COMMUNITY EQUIPMENT: USE AND NEEDS OF DISABLED CHILDREN AND THEIR FAMILIES

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CHAPTER ONE:
BACKGROUND

1.1_ INTRODUCTION

In April 2001 the Department of Health commissioned the Social Policy Research Unit at the University of York to carry out a small project looking at disabled children's equipment.

As part of the Community Equipment Services Project, the Department of Health wanted a specific piece of research to look at the following issues:

i the number of disabled children using equipment (in relation to a given population);
ii the types of equipment and adaptations (necessary to the use of equipment) used by disabled children (up to 18 years);
iii the extent to which equipment and adaptations have to be duplicated in different locations, such as home, school, and short term care setting;
iv the extent of unmet equipment/adaptation needs perceived by parents;
v the range of approximate values (at current replacement costs) of equipment and adaptations used by individual children, and how costs vary with age;
vi the potential for recycling (re-use) of children's equipment since it is often custom-built and age specific;
vii the actual, and parentally preferred, funding sources of the equipment and adaptations.

1.2 DISABLED CHILDREN'S EQUIPMENT - BACKGROUND

There is an enormous range of 'equipment' that a disabled child may require and use. This includes therapeutic equipment, mobility equipment, equipment to support learning in schools, and health care technologies. Social services, education, health and housing authorities all have responsibilities for meeting certain needs of disabled children through the provision of equipment. The focus of this project was on equipment which falls within the remit of community equipment services.

Community Equipment

A recent circular from the Department of Health defines community equipment in this way:

- Community equipment enables children and adults who require assistance to perform essential activities of daily living to maintain their health and autonomy and to live as full a life as possible. This equipment includes, but is not limited to:
- Home nursing equipment, such as pressure relief mattresses and commodes.
- 'Equipment for daily living', such as children's special seating, shower chairs, raised toilet seats, teapot tippers and liquid level indicators.
- Minor adaptations, such as grab rails, lever taps, improved domestic lighting, and improving the use of contrasting colours.
- Ancillary equipment for people with sensory impairments, such as flashing doorbells, low vision optical aids, textphones and assistive listening devices.

- Equipment for short-term loan, including wheelchairs but not those for permanent wheelchair users, as these are prescribed and funded by different NHS services.
- Communication aids for people who are speech impaired.
- Telecare equipment such as fall alarms, gas escape alarms. health state monitoring and 'wandering detectors' for people who are vulnerable.

(pp 3-4; Guide to Integrating Community Equipment Services; Department of Health, March 2001.)

Community Equipment Services have been criticised in the past for failing to meet the needs of disabled and older people (Audit Commission, 2000). One of the reasons for this mismatch between need and provision must be a lack of information by which to project funding requirements. As with other groups of disabled people, the lack of data on numbers of disabled children and their needs is acknowledged to be a key barrier to improving services (Department of Health, 1999). This project appears to be the first attempt to produce data - at a national level - of use and need for community equipment since the OPCS survey of disabled children living in private households which was conducted in 1985 (Meltzer et al., 1989; Gordon et al., 2000).

Housing adaptations

Typically, in terms of service organisation, community equipment and housing adaptation services are separate. However, their effectiveness is often inter-dependent (Beresford and Oldman, 2000). The distinction used for deciding which service is responsible for providing and funding a piece of equipment works on the principle that equipment that is immoveable or fixed or plumbed (or its removal would require structural change or intervention) falls within housing adaptation services. Thus, for example, a ceiling hoist to assist with lifting a child in and out of the bath is an adaptation. A portable hoist or bath (pillar) lift are the remit of Community Equipment Services. Where applicable, this project also collected data on equipment installed within a housing adaptation.

1.3 THE PROJECT

The project approach

A recurring issue in terms of looking at services to disabled children and their families is dis-entangling the true recipient or beneficiary of a service. The same difficulty occurs with some areas of community equipment. For disabled children, community equipment can support independence and/or participation in everyday activities. For parents, community equipment assists with caring tasks. The difficulty is that while there is a solid base of research evidence on parents' needs (as carers), (for example, Beresford *et al.*, 1996) and the process of involving parents in an assessment process is usually relatively straight forward, the same is not the case for disabled children. It is only in recent years that disabled children are being directly involved in research about them and their lives (for example, Noyes, 1999; Watson and Priestley, 1999), and more active and considered efforts are being made to include children in needs assessment (Council for Disabled Children,

2000).

With respect to community equipment services there is no evidence, either of what disabled children and young people say they want from such a service, or its effectiveness in terms of enabling them to lead as normal life as possible. What is clear from the research which is now emerging is the priority disabled children and young people place on being able to participate in 'normal' everyday activities - in and out of the home (Mitchell and Sloper, 2001; Beresford, forthcoming). This seems to fit well with the aims or purpose of Community Equipment Services. Within this project we wanted to 'start the ball rolling' in terms of beginning to look at generic child-centred needs as well as the particular needs disabled children have which might be relevant to understanding what Community Equipment Services for disabled children and young people need to include.

A second feature of our approach to this project was the decision to include children with all types of impairments and disabilities. Again, we tried not to be constrained by 'what is already out there' in terms of the population who typically use Community Equipment Services. Thus, for example, children with behavioural problems and learning difficulties were included in the sample.

Research design

The project consisted of a survey of a nationally representative sample of parents of severely disabled children, and a small scale consultation phase with key organisations and individuals involved in meeting the equipment needs of disabled children. Further details on the methodology and sample are provided in Appendices 1 to 3.

The purpose of the survey of parents was to gather data on current levels of use of equipment, perceived unmet needs, extent of self-funding, extent of duplication of equipment in different settings. Over 3,000 families took part in the survey.

The aims of the consultation phase were to corroborate, question or explain findings from the survey, and to seek opinions or comment on the following: neglected groups (in terms of equipment provision); equipment needs that 'fall between stools' with no agency acknowledging funding responsibility; the relationship between equipment provision and housing adaptations; recycling of equipment; and the duplication of equipment in different settings.

1.4 THE REPORT

Chapters Two and Three report in detail the findings from the survey. Chapter Two presents data on the incidence of different impairments/inabilities among severely disabled children. This can be used to provide indicators of the potential size of populations requiring different forms of equipment. Chapter Three reports findings on parents' reports of equipment currently being used in the home, unmet needs, perceived reasons for needs remaining

unmet, duplication of equipment in different settings and self-funding. Chapter Four picks up many of these themes and reports the responses to these issues from those who took part in the consultation phase. Chapter Five provides an overview of the findings. Finally, a discussion of the findings and their implications, the limitations of the project, and suggested areas of further work can be found in Chapter Six.

CHAPTER TWO:
THE CHILDREN: ABILITIES AND IMPAIRMENTS

2.1 INTRODUCTION

This chapter describes the abilities and impairments of the children involved in the survey. In terms of equipment needs, rather than looking at the incidence of medical conditions, it is more helpful to look at abilities and impairments, and their implications in terms of care needs and needs relating to supporting independence.

The nature of a child's impairments, their abilities and inabilities, can be viewed as indicators of potential equipment requirements, either to assist the parent/carer or to enable the child to achieve as much independence as possible. We also present data here on the numbers of children in study who were dependent on medical equipment for their survival or the maintenance of their health.

2.2 IMPAIRMENTS AND ABILITIES

Two questions in the survey collected information about the child's abilities and impairments. The first asked parents to report the amount of help their child needed with the following basic activities: sitting, standing, moving about, eating/drinking, using the toilet, bathing/washing, dressing and keeping occupied. Parents could either respond that, compared to other (non-disabled) children of their child's age, their child needed 'no help', 'some help' or 'a lot of help'. The second question concerned the extent to which the child experienced difficulties with the following: hearing, seeing, learning, communicating, behaviour, continence, and awareness of danger. Here parents either reported 'no difficulties', 'some difficulties' or 'a lot of difficulties'.

Help with basic activities

Table 2.1 presents basic frequency data on the extent to which disabled children need help with daily activities. It shows that, among the children represented in the survey, over a third needed at least some help with sitting, and almost a half needed at least some help with standing. Over two-thirds of respondents reported their child needed some or a lot of help with moving about and eating/drinking. In terms of personal care, eight out of ten children needed at least some help with using the toilet and dressing. This figure rises to nine out of ten for bathing/washing and keeping occupied. Finally, nine of ten children were reported as needing at least 'some help' with keeping occupied, with two thirds of the sample rated as needing 'a lot of' help in this area.

Table 2.1: Help with basic activities

	Needs no help	*Needs some help*	*Needs a lot of help*
	%	*%*	*%*
Sitting	64	16	20
Standing	53	16	31
Moving about	33	34	33
Eating/ drinking	27	38	35
Using the toilet	20	29	51
Bathing/washing	8	29	63
Dressing	11	32	57
Keeping occupied	10	24	66

Age effects

Further analysis of this data looked at the effect of age on the proportion of children needing *a lot of help* with basic activities, see Table 2.2. Data from children aged less than two years have been excluded because this age group typically have very high care demands.

Overall, Table 2.2 shows the impact of the condition/impairment on the achievement of developmental milestones. The fall in the proportion of children needing a lot of help with many of these activities between the lowest two age bands reflects this delay. Among a population of non-disabled children this would be observed at an earlier age. However, what is equally striking from this table is that for each activity a sizeable proportion of the older children remain needing a lot of help. The levelling off in figures across the age bands also suggests that many of these children will continue to need a lot of help into their adult lives. There are clearly implications here in terms of the extent to which equipment (which is not 'age dependent') will become available for recycling given the fact that for a sizeable proportion there is a long-term need for equipment to support or assist with these activities.

Table 2.2: Proportion of children in each age band requiring a lot of help with each daily activity

	2-4 yrs. %	*5-7 yrs. %*	*8-11 yrs. %*	*12-14 yrs. %*	*15 - 17 yrs. %*
Sitting	23	12	14	14	15
Standing	40	20	23	24	22
Moving about	38	26	28	27	27
Eating/ drinking	46	28	26	22	23
Using toilet	74	51	42	39	34
Bathing/ washing	80	64	59	53	45
Dressing	77	58	49	42	36
Keeping occupied	70	70	65	63	57

Difficulties and abilities

The survey also asked parents to rate their child's abilities in the following areas: learning, hearing, seeing, continence, communication and awareness of danger, see Table 2.3.

Two-thirds of parents reported their child had a hearing impairment and a similar proportion said their child had a visual impairment. Over two-thirds of parents said their child had continence problems, with just under four out of ten parents indicating their child had a lot of difficulties with continence. Almost all children had difficulties with learning (87 per cent), with six out of ten parents stating that their child had 'a lot of difficulties'. Difficulties with communication were also frequently reported: with over half having 'a lot of difficulties' with communication.

Difficulties with behaviour, and more specifically awareness of danger, were reported by the majority of parents. One in four children had a lot difficulties with behaviour, and over two-thirds reported a lot of difficulties associated with their child's lack of awareness of danger.

Table 2.3: Abilities and difficulties

	No difficulties		*Some difficulties*		*A lot of difficulties*		*Total*
	n	*%*	*n*	*%*	*n*	*%*	
Hearing	2054	68	613	20	354	12	100% (n=3022)
Seeing	1935	65	685	23	354	12	100% (n=2974)
Continence	889	31	859	30	1122	39	100% (n=3401)
Learning	410	13	854	27	1934	60	100% (n=3198)
Communicating	558	18	902	28	1704	54	100% (n=3164)
Behaviour	763	24	1104	35	1272	41	100% (n=3139)
Awareness of danger	403	13	678	21	2076	66	100% (n=3157)

Age effects

The effect of the child's age on the proportion of children experiencing a lot of difficulty or inabilities with these areas is shown in Table 2.4.

Table 2.4: Proportion of children in each age band experiencing 'a lot of difficulties' with abilities

	2-4 yrs. %	*5-7 yrs. %*	*8-11 yrs. %*	*12-14 yrs. %*	*15 - 17 yrs. %*
Hearing	12	11	7	11	18
Seeing	11	10	11	9	13
Continence	55	39	34	33	30
Learning	53	62	64	69	67
Communication	60	57	50	53	53
Behaviour	31	46	49	48	40
Awareness of danger	69	72	67	65	57

Overall, the impact of age on the functions/abilities shown in Table 2.4 is different to the effect of age on the extent to which help is needed with daily activities (as shown in Table 2.2). Here there is no linear age effect on the proportion of children with sensory impairments. Problems with continence do decrease, though three out of ten 15-17 year olds have a lot of difficulties with continence. Similarly, while communication difficulties for children are resolved as the child grows older, over half of 15-17 year olds experience a lot of difficulties with communication. The proportion of parents reporting a lot of problems with learning and behaviour increases with age, and there is only a small decrease in the proportion of children where a lack of awareness of danger is reported as presenting a lot of difficulties.

2.3 THE EXTENT OF MULTIPLE IMPAIRMENTS OR COMPLEX DISABILITY

We then looked at these data together in terms of total number of activities with which children needed 'a lot of' help (n=8) and/or had had a lot of difficulties with a function/ ability (n=7), see Figure 2.1.

Figure 2.1: Mean number of activities/abilities have a lot of difficulties with by age

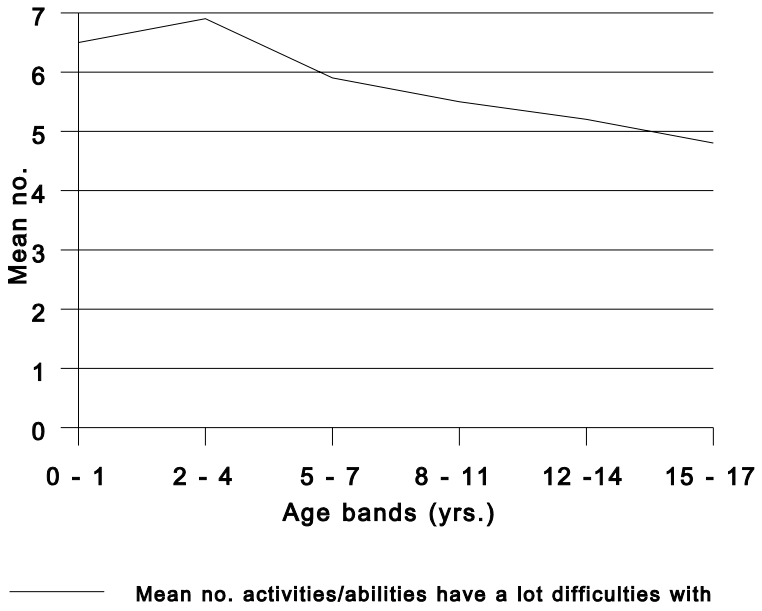


Figure 2.1 shows that, across age groups, the mean number of functions or activities with which children are rated as having a lot difficulties with peaks in early childhood and then decreases. Two features of this chart need highlighting. First, the high levels of need or disability reported among young children. Second, among older children a lot of difficulties with managing activities of daily life are still reported.

2.4 MEDICAL CARE NEEDS

Just under one in five children (18 per cent) were using medical equipment at home, either to sustain life or to optimise their health. Most of these children (81 per cent) were using just one or two pieces of piece of equipment. The types of equipment being used, along with the frequency of their use, are shown in Table 2.5.

Table 2.5: Children using medical equipment at home: extent of use

	n	*Whole sample %*	*Of children using medical equipment %*
Naso-gastric or gastrostomy feeding equipment	339	10	54
Oxygen therapy equipment	158	5	25
Breathing or heart monitor	156	5	25
Suction equipment	145	4	23
Intravenous line for administration of drugs	92	3	15
Catheter	83	2	13
Ventilator	66	2	11
Tracheostomy equipment	44	1.5	7
Dialysis equipment	13	0.5	2
		Base=3401	*Base=623*

Naso-gastric or gastrostomy feeding equipment was the equipment most frequently used with one in ten children needing this equipment at home. Oxygen therapy equipment, breathing or heart monitors, and suction equipment were other pieces of equipment being used by around one in 20 children.

There is a strong association between the age of the child and whether or not they are using medical equipment in the home. Almost half of children under two years of age were using at least one piece of the medical equipment listed in Table 2.5. Among two to four year olds this proportion drops to a quarter of children. Among children aged between five and 17 the proportion is fairly stable with just over one in ten children using such equipment at home. The number of pieces of equipment is also associated with the age of the child. Of those children using three or more pieces of medical equipment, four out of ten were less than two years old, three out of ten were between two and four years. This figure falls to just over one in ten among children five years and over.

2.5 OVERVIEW

This chapter has provided data on the impairments and (in)abilities of severely disabled children. The majority of these children have complex disabilities or multiple impairments. In some cases this is further complicated by a dependency on one or more pieces of medical equipment - this is especially the case among younger children. Dependency on others for assistance with self care tasks is often long term.

While not typically seen as falling within the remit of Community Equipment Services, the findings on the number of children experiencing a lot of difficulties with learning, communication, behaviour, keeping occupied and awareness danger are striking. They raise questions about the provision of equipment *in the home environment* to address needs associated with play, learning, communication, learning and safety.

The representativeness of the sample mean that the proportions reported in this chapter can be taken as being rough estimates of the proportion of all severely disabled children and young people with these impairments and (in)abilities. This data, in itself, is a valuable resource when looking at overall levels of potential need for equipment to assist with the daily lives of severely disabled children and their parents/carers in England.

CHAPTER THREE:
EQUIPMENT: USE, MET NEED AND UNMET NEED

3.1 INTRODUCTION

Primarily in this chapter we focus on reporting findings of levels of need, use and unmet need for equipment by disabled children and young people and their parents/carers. The chapter also reports findings on factors contributing to unmet equipment needs, self-funding of equipment, and management of equipment needs in different home/care settings.

3.2 IDENTIFYING LEVELS OF USE AND UNMET NEEDS

Needs for equipment can be met through the provision or installation of appropriate equipment (funded by a statutory agency, charitable organisation or self-funded) or they can remain unmet. Thus the extent of need within a sample can be computed from the proportion of the sample reporting met need and the proportion reporting unmet need. We begin by reporting overall levels of equipment use and unmet need before looking more specifically at different types of equipment. At this point the findings will be presented around a series of categories of equipment: lifting, seating, stairs/steps, safety, bathing, toileting, changing, dressing, sleeping, continence, using the home, and learning/playing. For each category of equipment, we put the follow questions to the data:

- How many parents/children have this type of equipment at home?
- How many parents report they have unmet needs for this type of equipment?
- How many children have an impairment or cluster of impairments which are likely to result in a need for this type of equipment?

Assessing the extent to which equipment needs are unmet

Identifying and measuring unmet need is notoriously problematic. A lack of information (in this case, about equipment options, future needs, constraints imposed by housing and so on) make it difficult for parents to know what might best meet their needs. Furthermore, user and practitioner definitions of unmet need may differ (Heaton and Bamford, 2001). Assessing need is something that requires an individualistic and holistic approach - something that can only happen through face to face consultation in the home setting by a someone with appropriate skills and training. However, what *is* possible from the scope of this piece of work are two things.

First, we can look at the extent of user-reported unmet need for equipment. In the survey respondents were asked to indicate which pieces of equipment (from a fixed list of just under 100 different items) they need but do not currently have at home. This will include those with no equipment to assist with meeting a particular function/activity, and those with some equipment but with equipment needs remaining. (For example, a family may have some lifting equipment (a hoist) but require further lifting equipment (such as tracking)).

