#### 1. Introduction

The study of people with disabilities travelling by air has been limited to date however, to the best of the authors knowledge no research has been conducted in this area that focusses purely on children with disabilities. It is important that this research is carried out to see if there are similarities or differences with previous research about the challenges disabled children and their parents face whilst travelling generally so this research studied children with mobility issues and other issues from the perspective of their parents.

## 1.1 Disability Prevalence of Children in the United Kingdom (UK)

The Family Resources Survey (FRS) is a survey carried out by the Office of National Statistics (ONS) on behalf of the Department for Work and Pensions (DWP) and UK Government (Office for National Statistics 2018). The survey is a representation of the UK population where 19,000 households were interviewed on a variety of topics and issues including disability and care needs. The FRS estimates that there are 13.9 (22%) million people with a disability in the UK, with 1.1 million of this population being aged between 0 and 19.

The National Health Service (NHS) in the UK provides wheelchairs for those who need them through wheelchair services. England is the only country in the UK that currently collects data regarding wheelchair users, with 66,209 children currently registered with wheelchair services although there are no figures that split these numbers into the levels of need (NHS England 2017).

#### 1.2 Aviation Growth in the UK

The aviation industry has always experienced growth in terms of flights per year and the number of passengers who go on them. The Civil Aviation Authority (CAA) collects data on these aspects and since 2012, flights have increased at a rate of roughly 1% a year which although sounds small equates to roughly 150,000 flights per year (Civil Aviation Authority 2012; 2017). The growth trend is even larger in terms of passenger numbers at a steady rate of roughly 5% a year, equating to an extra 64 million passengers per year compared to 2012 (Civil Aviation Authority 2012b; 2017b). To place these numbers in perspective this equates to an average of 8,780 aircraft movements and 789,155 passengers taking a flight every day of the year (totals divided by 365 and rounded) (Civil Aviation Authority 2017a; 2017b). The CAA does not publish data on passengers with disability who travel, although given that 22% of the population have a disability it could mean that 173,614 people per day fly with some form of disability.

#### 2. Aim and Objective

Previous research has identified several issues that adult people with disabilities encounter whilst travelling by air such as manual handling issues, being unable to access the toilet and a variety of negative emotional issues (Poria et al. 2010; Saari 2015; Davies & Christie 2017). These research studies focussed on adults and there is currently no published literature on children with disabilities who fly. Historic transportation research on children with disabilities who use a wheelchairs has found a difference between the minimum required

standard of safety and an observed reality of practice when travelling on ground transportation (Everly et al. 1994; Yonkman et al. 2010). Further guidelines exist on the transportation of children with special healthcare needs but do not mention or consider air travel (American Academy of Pediatrics 2002).

The aim of this study was to explore the viewpoints of parents with children with disabilities who utilise air transportation including preparing for flying, in and around the airport and on board the aircraft. Although there are many disabilities, this research focusses on children who are wheelchair users, aged between three and seventeen. The objective of the study was to carry out semi structured interviews with parents of children with disabilities. This was to find out if the issues identified in previous research on people with disabilities who fly are different or the same between adults with disabilities and children with disabilities. Consideration was given to interview the children directly however was decided against due ethical concerns and that parents are often the primary care giver for their child which offered an extra perspective from adults with disabilities.

## 3. Methodology

The social model of disability focusses on the idea that an individual is disabled by society rather than by their impairment (Oliver 1990). There is more to understanding the needs of people with disabilities than a health issue whilst interacting with an environment (O'Day & Killeen 2002). A qualitative approach was considered the most appropriate solution to obtaining the best quality data possible through the use of semi structured interviews to collect participants knowledge and experience of a subject or theme (Creswell 2012). To best collect and analyse the experiences, values and beliefs of the participants, content analysis was used to interpret the textualized data through identifying themes (Hsieh & Shannon 2005). This method of qualitative research is also favoured in the research of marginalised groups of the population, particularly those with health conditions (Graneheim & Lundman 2004; Erlingsson & Brysiewicz 2017).

