

Penyampai : DATIN SERI DR. SITI HASMAH BINTI HAJI MOHD. ALI
Tajuk : THE FAMILY: THE VITAL PROVIDER OF CARE FOR THE DISABLED
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Madame Chairman; Distinguished Guests and Speakers;

Ladies and Gentlemen.

It is a great privilege and honour to be given this opportunity to present my paper to you this morning. May I express on behalf of my Society, the Society for the Rehabilitation of the Disabled, Selangor and Federal Territory, and for myself, our very warm welcome and felicitations to you who have come from far and near. I am confident that the sharing of knowledge and experience regarding the prevention and rehabilitation of the disabled will give us all, particularly we in Malaysia, more insight into the complexities of the caring of the disabled and the various ways of overcoming them.

Ladies and Gentlemen, 2. My paper "The Family: The Vital Provider of Care for the Disabled" presents the experience that my colleagues in the Society and I had at various times in the course of our work here in the City of Kuala Lumpur or in the rural town like Jitra in the north of this Peninsular.

3. Most of us, if not all of us, here are blessed with normal healthy children, blessed with family happiness and the joy of seeing our children grow from infancy to childhood, adolescent and adulthood and the blessings of knowing that they would achieve their aspirations in life.

4. But let me present a few families who are otherwise blessed.

5. Mahmud married his first cousin Karina. Theirs was an arranged marriage. Unfortunately it did not turn out well family wise. Their first child was born with Hydro-cephalus and died at the age of two. Their second child is a girl who is a spastic and mentally retarded. Their third child, a boy, arrived three years later, and is suffering from Cerebral Palsy. Mahmud, the father was a teacher by profession but had gone into business. So he had great hopes for his son. He still refuses to believe that the boy will never be able to inherit and ultimately run his family business. He has made attempts to get his son treated and educated. Progress was slow but the boy was able to walk without assistance but still suffers from restlessness and a lack of concentration. The father still believes that he will get better than what he is now.

6. The girl of course is far worse. She has not responded to treatment and now depends on drugs to lead a fairly normal life. Karina the mother was badly affected by the birth of these three defective babies. She went through all the normal bitterness of mothers of such children. "Why did this have to happen to me?", she asked herself time and again. Fortunately for her, she did not wallow in self-pity for long. Nor did her husband make accusations against her.

They talked it over and sought help outside the family circle and adjusted themselves to their situation. They did not reject their children. Instead they cared for them and loved them and did what they could for them. Today they remain a happy family but the condition of their children who are now 15 and 12 years old remains unchanged.

7. Denis' case was slightly different. He was a healthy child at birth and grew up to the age of 10, a healthy vigorous child. Then he underwent a tonsillectomy under general anaesthetic. He came out of it with brain damage.

His parents were shocked. They were well to do and had other healthy children - one boy and two girls. What were they to do with this child? Being intelligent they sought help from specialists. Brain damage, they were told, cannot be treated, but the child could be trained to use all the skills he possessed and to use whatever new ones he was capable of developing. They followed that advice. Denis is now nearly twenty. He uses a wheel-chair to move around but he can read, speak, typewrite and use a computer. He

has become a self-reliant young man. He had the support of his parents and of his brother and sisters; also of his other relatives who were not ashamed of him. He has many friends too.

8. But life unfortunately is not always filled with happy stories like the above. Take Ali for instance. He is 13 years old and lives with his mother. He used to be "autistic" but he is now showing more social awareness and is interacting with his friends. His parents are separated.

His father lives overseas while his mother is a clerk with a local firm. The mother needs constant assurance and advice on her son's abilities. She is anxious of his future and of his well-being. Due to the pressure of work, she finds the boy sometimes unmanageable at home. So she has visited a few residential centres but is depressed and concerned about the conditions in those places. She hopes to find a suitable home where Ali can be managed by people who are specially trained and know what it is like to be mentally handicapped.

9. And then there is Swee Lin. She was born blind. Her parents abandoned her at a Convent. Her only "family" consists of the other handicapped children at the Convent and the nuns who looked after her. She was trained in braille and is now working as a telephone operator in a commercial firm.

The Attitude of the Family

10. Many parents and families have conflicts about a disabled child in the family. Positive attitudes of parents and normal siblings become the most vital therapeutic motivator for a disabled child to achieve his self image and to lead to positive action towards rehabilitation. On the other hand, negative attitudes might not only totally destroy the disabled child's development and make him apathetic towards all efforts to help him but might also disrupt normal family functions and unity.

