

# Handicapped Parents and Disadvantaged Children?

R. Bland, N. J. Smith & M. Hollingworth

*The ABS surveys of 1981 and 1988 show that within the total population of handicapped persons a number of families with dependents have one or both parents who are handicapped. Also included within this group are lone handicapped parents and families who have in addition some other non-dependent handicapped person living with them. Besides the usual socio-economic problems surrounding disabling conditions this group are also faced with the difficulties associated with the everyday tasks of parenting. Yet, judging by the professional and research literature, they have received scant attention here in Australia or elsewhere.*

*This paper reports the results of a small qualitative pilot study of 19 families in which one of the parents had some physical handicap and which examined the everyday parenting tasks faced by them. It reports on some of the difficulties they experienced and also the affirmative action they took to overcome those difficulties.*

## Background

From two national surveys of disability and handicap in Australia undertaken by the Australian Bureau of Statistics in 1981 and 1988 it was estimated that the proportion of the population who were deemed to be handicapped and disabled in 1981 was 8.6%. At the time of the 1988 survey it had risen to 13.0% (ABS 1984,1989). Hidden within these figures is a group subjected to serious social disadvantage which must effect the welfare of children. The group consists of nuclear families where one or both parents are handicapped, as well as lone disabled parents. In addition there are families with a handicapped parent and dependent children who also have another handicapped relative living with them.

Collectively the group is numerically small, approximately 14.8% of the total number of 1.153 million handicapped persons living in one family households in 1981, but this proportion grew to 15.2% in 1988 (ABS 1984 Tables 1.8, 1.9; ABS 1990 Table 1). Also, the proportion of lone female handicapped parents was high 6.5 females to every male lone handicapped parent. Compared to overseas results the proportion is very similar. Harris et.al's 1971 study of registered handicapped people in the UK also found that about 16% of the group of 'severe' and 'very severely handicapped' were parents with a spouse and mainly child dependents.

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On the face of it this group would be disadvantaged even without the presence of dependents because of their handicapped status. They have limitations arising from their impairments as well as the associated socio-economic problems all disabled people face including financial hardship, medical expenses, lack of services, isolation etc. But in addition they face other problems.



These are the difficulties which may arise from the impairment, or their handicapped status, which prevents, or hinders them from fulfilling a parental role. And this does not take into account the differential parental handicaps arising from the gender of the handicapped parent. Handicapped mothers in particular face discrimination with regard to their rights and capabilities as a

parent as well as a woman (Westbrook & Chinnery 1990). It is obvious that parental disability therefore is bound to have repercussions on the family environment including a child's developmental opportunities.

Yet, despite what is an obvious vulnerable group of people which should be of concern to us little seems to have been done, either to examine the problems these people face, or to study the social effects of parental handicaps on children. A small study of the literature to determine the extent of our knowledge of this group, supported by a special University of Queensland Research Grant, produced disappointing results (Smith, Bland & Grey 1992).

Following an intensive computerised literature search of a number of international databases which extended back to 1975 only 93 references were found. These covered both physical and mental disabilities, although predominantly focussed on the latter group. Of the references found the majority dealt with the effects of parental disability on children's cognitive, social and emotional development. There were very few which examined the problems faced by the parent. Nor was there any discernible trend in either, the type of disability being studied; methodology adopted in the studies, or problems faced by the families. In the main, all the studies, with the exception of Bleuler (1974), Buck & Hohmann (1981), and Brzozowska (1984), emphasised the negative implications of parental disability on both dependents and the family as a whole.

It was decided therefore, as a basic research step in the area of parents with disabilities and the handicaps they may face, to undertake a small semi structured exploratory study of disabled parents to develop a framework for understanding their experiences as a prelude to more specifically focussed studies.

## The Study

The central concern of the research was to develop a framework for understanding the experience of people with disabilities in their role as parents. A second focus was the barriers to effective parenting as perceived by the parents themselves, in particular the presence or absence of external social supports such as health and welfare services. We wished to take a positive focus, one which allowed parents to identify their strengths and successes as well as recognising their special challenges.

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A decision was made to interview two groups of parents. The first of these comprised parents who had responded to a request published in the Queensland newsletter of the ParaQuad Assoc. The second group were parents who were currently in-patients of a psychiatric hospital. Subsequently, after starting to conduct a series of interviews with parents in the hospital it was decided to focus only on parents with physical disabilities. It was felt that, despite following careful informed consent procedures, the interviews were too stressful for the parents. The issues of custody and child protection were major concerns for parents experiencing psychiatric illness. To discuss parenting issues emphasised these concerns, and we felt that the people interviewed were anxious to deny any problems in their role as parents. However, these findings reaffirmed our contention that disabled

parents face extra handicaps by reason, in this case, of the real or imagined threat to their parenting capacities and role.

