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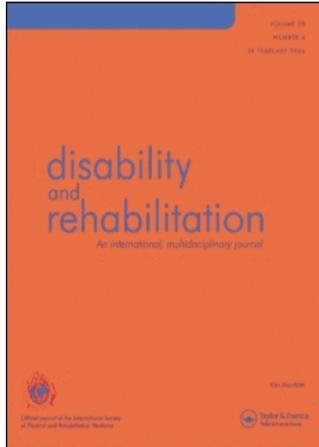
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RESEARCH PAPER

Young people's experiences using electric powered indoor–outdoor wheelchairs (EPIOCs): Potential for enhancing users' development?

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Abstract

Purpose. To examine the experiences of severely physically disabled young people who use electric powered indoor–outdoor chairs (EPIOCs).

Methods. *A priori* interview questions examined young people's functioning with EPIOCs, pain and discomfort with EPIOC use and accidents or injuries resulting from EPIOC use. Eighteen young people (13 males and five females) aged 10–18 (mean 15) years were interviewed by telephone using a qualitative framework approach. Participants were interviewed 10–19 (mean 14.5) months after delivery of the chair. Diagnoses included muscular dystrophy ($n=10$), cerebral palsy ($n=5$), and 'other' ($n=3$).

Results. Many children reported positive functioning following EPIOC use, including increased independence and social activities like wheelchair football. However, EPIOC use was also associated with pain and discomfort, as well as perceived lack of safety, and minor accidents. Most young people and their families were fairly satisfied with the service and provision of their wheelchairs.

Conclusions. The findings suggest that the development of disabled young people may benefit from the use of electric powered indoor/outdoor wheelchairs, although the advantages may come at certain costs to young people's perceived and real safety. Recommendations to powered wheelchair providers include the demonstrated need for additional driving training as these young people mature.

Keywords: *Powered wheelchairs, muscular dystrophy, cerebral palsy, sport, safety, accidents, carers, pain, user satisfaction*

Introduction

In 1996 the UK Government introduced a scheme to allow severely disabled individuals to obtain powered indoor/outdoor wheelchairs (EPIOCs) under the National Health Service (NHS) [1]. These chairs are small enough to manoeuvre through most adapted accommodation and strong enough to move along pavements. They are thus larger than electric powered indoor chairs (EPICs) that are readily available through the NHS. However, EPIOCs lack the size and power of electric powered outdoor chairs (EPOCs) which are usually not available through the NHS. Since EPIOCs have been available through the NHS, studies have shown that the quality of life for

disabled individuals has been enhanced [2,3]. It is possible that carers' lives have also been improved by EPIOC provision [4]. For significantly disabled people, powered wheelchairs allow increased independence for users and their families. EPIOCs increase the ability to engage in daily events including sports, attending college and work and social activities that would otherwise be difficult or even impossible to engage in without mobility.

Research has shown a range of advantages for child users of powered mobility [5,6]. However, these studies have tended to focus on the advantages of EPIOCs for *young* disabled children. The international literature gives no empirical information about the experiences of older children and adolescents

using powered wheelchairs. This is a considerable gap in the literature given that the teenage years represent a critical period of development.

Every child who is permanently disabled, with a disability that restricts mobility after the age when a child would ordinarily be walking, is eligible to be assessed by a wheelchair service in Britain [7]. Chairs in the UK are provided by charity and through personal funds, as well as the NHS. This study focuses on the experiences of young NHS EPIOC recipients.

It is estimated that 1.2 million wheelchair users live in England [8] with 57,600 wheelchair users in the UK under the age of 19 years [9]. Research is needed into the advantages and difficulties young EPIOC users experience, including descriptions of EPIOC safety and provision [10]. Consistent with the advantages reported by adult EPIOC users [3,4], young people are likely to report increased independence and ability to engage in social and schooling tasks. Yet children may also report threats to comfort consistent with the pain and discomfort that adult users report [11]. Individuals requiring EPIOCs are often profoundly dependent, sitting in wheelchairs for extended periods of time and developing posture-related pain and pain related to their underlying condition. Threats to safety, including accidents, represent another potential limitation of powered mobility that may affect young people. Mishaps such as tipping are common in adult users [4]. It is possible that accidents are at least equally common in child users, as young people are just as likely to have limited control over their environments as do adult users.

Prescribing mobility equipment to disabled children poses additional challenges that may not apply to adult users. Not only does the equipment need to contribute towards independence and the ability to engage in social and educational activities, but it also needs to respond to growth and development changes in children [7]. For example, if children have to wait too long for their chair, they may outgrow it. Restricted movement in disabled children can affect later development, such that passivity, frustration and over-reliance on other family members result [12]. It is therefore especially important to review, early on, child and family satisfaction with the new wheelchair.

Satisfaction with the wheelchair service is also important to gauge in young EPIOC users. State-provided services are increasingly expected to provide a reasonable standard of service [1]. Previous audits of specialist wheelchair services have shown dissatisfaction with the time taken to assess the individual for their chair and in the time taken to deliver it [13]. The present study offered an opportunity to investigate the attitudes of young people and their families to the service provided.

Information about the development of the Specialist Wheelchair Service examined in the present study has been reported previously [13], as have criteria for receiving an EPIOC in North West London (with a catchment population of 3.1 million people [4]). The criterion of being unable to walk effectively around their home is not always strictly adhered to for young people attending secondary school who need to travel extensively around various classrooms and on to school playgrounds etc. The presence of a condition that is expected to deteriorate over time e.g., Duchenne's muscular dystrophy is also a factor in determining whether the potential user should be given a chair. Thus, some of the young people in this study had limited, albeit deteriorating, levels of walking.

The purpose of this study was to address the gap in the young EPIOC user literature by undertaking a qualitative analysis of young people's experience using an NHS supplied EPIOC. Themes included functioning in EPIOCs – including use and frequency of use – pain and discomfort, accidents, and satisfaction with EPIOCs and service providers (including approved repairers contracted to maintain the chairs and provide emergency support as needed).

