while showering use simple instructions such as "take the dipper ", "

Take water ", " Pour water ", " Take soap ", " Soap yourself ", " Leave soap
in container "

If the child is not able to do than show the child.

You take a shower or pretend to do so while the child watches you do each step. Tell clearly what you are doing so that the child understands the instruction. Then let the child have a turn performing the step while you give the instruction.

If the child makes a mistake than show the correct step again.

If the child still has difficulty performing the step than physically guide the child. What this means is that you place your hand upon the child's hand and gently move him/her to perform the step. As the child learns to perform the step gradually remove your hand.

Tell the child what to do

eg. " Take the brush " AND IF THE CHILD DOES NOT UNDERSTAND POINT TO THE

BRUSH AND SAY " Take the brush " AND IF THE CHILD STILL DOES NOT RESPOND THEN SHOW THE CHILD BY PICKING UP THE BRUSH WHILE SAYING " I take the brush "

Once you have shown the child what to do repeat the first instruction and see if the child responds. If not than perform the step by guiding the child's hand to task.

REWARD THE CHILD FOR FOLLOWING EVERY INSTRUCTION

WHAT TO DO WHEN IT DOES NOT WORK

Ask yourself a few questions

Does he/she still like the reward or should we change it ?

Is the task too difficult ?

Is the session too long ?

Is he/she getting bored with the activity ?

Does the child have the basic skills for the task ?

Am I using the wrong materials ?

Is it the right time and place ?

Are my instructions clear ?

Am I giving sufficient help ?

Sometimes there can be other hidden reasons for a bad day eg. child not feeling well, child is tired, child had some problems in school etc.

Some play activities that keep students on task while you are busy.

STRINGING BEADS

Objective :- being on task without adult supervision

- using hands and eyes together
- can become a rewarding activity
- skills can be transferred to other skills such as feeding, writing tying shoelaces etc.

Materials : Shoe lace or string with one end tied as a knot, wooden or plastic beads. empty spools

Setting: Seated at a table or on the floor without any distractions.

Taking off beads

Method: Place your hand on child's hand and remove last bead while saying "keluar bead"

Slowly fade your physical help till child is able to work independently.

Reward child for effort.

Threading beads

- 1 Model to child by putting one bead through while saying " tengok sini "
- Next place your hand on child's hand and pick a bead
- 3 Thread it while giving full physical assistance.
- 4 Then let child hold the string in other hand.
- 5 Repeat steps 2 and 3
- 6 Once child is able gradually fade the physical assistance.

POINT TO REMEMBER

Use smaller or larger beads according to child's level.

Also stiffen the end of the string initially and gradually cut it off in to make activity more difficult.

PUZZLES

Materials: Puzzle with few pieces initially than go on to ones with more pieces as the child gets better.

Method:

- 1. Start with one simple piece ie a circle.
- 2. Tell child " masuk dalam ' demonstrating.

- Take the same piece half way out and say "masuk dalam" and give physical guidance if necessary
- Now hand child a piece and instruct child to put it in and if necessary with full physical guidance.
- 5. Slowly fade away the help till child can do it independently.

POINT TO REMEMBER

NEVER DO MORE THAN ONE PIECE AT A TIME . GRADUALLY REMOVE ASSISTANCE. SLOWLY PROGRESS FROM A ONE PIECE EASY PUZZLE TO MORE CHALLENGING ONES.

READING SIGHT WORDS FOR COMMUNITY LIVING

REMEMBER THAT THIS LESSON ONLY TEACHES THE CHILD TO IDENTIFY THE WHOLE WORD NOT TO RECOGNISE INDIVIDUAL LETTERS.

PREREQUISITE FOR SIGHT READING

- Child must be able to match picture to picture and word to word. (if not able start teaching with 1 set of pictures and then gradually increase)
- Must know the meaning of the word (if not teach by pairing with the picture of the word or object to be taught.)

What words to start with

own name, names of family and friends, things he sees each day, numbers, school name etc.