## Method

The researchers approached ParaQuad and asked if we could advertise the project through the association newsletter. We hoped to conduct personal interviews with parents, using a semi structured questionnaire, but we were prepared to send questionnaires through the post if participants preferred such contact or if they lived outside the metropolitan area. In all we collected information from nineteen parents. The information presented below is a summary from these parents. Because of the small sample and the nature of the research questions, we present mainly qualitative data. Also, since the sample is drawn from volunteer parents interested in the project we are not implying that the responses are representative of all parents with disabilities. Therefore, caution must be used in generalising the findings.

## Results

Of the nineteen respondents, thirteen were fathers and six were mothers. Ages of dependent children ranged from new born to mid-twenties. In six families there was only one child, seven families had two children, four families had three children, and two had four children. It is of interest that all parents who responded were married and living with their partner and children in an intact family setting. The absence of any single parent families in the sample means that parents who responded had a partner at home to help with the parenting role. But as suggested earlier, the ABS surveys showed a high number of single parent households headed by a parent with a disability.

Disability of the parent ranged from paraplegia (10 parents), quadriplegia (3 parents), tetraplegia (4 parents), and other disabling condition such as muscular dystrophy (2 parents). In fourteen of the families, the parent's disability had pre-dated the birth of children. This was the case for both fathers (9 of the 13) and mothers (5 of the 6).

## The Experience of Parenting.

As a preliminary question, parents were asked to reflect on the experience of being a parent and suggest things that we should know about their special experience. Three parents could make only positive responses suggesting that they could work through any problems, but the others reported a variety of experiences. Some suggested that the disability restricted many of the physical aspects of child care such as disciplining, lifting, and giving 'hugs'. Others said that the traditional parental roles were blurred as able-bodied partners took on supportive roles. One mother, who was wheelchair bound after a motor vehicle accident, reported that she had difficulty promoting a positive image of herself as a caring person and not the 'ogre in the wheelchair'.

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The experiences described are different for those who became physically disabled after having their children. These parents report a phase of painful adjustment for all the family to new and physically restricted roles. Families reported a crisis in housing as the existing family home was not designed for wheelchairs. For these parents, changes to new parental roles were but one of the many personal stresses accompanying the crisis of disability. Where the disability preceded parenthood, adjustment appeared to be somewhat easier as restrictions and compensatory responses were understood and anticipated.

Other problems reported included wheelchair access in schools and shopping centres, money worries with

managing on a pension, public transport, and significantly, the problem of finding wheelchair accessible holiday accommodation for the family. One couple were separated for an extended period of time because of the hot climate in the home town making temperature control for the parent with disability very difficult. A number of parents described their frustration in not being able to do some of the less tangible tasks of parenting.

One father wrote;

There is a great sense of loss of not having done things together, and in later life it is not easy to observe a lack of skills that could have so easily been shown.

This is a reminder that one of the tasks of parenting is to pass on our skills to our children. One mother described feeling sad that when her toddler hurt herself and needed a wound bathed or splinter pulled, she would turn to someone else knowing her mother was unable to help her.

All parents were able to identify positive aspects of being a parent when asked to do so. Some spoke of the compassion and understanding their children and able bodied spouse had developed. Children were seen as more independent and self sufficient. One parent wrote;

There is an early maturing in some areas such as considering the needs of others, the point of view of others, a notable sense of true compassion.

