PRIORITIZING WHEELCHAIR SERVICES: A PILOT DISCRETE CHOICE EXPERIMENT TO UNDERSTAND HOW YOUNG WHEELCHAIR USERS AND THEIR PARENTS PRIORITIZE DIFFERENT ATTRIBUTES OF WHEELCHAIR SERVICES

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ABSTRACT

Wheelchairs for disabled children (≤18 years) can provide health, developmental and social benefits, however not all children have access to the right equipment at the right time. State wheelchair services are provided by the National Health Service in the UK. Discrete choice experiments are a tool used by health economists to understand how individuals prioritize different attributes of healthcare services and treatments. We conducted the first pilot discrete choice experiment to explore how young disabled people and their parents prioritize different aspects of wheelchair services. A total of 29 parents and 11 children with mobility impairments were recruited. Analysis is currently ongoing (planned completion by April 2014). This paper outlines the background to the study and the methods utilized. We anticipate the results will be used to guide future development of wheelchair services.

BACKGROUND

Approximately 5% of children worldwide (around 95 million children aged 14 or under) have a disability (World Health Organization, 2008a). Access to appropriate mobility equipment is a worldwide issue, particularly in low-income countries (World Health Organization, 2008b). Independent mobility for disabled people and provision of equipment to facilitate this is considered a basic human right (United Nations, 1993). Without adequate wheelchair provision many disabled people are caught in a cycle of poverty and depravation, lacking the ability to access education, work and social facilities (World Health Organization, 2008b).

770,000 children and young people under the age of 16 in the United Kingdom (UK) have a disability (Papworth Trust, 2011), 10% of which have unmet mobility needs (All Party Parliamentary Group for Paediatric Reform & Whizz-Kidz, 2011). Early intervention with appropriate independent mobility for disabled children encourages functional mobility improvement (Jones et al, 2003), psychosocial development (Furumasu et al, 2008) and helps to develop communication skills (Butler, 1986; Jones et al, 2003; Jones et al, 2012). Furthermore, providing equipment that meets individual need encourages independence (Wiart et al, 2004), limits challenging behavior (Furumasu et al, 2008) and reduces reliance on assistance (Jones et al, 2003). In order to achieve effective and successful assistive technology interventions, it is essential that good assessment, training and information are provided by state wheelchair services, such as those provided by the National Health Service (NHS) in the UK (Aldersea, 1999). Wheelchairs offer more than just transport; they can provide a new lifestyle for children.

An inquiry into wheelchair services in Wales (National Assembly for Wales Health, Wellbeing and Local Government Committee, 2010) was launched in response to service user complaints. The report recommended the need for reduced waiting times, a more holistic approach to wheelchair provision (taking into account social, educational and developmental outcomes) and improvement of inadequate review procedures/information provision. Several other inquiries and reports have stressed that NHS wheelchair services for children and young people need improvement in order to meet the needs of service users (Audit Commission, 2002; Prime Minister's Strategy Unit, 2005).

Budgetary constraints, long waiting lists and strict eligibility criteria make it difficult for state wheelchair services to supply the most appropriate equipment to each child (All Party Parliamentary Group for Paediatric Reform & Whizz-Kidz, 2011). The cost of pediatric wheelchairs can be particularly high, with evidence suggesting that assistive technology related costs are highest in ages 0-15 (Bamer et al, 2010). Changes to the structure and organization of wheelchair services have been recommended by several reports, with a focus on integrated services between health, social care, education, voluntary and charitable organizations (Prime Minister's Strategy Unit, 2005; Audit Commission, 2002).

Several reports have called for engagement of disabled children and young people and their parents in shaping wheelchair services at a local level (HM Treasury and Department for Education and Skills, 2007). These services should be designed around the child and their family (Barnardos & Whizz-Kidz, 2006; HM Treasury and Department for Education and Skills, 2007), and should support service users to make informed decisions about treatment, care and support (Department of Health, 2004). Active engagement in the development of the services is a key priority (Department of Health Commissioning Team, 2010), with all children, young people and parents being involved in decisions about care and the provision of equipment (Care Services Improvement Partnership, 2006). In order for this to be achieved it is important to understand how service users prioritize the different attributes of wheelchair services, which in turn will inform how service development should be planned and prioritized.

Although service user feedback regarding wheelchair services has been reported previously, to date there have been no studies utilizing the discrete choice experiment (DCE) method to elicit stated preference for different attributes of wheelchair services. DCE is an established method used in health economics to elicit stated preferences for different services or different attributes of services. At present there is no published evidence as to how service users prioritize different attributes of wheelchair services, thus the relative importance of these attributes to service users is not currently known.