It might be argued that using parental reports of unmet need will lead to an overestimation of unmet need. We would argue that previous research has shown that parents with a disabled

child have very low expectations for support and there is no evidence that in other survey-type research parents exaggerate or over-report their needs (for example, Beresford, 1995; Chamba *et al.*, 1999).

Second, where possible, these findings will be considered alongside data on the numbers of children with an impairment or cluster of impairments which are likely to be associated with each specific equipment needs. The equipment category and associated impairments used for these analyses are shown in Table 3.1.

Table 3.1: Equipment category and associated 'equipment indicators'

Equipment category	*Variables used to identify population with potential equipment need*
Lifting	Child needs help with sitting, standing & moving about.
Seating	Child needs help with sitting.
Stairs/steps	Child needs help with sitting, standing & moving about.
Safety	Child has 'a lot of difficulties' with awareness of danger.
Communication	Child has difficulties with communicating.
Bathing	Child needs help with bathing/washing.
Toileting	Child is continent but needs help with using the toilet
Continence and changing	Child has a lot of difficulties with continence and is 4 years or older
Dressing	Child needs a lot of help with dressing and is 5 years or older
Sleeping/being in bed	No available indicators of population with potential equipment need
Auditory	Child has difficulties with hearing
Supporting independence about the home	No available indicators or population with potential equipment need. Children five years and over
Learning/playing	Total sample

In addition we will also report parents' preferences in terms of addressing their unmet needs. However, it is important to view these data as indicators of areas of preference, as opposed to definitive evidence as to the specific types of equipment a family might need.

3.3 OVERALL LEVELS OF EQUIPMENT USE AND UNMET NEED

An indicator of overall level of equipment need was computed from the total number of items of equipment listed on the questionnaire which a respondent currently had at home and the total number of items of equipment identified by a respondent as still being needed. Almost all respondents reported having equipment needs - met and/or unmet. Just one in 20 respondents indicated that they neither had, nor needed, any of the items of equipment listed on the questionnaire. Just under a quarter of respondents (23 per cent) reported needs for between one and five pieces of the listed items; one in five (22 per cent) had needs for between six and ten items; and a similar proportion (19 per cent) identified between 11 and 17 items.

Current levels of use

The number of different pieces of equipment being used by respondents ranged from none to over 50. Sixteen per cent of respondents currently had none of the equipment listed. Around a third (35 per cent) had up to four items, and over a quarter (27 per cent) between five and eight items. Over one in five respondents (22 per cent) had 9 or more different pieces of equipment.

Overall levels of unmet need

Over one in five respondents (23 per cent) did not report any outstanding needs for the equipment listed on the questionnaire. Over a third (36 per cent) identified between one and four items they or their child needed but did not currently have, and a fifth (18 per cent) stated needing between five and eight items. The remainder (23 per cent) reported unmet needs for nine or more items of equipment.

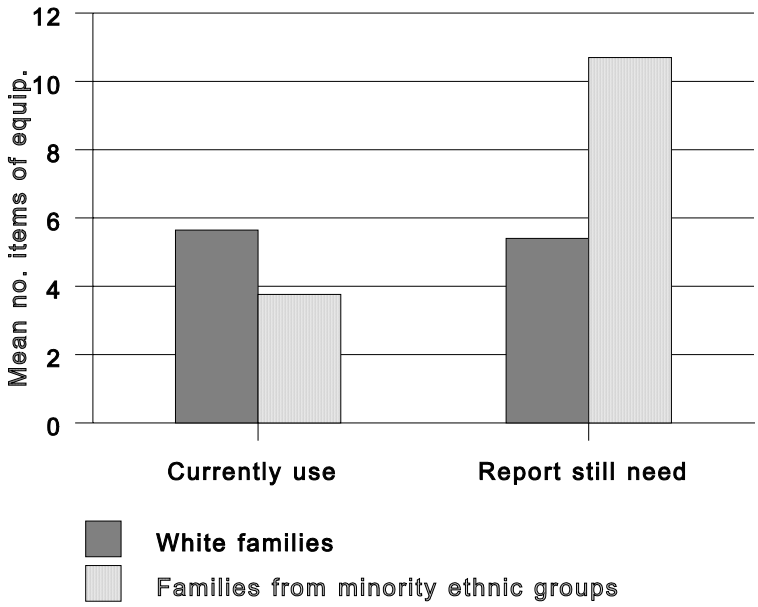
Factors associated with levels of met and unmet need

Ethnicity and the age of a child were both significantly associated with the number of items of equipment families currently have and their reported levels of unmet need.

Ethnicity

Compared to families from minority ethnic groups, white families reported having more items of equipment currently in their homes and had fewer unmet needs, see Figure 3.1.

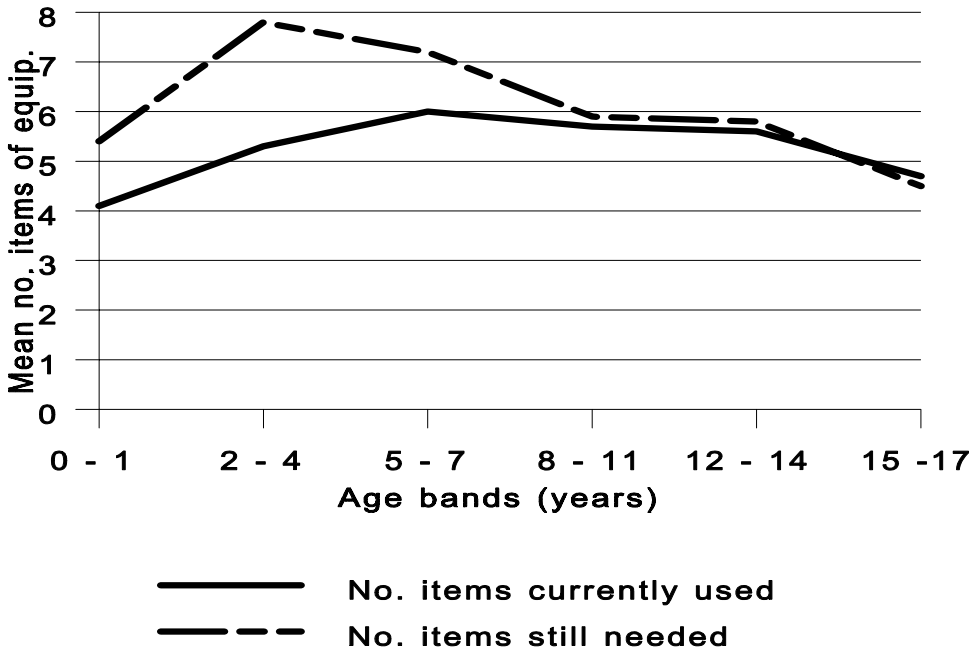
Figure 3.1: Association between levels of met and unmet need and ethnicity



Age

The age of the child was also associated with the amount of equipment currently being used and levels of unmet need, see Figure 3.2.

Figure 3.2: Association between age and overall levels of equipment use and unmet need



Provision or acquisition of equipment increases from the youngest age band, levelling off over the middle childhood years and declining between the highest two age bands. In terms of reported levels of unmet need, this increases more rapidly and peaks at a younger age (2-4 years) before decreasing to a lower level of reported unmet need in the 15-17 year old age band compared to the 0-1 year age band. The levels of current equipment use and unmet need among 0-1 year age range appear high. One explanation for this is the high level of

care needs of all babies and young children - disabled or non-disabled. Equally, there is now clear evidence (Beresford, 1995; Glendinning *et al.*, 1999; also Chapter 2) that, due to improvements in ante- and post-natal care, an increasing number of babies born very premature or with other life-threatening complications are surviving and being cared for at home with very complex medical and care needs.

3.4 EQUIPMENT TO ASSIST WITH LIFTING

Two hundred and eighteen respondents (6.4 per cent) had a hoist and/or tracking equipment in the home. The types of hoists/tracking being used across the total sample are detailed in Table 3.2. Among families with lifting equipment, the majority (61 per cent) had only one type of equipment.

Table 3.2: Need for lifting equipment

	With equipment		*Report need equipment*	
	n	*%*	*n*	*%*
Portable hoist	76	2.2	*144*	*4.2*
Ceiling hoist: bedroom only	110	3.2	*100*	*2.9*
Ceiling hoist: bathroom only	49	1.4	*124*	*3.6*
Hoist with track connecting bedroom and bathroom	69	2.0	*145*	*4.3*
Hoist with track connecting bedroom, bathroom and family living room	32	0.9	*135*	*4.0*

Just under eight per cent of respondents who, at the time of the survey, had no hoist/ tracking equipment reported that they needed at least one of the pieces of lifting equipment listed in the questionnaire. A further smaller group of respondents (1.8 per cent) had some lifting equipment in the home but were still reporting unmet needs for lifting equipment. Among families reporting unmet needs for lifting equipment, there is no clear preference in terms of the type of equipment.

An indicator of the proportion of families who are likely to need lifting equipment was generated by counting the number of children who were rated by their parents as needing ‘a lot of help’ with standing, sitting and moving about. This amounted to 14.5 per cent of the sample. (It is interesting to note that this figure is similar to that obtained when the number of families with lifting equipment (4.6 per cent) and those reporting unmet hoist equipment needs (9.3 per cent) are totalled (13.9 per cent)). A summary of data on met and unmet need and the proportion of children with a potential need for lifting equipment is provided in Table 3.3.

Table 3.3: Lifting equipment: summary of met and unmet need

	n	*%*
No. respondents with lifting equipment at home *and* reporting no further lifting equipment needs	157	**4.6**
No. respondents indicating unmet need for lifting equipment	317	**9.3**
(No lifting equipment currently in home	*256*	*7.5)*
(Some lifting equipment already in home	*61*	*1.8)*
No. children rated by parent as needing 'a lot of help' with sitting, standing and moving about	492	**14.5**

3.5 SEATING EQUIPMENT: USE AND UNMET NEEDS

Provision and funding of seating is complicated. Wheelchairs are seats as well as a means of moving about, and schools have a requirement to provide suitable seating. Both these sorts of 'seating' are likely to be used at home and at school. Thus while one in five respondents reported they had special seating for their child at home, a proportion of this equipment will have been funded by education or wheelchair services. Typically, respondents reported having only one type of chair. Less than one in 20 children had more than one seat to use at home (and they might have been using that same seat or chair at school). The seating equipment being used by the children represented in this survey is shown in Table 3.4.

Table 3.4: Need for seats and seating accessories

	With equipment		*Report need equipment*	
	n	*%*	*n*	*%*
Floor sitter	144	4.2	*220*	*6.5*
Moulded postural chair*	189	5.6	*189*	*5.6*
Multi-adjustable wooden chair (or activity chair)**	36	9.9	*243*	*7.1*
Multi-adjustable upholstered chair	204	6.0	*269*	*7.9*
Tray to attach to chair for feeding playing	506	14.9	*212*	*6.2*
Frame to raise the height of the activity chair	68	2.0	*132*	*3.9*

Notes
** Typically, forms part of or can be fixed to frame of wheelchair, therefore funding can be ambiguous.*
*** Can be 'shared' between home and school, therefore funding can be ambiguous.*

Just over 15 per cent of respondents reported unmet needs for the types of seating equipment listed in the questionnaire. A third of these respondents already had some form of special seating equipment. Just under one in five children were reported as needing 'a lot

of help' with sitting, and a slightly smaller proportion needed 'some help' with sitting; thus a third of the sample needed at least some help with sitting. A summary of data on met and unmet need and proportion of children with a potential need for seating equipment is provided in Table 3.5.

Table 3.5: Seating equipment: summary of met and unmet need

	n	*%*
No. respondents with seating equipment at home *and* reporting no further seating equipment needs	481	**14.1**
No. respondents indicating unmet need for seating equipment	540	**15.8**
(No seating equipment currently in home	*342*	*10.0)*
(Some seating equipment already in home	*198*	*5.8)*
No. children rated by parent as needing 'a lot of help' with sitting	584	**19.9**
No. children rated by parent as needing 'some help' with sitting	462	**15.8**

3.6 EQUIPMENT TO ASSIST WITH MANAGING STAIRS AND STEPS

Just over one in ten respondents (10.8 per cent) reported that they had equipment in the home to assist with managing stairs and steps. The equipment being used is shown in Table 3.6. Very few families (2.1 per cent) had more than one piece of equipment to assist with stairs and steps in their home.

Table 3.6: Need for equipment to assist with stairs and steps

	With equipment		*Report need equipment*	
	n	*%*	*n*	*%*
Stairlift (standing only)	7	0.2	*50*	*1.5*
Stairlift with platform for wheelchair	10	0.3	*70*	*2.1*
Stairlift with seat	61	1.8	*155*	*4.6*
Through floor lift	63	1.9	*68*	*2.0*
Rails for external steps	112	3.3	*112*	*3.3*
Rails for internal steps	199	5.9	*99*	*2.9*

Among those families with no step/stair equipment, over one in twelve (8.8 per cent) reported that they needed such equipment. In addition, ten per cent of families with existing step/stair equipment reported they needed other equipment to assist with getting up and down steps/stairs. Overall, this yields a figure of just under one in ten families (9.7 per cent) reporting an unmet need for equipment to assist with stairs and steps. Among those

reporting an unmet need, stairlifts were more frequently identified than through-floor lifts as the equipment needed.

Children who need help with sitting, standing and moving about are likely to have needs in terms of managing steps and stairs. Over 14 per cent of the sample had this level of physical impairments. This is a conservative view of the sorts of children who might require some sort of assistance with steps and stairs. It is not surprising, therefore, that the proportion of parents reporting needs for step/stairs equipment (both met and unmet) is higher (19.5 per cent). A summary of data on met and unmet need and the proportion of children with a potential need for equipment to assist with steps/stairs is provided in Table 3.7.

Table 3.7: Step/stair equipment: summary of met and unmet need

	n	*%*
No. respondents with step/stair equipment at home *and* reporting no further step/stair equipment needs	332	**9.8**
No. respondents indicating unmet need for step/stair equipment	331	**9.7**
(No step/stair equipment currently in home	*295*	*8.8)*
(Some step/stair equipment already in home	*36*	*1.5)*
No. children rated by parent as needing 'a lot of help' with sitting, standing and moving about	492	**14.5**

3.7 SAFETY EQUIPMENT

Over half the sample (54 per cent) had at least one piece of safety equipment in the home. Table 3.8 shows the types of safety equipment and the extent of their use.

Table 3.8: Need for safety equipment

	With equipment		*Report need equipment*	
	n	*%*	*n*	*%*
Safety glass in windows	574	16.9	*469*	*13.8*
Safety film on windows	42	1.2	*299*	*8.8*
Window locks	1363	40.1	*415*	*12.2*
Window bars	28	0.8	*129*	*3.8*
External door lock(s)	1477	43.4	*198*	*5.8*
Internal door lock(s)	485	14.3	*331*	*9.7*
Cupboard lock(s)	404	11.9	*614*	*18.1*
Lock(s) on kitchen appliance(s)	198	5.8	*612*	*18.0*
External door alarm(s)	172	5.1	*801*	*23.6*
Alarm to indicate child is out of bed	25	0.7	*514*	*15.1*
Gates between rooms	292	8.6	*286*	*8.4*
Locks on garden gate	762	22.4	*372*	*10.9*
Secure fences	567	16.7	*449*	*13.2*
'Padded' room	18	0.5	*200*	*5.9*

Families with safety equipment tend to have more than one type. Two-thirds of families (66.5 per cent) had three or more different types of equipment.

Just under a half of respondents (46 per cent) reported unmet needs for safety equipment. A greater proportion of families with safety equipment already in the home reported further unmet safety equipment needs (29 per cent) than reported their safety equipment needs were met (24 per cent). Comparing the distribution of types of equipment currently being used and those reported as unmet needs indicates high demand for alarms, locks for kitchen appliances, improving window safety. In addition, a not insignificant number of respondents stated that they needed a 'padded' room for their child.

Children identified by their parent as having 'a lot of difficulties' with awareness of danger are likely to have needs in terms of protecting their safety. Children falling into this category will include some children with learning difficulties and those with autistic spectrum disorders. Two-thirds of respondents reported that their child had 'a lot of difficulties' with awareness of danger. The figures obtained from parents' reports of unmet equipment needs do not, in the light of this, seem an overestimation. A summary of data on met and unmet need and the proportion of children with a potential need for safety equipment is provided in Table 3.9.

Table 3.9: Safety equipment: summary of met and unmet need

	n	*%*
No. respondents with safety equipment at home *and* reporting no further safety equipment needs	840	**24.7**
No. respondents indicating unmet need for safety equipment	1562	**45.9**
(No safety equipment currently in home	*599*	*17.6)*
(Some safety equipment already in home	*963*	*28.3)*
No. children rated by parent as having 'a lot of difficulties' with awareness of danger	2076	**65.8**

3.8 COMMUNICATION EQUIPMENT

The presence of equipment in the home to facilitate communication was low. Fewer than one in ten respondents stated they had either a symbol/communication board (5.4 per cent), a specially adapted computer (2.8 per cent) or an electronic speech synthesiser (0.6 per cent) at home. This is despite the fact that over half of the respondents (54 per cent) said their child had a lot of difficulties communicating.

Only one in 20 respondents indicated that they did not have any outstanding communication equipment needs. Over a quarter of the sample (26.4 per cent) reported needing at least one of the above items of communication equipment in their home - the vast majority had none on the communication equipment listed on the questionnaire already in their homes. A summary of data on met and unmet need and the proportion of children with a potential need for communication equipment is provided in Table 3.10.

Table 3.10: Communication equipment: summary of met and unmet need

	n	*%*
No. respondents with communication equipment at home *and* reporting no further communication equipment needs	197	**5.8**
No. respondents indicating unmet need for communication equipment	898	**26.4**
(No communication equipment currently in home	*832*	*24.5)*
(Some communication equipment already in home	*66*	*1.9)*
No. children rated by parent as having 'a lot of difficulties' with communication	1704	**54.0**

3.9 EQUIPMENT TO ASSIST THOSE WITH HEARING IMPAIRMENTS

Two hundred and eighteen respondents (6.4 per cent) had one or more items of the equipment to assist with hearing listed on the questionnaire, see Table 3.11. The most

frequently reported form of equipment were flashing indicators for the smoke alarm, doorbell and telephone.

Table 3.11: Need for equipment to assist those with hearing impairments

	With equipment		*Report need equipment*	
	n	*%*	*n*	*%*
Flashing indicator for doorbell	67	2.0	*190*	*5.6*
Flashing indicator for smoke alarm	132	3.9	*234*	*6.9*
Flashing indicator for telephone	53	1.6	*145*	*4.2*
Vibrating indicator for doorbell	15	0.4	*104*	*3.1*
Vibrating indicator for smoke alarm	42	1.2	*141*	*4.1*
Vibrating indicator for telephone	26	0.8	*136*	*4.0*
Loop system for television	56	1.6	*158*	*4.6*

Over one in ten respondents reporting outstanding needs for at least one of the items of hearing equipment listed on the questionnaire. This is more than twice as many as those reporting their hearing equipment needs were met.

Just under a third of children in the sample had some sort of hearing impairment, and virtually all had one or more other impairments. However, only 15 per cent of respondents reported hearing equipment needs (either met or unmet). Reasons for this might be that for some children the types of hearing equipment for the home included in the questionnaire were not relevant to their particular needs, or the presence of other impairments or the child's age had an impact on the types of equipment which might be needed or suitable. Thus as well as looking at reported levels of unmet need for all the items of hearing equipment included in the survey, we also looked at equipment which is may be needed by any child with a hearing impairment (that is, smoke alarm equipment and a loop system for the television). Just under one in ten respondents reported an unmet need for one or other of these types of equipment. In terms of preferences for the different types of equipment being identified by respondents with unmet need, they reflect the pattern of provision of provision to those already with some equipment to assist with hearing in the home. A summary of data on met and unmet need and the proportion of children with a potential need for equipment to assist with hearing is provided in Table 3.12.

