Recipients of Electric Powered Indoor/outdoor Wheelchairs (EPIOCs) provided by a National Health Service: a cross sectional study

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Initially presented as an abstract to the 4th International Interdisciplinary Conference on Posture and Mobility, June 7-9 2010, Glasgow, UK.

We did not receive any funding for this study

Acknowledgements: Mike Pugh for technical assistance with identifying those with tilt-in-space wheelchairs and commenting on engineering aspects of this paper.

We certify that no party having a direct interest in the results of the research supporting this article has or will confer a benefit on us or on any organization with which we are associated and we certify that all financial and material support for this research and work are clearly identified in the title page.

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Abstract

Objective: To describe the characteristics, across all ages, of powered wheelchair users and the assistive technology prescribed by a regional specialist wheelchair service

Design: Cross-sectional study

Setting: Regional wheelchair service provided to those fulfilling strict eligibility criteria by a National Health Service serving a population of 3 million.

Participants: 544 Electric Powered Indoor/outdoor wheelchair (EPIOC) users.

Interventions: Not applicable

Main Outcome Measures: Demographic, clinical/diagnostic details of EPIOC recipients including pain, (kypho)scoliosis and ventilators. Technical features including specialised (adaptive) seating (SS), tilt in space (TIS), and modified control systems. Factors were related to age groups: 1 (0-15), 2 (16-24), 3 (25-54), 4 (55-74) and 5 (75+).

Results: 262 men mean age 41.7 (range 8-82, sd 20.7) and 282 women mean age 47.2 (range 7-92, sd 19.7) years were studied. Neurological/neuromuscular conditions predominated (81%) with cerebral palsy (CP) (18.9%) and multiple sclerosis (16.4%). Conditions presenting at birth or during childhood constituted 39%. 99 had problematic pain, 83 a (kypho)scoliosis and 11 used ventilators.

SS was provided to 169 users (31%), the majority had CP or muscular dystrophy. TIS was used by 258 (53%). Younger people were more likely to receive TIS than older ones. Only 92 had SS and TIS, mean age 29 (range 8-72, sd 17.8) years. 52 used modified control systems.

Discussion: The diversity of EPIOC users across age and diagnostic groups is shown. Their complex interrelationships with these technical features of EPIOC prescription are explored. Younger users were more complex due to age-related changes.

Conclusions: This study provides outcomes of the EPIOC prescription for this heterogeneous group of very severely disabled people.

Keywords: assistive technology; powered wheelchairs; age; specialised seating; adaptive seating; tilt-in-space

Abbreviations

AT	Assistive technology
CP	Cerebral Palsy
CVD	Cerebrovascular Disease
EPIOC(s)	Electric powered indoor/outdoor wheelchair(s)
MD	Muscular Dystrophy
MS	Multiple Sclerosis
NNC	Neurological or neuromuscular conditions
NHS	National Health Service
PM	Powered mobility
RA	Rheumatoid Arthritis
SB	Spina Bifida
SCI	Spinal Cord Injury
SS	Specialised seating
TIS	Tilt-in-space
UK	United Kingdom

The benefits of powered mobility (PM) for people with severe disabilities are now better understood. By using powered wheelchairs, individuals can experience greater participation in activities such as education[1-4] or work[1-3,5], and a range of social activities such as shopping[1-3;6;7;7;8], church going[1;2;6;9], socialising with family and friends[1;2;6;9;10] and accessing healthcare facilities[2;6;9;11]. In addition, the increased mobility provided by PM enhances quality of life and wellbeing[5;10;12]. Benefits to carers have also been reported[2;5;9;11]. However, it has been noted that there are problems associated with powered mobility (PM). For some wheelchair users (referred to as users), pain and discomfort remain problematic[1;13;14] as do difficulties with transport[5;9] and equipment breakdown or accidents[1;2;15]. Nonetheless, successful community dwelling and interaction involves activities that are dependent on a successful PM prescription minimising immobility. Studies generally have involved small numbers of users and are usually exploratory in nature, an issue also identified in the review of Greer et al[16].

Recently, gaps have been identified and recommendations made for future studies to strengthen the evidence base. Research suggestions are to include people with different physical limitations, needs and goals[16]. Lack of standardisation of service delivery in the published literature is perceived as a problem to improving practice and understanding who might benefit from PM. Such information is needed to develop standards and guidelines[16], and to identify groups of users who would justify additional expense, an issue of concern for policy makers and payers[16].