11. All parents have a right to expect normal children and when they discover soon after birth or later that their child is defective, parents feel shocked and traumatised.

It often happens that one parent may begin to accept the child sooner than the other.

12. Father's pride may be so wounded that he may not be able to face realities. His reactions of shock and anger and disappointment come from the shattered dream of not having a child that will fulfil his expectations and aspirations. There is a tendency for fathers to isolate themselves away from the home so that they may not come into contact with the disabled child. It has been pointed out by Klaus and Kennel that "American fathers often become extremely active outside the home after the birth of a defective child, frequently taking on extra jobs or duties, ostensibly to provide more money for the family, but unconsciously to avoid contact with the disabled child as much as possible and thus avoid facing their feelings." 13. Motherhood is everything to most women and although the joys and expectations for the new baby have been somewhat shattered, generally the motherly instinct will allow her to accept the child for what he is, more quickly and more easily than the father. Some mothers on the other hand, reject their disabled child soon after birth.

14. The feeling of guilt, "Why me? What have I done?" is still common here in Malaysia as is everywhere. Accusations of each other for nameless faults, accompanied by feelings of revulsion, of inadequacy and of grief commonly occur even among the educated and the highly intelligent. The first interaction of emotions between mother and father may even lead to a break-up of the family unit. If it does not, the reactions later of in-laws and relatives may bring matters to a head. In Asian societies, such happenings are not unusual. Somebody is to be blamed: if it is not the father, then it must be the mother. That seems to be the rationalization, and very often it is the woman who is ultimately saddled with full responsibilities of the disabled child. There could not be far worse a situation than a mother, who is already in want of emotional support for having a defective child, being left by her husband, scorned and boy cotted by in-laws and relatives. The additional crises in her life may lead her to reverse her attitude towards her child to total rejection and abandonment. Sometimes death of the severely defective child comes as a relief for both the divorced mother and the child.

15. Abandonment of a defective child is an extreme case.

Sometimes the child is placed in the care of relatives or in foster homes. This is another way out. As in the case of Ali, the parents seek a place which would take over their responsibility.

16. However not all parents react in this way. Many ultimately overcome their initial shock and self-pity and for love of the child seek help. Initially they may not accept the fact that the child is defective. They may seek second opinions hoping for better news. But ultimately they come to accept the fact that the child is handicapped and during the process make the emotional adjustments necessary within themselves to deal with the situation.

17. Parental care of the handicapped child may take many forms depending on the reaction of the parents to the child.

If they are embarrassed by it they may keep the child isolated - away from the eyes of the world. If they feel that the child is a curse of some kind then the child may be subjected to many cruelties - beatings, starvation, kept in a filthy state, etc. There could also be the other extreme where the child is over-indulged or given highly protective treatment. If the parents are sensible and intelligent like Mahmud and Karina, they will first make adjustments within themselves. Then they will love and cherish the children even if the case is hopeless. They will seek advice on the treatment and training of such children and will nurture hopes for their future. Those hopes, of course, must be reasonable ones. They will also encourage their relatives and friends and their other children to react favourably to the handicapped child.

The Attitude of the Normal Siblings.

18. The part played by parents in the care and training of handicapped children cannot be overemphasised. It is indeed extremely important. We hear much these days of leadership by example. It is by example that parents can induce a similar attitude of loving and kindness towards handicapped children in the other members of the family. Children can at times be cruel in their reaction to the handicapped. But children as we know are great imitators. If parents treat their disabled child as naturally as his handicap permits, then his siblings will think much less about it being a problem than if the parents are very tensed and depressed by the situation and are in constant sorrow over his condition.

19. Admittedly it is difficult for normal siblings in a family to accept the presence of a disabled child. If the child had been normal and then became incapacitated, like Denis for instance, his incapacity would be acceptable in the normal course of events. The other children will feel sorry for him and will be protective. So will his true friends. But all will need guidance in order not to be over-protective. The presence of the disabled child from birth too is not difficult for the other children to accept.

Children on the whole are much more adaptable than adults.

20. They will be more ready to accept a disabled brother or sister into their games if they know it does not have to happen all the time, that they do have some time to themselves. This acceptance into play, of course, depends on the disabled child's age, personality, level of play and degree of handicap.

