

# **Sport and Recreation Activities and Opportunities for Children with Spina Bifida and Cystic Fibrosis**

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A survey, completed by 69 parents whose children have cystic fibrosis and 97 parents of children with spina bifida, showed that opportunities for participation in sport and recreation activities were significantly greater for children with cystic fibrosis than for children with spina bifida. Parents from both groups felt that there was not enough variety available, that there was difficulty finding suitable activities which involved the whole family and that they had found barriers to their child participating in sport and recreation activities. The stresses of having a child with a significant disability and trying to balance the needs of these children with those of other non-affected family members was reflected by the finding that both groups of parents had double the rate of psychological health problems that would be expected in the population.

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## **Introduction**

Spina bifida and cystic fibrosis are two relatively common, long-term disabling problems of childhood.

Spina bifida is a developmental defect in the arches of one or more of the spinal vertebrae, allowing some of the contents of the spinal canal (the spinal cord and surrounding membranes) to protrude onto the surface of the back. It occurs in approximately 1 in 1,000 births and has a familial tendency. Problems commonly associated with spina bifida include paralysis and loss of sensation in the lower limbs, incontinence and hydrocephalus. Intelligence is normal but can become impaired by the effects of hydrocephalus and meningitis.

Cystic fibrosis is a genetic disorder of the exocrine system. It occurs in 1 in 2500 births. The disorder results in abnormalities in the secretion of many exocrine glands leading to difficulties in digestion, liver damage and excessive salt loss. The major complications are in the respiratory system with serious respiratory infections and impairment of lung function.

As recently as 25 years ago, many children with cystic fibrosis and spina bifida died in early childhood with survival into adult life being unusual. Now, many complete their schooling and live into adult life. However, their childhoods are not normal. There are frequent medical visits and often hospitalisations. For the 90% of children with spina bifida who have hydrocephalus, surgery is required and revisions of the surgical procedure are often necessary. These children also have problems associated with varying degrees of lower limb paralysis, sensory loss, incontinence and urinary tract infections.

For children with cystic fibrosis, there is the need for regular medication to assist digestion, daily physiotherapy (usually performed by the parents at home),

regular contact with dietitians, physiotherapists and paediatricians, and the proneness to develop severe respiratory infections leading to progressive lung damage.

In addition to these medical problems, the families of these children have the difficulties of balancing the needs of their affected child with those of their unaffected siblings, ensuring that the child's educational needs are met as well as coping with the disrupted family routines and added complexity of life that these problems bring.

While much has been written about educational activities for children with long-term disabling medical problems, less thought has been given to the recreational and sporting activities that are available to these children. Missuina and Pollock (1991) have suggested that children with physical disabilities who are deprived of normal recreation activities have a second disability that hinders their potential for independent behaviour and performance. As well, those with physical disability have psychological gains from being involved in physical activity, including a reduction in anxiety and depression, feelings of greater self-sufficiency and an improvement in perceived health (Shepherd, 1991). Disabled young athletes who reach a level of competitive sport have been shown to have self-concept within or close to the norm for able-bodied youth (Sherrill et al., 1990). As leisure satisfaction has been shown to be the most significant factor of life satisfaction (Kinney & Coyle, 1992), this stresses the need to develop interest in and access to regular activities in childhood. This includes children with disabilities. This may not be easy for parents of disabled children who often also have able-bodied children and so have to strike a balance between the amount of time they spend on sport and recreation activities for their disabled child and those which involve other family members. In addition, some parents may not be aware of the varieties of recreation activities available for disabled children and for many parents there are additional barriers to these activities, such as cost, distance and transport.

In view of the importance of sport and recreation for children with physical disabilities, we looked at these activities in two groups of children, one being children with spina bifida which produces a significant physical disability, the other being children with cystic fibrosis, who have a long-term medical problem but where, compared with spina bifida, the physical disability is less of a problem, particularly in the early years. We did this by asking the parents of these children their views about sport and recreation activities: how much they were integrated with non-disabled children; the opportunities which were available; the range of activities; the degree to which financial considerations may be a limit and the effect providing sport and recreation activities for the disabled child may have on these opportunities for other children in the family. As a measure of mental stress which may occur in families of children with a significant medical problem (McKinney & Peterson, 1987), we looked at the mental health of the parents in both groups of children.