### 3.1 Participant Recruitment

We aimed to recruit a variety of adult participants aged 18 years old and over. An appeal on Twitter, a social media platform was used to advertise for participants. The advert was well received which led to seven parents of children with disabilities emailing the author enquiring to take part, all of whom did. Further recruitment of participants was not sought at this stage because this was an initial study and the targeted group of people is very small (Guest et al. 2006).

In compliance with the University College London (UCL) Research Ethics Committee (REC), the participants were sent an information sheet and a consent form prior to being interviewed as per the approved ethics application 10337/002. Semi structured interviews were conducted with seven participants who agreed to offer their experiences as parents of children with disabilities who travel by air.

### 3.2 Interview Topic Guide

A semi-structured topic guide was designed into seven sections to capture the experiences of the participants. The first section was a collection of 'Individual Characteristics', obtaining information about the participant whilst allowing the interviewer and participant to build a relationship. The next four sections were the main focus of the interview that included: Procedures, Preparation & Planning; Around the Airport; The Aircraft and Leaving the Airport & Equipment Issues. Two further sections followed that allowed the participant to offer their own recommendations to the aviation industry and to discuss anything else regarding flying with a disability.

### 3.3 Interview Analysis

The interviews were transcribed by a professional transcription company and then anonymised to remove bias so that the researcher could analyse the data neutrally. Inductive content analysis was used to identify themes as there were no previous studies found in this area of research and several themes were found amongst the seven transcripts (Elo & Kyngäs 2008). The data was coded manually, and another experienced researcher also themed a transcript to ensure consistency.

#### 4. Results

The following section is a presentation of the results and themes identified in this piece of research.

## 4.1 Participants

Seven parents of children took part including two fathers and five mothers aged between 36 and 61 years old. The average age of a participant was 47.71 years. All of the participants children have been disabled since birth and have complex care needs in addition to the primary diagnosis. The majority of the children had a wheelchair that required someone else to move it as they were unable to do it themselves. All of the children had professional personal assistance except for one child who was too young for them and still cared for by their parents.

Participant	Gender	Age	Childs Disability	Disabled from Birth	Chair Type	Personal Assistants
A	М	56	Undiagnosed	Yes	Powered	Yes
В	F	45	Cerebal Palsey	Yes	Manual (Attendant Propelled)	Yes
С	F	46	Cerebal Palsey	Yes	Adapted Pushchair/Buggy	No
D	F	36	Global Development Delay	Yes	Manual (Attendant Propelled)	Yes
E	М	61	Cerebal Palsey	Yes	Manual (Attendant Propelled)	Yes
F	F	47	Cerebal Palsey	Yes	Manual (Attendant Propelled)	Yes
G	F	43	Neuromuscular Disorder	Yes	Manual and Powered	Yes

Table 1 – Participant Characteristics

### 4.2 Feelings Before Flying

Parents of children with disabilities stated that they primarily fly for the purpose of going on holiday or for medical treatment. Participants were asked how they felt before they travelled by air, with the majority being worried due to being removed from familiar

settings and having to prepare for all potential eventualities. Those who travelled frequently were less anxious because of their previous experiences.

'I suffer with a bit of anxiety and flying with a child, it makes me anxious for lots of different reasons' [Participant D, Female, 36]

'I've travelled quite a bit so I'm not too anxious about it.' [Participant E, Male, 61]

### 4.3 Preparing for Flying

Preparing luggage for a child with a disability to go on a trip was described as difficult and like a 'military manoeuvre'. This was to ensure that suitable equipment was available in addition to having enough medical supplies to last the duration of the trip whilst absent from a setting fit for purpose.

'... we've taken eleven plus cases, and the majority of them are [Name of wheelchair user]'s obviously with all of the equipment that we have to take and fit into suitcases and pack and the cross-infection gloves, wipes; everything, absolutely everything – hoisting, the lot.' [Participant B, Female, 45]

'... we just deal with it as a normal everyday thing but it is definitely more things to think about and carry and make sure that you've got because there's always the worry of things going astray when you put suitcases in the hold so we try to make sure that things are in different cases so that if one goes astray we've still got access to things that we need.'