Method

All EPIOC users aged 18 years and under identified on a specialist wheelchair service departmental database who received their chair between February and November 2002 were invited to participate in a telephone questionnaire and an interview. Harrow Research Ethics Committee approved the study.

Eighteen children and young people were invited and consented to be involved in the study. Parental consent was obtained for those young people under 16 years of age. Participants were interviewed by telephone. Some young people had difficulty communicating due to their disability and parents continued the interview on their child's behalf. In these cases, children were present at the interviews and parents simply relayed their child's views. Parents were asked to verify their child's answers to the chair use, pain and accident questions before the interviewer continued. The questions related to service satisfaction included the experiences of children and parents, as parents were often the primary point of contact for services.

Types of wheelchairs used before the current EPIOC included manual chairs ($n=5$), EPICs ($n=3$), EPOCs ($n=1$), and EPIOCs ($n=5$). Some respondents used both manual and EPIC chairs in conjunction ($n=4$). Young people had received their chairs an average of 14.5 months before they were interviewed (range 10–19 months).

A researcher independent of the NHS wheelchair service carried out the interviews. *A priori* interview topics were set based on items from the EuroQol EQ-5D, which has been used previously with EPIOC adult users [3]. To ensure that this study was relevant to wheelchair users, extensive advice was taken from the National Forum of Wheelchair User Groups in the content and design of the interview questions. Care was taken in the wording of interview questions to take an open stepped approach in the ordering and structuring of questions. Initial questions were open-ended and general. Depending on the information participants raised, more specific domains were then explored within each area. Topics included:

- Functioning with the EPIOC (questions such as use during different weather conditions, situations that limit EPIOC use, new activities, and good and bad points about the EPIOC for the user, family and friends).
- Safety of EPIOC (questions included provision of safety material and training, accidents or mishaps, safety issues concerning curbs, ramps, mechanical mishaps and the social environment, and perception of safety).
- Pain/discomfort (questions included presence of general pain, pain related to EPIOC, and steps taken to manage pain).
- Satisfaction with service and support (questions included satisfaction with initial assessment, hospital staff, and contracted repairers).

A number of demographic questions were asked (Table I). Thirteen boys and five girls participated in the study. Mean age was 15 years 3 months (range 10–18 years). Most participants were White British ($n=15$), with Asian British ($n=3$) the only other ethnicity represented. Diagnoses included muscular dystrophy ($n=10$), cerebral palsy ($n=5$), and 'other' ($n=3$). Most participants lived with their families, although one young person lived at college. Most participants were severely disabled and could not stand or walk ($n=13$). Five young people were able to respond to the questions, although 12 mothers had to communicate to the interviewer on behalf of young people at some point in the interview, and one father assisted.

The interviews lasted for an average of 33 min, range of 20–67 min, depending on the information participants were willing to reveal. Interviews were transcribed verbatim from tape-recordings. Answers to yes/no questions were given codes and entered along with the interviews in a Microsoft Excel spreadsheet. Once the interviews and answers were entered into cells, analyses were conducted using a qualitative conceptual framework

approach [14,15]. This approach is recommended for deductive data categories, where interview questions and categories of interest are considered before the interviews. The method tends to be more structured than would be the norm for much other qualitative research and the analytical process tends to be more explicit and strongly informed by *a priori* reasoning [14].

An independent researcher, who was not involved in the interviews, reviewed the data. Each transcript was read in detail twice. On the first reading, data was studied for familiarization and to identify the subjects' words and phrases for the key issues under investigation, i.e., occurrence and description of accidents in the chair. Data were then extracted from answers in the form of words and phrases using thematic content analysis and indexed and charted. Primary analysis of the extracted data indicated the range and pattern of the accounts given by subjects when addressing issues within these themes. Further analysis grouped descriptions according to type and formulated categories. Data that did not fit the *a priori* categories and formed new themes were also considered. All data fitted into the general categories of function, safety, pain/discomfort, and satisfaction with service. Tables of responses reflecting these key categories were used for interpretation and explanation of findings.

Results

All participants responded to at least some of the open-ended and yes/no closed ended interview questions, with results for these responses presented in Tables II–V.

Functioning with EPIOCs

As shown in Table VI, the majority of young people used their EPIOC everyday ($n=13$). The primary use for EPIOCs was attending school or college ($n=16$). Other uses included shopping and a range of social purposes, such as meeting with friends, and going to the park, cinema or restaurants. The most common social use of the EPIOC was to play wheelchair football, with a total of eight young people (44%) saying they had taken up wheelchair football with their new EPIOC (although one participant said he preferred to play a rough version of wheelchair football and often used his old manual wheelchair instead).

Most young people ($n=16$) travelled in a vehicle, including family cars, buses and taxis. Fifteen of these young people put the EPIOC in the vehicle, with all of them staying in the EPIOC for the journey at times. At other times, all participants either dismantled parts of the EPIOC, or folded it in order

Table I. Demographic and Clinical Data of 18 young people using EPIOCs.

