

Record

170

File Number

10142

Author: Fawcett, Debra

Title: The impact of disability on the family...Are existing support services enough?

Original source: Interaction Volume 6 Number 3 1992/1993

Resource type: Written

Publication Date: N/A

Publisher info: NCID

Abstract

Fawcett describes the impact of disability on the family. She calls for an improvement in services for families which acknowledges the emotional upheaval involved for the whole family. She emphasises that families particularly need and want contact with other families in the same situation and that service providers must take this into account when looking at service provision. She stresses the need for service in the rural areas which are currently under serviced and mentions single parent families in particular which are especially vulnerable to stress. She also suggests the inclusion of grandparents and other interested relatives in family support groups. **Keyword: Families**

DISABILITY AND FAMILY

Naturally, the impending birth of a child brings with it a multitude of changes and expectations within the family unit. For most families, the expectations of bearing an ideal healthy infant are accompanied by plans and hopes and dreams for their newborn, as well as anxieties and challenges. However, these dreams and hopes can be completely shattered when a child is born with a disability.

The parents of the disabled individual not only have to deal with the extra responsibilities of being parents, but also with their emotional responses and the extra stresses and frustrations that having a disabled child can create in their lives. Some of these families may find few of the joys that often compensate for the frustrations and inconveniences that a new child brings. In addition to this, as Falvey, 1989, aptly states:

...they (the parents) have often experienced additional pressures and stresses related to parenting a child in a society that is not always committed to accepting and assisting children with disabilities. "(p 15).

The purpose of this paper is to discuss the impact on the family that a disabled member has and to suggest some initiatives that services could/should develop in order to support such families. This will be addressed by discussing some common emotional reactions and problems faced by the family and the effects that this can have on their relationships with each other

and professionals. Where research has indicated a lack of support services, suggestions will be made for initiatives which services could develop.

A child with a disability will have a profound impact on the family system. In the cases where the disability is not evident at birth, it is only with the passage of time that the disability will manifest itself. Many parents are unaware that their child is disabled until they enter school, are seen to be academic failures and are tested and labelled as intellectually disabled. Even so, as Roberts (1986) found the emotional reactions experienced by family members are the same as if the disability was evident from birth. (as in Fewell & Vadasy, 1986)

Drotar et. al (1975), present a model of a series of stages which parents of a child born with a disability will experience. These are:

shock, denial or disbelief, sadness and anger, adaptation and reorganisation. "
(Hanson & Lynch, 1989:24 1)

Hanson & Lynch go on to say that even though no two people will react exactly the same to a child with a disability, these emotions are very common and that it is the depth and length of time these feelings are felt that will alter. Not all families experience these stages of reaction, and each member of the family will progress through the stages at

different rates of time, however these experiences are common to most families.

Other affects that disability may have on family members are:

"... lowered self esteem, shame, ambivalence, depression and self sacrifice."
(Whaley & Wong, 1991:929)

The initial reaction to a child with a disability is often one of a sense of grief and mourning for the loss of 'the perfect child'. Intense emotional feelings of shock, denial and fear often follow. The unknown can generate anxiety in an individual and this anxiety in turn, may generate fear and denial. The family of a disabled individual face so many unknowns that fear is a natural and common reaction. Denial provides the person with a sort of self-protection against the pain of reality.

In 1986, when referring to parents of disabled children, Roberts found:

"... almost always, parents report they are numb with pain in the early stages of adjustment. The initial shock of the disability seems to obscure everything else ... their world had been shattered."
(Fewell & Vadasy, 1986:217)

Many families will find support and comfort from those who have 'been through it', because they know that these people will understand how they feel. Roberts, 1986, maintains that:

"Parents' need for solid information is painfully clear from the start ... the

frustration they can experience often ends only when they find relief, comfort and guidance from others who have already been through it - other parents."

(Fewell & Vadasy, 1986:2 18)

Given that parents speak of other parents being their most beneficial support network, existing services should continue to make a concerted effort to organise parent groups and refer parents to groups within their local community. Not only should services provide this at the initial stage of diagnosis, but also this service should be provided as an ongoing support network for the families of a disabled individual.

Perhaps local councils could inject more funding and energy into developing an organisation which involves professionals and/or volunteers who have 'been through it' going to the family home, rather than the family having to go out, to have a "check in" session with the family members as a source of release and/or information and support that the family are needing and/or wanting.

In contrast to this however, some families may choose to avoid such interactions and building support networks because they fear the very real possibility of stigma and/or social rejection. As their disabled child grows older, this fear of social rejection and stigma may increase. For example, taking a two year old severely disabled child to the park is less noticeable than taking a twenty-two year old disabled adult.

Society's views and attitudes towards the disabled are changing somewhat towards a more accepting, non-judgemental and open attitude, however the disabled individual and their families are still subjected to prejudice, ostracism and/or criticism.