Materials :

Write the words CLEARLY on 3 in. x 6 in. white manila cards. Use CAPITAL LETTERS BECAUSE MOST SIGNS IN THE COMMUNITY ARE IN CAPITAL LETTERS.

ASSESSMENT

Write all the words you want to teach on cards and put them in a shoe box. Take out one at a time and ask child to name the word. Put aside all the words the child is able to name on one side. The remaining words will be the ones you will have to teach. Make it into a game by including other members of the family but REMEMBER TO BEGIN ALWAYS WITH THE CHILD.

TOILET TRAINING

Toilet training is among the most important skills your child needs to learn. It is not an easy skill to teach but many of you have successfully trained your child to learn to use the toilet. Even normal children vary in the length of time they take to be toilet trained. There are however few principles that may be helpful to know for you to teach your child this skill.

What are the skills involved in toiletting

- 1. Knowing when to go to the toilet
- 2. Holding on
- 3. Knowing where to do it
- 4. Pulling pants down
- 5. Sitting on the toilet or standing (for boys)
- 6. Eliminating in the toilet
- 7. Cleaning up
- 8. Pulling pants back up
- 9. Flushing the toilet

10. Washing hands.

Your child may already know some of these skills. However you may just want to teach him one skill only initially ie. eliminating in the toilet and do most of the others for him. Gradually as he cooperates you may want to teach the other skills to complete his training.

Is my child ready for toilet training.

Yes, he is ready if

- He can follow simple directions eg. Come here , Hashim
- 2. He can sit in a chair for 5 minutes
- 3. He eliminates at intervals of more than 1 1/2 hours.
- 4. He does not have other medical problems that affect elimination eg. urinary tract infection etc

TOILET TRAINING TAKES TIME AND EFFORT BUT IT'S WORTH IT !

The most important step in toilet training is to keep a record of his eliminations. This will give you a pattern of his eliminations. Do this for 2 weeks prior to beginning your training program.

How to keep a record

During the 2 weeks continue whatever programme you are presently following.

Don't start a new programme. If he is in a programme already then keep a

record of whether he urinates or has bowel movement in the toilet. Otherwise check your child every hour or so and see if he is wet, dirty or dry and record this information in the RECORD SHEET. This can be hard because you will have to do this from the time he wakes up till he goes to bed.

Your record sheet can look like this

Tarikh :			Та	rikh	T	Tarikh:		
waktu	seluar	tandas	waktu	seluar	tandas	waktu	seluar	tandas
7.00								
8.00								
9.00								
10.								
11								
12								
1.00								
2.00								
3.00								
4.00								
5.00								
6.00								
7.00								
8.00								
9.00								

...and on this sheet you can record in the column under 'seluar' basah (b), kotor (k) kering (ke) or basah dan kotor (bk) to indicate that these actions have been performed outside the toilet. If the child performs the following functions in the toilet than record them in the tandas column. Do not forget to record your date of observation.

Start with Bowel or Urine training ?

It is advisable to start with the bowel training first because it is messy and performed less frequently than urination. It is also easier to notice if your child wants to move his bowels because of the tell tale signs that frequently follow such an action.

HOW TO WORK OUT A TOILET TRAINING PROGRAM

On your record circle all the B with Blue, all the K with green, all the Ke with yellow and the KB with red. Then add each up in the row they appear and insert the total in the table shown.

JUMLAH

		JUILA		
waktu	KB	К	В	Ke
7.00				
8.00				
9.00				
10.				
11				
12				
1.00				
2.00				
3.00				
4.00				
5.00				
6.00				
7.00				
8.00				
9.00				

For most children there will be some pattern to the elimination. It will indicate the most likely times of elimination. For example if 1 p.m and 2 p.m

have higher scores of K and KB it is most likely that if the child is taken to toilet 15 minutes before 1 p.m or around that time he is likely to perform. This chart also helps you to inform the teacher or baby sitter that the child will usually do his business between such and such a time.

