

## Children and Young People Review – support for disabled children and their families

### Introduction

Working Families provides a unique service to parents of disabled children who work or wish to work. Our policy is based on evidence from parents using our advice line and our “Waving *not* drowning” network of 2000 families with disabled children.

The life chances of disabled children are inevitably affected by the nature and severity of their disability. However, the fact that half of all families with a disabled child are living in poverty, or on the margins of poverty, also has a profound impact on the life chances of disabled children. Parents of disabled children face particular difficulties in combining work and their caring responsibilities. Yet many parents of disabled children do want to work, and see employment as important as a route out of poverty. Parents of disabled children also want to be economically active for their own well being, for the wellbeing of their disabled child and their siblings, and to act as a role model for their children.

Working Families would like to see the Government tackle three key areas of support (outlined below) for disabled children and their family. Success should be measured by:

- the number of parents of disabled children in paid work;
- the availability of affordable and accessible, good quality childcare for disabled children; and
- the availability of comprehensive information and support services for disabled children and their families.

### Supporting parents into work

Many parents of disabled children cannot manage a full time job as well as their caring responsibilities. But many who contact Working Families want to work more hours than they currently can. The right to request flexible working and tax credits have helped many parents back into employment. However significant barriers remain:

- **not enough jobs are advertised on a flexible basis** and the right to request flexible working can only be used once a parent has been in employment for 26 weeks. Parents of disabled children need to be able to work flexibly from day one. **Working Families would like the 26 week rule for the right to request flexible working removed.**
- **The withdrawal of benefits can act as a disincentive to work.** Parents entitled to Carers’ Allowance (at £46.95 per week) lose the whole allowance as soon as they earn over £84 per week net. There is a disincentive to work if their salary is between £84 and £130.95 per week. This makes it difficult for a parent in receipt of Carers’ Allowance to be flexible – for example, working additional hours when the workload is heavy. **Working Families would like to see the cut off for Carers’ Allowance tapered.**
- **The Working Tax Credit system fails to take account of the additional cost of paying to care for a disabled child.** Children with severe disabilities or complex needs may require one to one care, or highly specialist support. This is inevitably more expensive than group based childcare. The childcare element of the WTC is claimed per child and

takes no account of the additional costs incurred by disabled children and their families. Inland Revenue figures also show that working families with disabled children are less likely to benefit from the childcare element with only 7.8% of families with one disabled child receiving the childcare element compared to 14.6% of families with no disabled children.<sup>1</sup> The nature of a child's disability may mean wide variations in their childcare needs (eg if they need to spend time in hospital) which makes the claiming of WTC difficult. **Working Families would like reform of the Working Tax Credit to reflect the additional costs of caring for a disabled child.**

- **Childcare assistance (via WTC) is not available to those working less than 16 hours per week.** Nor is it available to those studying or in training. This makes it difficult for parents who can't work very many hours, but want to work a little, or those who want to retrain for new types of work. **Amending the 16 hour rule** would help those with heavy caring responsibilities.
- Taking time off for hospital visits is a problem in combining work and parents for a third of parents of disabled children<sup>2</sup>. **Paid time off for hospital appointments** would help many parents, particularly around the time at which their child's disability is being diagnosed.

### **The availability of suitable and affordable childcare**

Almost seventy percent of parents with disabled children face difficulties in finding suitable childcare<sup>3</sup>. The lack of childcare has an impact both on the parents' ability to work and on the social wellbeing of the child. Many parents of disabled children resent assumptions that they will not be working, and will therefore be available to pick up the gaps in care during school holidays. Holiday play schemes are criticised by our network of parents as very expensive and as not filling the whole of the holiday period. A lack of support for children with autism is a regular criticism of callers to our helpline. Challenging behaviour may need specialist care, and some children may be best cared for in their own home or a familiar setting. When an autistic child is excluded from school their parents often have to take time off work (unpaid) to look after their child.

- **Further assistance for local authorities to realise their new childcare duty.** The new duty on local authorities under the Childcare Bill to provide sufficient childcare places with a special emphasis on disabled children is extremely welcome. **Extra money may be needed to improve the supply of places for disabled children** if local authorities are to meet their new duties. Research suggests that many childcare settings say they are able to accommodate disabled children, yet have only one place available<sup>4</sup>. The resources for support workers need to be provided to ensure that these places can be taken up by a disabled child.

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<sup>1</sup> Analysis by Contact a Family quoted in Everyone Counts. Daycare Trust 2004

<sup>2</sup> Flexible Enough? Employment Patterns in families with disabled children. Contact A Family 2004

<sup>3</sup> 69% of parents of disabled children said it was difficult to find appropriate childcare to meet both their needs and their children's needs. Everyone Counts. Daycare Trust 2004.

<sup>4</sup> National Audit Office, Early Years: Progress in developing high quality childcare and early education accessible to all. 2004

- **Allow childcare payments to family members.** The restrictions on childcare payments to family members disadvantage families with disabled children as a family member may best understand the child's needs.
- **A greater emphasis should be placed on direct payments** to give parents greater flexibility in their childcare arrangements. For older children this can be particularly important as they seek to establish their independence and can use resources to pay for personal assistants. The direct payments granted need to reflect more closely the cost of the childcare available to parents of disabled children in the locality.
- **There is a need to invest in training and support for the childcare workforce, particularly for disabled children.** The special needs of disabled children require consistent and specialist support. Carers provided by social services can change too often to allow bonding with children. Parents (who often know best about the needs of the child) should be involved in the training of support workers to meet their child's needs.
- **Provision for older disabled children** should be more inclusive with a variety of after school and holiday provision to meet the needs of the family. As disabled children reach college after-school provision dries up. College hours tend to be shorter and holidays long so care arrangements – for example to transport older children - are more complex, and may be more difficult for a working parent to accommodate.

### **A one stop shop for information and improved co-ordination of services**

An early intervention that can make a huge difference to a family is the provision of information about entitlements to benefits and services available. Getting the right advice is crucial to accessing services and to the effective planning of care and support. However, parents of disabled children report a fractured picture of information provision and often rely on other parents and informal support networks for advice. Many parents feel that social services are failing them as they struggle to extract information rather than have it voluntarily given. Parents tell us that there is no single place they can go for help. This leads to a lottery of support and in the take-up of entitlements across the country. Parents who have joined networks – often based around the nature of their child's disability – feel the most supported and able to find the information they need.

**Working Families would like every family with a disabled child to be allocated one key worker. The new Children's Trusts provide an ideal opportunity to develop this.** A key worker available from the time that the child's disability is diagnosed, would be able to help the family through the benefits system, to contact the education and social services departments, to arrange any necessary transport or housing adaptations, and to link with the health service.