The Special Family

As special educators all our concern, energy and expertise is expended on the special children in our care. Until we understand a special family with all its struggles and joys we cannot hope to adequately reach the special child.

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We, as teachers, are often unaware of the problems a special family faces, and the stresses and strains a handicapped child inflicts upon them. Children are formed by their families, they define themselves through parents and siblings.

The arrival of the handicapped child

When parents have been told their child is handicapped, their reactions can be very varied. They feel anger and resentment, they feel helpless and fearful and most experience a long period of grief. "How will we cope?", "What will become of our child?" are only two of the many disturbing questions which will add to the stress of the couple. The manner in which they have been told, their own abilities to give each other support, their attitudes towards cause and blame, towards telling others, towards looking for and accepting support, all have vast implications for the future of both their child and the whole family.

How should parents be told? This is a very delicate area and in frequently mishandled. What is sometimes intended by a doctor to protect the parents can in fact offend and intensify their pain.

In their book "A Handbook for Parents with a Handicapped Child" (Arrow 1977) Judit Stone and Felicity Taylor list the following suggestions to the medical profession:

1. As far as possible to tell both parents together.
2. If it is reasonably certain that there is evidence of handicap, tell parents as soon as possible.
3. In the early days there should be someone to talk to – possibly another parent.

4. Special training for all medical and nursing staff to inhibit uninformed comment.
5. Ensure that parents, G.P.'s and health visitors are fully aware of the child's condition and what this will mean. "It is very difficult for parents to understand after being told by their hospital doctor that their child is handicapped, how their G.P. and health visitor can be unaware of this fact" (Stone/Taylor 1977)

Getting and giving help

Parents of handicapped children need support, a willing ear and time to talk their problems through.

Professionals can help parents, children and themselves by listening. Listening conveys respect. Many doctors do not feel qualified to listen professionally. They see counselling as the domain of the social worker, the professional counsellor or the psychiatrist and are reluctant to get involved in case they might mishandle delicate issues.

Parents should be encouraged to contact whatever organisation deals specifically with their child's handicap. These organisations can help put groups of parents in contact with each other so that they can meet and discuss their mutual problems and offer each other support in difficult times.

Caring for a handicapped child

One of the worst things that can happen to either a handicapped child is that its mother may be so afraid of doing something wrong that she'll do nothing for him at all. A mother whose first child is handicapped is particularly vulnerable in this situation. She needs to be assured that she is most unlikely to harm him, as caring for a handicapped baby presents the same difficulties encountered in caring for any baby.

In her book "Daily Living with a Handicapped Child" (Croom Helm 1984) Diana M. Millard says it is important that family, friends and neighbours should be alerted as soon as possible to the child's handicap, as this removes some of the feelings of isolation which can be very stressful for the family.

Arguments arise every now and again that parents are not the best people to care for their handicapped child. These seem to fall very flat if one examines some of the counter arguments given by Clara Claiborne Park in her book "The Seige" (Penguin 1972).

a) Parents know the background of their child's handicap, and can see in the stimulating and warm environment of the home how he is progressing.
b) Parents can act immediately when necessary. With constant contact all year round, small alterations in the child's behaviour or development, are quickly spotted.
c) Parents will know the child's language. This is frequently seen by professionals when parents can translate what appears to be pieces of unconnected sound.

d) Parents are in a position to provide stimulation whenever they think it necessary and can, through their deep knowledge of the child, see the difference between stimulation and pressure.

THE NEEDS OF PARENTS WITH HANDICAPPED CHILDREN

1. The need to accept.
2. The need to know the nature and extent of their child's handicap.
3. The financial need. Trips to doctors, hospitals and clinics all may have to be paid for. Also the purchase of special equipment .
4. Parents need to be aware of the benefits to which they are entitled.
5. Parents need help to cope with tension.
6. Parents need to see a solution to the lifelong care of their child.
7. Parents need accurate and well-timed professional advice.
8. Parents need a comprehensive supportive counselling programme.

Grief

The reaction of parents to the birth of a handicapped child has often been explained in terms of the grieving process. Cunningham, in his book "Down's Syndrome: An Introduction for Parents" (London: Souvenir Press 1982), points out that in bereavement we grieve for someone who has died, but in the case of a disabled child, the parents grieve for the loss of the expected "normal" baby. Many parents continue to feel a sense of "aloneness' long after a bereaved person would. A possible explanation for this might be that in our culture parents are not expected to express their negative feelings regarding their handicapped child, whereas it is quite acceptable that the bereaved would express such negative feelings as sadness, anger and guilt.

Parents of a handicapped child cannot escape their sorrow: their child is a constant reminder of what has been lost and of what trials the future may hold. For them the grief has no end. Before they can begin to accept their child, they must recognise their grief and deal with it as best as they can; hence, the need for sympathetic help and practical guidance from both professionals and friends.

Loneliness

Pain of any kind isolates. Families of handicapped children experience a special kind of loneliness. When a normal baby arrives in a family, everyone tends to be excited, but for parents of a special child, people don't exactly know how to react. They don't want to bring up the topic, not knowing how parents feel about their baby, so often they ignore the fact that the child is different. Ignoring such an obvious fact can put much strain on friendships.