There is a need to capture data from greater numbers representative of the population of wheelchair users[17]. Whilst such populations have been described[18], the diagnoses, age and gender of a large and specific population of powered wheelchair users is lacking. Objectively verified data are needed for these factors as declarative data gathered through self-report

surveys have been criticized for biases[18]. Descriptive studies are needed to identify the issues important to effective matching of severely disabled users who have complex needs with appropriate PM.

In 1996 the United Kingdom (UK) government directed the National Health Service (NHS) to provide electric powered indoor/outdoor wheelchairs (EPIOCs) to people with severe and complex disabilities who fulfilled strict criteria, fully funded by the government[2]. In essence those unable to walk around their home unaided, unable to self propel and able to utilise the chair independently are eligible. They are similar to those required by Medicare [19] .The EPIOC provided is based on functional need and the potential benefit. Scooters are not provided by the NHS. Users may choose to take the value of the prescribed EPIOC in vouchers and purchase a chair privately[20].

A Specialist Wheelchair Service was set up in 1997 to provide EPIOCs for a geographical region spreading from inner London, the north west suburbs and rural Home Counties. This area comprised 11 health primary care trusts serving a population of approximately three million.

This cross-sectional study aims to describe the clinical characteristics and assistive technology (AT) prescribed across the age span of users of a fleet of EPIOCs at a given time, as suggested by Karmakar et al[7]. We studied a large group of community-dwelling EPIOC users who by definition are the most severely mobility disabled people. This contrasts with studies that include those able to use scooters[6;17] or are able to walk indoors[6]. Furthermore, these studies did not include any clinical assessment by health professionals. The study by Karmarkar et al[7], although including assessment by a sophisticated multiprofessional rehabilitation team, was limited to older users.

Methods

Potential users were referred from locally based NHS wheelchair services. Clinic records including assessment and wheelchair equipment of those provided with an EPIOC, and still using it, were reviewed in June 2007 and data were extracted. Average time from the initial assessment in clinic to the case note review was 72.4 (range 0-1166, sd 73.2) months.

The data relevant to this study had been recorded by health professionals following a physical examination and assessment and consisted of:-

Demographic data

- age at initial assessment
- gender

Medical factors

- Major diagnosis contributing to the need for a wheelchair as described previously[2] but with the addition of a category for inherited metabolic conditions.
- Ventilator issues
- Problematic pain – that needed intervention(s).
- (Kypho)scoliosis

Users with multiple sclerosis (MS), cerebral palsy (CP), muscular dystrophy (MD), cerebrovascular disease (CVD), other neurological conditions, spina bifida (SB), spinal cord injury (SCI) and polio were grouped together as having neurological or neuromuscular conditions (NNCs).

Wheelchair factors

- Specialised seating (SS) – that which is needed by people who require a wheelchair but due to instability or deformity need additional support in order to function[21], (similar to that of adaptive seating[22])
- Tilt-in-space (TIS)
- Complex controls e.g. central joystick / tray mounted controls, head controls, switch controls, non-standard control system, interfacing with other assistive technology

Methods of analysis

Users were grouped by age according to the categories published by Warren[23]. We added one further category, 'under 16 years of age' (school children). These will be referred to as: Group 1 (0-15 schoolchildren); Group 2 (16-24 school leavers and young people); Group 3 (25-54 those developing families, jobs and careers); Group 4 (55-74 those reaching the end of employment and in active retirement); Group 5 (75 and older).

Age group data were analysed to describe proportions and frequencies of variables to determine the range and pattern of the wheelchair and medical factors recorded.

T-tests were used with ratio and interval data to determine significant differences between sub-groups.

This study was approved by the National Research Ethics Service.

Results

The sample consisted of 544 users mean age 44.6 (range 7-92, sd 20.4), 262 men mean age 41.7 (range 8-82, sd 20.7) and 282 women mean age 47.2 (range 7-92, sd 19.7) years (Table 1). One hundred and fifty seven were over 60. Ten users were aged 80+ and one was aged 92.

All but 2 children were over 10 years old at assessment. There were more males in Groups 1 and 2 and more females in Groups 3-5. Males were significantly younger than females ($p < 0.002$ Two-tailed T-test).