Take the child every 15 or 20 minutes till he eliminates.

If your child does not have a pattern, then you may have to take your child 15 minutes before the earliest bowel movement and then every 30 minutes or so. If the child has only one bowel movement a day then it's not necessary to toilet him after he has performed.

Follow the same procedure as bowel movement for urination to determine a pattern.

USE REWARDS AS OFTEN AS POSSIBLE TO ENCOURAGE SUCCESS!

- 1. Ah Meng is intellectually handicapped and for the past 9 years his mother has felt sorry for him and done everything for him. She now wants to teach him to feed by himself. Can you help break the task into simple steps? Where should she start? Can you please show her?
- Whenever Manimalar hears the sound of trucks she is afraid and runs away as fast as she can. The mother tries to hold her but she breaks free and runs. What is the ABC of Manimalar's behaviour? How will you advise the mother?
- 3. Zul likes being praised and tickled and whenever his father sees him doing something helpful around the home his father tickles him and says You are a great helper!
 Will Zul's behaviour continue ? Why ?
- 4. A young man came to Bethany asking for money and we refused to give him any knowing that he is an alcoholic and offered food instead which he refused. He came again a few days later and we sent him away and we did not see him for several weeks when he came we consistently did the same. What the ABC of his behaviour. Is it being increased or decreased? Why?

Unfortunately on his 4th visit after several months someone gave him the \$2 that he asked for. He then began coming more often? Why do you he came again? Will it be easy to terminate or extinguish his behaviour?

5. Vasu is constantly fighting with his brothers and sisters and always

gets told off by his mother but his behaviour is on the increase?

His mother insists that he is being punished? What do you think?

Can you give her some suggestions.

- 6. Sometimes Liew's parents give him hugs when he does what he is told and at other times they give him an ice cream eg.if he behaves well at the supermarket and when he has had a bath and put on his clothes they take him for a walk. What types of rewards or reinforcers did Liew receive?
- 7. If behaviours are _____ they are most likely to happen again.
- 8. Razali's father told him that if he wanted to go on the weekend Bethany camp he will have to earn 5 stars for good behaviour at the makan table.
 What kind of reward system was Razali's father using?
- 9. Musa's mother told him to get changed for school but he refused to do it immediately. She scolded him and threatened to tell dad when he came home from work. Musa became annoyed and shouted at mum and said unkind words to her which upset her so she smacked him. Musa angrily got changed and went to school. When he returned from school he faced an angry father who caned him and when he started crying Musa's mother felt sorry for him and told him to go and ride his bicycle which is Musa's favourite activity. Musa's relationship with mum and dad is strained and he is beginning to spend hours on the phone with his friends.

Is there another way Musa's parents could have sorted out the problem ?

10. Jane's wanted her sister's text book and when she was refused she threw herself on the ground and cried. Everyone ignored her behaviour and when she tried to throw articles around her father took her firmly by her hand and told her that she will remain in the toilet for 1 minute for throwing. As soon the 1 minute was up, her father went back and when he found her quiet he brought her out and allowed her to pick an activity that she wanted to keep her occupied. Whenever she left the table and went to her sister he took her activity away and told her that she will only have it when she was at the table. She remained on task for a long time.

Did the father manage her behaviour well ?

What kinds of consequences(punishment) did he try and which one worked?

What should the father do if he found Jane not in the toilet but out washing dishes (which she likes doing) in the kitchen ?

- 11. Whenever in a crowd Chin Fong gets very upset ? Her parents are keen to help her overcome her fear of crowds. Can you help ?
- 12. How should behaviour be described ? Why ?
- 13. Give 5 good and 5 bad points about physical punishment ?
- 14. While travelling in the car Rahim's brothers and sisters were making noise and fighting with each other while Rahim sat quietly. Rahim's father scolded the children and threatened to stop the car and smack them if they did not settle down. It worked for a while but soon resumed again. Do an ABC and see if you could change the children's behaviour by changing the A or the C?
- 15. Can behaviour be measured ?