Participant no.	Age (years)	Sex	Ethnicity	Diagnosis	Months since receiving chair	Other household members	Mobility	Help with the interview?
1	14	Male	White British	Spina bifida	17	Parents	Cannot stand	Yes; mother
2	12	Female	White British	Cerebral palsy	17	Parents	Cannot stand	Yes; mother
3	14	Male	White British	Muscular dystrophy	15	Mother & sister	Cannot stand	Yes; mother
4	11	Male	White British	Muscular dystrophy	15	Parents & brother	Cannot stand	Yes; mother
5	16	Male	White British	Other	15	Parents & sister	Can walk, but decreasing	No
6	16	Male	White British	Muscular dystrophy	14	Mother & brother/sister	Cannot stand	Yes; mother
7	14	Male	White British	Muscular dystrophy	15	Parents & sister	Cannot stand	Yes; mother
8	18	Male	Asian British	Cerebral palsy	15	Mother & sister	Can stand; cannot walk	Yes; mother
9	18	Male	Asian British	Muscular dystrophy	13	Mother & sister	Cannot stand	Yes; mother
10	17	Male	White British	Muscular dystrophy	13	Mother	Cannot stand	No
11	10	Male	White British	Muscular dystrophy	12	Parents & brother	Can walk, but decreasing	Yes; mother
12	18	Female	White British	Spina bifida	13	College peers	Cannot stand	No
13	14	Female	Asian British	Muscular dystrophy	19	Parents & brother	Cannot stand	Yes; mother
14	16	Male	White British	Cerebral palsy	19	Parents & brother	Cannot stand	Yes; mother
15	18	Male	White British	Cerebral palsy	18	Parents	Can stand; cannot walk	No
16	18	Male	White British	Cerebral palsy	18	Parents	Can walk, but decreasing	No
17	11	Female	White British	Muscular dystrophy	18	Parents & brother/sister	Cannot stand	Yes; mother
18	14	Female	White British	Muscular dystrophy	10	Parents	Cannot stand	Yes; father
TOTAL (<i>n</i> =8)	Mean = 15.25	Male = 3 Female = 5	White British = 15 Asian British = 3	CP = 5; MD = 10; SB = 2; Other = 1	Mean = 14.5	Family = 17 College peers = 1	Can walk = 3 Stand; no walk = 2 Cannot stand = 13	No help = 5 Mother helped = 12 Father helped = 1

Table II. Descriptions of functioning with EPIOC.

Participant	
1	The house is full of little chinks everywhere. But that's a normal life with a chair. In the rain . . . he gets soaked because the system issues the chair, but not the covering. And I can't find . . . covering that doesn't get tangled up in the wheels.
2	Too bulky to fit under table in restaurant and so isolates her in the social environment. Take the manual chair on holiday because don't know what we will be faced with when we get to the other end. And the EPIOCs don't go up and down curbs and things like that. Uses it at home and school and wherever she can. On school trips we are often asked to send a manual chair as well because places are not accessible. She uses the EPIOC very well, but the design of the EPIOC could be improved because it's not really an outdoor chair, it's more of an indoor chair – given the situation that we live in rather than an ideal world.
3	Uses less when he's not in school. The fact that we can actually go out more. It's a bonus to do that.
4	He uses it all the time. When we go out to eat anywhere, we have to transfer him because sometimes he can't get under tables in restaurants and stuff like that. Just silly little things, really. If it has rained heavy he can't go to certain places and things. The EPIOC is a lot harder than the manual because it doesn't fold away.
5	I just use it to go to school. I get round a lot more, outside and that. I play electric wheelchair football, but I use my other wheelchair. I like having crashes and that and I don't want to break this up.
6	If we're going out somewhere he'd have to use the other chair because that one (the EPIOC) is too big. He thinks its ugly looking, too small and it's very high . . . so he's not able to get under tables in restaurants, things like that.
7	He's gained independence with this wheelchair. It's made life easier due to not pushing. If he goes out in the family car we would take the manual chair because the car isn't adapted for EPIOC. And EPIOC is heavy so we would need a lift or ramp.
8	Enables him to go out with his friends. It is helpful. He feels good. He can go out. He's not dependent. He likes to use it all the time. He's not dependent on somebody pushing him. Because he feels good, then I feel good also (mother).
10	It gives me more independence (mother).
11	It made a huge difference as soon as we had it, going from a manual. It made him really independent. Increased his activities. He uses it everyday, all the time. If it's really rainy and it's really slippery, he doesn't sort of go too far in it. He can't use it in snow.
12	I can do everything myself. It's been fabulous. It's been great to have it.
13	I'm basically using it all the time except in certain places I cannot get to 'cos there's steps like going into houses.
14	Its great . . . Where do we start? The size of the chair limits him to where he can be. Most homes aren't EPIOC friendly and so he'll have to use the manual then. So we interchange with a manual. The EPIOC can be difficult to maneuver.
15	Makes getting round my school a lot easier. I feel more independent. I can join in with more things 'cos I keep up with them (friends and family). It might slip and slide a bit in the rain, but wouldn't stop me using it. It's made life easier when we do go out 'cos they don't have to push me. If the terrain is ok . . . obviously I'm not usually on my own, but if the terrain's ok and I'm confident with the surroundings, then I'm ok.
16	I use it mainly for college. Because of the independence and I don't have to rely on anyone for help. We don't have the right car for it at the moment. They can get it in the car at the moment, but it's extremely heavy.
17	It's given her far more freedom, independence. To go out with friends, she doesn't need someone. She's able to get around quite well close to home. She works out how to get up and down curbs, where the curbs are dropped. She can travel reasonably well around here. If it's really absolutely pouring with rain, then she doesn't go out because the wet can get into it and we have had it where it's just stopped because it's got too wet.
18	Would think she's got more positive relations with friends since having the powered wheelchair. It's provided some sort of independence. It's made it a little bit easier. She does a bit more herself. Lack of dropped curbs are a problem. Lack of maintenance. General state of repairs really. It limits her independence if she can't access the buildings or get to buildings in the first place.

Table III. Descriptions of safety.