The largest diagnostic categories (Table 2) were CP (18.8%) and MS (16.5%). Males had conditions like MD and were younger whilst women had conditions such as MS and rheumatoid arthritis (RA) and were older. Three women were noted to have had a child whilst using an EPIOC. MS, CVD, RA, SCI, polio and amputation were not seen in Groups 1 and 2. Conversely, those with CP, MD, SB and amputation were not seen in Group 5. Of those users with known diagnoses (n=542), 438 (81%) had neurological or NNC and 155 (29%) had the progressive conditions of MS and MD. Diagnoses associated with childhood (CP, MD, SB and inherited/metabolic conditions) constituted 39% (n=212) of the cohort.

Problematic pain was reported by 56 women and 43 men (18%) of the 544 users. There was no significant difference in age of those with or without problematic pain. Seventy six (77%) users reporting pain had NNC.

Eighty three (15%) had scoliosis, kyphus or both. Of the 83 users with a (kypho)scoliosis, 53 (64%) were provided with a TIS and 60 (72%) with SS. Forty one (49%) of those with scoliosis had CP or MD. The majority were in Groups 2 and 3 (n=52; 63%).

Equipment

One hundred and sixty nine users (31%) were provided with SS (Table 3), with 99 (59%) provided to users with CP and MD. Despite the large number with MS, only 15 (9%) needed SS. Of 169 users with SS, 100 (59%) were in Groups 1 and 2. There were no statistically significant differences in the ages of those with or without SS. There were wide differences in diagnoses of users requiring SS. The majority of those with CP (n=64, 63%), and MD (n=35,

54%) had SS whilst only one of 58 users with musculoskeletal conditions had SS (68 year old with obesity, severe cellulitis of legs and osteoarthritis of knees).

Information on TIS was available from 489 (90%) of which 260 (53%) EPIOCs had this feature (Table 4). Users with TIS were significantly younger (mean 42.3, sd 21.1 years) than those without (mean 47.3, sd 19.3 years) ($P<0.01$). For those with MD, 65% were provided with TIS.

Of those using TIS, only 92 had SS, mean age 29 (range 8-72, sd 17.8) years. They were not significantly different in age to those without SS (N=168) (mean 49.7, range 11-87, sd 19.2 years). Eighty one (88%) users with both TIS and SS had NNC. Another notable group, although small, were those with inherited metabolic conditions where eight users had both TIS and SS.

Complex control systems

Fifty two (10%) users mean age 29 (range 10-69, sd 16 years) needed individualised adaptations to their control system. The commonest was tray-mounted controls provided to 32(6%) users, predominately people with MD (n=14, mean age 20, range 11-33 years) and CP (n=11, mean age 27, range 16-48 years). Groups 1 and 2 accounted for 62% of users with complex controls. Other approaches were light touch controls, head, chin and/or foot controls, non-standard switches, interfaces with other assistive technology and personal equipment (e.g. computers), different shaped control knobs and combinations of these features.

Of the 52 provided with complex control systems, 35 (67%) had SS and 28(54%) had TIS. Nineteen (37%) had both SS and TIS and their diagnoses were CP (n=6), MD (n=9) and other (n=4). Thirty two of the 35 users with complex controls systems and SS had NNC.

Ventilators

Eleven (seven male) users (mean age 39.6 range 17-72, sd 21.8 years) required their wheelchair to accommodate their ventilation system including oxygen. Four had MD (including one man who worked part time), and others included motor neurone disease, Charcot-Marie-Tooth Disease, chronic obstructive airways disease, SCI, spinal muscular atrophy, severe spinal pain (following vertebral fractures due to osteoporosis secondary to Cushing's syndrome) and Morquio's Disease. Nine users with ventilation required TIS.

These findings show that EPIOC users are a heterogeneous group in terms of diagnoses and the age at which a powered chair is provided. Younger groups require more complex equipment than older groups. The most complex cases had NNC.

Discussion

This is the first study, to our knowledge, describing a large cross-sectional cohort of users of a fleet of EPIOCs at a given time. Its uniqueness relates to consistent use of stringent eligibility criteria for EPIOC provision and users coming from a defined catchment area embracing inner city, suburban and country areas. Our results demonstrate the diversity of EPIOC users across the age range and diagnoses. Noteworthy are the inclusion of individuals with rare diagnoses, mostly inherited metabolic conditions, not previously reported in cohorts of users studied over limited periods of time[2;12;17;24].