(Whaley & Wong, 1991)

An explanation for this stems from the community's Ignorance and fear. This remains a crucial area for intervention by both health professionals and special educators. Existing services need to inject more time and energy into developing programs and awareness into issues about disability so that the general public is educated and knowledgeable. Schools and organisations could develop awareness programs and displays around their local regions, for example displays in local shopping centres, sending pamphlets to households and having open days at the Special Developmental Schools.

Another of the family's reactions to disability may be withdrawal from society. This may also be a fear of social rejection or a fear of invasion of privacy. (Prader, 1981). Either way, their social life can become very restricted and feelings of isolation can be manifested. This in turn can create the situation where the child's disability is the main focus of attention, which is of course counterproductive for both the child and family. Strains within the relationships of family members will ultimately appear.

The presence of a disabled member within the family will have a significant effect on the functioning of the healthy family

system, and to maintain this healthy system, the family may also have to deal with reorganising old 'rules' and 'ideologies'. An example of this would be the family who values intellectual achievement and now has an intellectually impaired member - within it. This may be considered as threatening to the family's status and/or value system and identity.

Goldfarb et al 1986, mentions that parents strongly support the need for advocates who could help the family as so much of the family's time is spent on getting services that are appropriate and parents just don't know where to go.

Even though advocacy is available from services such as Community Services Victoria, Interchange and Family Focus, their waiting lists are so long that a lot of families do not have the advocates when they most need them. This supports the ideas that, firstly, existing organisations need to expand advocacy services available, and secondly, a central resource service is needed for parents to contact that can direct families to the needed and most appropriate services within their municipality and explain the kinds of programs that are offered by these services.

Goldfarb et al, (1986:54) also argue that:

"Probably one of the biggest roadblocks to using professional support is that sometimes it doesn't exist, especially in rural areas..."

This indicates a need for services to expand into rural areas. Perhaps an existing service could develop an information and support network 'mobile library' type of concept that regularly visits rural areas.

The experience of being a parent of a disabled child may result in a continual series of unrewarding experiences and thus the feeling of failure and inadequacy are supported. (Whaley & Wong, 1991). Rather than the parents spending a lot of time with their children under these circumstances in a series of mutually unrewarding interactions, parents could be encouraged to spend less time with their children, with the support of home aid from a local organisation, and at the same time, increase the quality of the parent-child interactions.

Most families want information immediately when they learn that their child has a disability (Dovey & Graffam 1987). In addition to this, they need to be freely allowed to express their feelings of anger, guilt and blame. However this may not occur if the professional that the family is dealing with is not forthright about the child's condition, or tends to use medical jargon which is not understood by the parents. Services need to ensure that all professionals working with families in the initial stages of discovery are sensitive to these needs of the family.

Roberts, 1986, (also Fewell & Vadasy, 1986:219) supports this when it is stated that:

"...positive professional attitudes can significantly contribute to the parents' adjustment, particularly when a parent is not able to see the light from the depths of stress and depression ... (it) can also provide the parent with a model and an alternative to focusing not only on the child's problems and overlooking the child's unique characteristics.'

In relation to the impact that a disability within the family has, siblings may react differently from adults in that they are:

- a) less informed and
- b) in that they may act-up to get the attention that they feel they deserve which is being given to their disabled brother/sister.

(Whaley & Wong. 1991)

Each family member will experience different responses to the disabled person within their family, however as Pader, (1981:161) states:

"... generalities do apply because of the commonality of human experience. '

Anger, guilt, embarrassment, resentment and jealousy are common feelings that a sibling will feel in reaction to having a disabled brother or sister. (Whaley & Wong, 1991). Like their parents, they will feel these feelings over and over again each time a new hurdle arises.

For example, when inviting friends' home from school or going shopping with their mother and disabled sibling. Outside the home environment, children will want to be

like their peers and have their peer approval and can be caught in a dilemma when there is a disabled member within the family. At home, they will want to be 'special' in their parents' eyes and having to compete with a sibling who really is 'special' can be difficult and may manifest in the child being over protective or over disruptive. The 'normal' sibling will understandably be jealous and resentful of the other who is attracting the attention.

Services need to include siblings in information sessions and program planning more often than they are in order to help alleviate some of the stress and anxieties that they experience. Also, mainstream school could devote a part of their curriculum to include a section on disability, especially if there is a disabled student present, or a student who has a disabled sibling.

In relation to the future needs of the disabled individuals and their siblings, services could ensure that they also be more informed by professionals about alternative living opportunities within the community. Goldfarb et al (1986:41) support this suggestion, as they found:

"...siblings are often given the responsibility for their brother or sister... (they) worry about future responsibility; they are not sure what their role will be, and whether they can do the job. Will they have enough money? Will they have enough energy?"

Seligman, 1979, supports the idea that:

"... parents are a powerful teaching resource and ought to be utilised by professionals."

(in Dovey & Graffam, 1987:56)

This motion is incongruent to the findings of studies done by Vincent et al, (1981) and Donnellan & Mirenda, 1984, (in Falvey, 1989:16) who found that:

... parents are often viewed as ineffective, at best, and as dependent upon professionals for help in coping with their disabled son or daughter. "

Falvey, (1989:17) goes on to say that:

"parents are rarely seen as valuable, necessary resources for the planning and possible implementation of instructional programs."