Aim

The aim of this study is to explore how parents of children and young people with disabilities prioritize different attributes of wheelchair services. Furthermore, this study will examine how parent preferences contrast with the preferences of young wheelchair users. As a cost attribute is included in the DCE willingness to pay estimates will also be calculated for the first time in this field. As analysis is currently ongoing this paper will outline the background to the study and the methods used.

METHODS

Discrete Choice Experiments

Assessing the benefit of health care services in monetary value poses profound challenges to Health Economists. Alternative valuation techniques are required, as preferences for goods and services cannot be observed from market patterns of buying and selling (Ryan et al, 2008). Two techniques for valuing monetary benefit have arisen from economic theory; revealed preference and stated preference. Revealed preference is observed in the action of individuals in the market, while stated preference is based on individuals stating which alternative they would prefer in a hypothetical situation. Revealed preference has limited use in healthcare, as health care is not traded explicitly and is often free at the point of care (or subsidized by insurance) (Ryan et al, 2008). There also exists an asymmetry of information, as healthcare providers act as both the supplier and the agent of healthcare, creating an imperfect market balance. Practical application of revealed preference is also limited as it cannot be controlled in the same way that stated preference can (Ryan et al, 2008). Although stated preference lacks the validity and reliability of revealed preference, it has grown more popular in the valuation of healthcare benefits as it can be designed specifically in advance to address a predetermined hypothesis.

DCE is a form of attribute-based stated preference valuation and is designed as a range of hypothetical scenarios arranged into pairs (Ryan et al, 2008). These pairs have a predetermined number of attributes (e.g. cost) which in turn have varying levels (e.g. £50 or £150). Individuals are asked to make trade-offs between the attributes in the DCE based on the variation of levels between pairwise choices, and choose between two competing options, thus revealing their relative preference for different attributes.

DCE Design

A multiple generic forced choice design was used, with a mixed orthogonal array. The attributes and levels in the pilot DCE were derived from a mixed-method systematic review of the literature and through discussion with young wheelchair users and wheelchair providers. A list of possible attributes and levels was developed and then refined through discussion with experts in wheelchair provision. The design and layout of the pilot DCE were refined in order to make it easy to understand for adults and children from age 11. This included pictorial representations of the attributes and levels to increase ease of use. Two questionnaires were developed to allow for slight differences in wording of questions for parents and children/young people. The design and layout remained the same.

Five key attributes were identified; cost, waiting time for delivery, level of training, frequency of reviews and suitability of equipment. Of these five attributes, four had two levels (e.g. wait 1-3 months or 6-12 months for delivery) and one had four levels (e.g. pay nothing, £50, £150 or £300), see *table 1*. This combination of attributes and levels produced a full factorial design of 64 hypothetical service scenarios. An appropriate mixed-level orthogonal array (Sloane, 2011) was utilized to reduce the number scenarios down for ease of completion, producing sixteen unique service scenarios. Mirrored scenarios were paired to produce eight pairwise choices. For each pairwise choice participants were asked to choose which service (A or B) they preferred, see *figure 1.*

Table 1: DCE attributes and levels

Attributes	**Levels**			
Assessment of child's wheelchair needs	Health needs		Health, school and social life needs	
Cost of wheelchair service	£0	£50	£150	£300
Level of wheelchair training	Wheelchair skills		Wheelchair skills and life skills	
Delivery time of wheelchair	1 to 3 months		6 to 12 months	
Frequency of review	Every 6 months		Every 12 months	

Once the DCE was designed it was trialed with a small sample (n=5) of young wheelchair users in order to gage their understanding of the questionnaire and the appropriateness of the attributes and levels.

Aspect of service	Service A	Service B
Assessment of child's wheelchair needs	Health needs	Health, school & social life needs
How much you will have to contribute to the wheelchair service	No contribution	£50
Training you will receive from the wheelchair service	Wheelchair skills training	Wheelchair and life skills training
Waiting time to receive your new wheelchair	1 to 3 months	6 to 12 months
How often your needs and wheelchair will be reassessed	Every 6 months	Every 12 months
Please tick the box for the service you prefer (please tick only one)	☑	☐

Figure 1: Example of DCE pairwise choice

Study setting and recruitment

The study was approved by a university ethics board and an NHS research ethics committee. The sampling frame for this pilot DCE was children and young people who use a wheelchair to aid mobility due to physical disability (and their parents) who had accessed mobility equipment through a state wheelchair service, a private wheelchair manufacturer and/or a UK wheelchair charity. The pilot DCE was part of a larger study called the Wheels Project, which focused on applying health economics to wheelchair provision through this pilot DCE, measurement of health related quality of life (HRQoL) and a qualitative interview exploring wheelchair services and defining quality of life.