Table 3.12: Equipment to assist with hearing: summary of met and unmet need

	n	*%*
No. respondents with equipment to assist hearing at home *and* reporting no further hearing equipment needs	137	**4.0**
No. respondents indicating unmet need for equipment to assist with hearing	359	**10.6**
(No hearing equipment currently in home	*278*	*8.2)*
(Some hearing equipment already in home	*81*	*2.4)*
Unmet needs for smoke alarm equipment or loop system for television only	340	**9.4**
No. children rated by parent as having at least some difficulties with hearing	967	**32.0**

3.9 WASHING, BATHING AND SHOWERING EQUIPMENT

The extent of use of items of equipment to assist with washing, bathing or using the shower are given in Table 3.13.

Table 3.13: Need for washing, bathing and showering equipment

	With equipment		*Report need equipment*	
	n	*%*	*n*	*%*
Washbasin lever taps	257	7.6	*376*	*11.1*
Height adjustable washbasin	71	2.1	*282*	*8.3*
Grab rails in bathroom	596	17.5	*314*	*9.2*
Support cushions for bath	64	1.9	*238*	*7.0*
Bath seat	420	12.3	*298*	*8.8*
Bath lift	86	2.5	*217*	*6.4*
Hammock support for bath	24	0.7	*71*	*2.1*
Bath lever taps	92	2.7	*275*	*8.1*
Grab rail in shower	246	7.2	*194*	*5.7*
Level access shower	189	5.6	*200*	*5.9*
Free standing shower seat/stool	50	1.5	*99*	*2.9*
Fixed shower seat	70	2.1	*105*	*3.1*
Height adjustable shower seat	20	0.6	*131*	*3.9*
Moveable shower chair	107	3.1	*122*	*3.6*
Shower trolley	41	1.2	*82*	*2.4*
Fold down shower stretcher	28	0.8	*65*	*1.9*

Just over one in 20 respondents (6.5 per cent) had at least one piece of equipment to assist with using the washbasin. Almost three out of ten respondents (29 per cent) had at least one piece of equipment to assist with bathing, and more than one in ten (12 per cent) had at least one item of equipment to assist with showering. Equipment most likely to be found in families' homes were grab rails in the bathroom or shower, a bath seat, washbasin lever taps and a level access shower. Among those with equipment for washing, bathing and/showering, the majority had only one piece of equipment for the washbasin (81 per cent) or bath (75 per cent). However, half of those respondents with shower equipment had at least two pieces of equipment.

A greater proportion of respondents reported unmet needs for equipment to assist with using the washbasin (13.7 per cent) compared to those whose needs were met (5.5 per cent). Likewise, in terms of showering equipment, a greater number of respondents reported unmet equipment needs than reported this area of equipment need was met.

Levels of met and unmet need for bathing equipment across the sample were similar, with one in five reporting that all their equipment needs for bathing were met and the same proportion reporting unmet needs. Overall, respondents with equipment for the washbasin or the shower were less likely to report further unmet equipment needs compared to those with at least one item of bathing equipment. The pattern of preferences expressed by respondents for equipment to address unmet equipment needs for bathing and washing is similar to the distribution of type of equipment currently being used.

More than eight out of ten parents reported their child needed at least some help with bathing and washing, with over half the sample stating their child needed a lot of help. There are a number of reasons why bathing may be difficult for a disabled child and/or their parent/carer. Washing or bathing a child with behavioural difficulties, or those with very little safety awareness can be as problematic as caring for a child with physical impairments. For children with complex disabilities, providing equipment to address physical needs will not necessarily fully resolve the difficulties experienced by the child and/or parent/carer.

A summary of data on met and unmet need and the proportion of children with a potential need for washing, bathing and showering equipment is provided in Table 3.14.

Table 3.14:Washing/bathing/showering equipment: summary of met and unmet need

	n	*%*
Using the washbasin		
No. respondents with equipment to assist with using *wa*shbasin *and* reporting no further needs for washbasin equipment	187	**5.5**
No. respondents indicating unmet need for equipment to assist with using washbasin	467	**13.7**
(No equipment currently in home	*432*	*12.7)*
(Some equipment already in home	*35*	*1.0)*
Bathing		
No. respondents with equipment to assist with bathing *and* reporting no further needs for bathing equipment	736	**21.6**
No. respondents indicating unmet need for equipment to assist with bathing	767	**22.5**
(No bathing equipment currently in home	*521*	*15.3)*
(Some bathing equipment already in home	*246*	*7.2)*
Showering		
No. respondents with equipment to assist with showering *and* reporting no further needs for showering equipment	338	**9.9**
No. respondents indicating unmet need for equipment to assist with showering	441	**13.0**
(No showering equipment currently in home	*360*	*10.6)*
(Some showering equipment already in home	*81*	*2.4)*
No. children rated by parent as needing help with bathing/washing	2937	**86.3**
(Needs 'some help'	*913*	*26.8)*
(Needs 'a lot of help'	*2024*	*59.5)*

3.10 TOILETING EQUIPMENT

Table 3.15 shows the levels of use of equipment to assist with using the toilet. The presence of equipment in the home to assist with using the toilet is low. The most frequently occurring items were equipment to provide support while using the toilet and commodes. Just 113 respondents (3.3 per cent) had one or more items of equipment to assist with toileting.

Table 3.15: Need for toileting equipment

	With equipment		*Report need equipment*	
	n	*%*	*n*	*%*
Moveable chair/sanichair (also used with shower)	70	2.1	*76*	*2.2*
Moveable chair/sanichair (toilet only)	79	2.3	*83*	*2.4*
Potty chair or commode (immoveable)	121	3.6	*101*	*3.0*
Toilet support frame	134	3.9	*191*	*5.6*
Toilet support seat	117	3.4	*208*	*6.1*
Toilet with washing and drying facility	49	1.4	*191*	*5.6*

A greater proportion of the sample reported unmet needs for equipment to assist with toileting (6.7 per cent) than reported that their needs were met (3.1 per cent). Toilets with a washing and drying facility appear to be an item of equipment that parents tend to prefer over other types of equipment to assist with using the toilet.

Where toileting equipment was in the home, nine out of ten respondents did not have any further needs for toileting equipment. The factors used to identify the population potentially needing equipment to assist with toileting were children who were continent but were reported as needing 'some' or 'a lot of help' with using the toilet. Just over one in ten (12.5 per cent) children were reported to have these characteristics. (It is worth noting that this figure is similar to the proportion reporting needs, met and unmet, for toileting equipment (9.8 per cent)). A summary of data on met and unmet need and the proportion of children with a potential need for toileting equipment is provided in Table 3.16.

Table 3.16: Toileting equipment: summary of met and unmet need

	n	*%*
No. respondents with equipment to assist with toileting *and* reporting no further toileting equipment needs	105	**3.1**
No. respondents indicating unmet need for equipment to assist with toileting	228	**6.7**
(No toileting equipment currently in home	*220*	*6.5)*
(Some toileting equipment already in home	*8*	*0.2)*
No. children who are continent but need help with using the toilet	424	**12.5**

3.11 CONTINENCE EQUIPMENT

Parents expect to change and dress any baby and very young child. Thus for this set of analyses, a lower age limit of three years was imposed. Table 3.17 shows the extent of use

of continence and changing equipment. Although a third of the sample (34.2 per cent) were using nappies or continence pads, very few had other equipment such as changing boards or tables or special changing mats. One in 20 respondents had the latter item.

Table 3.17: Need for continence and changing equipment (children aged three years and over)

	With equipment		*Report need equipment*	
	n	*%*	*n*	*%*
Nappies/continence pads	930	34.2	*123*	*4.5*
Changing board/table: fixed height	28	1.0	*56*	*2.1*
Changing board/table: adjustable height	29	1.1	*162*	*6.0*
Moveable changing board/table	9	0.3	*95*	*3.5*
Changing mat	157	5.8	*143*	*5.3*
Base=2720				

Almost four out of ten respondents (39.4 per cent) had the need for continence and changing equipment. This figure reflects the fact that over a third (37.5 per cent) of children had a lot of difficulties with continence.

Among those reporting needs for continence and changing equipment, the majority (81 per cent) reported these needs were met. Those reporting unmet needs for continence/ changing equipment were twice as likely to have no such equipment in the home than to already have at least one item of continence changing equipment. While nappies/ continence pads were, by far, the most frequently reported item of continence equipment being used, in terms of addressing unmet needs for continence equipment, a suitable changing board or table are frequently identified. A summary of data on met and unmet need and the proportion of children with a potential need for continence and changing equipment is provided in Table 3.18.

Table 3.18: Continence and changing equipment: summary of met and unmet need

	n	*%*
No. respondents with equipment to assist with continence/changing *and* reporting no further equipment needs	867	**31.9**
No. respondents indicating unmet need for equipment to assist with continence/changing	204	**7.5**
(No equipment currently in home	*138*	*5.1)*
(Some equipment already in home	*66*	*2.4)*
No. children with difficulties with continence	1666	**69.2**
(Children rated as having 'some' difficulties	*763*	*31.7)*
(Children rated as having 'a lot of' difficulties	*903*	*37.5)*

Base=2720

3.12 EQUIPMENT TO ASSIST WITH CONTINENCE IN BED

Just under one in five respondents (18.9 per cent) had night-time or sleeping continence equipment (waterproof bedding/mattress or wetting/enuresis alarm). However, very few respondents (0.7 per cent) had an alarm.

Table 3.19: Need for equipment to assist with continence in bed

	With equipment		*Report need equipment*	
	n	*%*	*n*	*%*
Waterproof bedding	631	18.6	*698*	*20.5*
Wetting/enuresis alarm	24	0.7	*267*	*7.9*

While one in ten respondents indicated that their needs for equipment to assist with continence in bed were met, a greater proportion (23 per cent) reported unmet needs. One in ten respondents already with some equipment to assist with continence in bed reported unmet needs. Overall one in five respondents reported unmet needs for waterproof bedding and just under eight per cent reported an unmet need for an enuresis alarm. These levels of reported unmet need are not unsurprising given that nearly one in four children were rated as having a lot of difficulties with continence. A summary of data on met and unmet need and the proportion of children with a potential need for continence equipment for use in bed is provided in Table 3.20.

Table 3.20: Equipment to assist with continence in bed: summary of met and unmet need

	n	*%*
No. respondents with equipment to assist with continence in bed *and* reporting no further equipment needs	576	**11.3**
No. respondents indicating unmet need for equipment to assist with continence in bed	795	**23.4**
(No equipment currently in home	*729*	*21.4)*
(Some equipment already in home	*66*	*2.0)*
No. children with difficulties with continence	1666	**69.2**
(Children rated as having 'some' difficulties	*763*	*31.7)*
(Children rated as having 'a lot of' difficulties	*903*	*37.5)*

Base=2720

3.13 EQUIPMENT TO ASSIST WITH SLEEPING/BEING IN BED

One in four respondents (21 per cent) had at least one item of equipment used to assist with sleeping or being in bed. The types of equipment and the extent of their use is summarised in Table 3.21. Intercoms and equipment to prevent the child falling out of bed were more common than the use of pressure relieving mattresses. The figures in Table 3.21 show that parents report the need for pressure relieving mattresses more frequently than would be expected from figures on current levels of use.

Table 3.21: Need for equipment to assist with sleeping/being in bed

	With equipment		*Report need equipment*	
	n	*%*	*n*	*%*
Bed rails or safety nets	407	12.0	*346*	*10.2*
Pressure relieving mattress	81	2.4	*212*	*6.2*
Intercom	385	11.3	*417*	*12.3*

Over one in five respondents (22 per cent) reported unmet needs for equipment used for sleep or being in bed, see Table 3.22. A summary of data on met and unmet need for equipment to assist with sleeping or being in bed is provided in Table 3.22.

Table 3.22: Equipment to assist with sleeping/being in bed: summary of met and unmet need

	n	*%*
No. respondents with equipment to assist with sleeping or being in bed *and* reporting no further equipment needs	552	**16.2**
No. respondents indicating unmet need for equipment to assist with sleeping or being in bed	747	**22**
(No equipment currently in home	*599*	*17.6)*
(Some equipment already in home	*148*	*4.4)*

3.14 EQUIPMENT TO ASSIST WITH DRESSING

The two items of equipment to assist with dressing included in the questionnaire pertained to children who need some sort of physical support while dressing themselves, see Table 3.23. Very few children (4.1 per cent) had these items of equipment: 119 children (3.5 per cent) had a bench to sit on while dressing, and 32 (0.9 per cent) children had wall rails to provide for support while dressing. However, over one in ten respondents stated that they needed at least one of these items.

Table 3.23: Need for equipment to assist with dressing

	With equipment		*Report need equipment*	
	n	*%*	*n*	*%*
Bench for child to sit on while dressing	119	3.5	*372*	*10.9*
Wall rails	32	0.9	*182*	*5.4*

3.15 EQUIPMENT TO SUPPORT INDEPENDENCE ABOUT THE HOME

A number of items of equipment listed in the questionnaire have the function of supporting the child's independence within the home. (Other items of equipment promoting independence have already been covered in earlier sections, particularly if the equipment functions to support caring *and* independence.) For this aspect of equipment provision, we have restricted our analysis to children in the sample aged five years and over.

Table 3.24: Need for equipment to support independence about the home

	With equipment		*Report need equipment*	
	n	*%*	*n*	*%*
Easy to use door handles	327	14.2	*174*	*7.5*
Easy to use handles on cupboards	244	10.6	*162*	*7.0*
Easy to use/reach light and other switches	342	14.8	*167*	*7.2*
Rounded corners on kitchen units	117	5.1	*225*	*9.7*
Adapted kitchen appliances	28	1.2	*154*	*6.7*
Lower kitchen units with wheelchair access	36	1.6	*107*	*4.6*
Base=2308				

One in ten respondents reported having 'easy-to-use' handles on cupboards. A slightly greater proportion had easy to use door handles and switches. One in 20 had had rounded corners installed on kitchen units. Very few respondents had adapted kitchen appliances or wheelchair accessible kitchen units.

One in ten respondents reported unmet needs for equipment to assist with their child using handles and switches. As slightly greater proportion (15.7 per cent) reported that their child's needs in this area had been met. For equipment to assist with independence in the kitchen a greater proportion reported unmet needs (13.2 per cent) compared to those who reported their needs were met (6.1 per cent). In terms of addressing unmet need, it would appear that changes to kitchen units (for example, installing rounded edges) need to be considered more frequently than are suggested by current levels of use. A summary of data on met and unmet need for equipment to support independence in the home is provided in Table 3.25.

Table 3.25: Equipment to support independence in the home: summary of met and unmet need

	n	*%*
Handles and switches		
No. respondents with equipment to assist with using handles and switches *and* reporting no further equipment needs	362	**15.7**
No. respondents indicating unmet need for equipment to assist with handles and switches	261	**11.3**
(No equipment currently in home	*209*	*9.1)*
(Some equipment already in home	*52*	*2.2)*
Assisting independence in the kitchen		
No. respondents with equipment to assist with independence in the kitchen *and* reporting no further equipment needs	140	**6.1**
No. respondents indicating unmet need for equipment to assist with independence in the kitchen	304	1**3.2**
(No equipment currently in home	*293*	*12.7)*
(Some equipment already in home	*11*	*-)*

Base=2308

3.16 LEARNING AND PLAYING EQUIPMENT

Learning and playing (or spending leisure time) are universal activities among children and young people. Responsibility for funding equipment to assist with learning and play in the home environment has not been made explicit. While not falling within the definition of community equipment it is something that is central and critical to children and young people's lives, development and well-being. Thus it was included on the survey questionnaire and the data are reported here - if only as a means of identifying it as an area for further research or discussion.

Just a quarter of respondents (25.6 per cent) reported that their child had a computer and/or specialist play equipment at home. Typically, respondents had only one of these pieces of play/learning equipment at home (87 per cent).

Table 3.26: Need for play and learning equipment

	With equipment		*Report need equipment*	
	n	*%*	*n*	*%*
Computer - no adaptations	596	17.5	*725*	*21.3*
Computer - specially adapted for child's needs	94	2.8	*647*	*19.0*
Special play equipment	283	8.3	*847*	*24.9*

Almost half the respondents (45 per cent) reported their child had unmet needs for play and learning equipment. One in five respondents had at least one item of the play and learning equipment listed in Table 3.26 and did not report any further unmet equipment needs. One in 20 respondents (5.3 per cent) with play/learning equipment reported needing at least one more item of equipment as listed on the questionnaire. Just under a third of parents (30.3 per cent) who did not have any computer or special play equipment at home reported these as unmet equipment needs. These high levels of reported unmet need are corroborated by the fact that eight out of ten children were rated by their parents as having some sort of difficulty with learning, and over half were rated as having 'a lot of difficulties' with learning. A summary of data on met and unmet need and the proportion of children with a potential need for learning equipment is provided in Table 3.27.

Table 3.27: Equipment for learning and playing: summary of met and unmet need

	n	*%*
No. respondents with equipment to assist with learning or playing *and* reporting no further equipment needs	641	**18.8**
No. respondents indicating unmet need for learning or playing equipment	1535	**45.1**
(No equipment currently in home	*1304*	*38.3)*
(Some equipment already in home	*231*	*6.8*
No. children with learning difficulties	2786	**81.9**
(Children rated as having 'some' difficulties	*854*	*25.1)*
(Children rated as having 'a lot of' difficulties	*1934*	*56.9)*

3.17 EXTENT OF NEED

Within the previous section parents' reports of unmet need were 'corroborated' against frequency data on impairments, or clusters of impairments, which are likely to generate specific equipment needs. We would argue that these data support and give credence to the levels of unmet need being reported. Indeed in some cases it appeared that parents were under-reporting unmet equipment needs, a phenomenon similarly found in the 1985 OPCS survey (Gordon *et al.*, 2000). It is also important to note here that quite conservative criteria were applied in identifying the sub-samples with potential equipment needs. For instance, we usually only included children where parents reported the child needing a lot of help or having a lot of difficulties with an activity or function.

Taking into account arguments about the representativeness of the population from which the sample for this survey was drawn (see Appendix 2), we would suggest that the figures on levels of need reported by the sample can be used as an indicator of the extent of need for equipment among all severely disabled children. Table 3.28 summarises the levels of need across the whole sample for the 16 different categories of equipment included in the survey.

Table 3.28: Extent of met, unmet and overall levels of need for equipment reported by the sample

Type of equipment	*Need met %*	*Need unmet %*	*Total need %*
Lifting and handling	4.6	9.3	13.9
Seating	14.1	15.8	29.9
Assist with steps/stairs	9.8	9.7	19.5
Safety	24.7	45.9	70.6
Assist with communication	5.8	26.4	32.2
Assist with hearing	4.0	10.6	14.6
Assist with using washbasin	5.5	13.7	19.2
Assist with bathing	21.6	22.5	44.1
Assist with showering	9.9	13.0	22.9
Assist with toileting	3.1	6.7	9.8
Continence	31.9	7.5	39.4
Assist with sleeping/being in bed	16.2	22.0	38.2
Assist with dressing	4.1	10.3	14.4
Handles and switches	15.7	11.3	27.0
Assist with independence in the kitchen	6.1	13.2	19.3
Learning/play	18.8	35.7	54.5
Base=3401			

Met and unmet need

It is important to remember here that these data cannot be interpreted as implying levels of service provision. Families self-fund equipment - and we report findings on this later in the chapter.