Participant	
1	When I'm driving my wheelchair people like to sort of pass in front of me as if I should stop dead. Accident due to driving into a crack in the park. Two minders helped him back up. He's very dangerous outside because his idea of danger isn't top priority. I just feel that people should be given lectures on how to behave and not pretend it doesn't exist.
2	It's a safety hazard for outdoor use because of the condition of the local environment; pot holes. Needs constant supervision because of this. It's less safe in wet weather. She's got curb climbers, but they're just not safe. She doesn't use them. It's a hazard. Drove into a car. We're going through insurance at the moment. No one was hurt as the mother jumped in between her daughter and the car . . . and the car was stationary in a car park.
3	He's nervous. Even when we're out in his manual chair, he's nervous. It's to do with going out in the road. He's nervous going out in traffic.
4	He's backed into a few things by going too fast and things, that's about it. Nothing major.
6	He tipped upside down because there was a pot hole in the grass. The worst thing round where I live is they actually drive like lunatics. So he wouldn't have any chance at all if someone was to hit him. He doesn't feel safe to go up the road. He goes out with someone with him, but he's sixteen years old. He should really feel alright to go out by himself. We do try and avoid any dangers. He went up the road and I told him not to because the battery's low and he conked out. Someone actually called the police and everything. He was by himself then, so he was stuck there. The concerns I have about the EPIOC is the way it veers off and in ice, that's going to be a problem.
7	Bit unsure going up a curb. In comparison to the other powered chair he had, there was no problem at all. Never had a problem on his other chair. Maybe its because it's a more powerful chair. The joy stick got jammed under one of the tables at school. He's got a taller joystick now. Feels very unsure about the EPIOC.
8	I make him take someone with him. Because sometimes if the road is slippery and if he's alone, I don't feel 100%. The battery isn't charging properly. Holds a weak charge and has caused him to break down away from home. The arm rests. They keep coming off. The protectors . . . the cover comes off. The arms are wobbly.
11	When it snows it's quite dangerous for him to go out in it. We have tried it. We can get down the path and that, but it's not advisable. The chairs don't grow particularly well with children.
14	Well he can only travel on good terrain. He can just about go on some rough terrain, but it's difficult. Especially when he's driving with his chin, which is how he drives. He's not actually gripping the control with his hand. His head flies off and he loses control of the chair if the terrain is rough. In the rain it's slippery. He does go out in the rain, but he doesn't have as much control. In some gradients, if no one's behind him, it could tilt backwards. We had a faulty battery charger, which didn't detect if the battery was overheating. It was being charged overnight and the fluid in the battery was on the bubble. Fortunately it didn't explode.
15	I don't know whether they were put on wrong, but my front wheels would hit the curb before the curb crawler actually did, so I couldn't get up. It physically wouldn't lift the chair up, so I couldn't get up the curb.
17	Not too keen on using the curb-climbers. She prefers not to, but she can use them and she knows how to use them safely. Generally if you're using the curb-climbers, the chair moves at a bit more of an angle than if she's just going down a dropped curb. And I think she just feels not as safe in it.
18	One thing I do think is strange is that it hasn't got like a hooter. If you saw someone approaching you that wasn't looking at you, you could make a noise and that would bring them back to life and avoid the situation.

to fit in the vehicle. (It is likely that transport to school/college took place in large vans and that taking the wheelchair to fold up reflected travel in the family car.)

Seventeen of the participants made comments about their functioning using an EPIOC. As Table II demonstrates, a range of positive results and some negative issues associated with the EPIOC were revealed. Analysis of interview responses revealed that nine young people and their families (50%) mentioned increased independence as a result of the EPIOC (users 7, 10, 11, 13, 14, 15, 16, 17, 18). Of the nine participants who reported increased

independence, two previously used EPIOCs, three used a manual and an EPIC, and four only had access to a manual chair.

The main positive issues for users were increased independence, ability to engage in more tasks (users 3, 5, 6, 7, 8, 10, 11, 13, 15, 17, 18), and ease due to not having to push the chair or having others push it (users 7, 8, 11, 14, 15, 17). The independence mostly referred to the young people, although two mothers reported increased independence for themselves (users 8, 10). The main negative issues were difficulty maneuvering in certain environments, including around the house and in restaurants and

Table IV. Descriptions of pain and discomfort.

Participant	
1	He has wooden blocks deliberately under his feet so if he bashes into anything the wooden block goes into the thing and not his feet.
2	When sitting for long periods, the pain gets worse. Due to certain school policies where children are left in wheelchairs all day long, she is bound to experience pain and discomfort and yes, she does complain of it sometimes. Juddering happens just going along the road because of so many holes in the pavement. Children shouldn't spend all day in wheelchairs.
3	That comes when you're in the chair a long period of time.
6	Sometimes if he goes down a curb and it's a bit of a bump, his head does go and that does affect his neck. The jerk of coming down the curb. At the beginning (the pain) would have been moderate because of the arm rests.
7	Now and then he gets hip and knee pain when sitting in the chair for a long time, hence he gets out of it straight away.
8	I get back ache. Because of posture, like leaning forward. Have a special backrest and it sometimes helps.
11	I've taken him back to evaluate his seating again. Asked for a softer cushion and to upgrade the chair so he can move his seating position about. They really didn't do much with his seating cushion. It's not fabulous to sit on. It's really quite hard. The back rest and head support are the other things I haven't liked on it. They're quite flimsy, so when he's going up and down curbs it really does jutter about.
13	Her posture is very bad. She almost sits at between 45 and 60 degrees. So she's uncomfortable and she's got aches and pains. Her back rest doesn't give her any support, really. On one or two occasions she's complained about aches in her legs because of the foot rests and things. Probably they were not in the right place. We've recently had a little adjustment to the chair and she's fine with that now.
14	Using the chair for a long length of time, the circulation in his legs. In those times they unstrap his feet. And he can tilt with help. He only really gets pain when he's thrown out of the supportive seating.
15	If I sit too long in the same position, I'd say it was moderate (pain or discomfort).
17	Occasionally if her legs are not in the right position, it's uncomfortable, but I wouldn't say it's painful for her. She would say straight away and then we would adjust them.
18	She'll get to that stage where she's a little bit too big here or something's got longer there. She'll get a little bit of discomfort through that, then we'll adjust it. It's difficult to achieve a match between posture and the chair. Occasionally her upper back and shoulders will be uncomfortable because the posture's not very good. Obviously we're not designed to sit down all day. It's a very fine line between the two.

over unsmooth terrain (users 2, 6, 13, 14, 15, 17, 18), and a concern with functioning in wet weather and snow (1, 2, 3, 4, 6, 8, 11, 13, 14, 17, 18). One mother actually reported that the chair's bulkiness resulted in isolating her child socially (user 2). Nine participants reported that a manual wheelchair was required for situations such as the homes of friends and family, anywhere with steps, in cars and on holiday (users 2, 4, 6, 5, 7, 12, 13, 14, 15).