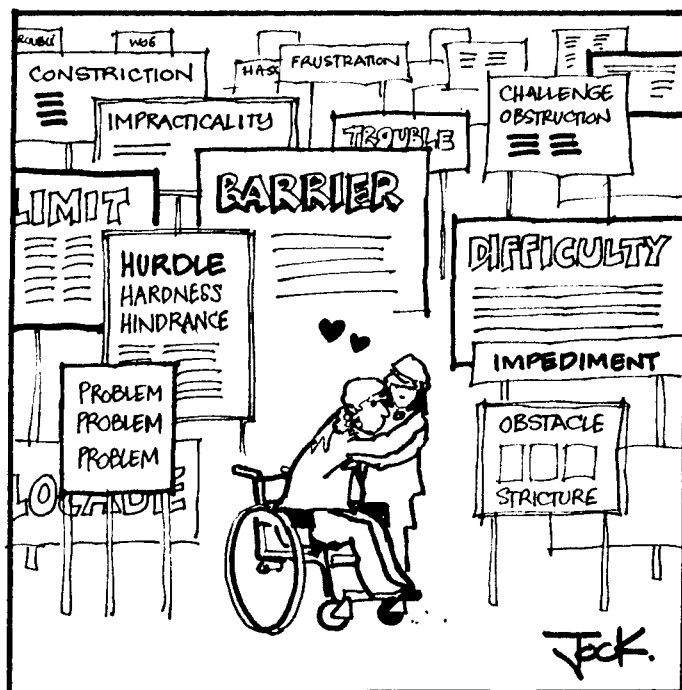
Others mentioned specific achievements they had been able to make despite the disability. One woman proudly boasted about her ability to mow the lawn in her wheelchair while her husband watches her and enjoys a beer, much to the amusement of their neighbours. Another father insisted that his experience of parenting was no different from other parents, and that his disability was irrelevant.

Some of the parents were able to recognise that their children had assumed a degree of caring and capacity to assist the parent with day to day tasks. One mother said that her 11 year old daughter could do any-

thing needed in the house, from cleaning to helping her mother to undress, a 'standing transfer', or putting her mother to bed. The mother realises that these are responsibilities other children would not assume and concluded that the daughter 'pulls her weight'. Other parents remarked on their children's sensitivity and understanding of 'differences'.

One parent summed up this essentially positive description of the parenting experience by suggesting that 'Everything is hard but possible - though it may take a few years.'

The physical care of the infant was also seen as an anxious time as feeding, changing, and nursing was difficult. Two parents suggested that the school years were difficult because of access problems at the school. One response summed up the changes over time by insisting that the tasks of parenting were essentially physical at first, and became more mental as the child became older. This would account for the stress in the early stages of development when the physical abilities of the parents are most tested.



### Difficult stages

Parents were asked about how the parenting experience changed over time and whether there were key stages of development that were more difficult than others. The time of pregnancy was identified by all the women whose disability preceded the pregnancy as a particularly difficult time. The mothers reported increased concerns about their mobility, bladder infections, taking prescription drugs, and anxiety about their capacity to cope with the pregnancy. One mother reported that the hospital staff at the time of delivery were unsure of how to manage the birth and she had to tell them what to do to meet her special needs.

### Supports.

Parents were asked about help they had received from family, friends and support services. Where the disability was acquired after children were born, parents tended to report help from extended family within the context of a response to the crisis of accident and sudden disability. For example, the maternal grandparents cared for the children over several months, for one man who was injured in a motor vehicle accident.

Two parents reported long term help from grandparents in day to day tasks such as shopping and putting the baby in the car seat. Others identified friends or supports in the church who had helped with

baby sitting. Six parents had found the Blue Nurses very helpful, and ParaQuad itself was found useful by one parent. By far the greatest support was found from the non-disabled spouse within the immediate family. This was identified by half the sample as the primary support.

### Interaction with community services.

Parents were asked to comment on their experience of dealing with services in key areas associated with the parenting role. Results are summarised below.

#### a) Maternal and Child Welfare

Eleven of the parents had had no contact with this service at all, or else found the services irrelevant to their

needs. Two parents reported considerable help was associated with home visiting from child health sisters. One found the service inaccessible to wheelchairs, while two others claimed to use the service sometimes but did not comment as to its suitability. Given the difficulties described by mothers with disabilities in caring for children in the first years of life, it would seem appropriate that a more outreaching service would be required to assist through this time.

#### **b) Medical Services for Children**

No families reported problems in arranging medical services for children. One mother suggested that there were difficulties in accessing any new specialist services for the first time. She found that it was easier to take a taxi to avoid problems in parking and access as the taxi driver would always help if there were steps. Overall, this does not appear to be a difficulty in using these services.

#### **c) Kindergarten and Preschools**

Five parents had not used these services because the disability had developed after this developmental stage. A similar number reported that the able bodied spouse handled the transport and liaison with the centre and that there was no difficulty. Two others relied on neighbours to help with transport, while one suggested that the cost of the service was a problem. Two parents found access difficult but manageable.