The findings bring together the objective data on the main technical considerations of EPIOC provision (SS, TIS and modified control systems) with the clinical information. This service was unusual as it had consultant physician support, as recommended[16]. This facilitated a more rigorous examination of medical issues and symptoms such as pain were identified and interventions initiated. This needs-led approach characterises the relationship between

clinical features and EPIOC provision and may help to identify who would benefit from different features of PM irrespective of the nature of payers[16]. Our results contribute to current evidence by identifying the appropriate PM that is likely to meet the needs of this diverse group.

There is no definitive or reliable data about the number of EPIOCS currently provided in the UK (Krys Jarvis, National Wheelchair Managers Forum - personal communication dated 12 July 2012). Data from Tayside in Scotland indicates that Tayside had about twice the number of EPIOCs provided per population. It seems likely that the North West London region under provided EPIOCs as it provided 151 by December 1998 compared to 271 provided by the Northern Region of England during the same period for a roughly equivalent sized population.

Group 1(0-15 years),

In the UK, children under 11 years are more likely to be in one classroom for most of their lessons, whilst older children have an increased mobility requirement to move between teaching rooms and laboratories at secondary school. This probably explains the age range of this cohort. Whilst some children will have been provided with PM[1] by charities e.g. Whizz-Kidz , others may have had unmet needs. It is noteworthy that Whizz-Kidz changed their priorities for use of their funds after the provision of EPIOCs by the NHS. After EPIOC provision, Whizz-Kidz only funded PM for those who had not been provided with an EPIOC e.g. because of severe learning difficulties which precluded them from acquiring age-appropriate independent use. Recently, the Wheelchair Service arranged with a children's charity to meet the capital and maintenance costs of functions not provided by the NHS[20].

Recent recommendations emphasize the importance of motor and cognitive skills development and the ability to explore the environment as reasons for powered mobility being provided for very young children (aged 12-13 months onwards)[25-27]. In addition, early introduction of an EPIOC allows children and families to plan for future environmental adaptations and make proactive choices for housing and vehicles[27]. Consequently these issues need further publicity throughout the UK.

This study shows that this group is dominated by those with CP and MD requiring SS reflecting the development of scoliosis (with/without kyphus) during teenage years[21;28;29]. Tilt and recline functions are also indicated in this Group who are susceptible to hip and other joint contractures[30] and require pain and pressure relief[13;29;30]. EPIOCs provided for these children and those starting work are reported to facilitate greater functional mobility and to conserve energy for the physical demands of the workplace or college[31]. This has implications for payers or service commissioners as more chair functions will increase costs, in addition to the chair replacement costs consequent to user growth.

Group 2

EPIOC users in Group 2 (school leavers and young adults) may be seeking further education or their first employment. The majority of this group are users with CP and MD and our data indicate they are likely to need TIS and SS. Groups 1 and 2 account for 61% of users needing complex control systems, significantly improving an individual's performance[32]. This has clear advantages for young adults entering further training or work[5].

Access to assisted mobility for young people aged 15-24 is crucial to successful transition from childhood to adulthood[33]. Research in young adults with SB has highlighted that under-use of AT may delay successful transition to independent living and community participation[34]. Developing social and sexual relationships is a vital part of transition to

adulthood. The independence provided by an EPIOC facilitates social activities leading to relationships[1].

Group 3

Group 3 (those developing families, jobs and careers) had the largest number of EPIOC users (35%) reflecting conditions such as MS, CVD and RA. This group appears poorly represented in the literature and less is known about their needs when compared to young and old. Middle aged users are often grouped with older users in the literature[35], despite having very different lifestyles and economic roles in society. Being neither children nor elderly, their specific needs are seldom addressed.

Our findings demonstrate the provision of SS is low but with substantial numbers of users with MS and SCI, it is possible that they have residual motor functions sufficient to accommodate postural adjustments and movement in the chair and thus not need SS. Furthermore, acquired impairments in adult life are unlikely to give rise to a scoliosis. As TIS has become more available on EPIOCs (and less expensive), it may be prescribed more frequently, offering greater comfort[13], improved pressure relief[36] and relieving fatigue in conditions like MS.

Individuals in this Group may be developing their families and EPIOC provision would need to accommodate demands of parenthood. Although the literature has begun to explore the issues of parenthood for some of the major diagnosis found in our data, e.g. MS[37], SB[38], and SCI[39;40] we will also need more study of this issue for people with CP and MD as they live longer and may have expectations to become parents and to participate in child care these issues need addressing. The three mothers reported in our group are likely to be an underestimate as our study did not explore social and family issues.