## **Methods**

A mail survey was sent to parents of children attending the spina bifida clinic and cystic fibrosis clinics of the Children's Hospital at Westmead. Only parents whose children were aged between 5 and 15 years were surveyed. The parents were asked to respond to 24 statements, using a four-point scale ranging from "strongly agree" through to "strongly disagree". The statements were designed to

determine what parents knew about sport and recreation facilities for their children, what proportion of such activities occur within and outside the family and what barriers, if any, exist for their child to gain access to these activities. For the analysis, the categories "strongly agree" and "agree" were collapsed to form one category of "agree", while "strongly disagree" and "disagree" were collapsed to form a "disagree" category.

Because of previous reports that parents of children with disabilities have more mental health problems than the general population (Singhi et al., 1990, Copley & Bodensteiner, 1987), the parents were asked to complete the General Health Questionnaire (GHQ) (Goldberg et al., 1970) as a measure of their psychological health. The GHQ is a simple, valid, reliable index of psychological health which has been validated in an Australian population where it has been shown to have 87% sensitivity and 94% specificity (Finlay-Jones & Burvill, 1977). A large Australian community survey showed that 14% of males and 19% of females have scores consistent with psychological impairment (Tennant, 1977). Letters were sent to 97 parents of children with cystic fibrosis and to 192 parents of children with spina bifida.

## Results

Sixty-nine of the 97 parents whose children have cystic fibrosis completed and returned the survey in forms that were suitable for analysis, a rate of 71%. The GHQ was completed by 89% of the mothers and 91% of the fathers who

Statement	Parents of Cystic Fibrosis Children Agreeing	Parents of Spina Bifida Children Agreeing	Significance $\chi^2$
1. Recreation is more important for children without disability.	6 (8%)	20 (21%)	$p < .025$
2. There are numerous opportunities for my child to participate in recreation.	63 (85%)	41 (44%)	$p < .001$
3. There is not enough variety in the types of recreation for my child.	17 (23%)	60 (63%)	$p < .001$
4. There are too few recreation opportunities for my child.	10 (14%)	54 (57%)	$p < .001$
5. The majority of recreation opportunities for my child are provided by hospitals and health professionals.	7 (9%)	21 (22%)	$p < .05$
6. Most of my child's recreation is outside the family.	37 (50%)	26 (27%)	$p < .01$
7. There are not enough recreation opportunities for my child which involve the whole family.	22 (30%)	56 (58%)	$p < .001$
8. My other children miss out on recreation activities because of the time I have to spend on recreation activities with this child.	6 (9%)	21 (22%)	$p < .05$
9. There are barriers for children like mine to participate in recreation.	18 (24%)	66 (70%)	$p < .001$
10. I have little knowledge of the recreation opportunities that are available for my child.	11 (15%)	54 (56%)	$p < .001$

Table 1: Significant differences between parents' views of sport and recreation opportunities for children with cystic fibrosis and spina bifida.

participated. The average age of the children with cystic fibrosis was 10.1 years. Ninety-seven (51%) of the 192 parents whose children have spina bifida returned fully completed questionnaires. Ninety-one per cent of the mothers and 79% of the fathers who participated completed the GHQ. The average age of the children with spina bifida was 9.9 years.

The ten questions where there were statistically significant differences between the views of the parents of children with cystic fibrosis and those of parents of children with spina bifida are shown in the table.

While every parent in both groups felt that sport and recreation were important for their own affected child, 21% of parents with a child with spina bifida and 8% of parents of a child with cystic fibrosis felt that these activities were more important for children who had no disability (question 1). Opportunities to participate in sport and recreation activities and the variety of such activities available were significantly less for children with spina bifida than for children with cystic fibrosis (questions 2 - 4) with 63% of parents with children with spina bifida saying there was inadequate variety of activities.

Hospitals and allied health professionals played a role in providing sport and recreation facilities (such as cystic fibrosis camps and riding for the disabled) but more so in children with spina bifida where 22% received the majority of their recreation activities from these areas (question 5).

Recreation activities were more likely to occur outside the family for children with cystic fibrosis than for children with spina bifida where only 27% occurred beyond the family (question 6). This is most likely due to the greater physical disability of children with spina bifida with many being in wheelchairs and others having to use crutches and calipers for mobility. However, for the children with spina bifida who had sporting activities outside the family, the range was wide including swimming and ten-pin bowling (the two most popular sports), wheelchair sports (including racing), little athletics, weight lifting, disabled skiing and archery.