What are the 2 ways of measuring behaviour ?

- 16. Ricky cries for a long time before sleep. His mother often goes in to settle him down but the crying gets longer and louder. Ricky finds it difficult to sleep when he hears the other children playing.

 Ricky's mother is keen to work out a program. Can you help her? How will you measure Ricky's behaviour to show that your program is working?
- 17. Break the task of feeding independently into small steps ?
- 18. Janet was on a feeding program. She had learnt how to hold the spoon, bring it to the mouth and feed herself but was unable to load the spoon. The staff eventually found a way of overcoming the problem and helping Janet feed herself. Can you guess what they did ? (Clue : they did not teach Janet but made a change Can you guess the change ?
- 19. What are the 3 known ways of teaching a child ?
- 20. What are the 3 basic learning skills ?

the child must l..., ide.... , follow.

APPENDIX 2

FAMILY INFORMATION NEEDS SURVEY

Family Information Needs Survey

This survey questionnaire is designed to find out what information or programs you as parents of a child with special needs would like to have and how best they can be presented to you.

How to fill in the form

STEP 1

The first box will tell us how much you need this information.

You can put either 0,1 or 2 in the box.

Write 0 if you do not need this information at all.

Write 1 if you are not sure if you need this information.

Write 2 if you definitely need this information.

STEP 2

The second box will tell us how best we can share this information with you.

Write A if you like it to be in the form of a group meeting. Write B if you like it to be shared on a one to one basis. Write C if you like the information in the form of reading materials. Write D if you like the information presented on video.

How to handle my child, s behaviour

How to teach my child to eat, to dress, to go to the toilet etc.

How to teach my child to communicate with others

How to teach my child to play

How to teach my child to do work at home

How to teach my child to make friends

To know if my child is getting better or not

To know what help is available for us

How to encourage my child

How to know what my child likes and dislikes

How to know if I am doing the right thing or the wrong thing

How to talk to the teacher about my child's problems

0	_1_	2_	_A_	B-	Lc_	D-
						1
				_	_	_
				_	_	-
-	-			-	-	+
						Γ
	-	-			-	-
	_	-		-	-	-
						1

How to plan for my child's future

What do the terms IEP, Task Analysis, Behaviour Modification etc. mean

What are my rights as a parent of a child with special needs?

How to help my family and friends better understand my child's disability.

How to get help from the government and other sources

To know what services are available at present for my child

To know what services my child might receive in the future

Please use this space to indicate any other information you may n ed

PART 2

Here please indicate your preferences for the format of a group training am, if conducted. Please tick the appropriate box or insert your own ails where necessary.

Group training programs must be week conducted during week public hol	ends	5		day day			ght/d	
A day's session must not be longer than		2	3	4	6	8	hours	
The whole program should not run for lon	ger	har	n	2 4	6	8 1	.0 day	s
The training program should include (pl	ease	tio	ck)				
Lectures videos slides notes (hand	ou	ts					
practical sessions (working with your c	hild	ren)					
role plays (play acting)	di	scu	ssi	ons				
time to ask questions	hor	new	ork	(hon	neta	sk)	
Participants must pay for the training						YE	S/NO	
I want a certificate at the end of the c	course	e				YE	S/NO	

APPENDIX 3

PARENTS'COURSE EVALUATION

PARENT COURSE EVALUATION QUESTIONNAIRE (PCE 1)	
Please answer these questions honestly and frankly as it will help me to revis	se the material and make it more
relevant and interesting. (Please tick the dots)	
The answers are in a scale of 1 -10 where 1 means Definite No and 10 means Defin	nite Yes ?
	1 2 3 4 5 6 7 8 9 10
The course content was relevant	
	1
I feel more confident in managing my child/rens behaviours	** * * * * * * * * * * *
	1
My behaviour has changed through this course	** * * * * * * * * *
	1
I am more positive and optimistic in my approach	*
	1
I can now teach my child new skills by simplifying them into small steps.	********
	1
I now know how to encourage my child through rewards	*******
	1
I am less angry when dealing with my child's problems	*
	1
I feel more confident to talk to teachers about my child's problems.	********
	ĺ
I feel confident to teach and encourage other parents.	
	1