[Participant G, Female, 43]

#### 4.4 Food & Drug Preparation

Due to the complex care needs of the children in this research, many of them required several different drugs to be taken routinely at the same time every day. This proved difficult when the drugs were in liquid form or if there were a lot of them because not having the drugs available would have a massive impact on the health of the child. Spreading the medication over multiple bags and taking surplus medication were reasons given to avoid being without.

'It's literally military precision with working out much drugs we have to take with us, getting the permission letters from consultants and making sure that they're all labelled correctly for customs to check, and the list of drugs, what doses they are, and emergency drugs we have to carry with us on-board' [Participant B, Female, 45]

'... there were five of us travelling on the flight so I had to split 30 bottles of feed between the five suitcases and just hope that none of them went missing.' [Participant C, Female, 46]

'... he's got problems with swallowing, he needs large portions of nutritional drink – we've learned how to handle it in terms of liquids going through the Security system ... but you need significant quantities of that and sometimes it doesn't really fit in with the baggage allowances' [Participant E, Male, 61]

# 4.5 Separation

The participants said that being separated from their children in certain scenarios could cause them and the child a high level of worry and anxiety. This was primarily a concern whilst going through security or when having to use an ambulift (a mechanical lift to transport people from the floor to the door of the aircraft) in the embarkation or disembarkation of the aircraft as it meant separation from the rest of the family.

'So the ambulift people it's like either their training was not very good or they had no clue about manually handling a severely disabled person from their aircraft seat into their wheelchair; it is a two man job minimum and they would not allow us to do that. They told me to get off the aircraft so I had to leave before my husband was even allowed to lift [Name of wheelchair user] up.' [Participant B, Female, 45]

'... because one person has to go through at a time, I had to push my daughter through and let them take over and then she freaked out because I wasn't allowed to go through and stand with her until they'd checked through the wheelchair, so she was screaming and I then had to go back to go through and so they wouldn't do it together, because of their security which is fine, but couldn't also understand why I was annoyed that my child was screaming, so that bit is horrendous.' [Participant D, Female, 36]

#### 4.6 On Board Issues

Children with disabilities who used wheelchairs encountered the same major problem areas as adult wheelchair users, however there were some major differences between adults and children.

## 4.6.1 Manual Handling

The main difference between adults and children in terms of manual handling is that the parents of children with disabilities do the manual handling instead of the staff at the airport. This is because they feel that the staff do not have enough experience or because they know that their children will not like being handled by an unfamiliar hand.

'... they'd be taken from a place of safety on a mobility device which is medically designed for your posture and your wellbeing, to be taken to – to remove from that is quite unnerving.' [Participant A, Male, 56]

'To be honest, we have to do it, it wouldn't be safe for him to be lifted by somebody he doesn't know so he does need to be lifted by people who know him so that you don't cause him any problems, so it's always been us that have actually done the physical stuff.'

[Participant G, Female, 43]

#### 4.6.2 Seating

The seats on the aircraft were described as unsuitable for wheelchair users, and even more so for children with disabilities. Aspects of seating were discussed including the difference between economy and business class seating from a space and comfort perspective whilst ignoring the obvious financial hurdles. Injuries to children and specialist seating were also mentioned.

### 4.6.2.1 Economy Seating

Participants described seating on the aircraft as being unsuitable for children with disabilities, however bulkhead seating was described as being preferential as it allowed parents more space to attend to their children's needs. The middle seat was the preferred seat for children as it meant that parents and carers could maintain their children's posture and physically support them when required.

'... if I was sitting one side of my son or daughter and a friend was sitting the other side, at least she's got support there' [Participant A, Male, 56]

'... we've been very lucky and got a bulkhead seat to Florida and back again so it was no problem for us, it was very good with the seats and there was room, to get him in and out to feed him, we could stand in front of him to feed him, to give him a drink, all of that.'