As 10% of EPIOC users contribute to the working population[5], difficulties travelling to work and appropriate job modifications require consideration during assessment[41].

Group 4

This group (those reaching the end of employment and in active retirement) constitutes one third of this cohort and is dominated by those with MS and SCI. The small proportion with SS is consistent with the findings of Karmarkar et al[7] who reported that older users were less likely to receive customised wheelchairs than their younger peers. This reflects the needs of users with predominantly acquired impairments with a reduced expectation of spinal deformity or limb contractures. Those ageing with probable comorbidities may need PM, particularly if their carer has age-related problems[9].

With 177 EPIOC users in Group 4 there will be a continuing demand for powered mobility with increasing age. In our experience, EPIOC withdrawal was unusual unless a user's condition deteriorated, although this did occur episodically.

Group 5

This group (aged 75+) comprised the elderly with severely disabling condition(s). However, by meeting the assessment criteria[2], they had potential for increased mobility and independence, suggesting those over 75 years (even up to age 92) should not be discounted from access to PM. Scandinavian data show important differences in use between older users aged between 65-76 and those aged between 77-92, indicating changing age-related needs (Brandt A. Paper read to the Canwheel conference, Toronto, 2011). Our results indicate no EPIOC users with CP, MD or inherited metabolic disorders in this age group in contrast to those in Groups 1-4. With improved life expectancy for those with illnesses presenting in

childhood e.g. some muscular dystrophies[42] there will be increases in the demand for PM as those in group 4 mature into group 5.

Elderly people in the community do not commonly use high technology[8]. However, they are likely to demand wheelchair technologies[43] to overcome social isolation, loneliness, decreased autonomy and loss of dignity . EPIOC provision contributes to active ageing, with increased activities, participation and community inclusion[6;9;11].

Study limitations

This study excludes users who bought wheelchairs privately. Our data did not record those who did not meet the criteria for provision, nor those who may have been eligible but were not referred.

As data were extracted from medical records that were designed for clinical use and not for research purposes, we experienced a small amount of missing information, an issue previously encountered by Karmarkar et al[7]. However, all data were extracted by the first author in a systematic manner.

We did not gather data on participation, or on parenthood which would have provided a more complete picture of the 554 EPIOC users. However, this information has been published for subgroups drawn from this population[1;9;11;12;29]. These studies demonstrated the limitations of NHS provision as well as considerable benefits to users and were most marked in the muscular dystrophy user group[29]. However, the data presented in this study represents the most appropriate EPIOC prescription that met the needs of each individual user according to the eligibility criteria – a limitation of the service.

The data represents a cross-sectional survey at a particular time which may limit generalisability to other powered wheelchair populations. Service reorganisation prevented further follow up to evaluate benefits.

Conclusions

Those with congenital and inherited conditions account for almost 40% of the cohort. Due to the increased longevity of those with these conditions, our findings should inform future planning for payers of powered wheelchair services. These data confirm the increasing use of newer functions on powered wheelchairs (e.g. TIS). These features have associated additional costs and are provided predominantly to younger users, as is SS. This study provides outcomes of the EPIOC prescription for this heterogeneous group of very severely disabled people.

Reference List

(1) Evans S, Neophytou C, De Souza LH, Frank AO. Young people's experiences using electric powered indoor-outdoor wheelchairs (EPIOCs): potential for enhancing users' development? Disabil Rehabil 2007; 19(16):1281-1294.

(2) Frank AO, Ward JH, Orwell NJ, McCullagh C, Belcher M. Introduction of the new NHS Electric Powered Indoor/outdoor Chair (EPIOC) service: benefits, risks and implications for prescribers. Clin Rehabil 2000; 14(December):665-673.

(3) Giesbrecht EM, Ripat JD, Quanbury AO, Cooper JE. Participation in community-based activities of daily living: comparison of a pushrim-activated, power-assisted wheelchair and a power wheelchair. Disabil Rehabil Assist Technol 2009; 4(3):198-207.

(4) Ward AL, Brooks BR, Holsten SE, Bravver EK. Multidisciplinary quality care after the power wheelchair delivery: Changes required over time. Amyotroph Lateral Scler 2012; 13:149-149

(5) Sanderson D, Place M, Wright D. Evaluation of the Powered Wheelchair and Voucher Scheme Initiatives for the NHS Executive and the Department of Health. 1-72. 2000. York, Health Economics Consortium, University of York.