21. It is most difficult for parents, especially the mother, not to devote the maximum of time and effort on a disabled child whose life expectancy was formerly considered short. But in doing so there is always the danger of causing deep resentment and jealousy of the disabled sibling by the normal siblings. It is therefore essential that parents should also give their normal children enough time, love, interest and concern to avoid any rivalry for affection and attention.

Maintaining Normal Family Functions within the Family Unit.

22. One of the more important needs of the families involved with disabled children is for the family unit to maintain normal functions as nearly as possible. There are many problems that may hinder such functioning. First, the parents may be so guilt ridden having produced the disabled child that they feel

they must dedicate every moment of their lives to the child's welfare. Unfortunately, these intense feelings of obligation may interfere with normal interactions of the parents with each other, with their normal children, and with their friends and relatives.

Second, the additional financial burden of the disabled child may hinder normal expenditure for recreation and other activities and even for necessities. Third, the problems of care may be of such a nature that the parents are either unwilling or unable to find someone to provide the necessary supervision while they engage in even minimal recreational or social activities.

23. Professionals counselling the parents, need to help the parents dissipate their feelings of guilt or at least minimise them. They must be helped to realise that the advent of a disabled child should not destroy normal family relations. For those of us who work with the disabled, it requires of us a great deal of knowledge of their struggles besides maturity on our part. We must be able to help when help is needed but encourage the person to do for himself even when the struggle is painful to watch. We need to give accurate but not hurtful feedback without the fears often felt that it is adding pain upon pain. We must be able to explore our feelings as to what we would feel in their situation. We need to be available to hear out the struggles and pain, frustrations and fear, yet not feel overwhelmed by their expression but rather know that these must be expressed in order to go on with the task of growing.

The Role of the Extended Family.

24. Much has been said about parents and siblings but let us not forget the extended family which can also play a vital role in providing care of the disabled. In Malaysia, the extended family system is still the system for most families and very much so in rural areas where traditions, customs and habits prevail. By tradition, the elders are respected and young couples are expected to approach them for suggestions and advice in all family matters. When given, it is expected to be taken in toto or be accused of disrespect. In normal circumstances the extended family takes part in all family events, be they happy ones or sad ones.

25. Well informed and understanding in-laws, and elderly relatives play a major supportive role for both the parents and the disabled. Just like the parents, they will be shocked and greatly disturbed at the initial stages but if parents discussed openly the condition, limitations and expectations of the disability, a positive attitude towards the disabled can be developed and a healthy understanding relationship established. Love and kindness from extended families can be fostered in the family circle and the parents helped out of their shock.

26. The extended family can be a great help to parents by caring for the disabled now and then to give parents a break. This is also good for the disabled as the company of others beyond his immediate family will assist him to get along with others and prepare him for the environment outside his home. There are instances where defective children were left with grandmothers and relatives who were totally responsible for the caring of the children and for the initial effort to seek treatment and rehabilitation.

Caution, however, has to be emphasised against over protectiveness and sympathy that will destroy the defective child's growth and will to learn and to adjust himself.

27. As mentioned at the very beginning, the views of in-laws and relatives can help to support or break the family saddled with a disabled child. We should, in this present era, come away from the guilty feelings, and the search for a scape-goat to blame, for these will only deter early efforts for self-adjustments and early caring for the disabled. There were many instances, when parents and in-laws accept the circumstances as "fate" and as such, do nothing about it. "It is God's will, so there is nothing else that we can do about it". Such expressions have been freely used among the ill-informed and the ignorant. They do not realise that even if God wills that their child be defective, He wills it also for them to make every effort to seek assistance from those who know.

The Needs of the Disabled from Parents and Family

28. Among the needs of the disabled to which parents and family should pay the utmost consideration are: a) Acceptance which is one of the basic needs of humans, and the disabled person is no different from anyone else. They need to be accepted as worthy individuals by his family and friends. Loss of self esteem, feelings of inadequacy, especially among disabled adults may lead to depression and loss of will to face the world. Bitterness and anger towards himself and people around him will result in more difficulty in getting understanding, acceptance and care by friends and family. A vicious cycle is built up, detrimental to both the disabled and the family. The family should therefore be the first to understand and accept the disabled member.

b) Communication is a primary need of the disabled for understanding of their disability and limitations.

They need to know how their disability will affect their lives and how they can make the best of achieving the maximum potential for a meaningful existence. The immediate family is again responsible for establishing communication through clear, concise and understandable messages, particularly so for the visually, aurally and linguistically handicapped.

c) The freedom to grow. Every disabled person no matter how severely disabled, has the ability to grow.