[Participant B, Female, 45]

#### 4.6.2.2 Business Class Seating

A business class seat was the preferred option available for the parent because of the space and the adjustment the seat offered which included the option to lie down. A downside was that although the seat offered more space, they could be too wide for a child and may not offer enough postural support.

'... I'd take them first class so they could lie down and have a kip ... but I also know a first class seat doesn't offer enough postural support, in other words, they're too wide' [Participant A, Male, 56]

'A business class seat with double the leg room because you need to be able to stand in front of them to help them' [Participant B, Female, 45]

'... you've got the adjustable seats, so you could – with some cushioning and support, [Name of wheelchair user] could fly in a lying down position – I think probably quite well.' [Participant E, Male, 61]

### 4.6.2.3 Injuries from Seating

A lack of space on board the aircraft led to the injury of children where they were incapable of controlling their motor function.

'[Name of wheelchair user] would literally draw blood with the relentless kicking of the chair in front of him because he hasn't got the leg room, so he needs the leg room to allow

his legs to do their thing and for us to stand in front of him to lift him safely into his chair without dropping him.' [Participant B, Female, 45]

'... his hips are sublux so they're actually not connecting in the normal way, he was in so much pain when he was sitting in the aircraft seat – he can't sit on his own in that position, so I was having to basically hold his body – it's almost an impossible physical act to hold his body steady and supported' [Participant E, Male, 61]

### 4.6.2.4 Special Seating

Some of the children required full postural support at all times, with some options being available including a tomato seat (Bergeron 2018) and a higher-fly go-to seat (Firefly Friends 2018) both of which had adjustable support and straps.

'... there's four of us trying to get [Name of wheelchair user] from his wheelchair seat down the skinny aisle and into the tomato seat and making sure he's strapped in and trying to bend him.' [Participant B, Female, 45]

'Well, what she uses is called a higher-fly go-to seat and what that is is a light-weight portable seat with lateral support, which goes around her chest, and it sits on top of the aeroplane seat. It fastens around the back of the aeroplane chair and she gets fastened into that.' [Participant C, Female, 46]

#### 4.7 Toileting

All of the participants referred to the toilet on the aircraft as being unsuitable for children with disabilities.

### 4.7.1 Experience of Going to the Toilet

In comparison to previous studies where adults did not even attempt to use the toilet, the children did go to the toilet although many failed to physically access the cubicle. Instead, curtaining off an area of the aircraft was utilised as lying down is essential for the children to be able to go to the toilet.

'I attempted to do it a couple of times which means carrying her to the toilet and sitting in there with her to support her because she can't sit on her own.' [Participant A, Male, 56]

'But obviously you can't get away from the fact that there's going to be the smell of urine and poo or whatever's happened because you're changing an incontinence pad. And it's not very nice for anybody. It's very embarrassing for [Name of wheelchair user], like I say, he's very aware of what's going on. And everyone is looking now going, "What's going on? They've made a tent around that person, what's happened? Have they collapsed?" You can hear it all, all the chatter.' [Participant B, Female, 45]

'Yes, in one word – nightmare, 100% nightmare (laughs). They're not big, they're not set up for disabled people, there's nowhere to lay her down to change her; it is one of the worst experiences ever, it is terrible.' [Participant D, Female, 36]

'Really hideous. They curtained off a very small area near the galley, and my husband and I would lift him down, carry him down to that little area, I would lie him down in this curtained area, sort clothes, lift him up and then my husband would poke the toilet chair into... so that my son could use the toilet and then again it would be same afterwards, I would be trying to clean him up, lift him off, my husband would then have to deal with the contents whilst I laid him back down in this relatively small space, sorted him out, got his clothes back on and then we'd have to carry him back up the plane.' [Participant G, Female, 43]

### 4.7.2 Experience of Not Going to the Toilet

For some children, it was not possible to use the toilet on the aircraft and so they would have to wait until after the flight. This risk can be reduced by using the toilet at the airport as close to the flight as possible.