#### **d) Primary School/High School**

Nine parents reported that the contact with the school presented no problems. Some parents remarked that even though access to classes may be difficult, teachers had met parents at convenient locations to overcome difficulties. This was much appreciated. Two parents reported that the school had made special modifications to allow wheelchair access thus eliminating any problems. For others however, access was a real barrier to participation in parent-school activities. One parent had wanted to join the P&C but was unable to do so. Two families had sent children to non-local schools so that the parents could have better access to the school buildings.

Only two parents reported problems in dealing with the high school, though for eight parents children had not yet reached this stage. One parent found access difficult, and another related a problem in talking with a teacher about a specific complaint his daughter had had in an English class.

Clearly parents need to be able to access school buildings if they are to take an interest in their child's learning. Inaccessible schoolroom architecture is a barrier to effective parenting.

#### **e) Children's Sport and Leisure**

Three parents reported some difficulty in taking a special interest in their children's sport or leisure activities, while the other sixteen parents said that there were no problems or that their children were not interested in sports. For two parents, the issue of access prevented their going to certain venues. One of these found distance from toilets an embarrassing problem. The third parent suggested that he felt cut off from his children because he could no longer see 'what they were talking about, for example Cub outings'.

### **Other Comments.**

When invited to make other comments, the parents interviewed offered a range of suggestions. Some covered the need to make government services more sympathetic and consistent. Four parents suggested the major problem was one of having to deal with bureaucrats who were either ignorant of their needs and entitlements, were unsympathetic, or interpreted the rules inconsistently. This generated considerable resentment. One parent suggested that it made for low self esteem and a sense of powerlessness. One parent said;

They can be very naive and ignorant when it comes to the practical needs of disabled parents - or anyone at all. They need educating.

Housing, income, support services and the hospital pharmacy policy were areas of concern to the parents. It was suggested that there was a need for more appropriate housing with bigger bedrooms and modifications that were affordable. This latter comment also referred to the cost of aids and support services. Parents received little

taxation concessions for these and the costs of supporting a child in Year 12 at school was inadequately compensated by the Government subsidy of \$25 per week. The issue of inadequate child care facilities and back up support for carers was also raised. The existing policy of dispensing prescriptions from hospital pharmacies on a monthly basis rather than a three monthly basis created inconvenience for a number of families.

Despite these negative comments to the sources of special support the comments of some parents reflected a high degree of commitment to the tasks of parenting. One parent wrote:

To some extent the disability must come second to parenting. You will have the disability for life, but the children only until they become parents and the roles reverse.

This idea is reflected in the essentially positive enthusiasm for the parent role in nearly all the parents studied. As one parent concludes;

No disabled person should be discouraged from having children if at all possible. The emotional rewards and joys of having the children to love and be loved far outweigh the physical disadvantages and complications.

### **Conclusions**

While the parents in the study reported a range of difficulties, the picture is one of successful coping. Disabilities do not seem to necessarily prevent parents from fulfilling and enjoying parental roles despite difficulties within the social context in which they have to live. Yet, it is obvious that the disability influences the life-style of other members of the family and has repercussions on the behaviour and role of the dependents. Its impact will vary according to the onset of the disability in relation to the dependents' stage of development. It will also influence the expectations placed on the dependent in the way they view the parameters of their social relationships within the family, as well as between the family and the outside world.

-Obviously this view is formed from a small self selected sample and also does not reflect the experiences of the dependents in the situation. So far, as

mentioned above, the literature has predominantly painted a negative picture in this regard. However, this may be the result of the fragmented way in which previous research has been done.

From the references uncovered so far (Smith, Bland & Grey 1992), there is a noticeable lack of any research framework which allows for the family to be considered as part of a dynamic process involving the interaction of all members and examining the differential effects on each of them and in their relationships. The work undertaken by Coates, Vietz and Gray (1985) is useful in this regard and, in conjunction with earlier work by Cogswell (1976), allows us to formulate stages, in what Oliver (1983) has termed the 'career', of disabled people as well as focussing on broad variable outcome categories for examination in the career process. However, at this stage of our limited knowledge of disabled parents, the problems and issues they face and the various ways dependents adapt we would concur with Coates, Vietz and Gray (op.cit) that any further work needs to consider each family as its own baseline in determining effects rather than against a set of unified linear set of stages of adjustment.

### Acknowledgments

We appreciated the interest shown in the project by ParaQuad, particularly Rod Walters, and by the staff at the Spinal Injuries Unit at Princess Alexandra Hospital, especially Pat Dorsett and Linda Richards. We would like to thank all the parents who helped us by completing the questionnaire and to the University of Queensland for a Special Research Grant to enable the study to take place.

