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Wheelchair needs for children and young people: a review - Diane L Cox British Journal of Occupational Therapy May 1, 2003, 66 (5)

Introduction

Children with a disability have complex and wide-ranging needs, which may not be met by a single agency (Ball 1998, Department of Health [DH] 2000a, Strategy Group 2002). One of the core principles of The NHS Plan (DH 2000b) is that health and social services must be shaped around the needs of the patient or client, ensuring a seamless service. The Children's National Service Framework (NSF) will be published this year (DH 2003). This NSF will develop new national standards across the National Health Service (NHS) and social services for children, with consideration of collaboration and coordination (Strategy Group 2002).

The members of a charity, the Physical Disability and Sensory Impairment Forum (PDSI), initially instigated the project owing to their concerns about the assessment of need and the provision of mobility equipment to young people. The PDSI and the Morecambe Bay Health Authority funded the project. Some parents and young people had expressed concern about the time between referral and assessment, the assessment for and provision of wheelchairs and the user and carer training. The study was intended to give young people and their parents or carers an opportunity to articulate those views.

A postal questionnaire was designed (Jack and Clarke 1998). However, only seven people from the potential 26 volunteers responded to the survey so it will be necessary to undertake further study to verify the findings (Oppenheim 1992, Bury and Mead 1998). The results of the survey are not, therefore, reported here. The project report is available from the author for those practitioners who would like further detail. Nevertheless, the issues raised during the literature review are presented because these may be of interest to practitioners working with children and young people.

Literature review

Wheelchair services in England

The Audit Commission (2000) has reported that there are at least 640,000 wheelchair users in the United Kingdom (UK), of whom 70% are over the age of 60 years. However, 9% of users are under the age of 19 years. It was suggested that young users, although fewer in number, were more costly per head because they were the most active and independent users when provided with the right equipment.

Currently, the key aim of the NHS wheelchair service is to provide a comprehensive service to people who have long-term mobility problems, including the consideration of comfort, function, posture and pressure relief (Royal College of Physicians 1995, Ham et al 1998). The majority of the wheelchair services in England follow the guidelines for eligibility for equipment (Aldersea 1999). These guidelines state that wheelchairs or buggies are available to children who are permanently disabled, with a disability that restricts mobility after the age when a child should, in normal development, be walking. In most services, this was considered to be 3 years of age. However, some

services have reduced the age limit to 24 months or, in some parts of the country, to 30 months (Aldersea 1999, Turner 2001).

It has been suggested that wheelchair services can offer only a limited range of wheelchairs, especially in the higher specification chairs (White and Lemmer 1998, Aldersea et al 1999a, Audit Commission 2000). In 1996, the NHS Executive announced two initiatives to support wheelchair provision and improve the range of equipment available to users (Jelier and Turner-Smith 1997, Sanderson et al 2000).

These were:

- The provision of electrically powered indoor/outdoor wheelchairs (EPIOCs) by the NHS for severely disabled people (NHS Executive 1996a)
- A new voucher scheme to be phased in to give wheelchair users more choice and financial aid from the NHS if they chose to buy a wheelchair provided by the private sector (NHS Executive 1996b).

The EPIOCs were intended to give the more severely disabled users (including children) the chance to enjoy enhanced levels of independent mobility, both inside and outside their home (NHS Executive 1996a, Frank et al 2000). In 1999, Aldersea et al noted that children appeared to have gained greatly from EPIOC provision, but that the chairs were not always robust enough to stand up to rough daily use. It has also been noted that funding restrictions may limit the provision of EPIOCs to full-time users, who would appear to gain the greatest benefit from independent indoor and outdoor mobility (Jelier and Turner-Smith 1997, Aldersea et al 1999a).

A recent national survey (Nicholson and Bonsall 2002) identified that some children under the age of 5 years can successfully be given powered wheelchairs. They found that this related to appropriate identification of eligible children through training and the need for post-provision training and supervision. This supports the findings of Home and Ham (2002), who found that most parents agreed or strongly agreed that powered mobility equipment had given their child under 5 years independent mobility, increased happiness, confidence and motivation and enabled greater participation in games, activities and family life.

