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Abstract

Deborah Fullwood, parent and former occupational therapist, discusses the difficulties of being a family with a disabled child in a society that values health, wholeness and "normality". She presents her views on behalf on many health care receivers and looks at the stresses families are subjected to apart from the worries of their child's education, their post-school opportunities and what lies ahead when parents are no longer able to care for their child at home. She suggests that health care workers need to closely examine and implement strategies in areas such as service provision, increasing the self worth of family members and health workers own education, listening and communication skills. **Keyword: Professionals**

Mum or Supermum?

By DEBORAH FULLWOOD, B.App.Sc. (*Occupational Therapy*)

The man in the street would probably admit that disabled children, just like disabled adults, are discriminated against from time-to-time, though he would possibly claim that he personally never shows any discrimination.

Those of you who are health care workers probably feel that you never show any discrimination, and perhaps even feel you tend to be a champion of the rights of the disabled, maybe not in any overt militant way, but you certainly do your best on their behalf.

If in contact with families of disabled children, you probably admit that these families have a hard job, but you may doubt that they are discriminated against, or disadvantaged in any significant way.

I'm an occupational therapist and, for many years I was probably as guilty as any other health care worker of underestimating the difficulties of being a family with a disabled child. I could treat a disabled child adequately enough, and tried to make the child's parents feel included, by discussing progress with them. I occasionally thought these parents were a bit aggressive, a bit unrealistic, a bit nosy, or a bit crazy, but I never really thought much beyond that.

Three years ago my son was born with Down's Syndrome, and I now need no convincing that there are difficulties in being a family with a disabled child in a society that values health, wholeness and the oblivion of normality.

I know that the family keeping their disabled child at home, trying to gain adequate treatment of the disability, trying to involve the child in normalising experiences, trying to do justice to other family members' changed needs and trying to maintain any semblance of former lifestyle activities, faces enormous obstacles.

Fox (1975) sees four main crises in the lifespan of the disabled person and his family.

Name(s):

- When the existence of the disability is recognised.
- When any education or schooling programme is considered.

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- When the child leaves school and emerges from an often protective environment into the real world with its problems of employment, sexuality and marriage.
- When, and if the parents feel they are no longer able to have their disabled child living with them.

While acknowledging that these are certainly times of great stress for families with a disabled child, I would like to suggest that the continuity of some issues that seem never to be resolved, poses just as great a stress as the four situations Fox outlines.

My opinion could be considered biased if my experiences as a health care receiver were considered atypical. Or if my background as a health care giver was considered to influence the treatment I received; but these opinions come from speaking to many people on the receiving side of the health care system.

I use the term "health care worker" globally here, to embrace anyone who is in contact with a disabled child or any of his family members, on matters relating to health, education, employment or social welfare.

One of the persistent stresses for families with a disabled child is their need to express their grief. I feel strongly that this opportunity is often denied them.

Certainly, grief is considered normal at the time of diagnosis, and is almost expected; but I see it not as a finite process, but more as a continuum. Unlike the family whose child has died, where reality cannot be denied for long, the family with a disabled child is continually confronted anew with the disparity between their child's actual capabilities, and those of the child they had anticipated.

Although the disability is unlikely to be able to be denied for long, hopes for an improved situation seem often to be raised and then dashed, precipitating grief again.

Each family has a unique way of expressing and coping with grief, and it is certainly not the prerogative of health care workers to issue comments such as — "Pull yourself together — It's not that bad"; or "At least he didn't die"; or "He's better off than so and so's child".

Grief may be a private matter, yet health care workers are so often looking for overt signs of grief in the belief that this means the parents are "accepting the diagnosis".

Privacy is rarely offered in hospitals, and yet I see it as almost a pre-requisite for expression of grief in our British stiff-upper-lip society.

Surely discussion of chromosome counts, family income and your child's declining health warrants privacy.

Another continual stress on families with a disabled child can be role upheaval and therefore role insecurity. Roles that family members had previously been comfortable with, seem now to be inappropriate.

The role of the "good parent" is changed as parents are made to feel ungrateful and selfish if they don't take advantage of all opportunities offered their child. Parents are expected to leap from personal grief and concern to a show of generalised concern for all disabled people.

Mother's role is now to be seen as a "competent, coping mother", and the family as a "well-adjusted family", yet role models are scarce to help mother and family in this task.

Family members are expected to "relate normally" to their disabled child as if, in fact, there is nothing abnormal.

Parents with strong professional or social roles may find these incompatible with that of parents of a disabled child, and so may have to radically modify or

abandon a former role. My professional role was certainly looked on suspiciously — "She's intellectualising his problems", and it was also trivialised "You used to be an occupational therapist, didn't you?"

Siblings' roles may also be affected. Normally a child's role changes along with his changing status within the family, but the limitations of the disabled child may affect this, and thus the complementary roles of his siblings.

Normal sibling rivalry may not be able to be expressed because of protection of the disabled child by his parents.

In attempting to find some stability among this role confusion, I believe parents of disabled children need to have a clear concept of how they can help their child.