It is the responsibility of parents and professionals to provide the fertile environment and proper atmosphere for the disabled young to grow to his maximum potential and for the disabled adult to adjust himself to a restricted environment.

d) Special attention and care. Disabled person need special attention from parents and family. It has been said that the temperamental characteristics of infants depend largely upon the response he gets from his parent. The first occasion for this mother-infant interaction is through feeding and the success of it depends upon how the infant reacts to it. Positive response from the infant would encourage the mother more into caring for it, thus creating a reciprocal love relationship between the infant and its mother.

29. The disabled child would demand the mother's exclusive attention and care for its needs. The disabled adolescent needs to depend upon others for help beyond the daily experience of the normal person. It may be as simple as helping him to stand, sit, eat or be bathed. This puts him in a position where he is much more dependent on the mood and personal inclinations of others whom he dare not alienate because he needs their help. The Family's Role in Prevention

30. I have discussed so far situations in which disability has already occurred in the family and their reactions towards the disabled person. More importantly is the family's role in the prevention of disability, particularly the responsibility of both parents to avoid repetition of having a congenitally defective infant. One would think that Mahmud and Karina whose 3 children were born defective, would ponder after the 2nd delivery, but the desire and hope of getting a normal child from the next pregnancy spurred them on to risk another chance but without success.

31. Health Information and Health education are important and vital to mothers with normal and abnormal children as most disabilities are preventable. At least, the disability could be reduced to a minimal degree. Although the majority of debilitating conditions here may be due to poor nutrition, infection, birth traumas, accidents, poor antenatal care and after-effects of drugs, alcohol and smoking, genetic counselling should be stressed to parents who have had a congenitally deformed child. Cousin marriages still take place among Asian societies regardless of the tragic consequences that may well arise. Often the excuse is that marrying a relative is better than marrying a total stranger and there is also the question of inheritance of property etc. A lot of in-breeding also occurs among certain groups in the Malay community where it seems that they cannot marry outside their flock.

32. Traditionally in Malaysia, as elsewhere in Asia, pregnant mothers do not attend ante-natal care and are attended to by indigenous birth-attendants during deliveries at home. Fortunately for Malaysian mothers, the Government Rural Health Services have expanded widely into the rural areas and 85% of ante-natal mothers are being covered by the Health Services. Health education of ante-natal mothers cannot be more emphasised in the prevention of congenital abnormalities of their unborn child and to

prevent post-natal and neonatal infection that may well be the cause of a lot of unhappiness later on.

33. Fathers and relatives can play a very important supportive role in encouraging mothers to seek sound advice throughout the pregnancy and to ensure of a safe delivery by trained health personnel. Many injuries to mother and new born have happened during deliveries conducted by traditional birth attendants in the past. Where transport is difficult in the late hour of the night and trained personnel not available, the mother has no choice but to resort to the traditional birth attendants in cases of emergency. It is most heartening to note that in Malaysia the percentage of deliveries attended by untrained midwives in the rural areas have now dropped from 22% to 8% of all deliveries in 1982.

34. Prevention therefore begins by the expectant mother attending ante-natal clinic regularly for examination and follow-up and to receive advice for a normal delivery of a live, healthy and normal baby. It should be regularly followed up by monitoring the child's health and growth at the child Health sessions and at home, and routine immunization, advice on proper infant feeding and nutrition and child care should be given.

35. Parents and families tend to forget that accidents and injuries are also causes of disability. We read of traffic accidents every day; the many that were crippled mentally and physically from such accidents. Perhaps these major accidents are beyond the scope of the role of the family to prevent, but let us think of the seemingly minor accidents that can occur within the home environment and which can cause just as serious results as traffic accidents.

Scalding by hot liquids and severe degree of burns causing severe scarring in the limbs, body and face and disfigurement. The innocent play of children with a sharp object ending in blindness and deafness. During festive seasons, how many parents knowingly sanction the firing of the home-made bamboo cannons and crackers by their young children and then face the tragedy of having a deformed child when the hand or eye is ripped off in the blast. Many of these home accidents have caused endless tragedies to families. It becomes more tragic because they are preventable and needs a little more than common sense to prevent its occurrence.

The Family's Role in Rehabilitation

36. The family has to understand the objective of rehabilitation and the duration required before any positive results can be seen. The rehabilitation process should work towards adjustment and total integration of the individual in the community so that he or she will be able to actively participate and contribute positively to the community. The ultimate objective of rehabilitation is to establish the independence of the individual and to enable him or her to live with dignity in the midst of other members of the community.