This course has helped me to deal better with my other children as well.	
	1
I feel confident to teach other parents about behaviour management and teaching.	*******
	1
The course content was not too simple.	******
mb	
There was enough homework	
There were sufficient examples.	*
	1
The lectures were interesting	
	1
There were enough practical sessions.	*
Who place was smitchle	1
The place was suitable	1
There was enough time for questions	·
	Ţ
This training should continue for all parents	·
961	
I want to help Bethany Home in future training.	
This was the star of Personal continuous for the star of the star	
I like the idea of Parents meeting staff to work together	1
I have seen / begun to see some changes in my child already	·
an de municipalitation → transferial de maniferial de maniferial de la companya de la companya de maniferial de la companya del la companya del la companya de la companya	e: COMMO 등 및 NUMB 및 N (1992)
The time was suitable	

PARENT COURSE EVALUATION (PCE 2)
PLEASE UNDERLINE THE STATEMENTS THAT REFLECT YOUR FEELINGS

more confident better relationship with my children/wife/husband

enjoyed the meetings boring too simple managed to put into practice

got what I expected lectures interesting lectures made me sleepy

learnt from the lectures learnt from other parents waste of time

eager to learn more very helpful I can become a trainer

feel I know as much as the teachers feel I know more than the teachers

I can be a good teacher less confident no change in myself

will not change my ways has changed my behaviour notes were good

I feel more in control of my anger notes are interesting

notes are difficult to read interesting to read boring to read

too dull to read enjoyed discussion times question time was interesting

my questions not answered ono chance to speak some answers not suitable

meetings too late should have more courses for parents

enjoyed meeting other parents keen to see other parents go for courses

want to change the attitudes of our community things have got worse at home

teaching is easier now I praise more now I shout less now

I believe that caning is the only way I can do a reinforcer survey

I dont think that the course has changed my ways in managing behaviour

I want more courses in epilepsy/ downs syndrome/ physical handicap/ autism/ others

invite more specialists print the notes in Malay

I know about ABC I can measure behaviour I can do task analysis

print the notes into books there are not enough examples

this is the best course I have attended I learnt a lot

should have videos should have practical sessions with children

homework was difficult homework was easy course not well organised

course well organised seating arrangement was good

APPENDIX 4

RECORDING FORMS AND TEST SHEETS

PRE AND POST INTERVENTION QUESTIONNAIRE - Individually administered

Are the following statements true or false.

Some children behave badly because they are naughty ?

Punishment reduces bad behaviour.

Scolding is punishment.

Behaviour is learnt through our interaction with the environment.

In a hospital ward every time the nurse pushes the food trolley into the ward Abu shouts and cries for food so the nurse scolds him but always gives him the food first to stop him making noise.

Is the nurse doing the right thing or not ?

What would you do ?

When a Devi screams at the supermarket and asks for chocolate in front of people her mother WILL GIVE THE CHILD what she asks for to avoid embarrassment.

If you were the mother or father will you do the same ?

Why ?

While the family is watching T.V. Rani screams and demands for something so the parents usually give in to what she wants so that they can watch the show peacefully.

Would you agree with the family's action ?

What will you do ?

Puspa takes her own sweet time to finish her meal although she can eat quickly. She gets a lot of scolding when she eats slowly but the behaviour is still the same.

What will you do ?

To stop Swee Ling from crying the mother gives her a sweet. The child stops crying.

Did she do the right thing ?

Why/Why not ?

Whenever it is time for a bath Selvi struggles and runs and waits for her

mother to chase her. The mother finds this difficult. She gets angry at the daughter, scolds her and occassionally hits her before giving her the bath. Sometimes she gives up and the child comes on her own accord after a while.