The main objective of the wheelchair voucher scheme was to enable disabled people eligible for the supply of a NHS wheelchair to have a greater choice in meeting their mobility needs (Sanderson et al 2000). The scheme introduced procedures that allowed the user, or his or her carer or representative, to contribute to the cost of a more expensive wheelchair of their choice (NHS Executive 1996b, White 1998). However, White (1998) noted that no children had applied for wheelchair vouchers in the three services studied. This may be due to the suggested average voucher period of 5 years and, therefore, the unsuitability for a growing child (NHS Executive 1996b, White 1998).

Training

For equipment to be regularly and effectively used for the benefit of children, families and carers require adequate information and training. Following the McColl (1986) report, the Department of Health (1991) produced a training package. All occupational therapists graduating from university

should have a basic knowledge of wheelchair matters (Silcox 1995, COT 1996a). However, recent studies have identified that undergraduate training is not enough; they have recommended additional postgraduate training in order to advance and sustain effectiveness in wheelchair provision on a national basis, in particular complex wheelchair and seating issues (White and Lemmer 1998, Aldersea et al 1999b). White (2003) recently commented on the positive evaluation of the impact of such training for occupational therapists, physiotherapists and engineers.

Aldersea et al (1999a) found that training was an essential factor in the successful use of an EPIOC, particularly for less able users. Beaumont-White and Ham (1997) found that 74% (n = 20) of their sample had received no therapy training on the handling of their powered wheelchair. Sanderson et al (2000) identified that training in wheelchair use varied, with only 19% of voucher users receiving training and access to advice compared with over 90% of EPIOC users.

Whizz-Kidz, a national wheelchair charity, is currently investigating provision and training with the aim of improving statutory and voluntary services (Nicholson and Bonsall 2002). Whizz-Kidz will be working with the Disabled Living Centres Council, Disablement Services Centres, NHS wheelchair services, mobility equipment dealers, manufacturers and therapists to set up six specialist mobility centres for children and young people throughout England (Anon 2002). Its aim will be to offer impartial advice and information on paediatric mobility related issues for children and their families, and training workshops, information and advice for professionals and health workers. Fleming (2001) has reported on a proficiency training programme for children aged 5-18 years in receipt of a wheelchair and attending a mainstream school. The parents reported that their child had increased confidence and independence when using his or her chair.

The role of the wheelchair in mobility for children

For a child, a wheelchair is not just a mode of transport but a tool for an independent lifestyle (Santangelo and O'Reilly 1999). Beresford et al (2002) found that 33% of disabled children in a survey sample (n = 3000) needed a lot of help in moving about, either with the use of a self-propelled wheelchair or with a special buggy/wheelchair pushed by another person. Disabled children can show signs of frustration, reduced motivation and lack of confidence if deprived of early movement and opportunities to explore their environment (Nicholson and Bonsall 2002).

Recently, a change in the paediatric rehabilitation philosophy to meet the needs of children with physical disabilities and their families has been identified (Wiert and Darrah 2002). The shift encourages the therapist to consider strategies that alter the task and the environment rather than focusing on changing the child. This would mean that, instead of encouraging a child to walk as much as possible at school, the child would be encouraged to walk short distances within the classroom and use a powered wheelchair to move between classes. This would increase rather than limit the child's overall independent mobility and assist in conserving energy for learning. This change is in line with the most recent version of the International Classification of Functioning, Disability and Health (ICF) (WHO 2001). The ICF depicts human function as a result of the interaction between health conditions and various environmental or personal contextual factors and encourages consideration of facilitators and barriers to participation in society (Wiert and Darrah 2002).

An occupational therapist is a key assessor and prescriber of wheelchairs and other mobility equipment for children (Ham et al 1998). A recent survey of paediatric occupational therapists

(Howard 2002) identified that they provide an extensive range of services, including assessment for and provision of wheelchairs. It has been suggested that not allowing a child to engage in the same childhood occupations as his or her peers by limiting mobility goes against the enabling occupational focus of occupational therapy (Nicholson and Bonsall 2002). A child's independent mobility can facilitate the breadth of learning experiences and cognitive and psychosocial development (Wiat and Darrah 2002, Richardson 2002). Deitz et al (2002) found that for two young children with severe motor impairments and developmental delay, the use of a powered mobility device may have increased self-initiated movement during free play and may facilitate the transition to wheelchair use in the larger community.

