

The community equipment needs of disabled children and their families

Bryony Beresford

R
E
S
E
A
R
C
H
W
O
R
K
S

Community equipment is those items which assist or enable a disabled person and/or their carer with everyday living and activities. This project provides, for the first time, information on the levels of use of community equipment by disabled children and their families, and the extent of met and unmet need. A postal survey of over 3000 families with a severely disabled child and consultation with key organisations and individual experts showed that:

- Families with disabled children typically need a wide range of equipment provided by Community Equipment Services (CES) including equipment to assist with: lifting, seating, managing steps and stairs, safety, communication, washing and bathing, toileting, continence, sleeping, supporting independence about the home, and learning and playing.
- The majority of families have unmet equipment needs. Four out of ten respondents said they had unmet needs for five or more different types of equipment.
- Across virtually all types of equipment, levels of unmet need were higher than levels of met need.
- Typically, where relatives are providing childcare for the child they are doing so without the equipment they or the child needs.
- A greater proportion of children are only able to use computers and communication equipment at school compared to those who can use these pieces of equipment at home and at school.
- Families from minority ethnic groups and families with preschool children reported the highest levels of unmet need.
- Improving Community Equipment Services' provision to disabled children and their families requires action at a number of levels including: funding; broadening the scope of CES, improving access to CES, greater coordination between CES and housing adaptation services and strategic collection of information by services on the use and need of equipment.

RESEARCH FINDINGS FROM THE
SOCIAL POLICY RESEARCH UNIT

S | P | R | U

THE UNIVERSITY *of* York

APRIL 2003
no. 2003-01

Background

Items falling within the remit of Community Equipment Services are those pieces of equipment which enable disabled people to carry out everyday activities in the home, or those which assist their carers. Thus items to assist with bathing and washing, using the toilet, eating and drinking, sitting and sleeping, and communication all fall within the remit of community equipment services.

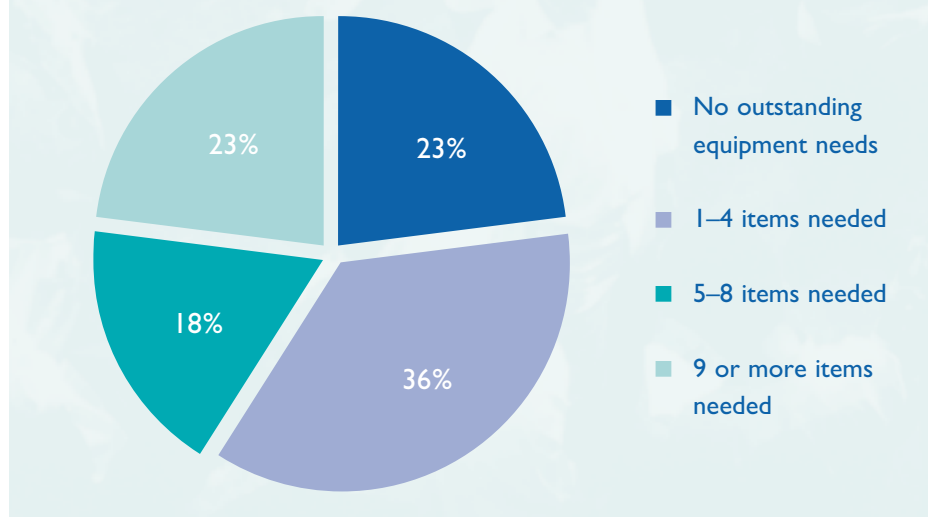
Community Equipment Services have been criticised in the past for failing to meet the needs of disabled and older people. One reason for this is the absence of data on population and levels of need. A lack of information about the current volume of use and extent of unmet need for community equipment by disabled children led to this project being commissioned by the Department of Health in April 2001.

Findings

Current levels of use

The questionnaire sent to parents listed 113 different items of community equipment. The number of different pieces of equipment being used by respondents ranged from none to over 50. Sixteen per cent currently had none of the equipment listed. Around a third (35 per cent) had up to four items, and a quarter (27 per cent) between five and eight items. One in five respondents had nine or more different pieces of equipment.

Figure 1
Number of items of equipment still needed by families



Levels of unmet need

The majority of respondents had unmet needs for at least one of the items of equipment listed on the questionnaire, *see Figure 1*.

A fifth of respondents reported they did not have any outstanding needs for the items of equipment listed on the questionnaire. Over a third identified between one and four items their family needed but did not currently have, and two-fifths needed over five items.

Areas of unmet need

For most types of community equipment, levels of met need were lower than levels of unmet need, *see Table 1*.

The extent to which equipment needs were being met varied according to the type of equipment. Types of equipment where there were disproportionately high levels of unmet need were: equipment to assist with lifting and handling, safety, communication, hearing in the home, using the washbasin, toileting, using the kitchen and learning and play.

Meeting equipment needs in different care settings

There were clear differences in the availability of equipment needed by children and their carers in different 'care settings' (i.e. residential short-term care, family based short-term care and being looked after by relatives). Access to community equipment needed by the child/carer was much lower in family home settings compared to residential short-term care settings. Having to manage without equipment needed by the child/carer was most likely in situations where children were being looked after by relatives.