'If the toilets weren't available and her bowels moved mid-flight she would have to sit until I got to the airport at the other end before I would be able to change her.' [Participant C, Female, 46]

'So, really you have to organise the time so that he's had a change before he goes that's left as late as possible' [Participant E, Male, 61]

#### 4.7.3 Coping Mechanisms to Avoid the Toilet

To avoid using the toilet on the aircraft, several alternative methods have been used including incontinence pads, catheterisation and fasting before a flight.

'... my son, he can't use the toilet, end of – he has a pad on and I attach a catheter, so that he can sit there and the catheter bag fills up while we're traveling by air.' [Participant A, Male, 56]

'... that's exactly what it is, it is a nappy. But when they get older, it's known as an incontinence pad because he's an older child and he's not a baby.' [Participant B, Female, 45]

'... he has his own coping mechanism which was if something is going to be a long time he will just not take fluids, but that's not good.' [Participant E, Male, 61]

#### 4.8 Wheelchair Issues

Many of the participants reported that they had found elements of damage to their children's wheelchairs. This was a key issue for children as they were unable to use the

airport wheelchairs due to them being unsuitable for them as they were too big or did not provide the correct postural support.

#### 4.8.1 Damage

Participants reported varying levels of damage to their children's wheelchairs, which was devastating due to it being essential for mobility.

'Crushed in the hold and we've had another issue where they took all the wires out – absolutely every single wire going, despite the fact that I'd made it inoperable, they just carried on taking wires' [Participant A, Male, 56]

'I think they've lost one or two bits of parts of the chair but then we got wise and made sure we detached things that were detachable, like footplates for example and said we were going to put those in the overhead luggage and they agreed. [Participant E, Male, 61]

'Well, all four wheels were no longer on the ground, the back was so badly twisted you couldn't have sat him in it, one of the lateral supports was broken, there were sharp edges all over it, it was severely battered.' [Participant G, Female, 43]

### 4.8.2 Baggage Claim

Sometimes the baggage handlers do not return the wheelchair to the door of the aircraft. This caused huge anxiety and stress due to the uncertainty of the location of the wheelchair, in addition to extra manual handling from a physical perspective.

'Anyway they just kept us waiting for over an hour so in the end my husband – he was only three – just picked him up and he carried him down to baggage where the buggy was, so then we set it all up and got him in it. But, we couldn't do that now because he's twelve and as tall as me.' [Participant B, Female, 45]

'... they had to get an adult wheelchair, I had to then carry my son, sit in the chair myself and someone push us both because he couldn't have sat in that chair because he couldn't support himself. So, he had to sit on my lap with someone pushing us both to get to where we could reclaim his chair which was really embarrassing, uncomfortable and stressful because you now don't know where your chair is.' [Participant G, Female, 43]

### 4.8.3 Emotional Appeal

In an effort to emphasise the importance of the wheelchair, some parents attached pictures and messages to the wheelchair to remind the baggage handlers that it was more than just a piece of equipment.

'I've made a sign with a big picture of [Name of wheelchair user] sitting in his wheelchair saying, "Please be careful with my wheelchair"; it's been laminated, it gets attached to the back of the wheelchair so that people just kind of humanise or realise that there's a little boy who uses this chair' [Participant B, Female, 45]

#### 5. Discussion

Participants views suggest that travelling with children who have disabilities was difficult but manageable. The participants fulfilled both the role of parent and specialist caregiver and so the study also found that the majority of assistance was given by the parents as they would prefer to do it themselves. Service providers often provide physical assistance to people with disabilities and often forget the emotional strain that can occur. Alternative assistance to children with disabilities and their parents could be investigated, particularly in terms of process issues around separation, loss of dignity and looking after the wheelchair.

