

Play/recreation experiences of young wheelchair users.

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Abstract

Despite a rapid increase in research into children and young people's lives, the experiences of disabled children – and in particular disabled young people – still remain largely overlooked. This chapter offers some reflections on the leisure experiences of young wheelchair users (13-17 years) in their homes and across a range of public spaces. The data that are presented were collected during a multi-method UK-based project which was designed to capture their use of different spaces away from the school environment. The teenagers and their parents discussed the physical and social barriers inherent in these places which impeded on their access to leisure. Their contributions signal the importance of situating the leisure experiences of young people in the context of families. The complex relationships and negotiations between parents and teenagers in accessing leisure are explored, signalling the ways that they work together, or at times in opposition, to open up or close down leisure opportunities.

Introduction

Despite a rapid increase in research into children and young people's lives, the experiences of disabled children – and in particular disabled young people – still remain largely overlooked. This chapter offers an introduction to debates on geographies of play/ recreation and disability, building on existing accounts of the recreational challenges experienced by disabled adults, and those experienced by non-disabled young people to introduce the complexities associated with how young wheelchair users negotiate both public and private recreational spaces. In order to illustrate these issues, the chapter draws on the findings of a project which focussed on the leisure experiences of young wheelchair users (13-17 years). These experiences were collected during a multi-method UK-based project which was designed to capture their use of different spaces away from the school environment. In particular, the chapter will illustrate a range of interplays between the family members – notably parents - of young wheelchair users which close down or open up leisure opportunities.

The study was designed to gather the views of the young people, and indeed strategies were developed at the outset to ensure that young people who used a range of communication approaches could be involved representing their own views rather than taking part with the use of adult proxies (Pyer and Campbell, 2013). As the research progressed, it became clear that the experiences of these young people were inherently linked to the views, anxieties and support of their parents. This chapter draws together some instances which illustrate the myriad of ways in which these relationships opened up or closed down leisure for the young people that participated. The chapter will be of interest to geographers with an interest in the play/ recreation of disabled young people, the range of environmental and social constraints that they encounter and the strategies that they respond with to improve their experiences.

Context: young wheelchair users and recreation

Leisure as a concept is hard to define. It varies across disciplines, cultures and time. Purrington and Hickerson (2013) draw a distinction between 'free' child play and 'restrained' adult leisure (p. 133), arguing that whilst they both generally occur in addition to everyday living needs, participating in leisure reflects self-discipline and the acquisition of cultural norms. It is not within the remit of this chapter to discuss in detail the meaning of these terms, however it is important to note at the outset that the focus of this study were the spaces that young wheelchair users used during their time outside of school, and those that they related to 'play' or 'leisure' activities. Thus, the experiences presented in the discussion that follows reflect their own interpretation of play, or leisure opportunities. These signal participation in a range of pastimes which incorporate both 'free' or 'restrained' activities. The term 'leisure' is used as an inclusive term to reflect the range of activities that they shared.

Leisure is important. Its value has been argued at a range of scales, from its potential to impact on community inclusion and participation, to its ability to enhance feelings of belonging in a range of settings (Welch, Collins, Hatton, Emerson, Robertson and Wells, 2013). Distinctions can be made between the long-term benefits of leisure, which signal its significance for children and young people's future selves, and its worth for their wellbeing in the present. Often, the former can be aligned to the (professional) developmental perspective of adults; leisure for future good (Pollard and Lee, 2003). Thinking about the importance of leisure from this stance signals its significance on growth and development, enabling exploration of the world and skill and identity development (Feinstein, Bynner and Duckworth, 2006; Fjortoft, 2004; Hixson, 2013). This is especially so during the teenage years. In this sense, leisure is important as a future investment (Purrington and Hickerson, 2013).

Research with disabled adults has similarly signalled the benefits of leisure and the opportunities it affords in terms of increased self-esteem, improved confidence and psychological wellbeing, physical health and fitness, reduced risk of illness and increased opportunities for social relationships (Aitchison, 2003). Research into the leisure experiences of disabled adults signals how particular leisure spaces are often discussed in terms of their usefulness for rehabilitation (Burns, Watson and Paterson, 2013), emanating the professional approach discussed above, rather than in relation to current enjoyment or wellbeing.