Parents may also find that few understand what they are going through. Many find the support of parents groups invaluable, because they meet other parents with similar difficulties. However self-help groups may isolate parents from "normal" families, instead of integrating them into the community as a whole. This must be guarded against.

Fear

Fear often strikes parents long before the handicap is detected in the child. Often the mother is the first to spot a slight difference in the baby. Parents may often carry the fear that something might be wrong with the child for weeks, months, even years without mentioning it to anyone – even to the other spouse.

Fears for the Child: In the early years, children spend most of their time with their parents, and are sheltered from rejection. But what happens when the special child goes out into the community? Parents agonize about the social implications of handicap. They may worry about how a child will cope with his disability if he reaches a stage when he is able to understand that he is different.

Fears for Parents: Ordinary parenting follows a cycle that respects mortality. A severe disability in a child disrupts this natural order, by extending the child's development beyond parents' strength, health and lifetime. Being a parent of a handicapped child doubles worries about death. The possibility that a disabled child may end his days in custodial care seems to mock parents' efforts to make him independant.

Fears of Love: Parents wonder about their capacity to love their child or to love what he may become. To fail to love our child seems unthinkable, unforgiveable, but in fact many parents reject their handicapped baby, in the early stages of shock and grief. Parents who cannot overcome feelings of rejection often focus on the handicap, not on their child; it is the handicap and what it represents that they find so hard to accept.

Guilt and Self Doubt

"What sin have his parents committed, that he was born blind?" (John 9:7)

Parents faced with a handicapped child are forced to abandon many of their bright dreams for the future. They also may experience a sense of inadequacy – feeling as if they were incapable of producing a normal healthy child. This feeling intensifies when the child's disability is the result of a genetic or hereditary condition. Feelings of guilt and inadequacy can be strong even when they have no justification; hence the need for clear, truthful and compassionate counselling for parents.

It is vital that parents are told that feelings of revulsion are normal in their situation, and usually transient, otherwise there may be dangerous consequences for the whole family. Parents may become over protective in order to make up for the earlier rejection. This over protectiveness can be damaging for all concerned; to the child because he is not given a chance to develop, and to the rest of the family, because the handicapped baby becomes a drain on family resources.

Parents of handicapped children are among the most vulnerable people in society. They and their parenting methods are often under the scrutiny of professionals.

Parents can be made to feel at best ineffectual and at worst neglectful and uncaring by professionals who are insensitive to their problems. Parents also have to cope with the pervasive myth, strong in Irish society, that they are some kind of saints struggling with a tremendous burden – their baby is a special challenge from God. Although this can be consoling to some parents, many find it yet another burden to be carried, another source of guilt and self-doubt when they don't "measure up".

Husbands and wives

Little empirical research exists on how a handicapped child affects a marriage. According to most writers on the subject, a marriage that was sound before the advent of a handicapped child will probably survive; if a marriage breaks up under these circumstances it would seem likely that problems existed before the birth of the special child. Despite the lack of clear-cut evidence, most couples would agree that the birth of a handicapped child attacks the fabric of a marriage; it may become a "dispiriting symbol of failure". (Featherstone 1980)

Parents often have differences in values which come sharply into focus when faced with an exceptional child. "A child's disability can magnify differences that cut close to the heart" (Featherstone 1980). To institutionalise or to keep at home? Some of these are issues that intensify with handicap. In some cultures options, such as abortion or withdrawal of medical help are available to parents, with even more potential ground for conflict and remorse. In these situations a person may feel as if they are seeing their partner for the first time. They may or may not like what they see.

If roles are rigidly adhered to, partners can find themselves locked into situations which may ultimately destroy their marriage. The traditional role of the mother, the sole caretaker of the handicapped child, may shut the husband out and prevent him form healthy expression of his feelings. The father may gladly accept the outsider role and leave the parenting to the mother. Having opted out of his responsibilities he may not even hear when his wife silently cries out for the support of her spouse.

Brothers and sisters

It is generally agreed among researchers that about half of the siblings of disabled children report problems, the remainder actually benefit from the challenge of coping with a special brother or sister. Much appears to depend on the age of the child when the disabled child is born, the sibling's sex and his/her position in the family.

Children feel the pain that inevitably goes with handicap. They sense their parents' grief and may feel the suffering of their brother or sister intensely. Older children may fear for the future, wondering if they will have to cope with their disabled brother or sister in later life. Many worry that future children of their own may be disabled.

Summary

The arrival of the handicapped baby is a time of great emotional stress and upheaval. Parents must find out where to get professional help and advice both for themselves personally and to aid them with the problems of caring for their new baby. This is a time when the support of family and friends is important to help parents identify their needs and see how they can be fulfilled. Parents may experience such a range of emotion from grief through lonelinees, fear and guilt to self-doubt.

The arrival of a disabled child may put great stress on a marriage. In cases where marital problems exist prior to the birth it often destroys the marriage. Siblings too are put under great strain when a special child arrives. They may share in the negative emotions of their parents and often have to help in the parenting role.

Professionals must learn to deal sympathetically with special families. Often because of overwork, lack of knowledge or compassion this is not the case.

Finally, society puts intolerable pressures on the special family, it canonizes all members of the unit and expects them to carry their cross as the saints of yore did. Members of special families are not saints. They are ordinary people with greater problems than most. We must never forget that.

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