Table 3.28 shows that the extent to which equipment needs are being met vary according to the type of equipment. For example, there are high levels of met need for continence equipment. For some types of equipment, a similar proportion of the sample reported met need as reported unmet need. Equipment such as seating, equipment to assist with stairs and bathing fall into this category. In others, the proportion of respondents reporting unmet need far exceeded those reporting their needs being met. Types of equipment where disproportionately high levels of unmet need were reported include equipment to assist with lifting and handling, safety, communication, hearing, using the washbasin, toileting, dressing, independence in the kitchen and learning/play.

Overall levels of need

The overall levels of need for the different types of equipment reflect the nature of the impairments, needs and abilities of the sample. Thus most frequently reported equipment need were for safety equipment (71 per cent of the sample), learning/play equipment (54 per cent) and equipment to assist with bathing (44 per cent). Least common areas of equipment need were equipment to assist with toileting, dressing, hearing and lifting and handling. However, the likelihood of whether or not a need for equipment is met is not necessarily associated with how common it is within the overall population.

Population estimates of equipment need

Using the data presented in Table 3.28 it is possible to provide broad estimates of the numbers of severely disabled children in England with needs for the different types of equipment covered by the survey. It is important to remember that these estimates are also *limited* in a number of ways. First, less severely disabled children were not included in the survey. Second, though taking a broad interpretation to what might fall within the category of 'community equipment', the survey only looked at equipment currently available. Third, parents were used as proxy informants to report their children's needs.

Generating population estimates: assumptions made

The population estimates are based on the assumption that the children represented on the Family Fund Trust (FFT) database (from which the sample was drawn) are representative of all severely disabled children in England. Unfortunately there are no up-to-date national data against which to test this assumption, though a number of studies have estimated take up for the FFT to be between 50 and 70 per cent of eligible families (Bone and Meltzer, 1989; Lawton and Quine, 1990). We do know, however, that very young children are under-represented on the database. This is for two reasons. First, it takes time for families to hear about and to apply to the Trust. Second is the difficulty (for parents and those assessing families' eligibility) of disentangling the extra care burden from the 'normal' high levels of care demanded by any baby or very young child. In the survey we sought to overcome this by stratifying the sample by age. In terms of calculating population estimates, this only serves to make the estimates calculated more conservative. A further strategy of this conservative approach was to assume a 50 per cent take-up rate.

Table 3.29 shows population estimates of current levels of use, unmet need and overall levels of need for the different categories of equipment. For each cell, the figures are the lower and upper population estimates obtained when a 95 per cent confidence level is applied.

Table 3.29: Population estimates of equipment need

Type of equipment	*Need for equipment met*	*Need for equipment unmet*	*Overall number with need*
Lifting and handling	8,070[1] - 8,430	16,510 - 16,870	24,590 - 25,300
Seating	24,940 - 26,660	27,990 - 28,710	53,300 - 54, 020
Assist with steps/stairs	17,407 - 17,760	17,230 - 17,590	34,630 - 35,350
Safety	43,970 - 44,680	82,013 - 82,730	126,340 - 127, 060
Assist with communication	10,050 - 10,590	47,020 - 47,740	57,430 - 58,150
Assist with hearing	6,700 - 7,360	18,840 - 19,200	25,840 - 25,560
Assist with using washbasin	9,690 - 10,050	24,230 - 24,940	34,100 - 34,800
Assist with bathing	38,400 - 39,120	40,200 - 40,920	78,780 - 79,500
Assist with showering	17,400 - 17,950	22,970 - 23,690	40,740 - 41,450
Assist with toileting	5,380 - 5,740	11,660 - 12,200	17,230 - 17,770
Continence	56,890 - 57,610	13,100 - 13,340	70,350 - 71,070
Assist with sleeping/being in bed	28,710 - 29,430	39,120 - 39,840	68,190 - 68,900
Assist with dressing	7,360 - 7,540	18,300 - 18,660	25,480 - 25,760
Handles and switches	27,820 - 28,530	20,100 - 20,460	48,100 - 48,810
Assist with independence in the kitchen	9,870 - 11,130	23,330 - 24,050	35,280 - 35,000
Learning/play	33,380 - 34,100	63,700 - 64,430	97,450 - 98,160

Estimated base[2]=179 460

[1] *Figures rounded to the nearest 10.*

[2] *The number of children on the Family Fund Trust database living in England at the time of extracting the survey was 89,730. Assuming 50 per cent take up, this yields a total population figure of 179,460.*

3.18 REASONS FOR UNMET EQUIPMENT NEEDS

Respondents were asked to indicate why they experienced unmet needs for equipment. Table 3.30 summarises their responses.

Table 3.30: Reported reasons for unmet equipment needs

	% of responses
Cannot afford to buy equipment	33
Do not know how to go about getting equipment	25
Do not have space/home not suitable for equipment	12
Waiting for assessment	9
Delays in equipment provision	7
Currently in assessment process	7
Disagreement with professionals	3
Equipment only provided at school	3
Base=2163	

The two most common reasons given by parents for experiencing unmet equipment needs were not being able to afford equipment, and not knowing how to go about getting equipment. Lack of space or unsuitability of the home was the third most frequently reported reason. Other data collected from the questionnaire shows that only one in five families (19 per cent) have adapted their home in response to their child's needs and/or associated care needs.

Reasons relating to difficulties with the provision of an equipment service were less common. This may reflect the fact that families were not receiving an 'equipment service', or a lack of awareness of equipment services and/or entitlements to equipment. This is a feasible explanation for at least some respondents. Almost a third of the sample stated that their and their child's equipment needs had never been assessed by an occupational therapy service.

3.19 MANAGING EQUIPMENT NEEDS IN DIFFERENT SETTINGS

Equipment used at home and at school

Among those of school age, the majority of children attended special school or college (63 per cent), one in ten children were placed in special units attached to mainstream schools, and the remainder were attending a mainstream school or college (27 per cent). We looked at how children's seating needs and needs for communication and computer equipment are managed in and between the school and home settings, focussing particularly on duplication of equipment. It is important to note here that while we were able to look at the extent of duplication it was not possible to ask about funding of the duplication of specific pieces of equipment. However, a later section in this chapter does look at items of equipment which were self-funded by families.

Seating equipment

Table 3.31 shows the ways in which children's seating needs are managed in and between the school and home settings. The number of children using the two types of seating equipment shown in the table attending special units or mainstream schools are very small and it would not be appropriate to draw conclusions from these data.

Table 3.31 shows that duplication of equipment in the home and school setting is much less common than either seating equipment being used in only one setting or shared between home and school. Of the two types of seating equipment, it was more likely that multi-adjustable wooden chairs (or activity chairs) were duplicated in the two settings compared to moulded postural chairs.

Table 3.31: Managing seating needs in the school and home environments

	Multi-adjustable wooden chair (%)	*Moulded postural chair (%)*
Children in special school/college		
Only used at home	15	22
Only used at school	50	50
Same chair shared between home & school	5	14
Different chair used at home & school	30	14
	Base=260	*Base=107*
Children in special unit attached to mainstream school/college		
Only used at home	35	18
Only used at school	30	64
Same chair shared between home & school	9	18
Different chair used at home & school	26	0
	Base=23	*Base=11*
Children in mainstream school/college		
Only used at home	27	27
Only used at school	48	50
Same chair shared between home & school	0	9
Different chair used at home & school	25	14
	Base=48	*Base=22*

Communication and computer equipment

Table 3.32 summarises how the need for computer and communication equipment is currently managed in and between school and home. As with seating equipment, the majority of children only have access to this sort of equipment at school. Of the equipment listed, access to non-adapted computers at home was most likely. Duplication, that is the use of different pieces of equipment at school and home, was unusual.

Table 3.32: Managing needs for computers in school and home environments

	Computer - no special adaptations %	*Computer - special adaptations %*	*Communication symbol board %*	*Electronic speech synthesiser %*
Children in special school/college				
Only used at home	17	5	3	7
Only used at school	61	85	75	73
Same piece of equipment shared between home & school	2	4	11	13
Different piece of equipment used at home & school	20	6	11	7
	Base=555	*Base=425*	*Base=346*	*Base=88*
Children in special unit attached to mainstream school/college				
Only used at home	14	13	12	28
Only used at school	56	69	64	72
Same piece of equipment shared between home & school	6	8	12	0
Different piece of equipment used at home & school	23	10	12	0
	Base=103	*Base=52*	*Base=42*	*Base=14*
Children in mainstream school/college				
Only used at home	25	9	10	
Only used at school	40	57	53	40
Same piece of equipment shared between home & school	8	19	20	30
Different piece of equipment used at home & school	27	15	17	30
	Base=214	*Base=53*	*Base=30*	*Base=10*

Staying in other settings during out of school hours

A quarter of respondents reported that their child regularly spends time in another home for child care, short term (respite care) or access visits, see Table 3.33.

Table 3.33: Where children regularly spend non-school time away from home

Location	***%***
Short term care in a residential unit	11
Relatives	7
Short term care with another family	4.5
Childminder	2.5
Does not spend time in another home regularly	73
Base=2949	

(Note: We do not have a sufficient sample size to report on access visits or use of child-minders.)

The age of the child affects both whether a child may be spending time out of the home and where the child is likely to be. The proportion of children regularly spending time in another home/care setting increases with age (20 per cent of children under five years rising to 35 per cent of those aged 12 years and over). Younger children are more likely to be spending that time in relatives' homes, while the number of children using short term care (family-based and residential units) increases with age, see Table 3.34.

Table 3.34: Relationship between age and location of alternative care setting

	Child's age (yrs.)					
	0 - 1 %	2 - 4 %	5 - 7 %	8 -11 %	12 - 14 %	15 - 17 %
Residential short term care	4	6	11	17	34	28
Family-based short term care	6	13	24	25	17	15
Relatives	19	21	17	19	17	6
Does not regularly spend time in another home/care setting	13	21	19	18	16	13
Total	*337*	*532*	*503*	*500*	*516*	*398*

(Note: We do not have a sufficient sample size to report on age effects on access visits or use of child-minders.)

Meeting equipment needs in other care settings

Table 3.35 shows how, among those who regularly spend time in another care settings, equipment needs are managed. Unfortunately, the number of children staying with a parent for access visits (n=49) or attending a childminder (n=73) were too small to look at how the child's equipment needs are managed in these settings.

The data show a very consistent picture of the differences between care settings in terms of the availability of equipment needed by children and their carers. Access to, or availability of, equipment is much lower in family home settings (that is, family based short term or relatives' homes) compared to residential short term care units. Consequently, in family home settings children and their carers are having to manage with no or inadequate equipment. The situation is worse for children staying with their relatives compared to children staying with 'Link' families through a short term care scheme.

Table 3.35: Presence of equipment (where required by child) in alternative care settings

	Equipment already in location			*Child takes equipment to location*			*Manage with no or inadequate equipment*		
	Res. stc %	*Fam. based stc. %*	*Rel. %*	*Res. stc. %*	*Fam. based stc. %*	*Rel. %*	*Res. stc. %*	*Fam. based stc. %*	*Rel. %*
Standing/sitting	68	12	9	21	34	34	11	53	57
Moving about	52	13	8	42	46	43	6	41	49
Learning/ communicating	74	18	25	10	31	20	16	51	55
Switches/handles	88	14	16	2	5	3	10	81	81
Keeping safe	93	39	30	1	12	3	6	49	67
Lifting	88	18	4	1	9	6	11	73	90
Hearing	88	6	0	4	29	30	8	65	70
Using wash basin	94	28	7	1	0	0	5	72	93
Bathing/ showering	92	30	16	2	2	5	6	68	79
Using toilet	88	30	9	4	13	15	8	57	76
Getting dressed	85	14	12	4	11	10	11	75	78
Changing/dressing	84	11	13	5	13	9	11	76	78
In bed	85	38	21	4	11	13	11	51	66
Using kitchen	89	28	9	2	0	6	9	72	85
Getting up steps/stairs	83	18	4	2	0	2	15	82	94

Key: Res stc = residential short term (respite) care
Fam. based stc = short term (respite) care provided in another family home
Rel. = child cared for in a relative's home.

3.20 SELF-FUNDING OF EQUIPMENT

Respondents were asked whether they had paid for or had to raise money for any of the equipment they had in the home.

Over a quarter of families had self-funded equipment. Table 3.36 shows the types of equipment most frequently being self-funded by families. Almost two-thirds of the equipment being self-funded by families fell into one of four categories: equipment to promote the child's safety inside the home, equipment to promote the child's safety outside the home, continence equipment and computers/computer equipment.

Table 3.36 : Types of equipment most frequently being self-funded by families

Type of equipment	*% of responses*
Equipment to promote child's safety inside the home (safety glass, window locks, internal and external door locks, window bars)	36
Continence equipment (waterproof bedding, nappies, continence pads)	10
Equipment to promote child's safety in the garden (gate locks, secure fencing)	10
Computer	6
Other (over 60 different pieces of equipment)	38

The levels of self-funding found in this survey may well reflect, to some extent, the under-representation of 'higher' income families in the sample. It is not unreasonable to assume that self-funding will be more common (and for greater amounts) among families with a greater disposable income.

CHAPTER FOUR:
PROFESSIONAL AND PRACTITIONER PERSPECTIVES

4.1 INTRODUCTION

This chapter reports the findings from a brief consultation exercise (see Appendix 1 for methodological details). The purpose of this part of the project was to seek 'expert views' on five issues: vulnerable groups (in terms of unmet equipment needs); equipment needs not currently the responsibility of any agency; the relationship between community equipment and housing adaptations; recycling equipment; and meeting equipment needs in different settings.

We have used the term 'informant' to refer to those who took part in this consultation exercise. In some cases the informant is an individual and in others it is an organisation that collectively worked together to present their position on the issues about which we sought their views.

4.2 COMMUNITY EQUIPMENT SERVICES - GENERAL POINTS

Within the consultation phase of the project, views on five quite specific issues were sought. However, in the course of conducting this consultation other issues were raised which provide useful 'contextual' information on the current state of Community Equipment Services from the perspectives of those informants who took part in the consultation exercise. Two over-arching themes emerged: service philosophy and funding.

Service philosophy

A consistent theme in the responses provided by informants was that current Community Equipment Services are 'budget led' as opposed to 'needs led', and a very constrained or inflexible view is taken as to what constitutes equipment.

One informant working for an independent voluntary organisation compared his organisation's approach to addressing the equipment needs of disabled people and the approach of statutory agencies in the following way:

> 'The approach of (statutory agencies) is to think: "What's on the market and how can we make them [disabled people] fit it?". Our approach is: "What do they say they need and how can we make it?".'

There were calls for greater creativity in terms of what is understood as 'community equipment'. In addition, there should be increased support for independent organisations who are skilled in providing 'custom-built' equipment to suit an individual's needs.

All informants drew attention to the fact that, at the moment, equipment services do not meet children's needs in all aspects of their lives - both in home settings and outside the home in community and other contexts.

> ‘I am very concerned about the inability of services to ensure that equipment is provided in all of the areas of a child’s life.’

The complexity of funding, in terms of the number of different authorities involved, was identified as a factor contributing to the lack of an holistic approach.

Funding

There was consensus that equipment provision is under-funded. One of reasons for this under-funding is the lack of local and national data on levels of need and unmet need. This, it was felt, was partly due to the fact that unmet need is not routinely recorded by front line workers which then presents an inaccurate picture to service managers and so on. One informant said that occupational therapists ‘no longer assess need, they just worry about the budget.’

A number of informants raised the issue of ring-fenced budgets, citing the example of the recent ring-fencing of money for communication aids as a possible way forward for all disabled children’s equipment.

Cost effectiveness

The need for more effective use of funds was also stressed. Prices on some items of equipment (of the same quality) can vary considerably between manufacturers. However some informants believed that service managers did not always seek out the ‘best deal’ and there was a lack of competitive tendering.

Working within an under-funded service had, one informant believed, led to occupational therapists spending too much of their time negotiating for a level of equipment provision that met assessed needs. While the current shortage of occupational therapists is a concern, increased funding of equipment services would have the effect of freeing up time currently spent negotiating with budget holders.

Planning and budgeting

As well as recording current levels of need, one informant also pointed out the need to use information collected to project *future* needs. For example, it might be clear to an occupational therapist making an assessment of a very young child that in a number of years time that child will need a specialist bed. At the moment this sort of information is not collected routinely. Neither is the management of information systems in place to enable that information to be used strategically. This is perhaps particularly salient in terms of planning children’s equipment provision.

Maintenance

Concerns about the maintenance of equipment owned by families were voiced by a number of informants. Manufacturers are equally disturbed, to such an extent that they presented their concerns to the All Party Disablement Group some two years ago.

4.3 NEGLECTED GROUPS

Among those groups who use Community Equipment Services, one informant argued that disabled children and their families are at greatest risk of their equipment needs remaining unmet. Furthermore, a number of informants pointed to the adult-centred approach of both community equipment and housing adaptation services.

> 'I am concerned that in my contacts with children's services that none of them have heard of it [recent DoH guidance on integrating Community Equipment Services]. Local authorities still see equipment as something that relates to the elderly and I am concerned that unless a children's voice is heard early that their needs will be overlooked.'

Groups of children likely to be neglected

Specific groups of disabled children identified by informants as currently being neglected by Community Equipment Services were:

- children with learning difficulties
- children with behavioural problems
- very young or very small children
- child with mild or moderate impairments
- children with temporary needs for equipment
- children with complex health care needs.

Children with learning difficulties and/or behavioural problems

There was agreement among those consulted that children with learning difficulties and/or behavioural problems were a neglected group in terms of equipment provision. It was difficult to get the needs of these children acknowledged by service providers because they were not physically disabled. Currently, a very rigid definition of equipment, based on the types of equipment currently provided, is applied.

The sorts of equipment needs these children are likely to have include safety equipment for home and garden (for example, for windows, electrical sockets, locks, alarms), equipment to occupy and provide stimulation, and equipment to minimise damage to the home (for example, waterproof flooring to ease cleaning in cases where the child is smearing).

In addition it was noted that addressing the equipment needs of these children may require creativity and flexibility in terms of what is understood as 'equipment'. The following case history was given by one informant:

> ‘A family with a six year old boy with autism was referred to a disabled children’s team. The child’s placement at home is at risk because of his behaviour. However, getting agreement to provide locks or fencing is almost impossible from an equipment budget. It was also noted that the child stayed calm for longer periods if he had access to a Play Station. The family income was such that this was a luxury they could not afford. In the end it was bought from Section 17 money. This at least will give the child a chance to remain at home longer.’

Very young or very small children

It was noted that it is hard to access equipment which is suitable for very young children. Different informants highlighted difficulties both in terms of ‘care’ equipment (for example, the scarcity of very small slings for hoists); and play and learning equipment.

> ‘Pre-school aged disabled children may be considered as a neglected group if play/development items are only considered as useful rather than essential, if their home provision is regarded as the responsibility of the family alone, and if play groups and nursery schools fail to cater adequately for children with special needs.’

A number of informants also felt that very young children are precluded from having equipment provided to them: ‘equipment is supplied according to age not to need.’