Mothers may doubt their own mothering skills as professionals tell them how to hold, how to feed and how to talk to their child.

What role is a parent left with when a health care worker states: "Only professionals can give this child the kind of care and training he needs?"

One of the big advantages of early intervention programmes for young disabled children is that they do give family members an opportunity to help their child.

Besides providing the child with a structured learning programme, they provide parents with a sharing of the responsibility for their child's development and an opportunity to meet other parents.

Professionally, I believe early intervention programmes offer one of the best chances for the child, but I have some reservations about their effects on other family members. The prolific use of checklists, normative graphs, and skill acquisition charts, often clouds the simple sweetness of success. No sooner is one skill mastered, than another skill from the developmental checklist is presented, leaving little time for basking in the glory of what was quite possibly a hard-fought achievement.

The strong reliance of many early intervention programmes on parents as teachers also concerns me. While not denying the normality of parents teaching their children many skills, I think that expecting mothers of disabled children to assume a major teaching role for their child may be counterproductive. It may make playing with the disabled child, for playing's sake difficult. By "mother" becoming "teacher" I feel it inherently changes the mother-child relationship which may be fragile anyway.

Another strong and constant issue for parents of disabled children is "Just how different is my child"? Will nothing about him be normal? While recognising the value of developmental checklists in answering this question on a concrete level, parents' real concern is often on a social, emotional and interaction type level. *Will I be able to take him to McDonald's? Will he be able to play with other children?* Being told how to feed, hold and talk to your child seems to subtly suggest that everything about the child will be different, yet on the other hand you are glibly told: "Just treat him normally".

No-one asks the normal questions when a disabled child is born — about hair colour or body length. No-one would think of asking if the child looks like father for fear of insulting the poor man. Friends and relations rarely offer the disabled child the cuddling, gooing, and chin-chucking that normal children receive. Another insidious and continual pressure for the family is whether to, and how much to tell people they meet. Too much too soon, and they tend to think you are obsessed by the problem. Too little, too late, and they tend to think you don't want people to know.

To improve the quality of life for these families, health care workers need to closely examine and consciously implement strategies in four main areas.

The first is in the area of their own education. While recognising the number of health care workers who do work with disabled children and their families, and the diversity of their training, I believe that specific skills and awarenesses need to be commonly taught.

Primarily, health care workers need to improve their listening skills. They need to listen to what family members are really saying. They should avoid phrasing an answer till they have heard the question fully, and avoid the mentality of "I tell them what they should know, no matter what they ask".

If parents are concerned enough to form a question, it warrants an answer, no matter how trivial, diversionary or unrelated the question may seem.

Health care workers also need a better understanding of the grieving process to avoid making comments such as "Have you got over it, yet, dear?". They need to be prepared to see parental aggression as a healthy step forward in the grieving process from shock, disintegration or denial. Bearing in mind that families with disabled children may continually grieve anew, anger may well be a chronic problem.

I am suggesting that not only should health care workers be prepared to see parental aggression as fairly normal, but that they should also be prepared to accept some of this aggression personally. There may be few socially acceptable outlets for this aggression, but the current fashion of "doctor-bashing" may mean that parents see displacing their anger onto health care workers as vaguely acceptable.

On being accused of offloading her anger onto the medical profession, I agree with one mother's reply that it seemed healthier than offloading it onto her defenceless disabled child.

It also seems healthier than repressing anger, for fear of being labelled aggressive, unrealistic or maladaptive, and thus risking retarding the grief process. Health care workers need also to look at their communication skills both between themselves, and with parents.

They need to explain what they have to offer, and how they relate to other disciplines. They also have a responsibility to explain the purpose and extent of any examination or treatment.

Honest communication with parents is needed about long term disability and life expectancy. Careful explanation will avoid misunderstandings such as saying that a spina bifida child will walk, meaning with long calipers and crutches, whereas the parents perceive walking as unaided.

It should be unnecessary to say that flippancy is the parents prerogative, and that flippancy from health care workers, such as this to the parent of a child with a genetic defect: "Got an extra chromosome, have we?". And this to the mother who diagnosed her child's disability before the paediatrician: "So I suppose you think you're pretty cocky".

Sharing of information with parents encourages mutual respect, rather than professional omnipotence. Mutual respect is important to avoid the competitiveness which may spring up between parents, and those treating their children.

Improved interprofessional communication would also improve the situation for parents. It seems true to say a team effort is needed, but a soundly based appreciation and respect for other health care workers needs to be communicated to parents, to whom role fights pose another obstacle.

Improved interprofessional communication should also avoid the need for

parents to repeat their child's and their own history, again and again, bearing in mind that it is painful enough to experience once, let alone repeat.

The second area for forming new strategies is in health care service provision. Each family is unique, and the type, duration and depth of service they need will obviously vary.

Health care workers have a responsibility to explain all avenues of potential financial assistance whether they perceive a family as being financially disadvantaged or not. Besides the primary cost of supporting a disabled child, Kell (1975) reports an increased incidence of mothers leaving employment, because of the special needs of their child.