37. Voluntary efforts of parents to seek help for their deformed child and their support in the early days and months of rehabilitation are of crucial importance for long term rehabilitation programmes. Parents should be willing to be taught how they could daily help their child at home so that progress towards achieving his potential can be more rapid than if the child were to rely solely on the therapists.

38. The normal siblings in the family could also help in the rehabilitation process by understanding the condition of their deformed brother or sister and by being helpful in whatever way they can, without being overprotective and overly sympathetic. Love and kindness, patience and encouragement are the incentives to successful rehabilitation. These can only be adequately provided for by the immediate family of the disabled person.

The Government's and Voluntary Organisations' Role in Helping the Families.

39. Many families do not realise the importance they play in their children's lives. The child looks towards its own family for acceptance and guidance. However, very often, the family feels inadequate to the task, for it has been placed in a situation out of the ordinary. They will then seek help outside the home.

40. Parental counselling at the critical period when the parents are in shock, fear and anxious about their child is very important. Perhaps the greatest initial assistance that can be offered to parents is respect for their feelings. The primary person involved with the family is usually the doctor who often assumes a therapeutic role.

Time and ability to listen and comfort are essential considerations because parents need to express their feelings rather than to merely listen to reassurances that everything will turn out all right.

41. The availability of counselling services either in Government Hospitals and Clinic or Voluntary Organisations is therefore indispensable in helping parents tide over this emotional shock and to guide them to the treatment and rehabilitation of the child. Periodic counselling will slowly but surely equip the parents with knowledge of management of the child effectively.

42. Once the mother gains confidence in herself and braves the traditional obstacles that confront all mothers of disabled children, facilities in either the outlying Hospitals and Health Centres or General Hospitals must not only be available but also be easily accessible to her. The Health and Hospital Staff must be sympathetic and supportive at this prime moment when the mother is self motivated and in a receptive mood to do something for her child.

Referrals from doctors and staff to specialists in the various disciplines of handicapping conditions should be made available. There should not be too many delays. Every mother with a young disabled child is already under stress.

Hospital procedures and regulations should be reduced to the minimum to avoid the agony of waiting and finding solutions to problems indirectly related to her disabled child, e.g.

producing an official letter from the husband's employer, from the referral Staff, paying hospital deposits etc.

43. The importance of immunization and nutrition in the prevention of diseases that can cause disability must be regularly stressed by Health Staff in all the Clinic sessions, and homes visited for detection of defaulter's.

It is heartening to note that the Ministry of Health has already started a nutritional surveillance of children in rural and urban areas and will also detect the handicapped in its various forms for ultimate registration.

44. Another aspect of assistance required by parents of disabled children is educational guidance. Voluntary organisations dealing with disabled children can play an initial role of taking these children for preparation for integration into normal or special schools later. Every parent would want to see their child progress in either the academic or vocational field and places for them should be available.

45. Workshops and informal gatherings for parents with disabled children could be organised by voluntary organisations periodically to enlighten them with the facilities available for them and their responsibilities towards caring for their children.

46. There are many disabled people in Malaysia and through out the world who have done remarkably well despite their disabilities. In Malaysia, we know of visually handicapped people who have reached the highest level of education. Few more, including the physically handicapped, will be trained overseas. Such people, and also well known persons in other parts of the world, should be quoted often enough or shown on TV programmes and in the press media so that others like them may be encouraged to emulate the determination and faith that each of these successful persons had in attaining independence and meaningful lives despite their disability. Some of them reached even more than a normal person could.

47. We recently had a documentary film of the Japanese thalidomide girl Noriko shown in Kuala Lumpur. It was a fine example of the determination and courage of a girl, who was lovingly cared for by her

mother, until she could fend for herself and, excel herself in education, music and swimming using her head and 2 feet. The Government and Voluntary Organisations could do well to help families overcome their distress and problems by showing more of such films regularly to the public.

Conclusion

48. Much of the disabilities that occur in children and adults are through no fault of their own. The parents and families will be the immediate circle around the disabled persons that can create a suitable and conducive environment for development and adjustment to society and independent living. Acceptance, positive and realistic attitudes of parents and families will greatly influence the future of the disabled. Love, care and support of families are vital.

There can be no substitute, for the disabled child has been born into the family and the disabled adult live and grow with them.