The children with cystic fibrosis participated in a wider range of external sporting activities, including soccer, cricket, squash, tennis, cycling, fencing, aerobics, karate and netball; a range of sports similar to those undertaken by able-bodied children, except that for the children with cystic fibrosis, their prowess at these sports was often limited by their generally small size (a result of their nutritional problems) and their reduced lung capacity.

Of the parents of children with spina bifida, 58% were more likely to feel that there were not enough recreation opportunities for their child which could involve the whole family, although this was also a problem with 30% of the parents in the cystic fibrosis group. The problem of other children in the family missing out on sport and recreation activities because of the time spent on these activities for the disabled child, was also a greater problem in the spina bifida families (22% compared with 9%) (questions 7 and 8).

Both groups of parents felt that there were barriers to their child participating in recreation, although spina bifida parents were more than twice as likely to believe this (70% compared with 25%). Spina bifida parents also felt that they were much less knowledgeable about the opportunities that were available for their child (questions 9 and 10).

The results of the GHQ showed that there was a higher incidence of poor psychological health in both groups of parents than would be expected in the

average Australian adult population. Thirty-three per cent of fathers and 34% of mothers of children with cystic fibrosis had GHQ scores consistent with poor psychological health. The incidence was slightly higher, though not statistically significant, in the parents of children with spina bifida, with 38% of fathers and 39% of mothers being in this range compared with the 14% of males and 19% of females that would be expected from a random sample of the adult population (Tennant, 1997).

## **Discussion**

Many parents of children with cystic fibrosis and spina bifida reported that they found some difficulties in having access to an adequate range of sport and recreation facilities for their affected children, had problems in balancing the recreational needs of their affected and non-affected children and felt that they needed more knowledge about the range of activities that are available.

The problems were much greater for the parents of children with spina bifida. This is not surprising. The disability in spina bifida is present from birth and usually involves significant weakness of the lower limbs, often requiring a wheelchair for mobility. Although children with spina bifida often develop complications, particularly involving kidneys and bladder, the disability is generally not a progressive one. On the other hand, the defect in cystic fibrosis leads to a progressive disorder. Maintaining adequate nutrition for optimum growth becomes a problem and the progressive deterioration in lung function, often caused by their susceptibility to severe lung infections, means that as they become older their ability to participate in sporting activities requiring strenuous physical exertion becomes less. This progresses to the point where some of these children receive heart-lung transplants to give them extra years of life which they would not otherwise have. The desire to avoid lung infections made many parents of children with cystic fibrosis wary of public swimming pools as they perceived these as places where their child may contract an infection.

With both groups of children being of similar ages (average age of 10.1 years for the children with cystic fibrosis and 9.9 years for those with spina bifida) it is likely that as they become older the problems for the children with spina bifida in having access to sport and recreation activities may diminish as they become more adept at using their mobility devices and develop more independence. This is contrast to some of the children with cystic fibrosis who will be more likely to have increasing difficulties because of the progressive nature of their condition.

The birth of a child with a life-long serious medical problem adds greatly to the stresses and complexities of family life. The GHQ findings in this study, while showing that parents of children with cystic fibrosis and spina bifida have approximately double the incidence of psychological health problems compared with the normal population, can also be interpreted as showing that, despite the difficulties that these families have, 66% - 67% of parents of children with cystic fibrosis and 61% - 62% of parents of children with spina bifida in this sample had a GHQ profile consistent with satisfactory mental health. On the surface, one may have expected the parents of children with cystic fibrosis to have greater mental health problems, knowing that cystic fibrosis can be a fatal condition, even though it is now usually in adult life when death occurs. However, cystic fibrosis parents have some advantages in that they are a well-organised group, most belong to the Cystic Fibrosis Association which provides considerable support for

families, as well as providing activities for the children. There is considerable research into cystic fibrosis, the gene which causes it has been identified, new therapies are becoming available and there is a degree of optimism among parents that a major breakthrough is on the horizon.

## Conclusion

This study has shown that in this sample of children with cystic fibrosis and spina bifida, opportunities for sport and recreation activities are limited in scope and variety, particularly for children with spina bifida. There are barriers to participation and difficulties in balancing the needs for the affected as well as the non-affected in these families to have optimum involvement in sport and recreation activities. Such factors need to be taken into account by schools, local councils, governments and sporting bodies when planning sport and recreation activities so that these children are not further disadvantaged.

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