Families need to understand their claim on the Federal Handicapped Child Allowance, and be prepared to present a case to claim the maximum amount. They need also to understand the intricacies of the council-extended Home Help Service where geographical differences mean variations from 30 cent/hour charge Oakleigh to \$2.00/hour charge in Camberwell.

Besides financial assistance, physical assistance is often a priority. The local council's domestic home help, and their extended home help may be appropriate. Friends may seem more likely to offer to look after a normal sibling than disabled child, and parents may not independently pursue the possibilities fostered-mother play groups, or attendance at a normal creche or kinder for the disabled child.

These ideas need to be explored by the health care worker with the parents, both parental time alone, and the chance for the child to relate to other adults as children is a positive step.

Health care workers need to be attuned to the day-to-day problems of the family and help them find solutions. However, parents may prefer to try to overcome problems themselves, rather than accept assistance just because it is offered. I sympathise with the mother, who, having successfully house-trained two dogs and one cat, and toilet trained two children, was offended at being handed a pamphlet on "How to Toilet Train Your Retarded Child".

Health care workers should not pretend to know the reality of having a disabled child. In fact, Turnbull (1978), a child psychologist in the field of developmental delays, who subsequently became the mother of a retarded son, compared the difference between the professional and personal views. She felt that the 24-hour reality test of living with and caring for a disabled child, had a far higher pass mark, than that required to earn a degree.

Providing for both fathers and grandparents of disabled children are two areas where health care workers could profitability expand their services.

Fathers often have little contact with each other, and seldom get to know each other well enough for mutual support. They usually have less contact with health care workers than mothers, and may well be threatened by their spouses possible preoccupation with discussion, plans and achievements of their disabled child.

The gulf between the actual capabilities of disabled children and the role that grandparents had anticipated for them is just as large as for parents, yet the role of "mother of a disabled child" has more form, even if it is vague, than does "grandparent of a disabled child". Remember, too, that grandparents have not only a disabled grandchild, but a grieving child, as well as their own grief to deal with.

Health care workers have a responsibility to be aware of community resources from which disabled children and their families may benefit. This includes presentation of factual information about any possible resource, and a subjective opinion of the value of that resource in relation to the family.

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But the responsibility of service choice is the family's alone.

An enormous variety of factors influence parental choice of any education or schooling programme for their disabled child, if they are committed to the concept of such a programme at all. And they may need help in establishing their priorities.

They may prefer a programme with a high time commitment away from home, leaving the home environment for free play, or a programme with one-to-one child-therapist contact, leaving family and social occasions for group experiences, or a programme training parents to be teachers in the home; or a programme allowing "treatment" by professionals, and "normalisation" at home, or any combination of these and other factors.

They may prefer a programme with a heavy cognitive emphasis, or a strong language emphasis, or one stressing community survival skills.

Parents and the disabled child need to be accepted as full members of the team, with the health care worker being responsible for methods and techniques, but with the parents and child being responsible for goals and objectives.

So often professionals presume they are the source of all knowledge and can make wise decisions about other people's destinies and that parents are ignorant.

The family may be helped in setting realistic goals, and in recognising changes in their child, by learning to make records, where the child is compared to previous performance.

Comparison with normal at some stage is necessary, in order to realistically plan for the long term, but continual comparison with normal may be detrimental. For the parents of the children who move further away from normal in their age attainment of skills, it may be unnecessary and destructive to have this repeatedly shown.

For the parents of the child who is close to normal in age attainment of skills, the battle to maintain or reduce this difference may be harrowing, and the child's genuine difficulties may not be well-tolerated.

Finally, I believe that the most productive strategy for both health care workers and families of disabled children is to enhance the self-worth of family members, and thus increase their effectiveness in dealing with daily stresses, and so decrease their dependence on health care services.

Family members need to feel confident in using the skills and information they have to help their disabled child in the short term, and plan for the long term.

They need also to feel confident in dealing with the myriad of people and pressures they will meet.

They may need parent effectiveness training not only to use with their children, but also with their spouse or health care worker, and in fact in any situation where listening and communication plays a part.

They may need to learn to be assertive with health care workers, friends and relatives.

They may need to learn to ask for help, or to define the specific help they need.

They may need to learn how to phrase the questions they really want to ask.

They may need help in developing a strategy for people who stare. They may need help in developing responses they are comfortable with to the inane comments that seem never to stop: "Couldn't have happened to a nicer couple"; or "These things are meant to be"; or "That must have been a shock when you found out".

Once acquired, these skills help family members to resume control over their fate again, and to recognise their own worth. They also give family members the opportunity to deny that a disabled child equates with a disadvantaged family.

As with a physical injury, the wound of loss heals gradually. Complications may delay the healing process or reopen the wound. In the same way as a fractured bone may end up stronger than originally, so the experience of loss may bring strength to families with a disabled child.

I believe health care workers are potentially the strongest catalyst in fostering this strength, and avoiding complications in this healing process.

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