What would you advise the mother ?

Annie is a sweet little girl but she has a big mouth. She talks back all the time and must always have the last word. This irritates her family and she constantly gets told off by every one in the family. She occasionally gets smacked and when she cries her mother feels sorry and so comforts her.

Did the mother do the right thing ?

Rajan loves to slap his father. Everytime he does it his father pretends to cry and says not to beat him but Rajan gets more excited and continues slapping him.

How will you stop this behaviour ?

Abu went late to work and his boss was sympathetic and excused him, so Abu continued to arrive late every day till his boss warned him and told him not to be late again. Abu decided to come early to work for the next 2 days and then came late again. His boss just ignored Abu's late coming so Abu continued coming late.

What would you do if you were Abu's boss ?

Why do people find it difficult to observe anti litter laws?.

Rahim always jumps about during mealtimes. He goes and opens the kitchen cupboard and throws things on to the floor or wanders around. When he is told to sit down and eat his meal , he screams and shouts. RAHIM'S MOTHER WAS WORRIED THAT HE WAS NOT SITTING DOWN LONG ENOUGH TO EAT HIS MEAL. Rahim mother wanted to find out what causes the behaviour to occur. What do you suppose she did?

How will you teach a child to feed herself?

How can you tell if a child's behaviour is getting better or worse?

If your child refuses to do a given task what will you do?

Do you feel confident to deal with your child's behaviour problems?

Can you measure behaviour? How ?

Whose responsibility is it to teach your child?

REKOD ABC

Mama	Murid		Nama	Cigku	
Nama	nullu	•	Nama	CIERU	- 6

Umur : Tempat :

Tarikh: Aktiviti:

lasa	A pa berlaku sebelum kelakuan	Kelakuan murid yang di nampak B	Apa yang berikut
	A		С
	9		
		1	
		1	
			1
	1	1	
	*		
			06

Borang Kiraan Berapa Lama (Duration Count)

Nama Murid : Nama Cigku :

Umur : Tempat :

Tarikh: Aktiviti:

Kelakuan (Apa yang di nampak)

	Masa Mula	5	10	15	20	25	30	35	40	45	50	55	60	Masa Tama	Jumlah Masa
														t	
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	Masa Mula	5	10	15	20	25	30	35	40	45	50	55	60	Masa Tama t	Jumlah Masa
		-	-	-	-			_		-		-			

Borang Kiraan Berapa Kali (Frequency Count)

Nama Murid : Nama Cigku :

Umur : Tempat :

Tarikh: Aktiviti:

Kelakuan (Apa yang di nampak)

Tarikh	Waktu Mula	Kiraan (Frequency Count)	Waktu Tamat	Jumlah Masa	Jumlah Kiraan
		*			

AKTIVITI HARIAN (Daily Activities)

the state of the s		
Mama	Murid	
Mama	TIULIU	

Nama Cigku :

Umur :

Tarikh:

Masa	Tempat	Bahagian	Aktiviti	Kebolihan
				-2
			4	

MAKLUMAT GANJARAN (REINFORCER SURVEY)

Nama	Murid	:		Nama	Cigku	:
Hmur				Tempa	at :	

Jenis	Ganjaran yang sesuai	Ganjaran yang tidak sesuai
Benda		
Aktivi ti		
ti		
		120
Lain-		
lain		*

APPENDIX 5

CERTIFICATE OF ATTENDANCE



RUMAH BETHANY

HUTAN MELINTANG, PERAK.

Certificate of Attendance

This is to certify that

attended

A BASIC COURSE ON BEHAVIOUR MANAGEMENT AND TEACHING SKILLS

FOR THE EDUCATION OF CHILDREN WITH SPECIAL NEEDS.

(**30** hours)

Solomon John Lecturer Bethany Home Dr. A. Victor Chairman Bethany Home Jayasingh Rajiah Director Bethany Home