Safety

All parents and young people said they were given adequate safety directions regarding EPIOC use. This included a driving test at the hospital before they were issued with the chair, instructions from the assessors, leaflets, and instructions at school.

A total of 10 young people reported accidents in their EPIOCs. Accidents included tipping over (users 1, 6, 7, 14, 18), the chair running into people (users 11, 15, 17), banging into furniture (user 13), and in one case, the EPIOC drove into a stationary car, narrowly missing a child (user 2). The family in

this case was currently claiming insurance to pay for damages.

Reasons for the accidents included a wheel falling off, the joystick getting stuck in a forward position, tipping due to potholes and bumps in pavements and grass, clipping the edge of curbs, losing control of the chair, and people walking into the path of the EPIOC.

Three young people reported that they felt unsafe or insecure in the EPIOC (users 3, 7, 18) – they were all aged 14 with muscular dystrophy. Eleven young people reported that they felt safe and secure (users 2, 4, 5, 8, 9, 10, 11, 12, 13, 14, 15). Three of the safe and secure respondents reported that they only felt so if the weather conditions were reasonable and the pavements were not uneven (users 14, 15, 16). This suggests that weather conditions may moderate feelings of safety and security.

The main themes that emerged regarding feelings of insecurity in EPIOCs were tackling curbs (user 7, user 18); uneven terrain such as pot holes (user 2); inattentive drivers (user 6); the child not being responsible (user 1); and the chair's faulty mechanics (user 14).

Table V. Descriptions of service.

Participant	
1	<p>Disgusted that [the service] hasn't been able to replace his knee block because he's grown. They drilled another hole and now you can see the retaining clip for the little sprocket that comes out, which I find a bit pathetic. They are remarkably efficient once they have the understanding of what's going on.</p> <p>They live on another planet (administration staff). They're full of what can't be done and they don't come out with much of what can be done.</p> <p>Doctor is very good at measuring them up and making sure all the right things are there. She's fantastic. She's very aware of what a wheelchair's all about and what the needs of the individual are. She's been superb with my child.</p> <p>They want to take the wheelchair away over half term to change the back tyres (repairers). How is he supposed to exist in that time?</p> <p>Room for improvement is the speeding up. Also not saying that they're short of money, that's why it's not happening. There aren't that many disabled children. They should manage without coming up with reasons why it's not working.</p>
2	<p>The guys at [the service] are very good. They listen carefully and we had a very good service.</p> <p>It wasn't a quick process. Everything takes so long, but you tend to get resigned to it.</p> <p>The people that have the contract to actually fix them . . . that service could probably be improved.</p> <p>We had some very good people actually carrying out the assessment.</p>
3	All been excellent.
6	They do the best that they can with whatever budget they're given and time scales and things like that.
7	<p>It went very well. Very pleased with staff. They were all very outgoing, polite and nice and had a laugh with him.</p> <p>Very friendly. They do the best they can for what they've got there.</p>
8	It's ok.
10	<p>It's a good service. Sometimes it can be a little bit slow. Had to wait some time for a part to arrive after I first received the EPIOC.</p> <p>No bad points.</p> <p>I think it's been great so far. It came at a time that we really desperately needed it and it was fabulous.</p> <p>Repairers have been fantastic. They've been great. Every time anything's gone wrong, they've been straight out.</p> <p>They go to his school. They do whatever they need to do.</p>
13	<p>They've not really been able to come up with any good solutions and we've had a lot of the time to go there. . . spend a few hours and nothing has really come up . . . even something very simple like the tray. Last time when we went we were supposed to have it all sorted out and nothing was there and we still haven't heard anything.</p> <p>I can't say anything negative about them (the repairers).</p> <p>At the moment her posture is constantly changing. We need the changes done quicker. It just takes a long time.</p>
14	<p>They're good. EPIOC are good, but they're limited in the range of chairs they're willing to supply. Because they're a bit set in their ways, aren't they?</p> <p>They could do better (regarding waiting times for appointments).</p> <p>Feel we were talked down to.</p> <p>More advice on the variety of chair could have been given.</p>
15	<p>I didn't have to wait too long for my appointment at [the service], so they've been quite quick. It's ok, but obviously the chair is our legs basically, so we do like things to come quick.</p> <p>It took quite a long time to actually get assessed for a wheelchair, but once I'd got assessed and any repairs or whatever come quick.</p>
16	<p>[The service] are very good. I've never had any problems.</p> <p>I think I was quite impressed by how quick it was. It was quicker than I expected.</p>
17	<p>Very good. We've had to call the engineer out about half a dozen times and they've always been very prompt at coming out.</p> <p>Very helpful.</p>
18	<p>It just seems from our point of view, the parents, there's too many chains of commands you have to go through or different people you have to go through to get what you need.</p> <p>The team of people that saw her, they were very thorough. Very good actually.</p> <p>The company itself, are fine (for repairs). The times we have seen them have been top notch. No problem.</p> <p>They've come out, kept appointments. Everything. Nothing's been any problem there at all.</p>

Pain/Discomfort

Nine young people reported that they experienced no pain or discomfort. Nine young people reported moderate pain or discomfort. Pain relief included movement and exercise of painful limbs (users 2, 7, 13, 15, 7), use of cushions in chair (users 3, 11) and regularly using pain medication (users 3, 7, 12, 16).

