

Waving not Drowning: Supporting Carers and Parents of Disabled Children Who Work or Wish to Work

Janet Mearns



Janet Mearns runs **Working Families'** project to support parents who are trying to combine paid work and caring for disabled children. She edits **Working Families'** newsletter, *Waving not drowning*, and staffs the helpline. She wrote *Getting into Work*, **Working Families'** new publication for carers and parents who want to return to the workplace.

Summary

Working Families' 'Waving *not* drowning' project supports carers and parents of disabled children who are trying to combine paid work with their caring responsibilities. The project also campaigns for a better deal for carers and parents of disabled children in the workplace. Their recent survey of parents of disabled children (Summer 2009) showed that nearly 70% were not satisfied with the summer childcare available.

Introduction

Parents of disabled children find their wish to stay in the workplace or to re-enter it all the more pressing because their children tend to remain dependent for much longer.

When parents of disabled children call my helpline about their rights in the workplace I'm able to help them more and more. Since **Working Families'** 'Waving *not* drowning' project for parents of disabled children who work or wish to work was established 13 years ago, legislation has been introduced instigating parental and emergency leave and the right to request flexible working. The Disability Discrimination Act (DDA) has been challenged by a working mother, Sharon Coleman, whose employer discriminated against her because of her disabled child.

Parents seeking appropriate childcare can approach their local children's information service but still they ring me. They want to know where they can find childcare for a youngster with challenging behaviour who has been excluded from after-school clubs, and where is the care for 14, 15 or 16 year-olds who cannot be left on their own but want to follow their interests in their leisure time in the same way their non-disabled peers do?

Our survey of summer 2009

This anecdotal information led us to do a formal survey this summer of our network of parents of disabled children who work or wish to work. We contacted a sample including parents from all parts of the country with disabled children of different ages with a variety of impairments and asked them about their experiences of finding summer holiday childcare. Sadly, but not surprisingly, nearly 70 per cent of the parents of disabled children surveyed said that they were not satisfied with summer childcare available. Over half of them also said that information was hard to come by. One parent summed up the feeling of many when she said 'It's brick wall after brick wall.'

The lack of care to meet their children's needs impacts on the parents' ability to do paid work. A quarter of the parents we spoke to had had to take unpaid leave this summer and 39 per cent felt their responsibilities prevented them progressing in their careers or limited their ability to change jobs. The research demonstrates the real strain felt by many families with disabled children. Over three quarters of parents said it was very difficult balancing work and care responsibilities in the summer. Three per cent had had to leave their jobs because of lack of summer holiday childcare.

Working Families, the work-life balance charity, knows why parents want to work. It is not only for financial reasons but to socialise, to spend time being themselves, to improve their self-esteem and to be a role model for all their children. Parents of disabled children find their wish to stay in the workplace or to re-enter it all the more pressing because their children tend to remain dependent for much longer.

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'**Waving not drowning**' was set up in 1996 by Working Families (then called Parents At Work) to support parents of disabled children. The free newsletter goes to 2,000 parents and 900 interested professionals. The dedicated helpline advises parents about rights in the workplace. Over the years '**Waving not drowning**' has produced various publications and held conferences and information-gathering events. The latest publication, *Getting into Work*, was written as the direct result of requests from the network. It has advice about where to look for jobs, writing CVs and going for interviews. It raises parents' awareness of the skills they have gained while looking after their disabled child, such as time-management, telephone skills and knowledge of social services and benefits systems. Many parents who contacted **Working Families** when they had young children are now carers of their adult children and they share issues with other carers of adults so '**Waving not drowning**' has expanded its brief to encompass all carers who work or wish to work.

The experiences of the parents in the '**Waving not drowning**' network inform **Working Families'** campaign for a better deal for parents and carers in the workplace. The fact that parents of disabled children are entitled to more parental leave and can take it more flexibly is one of our achievements. A right to time-off to take children to their various appointments has always been an issue that we need to pursue. Carers of adults need parallel rights to those of parents. This summer's survey provides the facts to back up our campaign for appropriate care which would not only allow parents to do their paid work but would support their disabled children while they enjoy their own leisure interests.

Contact

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