(6) Brandt A, Iwarsson S, Stahle A. Older people's use of powered wheelchairs for activity and participation. J Rehabil Med 2004; 36:70-77.

(7) Karmarkar AM, Dicianno BE, Graham JE, Cooper R, Kelleher A, Cooper RA. Factors associated with provision of wheelchairs in older adults. Assist Technol 2012; 24(3):155-167.

(8) Lofqvist C, Pettersson C, Iwarsson S, Brandt A. Mobility and mobility-related participation outcomes of powered wheelchair and scooter interventions after 4-months and 1-year use. Disabil Rehabil Assist Technol 2012; 7(3):211-218.

(9) Frank AO, Neophytou C, Frank J, De Souza LH. Electric Powered Indoor/outdoor Wheelchairs (EPIOCs): users views of influence on family, friends and carers. Disabil Rehabil Assist Technol 2010; 5(5):327-338.

(10) May M, Rugg S. Electrically powered indoor/outdoor wheelchairs: recipients views of their effects on occupational performance and quality of life. Br J Occup Ther 2010; 73(1):2-12.

(11) Evans S, Frank A, Neophytou C, De Souza LH. Older adults' use of, and satisfaction with, electric powered indoor /outdoor wheelchairs. Age and Ageing 2007; 36(4):431-435.

(12) Davies A, De Souza LH, Frank AO. Changes in the quality of life in severely disabled people following provision of powered indoor/outdoor chairs. Disabil Rehabil 2003; 25(6):286-290.

(13) Frank AO, De Souza LH, Frank JL, Neophytou C. The pain experiences of powered wheelchair users. Disabil Rehabil 2012; 34(9):770-778.

(14) Gibson J, Frank A. Pain experienced by electric-powered chair users: a pilot exploration using pain drawings. Physiother Res Int 2005; 10(2):110-115.

(15) Kirby RL, Ackroyd-Stolarz SA. Wheelchair safety - adverse reports to the United States Food and Drug Administration. Am J Phys Med Rehabil 1995; 74(4):308-312.

(16) Greer N, Brasure M, Wilt TJ. Wheeled mobility (wheelchair) service delivery: scope of the evidence. Ann Intern Med 2012; 156(2):141-146

(17) Fitzgerald SG, Kelleher A, Teodorski E, Collins DM, Boninger M, Cooper RA. The development of a nationwide registry of wheelchair users. Disabil Rehabil Assist Technol 2007; 2(6):358-366.

(18) Vignier N, Ravaud JF, Winance M, Lepoutre FX, Ville I. Demographics of wheelchair users in France: Results of national community-based handicaps-incapacites-dependance surveys. J Rehabil Med 2008; 40(3):231-239.

(19) Medicare. Electric Wheelchairs. http://www.medicare.com/equipment-and-supplies/electric-wheelchairs.html http://www.medicare.com/equipment-and-supplies/mobility/electric-wheelchairs.html - 22-05-13, 1-2. 2013. Medicare.com.

(20) Frank AO, Ellis K, Yates M. Use of the voucher scheme for provision of Electric Powered Indoor/outdoor Wheelchairs (EPIOCs). Posture & Mobility 2008; 23(1):17-26.

(21) British Society of Rehabilitation Medicine. Specialised wheelchair seating national clinical guidelines. Report of a multidisciplinary expert group (Chair: Marks, LJ). 1-39. 2004. London, British Society of Rehabilitation Medicine.

(22) Washington K, Deitz JC, White OR, Schwartz IS. The effects of a contoured foam seat on postural alignment and upper-extremity function in infants with neuromotor impairments. Phys Ther 2002; 82(11):1064-1076.

(23) Warren M. The prevalence of disability. J Roy Coll Phys of London 1989; 23(3):171-175.

(24) Cooper E, Fyfe N. The provision of powered wheelchairs: one year on. Brit J Ther Rehabil 1998; 5(6):280-281.

(25) Arva J, Furumasu J, Harris M, Lange ML, McCarthy E, Kermoian R et al. RESNA position on the application of power wheelchairs for pediatric users. 2008. Arlington, VA, USA, Rehabilitation Engineering & Assistive Technology Society of North America (RESNA).

(26) Rodby-Bousquet E, Hagglund G. Use of manual and powered wheelchair in children with cerebral palsy: a cross-sectional study. BMC Pediat 2010; 10. http://www.biomedcentral.com/1471-2431/10/59

(27) Wiart L, Darrah J, Hollis V, Cook A, May L. Mothers' perceptions of their children's use of powered mobility. Phys Occup Ther Pediatr 2004; 24(4):3-21.