Children with mild/moderate impairments

It was argued that inflexible and ‘over-tight’ assessment criteria meant that the equipment needs of mild or moderately disabled children remained unmet. The fact that these children are not even assessed means very little is known about this population.

Children with temporary needs for equipment

Children with acute or episodic illnesses, including acute injuries, who have short term needs for equipment were also identified as a neglected group.

Children with complex health care needs

Finally, while not a neglected group as such, very little is known about the equipment needs (and the extent to which they are met) of the growing population children who are discharged from hospital to a ‘hospital at home’ and their parents/carers.

Family characteristics associated with unmet equipment needs

Over and above these specific groups of children, certain family characteristics were believed to contribute to families’ equipment needs being neglected. These were:

- families from minority ethnic groups
- ‘Uninformed’ families
- Middle-income families
- Families living in unsuitable housing

Families from minority ethnic groups

Concerns were raised by a number of informants that what is known about the difficulties experienced by families from minority ethnic group in accessing health and social care services is also likely to be happening in relation to equipment services.

'Uninformed' families

The difficulties of knowing about and accessing services are not only experienced by families from minority ethnic groups. One informant, who works for an organisation which provides key workers to families (someone providing information, support and advocacy), noted that families without a key worker are likely to be enormously disadvantaged when trying to address their equipment needs. Yet research shows that less than a third of families have a key worker (Beresford, 1995).

Middle income families

At the moment a lot funding for play or learning equipment for use at home comes from charities. Some of these organisations apply some sort of means test as part of their eligibility criteria. In addition, while low income families may get assistance with items such as bedding/clothing/kitchen items, and so on, from social security or from charities, those who are above a certain income may find it impossible to get assistance. This disadvantages middle income families who are expected to be able to cover these sorts of costs themselves despite the well documented extra costs associated with having a disabled child.

Families living in 'unsuitable' housing

Unsuitable housing, a lack of space being one feature specifically identified, can significantly limit the options in terms of equipment which can be installed or used in the home.

4.4 TYPES OF EQUIPMENT NEED THAT 'FALL BETWEEN STOOLS'

Informants were asked about the types of equipment that, in their experience, families found difficult to obtain because of local inconsistencies in funding policy or because no single agency had yet accepted responsibility for funding that area of equipment.

Eight different types of equipment were identified by informants:

- specialist play and leisure equipment
- equipment to support learning at home
- lifting and moving equipment in family living, as opposed to self care, areas
- safety equipment
- beds
- chairs/seating
- clothing and bedding
- low cost items.

Play and leisure items

Commented on by a number of informants, play and leisure items were reported as being regarded as, at best, 'desirable' rather than 'essential' items: 'the icing on the cake'. It is not uncommon for councils to suggest to families that they either self-fund or apply to charities.

Depending on their area of expertise, informants identified different types of specific pieces of equipment currently 'falling between stools'. These included:

- equipment to support participation in leisure activities outside the home environment
- play consoles for computers
- specialist toys
- furniture to support play (for example, a 'work surface' at the right height for the child to use).

It is worth noting that, especially among young children, the boundary between play and learning is blurred (if not non-existent), and this may muddy the waters in terms of resolving funding responsibilities.

Equipment to support learning

In the main, informants' comments on unmet needs for 'learning equipment' were concerned with computer equipment. Most informants drew attention to the fact that funding of computer equipment at home is a significant, and unresolved, issue. Education authorities are perceived to be extremely reluctant to provide equipment for use at home. Informants argued for the need to challenge the notion that 'learning stops at the school gate', and also that education authorities recognise their wider responsibility for supporting development.

> 'There appears to be good funding earmarked for supporting children's use of computers in schools. There does, however, appear to be a problem for computers, including adapted consoles, for play and completing homework.'

One informant, also a parent of a disabled child, wrote: 'I have, like others, begged and borrowed equipment, especially to cover the summer break.' In addition to the equipment itself, is the need for a suitable surface on which to place and use a computer.

Lifting and moving equipment in family living, as opposed to self care, areas

The ability of a child to access parts of the home that were not related to their self care was rarely addressed by statutory services. For example, informants noted that while it may be possible to be provided with a hoist and tracking system to assist with moving the child between the bathroom and bedroom, it was very unusual that the tracking extended into the family living room. Similarly, the needs of a child to access 'play areas' such as siblings' bedrooms and the garden were rarely included in an assessment for equipment and/or housing adaptations.

Safety equipment

Highlighted in the earlier section, safety equipment was seen as something of a grey area in terms of funding responsibility, and can result in families being referred backwards and forwards between different agencies or departments, none of whom want to fund (or recognise their responsibility to fund) safety equipment.

As well as the types of safety equipment needed by families with a child with behavioural difficulties, parents are also being asked to self-fund other safety items such as car seats.

Beds

Another type of equipment where funding issues arise is in the provision of specialist beds. One informant reported that some local authorities do not have a 'bed budget' and many do not know the current, nor future, demand for specialist beds in their area. There appears to be an argument between health and social services as to who is responsible for paying for such equipment, and the result is families are 'pushed from pillar to post'.

Chairs/seating

A number of informants highlighted the issue of chairs or seating. Seating involves a number of different services: education authorities have a responsibility to ensure the child is properly seated at school, Wheelchair Services are responsible for meeting mobility needs, and Community Equipment Services are also meant to assess seating needs.

Informants reported that what can happen is once a child's wheelchair has been provided, it is seen as meeting all the child' seating needs. As one informant commented: 'It is unreasonable to be expected to sit in the same chair or position all day long'. The belief was that disabled children's needs for a suitable 'soft' chair often remained unmet.

Clothing and bedding

Clothing and bedding were other areas identified by informants where funding was problematic, typically falling to the family to cover the costs. It is well known that some disabled children wear out or dirty their clothes and/or bedding more frequently than other children. In addition, some children need specialist items of clothing or to have their clothing adapted. One informant stated that 'clothing (and sheeting) is rarely considered as something which the statutory services should assist with, with again the presumption that the parents will be the provider'.

Low cost items

Finally, the comment was made that the cost of low-cost items (bibs, cutlery and crockery), can 'add up to a fair amount'. They can, it was argued, 'be the straw that broke the camel's back when they are added to all the other disability-related and other non-avoidable costs which a person/family may face'.

4.5 THE RELATIONSHIP BETWEEN COMMUNITY EQUIPMENT AND HOUSING ADAPTATIONS

Views were sought on the relationship between community equipment and housing adaptation services. A number of themes emerged. These were:

- the interdependency of community equipment provision and housing adaptations
- the impact of under-funding of the adaptations service on equipment provision
- temporary provision vs long-term solutions
- lack of recognition of space needs
- regional differences in funding practice
- the plight of middle-income families

One informant pointed out the *inter-dependency* between equipment provided by Community Equipment Services and housing adaptations installed by local housing authorities. In many instances the success of one is dependent on the other, certainly in terms of maximum benefit to the family being experienced.

> It is obviously vital that equipment provision and any adaptations/work needed to make the equipment usable are seen as a whole, and that there are sufficient resources for both to be provided promptly and effectively.'

There was considerable concern about what was seen as significant *under-funding* of housing adaptations for disabled children. It was reported that in some local authorities annual budgets were being spent within the first two months of the financial year, leading to considerable delays. 'Expensive' adaptations are also resisted because of their inroads into the overall budget.

> 'I worked with one family who waited three years for the provision of a ramp and an adapted bathroom with a tracking hoist, and one who waited fourteen years for a through floor lift. Both of these despite advocacy and lobbying.'

Where the provision of community equipment requires some structural alterations, these delays 'spill over' into that service too.

A related concern was that equipment provided by Community Equipment Services as a *short term measure* ends up as a being seen as the long term solution. The example was given of a commode and basin temporarily provided by Community Equipment Services to cover for the lack of a downstairs toilet becoming the long term provision, instead of downstairs facilities being built or a lift installed in order to access the upstairs bathroom.

A number of separate, but related, issues were raised by a number of informants concerning *space* in the home. First, equipment can be space expensive - both when it is being used and/or stored - taking up family living space. This has wider implications in terms of the well being (physical and mental) of family members. Second, there was little appreciation of the conflicting demands on domestic space in terms of equipment design and the types of equipment offered. For example, it is very difficult to persuade authorities to provide a laptop

as opposed to a PC. Third, there was a belief that increasingly families are being asked, as a cost cutting measure, to relinquish family space.

> 'In recent months we have had repeated concerns from families about the application of Disabled Facilities Grants (DFGs). One consistent concern is that there appears to be advice that says that when a family has a living and dining area, even if there are within the same through room, that grants for an additional bedroom are not awarded. Families are being told they must use the dining area as a bedroom space. For many families this is clearly unacceptable as it leads to a loss of family space and an '"ordinary" life.'

Overall, demands on space were seen to be particularly an issue for disabled children and their families and were not adequately addressed within the rather adult-centric housing adaptations service.

Informants agreed that there was *inconsistency between local authorities* in terms of which service funded 'larger' items of equipment. It is not possible to comment on whether this inconsistency creates problems. What was of concern to informants was the extent to which families are passed from one agency to another when trying to apply for and install equipment. One informant felt this was particularly a problem in the social housing sector.

Finally, once again *middle-income families* were flagged up as a vulnerable group. The means test applied to the Disabled Facilities Grant (DFG) (by far the main route to funding housing adaptations) results in many financially hard-pressed 'middle-income' families having to self-fund housing adaptations - or manage without.

4.6 RECYCLING EQUIPMENT

All informants believed there was greater potential for recycling equipment (either provided by Community Equipment Services or installed in housing adaptations) than was currently being exploited. They also agreed this was something that needed further research to look at the cost-effectiveness of recycling different types of equipment, and the systems that need to be in place to support the process of recycling both child-specific, and generic, equipment. The viability of recycling computer equipment was questioned due to the very high refurbishment costs, and there are likely to be other types of equipment where recycling is not cost effective.

The point was made that to maximise the potential for recycling equipment, there should be greater collaboration between health, social services and education through the use of joint databases and joint funding.

It was also noted that recycling was likely to be more viable if equipment was routinely maintained while it was being used. In addition, this would also avoid the need for equipment to be returned to the manufacturers before recycling. In addition, those involved in designing equipment need to take far greater account of the potential of recycling. This issue was particularly raised with respect to equipment which has to be 'fitted' to an individual child.

The issue of ownership of equipment was also raised. Items of equipment installed within an adaptation funded by a DFG are the property of the family. There are no systems routinely in place to deal with such equipment, and other items self-funded by families, once it is no longer needed. At the moment equipment is sold privately or donated. This is more difficult with larger 'fixed' items and those specialist pieces used by few children.

One informant was working for a social services department which had recently taken over provision of hoists in order to overcome this difficulty and they were now able to recycle hoists. Other informants agreed that more of the larger 'fixed' items of equipment (hoists, baths, toilets, lifts) should belong to social service departments and merely be loaned to families for as long as was needed.

4.7 EQUIPMENT PROVISION IN OTHER SETTINGS

We asked informants to respond to the issue of duplication of equipment in places other than home where disabled children spend time. What was apparent from their responses was that duplication was a rather inappropriate phrase as, in their opinion, it is the scarcity of equipment in places where disabled children spend their time which is of considerable concern. On the whole, informants did not refer to duplication across home/school boundaries. Instead they highlighted equipment provision in informal care settings (for example, relatives' homes); family based short term (or respite) care services; and in the community.

One informant in discussing this issue in relation to physically impaired children made the following points:

> 'Children have the right to be safe and the right to the same experiences as their peers. These are currently being infringed. Children who need everything from handling sheets and transfer boards to tracking hoist systems are finding that these cannot be duplicated in community settings. The evidence we are gathering suggests this affects children in education, play and leisure, and family support services.'

Informal care settings

Concern was raised by a number of informants about the difficulty of getting funding for equipment for use in a child's 'second home' - perhaps grandparents or separated parents. It was extremely unusual for local authorities to fund equipment in these settings. For children whose parents are separated, the consequence can be loss of contact with the separated parent.

Family based short term care services

One informant stated that: 'The lack of moving and handling equipment in the homes of families providing short term care is a major problem. This has to change.' This was the view was shared by all informants who chose to comment on this issue. One informant cited a survey, carried out by Shared Care Network UK, of short term care service providers which found that very few providers have a policy on equipment and adaptations and many have no equipment or adaptations budget. In addition, the new legislation on lifting and handling had caused wide spread concern and confusion with services suspending placements of children with mobility impairments.

Conversely, the different funding sources can mean that 'Link families' providing short term care have better equipment than families themselves.

> 'Councils are often avoiding doing full risk assessments with families because of resource implications. So our experience is that issues come up for short break carers about lifting or bathing, for example, with families (with a disabled child) then saying "What about us?".

One informant noted that the presence of occupational therapists in social service disabled children's teams did serve to raise awareness of this issue when the support needs of a family were being reviewed.

Equipment in community settings

Despite the provisions of the Disability Discrimination Act, informants believed that the lack of equipment (particularly that to assist with lifting and handling, mobility and toileting/changing, and bathing) in community facilities and mainstream child care services promoted the social exclusion of disabled children. In addition, it was noted that transport services should be included when looking at what needs to be provided in order to promote and support inclusion of disabled children in the community.

Moving home

Finally, one informant highlighted the difficulties faced by families moving across a local authority boundary. Currently families are required to return loaned equipment. This inevitably results in additional tasks of sorting out new equipment at what is always a busy and stressful time:

> 'Consideration needs to be given to the issue of disabled children moving home to another location… to ensure that they are enabled to take with them and continue to use any statutory provided items of equipment. This should include the movement and responsibility for maintenance of educational items from one local authority to another to ensure there is no delay and hindrance to the progress and development of the child.'

CHAPTER FIVE:
SUMMARY OF KEY FINDINGS

5.1 SOURCES OF DATA

The data were obtained from two sources. First, a postal survey of a nationally representative sample of over 3000 parents of severely disabled children was used to collect detailed information about types of impairment and equipment use and needs at home, school and other care settings. This is by far the more substantial data source. Second, a small scale consultation exercise with a number of key organisations and individuals involved with equipment provision to disabled children and their families was used to obtain overall impressions on issues relating to disabled children and their equipment. (Where appropriate the source of the finding is indicated.)

5.2 IMPAIRMENTS AND ASSOCIATED NEEDS: FINDINGS FROM THE SURVEY

- Severely disabled children have multiple impairments (or complex disabilities) which can have an impact on all aspects of daily life.

- There are an estimated 179 500 severely disabled children (0-17 years) living in England.

- Within this population all have long-term needs for assistance with at least one of the following activities: standing, sitting, moving about, eating/drinking, using the toilet, bathing/washing, dressing and keeping occupied.

- Typically, dependency on others to assist with these activities decreases with age. However, among the young people in the highest age band in this study (15-17 years), over a half still needed a lot of help keeping occupied, more than four out of ten needed a lot a help with bathing/washing, and a third with dressing and/or using the toilet.

- In addition, almost all had difficulties with at least one of the following: hearing, vision, continence, learning, communication, behaviour and awareness of danger.

- Difficulties with behaviour and a lack of awareness of danger were reported frequently across all age groups but peaked in middle/late childhood.

- Reports of difficulties with learning were highest among 12 to 17 year olds. Almost seven out of ten of these young people had a lot of difficulty with learning.

- Although the number of parents reporting difficulties with continence decreased with the child's age, a third of 15 to 17 year old young people still had a lot of difficulties with continence.

- Similarly, while there was a decrease in the proportion needing help with communication with increasing age, it still remains that a half of 15 to 17 year olds were reported as having a lot difficulties with communication.

- Some, especially children less than five years of age, were also dependent on medical equipment. Half of the children in the sample who were less than two years of age were using at least one item of medical equipment. This figure fell to a quarter of two to four year olds. Among older children the figure dropped to one in ten children.

5.3 EQUIPMENT USE AND UNMET NEEDS: THE OVERALL PICTURE

Findings from the survey

A list of just less than one hundred different items of equipment was used to assess current levels of use of equipment by disabled children and their families and extent of unmet need.

- While giving an indication of current levels of equipment provision, it was not possible to distinguish between equipment provided by statutory agencies and that obtained by other means. Over a quarter of families had 'self-funded' at least one item of equipment. Equipment typically self-funded was safety equipment, continence equipment (waterproof bedding, nappies, continence pads) and computer equipment.

- Less than one in 20 respondents were neither using any of the listed equipment at the time of the survey nor reported unmet equipment needs.

- Almost half of the sample was using at least five different items of equipment. However, four out of five respondents reported unmet equipment needs.

- Ethnicity was associated with the extent to which equipment needs were met or unmet. White families were more likely to report fewer unmet equipment needs and also had more items of equipment already in the home compared to families from minority ethnic groups.

- Current levels of equipment use among very young children were unexpectedly high, though it peaked in middle childhood. In terms of unmet equipment needs, respondents whose children were aged between 2 and four years reported most unmet equipment needs.

- Parents' reports of need - met and unmet - were corroborated against data on the children's impairments and abilities. There is no indication that parents systematically over-reported unmet equipment needs: a view supported by the findings from the consultation phase of the project.

- The perceived reasons underlying unmet equipment needs most frequently reported by parents were: lack of financial resources, lack of information or advice, unsuitable housing, and problems with service delivery.

Findings from the consultation exercise

- The views of organisations and individuals involved in the consultation phase of the project support the findings from the survey of parents. Overall, disabled children were identified as a neglected group in terms of community equipment provision.

- The absence of a child-centred approach to the needs of disabled children within Community Equipment Services was seen as one of the reasons behind current inadequacies of community equipment provision.

- There was a belief that some disabled children are deemed ineligible for support from Community Equipment Services because their needs cannot be met from what is traditionally provided by Community Equipment Services. There is a need, it was argued, to re-look at what is meant by 'community equipment', and to take a far more creative, flexible and user-led approach.

- The lack of any systematic recording of unmet need meant that it was impossible to plan and budget in an informed or strategic way. This also perpetuated under-funding of equipment for disabled children.

- Groups identified as being particularly neglected by Community Equipment Services included: children with learning and/or behavioural difficulties, very young or very small children, children with mild or moderate impairments, and children with temporary, or short term, equipment needs.

- In addition, families from minority ethnic groups were identified as being vulnerable to unmet equipment needs. A lack of parental information about equipment services and entitlements was cited as a more general reason for unmet equipment needs.

- Finally, there was concern for middle-income families who are expected to be able to afford to fund smaller items and 'non-essential' items of equipment. Furthermore, this expectation is found within other services for disabled children (such as housing adaptations, short term care).

5.4 SPECIFIC CATEGORIES OF EQUIPMENT: USE AND UNMET NEED

Findings from the survey

- Overall, across different categories of equipment, levels of met need tended to be lower than levels of unmet need. There were only two categories of equipment (continence, handles and switches) where a greater proportion of respondents reported their needs being met compared with those reporting unmet needs for these types of equipment.

- Hoists and/or tracking equipment were being used by less than one in 20 families. A further ten per cent of families reported unmet needs for this sort of equipment.

- A third of children had needs for specialist seating, of these half had unmet seating needs. Less than five per cent of children in the sample had more than one type of specialist seating at home.

- Just under one in ten families had equipment in the home to assist with the child using stairs or steps. A similar proportion reported unmet needs in this area.

- Many families already had some sort of safety equipment in the home. However, unmet needs for safety equipment were reported by over half the sample. In contrast only a quarter of families reported their needs for safety equipment were fully met.

- Five times as many respondents reported that their child's needs for communication equipment were unmet compared to those reporting met need.