With these considerations in mind, it is also important that the intrinsic enjoyment of leisure in the everyday lives of disabled children and young people is not overlooked; indeed it is this element of leisure that has been prioritised by young people when discussing the benefits of leisure opportunities. In this way, leisure can be situated as an end in itself (Harker, 2005; Powell and Wellard, 2008) with the potential to positively enhance current wellbeing (Shikako-Thomas, Kolehmainen, Ketelaar, Butt and Law, 2014; Statham and Chase, 2010).

Barriers and restrictions to participation can impact on how young people view, relate to, use and experience particular spaces, challenging ideologies which promote leisure as associated with free time and free will (Purrington and Hickerson, 2013). Some of the barriers experienced by disabled young people in attempting to access leisure opportunities are not dissimilar to those experienced by their non-disabled peers (John and Whewey, 2004); however they may face additional challenges. These become all the more significant when placed in the context of exclusion from fully-participatory education or employment, freeing up more of their time (Kelly, 2005) and inadvertently promoting exclusion, particularly during holidays and out of school term time (Knight, Petrie, Zuurmond and Potts, 2009).

A number of issues might impact on the decision making associated with visiting particular leisure spaces outside of the home. In general, choices are often

influenced by the social environment that they offer, time and cost implications. Young people also have to negotiate permissions from adults in the context of increasing social fears for their safety (Giddings and Yarwood, 2005). One of the key barriers to leisure participation cross-cutting research with young people and disabled adults is the notion of 'risk'. In the case of young people, adult fears for safety mean that spatial sanctions are imposed at a variety of levels (Jones, 2000), impacting on the ways in which they access and make use of public and private spaces. In public spaces, young people often have to re-negotiate their place between constraint and choice (O'Brien, Jones, Sloan and Ruston, 2000). Countless accounts exist of the contrasting ways that adults and young people see the world around them, illustrating that there is no 'one' leisure experience.

Young people therefore face multifaceted challenges in accessing leisure. The challenges experienced by young disabled people – and in the context of this study young wheelchair users – are further compounded by issues of exclusion associated with the social and physical environment. Certain aspects of places which are taken for granted by non-disabled people might be considered in different ways by the gaze, choices and actions of a wheelchair user (Imrie, 2000; Matthews, Beale, Picton and Briggs, 2003). Inaccessibility in public environments can close down or limit leisure opportunities for young people where spatial characteristics serve to disable people (Knight, Porcellato and Tume, 2013; Park, Radford and Vickers, 1998). Spatial construction can serve to exclude by keeping disabled people 'in their place', whilst simultaneously highlighting them as 'out of place' (Kitchin, 1998, p. 345).

The challenges associated with accessing public leisure environments provide a context in many minority world countries in which young people are increasingly spending their spare time at home (Valentine, 1999). This is particularly the case for disabled young people who spend more time at home than their non-disabled peers (Beresford and Rhodes, 2008). Homes have also been signalled as a site of conflict for young people and their parents (McNamee, 1998), where the power held by each individual is constantly renegotiated (Blunt and Dowling, 2006). Teenagers often do not have the opportunity to exert power and adapt space in the home to their own needs, particularly in familial areas. Lincoln (2005) illustrates the importance of bedrooms to teenagers, as they are 'often the first place in which they are able to exert some control' (p. 400). A growing number of texts have discussed the need for (service supported) adaptations to be made in the homes of disabled young people, focussing largely on their daily needs in relation to washing, sleeping and eating (Beresford, 2003; Heywood, 2004). This signals where distinctions are made between provisions aimed towards supporting basic living needs, and others which might support the autonomous, spontaneous use of home spaces for leisure activities.