(28) Lord J, Behrman B, Varzos N, Cooper D, Lieberman JS, Fowler WM. Scoliosis associated with Duchenne Muscular Dystrophy. Arch Phys Med Rehabil 1990; 71(1):13-17.

(29) Richardson M, Frank AO. Electric powered wheelchairs for those with muscular dystrophy: problems of posture, pain and deformity. Disabil Rehabil Assist Technol 2009; 4(3):181-188.

(30) Muscular Dystrophy Campaign. Wheelchair provision for children and adults with muscular dystrophy and other neuromuscular conditions: best practice guidelines. First ed. London: Muscular Dystrophy Campaign; 2006.

(31) Murphy KP, Molnar GE, Lankasky K. Employment and social issues in adults with cerebral palsy. Arch Phys Med Rehabil 2000; 81(6):807-811.

(32) Dicianno BE, Cooper RA, Coltellaro J. Joystick control for powered mobility: Current state of technology and future directions. Phys Med Rehabil Clin N Am 2010; 21(1):79-86.

(33) Lindsay S, Tsybina I. Predictors of unmet needs for communication and mobility assistive devices among youth with a disability: the role of socio-cultural factors. Disabil Rehabil Assist Technol 2011; 6(1):10-21.

(34) Johnson KL, Dudgeon B, Kuehn C, Walker W. Assistive technology use among adolescents and young adults with spina bifida. Am J Public Health 2007; 97(2):330-336.

(35) Auger C, Demers L, Gelinas I, Jutai J, Fuhrer MJ, DeRuyter F. Powered mobility for middle-aged and older adults: systematic review of outcomes and appraisal of published evidence. Am J Phys Med Rehabil 2008; 87(8):666-680.

(36) Sonenblum E, Sprigle S. Distinct tilting behaviours with power tilt-in-space systems. Disabil Rehabil Assist Technol 2011; 6(6):526-535.

(37) Burnfield AJ. Sex, pregnancy and children. In: Burnfield AJ, editor. Multiple Sclerosis: a personal exploration. 1 ed. London: Souvenir Press (Educational and Academic) Ltd; 1985. 106-124.

(38) West C, Brodie L, Dicker J, Steinbeck K. Development of health support services for adults with spina bifida. Disabil Rehabil 2011; 33(23-24):2381-2388.

(39) Albright KJ, Duggan CH, Rahman RO. Motherhood in the context of spinal cord injury. Top Spinal Cord Inj Rehabil 2009; 15(1):43-58.

(40) Westgren N, Levi R. Motherhood after traumatic spinal cord injury. Paraplegia 1994; 32(8):517-523.

(41) Arthanat S, Strobel W. Wheelchair ergonomics: implications for vocational participation. J Vocat Rehabil 2006; 24(2):97-109.

(42) Kenneson A, Vatave A, Finkel R. Widening gap in age at muscular dystrophy-associated death between blacks and whites, 1986-2005. Neurol 2010; 75(11):982-989.

(43) Cooper RA, Cooper R, Boninger M. Trends and issues in wheelchair technologies. Assist Technol 2008; 20(2):61-73.

Table 1. Age and Sex of 544 EPIOC users

	Age Group 1 (0-15y)		Age Group 2 (16-24y)		Age Group 3 (25-54y)		Age Group 4 (55-74y)		Age Group 5 (75+y)		Total	
	N	mean (±sd)	N	mean (±sd)	N	mean (±sd)	N	mean (±sd)	N	mean (±sd)	N	mean (±sd)
Men	31	12.8(1.9)	54	20.3(2.4)	85	40.7(8.7)	79	62.7(5.2)	13	78.5(2.3)	262	41.7(20.7)
Women	14	12.6(2.3)	45	20.2(2.4)	106	42.3(8.1)	98	63.6(5.7)	19	79.6(4.7)	282	47.2(19.7)
Total	45	12.8(2.0)	99	20.3(2.4)	191	41.6(8.4)	177	63.2(5.5)	32	79.2(3.9)	544	44.6 (20.4)

Table 2. Diagnoses and age groups of 544 (with % male) users of EPIOCs.