The physical impact on parents is acute in terms of manual handling their children around the aircraft and supporting their postural requirements or preventing injury whilst sitting on the seat. Physically moving or supporting children with disabilities increases in difficulty over time as the child grows and the parents age where one female participant stated that it got more difficult after the onset of the menopause. This was of particular concern as there will be a time when the parent will be unable to physically handle their child, that could lead to the emotional and physical distress of both parent and child.

Previous research indicated that adults with disabilities will not attempt to use the toilet on board the aircraft and instead use multiple coping strategies to avoid incontinence (Poria et al. 2010; Davies & Christie 2017). Children with disabilities will employ similar tactics to their adult counterparts to avoid needing the toilet, however their parents will help them go if required. Considerable emotional distress was experienced if the child went to the toilet in their seat with a tent over them or on the floor of the aircraft in the galley. The space inside the cubicle remains a big issue as many of the children in this research were unable to sit unsupported and therefore for a parent to physically support them proved difficult. Depending on the children's care requirements, many of them required a commode or a changing table in addition to a medical grade hoist so that they can lie down whilst being attended to by a parent or carer.

The findings from this research could have an impact on disability legislation, policies and service providers as flying with a disability is not the same as an able-bodied person. Therefore the legislation that protects people with disabilities whilst flying such as The Equality Act 2010, European Union Regulation (EC) 1107/2006 and The Air Carrier Access Act 1986 could be at risk of being of being violated with the potential of many negative outcomes (U.S. Department of Transportation 1986; Kingdom 2010; The European Parliament 2006).

#### 5.1 Strengths and Weaknesses

This study focussed on the children with the most severe disabilities and thus they represent the most vulnerable group of users who choose to fly. The participants, who are also the parents of the children provided a strong insight into the needs of the children as they were fully able to articulate their children's disabilities and needs given that they are also the primary caregiver. The sample was recruited through a social media campaign and so were all fresh contacts to the researchers who were from all parts of the UK whilst having

children of varying ages. Although the sample size was relatively small, the total population of these users will also be very small and so is not considered an issue.

#### 6. Conclusions

Children with disabilities largely experience the same issues as adults with disabilities with some differences. Fundamental issues included helping children with disabilities go to the toilet either not having enough space or a lack of equipment; separation issues at security and from their wheelchairs and the seats on board the aircraft being inappropriate. The presence of parents largely renders the disability service provision redundant because parents would prefer to help their children themselves.

#### 7. Recommendations

The following recommendations are suggested to improve the transit of children with disabilities who fly.

## 7.1 Toileting Issues

> Standard disabled toilets are unsuitable for a child with complex care needs. These should be changed where possible to or have access to the correct facilities, known as a Changing Places toilet in the UK, at all areas of an airport (Changing Places Consortium).

Airlines should show more sympathy in allowing additional hand luggage for incontinence on board the aircraft

### 7.2 Aircraft Design

➤ The seating position for children is vital and so a redesign of the seat, equipment or aircraft should be considered for the comfort of the child and the parents that help them.

A parent and child should always have the seat on the aircraft with the most space, preferably a seat with the ability to be turned into a bed or flat surface.

 > Aircraft designers should investigate using a wheelchair as a seat on board the aircraft.

## 7.3 Policy Considerations

 Disability service provision at airports should think about how the service could be different for children with disabilities and provide specialist training in this area in conjunction with parents.

Legislators should investigate and consider the extent to which regulations are currently being met or missed and advise changes if appropriate.

#### 8. Implications for Future Research

The scope for further research in this area is vast. The double edge sword of being both a parent and the primary caregiver has given a different insight into the way children with disabilities fly and so further global qualitative research on this population should be carried out. These views could also be enhanced by collecting the experiences of the airlines and airports. Participants felt that the ultimate goal of their children being able to fly in their own wheelchairs was essential and so research into all the aspects of this form of travel should be investigated to see if it is possible.

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### **Acknowledgements**

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The authors would like to thank the participants for their input and time.

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comparison of best practice to observed and reported practice in a pilot sample.

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