Methods: hearing from young people (and their parents)

The primary participants of the study were wheelchair using young people, aged 13-17 years. This is an age where non-disabled young people are reportedly increasing their autonomy in relation to leisure. The 13-17 year range is also the time when young people have potentially have the most multifaceted experiences of space, situated between considering themselves as having outgrown adult organised activities but still experiencing the confines of adult regulations (Childress, 2004; Valentine and McKendrick, 1997). Participants were initially recruited through special schools in the Midlands, East and South East of England. These locations provided opportunities to work with a variety of young people in a range of settings, rural and urban, in the counties. Throughout the chapter, the terms 'indoor' and 'outdoor' public spaces are used: 'indoor' public spaces refers to shopping areas, cinemas and fast food restaurants, whilst 'outdoor' public spaces refers to streets and roads, parks and playgrounds and natural environments such as woods or open fields.

The key driver underpinning the methods used during the study was inclusivity. A multi-method approach was selected in order to facilitate the collection of experiences and views from a large number of young people, as well as providing the opportunity to work in-depth with a sub-sample of them. Often, the only people recruited to participate in research are those who can express themselves verbally (Lloyd, Gatherer and Kalsy, 2006) and so for this research methods were selected on the basis that they enabled the young people to share their experiences in ways which did not rely solely on the written and spoken word. This was particularly necessary because many of them used non-spoken forms of communication (e.g. sign language, communication symbols or responsive movements). The participants used a range of different wheelchairs, including manual and electric (self and assistant propelled); many of them used multiple wheelchairs.

The methods employed included structured interviews with 69 young people, a photography exercise with associated interview (13 participants) and participant led video tours (9 participants). The findings that follow are drawn from discussions arising from each of these methods of data collection. Transcribed data were analysed thematically (O'Reilly, Ronzoni and Dogra, 2013) and a process of ongoing analysis was applied whereby during discussions participants of the second and third stages of the project were asked to reflect on the themes arising from the method that preceded it.

In the research, the position of the researcher as an adult 'outsider' meant that steps were taken to avoid influencing the activities that they took part in. It was recognised from the outset that only partial understanding of the lifeworlds of teenage wheelchair users may be gained; although children and adults may use the same spaces, they view them differently because what they expect and what they are expected to do there is likely to differ (Young and Barrett, 2001). For this reason at the planning stage of the study careful consideration was given to ensuring that the views obtained were those of the young wheelchair users

themselves, and not those around them (a detailed discussion of the issues considered as part of these strategies has been published elsewhere: Pyer and Campbell, 2013).

Family geographies and leisure: barrier, cause and response

The research discussed in this chapter was designed to capture the experiences of young wheelchair users in accessing leisure opportunities. A focus on indoor and outdoor public and private spaces away from their schools were loosely defined as the geographical remit; further to this the discussions completed with the teenagers drew on their own interpretations of the places that were important to them during their leisure time.

Whilst from the outset of the study priority was given to the views of young people in isolation, as the project progressed it became increasingly evidence that the experiences of the teenagers were intricately associated with the actions, anxieties and decision-making of their parents. These underpinned many parents' willingness (or not) for their child(ren) to spend time independent from them in public places. During the photography exercise, participants were asked to complete a diary which illustrated how (and where) they usually spent their time on a weekday during school term time and at the weekend. Typical examples of these are offered in Figure 1 and Figure 2, which illustrate the extent to which the teenagers spent leisure time with their parents.

Figure 1: Spending time with adults (1)

Figure 2: Spending time with adults (2)

These timetables begin to intimate the close relationships of the teenagers with their parents, and the extent to which they spent much of their leisure time together. Discussion of the experiences of the teenagers in isolation would therefore, not represent the range of inter-plays associated with their leisure time. The discussion that follows teases out some key examples that the teenagers - and their parents - discussed with a view to illustrating some of the complex ways that these interactions could open up or close down leisure opportunities for these young people.

'Closing down' leisure: environments, decision-making and anxieties

In discussing their leisure experiences, the teenagers cited a range of challenges, or barriers, which acted to close down leisure opportunities for them. These barriers arose from both the built environment and in the form of restrictions introduced by the decision-making of those around them. The restrictive nature of their homes was frequently cited in relation to their leisure needs. Whilst the layout of their homespace was often considered accessible by service providers (who often implemented adaptations based on the everyday living needs of the young people), the stories recounted by the teenagers

intimated that their homes were often not geared towards their leisure wants and needs. Figure 3 gives an example of a diary completed by a fifteen year old male which was typical of the responses received. Some of the teenagers spent relatively short periods of time in their rooms, and, in contrast to non-wheelchair using young people, a number also explained that the use of these spaces for leisure in their spare time was problematic. This is particularly significant given the findings of previous research which asserts that young disabled people often spend more time at home than their non-disabled peers (Beresford and Rhodes, 2008).