Diagnosis	Age Group 1		Age Group 2		Age Group 3		Age Group 4		Age Group 5		Total	
	N	%M	N	%M	N	%M	N	%M	N	%M	%M	N
Multiple Sclerosis	0		0		30	37	52	27	8	38	31	90
Cerebral Palsy	11	73	46	41	38	47	7	43	0		47	102
Muscular Dystrophy	21	86	25	88	16	50	3	100	0		78	65
Cerebrovascular Disease	0		0		9	33	18	61	5	60	53	32
Rheumatoid Arthritis	0		0		5	40	12	33	2	50	37	19
Other Musculo-skeletal	0		1	0	10	10	19	58	9	22	36	39
Other Neurological	6	50	9	44	23	57	19	42	3	33	48	60
Spina Bifida	1	0	3	33	10	20	3	33	0		24	17
Spinal Cord Injury	0		0		30	63	25	60	2	50	61	57
Polio	0		0		5	40	9	33	1	100	40	15
Amputation	0		0		0		6	67	0		67	6
Mixed impairments	0		2	50	4	25	1	100	1	0	38	8
Other	0		0		1	0	1	100	1	100	66	3
Not known	0		1	0	1	0	0		0		0	2
Inherited/metabolic	6	33	12	58	9	56	2	0	0		48	29
Total	45	69	99	54	191	45	177	79	32	41	48	544

Key: M = Male; N = Number; Age Group 1 = 0-15 years; Age Group 2 = 16-24 years; Age Group 3 =25-54 years; Age Group 4 = 55-74 years; Age Group 5 = over 75 years

Table 3. Provision of specialised seating (%SS) for 544 EPIOC users according to their age and diagnosis.

Diagnosis	Age Group 1		Age Group 2		Age Group 3		Age Group 4		Age Group 5		Total	
	N	% SS	N	%SS	N	% SS	N	%SS	N	%SS	N	%SS
Multiple Sclerosis	0		0		30	13	52	19	8	13	90	17
Cerebral Palsy	11	100	46	78	38	40	7	27	0		102	63
Muscular Dystrophy	21	71	25	64	16	25	3		0		65	54
Cerebrovascular Disease	0		0		9	11	18	6	5		32	6
Rheumatoid Arthritis	0		0		5		12		2		19	
Other Musculo-skeletal	0		1		10		19	5	9		39	3
Other Neurological	6	67	9	44	23	35	19	5	3		60	28
Spina Bifida	1	100	3	67	10	30	3	67	0		17	47
Spinal Cord Injury	0		0		30	23	25	12	2		57	18
Polio	0		0		5		9	33	1		15	20
Amputation	0		0		0		6		0		6	
Mixed impairments	0		2	100	4		1		1		8	75
Other	0		0		1		1		1		3	
Not known	0		1		1		0		0		2	
Inherited/metabolic	6	50	12	50	9	33	2		0		29	41
Total	45	76	99	67	191	24	177	13	32	3	544	31

Key: N=number; For Age Groups 1-5, see Table 2 key

Table 4. Provision of Tilt-in-Space feature (%TIS) for 489 EPIOC users according to their age group and diagnosis.

Diagnosis	Age Group 1		Age Group 2		Age Group 3		Age Group 4		Age Group 5		**Total**	
	N	%TIS	N	%TIS	N	%TIS	N	%TIS	N	%TIS	N	%TIS
Multiple Sclerosis	0		0		27	41	47	53	7	43	81	49
Cerebral Palsy	11	73	36	50	36	56	7	71	0		90	57
Muscular Dystrophy	21	67	20	75	16	56	3	33	0		60	65
Cerebrovascular Disease	0		0		8	38	14	50	5	60	27	48
Rheumatoid Arthritis	0		0		5	20	11	46	2	0	18	33
Other Musculo-skeletal	0		1	100	7	86	18	33	7	27	33	46
Other Neurological	5	60	9	44	20	65	17	59	2	50	53	58
Spina Bifida	1	100	3	33	10	40	3	33	0		17	41
Spinal Cord Injury	0		0		27	41	21	48	2	50	50	44
Polio	0		0		4	75	9	44	1	100	14	57
Amputation	0		0		0		6	50	0		6	50
Mixed impairments	0		2	100	4	50	1	0	1	100	8	63
Other	0		0		1	0	1	0	1	100	3	33
Not known	0		0		1	0	0		0		1	0
Inherited/metabolic	5	60	12	83	9	67	2	50	0		28	71
Total	43	67	82	61	175	60	160	49	28	46	489	53

Key: N= number; For Age Groups 1-5, see table 2 key.