Evans (2000) and Nicholson and Bonsall (2002) found that, through EPIOC use, occupation had been enhanced and that this might have had a positive effect on users' health. In particular, the respondents felt more able to experience life, expand their roles and take part in social activity. Frank et al (2000) and Sanderson et al (2000) found that the EPIOC initiative improved personal independence and quality of life for users and eased the burden on informal carers. However, they added that significant unmet need remained and that the choice of EPIOC was at times decided by the provider, with the user having little role in the decision. Bottos et al (2001) have suggested that powered mobility can enable children between 3 and 8 years with severe motor disabilities to become more active and autonomous participants in their own lives.

Meeting a child's total need has been noted as difficult, however, because a single wheelchair cannot be suitable for all purposes (White and Lemmer 1998). The dilemma would appear to be balancing functional and/or supportive seating capacity with robustness and usability (Cornwell and Kavanagh 1996, Freney 1997, Aldersea 1999). Aldersea (1999) has proposed that equipment suitable for independent mobility might not be appropriate for transport and that a compromise would need to be agreed. A powered wheelchair can require specialised transportation and pose difficulty with the accessibility of some environments (Wiat and Darrah 2002).

The Disability Discrimination Act (DDA) (1995) describes disability as a physical or mental impairment that has a substantial and long-term adverse effect on the ability to carry out normal daily activities, such as mobility (Nicholls 2001). The DDA outlined the powers to make employment, services, education, and public transport vehicles, such as new taxis, buses, coaches and trains, more accessible to and safer for disabled people. In order to use the intended greater participation as a consequence of the DDA, a person will require a means to move within his or her locality and get to public buildings (Cornwell and Kavanagh 1996, Madigan and Milner 1999). Limited access for wheelchair users due to physical barriers has been shown to be a limiting factor for young people entering a higher educational institution of their choice (Paul 1999).

Wheelchairs and seating for children

The National Prosthetic and Wheelchair Committee (COT 1996b) identified that 6% of wheelchair users registered with the NHS in England were aged 16 years and under, with a range within wheelchair services of 2% to 14% of users under 16 years (Aldersea 1999). The Audit Commission (2000) identified that 57,600 wheelchair users in the UK were under the age of 19 years.

All children who have limited mobility and severe postural problems should be assessed by a wheelchair service (Aldersea 1999). However, in the UK both manual and powered wheelchairs for

children are provided by a number of sources: the NHS, charities and private purchase (Turner 2001, Whizz-Kidz 2002). Appropriate seating and mobility equipment can result in energy conservation for the child, allowing enjoyment of other activities, such as independent mobility at school and, in the community, going shopping or to a park (Freney 1997, Wiart and Darrah 2002). A comprehensive assessment is central to this process and will lead to effective prescribing (Aldersea 1999, Turner 2001). However, assessing a child for mobility equipment, such as a wheelchair, is not the same as assessing an adult (Aldersea 1999, Amsterdam 1999, Turner 2001).

The assessment of a child must be child focused (DH 2000b) and coordinated across health, education and social services (Ball 1998, Strategy Group 2002). White and Lemmer (1998) have commented that differences in approaches to wheelchair assessment could lead to differences in wheelchair prescription. Jelier and Turner-Smith (1997) found that correct prescription from referral forms also depends on the training and knowledge of the prescribers. Face-to-face assessments enable the exchange of information between providers and users and are the preferred method of assessment by users (Jelier and Turner-Smith 1997). However, those people who received a therapist assessment before their wheelchair was issued experienced the longest delays in supply. Paediatric clients and people with complex needs generally have a face-to-face therapist assessment (White and Lemmer 1998).