Figure 3: Time spent at home

A large number of the teenagers in the study noted that there were areas of their home that they could not access unaided. Further exploration of this issue showed that, in addition to the structural barriers within their homes, opportunities were also closed down as a result of decision-making within the home. Restrictions often arose where leisure-related equipment (most notably computing or gaming equipment) was placed in parts of the home which were inaccessible to them. One example of this is shown through Sarah's contribution to the study. Sarah wanted to make use of the internet to play online games, however the physical and social restrictions within her home prevented this. She explained that restrictions on school computers which placed limitations on access to sites of this kind.

I can't use [the internet] at school either because all the sites...I like going on games sites, where you get to play games for free, but you can't do it on them because of the access and it says 'access denied'. It *sucks*.

Sarah, 15, electric wheelchair

Sarah explained how her younger brothers, who could access this area of the home, were able to use these sites. Previous research has signalled the sibling rivalry resulting from young people's use of media equipment in the home and the contested use of bedroom space where computers or games are located in the bedroom of a particular sibling (McNamee, 1999). In Sarah's case, the phone connection which supported internet use was located in a room which was inaccessible to her, unless supported by another member of the family to access it.

This is one example where decision making within the home environment influenced the impact of building inaccessibility in relation to leisure opportunities. Parental influence was also apparent in other, more subtle, ways around the home in relation to leisure. The contributions of James and his mother illustrate one way in which this was the case. Whilst James was able to spend time playing computer games in his room, his parents instigated rules to limit the types of games that he used, and the length of time that he spent

playing them. Whilst this is not unusual behaviour for families with teenagers of James' age (15 years old), the ways in which these rules were enforced relate back to the spatial restrictions that his home afforded.

Mother: Because sometimes he can play for quite a while. He doesn't like to use the one hour rule...For some reason [playing the playstation] really triggered aggression with him, and he screamed and screamed all the time as he was playing...and if he loses control and starts banging, his room's up above the dining room and that's our second light fitting there...and we give him a warning. If he bangs all I do is go to the bottom of the stairs and say 'that's one'...

James: Yeah and then there's the electric switch.

Mother: ...that was one of the best things, I could do it from here, yes he's mad but, I'm not getting hit, I'm not getting things thrown at me.

Mother and James, 15 years, manual wheelchair

In this instance, the restrictions stopping James from moving independently around his home were used by his parents to re-enforce rules around the use of gaming for leisure.

The interplay between family members also had an impact on the leisure opportunities that were opened up to the young people outside their homes. Concerns of adults – most notably parents – for the young people's safety were a frequently discussed issue in relation to accessing leisure. Examples of this were apparent in the transport use of the young people. Some parents voiced reservations for their child using public transport to access leisure. Their anxieties were often drawn from worries about the inaccessibility of transport services and anticipation that their child would meet barriers in making use of them making them unsafe.

I'd be worried in case there was a problem getting on the train or something. I wouldn't want him doing that on his own.

Mother of 15 year old male, manual wheelchair

I can't go to the cinema on the bus...mum says I might get stuck somewhere.

Female, 15 years, multiple chairs

Whilst the teenage years are usually a time for expanding independence from the family and increase agency (Wray-Lake Crouter and McHale, 2010) this was not the case for most of the young people who participated in this study. Whilst young people's wish to develop their autonomy at this age can sometimes be at odds with those of their parents, leading to disagreement and conflict, this was

not the case for these families in relation to transport use. The concerns of the parents illustrated above were also mirrored in the contributions of the young people. A number discussed a wish for opportunities to develop their autonomy whilst at the same time sharing the concerns of their parents for their safety. The use of public transport often signified worry and fear on the part of the teenagers but for reasons which contrast to those detailed in research with non-wheelchair using young people which intimates that their concerns often arise from social factors, for example bullying on public transport (Osborne, 2005). Examples given by the people participating in this study centred on physical access issues, illustrating that on occasion their fears had been realised.