- Almost a sixth of the sample reported needs for equipment to assist with hearing telephones, door bells, alarms and/or the television. Yet only a third of these respondents reported these needs had been met.

- Equipment to assist with using the washbasin was more likely to remain an unmet equipment need compared to bathing/showering equipment. Four out of ten respondents reported their child had a need for equipment to assist with bathing, and half of these reported their needs had been met. One in five reported shower equipment needs, though here a greater proportion reported their needs remained unmet.

- One in ten children needed equipment to help them use the toilet. However, two thirds of these children did not have the equipment they needed.

- Levels of unmet need for continence or changing equipment were significantly lower than levels of met need. While needs for nappies or continence pads tended to be met, needs for suitable changing tables or boards remained unmet.

- In addition to nappies or continence pads, over a third of children needed other sorts of continence equipment in bed. Within this group, however, two thirds had unmet needs.

- Almost one in four children needed some form of equipment to assist with sleeping or being in bed. Across the sample the needs for pressure relieving mattresses was low. However, it was also a need that, far more frequently, remained unmet as opposed to being met.

- Very few children had access to equipment to help them get dressed independently. More than twice as many (one in ten of the sample) reported still needing this sort of equipment.

- Among children over five years of age, one in five respondents identified needs for equipment or adaptations to support their child's independence in the kitchen. However, these needs were much more likely to remain unmet as opposed to being met by the provision of adapted appliances and structural changes to kitchen furniture.

- Supporting independence through installing easy to use switches and handles were equipment needs identified by one in four respondents. These needs were more likely to have been addressed, as opposed to being left unmet. However, over one in ten children still had unmet needs in this area.

- Almost half of respondents stated their child's needs for play and learning equipment in the home were unmet.

- Items of equipment most frequently self-funded by families were: safety equipment (inside and outside the home), continence equipment and computer equipment.

Findings from the consultation exercise

The views of those involved in the consultation phase of the project concur with the findings from the survey about types of equipment need that are likely to remain unmet. In particular, the following types of equipment were identified either as 'falling between stalls' (that is, no agency assuming responsibility for their funding or provision) or as being regarded as non-essential: play and leisure equipment, equipment to support learning, safety equipment, upholstered or 'soft' seating, equipment to assist with lifting and handling in, and to and from, family living areas, and specialist beds.

5.5 MANAGING EQUIPMENT NEEDS IN DIFFERENT SETTINGS

Findings from the survey

- Duplication of seating and computer equipment in home and school was much less common than either the child sharing the equipment between home and school, or (as was especially the case for computer equipment) only having access to the equipment at school.

- A quarter of children regularly spent time in another home for child care, short term (respite) care or access visits.

- The way in which the child's equipment needs are managed in these non-home care settings varied considerably. Compared to children using residential short term (respite) care facilities, children being looked after in other home settings (either relatives or through family-based short term break schemes) and their carers are much more likely to have to manage with none or inadequate equipment.

Findings from the consultation exercise

- Views of informants involved in the consultation exercise supported the findings from the survey. There was considerable concern about the lack of equipment provision in short-term family-based care settings and where informal care was being provided in relatives' homes.

- In addition, the lack of appropriate equipment in community or mainstream facilities was seen as a key barrier to the promotion of the social inclusion of disabled children and their families.

5.6 RECYCLING EQUIPMENT

Views about current practice in terms of recycling equipment, and future potential were explored in during the consultation exercise:

- Overall, it was felt that potential for recycling equipment has not been fully exploited.

- Future developments needed to be based on research into the cost-effectiveness of recycling different types of equipment.

- In addition, appropriate information management and storage systems (preferably working across agencies) would need to be developed to support cost-effective recycling practice.

- On-going equipment maintenance and 'recycling-minded' equipment design were important factors in ensuring maximum recycling of equipment.

- Current policy regarding ownership of equipment installed as part of a housing adaptation was seen as a barrier to recycling equipment. It was argued that, instead, social service departments should loan such items to families.

5.7 THE RELATIONSHIP BETWEEN COMMUNITY EQUIPMENT AND HOUSING ADAPTATIONS

The second issue explored only in the consultation phase of the project concerned the relationship between community equipment and housing adaptations. A number of issues were raised.

- There was a belief that under-funding within housing adaptations budgets affected Community Equipment Services. Either families were having to 'make do' with equipment provided through Community Equipment Services; or alternatively, budget-led delays in the adaptations service meant that community equipment could not be provided or used to maximum benefit.

- The space demands of certain pieces of equipment reduced family living space. However, a lack of space is very rarely seen as grounds for funding a housing adaptation.

CHAPTER SIX:
DISCUSSION AND CONCLUSIONS

A summary of the findings from this research is provided in the previous chapter. In this final chapter we consider the implications of these findings in terms of a number of issues:

- funding
- access to services and assessment
- reconsidering the remit of Community Equipment Services
- housing issues
- strategic collection of information
- meeting equipment needs in other settings

The chapter concludes with a discussion of the limitations of the research and suggestions for further research.

6.1 RESPONDING TO THE FINDINGS OF THE SURVEY

Many of the issues we discuss here are related or inter-dependent, reflecting the complexity of this area of service provision.

Funding

The findings from the survey, and supported by comments from those involved in the consultation phase, suggest that currently Community Equipment Services are significantly under-funded. This research has provided population estimates of the number of children in England with needs for different types of equipment, along with data on the extent to which equipment needs are currently met.

Underfunding can results in one of the following: i) no equipment is provided; ii) there are substantial delays in provision; iii) a cheaper, 'second best' option being provided that fails to meet the family's needs (for example a portable hoist instead of fixed hoist and tracking); or iv) a family is required to 'make do' with equipment provided by a different agency for a similar, but different, purpose (for example, seating equipment). While an increase in funding is clearly necessary, it is important that other issues or measures are also addressed to ensure the effective use of any increase in funding. These are discussed below. At the same time, however, recognition of the complexity of this area should not become a reason for "financial inaction".

Access and assessment

A clear finding from the research was that for almost all categories of equipment many families were reporting unmet needs. Gordon *et al.* (2000) report a similar finding from their re-analysis of the 1985 OPCS survey of disabled children. They offered a number of explanations including: i) a lack of information about equipment and entitlements to

equipment; ii) difficulties with accessing services; iii) fragmentation of services; iv) lack of financial resources to self-fund equipment. Gordon *et al.* also suggested that equipment needs associated with so-called 'secondary disabilities', and typically behavioural difficulties fall into this group, can be overlooked if the assessment of equipment needs focuses on the main condition or diagnosis.

We also know that factors such as income and ethnicity are associated with levels of service provision, and families who are perhaps the most vulnerable are the least likely to be receiving services (Beresford *et al.*, 1996; Chamba *et al.*, 1999; Gordon *et al.*, 2000). Taken together, these research findings counsel against a response which merely increases the funding of community equipment for disabled children *per se.* Other factors need to be addressed including access to community equipment services and the way in which needs for community equipment are assessed.

Reconsidering the remit of Community Equipment Services

Children with learning and/or behavioural difficulties

The findings from both stages of the research suggest that the needs of children with learning difficulties and/or behavioural problems have not been properly considered or addressed by Community Equipment Services. This research has drawn attention to this issue, however further work would be needed in order to ascertain its implications in terms of the sorts of equipment these children require and the consequent financial implications.

A child-centred approach

The focus of current provision seems to be with meeting parents' or carers' needs. We would argue that current provision has failed to take a child-centred approach to what is understood by the phrase 'essential activities of daily living'. Action needs to be taken to ensure that responsibility for funding items such as play and learning equipment and equipment to promote and support independence is clarified. This may result in the need for further increases in funding for community equipment.

Housing issues

Action taken to improve community equipment provision is, to some extent, constrained by housing factors. Unsuitable housing can limit options in terms of equipment provided. In addition, funding for housing adaptations for disabled children and their families is also sorely under-funded (Oldman and Beresford, 1998). Delays and inadequacies of housing services will have an impact on the effectiveness of equipment provided by Community Equipment Services.

Strategic collection of information

Systems need to be put in place so that information about current (and future) needs are collected at a local level. This information should be used strategically in planning and budgeting. It should be remembered that any assessment of need should reflect the child's

and parent's needs, and that children with learning and/or behavioural problems are included. Ideally this process should tie in with other multi- or across agency strategies currently being developed on collecting local data on the numbers and needs of disabled children.

Managing equipment needs in other settings

Concerns about equipment provision in community settings (such as local sport and leisure facilities) were raised by those who took part in the consultation phase of the project. This is an issue clearly requiring further research, and the issue of funding responsibilities needs to be resolved or clarified.

Consideration also needs to be given to meeting the equipment needs of children and their carers in care settings which are not the child's home. This includes relatives and (separated) parents who regularly care for a disabled child, and those families providing short term care services in their homes.

6.2 LIMITATIONS OF THE STUDY

When considering the findings from this study it is important to bear in mind its limitations.

First, the survey only included severely disabled children. Adding children with mild or moderate impairments and those with short term equipment needs will increase the estimated number of children with equipment needs.

Second, much of the survey was based on current provision. It was seeking to establish current levels of use of equipment as well as identifying areas and levels of unmet need *with respect to current equipment provision*. It has only been possible to begin to look at needs for other types of equipment that are not typically funded by statutory agencies but might well be perceived by users as items which support the 'essential activities of daily living'.

Third, given that we were working within the parameters of current provision, it is also likely that as well as neglecting child-centred needs, we were also unable (due to a lack of background research evidence) to look comprehensively at the equipment needs of children with learning difficulties and/or behaviour problems.

Fourth, in reporting unmet need, for some items of equipment parents were acting as proxies for their children. Our previous research experience suggests that parents may under-report unmet needs for equipment that supports the child's independence (Oldman and Beresford, 1998).

Fifth, while attempts were made to include a wide range of practitioner, professional and voluntary organisations in the consultation phase of the research, not all responded to the invitation. We do not know whether their views would agree with those reported.

6.3 SUGGESTED AREAS FOR FURTHER RESEARCH

The following suggestions for further research are by no means an exhaustive list. Rather they reflect either the findings, or the limitations, of this project. Within each suggested area more than one piece of work may be necessary, perhaps involving a number of different disciplines or approaches including, for example, social science, engineering and economics.

Recycling of equipment

Informants involved in the consultation phase of this project were unanimous in the view that any increase in recycling of equipment needs to be based on research into the cost effectiveness of recycling the different types of equipment. In addition, research to inform the development of effective systems to manage recycling was seen as important.

Identification of user-defined priorities and outcomes of equipment provision

Research is urgently needed which seeks to identify user (children and parents'/carers') views on what they want from Community Equipment Services: their priorities and desired outcomes. It is essential that this research includes children and young people with a wide range of impairments.

The potential of assistive technologies

One of the issues likely to emerge from greater consultation with children and young people about Community Equipment Services is the need for equipment to support their independence. The development of assistive technologies for disabled adults is a rapidly developing field (Mitchell, 2001, personal communication). Research is needed which will explore the potential use of these technologies among disabled children and young people.

Equipment needs in community settings

At the moment, it appears that many disabled children are excluded from mainstream services and local community facilities due to inadequate equipment provision. Informants involved in the consultation phase of the project highlighted the need for research into ways of ensuring disabled children's equipment needs can be met in community settings.

Effectiveness of equipment

To our knowledge, there has been no research which has looked specifically at the effectiveness of community equipment provided to disabled children and their parents/carers.

Factors underlying unmet need

A major finding from this project was the high level of unmet need. While a lack of resources is likely to be one factor, the data (and findings from Gordon's reanalysis of the 1985 OPCS survey) suggest that other factors are involved. This needs further research - ideally followed by development work to improve access to Community Equipment Services.

APPENDIX 1
METHODOLOGY

The methodology chosen to address the aims of the study was a postal questionnaire for completion by parents of disabled children, and a short consultation exercise with key individuals or representatives of organisations who are involved with issues relating to disabled children's equipment.

The survey

A postal survey of 5,000 families with a severely disabled child (aged 0-17 years inclusive) was carried out. The sample was drawn from the Family Fund Trust database. Details on sampling and the representativeness of the sample are provided in Appendix 2, and the basic characteristics of the sample are reported in Appendix 3.

In essence, the purpose of the survey was to obtain nationally representative, quantitative data on current levels of use of equipment covered by Community Equipment Services and the extent of unmet need.

The questionnaire

The content of the questionnaire was informed by the requirements of the funding body and previous research on disabled children and their domestic environments (Oldman and Beresford, 1998; Beresford and Oldman, 2000). There was also some consultation with representatives from key organisations on the content of the questionnaire.

The questionnaire was for completion by parents. In our experience this tends to be the main carer of the disabled child - typically mothers.

The questionnaire began with questions about the child (age, the nature of the child's impairments and abilities, requirements for medical equipment in the home) and the family (family structure, composition, ethnicity, and tenure). The main section of the questionnaire consisted of a list of different types of equipment that are used by disabled children. This was not (and could not be) an exhaustive list, rather it sought to cover key areas of daily living, and focussed on the more costly items. On the whole this list was restricted to equipment typically covered by Community Equipment Services. However, for some types of equipment funding responsibilities are unclear or practice differs between authorities. (For example, within the funding of a housing adaptation, some housing authorities will include items that another authority will define as community equipment and will therefore not fund within a Disabled Facilities Grant.) In addition, there are other items of equipment (for example, play and learning equipment for use in the home setting), where funding responsibilities are unclear. These types of equipment were included on the questionnaire.

This generated a list of just under one hundred different items of equipment. (This was by no means comprehensive and small items (for example, special crockery and cutlery, bibs) were not included.) For each item on the list parents were asked to choose *one* of three responses:

i they currently had the item of equipment at home;
ii they needed the item of equipment but did not currently have it at home;
iii they did not need the item of equipment.

Further questions concerned self-funding of equipment, difficulties with meeting their equipment needs, and managing the child's and/or carer's equipment needs in different settings (school, care settings away from home).

Almost all questions were of fixed response format.

Administering the survey

The questionnaire (Appendix 4) was in the field during May and June 2001. Families received a letter from the Chief Executive of the Family Fund Trust inviting them to complete the enclosed questionnaire. An information sheet (Appendix 5) about the project was enclosed as was a reply paid envelope for families to use to return the questionnaire to the Social Policy Research Unit. Two and a half weeks after the initial letter was sent, a reminder letter was posted to all families who had not responded. A second reminder (enclosing another copy of the questionnaire) was sent out two weeks after the first reminder. All correspondence with families made it clear that participation was entirely voluntary and that their decision whether or not to take part would not influence any subsequent applications to the Family Fund Trust. Full confidentiality was assured.

Response rate

Response rate for the survey was very high. From an initial sample of 5,004, 3,401 completed questionnaires were returned by the cut-off date imposed by the project team in order to keep to the project timetable. (Over a hundred questionnaires were returned after that date.) In addition, 119 questionnaires were returned undelivered because the family had changed address, and we were informed by 42 families that their child had died. A further 12 families reported a change in circumstance which meant they no longer fulfilled the eligibility criteria for the project. Together this reduced the initial sample to 4,831, yielding a response rate of just over 70 per cent.

Analysis

The data were input and analysed using SPSS (Statistical Package for Social Sciences). The majority of analyses used descriptive statistical techniques. Analysis of variance was used to establish the association between levels of unmet need and factors such as child's age and ethnicity. National level estimates of current use and unmet need were also

calculated. This required using data on the total size of the population of families living in England on the Family Fund Trust database. This was kindly provided to the project by the Trust.

The consultation exercise

A small number of key organisations or individuals were approached to take part in a consultation exercise. The purpose of the consultation was to obtain national perspectives on issues such as funding, current provision and areas of unmet need, neglected groups, duplication of equipment in different settings, and recycling of equipment.

The option was given to either take part in a telephone interview, or to provide written responses - either postally or via email. All those taking part in the consultation were provided with the same briefing paper which outlined the issues on which the project was seeking informed comment. 'Informants' chose the issues on which they felt in a position to respond. One or two organisations involved took on the task of canvassing the views of all or a number of their staff, thus widening the consultation process quite considerably. Some organisations invited to take part did not respond to the invitation. The fact that this phase of the project took part over the summer may have influenced ability to respond to the invitation.

The following individuals/organisations took part in the consultation exercise:

AbilityNet
Council for Disabled Children
Disabled Living Foundation
Muscular Dystrophy Campaign
National Network of Local Authority Occupational Therapists Working With Children
REMAP
Shared Care (UK) Network
Whizz Kidz

Finally, over thirty suppliers and manufacturers of equipment used by disabled children provided information about their products' prices (see Appendix 6).

APPENDIX 2
SAMPLING

The sample for the survey was drawn from the Family Fund Trust (FFT) database. The Family Fund Trust is a government funded, independent charitable organisation providing modest grants to families caring for a severely disabled child. Set up in the mid-1970's in response to the Thalidomide crisis, the database now contains information on over 200,000 families. Information held on the database means both random or stratified (according to a number of different factors) samples can be drawn for research purposes.

The Family Fund Trust database

The FFT database is, arguably, the best national database of severely disabled children and their families. It represents over half of the population of all families with a severely disabled child in England. (Estimates of take-up suggest that between 50 and 70 per cent of eligible families have applied to the Trust, Lawton and Quine, 1990). While there is bias within the database toward lower income families (a higher income cut off is applied with families with household incomes of ~£20,000 being ineligible), this does not apply to the representativeness of the database in terms of the conditions and impairments which result in children being severely disabled.

For this project, the disadvantages of the database is that it only concerns severely disabled children, as opposed to those with moderate or mild impairments. In terms of research, these two latter groups are very difficult to identify or access as many are unlikely to be in contact with social services and/or use specialist health provision. The scope of this project did not allow for a different set of sampling and recruitment procedures to be put in place in order that child with mild or moderate impairments could be included.

Extracting the sample

Sampling took place in early April 2001 and families whose last contact was before the beginning of April 1999 were excluded[1]. The sampling frame was confined to families living in England where the disabled child would still be under 18 years of age at the time of the project.

In order to ensure the study population reflected the overall population, sampling was conducted region by region within six age bands. Thus the regional distribution within the

1 Studies that use the FFT as a research resource have to adhere to particular constraints in order to minimise disruption to the everyday work of the Trust and to avoid unnecessary 'distress' to families. One criterion imposed following difficulties encountered with using the database as a research resource is that families who have not had 'recent' contact with the Trust should be excluded from research projects.

database was used as the basis of the regional distribution for the sample, and sample selection was designed to produce equal numbers of children within each of six age groups, 0-1, 2-4, 5-7, 8-11, 12-14 and 15-17. Table A2.1shows the sample structure required to obtain the desired sample size of 5,000 children.

Table A2.1: Required sample structure by region and age group

	Proportion of families on database/region %	*Cell size for each age group*	*Total sample size*
North	8.8	74	444
Yorkshire	13.3	111	666
North West	16.3	136	816
West Midlands	13.2	110	660
East Midlands	8.4	70	420
South West	7.7	65	390
London North	9.7	81	486
London	13.2	110	660
South	9.2	77	462
Total	*100*		*5004*

Before the sample selection could be made the sampling frame had to be further refined in a number of ways.

1.1 Children known to have died were excluded.

1.2 Families already contacted for earlier research projects were excluded.

1.3 Families with no address yet on database were excluded.

1.4 Families who have not received help were excluded unless rejected on the basis of their economic circumstances.

1.5 Children with no principal disabling condition recorded were excluded.

These criteria were imposed in order to maximise response rate and to minimise difficulties that can be encountered with an exercise of this nature.