Managing equipment needs at home and school

Where a child needed seating, communication or computer equipment in more than one setting, it was more likely that either the child was sharing the equipment between home and school, or was only able to access it in one location, than that there was duplication of equipment in the two settings.

Table 1:
Levels of met and unmet need by equipment category

EQUIPMENT CATEGORY	RESPONDENTS WITH EQUIPMENT AND REPORTING NO FURTHER EQUIPMENT NEEDS (%)	RESPONDENTS INDICATING UNMET NEED FOR EQUIPMENT (%)
Lifting	4.6	9.3
Seating	14.1	15.8
To assist with stairs and steps	9.8	9.7
Safety	24.7	45.9
Communication	5.8	26.4
Hearing in the home	4.0	10.6
Washing and bathing		
– using the washbasin	5.5	13.7
– bathing	21.6	22.5
– showering	9.9	13.0
Toileting	3.1	6.7
Continence	31.9	7.5
Sleeping/being in bed	16.2	22.0
Supporting independence about the home		
– handles and switches	15.7	11.3
– using the kitchen	6.1	13.2
Learning and playing	18.8	45.1

Box 1
Experts' views on groups currently neglected by Community Equipment Services

Groups of children likely to be neglected

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

Families who are vulnerable to unmet equipment needs

- 'uninformed families', including families from minority ethnic groups
- middle income families
- families living in unsuitable housing

A greater number of children were only able to access computer and communication equipment in school than were able to access such items at home and school.

Factors associated with levels of met and unmet need

Analysis of the survey data revealed higher levels of unmet need for community equipment among families from minority ethnic groups compared to white families, and among families with preschool children compared to those with school aged children. Informants

involved in the consultation phase of the project also identified additional 'neglected' groups in terms of current community equipment provision. *Box 1* shows the types of children and families most likely to have unmet needs.

The way forward

The major finding from this project was the high levels of unmet need for community equipment among families with a disabled child. Those

involved in the consultation phase of the project argued that resolving this issue will require multi-faceted action or change. This should include:

- ▶ An acknowledgement by all agencies involved that disabled children's equipment needs are not location-specific. Equipment should 'follow the child', rather than the child having to go to where the equipment is.
- ▶ An increase in funding for community equipment for disabled children and their families.

Improvements to the way Community Equipment Services are accessed by families, with particular attention being paid to families from lower income groups and those from minority ethnic groups.

A redefinition of what falls within the remit of 'community equipment' provision for disabled children, which takes account of the needs of children with learning and/or behavioural difficulties, and more general child-centred needs (for example the need to play and to learn). This redefinition should then be reflected in the assessment process.

Greater co-ordination in the delivery of housing adaptation and Community Equipment Services to avoid delays and wrangling over funding responsibilities.

Strategic collection of information by local agencies to inform planning and budgeting of services.

The project also revealed a number of issues which require further research. They included: recycling of community equipment; identification of user-defined outcomes of community equipment provision; the potential of assistive technologies; and the equipment needs of disabled children in 'mainstream' community settings.

Methods

The project was carried out in 2001 and the data were obtained from two sources.

A postal survey of a nationally (England) representative sample of over 3000 parents of severely disabled children was used to collect detailed information about types of impairment, and equipment use and need at home, school and other care settings. Thirteen different categories or types of equipment were covered in the questionnaire: lifting, seating, stairs/steps, safety, communication, bathing, toileting, continence and changing, dressing, sleeping/being in bed, auditory, supporting independence about the home, and learning/playing. The sample was drawn from the Family Fund Trust database: this is the best available national database of families with a severely disabled child. The survey achieved a response rate of over 70 per cent.

A small-scale consultation exercise with a number of key organisations and individuals involved in community equipment provision to families with a disabled child. The purpose of the consultation exercise was to obtain national perspectives on issues such as funding, current provision and areas of unmet needs, neglected groups, duplication of equipment in different settings, and recycling of equipment. 'Informants' participated via telephone interviews, written submissions or email dialogues.

Further information

This publication should be cited as: Beresford, B. (2003) 'The community equipment needs of disabled children and their families', *Research Works*, 2003-01, Social Policy Research Unit, University of York: York.

Copies of the full report 'Community Equipment: use and needs of disabled children and their families' (Ref DH1841 3.02, price £7.00) are available from SPRU's Publications Office. Contact Ruth Dowling on **01904 433608** or email spruinfo@york.ac.uk

We can send an email notification to you when each new issue of **Research Works** is posted on the website.

To register for this service please email us at spruinfo@york.ac.uk with the following information:

Name (Mr/Ms/Mrs/Dr etc.);
Job Title; Organisation; Address (including Postcode); **Tel/Fax/Email**

The Social Policy Research Unit is an independent research organisation at the University of York. Established in 1973, SPRU has an international reputation for excellence in key areas of social policy, including health and community care, and social security. Its Director is Professor Peter Kemp. For further information about SPRU contact the Director or the Information Office, or visit our website at <http://www.york.ac.uk/inst/spru/>

Social Policy Research Unit,
The University of York, Heslington,
York YO10 5DD, United Kingdom.
Telephone +44 (0)1904 433608
Fax +44 (0)1904 433618
Text +44 (0)1904 432626
E-mail SPRU@york.ac.uk