Children's equipment poses additional challenges, because the equipment needs to encourage the development of skills and independence and, at the same time, to respond to growth and changes in body shape, in environment and in treatment plans (Freney 1997, Aldersea 1999). A young person frequently requires two chairs and seating systems rather than just one, particularly at times of repair or change of the child's circumstances due to growth or changes in treatment (Freney 1997, White and Lemmer 1998, Turner 2001).

A child's growth can also be a factor if time delays occur. Providers need to take this aspect of provision for children into account (Freney 1997, Aldersea 1999, Amsterdam 1999), because prolonged delays may mean that the equipment is no longer suitable when it is provided (DH 2001). The average waiting time for EPIOC assessment identified by Sanderson et al (2000) was 4-5 months; delivery was generally within 6-8 weeks, with the average time between referral and delivery being 6 months. Some participants commented that the wait was 'far too long' and 'ages' and that the process was 'unnecessarily long' (Sanderson et al 2000, p28).

When evaluating a child's needs, certain considerations have to be taken into account. Those include child, parent and therapist goals, growth, transportation safety, future needs, cost and parental concerns (Amsterdam 1999, DH 2000b). In addition, wheelchairs and seating systems need to be compatible with families' needs and transport arrangements because children up to school leaving age predominately live with their parents (White and Lemmer 1998).

For a family, appearance is often the priority (Aldersea 1999). Aldersea (1999) found that the chair needs to look good as well as fulfilling the child's mobility and postural needs and that striking this balance can lead to requests for equipment that is unavailable through the NHS. The need for aesthetically appealing wheelchairs has been recognised by manufacturers and they are working to address the paucity of equipment available in the UK (Turner 2001).

Manual wheelchairs can be difficult to propel for some users and, therefore, alternatives such as powered outdoor chairs, scooters and buggies also need to be available (Kelsall 1996). Users and carers are expecting and demanding an increase in the range of provision, with requests for a greater availability of lightweight, high performance chairs, special buggies and powered outdoor wheelchairs to enhance the quality of life of the user and fulfil the needs of carers (White and Lemmer 1998, Turner 2001).

During the course of a day, children can access a variety of environments, such as home, community and school (Aldersea 1999) and, as they get older, higher education (Paul 1999). Standards to provide better and safer transportation for children in wheelchairs have been identified as crucial (Schneider 1998). A recent Device Bulletin (Medical Devices Agency 2001) considered the issues of safe transportation of wheelchairs and regarded it as the responsibility of all: user, carer, health services and health care professionals.

The provision of mobility equipment and seating for children is complex. Satisfaction and success have been shown to be dependent on the combination of good assessment and appropriate training and information for all who handle the equipment (Aldersea 1999, Medical Devices Agency 2001). Equity in provision is dependent not just on the skills of the prescribing therapist but also on the operational policies of the individual wheelchair service (White and Lemmer 1998, Audit Commission 2000).

Met and unmet need

The timely provision of equipment is a crucial factor. Younger users are often severely disabled and the failure to supply appropriate equipment could result in severe deformities in later life (Audit Commission 2000). Kersten et al (2000) suggested that the high prevalence of unmet need of disabled people who were already in touch with community rehabilitation services raised concern. They commented that wheelchairs might enable people to be more independent and fulfilled. Fairhurst (2002) has proposed that as movement plays a major part in experiential learning, restricted mobility in early childhood could result in a passive and dependent adult.

Sanderson et al (2000) concluded that there were a considerable number of wheelchair users and their carers that would benefit from either an EPIOC or an electrically powered outdoor chair provided through additional funding; without additional funding, the EPIOC scheme could not meet its objectives fully.

Conclusion

The main issues for children and young people appear to be the type and choice of equipment available, the style of assessment, time delays in provision, user and carer training and the knowledge and information of the wheelchair service facilities (Whizz-Kidz 2002). The Audit Commission (2000) stated that wheelchair services can be improved and need to be more responsive to users' views, despite budgetary pressures.

A project to consider the social implications of increases in wheelchair use is being undertaken (Sapey et al 2000). However, further study is required to explore the views of children and young

people and that of their parents and/or carers on the assessment for and provision of wheelchairs, involving wheelchair service providers and wheelchair and primary care therapists.

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