Participants were initially sent a study pack containing a participant information sheet and questionnaire by their wheelchair service. For children under the age of 16 the study pack was addressed to their parent(s). Participants were given the choice to participate on their own or as a child/parent dyad. Young people were also given the option to participate with a partner. Participants were recruited between June 20th and October 31st 2013

Data collection

Once a completed questionnaire was returned participants were contacted by the study team to arrange a date for an interview. At the interview the self-administered DCE questionnaire was presented to participants and explained by the interviewer. A small number of participants chose not to take part in the interview but did agree to complete a DCE which was posted to them. The DCE questionnaire contained an attribute ranking task and eight pairwise choice tasks, each with five attributes. Instructions on how to complete the questionnaire were presented at the beginning of the questionnaire, with example answers where appropriate. A supplementary notes section was included with the questionnaire for further information on the attributes and levels.

Data analysis

Data analysis is still ongoing; results will be ready by April 2014. Computer programs SPSS and Stata will be used to analyze the data. Descriptive statistics will be produced using SPSS. Stata will be used to analyze the DCE results using a random-effects logit logistic regression technique. We hypothesize that a positive β-coefficient will be observed for level of wheelchair assessment and level of training, as participants are expected to prefer to have additional in-depth assessment of needs (including assessment health, social and school needs) and additional training (wheelchair and life skills training). For the other attributes we hypothesize that a negative β-coefficient will be observed, as participants are expected to prefer reduced waiting time for delivery, lower cost services and more regular reviews. The magnitude of the β-coefficient is relative to the change in utility as a result of changes to the attribute level. A positive β-coefficient indicates that as the level increases so does the likelihood of a participant choosing it. Likewise, a negative β-coefficient indicates that as the level decreases, the likelihood of the participant increases.

As the attributes and levels are a mixture of quantitative and qualitative and thus not directly comparable on the same scale, marginal rates of substitution will be calculated. A marginal rate of substitution is the amount of a given attribute that a participant is willing to forgo to obtain one additional unit of another attribute. For instance, an individual may choose to pay more (move from a free service to a £50 service) to reduce the review delay by six months. Cost of the service will be used as the continuous scale to calculate marginal rate of substitution, this will also allow calculation of willingness to pay for a one-unit increase of the remaining attributes. By dividing the other attribute coefficients by the cost coefficient indirect willingness to pay values and marginal rates of substitution can be estimated. 95% confidence intervals for the β-coefficients will be calculated using non-parametric bootstrapping methods, based on 1000 iterations, as the marginal rate of substitution is ratio based.

RESPONSE RATES

A total of 125 study packs were distributed across England and Wales by the three recruitment sites. 38 initial HRQoL/demographic questionnaires were returned [initial response rate of 30.4%], three of which were from young people participating without their parents. Therefore 35 parents were invited to take part in the interview/DCE. Of those parents who returned the HRQoL/demographic questionnaire two declined the DCE; three were unable to take part in the interview/DCE due to study time constraints; and five declined the interview but completed the DCE. A total of 29 parent DCEs were returned, giving a response rate of 82.9%. An overall parent DCE response rate of 23.2% [n=29] was observed for all of the 125 invitation packs sent out. All returned DCE questionnaires were completed in full with no major data omissions.

Of the 38 HRQoL/demographic questionnaires returned, thirteen children and young people were eligible to complete the DCE questionnaire (aged >10). Of that number eleven children and young people completed the DCE; one was unable to take part due to study time constraints; and one was not deemed capable of completing the questionnaire by their parents. For those eligible to take part [n=13] a response rate of 84.6% was achieved.

EXPECTED IMPLICATIONS

As this project is ongoing full results cannot be reported. Analysis will be completed by April 2014. The results from this study will give a better understanding of how parents and young wheelchair users prioritize different aspects of wheelchair services. Furthermore, willingness to pay estimates will be calculated, allowing analysis of what parents are willing to pay for changes to wheelchair services. These results could be used to reform wheelchair services in-line with the priorities of service users.

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