Ten young people reported that their pain or discomfort was affected when using their EPIOCs. Pain was specifically affected by seating and posture (users 2, 3, 7, 9, 11, 13, 14, 15, 17), lack of support from back and arm rests (users 6, 8, 13), and jarring from curb climbers (users 6, 11). The young people reporting pain from EPIOC use were not all the same respondents who experienced general pain and discomfort as detailed above.

Table VI. EPIOC use.

	N (%)
Frequency of use:	
Daily	13 (72%)
6 days/week	1 (6%)
5 days/week	2 (11%)
4 days/week	1 (6%)
1–2 days/week	1 (6%)
Purpose of use:	
School/College	16 (89%)
Shopping	15 (83%)
Social:	
W/chair football	8 (44%)
Meet friends	5 (28%)
Park	5 (28%)
Cinema	4 (22%)
Restaurant	2 (11%)
Disco/pubs	2 (11%)
Doctor	1 (6%)
Vehicle travel*:	
Yes	16 (89%)
No	2 (11%)
Put EPIOC in vehicle?	
Yes	15 (83%)
No	1 (6%)
Stay in EPIOC?	
Yes	15 (83%)
No	1 (6%)
Dismantle/fold EPIOC?	
Yes	15 (83%)
No	1 (6%)

*NB Most users accessed more than one vehicle.

Three respondents reported no general pain, but had pain and discomfort related to their EPIOCs. Four respondents had general pain which they did not attribute to EPIOC use. Six respondents complained of pain and discomfort that was related to EPIOC use. This would suggest that a number of these young people experienced regular pain and discomfort irrespective of whether they were using their EPIOC. This might reflect muscle pain from muscular dystrophy or the painful spasticity sometimes experienced by those with cerebral palsy. Adding the general pain and discomfort complaints ($n=10$) with the complaints of pain and discomfort related to EPIOC use but no report of general pain ($n=3$) suggests that at least 13 of the 18 respondents (72%) experienced regular pain/discomfort. Ten of these 13 complaints (77%) were related to chair use.

Satisfaction with service

Users heard about getting an EPIOC from a variety of sources. These sources included occupational therapists (users 3, 7, 8, 10, 15), physiotherapists (users 4, 11, 14, 17), the service provider (users 1, 5, 13, 16), social services (users 6, 9), the school (users 6, 9), and a consultant paediatrician (user 2).

Some families felt that the waiting times for the initial appointment for assessment and to have the EPIOC delivered were too long. Waiting for the initial appointment varied between 1 month and 2 years. Most waiting times were around 6 months. Waiting for delivery of the EPIOC varied between 'a few' weeks and 18 months, with most young people receiving the chair within 2–3 months. Eight families were satisfied with the waiting times (users 1, 9, 10, 11, 12, 16, 17, 18). Three were not (users 5, 8, 14).

On the whole, wheelchair users and families were happy with the service they received from their NHS Service Provider. With respect to interactions with administration staff, 12 families said they were satisfied (users 3, 6, 7, 8, 9, 10, 11, 12, 13, 15, 17), and two families were dissatisfied (users 1, 14). With respect to the medical clinician, seven families were satisfied with the service they received (users 1, 2, 6, 11, 13, 16, 18), and 1 was not satisfied (user 14). Eleven families reported positive interactions with the engineers (users 1, 2, 3, 5, 6, 11, 13, 15, 16, 17, 18). None were dissatisfied. Finally, 8 families were satisfied with the occupational therapist on the team (users 2, 3, 5, 13, 14, 15, 16, 18), and 1 family was dissatisfied (user 1).

Sixteen families had to contact the repairer to fix various problems with the EPIOC (89%). Generally, comments regarding the service were positive. Eleven respondents said they were satisfied with the repairs (users 1, 3, 4, 7, 9, 11, 13, 14, 15, 17, 18), two said they were dissatisfied (users 2, 15) and the remaining respondents did not comment. Not all problems with the chair were listed. Those that were included tyres (users 1, 12), faulty tilt mechanisms (users 13, 14), 'things' falling off (users 7, 18), faulty chargers (user 3), faulty steering (user 16), and battery problems (user 11).

Discussion

This is the first reported study of powered wheelchair use in older children and adolescents. The study investigated the advantages and risks of NHS provided EPIOCs for disabled young people in the UK. Although the majority of experiences were positive, in that young people and their families reported increased independence and ability to engage in tasks as a result of EPIOCs and most families were satisfied with their service providers, a number of concerns were raised. These included caution when using the chairs in certain weather conditions and terrain, pain and discomfort, accidents, and dissatisfaction with NHS waiting times. It is likely that the interview time (i.e., 10–19 months after chair delivery) was sufficient for respondents to experience a range of advantages and risks, and thus

provide an accurate picture of functioning in an EPIOC.

Advantages of EPIOCs

Young people's responses show that the chairs are well used. All children and young people used their chairs at least once a week, with most using their chair daily. Most young people used their EPIOCs for attending school or college. This is reason enough to provide EPIOCs to disabled young people with limited mobility. A range of other positive uses were also reported. Young people were able to engage in outdoor and social activities, including shopping, meeting friends, going to the park, cinemas and restaurants and most notably, playing wheelchair football. Almost half of the respondents reported that they were able to play wheelchair football. Disabled children have exercise needs. Although these may be different to able-bodied children, exercise and sports play an important role in physical and emotional fulfilment for disabled children [16]. The ability to play wheelchair football is likely to be a highly significant achievement for young people using wheelchairs.

EPIOCs give disabled young people more access to social activities and their peers. Social acceptance and peer interaction during adolescence are associated with a host of positive developments for non-disabled and disabled young people including: the likelihood of success in school [17], enhanced mental health including self-esteem [18] and increased prosocial skills and autonomy [19]. In fact, peer relationships are more influential in the formation of adolescents' emotional stability than parental relationships [20]. In terms of a developmental perspective, whereby the ability to engage in age-appropriate activities signals future healthy physical and mental functioning [21], the fact that the young people in this study were able to perform a range of schooling, social and sporting activities due to their EPIOCs, bodes well for their future sense of achievement, well-being and ability to function with independence.