This incongruency indicates a definite need for professional services to both re-evaluate their attitudes towards parents and to provide the parents with the opportunity to assist. The focus of optimal early intervention programs is a family focused approach (Hanson & Lynch, 1989). Parents who require education to be effective teachers for their disabled children should be given this rather than the professionals taking over. More services could develop a program, which involves an intensive workshop situation for family members to acquire the skills that they need.

Families are faced with the sometimes-daunting task of finding appropriate services for their child's needs. These

requirements may increase, as the child grows older due to the increasing need for formal services such as recreation programs, further education after the age of eighteen and even respite care.

Negotiating the myriad of services within the system can be somewhat parallel to going through a maze! Dovey & Graffam, (1987:72) support this as they argue that:

"whilst all parents emphasise the importance of early intervention strategies, it appears that luck still plays a considerable role in whether or not appropriate services are discovered and/or recommended at the time of identification of the disability... most parents report confusion and an inability to find appropriate services".

Some sort of central source of information could be developed within each local government area, with a member of the council for example, searching out the needs within the community and then co-ordinating information and making this information easily accessible to those who require it.

Pader, (1981) suggests that fathers of disabled children are more likely to reject the idea that their child is disabled because they are less involved in the child's daily care and they therefore miss the small warning signals that the mother has observed. As a result of this, fathers may experience the impact of disability at a later stage than do the mothers and this in turn can lead to communication

difficulties and a breakdown of the marital relationship and the family unit.

On the other hand, a study done by Darling & Darling, 1982, (in Dovey & Graffam, 1987), implied that in fact a large percentage of families who have a disabled member, do in fact increase their cohesiveness and marital relationships by supporting each other and openly sharing their feelings of anger, blame, resentment, and anxieties. Taking this point of view however, when a single parent family is affected by the presence of a disability, one could say that this parent could well be at risk. Services could therefore offer special singles club support to these families.

In addition to this, (Whaley & Wong, 1991:93 1) maintain that:

"Organisations for parents of children with special needs tend to offer fewer services to fathers ... as a result, they have fewer opportunities available to them to mourn the loss of the perfect child and to deal with the lowered self esteem associated with fathering..."

This indicates a real need for existing services, or new services, to develop support programs and workshops for fathers to express themselves in relation to having a disabled child. A network of fathers could be established needs to a volunteer group and/or existing services and their existence involve made known to those.

Other impacts that disability create on the family, are that the family, the parents in particular, face the very real problems of their child's need for ongoing supervision, a potential out of home placement when adulthood is reached and the knowledge of their eventual deaths and the implications that this will have for their disabled son or daughter. Services could definitely contribute substantially to easing these anxious feelings of parents, by expanding foster care, shared caring programs and residential placements for adults. Naturally this will depend upon funding as it all costs money, however injection of and redistribution of funds already received may be a viable alternative.

In conjunction with the loss of their dreams ' of a 'perfect' child, parents also will lose a previously held sense of identity of themselves as parents in relation to both their existing disabled child and their future child bearing, child rearing and their ideal of grandparenting. Other very real losses experienced may be financially, socially and in relationships with the extended family. (Whaley & Wong, 1991)

Grandparents are somewhat removed from the situation and as a result may have an even harder time accepting the disability. The processes and support services which parents use to accept and deal with the disability could also be taught and made available to the grandparents by allowing them to have access to information made readily available to parents. They could be involved in support networks with other

grandparents who have been through the same situation.

Services could be developed to incorporate the grandparents and other interested extended family members in learning and implementing programs for their grandchildren. Organised outings and camps could be offered to help foster the relationships between the extended family members and the individual with the disability. This could be incorporated with programs that are already established, such as those in local Senior Citizens Clubs.

In addition to the effects of the disability itself, the individual's response to the disability will naturally depend upon his or her developmental level, coping mechanisms and especially on the reaction of significant others. Whaley & Wong, (1991: 1009) maintain that:

... the parent ~ behaviour toward the child, especially in terms of childrearing, is one of the most important influencing factors in the child's adjustment.'

Naturally, the parents' positive (or negative) attitudes will undoubtedly affect the person's development of self-perception and esteem. The attitudes of the general community will also affect these perceptions. However, if the disabled individual is perceived as having worth and is supported with experiences of success and helped to deal with their feelings, their life potential and goals are more likely to be fulfilled.

In conclusion, the past emphasis of dealing with the negative impact of disability on the family could be replaced with a more supportive stance upon the positive. The effects on the parents and their responses to the child are so critical that they directly influence the other members' reactions and also the development of their child. Within the family unit, resources include cohesion, adaptability and each other as modes of support. Outside of the family unit, community resources, such as respite care, educational facilities and support groups

are vital for the family in achieving and maintaining a healthy adjustment. A balance between the family's needs and the resources available is best achieved when attitudes and beliefs shared by professionals in the community create a community climate that is supportive and empowering for those families who have a disabled member.

(References are available on request)