### Bibliography

Australian Bureau of Statistics (1984). *Handicapped Persons Australia 1981*. Canberra: ABS Cat: 4343.0.

Australian Bureau of Statistics (1989). *Disabled and Aged Persons, Preliminary Results*, Canberra: ABS Cat: 4118.0.

Anderson, E.M. and Clarke, L. (1982). *Disability in Adolescence*, London: Methuen.

Australian Bureau of Statistics, (1990). *Specially prepared Tables*, Canberra: ABS.

Bleuler, M. (1978) *The Schizophrenic disorders: long term patient and family studies*, New Haven: University Press.

Brzozowska, W. (1984) 'The educational environment of the disabled family' *International Journal of Rehabilitation Research*, 7 (1), pp 53-55.

Buck, F. M. and Hohmann, G. W. (1981) 'Personality, behaviour, values and family relations of fathers with spinal cord injury' *Archives of Physical Medicine and Rehabilitation*, 62, (9), pp 432-438

Chilman, C.S., Nunnally, E.W. and Cox, F.M. (1988). *Chronic Illness and Disability: Families in Trouble* Vol 2. Beverley Hills: SAGE Publications.

Coates, D.L., Vietze, P.M. and Gray, D.B. (1985). 'Methodological Issues in Studying Children of Disabled Parents', in Thurman, K. (ed) *Children of Handicapped Parents: Research and Clinical Perspectives*, New York: Academic Press.

Cogswell, B.E. (1976). 'Conceptual model of a family as a group: family response to disability', in Albrecht, G.L. (ed) *The Sociology of Physical Disability and Rehabilitation*. Pittsburg: The University of Pittsburg Press.

Doherty, W.J. and Campbell, T.L. (1988). *Families and Health*. Beverley Hills: SAGE Publications.

Harris, A.I., Cox, E., Smith, and CRW, (1971). *Handicapped and Impaired in Great Britain: Part 1*. London: HMSO, Office of Population Censuses and Surveys.

Jordan, A. (1989). *Lone Parent - and Wage Earner? Employment prospects of sole - parent pensioners*. Woden: Social Security Review, Department of Social Security.

Murphy, M.A. (1982). 'The family with a handicapped child: A review of the literature'. *Developmental and Behavioral Pediatrics*, 3, (2), pp 73-82.

Oliver, M. (1983) *Social work with disabled people*. London: MacMillan.

Rutter, M. (1966). *Children of Sick Parents*. London: Oxford.

Shaul, S., Dowling, P.J. and Laden, B.F. (1985). 'Like other Women: Perspectives of Mother's with Physical Disabilities', in Brooks, N.A. (ed) *Women and Disability: The Double Handicap*. New Brunswick: Transaction Books.


Smith, N.J., Bland, R. and Grey, C. (1992). 'Handicapped Parents: An area in need of research'. *International Journal of Rehabilitation Research*, (submitted for publication)

Thurman, K. (ed) (1985). *Children of Handicapped Parents: Research and Clinical Perspectives*. New York: Academic Press.

Westbrook, M.T. and Chinnery, D.L. (1990). 'Negative Attitudes Toward Physically Disabled Women Having Children: An Additional Handicap'. *Australian Social Work*, 43, (4), pp 17-22.

World Health Organization (1980). *International Classification of Impairments, Disabilities and Handicaps*. Geneva: WHO.

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- Enriching the Play Environment: *Creativity, Culture and Tradition*
- Close-ups of the Physical Environment: *Nature, Architecture and Townscape Issues*
- Play as an International Concern: *Implementation of Article 31 of the UN Convention on the Rights of the Child*

**KEYNOTE SPEAKERS**

- **Prof. Geoffrey Godbey**, Professor of Leisure Studies, Pennsylvania State University. He is a well-respected author of many books in which play is a theme.
- **Richard England**, leading Maltese architect, who has designed buildings throughout Europe and the Middle East.
- **Dr June Factor**, writer, critic and folklorist, an Associate at the Australia Centre, University of Melbourne and Director of the Australian Folklore Collection, the only archive of children's folklore in Australia.
- **Gienys Carter**, vice president of the International Toy Libraries Association and Director of *Play Matters*, the National Toy Libraries Association of the UK.

**WHO SHOULD ATTEND**

- People working in play programs
- Architects, and recreationists
- Youth and community workers
- Child psychologists and educationalists
- Planners and designers of play environments
- Early childhood, school & toy library staff and parents
- People working with children at risk

**MORE INFORMATION**  
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