The sample was then constructed by taking a random sample of the necessary size from each of the sample cells. However, after applying the exclusion criteria described above, the sampling frame had shortages in the youngest age group in three of the regions. In these sampling cells all cases were included and augmented by adding the youngest children in the next age category. The resulting sample structure is shown in Table A2.2.

Table A2.2: Achieved sample structure by region and age group

Region	*Age group*						*Total*
	0-1	*2-4*	*5-7*	*8-11*	*12-14*	*15-17*	
North	60*	88*	74	74	74	73	444
Yorkshire	111	111	111	111	111	111	666
North West	136	136	136	136	136	136	816
West Midlands	110	110	110	110	110	110	660
East Midlands	70	70	70	70	70	70	420
South West	65	65	65	65	65	65	390
London North	81	81	81	81	81	81	486
London	66*	155*	110	110	110	110	661
South	72*	83*	77	77	77	77	463
Total	771*	899*	834	834	834	834	5006

Note: Achieved sample varies from required sample due to insufficient numbers in youngest age group.*

APPENDIX 3
THE SAMPLE

The following provides information about the basic characteristics of the sample.

Family size and number of disabled children

The majority of respondents (77 per cent) had two or more children living at home. In most cases, there was only one severely disabled child in the family (89 per cent).

Housing

Less than four out of ten families (39 per cent) were home owners. A third of families (35 per cent) were living in local authority housing, and 16 per cent were renting their homes from a housing association. Fewer than one in ten families rented from private landlords. Most families (86 per cent) lived in a house.

The child's ethnicity

Table A3.1 shows the distribution of ethnicity across the sample. The representation of non-white families in the sample is pleasing: over 17 per cent of respondents were from minority ethnic groups.

Table A3.1: Child's ethnic origin

	n	*%*
White	2816	83.9
Pakistani	151	4.5
Black African	60	1.8
Black Carribean	56	1.7
Indian	53	1.6
Bangladeshi	43	1.3
Chinese	7	0.2
Other	171	5.1
Base=3357		

Child's age

The distribution of the sample by the child's age is shown in Table A3.2.

Table A3.2: Child's age

Age at time of survey (yrs)	*n*	*%*
0 - 1 yrs	408	12.2
2 - 4 yrs	634	18.9
5 - 7 yrs	598	17.6
8 - 11 yrs	613	17.7
12 - 14 yrs	592	17.7
15 -17 yrs	491	14.6

APPENDIX 4

THE EQUIPMENT DISABLED CHILDREN
USE AND NEED: QUESTIONNAIRE

THE EQUIPMENT DISABLED CHILDREN USE AND NEED

Filling in the questionnaire

This questionnaire is about *all* the different sorts of equipment disabled children and their parents or carers may use or need. Because of this you will find that some of the equipment mentioned in the questionnaire does not apply to you. But overall we hope this questionnaire does cover your needs and experiences.

Please answer every question unless asked to do otherwise. The first few questions are about you and your family, then we ask you about the equipment your disabled child uses and where they use it.

If you need help filling in the questionnaire, or have any questions please contact Bryony Beresford: 01904 433608, or write to her at: Social Policy Research Unit, University of York, York YO10 5DD; e-mail: bab3@york.ac.uk.

Please use the brown reply paid envelope to return your completed questionnaire. You do not need to use a stamp.

If you would like to receive a report of the finding of this research, please tick this box □

THANK YOU VERY MUCH

Are you.... ? (Please tick one box only)

□	Married or living as married	□	Separated or divorced
□	Single	□	Widowed

1. How many of your children do you have living at home with you?
   _____ *(number of children)*

2. How many of your children have a long-term illness or disability and are living at home with you?
   _____ *(number of children)*

   If you have more than one disabled child living at home with you, please complete the remainder of the questionnaire with respect to the older child.

3. How old is your disabled child? _____ *years*

4. Which best describes your child's origin? *(Please tick one box only)*

□	White	□	Indian
□	Black African	□	Pakistani
□	Black Caribbean	□	Bangladeshi
□	Chinese	□	Other *(please describe)*
			_____

6. Compared with other (non-disabled) children of your child's age, how much help or support does your child need with the following?

	Needs no help	*Needs some help*	*Needs a lot of help*
Sitting	□	□	□
Standing	□	□	□
Moving about	□	□	□
Eating/drinking	□	□	□
Using the toilet	□	□	□
Bathing/washing	□	□	□
Dressing	□	□	□
Keeping occupied	□	□	□

7. Listed below are some things that a disabled child might find difficult to do, or is unable to do. Please tell us which things are difficult for your child.

	No difficulties	*Some difficulties*	*A lot of difficulties*
Hearing	☐	☐	☐
Seeing	☐	☐	☐
Learning	☐	☐	☐
Communicating	☐	☐	☐
Behaviour	☐	☐	☐
Continence	☐	☐	☐
Awareness of danger	☐	☐	☐

8. Does your child's condition mean that you have any of the following at home? *(Please tick all those true for you)*

- ☐ Naso-gastric or gastrostomy feeding equipment
- ☐ Breathing and/or heart monitor
- ☐ Intravenous line for drugs (eg. Hickman line)
- ☐ Ventilator
- ☐ Oxygen therapy equipment
- ☐ Tracheostomy tube
- ☐ Dialysis equipment
- ☐ Catheter
- ☐ Suction equipment
- ☐ We do not have any of this sort of equipment at home

9. Do you...? *(Please tick ONE box only.)*

- ☐ Own your own home
- ☐ Rent from the council
- ☐ Rent from a private landlord
- ☐ Rent from a housing association
- ☐ Other (*please describe*) _____

10. What sort of home do you live in? *(Please tick ONE box only)*

- ☐ Ground floor flat
- ☐ House
- ☐ Flat (not ground floor)
- ☐ Bungalow
- ☐ Other (*please describe*) _____

11. This is a list of all the different types of equipment disabled children and their parents might use at home.

Tick the SQUARE □ if you HAVE the item of equipment at home. If your child NEEDS the item of equipment but you do NOT have it at home, please tick the CIRCLE ○. (If you do not have or need an item of equipment, just go on to the next item on the list.)

Standing and sitting

Have	*Need*	
□	○	Standing frame
□	○	Floor sitter (or corner seat)
□	○	Moulded postural chair
□	○	Multi-adjustable wooden chair (school or activity chair)
□	○	Bean bag
□	○	Multi-adjustable upholstered (soft) chair
□	○	Tray for chair for feeding/ playing
□	○	Extra frame to raise the height of the activity chair

Moving about

Have	*Need*	
□	○	Walking frame or rollator
□	○	Wheelchair usually propelled by the child
□	○	Special buggy, wheelchair pushed by another person
□	○	Crutches, walking stick
□	○	Outdoor powered wheelchair
□	○	Powered/electric wheelchair (mainly for use indoors)

Learning and communicating

Have	*Need*	
□	○	Computer/laptop/keyboard - no special adaptations
□	○	Communication or symbol board/book(s)
□	○	Special play equipment to suit child's needs
□	○	Computer/laptop/keyboard adapted for your child's use
□	○	Electronic speech synthesiser

Switches and handles

Have	*Need*	
□	○	Easy to use door handles
□	○	Easy to reach light and other switches
□	○	Easy to use handles on cupboards

Lifting

Have	*Need*	
□	○	Portable hoist
□	○	Ceiling hoist - in bedroom only
□	○	Hoist with track connecting bathroom, bedroom and family living room
□	○	Ceiling hoist - in bathroom only
□	○	Hoist with track connecting bathroom and bedroom

(... please turn over)

Question 11 cont'd

Tick the SQUARE □ if you HAVE the item of equipment at home. If your child NEEDS the item of equipment but you do NOT have it at home, please tick the CIRCLE ○. (If you do not have or need an item of equipment, just go on to the next item on the list.)

Keeping safe

Have	*Need*	
□	○	Safety glass in windows
□	○	Window locks
□	○	Front/back door locks
□	○	Internal door locks
□	○	Cupboard locks
□	○	'Locks' on kitchen appliances
□	○	Alarm indicating front/back doors have been opened

Have	*Need*	
□	○	Safety film on windows
□	○	Window bars
□	○	Locks on garden gate
□	○	'Gates' between rooms
□	○	Secure fences
□	○	'Padded' room

Hearing

Have	*Need*	
□	○	Flashing indicator for door bell
□	○	Flashing indicator for smoke alarm
□	○	Vibrating indicator for telephone
□	○	Vibrating indicator to smoke alarm

Have	*Need*	
□	○	Flashing indicator for telephone
□	○	Vibrating indicator for door bell
□	○	Loop system for television

Using the washbasin

Have	*Need*	
□	○	Lever taps

Have	*Need*	
□	○	Height adjustable basin

In the bath

Have	*Need*	
□	○	Grab rails
□	○	Foam/cushion supports
□	○	Bath seat

Have	*Need*	
□	○	Bath lift
□	○	Hammock support
□	○	Lever taps

In the shower

Have	*Need*	
□	○	Grab rail
□	○	Level access shower
□	○	Electric/height adjustable shower seat
□	○	Shower trolley

Have	*Need*	
□	○	Fixed shower seat
□	○	Seat or stool standing in the base of the shower
□	○	Moveable shower chair (shower only)
□	○	Fold down shower stretcher

Using the potty or toilet

Have	*Need*		*Have*	*Need*	
□	○	Moveable chair/sanichair (also used in the shower)	□	○	Moveable chair/sanichair (used only with the toilet/potty)
□	○	Potty chair or commode (not moveable)	□	○	Toilet support seat
□	○	Toilet support frame	□	○	Toilet with washing and drying facility (eg Clos-o-mat)

Getting dressed

Have	*Need*		*Have*	*Need*	
□	○	Bench for child to sit on while dressing	□	○	Ladder back or wall rails for child to hold on to

Changing and dressing

Have	*Need*		*Have*	*Need*	
□	○	Nappies/continence pads	□	○	Changing board or table (fixed height)
□	○	Changing board or table (adjustable height)	□	○	Moveable changing board/table
□	○	Changing mat			

In bed

Have	*Need*		*Have*	*Need*	
□	○	Lying board	□	○	Pressure relieving mattress
□	○	Waterproof bedding	□	○	Wetting or enuresis alarm
□	○	Bed rails or safety nets	□	○	Alarm to indicate child is out of bed
□	○	Intercom	□	○	Special supports for posture

In the kitchen

Have	*Need*		*Have*	*Need*	
□	○	Lower kitchen units with wheelchair access	□	○	Rounded corners on kitchen units
□	○	Adapted kitchen equipment			

Getting up stairs and steps

Have	*Need*		*Have*	*Need*	
□	○	Stairlift - for standing only	□	○	Stairlift with a seat
□	○	Stairlift with a platform for a wheelchair	□	○	Through-floor lift
□	○	Rails by external steps	□	○	Rails by internal steps

12. Overall, how satisfied are you with the equipment you have been provided with?

□ Not at all satisfied □ Quite satisfied □ Very satisfied

13. Have YOU paid for and/or had to raise money for any of the equipment listed in Question 11?

□ No
□ Yes *(please describe)* _____

_____

14. In Question 11 we asked you to tell us about any equipment you or your child need at home but which you do NOT have at the moment. Why is this?
(Please tick all those which are true for you.)

□ We are waiting for an assessment of our equipment needs
□ Our equipment needs are being assessed at the moment
□ Professionals do not agree that we need the equipment
□ Our home is not suitable for the equipment we need
□ We do not have enough space for the equipment
□ The equipment will only be provided at school
□ We cannot afford to buy the equipment
□ I do not know how to go about getting the equipment we need
□ Delays in providing equipment

15. How long ago was the last time you and your child's equipment needs were assessed by an occupational therapist? (This might have been your first assessment or a review)

□ Less than 6 months ago
□ 6-12 months ago
□ 1-2 years ago
□ More than 2 years ago
□ Our equipment needs have never been assessed

16. Has your house been adapted in any of the following ways?
(Please tick all those true for you.)

□ Internal doorways widened
□ Front and/or back door widened
□ Ramps to front and/or back door
□ Internal wall removed to provide more space
□ Ground floor room converted into bedroom and en-suite bathroom
□ Changed use of room *(please describe)* _____

_____

□ Existing room(s) made larger/extended *(please state which room(s))*_____

_____

□ Ground floor extension with bedroom and en-suite bathroom
□ Other rooms added to the home *(please describe)* _____

_____

□ None of these *(please go to question 18)*

17. Who paid for these adaptations? *(Please tick ONE box only.)*

□ The council paid for it all
□ We paid for it all
□ Partly by council and partly us
□ Other

18. Does your child REGULARLY spend time in another home for child care, respite (short term) care or access visits? If yes, please tick the box where your child spends MOST time. *(Please tick ONE box only.)*

□ No *(please go to question 20)*
□ Childminder
□ Respite (short break) care in a residential unit
□ Relatives
□ Respite (short break) care with a 'Link Family'
□ Access visits to other parent

19. When your child spends time in this other home, what happens about the equipment your child and his/her carer needs?

	Equipment already there	*Child takes equipment*	*Child/carer has to manage with no/ inadequate equipment*	*Not applicable*
Standing & sitting	□	□	□	□
Moving about	□	□	□	□
Learning/communicating	□	□	□	□
Using switches & handles	□	□	□	□
Keeping safe	□	□	□	□
Lifting the child	□	□	□	□
Hearing	□	□	□	□
Using the washbasin	□	□	□	□
Bathing/showering	□	□	□	□
Using the toilet	□	□	□	□
Getting dressed	□	□	□	□
Changing & dressing	□	□	□	□
In bed	□	□	□	□
In the kitchen	□	□	□	□
Getting up stairs/steps	□	□	□	□

20. Is your child at school?

□ Mainstream school/college
□ Special school/college
□ Special unit attached to mainstream school/ college
□ No *(please go to question 22)*

21. What happens about equipment your child might need to use at home and at school? For each item of equipment, use the tick boxes to show where your child uses the equipment

	Only used at home	*Only used at school*	*Same piece shared between home & school*	*Different piece used at home & school*	*Not applica*
Standing frame	□ □	□	□	□	
Bean bag	□ □	□	□	□	
Multi-adjustable wooden chair ('activity chair')	□ □	□	□	□	
Moulded postural chair	□ □	□	□	□	
Floor sitter (or corner seat)	□ □	□	□	□	
Walking frame/Rollator	□ □	□	□	□	
Crutches/Walking stick	□ □	□	□	□	
Special buggy/wheelchair pushed by another person	□ □	□	□	□	
Wheelchair usually propelled by the child	□ □	□	□	□	
Powered/electric wheelchair (mainly for use indoors)	□ □	□	□	□	
Computer/laptop/keyboard - no special adaptations	□ □	□	□	□	
Computer/laptop/keyboard adapted for your child's use	□ □	□	□	□	
Communication/symbol board	□ □	□	□	□	
Electronic speech synthesiser	□ □	□	□	□	
Special play equipment	□ □	□	□	□	
Loop system for the television	□ □	□	□	□	

If your child does not use any of this equipment please tick this box □

22. In general, what happens when some equipment needs repairing or has to be taken away to be updated? *(Please tick ONE box only.)*

□ We are provided with a temporary replacement
□ We have to make do without the equipment
□ This has not happened to us

23. Finally, please put a tick by those places where a lack of equipment means your child finds it difficult or impossible to go there. *(Please tick all those true for you.)*

□	Swimming pool	□	Leisure centre
□	Library	□	Other *(please describe)* _____
□	Cinema		_____
			_____

Thank you very much for taking the time to fill in this questionnaire. We have left the space below blank for you to write down any comments you may have about the questionnaire, or for you to tell us more about your experiences relating to your child's equipment needs. Please use this space if you would like to.

APPENDIX 5

THE EQUIPMENT DISABLED CHILDREN
USE AND NEED: INFORMATION SHEET

THE EQUIPMENT DISABLED
CHILDREN USE AND NEED

~ Project information sheet ~

What's it all about?
The government's Department of Health has asked some researchers at the University of York to look into the equipment disabled children need and use. Little is known about the numbers of disabled children in England using equipment to assist them with their daily lives, and whether some children and their parents aren't getting the equipment they need. The right sort of equipment can make a big difference to families' lives, so it's important to know how many disabled children use or need equipment to enable or help them with their day-to-day activities. This will help people working in government departments to decide how much money needs to be put aside to pay for equipment for disabled children.

Why me?
In order to understand what is happening throughout the country we need to hear from as many families as possible. The **Family Fund Trust** is helping us with this project by writing to lots of families who have applied to the Trust, asking them to complete this questionnaire.

Disabled....?
Different people use different words to describe their child's needs or condition. We have chosen to use the phrase 'disabled child'. By this we mean a child with one or more of the following: physical disability, learning difficulty, hearing or sight impairment, behaviour problem, communication difficulty, or serious health problem.

What we would like to ask you to do....
We would like to ask to you to fill in the enclosed questionnaire. For most of the questionnaire you only need to tick boxes, so it shouldn't take too long. Your answers will be treated in total confidence and you will not be identified in any way.

What we will do....
We will write a report about what everyone's answers to the questionnaire tell us about disabled children and the equipment they use and need. This report will be given to people working in the government's Department of Health. We will also make sure to send the report to other people who need to know, such as professionals working in local hospitals, social services, occupational therapy and schools. If you would like us to send you a summary of what we find out, please tick the box on the front page of the questionnaire.

Help with questionnaire?
If you need help filling in the questionnaire or have any questions about the project, please contact: *Bryony Beresford, Social Policy Research Unit, University of York, York YO10 5DD. Telephone: 01904-433608.*

APPENDIX 6
COMMUNITY EQUIPMENT: COSTS

Over 30 companies or manufacturers who supply equipment to disabled children and their families were contacted by the research team and asked to provide information about their products and prices. For many items of equipment a bespoke service has to be provided, accounting for the child's needs and size, and the setting in which the equipment will be used or installed. (Indeed some companies felt unable to provide a price list for these reasons). Overall, this makes identification of basic prices of equipment difficult. In addition, the figures obtained can be misleading as customising equipment can add considerably to a basic price.

Variations in pricing

Variations in prices between companies were found for all products. However, without detailed inspection of product specifications and obtaining user views on suitability and effectiveness it is not possible to comment on whether these variations are an indicator of quality or 'over-pricing'.

Changes in price according to age

Certain products were available in a number of 'child sizes', and increase in size was reflected in price increases. Other products are designed in such as way that they can be made to fit the child, or padding is used to achieve the right size.

Discounts

Not unexpectedly, practice in terms of offering discounts varied. Discounts from trade prices were applied to direct purchases from families and bulk orders .

Leasing

Some companies offered a leasing service.

Information on current prices

Table A5.1 provides information on 'basic prices' (or range of 'basic prices') of some of the items of equipment included in the survey. All prices do not include VAT. The purpose of this table is to offer a *broad brush* data on the cost of some of the larger or more expensive items of equipment provided by Community Equipment Services and/or a housing adaptation.