Independence and not requiring family members and friends to push the chair were advantages reported by young people. Freedom to engage in their environment without needing constant supervision and assistance from others was a resounding theme that emerged. Given that the majority of the participants were adolescents, it is likely that this benefit is especially noteworthy. A sense of independence and personal control becomes increasingly important as children mature [22,23]. The use of an EPIOC facilitates this developmental need.

Young people's ability to experience a range of meaningful activities such as school, socializing and

their increased independence and personal control are consistent with previous reports of parents caring for disabled children using electric wheelchairs [5,6]. The young people in this study were substantially older than the children in these previous studies. It is likely that the benefits of EPIOC use are especially profound for teenagers.

Consistent with the adult EPIOC user literature [4], another positive yet little studied consequence of the EPIOC is that the chairs greatly enhance the lives of carers as well as users. Parents reported increased independence for themselves, positive feelings that they no longer had to push their child's chair, and children being able to do more around the house for themselves, thus freeing up parents' time. The number of advantages that EPIOCs bring to the lives of users and their families suggest that these devices are well worth their expense.

Risks and concerns

The primary issue surrounding the use of EPIOCs is their suitability in most situations and conditions. Although EPIOCs give access to more of the world than other kinds of wheelchairs, a large portion of the environment is still essentially 'out of bounds' to users. Reports pointed to potholes in roads and pavements, uneven terrain, steps leading up to most houses and offices, and difficulty fitting the chair in doorways and under restaurant tables. Most young people did transport their EPIOCs. However, nearly all said that the chair was heavy and cumbersome to take in the family vehicle, thus limiting the chair's use away from home. Perhaps the most common concern was taking the EPIOC out in certain weather conditions. Rain and snow were identified as impediments to users' safety and mobility. Most young people did not use the chair in adverse weather conditions, significantly limiting mobility during the colder months. Due to these issues, most respondents said they still made good use of the young person's manual wheelchair, as this provided them access when the EPIOC did not.

Accidents in the chair were relatively common. At least half of the young people were involved in tips and collisions with furniture, people and even a car. Although most of these accidents were relatively minor, at least one accident was major enough to involve an insurance claim. The incidence of accidents also begs the question that if such a range of mishaps occurred after approximately 1 year, what other hazards are in store for young people? The adult EPIOC user literature suggests that accidents are relatively common [4,24], with falls being the commonest cause of wheelchair deaths in the US [25]. It is possible that further training for users would minimize accidents. Many of the accidents

seem to have involved terrain difficulties, but this study raises the question as to the adequacy of the stability testing of these users in their chairs – and the possibility that stability is influenced by carrying items on the back of the chair [26]. Another concern is that of other people not minding the wheelchair user. One parent asked why a horn or sounding device could not be installed on the wheelchairs to prevent collisions in the future.

Even minor mishaps may affect children's confidence in the chairs. Many young people said they did not always feel safe in the chair. Sometimes this was due to reasons outside the EPIOC, for example, 'lunatic' drivers in the neighbourhood. Insecurity in the chair was also common. Most chairs are fitted with curb climbers, suggesting that small curbs should not be a problem for users. However, curbs and curb climbers were a problem for many of the young people with feelings of tipping back and general insecurity when negotiating curbs. Further training in tackling curbs may greatly increase children's confidence in the chairs. Joysticks getting stuck and faulty batteries were other problems that hindered young people's security.

A substantial number of young people had moderate levels of pain and discomfort that were related to posture, jarring and insufficient support from the chair. Although less is known about child wheelchair users, many adult users experience pain [11,27]. It is possible that such discomfort is associated with being in a wheelchair, and applies to most individuals who have limited mobility. EPIOC users generally have profound disabilities, are often dependent on their wheelchairs, and may therefore be at even greater risk of developing pain than general wheelchair users. Some of the interview responses provide clues about pain prevention strategies in young EPIOC users. Cushioning, exercises, the possibility of 'tilt-in-space' chairs, and changing position throughout the day are important. As one mother noted 'children shouldn't spend all day in wheelchairs'. Clinical professionals should bear in mind the possibility that young people may develop pain associated with EPIOC seating, and advise young people and parents about management strategies.

Satisfaction with service

Most service and support staff received positive reviews by young people and their families. Respondents were generally happy with their EPIOCs and the service they received from administration staff, doctors, occupational therapists, engineers and the contracted repairers. However, respondents were less satisfied with waiting times for appointments and chair delivery, and the lack of choice of EPIOCs and equipment.

At least one young person waited 2 years for an initial assessment, while another who required special seating had to wait 18 months until their chair was delivered. Although most respondents were quite understanding about waiting times, many felt that the time was too long given their level of disability. As one young person expressed: 'It's ok, but obviously the chair is our legs basically, so we do like things to come quick'. A consistent comment was that waiting times were made easier to bear by being provided with updates from the service about how much longer families would have to wait. Concern over long waiting times has been expressed for a number of years since NHS wheelchair services first started providing EPIOCs in 1996 [9]. It seems the concern remains.

Given that the majority of these young people have muscular dystrophy, it is likely that their condition will deteriorate. This has additional implications for the efficiency of service providers as regular, timely reviews are necessary. The needs of young cerebral palsy sufferers will change as they grow and the suitability of their chairs must be monitored to ensure that the chairs continue to meet their needs.

Respondents identified a number of improvements that could be made to the system. These centred on waiting times and lessening the bureaucracy of receiving chairs. Some respondents raised the issue that the chairs need changing as young people grow, and the system does not always accommodate these changes in time for the young person's comfort. As one mother said: 'It's all very longwinded (the system) and to do with money. It's an April to April budget. I've got a disabled son who's disabled for life, these sort of people don't need April to April, they've got it for the rest of their lives'.