Table A5.1: Current basic price or price range for some items of community equipment

Type of equipment	*Approximate basic price (exc. VAT)*
Seating	
Floor sitter	£130 - 190
Multi-adjustable upholstered (soft) chair	£780
Adjustable activity chair	£140 -180
Multi-adjustable activity chair	£560 -630
Toileting/showering/bathing	
Potty chair	£100 - 130
Commode	£150
Toilet support frame	£60
Toilet with shower/drying facility	£1900
Moveable shower and toilet chair	£340 - 420
Adjustable shower and toilet chair	£600 - 670
Folding shower seat	£ 46 - 200
Adjustable shower stool	£60
Freestanding shower chair	£180 - 250
Level entry shower base	£350
Bath seat	£120 -230
Bath support	£240
Foam/cushion supports	£80
Bath hoist	£940 - 2045
Bath cradle	£570 - 700
Bath stretcher	£340
Domestic bath with powered lift	£2000
Bath with integral adjustable seat and lift	£3300
Lever taps	£40
Grab rail	£30
Adjustable washbasin	£150
Electrically operated wall mounted changing table	£1550
Lifting	
Electric moveable hoists	£2150
Slings	£80 - 250
Other	
Variable height activity tables	£230
Intercom	£50 - 80
Bed rails and safety nets	£153

APPENDIX 7
PAPER SUBMITTED TO THE PROJECT BY THE DISABLED LIVING FOUNDATION

1. Introduction

The Disabled Living Foundation (DLF) is the UK's leading charity in the field of information and advice on aids and equipment for disabled and older people.

The DLF is pleased to have this opportunity to contribute to the research conducted by the Social Policy Research Unit on behalf of the Department of Health. It is, however, concerned at the length of time allocated to this project, which may not enable organisations and individuals to give their fullest response to this project, and hopes that more time will be given to future research projects.

Issues which were specifically raised for consultation by the Research Unit are indicated by the use of inverted commas in the headings. Although the research is looking at these issues in particular, it is worth considering other implications and connected needs, hence the widened scope of comment from the Foundation.

2. Staffing Issues for Equipment Assessment and Provision

The DLF believes that more therapists and social workers are needed in the UK to help reduce delays with assessment and provision. Delays are bad for all disabled people, but may cause particular problems when young children are concerned (developmental and social growth delayed, added stress on parents and rest of family who probably dealing with disability issues for the first time, etc). An increase in the number of GPs and Health Visitors would also be welcome to allow more time within consultation periods and home visits to pick up 'hidden' impairments/ conditions sooner.

The provision of portage teachers varies from area to area, and their more wide spread recruitment (with full training and support) should be considered to assist with the fuller and more effective usage of equipment.

Better and continuing training, and access to relevant and up-to-date information, is needed for health and social service staff on the range of equipment and services available. Assessment is often based on a narrow knowledge base, with provision centering around a small range of items as a consequence. At the very least, staff should be aware of and enabled to make full use of their local Disabled Living Centre and/or resources such as the Disabled Living Foundation's equipment data (the Hamilton Index print version, the CD Rom for use on computer, and the website).

Although there are stipulated checks made by the GP during the early stages of a child's development, these end after the final check at four and half years. The education authority is expected to, and often does, pick up conditions which 'appear' at a later stage in the child's life, such as dyslexia for example. However, we believe that it would be useful if a more formal health and development assessment could be offered at the age of around seven by the GP as well.

3. Financial Implications for the Disabled Person/Family

Means-testing for provision of equipment (and for other social services) should not just be based on income, but should take into account the person's/families' total disability-related expenditure, as well as considering other non-avoidable/essential out-goings.

Consideration should be made by the Government on assisting individuals/families with the running costs of disability-related items (higher electricity bills, for example). The consideration should take into account not just those who are on low incomes, including those who just miss out on other methods of income-related financial support, but also those with other disability-related costs which take their available income down to low levels.

The cost to the individual/family in travelling to certain assessments and hospital appointments (for example, for wheelchair assessments, for communication aids assessment) should be considered. This should be on top of the hospital fares assistance system which is currently available, as there will be many people who 'lose out' due to higher than stipulated incomes who's actual available finances will be greatly limited due to disability-related expenses.

4. Statutory Funding Issues

We believe that more investment from the Government is needed to support local equipment provision by health, social and educational services. As the Audit Commission's 'Fully Equipped' report stated, 'equipment for older or disabled people provides the gateway to their independence, dignity and self-esteem. It is central to effective rehabilitation; it improves quality of life; it enhances their life chances through education and employment, and it reduces morbidity at costs that are low compared to other forms of healthcare.' The long-term cost-effectiveness of the UK providing its citizens with a well funded, comprehensive and efficient equipment provision service is obvious.

We look forward to seeing the money provided under the integration of community equipment services initiative spent to the real and increased benefit of disabled people.

The Foundation believes that more ring-fenced money is needed under the Schools Access Initiative to assist accessibility of education; it is no use providing a child with the equipment needed for school life if the school premises themselves are inaccessible to the pupil.

The provision of items for pupils who do not have a Statement of Educational Needs needs to be addressed. The pupil may not have an 'obvious' disability and may not be assessed as actually needing a statement, but may still benefit from the provision of an item or a facility.

The 'postcode lottery' of statutory provision – provision according to where you live based on local criteria, local spending arrangements, and local funding – is a key issue. It should not be considered acceptable in any way that a citizen of this country can find him/herself penalised/disadvantaged because s/he lives in the 'wrong area', and the Government must take active steps to stamp out this inequality.

5. Assessments and Provision of Equipment

Effective joint working between statutory services should take place to ensure the child's current and immediate future is seen holistically rather than in a compartmentalised fashion. If the child needs specialised eating and drinking items at home, for example, then s/he is likely to need it at school and for any hospital inpatient treatments as required as well.

Increased state financial provision, better joint working, and the pooling of budgets should, we hope, end the 'financial buck-passing' problem, the situation where one service delays provision/refuses to provide an item at all, while it fights it out with another service, with the disabled person left waiting in the middle.

A disabled child's needs (as for adults) should be looked at holistically within each statutory service as well as between services. For example, educational provision must take into account the child's need to have educationally-related equipment at home to do homework as well as to do work at school. Provision to ensure that the child is enabled to take part in other educationally-related areas, such as going on school trips and taking part in out-of-hours activities, should also be part of any assessment/provision.

The individual situation and lifestyle of both the disabled person and, where appropriate, their family, should be taken into account. For example, the affect of disruptive behaviour on the siblings and parents of a child with severe attention deficit, should warrant help with a separate bedroom for the disabled child; the most cost-effective version of an item may be fine for a small child, but the developmental and social implications of being a teenager might mean that a more expensive/up-to-date/trendier version of that item should be provided; a child who does not have a communication or manual dexterity disability may still be appropriate for assessment for a computer if they find it difficult to get to a library to do their homework due to inadequate and inaccessible public transport and library facilities.

Statutory services should record un-met need (for example, when the disabled person is known to require an item/service, but it is not provided as it not considered 'essential'/not fitting local criteria), and then pass their findings on to the Government. By not recording un-met need, a false picture of 'need' and 'adequate state provision' is given.

Consideration should be given for the 'duplication' of essential items (such as wheelchairs if storage space permits) either by the state providing the two items, or by the state not penalising someone who already has obtained one item for themselves by refusing to provide the duplicate.

There should be a rapid and effective replacement and repair service for essential items where it can be guaranteed that the item can be replaced (perhaps on a temporary basis while the item is being repaired) within, say, a day.

Regular and frequent assessments are needed for disabled children in particular, as the child's needs may change rapidly (because, for example, the condition and/or the child's capacity to deal with it improves or gets worse, because the family's situation alters for whatever reason, or simply because the child is growing).

There should be better provision for equipment for people/children with 'temporary disabilities', such as children with congenital hip replacements.

It should be clearly recognised that simply referring a client to a source of charitable funding for an item does not discharge the social services' responsibility to ensure that an accepted need is catered for. As a minimum, the service should take account of the delays in provision caused by the application process to charities, the high possibility that client will be turned down due to charity's resources being over-stretched, and the fact that the client may well feel uncomfortable at having to go to a charity for assistance. If the charity is unable to meet the need, the onus is still on social services to find a way of ensuring provision.

Relevant reports/surveys to consider include the 'Out of Services' report from Needs Must, a coalition of around 30 organisations campaigning to restore people's rights to community care. The summary of the report states that areas which require attention include 'poor assessment procedures and practices which undermine independence' and 'eligibility criteria which undermine adequate service provision… 59 per cent of respondents (to the 'Out of Services' questionnaire) experienced problems with the provision of adaptations and equipment. More than half (56 per cent) of these were refused such help outright. The remainder experienced long delays.'

6. Information for Equipment Users

To help ensure that aids and equipment are used fully, safely, and with ease, comprehensive, clear training/instructions should be made available to disabled people/their families on the usage and maintenance of the items provided. Written information (or in the format most suited to the user) should be made available where appropriate. Details should cover the correct usage of the item, contact details in case the item goes wrong, where to return the item when it is no longer needed, how to maintain the item, and so on.

Relevant information should be provided for parents as soon as they are made aware that their child has a disability. This should be available via local health, educational and social services professionals and outlets, and should include issues such as the child's rights, local assistance available, and national support groups. It should also included equipment issues such as statutory provision, the second hand market, toy libraries, the local disabled living centre, the Disabled Living Foundation's Helpline, and so on. It is often the first time that the parents have dealt with disability issues, and lack of information can seriously disadvantage parents and child alike.

7. 'Neglected groups' – who might be missing out when it comes to equipment provision for disabled children

Pre-school age children:

Many/most children start learning to read and write before going to school, and will use learning/development related play items. Some disabled children will need specialist or adapted items to enable them to access the same early development opportunities as their non-disabled peers; their parents, however, may not be able to afford these or even standard play/development items. Appropriate items may also not be available at local play groups and nursery schools. Pre-school age disabled children may therefore be considered as a 'neglected group' if play/development items are only considered as useful rather than essential, if their home provision is regarded as the responsibility of the family alone, and if play groups and nursery schools fail to cater adequately for children with special needs.

Children with difficult to identify or 'minor' conditions:

Conditions such as ME, mild dyslexia, mild attention deficit, 'minor' muscular or joint conditions, and so on, can be overlooked, ignored, or misdiagnosed. The child could be simply seen as lazy or attention seeking, or their condition could be recognised but still not seen as making the child 'disabled' as defined under the various Acts and criteria. The condition, however, may well be or become 'disabling' in some way, and over-tight assessment criteria and inflexibility of provision can exclude help for these seemingly 'less serious' disabilities, to the real disadvantage of the child in question.

Children from minority ethnic families:
Families whose customs and practices are not based on those of the population generally may be a 'neglected group' when it comes to equipment or service provision for various reasons (such as not being happy with seeing or their child being seen by a doctor/therapist of the opposite sex). Also, it is thought that some cultures may traditionally have had generally low expectations for a child who is disabled, so may need more encouragement/ help to show what can be done/why it worth the effort, and that is not shameful to have a disability.

Children from families who have a poor grasp of English or literacy, or who have communication/sensory disabilities themselves:
This can make it difficult for the families to communicate fully with others to make their needs known, to understand and utilise their rights, to find out how to use and maintain any equipment offered, and so on. Offering information in an appropriate format or language, ensuring a communication 'tool' is available if needed (such as a sign language interpreter), using plain English verbally and in any written material, demonstrating usage carefully, working with appropriate local support groups, and so on, can make a real difference.

Children from families who are wary of state intervention:
Some families see statutory services as something to fear (those who worry that their child may be taken into care if they as parents show any sign of requiring help, for example), or that it's a stigma to have someone from, say, social services, involved with their child. They may therefore hide any difficulties which their child may face/ needs that they have in order to reduce their contact with the relevant professionals. Ensuring suitable training on social and customer-led issues for relevant staff, promoting the statutory services as a positive benefit and a right in law to access, making use of local support groups to bridge the gulf where possible, and so on, may help.

Children with learning disabilities or behavioural problems:
These children may well 'miss out', as some of their needs (or their family's needs) - such as play items, some home-safety items, a separate bedroom, and so on - may not be assessed as being essential or part of the local criteria for provision. Groups like MENCAP and the Challenging Behaviour Foundation are likely to be able to expand on this issue.

8. 'Types of equipment need that 'fall between stools''

Play and leisure items:
These are usually seen as 'desirable' rather than 'essential' items, something which the parents should be providing themselves as a matter of course and outside the provision of the statutory services. For many disabled children and teenagers, however, they are a vital part of their social interaction and personal development. As a minimum there should be far

greater access to toy libraries for parents to borrow items. The definitions of 'essential' and/or 'need' for state provision needs to be flexible, and the presumption that parents will always be able to/should provide these items should be challenged.

Clothing:
Clothing any growing child is expensive, but there can be added expense with some disabled children. Some parents will need to buy extra items if their child wears out or dirties their clothes more frequently than other children, some need to buy specialist items of clothing for their child, others have to pay for clothing to be adapted. Clothing is rarely considered as something which the statutory services should assist with, with again the presumption that the parents will be the provider. The need for additional or specialist/adapted clothing should, however, be taken into account on an individual basis, particularly when the costs of these items have to be added to other disability-related costs.

Low cost items:
Items which cost (relatively) small amounts (such as cutlery and other kitchen items) are 'priced out' of provision by some, perhaps many, local criteria. Consideration needs to given to person's needs as a whole, rather than pricing up needs individually. Lowish-cost items can add up to a fair amount if several of them are needed, and they can be the straw that broke the camel's back, so to speak, when they are added to all the other disability-related and other non-avoidable costs which a person/family may face.

Extra bedding:
Extra sheeting may be needed by some disabled children (and adults) due to incontinence and/or extra wear and tear. Again, making a blanket decision that an item such as 'ordinary' sheeting will not be provided fails to look at individual circumstances and the combined costs of disability-related items. Although people on 'the breadline' may get assistance with items such as bedding/clothing/kitchen items, and so on, from social security or from charities, those who are above this line may find impossible to get assistance even though the combined costs bring them near or on to this breadline.

Non-standard items:
Children who are larger or smaller than 'the norm', or larger/smaller than a product usually caters for, are often provided with a standard product which, even with adaptation, is not the most suitable item, although usable. This is often due to budgetary considerations, as a more suitable item may cost more due to its 'non-standard' design. As for all areas of provision, 'cost-effectiveness' should not just be based on bare need and currently-accountable finances, but should take into account the 'bonus' to the person's life (mentally, physically, emotionally, and personally, socially and professionally) now and in the future.

9. 'Relationship between equipment provision and housing adaptations'

The following, taken from Therapy Weekly (August 9, 2001), is useful as a summary of the necessity and positive value of adaptations, as well as some of the problems that can occur when adaptations are insufficient/unsuitable:

Quote in Therapy Weekly from Frances Haywood, research fellow at Bristol University and the author of the 'Money Well Spent: the effectiveness and value of housing adaptations' (a report by the Joseph Rowntree Foundation this year):

> "All the evidence suggests that successful home adaptations deliver many of the government's key social care objectives. They keep people out of hospital, reduce the strain on carers, improve the dignity of disabled people and enable them to lead fuller, more socially included lives. For disabled children and their siblings, they improve educational and life chances."

Therapy Weekly also states – 'Although most of the evidence was positive, the research uncovered some serious problems. Some extensions for children were so small there was no room for a parent to sleep when the child was seriously ill; others were too cold to be useable. Through-floor lifts often left families with even less room to manoeuvre.'

It is obviously vital that equipment provision and any adaptations/work needed to make the equipment usable are seen as a whole, and that there are sufficient resources for both to be provided promptly and effectively. For example, the supply of a temporary item (for example, commode and basin to use downstairs) must not be seen as a 'solution' which could justify the delay of the most appropriate outcome (such as stairlift installation to get to the bathroom upstairs or the creation of an other bathroom via an extension).

As indicated earlier, some social service departments seem unaware of their obligations to ensure provision of an item/service once a need has been accepted, even if that provision is dependent on an item/service provided by another statutory service. For example, adaptations needed to ensure usage of a piece of equipment (the installation of an accessible shower, for example) may come under the Disabled Facilities Grants system administered by housing rather than social services, but the social services duty is still there if the DFG and/or any other source of funding is inadequate to ensure provision. Local and national government should ensure this is known and catered for, especially financially.

10. 'Recycling of equipment'

As for all the issues raised by this research, more time and resources would be needed for a 'proper' response to this issue. In general, however, the Foundation considers it appropriate for there to be research into a system which would allow the appropriate, speedy, and safe recycling of good quality, working equipment from one user to another.

The design of equipment for children should seek, where appropriate, to ensure it can 'grow' with the child for long-term usage and to aid in its 'recycling' to other children at different stages of life/growth. Government funding to assist research such design would be useful.

It may not be cost effective for the statutory services to actively pursue the retrieval of low-cost items. However, on provision of an item, the individual/family could be asked to think about giving the item back (or to the Red Cross or to charities such as Oxfam, or to the local DLC as a demonstration item) when the item was no longer required (if it was in good/working condition, of course).

Ways of 'recycling' privately bought items could also be considered. For example, could there be a way for the statutory services to make use of second-hand/nearly new equipment registers (such as Lexiquip for disabled children's equipment and the Disability Equipment Register) for the purchase and provision of some items? Perhaps research should be undertaken by the Government to see whether there could ever be a foolproof system for ensuring the usability, safety and quality of items purchased by the state from the nearly new market.

For appropriate recycling to take place, high quality (and properly-funded) product-checking and reconditioning services would obviously be needed, covering the item's look as well as its safety and working ability.

There should be greater provision to enable items (both mainstream and specialist items, new and second/hand) to be customised to suit individual's wishes and needs (for example, through local rehabilitation engineers, and/or through better access (that is, funding) to voluntary bodies such as REMAP and DEMAND), taking into account health and safety issues and manufacturers' guarantees.

11. 'Duplication of equipment in different settings' – problems with provision in settings other than home and school?

Equipment provision as it is currently in this country - for example, under-resourced, available only under often extremely tight and locally-varying criteria (and including means-tested charging if it is provided by the social services), and coming from separate authorities's budgets – does not lend itself well to the comprehensive, holistic and flexible

service disabled people (including children) require. It can limit or even exclude some disabled children from using services such as community facilities (such as sports and leisure facilities) and holiday facilities, despite the provisions of the Disability Discrimination Act.

Consideration needs to be given to the issue of disabled people/children moving home to another location for personal or parental career or other reasons, to ensure that they are enabled to take with them and continue to use any statutory provided items of equipment. This should include the movement and responsibility for maintenance of educational items from one local education authority to another to ensure there is no delay and hindrance to the progress and development of the child.

12. 'Examples of good practice'

The Government recently ring-fenced money for communication aids for disabled children. The child can keep the items once they leave education to assist them while they are looking for work. Extra money, ringfenced and following the child's life through to adulthood = an example of good practice.

Examples of good and bad practice are to be found in reports by groups such as RADAR and Needs Must. Scope's recent report on social exclusion among disabled young people ('That Kind of Life') may also be useful. The report's author, Jenny Morris, is quoted in a recent Community Care article as saying 'Many of (the young people) were even denied the possibility of communicating because adequate assessment was not given – or the equipment provided was unavailable. Inadequate or out of date – it amounts to a violation of their human rights. These people are being silenced because they are simply not given the support that can allow them to have a voice.'

13. 'Other research, resources, contacts'

It is worth making contact with organisation's such as the Council for Disabled Children, Parents at Work, the Family Fund, Deaf Children's Society, British Institute for Brain Injured Children, ICAN, Asian People with Disabilities Alliance, ABCD (Access to Services for Black/Minority Ethnic Children), Challenging Behaviour Foundation, Action for Sick Children, RICA, Whizz Kids, Steps, ACE, Disabled Living Centres Council, Action for Leisure, Kids Active, Sequal, RADAR, Network 81, MENCAP, Sense, Scope, RNIB, RNID, MND, and ASBAH.

Disabled Living Foundation

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