Limitations

The use of parent responses when young people had difficulty communicating may present some methodological issues. Incongruence may exist between carer and young people's reports and this might be especially pertinent to the more personal questions such as experiencing fears and occurrence of accidents. Reports of parents and children do not always share concordance and young people are seen as the most important source of information when investigating their behaviour [28]. However, families have high involvement with EPIOC services and are likely to possess valuable insights about the issues surrounding EPIOC use. When young people with disabilities are unable to communicate, parents are able to effectively articulate about young people's EPIOC use as they are involved in the day-to-day lives and care of their children. The interviewer also ensured that parents verified responses with their

child on the chair use, pain and accident questions in order to ensure that parents relayed the child's views.

Future work should obtain information from young people *and* parents in order to understand more about the ways that carers may perceive benefits and risks to themselves and their children as a result of their child receiving an EPIOC. Events generally happen to families, rather than simply affecting one member of the family [29]. It would be useful to know more about the ways that EPIOCs affect the entire family.

The number of participants was small. Our findings may not be representative of all young people using EPIOCs, such as those who receive their chairs through charitable or private funding. It is possible that our sample may be increasingly representative as the charitable sector moves away from providing wheelchairs for those young people eligible for NHS EPIOCs. Nevertheless, further research should compare the experiences of different EPIOC users, namely those who receive chairs from private, charity and NHS funding in order to obtain a clearer picture of all young people's experiences of EPIOCs.

Assessing comments on waiting times is difficult as users may be referring to the time that someone first mentioned getting an EPIOC, the time from home assessment by district team, or the time from the service accepting a referral. Future work should delineate satisfaction with each of these waiting times.

There may also be disparities in the way that young people and professionals supplying the chairs perceive benefits and risks. For example, it is not known whether the NHS is aware of the number and nature of the accidents and discomfort that children report. It may be advantageous to explore whether the reports of young EPIOC users 'fit' the knowledge of their service providers.

Implications for wheelchair manufacturers and service providers

Given the high frequency of wheelchair football as a recreation, service teams should potentially make enquiries about users playing wheelchair football in chairs, with consideration given to strengthening footplates for those young people expressing a desire or motivation to play. Service teams should also bear in mind that the manual wheelchair still seems to be a prerequisite for many young people travelling. Services need to ensure that the manual chair is as carefully provided as the EPIOC and not just considered as a 'backup' chair.

Users and families are left to their own devices to arrange car adaptations, ramps and chair lifts. EPIOC use becomes limited to the local environment due to the cost, time and energy needed for

transportation. This potentially results in less independence and a higher burden to families. In the UK, funding for vehicles is assumed to have been given through the 'mobility' component of the Disability Living Allowance. If this has been used, it may be difficult for users to find a deposit often needed to enable purchase of a vehicle. The young age of the users may also mean that parents have not had the ability to acquire financial reserves to cover such costs, particularly as disabled children incur many additional costs on the family [30]. Some young people would have had special seating on their EPIOC base which is needed for pressure relief, comfort and support, but also contributes to bulkier chairs. Further financial support is needed for users in the area of EPIOC transportation. This would require extra funding, but transporting mobility equipment may be as important for some users as having the EPIOC.

The findings indicate that safety is an important issue. Young people who are unable to effectively command an EPIOC are potentially being given chairs. The eligibility criteria have been published previously [4], but the service has interpreted such criteria flexibly for young people in view of the perceived detriment to their education if they do not have powered mobility. Specifically, it is assumed that young people in wheelchairs will have the same degree of supervision as their peers, and thus may not fulfill a strict interpretation of the need to 'operate a powered wheelchair safely and responsibly on their own without assistance'. One mother's comment '*He's very dangerous outside because his idea of danger isn't top priority*' would suggest that there are risks to this approach, even though all young people assessed for EPIOCs have a full report from a paediatric service available which comments on their age-related level of maturity.

With regard to chair improvement, the safety and comfort of chairs is likely to be enhanced in a number of ways:

- Although EPOC chairs have suspension, EPIOCs do not. Hence, users are likely to experience a certain amount of pain due to the vibration of moving about. Service providers may give extra thought to providing cushions to inhibit some of the vibration.
- Users may appreciate 'swing-away' control boxes on their chairs in order to facilitate access to tables and other furniture when away from home.
- The provision of a horn on chairs may serve to reduce collisions involving other people.
- The design of a suitable 'cape' seems highly desirable, so that young people can still use their chairs in wet weather.

- Further safety training of EPIOC use in different conditions and terrain is essential. Young people being educated in mainstream schools do not usually have access to a therapist to help with this. It is possible that training could be provided through: – a recommended RoSpa scheme; or a charitable sector such as WhizzKids or a Wheelchair user group. One suggestion is a manual or video of the risks of EPIOC use. There is potential for an audiovisual programme, such as an interactive website, to be created to assist young people in identifying risky situations and problem-solving solutions.

Conclusions

EPIOCs provide benefits to young wheelchair users in terms of increased physical and social opportunities. Enhanced functioning translates as independence and personal control for many young people. The value of EPIOCs extends to carers. Mothers and fathers of young people report that EPIOCs not only make their children's lives easier, but their own as well.

EPIOC use is also associated with a number of risks and costs, such as pain and discomfort, accidents and perceived lack of safety, and limited use depending on weather conditions and terrain. Young people still often rely on their manual wheelchairs as a result. When lengthy repair times, wet weather, difficulty transporting EPIOCs, inaccessible buildings or unpredictable terrain such as that experienced when travelling to unfamiliar places do not permit the use of an EPIOC, young people must revert to a 'back up' wheelchair. Despite the imperfect nature of EPIOCs for every situation, most young people and their families were satisfied. The primary area for improvement is ensuring that children and young people do not have to wait for extended periods of time to be assessed for and to receive their means of mobility.

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