Mark does not risk using public transport in case of getting stranded. At certain train stations there is only one lift. If it is not working then it is impossible to get off at certain platforms. When Mark was nine a train ended the journey on a different platform and Mark had to cross the tracks to get back to the ground floor leaving Mark scared for his safety.

Researcher diary extract

Where this was the case the result was often that public transport was closed down to the teenagers, through a combination of their own, and their parents, fears for their safety.

Whilst the feelings of the teenagers reflected those of their parents in the use of public transport, they offered somewhat different accounts when discussing their experiences of trying to access leisure in public places. A range of barriers exist for wheelchair users which impede access to public places. Queues, negative social responses and physical access issues are all commonly cited issues in previous studies (Knight et al., 2013) and these can contribute to a reluctance from parents to spend time in particular settings. The teenagers in this study signalled the presence of barriers in the built environment including steps into buildings, corridors not wide enough for a wheelchair to pass and the height of reception desks (see also Bromley, Matthews and Thomas, 2007; Church and Marsden, 2003). The stories that these young people told went further, signalling the social impact of social 'othering'. Whilst previous research has noted the lack of status afforded young people in public spaces (Giddings and Yarwood, 2005), the teenagers recounted how the 'gaze' of others – adults, children and young people alike – influenced their willingness to access particular places; it was here that socially-based fears were most apparent.

When people look at me, your disability, and then it's 'what's the matter' and 'what's wrong'...it's like when we went to town, it's like that 'what's the problem' because they said I'm paralysed on my legs.

Greg, 16, electric wheelchair

I expect it rather than, I expect them to do it and then I'm surprised when they don't, rather than expect them not to do it, if you can see what I mean. It sounds a bit backwards, but it's just how I've got used to it.

Lucy, 17, electric wheelchair

The challenges that the young people met in accessing outdoor public places were represented differently. Geographical research with non-wheelchair using young people has signalled the importance of public outdoor spaces like local streets to young people's enjoyment. They afford opportunities to socialise with peers and to spend time independent of the adults in their lives, developing autonomy (Hopkins, 2010; Valentine, 2004). The young people participating in this research noted spending very little time in outdoor public spaces, indeed when asked about the time that they spent outdoors responses often included experiences of time spent in the private gardens of their homes. Barriers inherent in the built environments such as surface type or kerb height (see also Bromley et al., 2007) often played a part in closing down these spaces to them. In addition, barriers of this kind often led to a need for assistance from adults (most often their parents) and limiting autonomous use of these places.

With these issues in mind, the relationships that the young people had with adults also impacted on their use of public outdoor spaces. The concerns of parents for their child's safety illustrated in discussions on indoor public spaces were again evident in considerations of outdoor public spaces. These concerns were also often coupled with concerns for their child's particular (in)competence at negotiating these spaces, leading to mediation of their free time through the introduction of rules.

Mother: ...there is nothing in this county that will do that, where you can know that...they're there and they're safe. I have to be there every second...

Mother of 15 year old female, multiple chairs

Chris: If I go out [with my friends] for a walk after school we always have to have someone with us...to make sure we're OK. They make sure we don't go too far...

15 year old, manual wheelchair

The teenagers would often only be enabled to use particular spaces if the adults with them deemed them safe and their children competent in their use of them. Where this was not the case – which was a common reaction – many spaces open to their able-bodied peers of the same age were closed down to them, often completely. Alex, a 15 year old, often made comparisons between his spatial range and that of his brother, citing instances where his brother had

opportunities to spend time with friends outdoors; Alex's parents feared for his safety and therefore these places were off limits to Alex himself.

Alex: I want to go and play out with my [twin] brother, which I can't do.

Mother: Because there's nowhere safe...he just couldn't go out on his own [to brother] could he? Not to the places that you go to.

Alex, 15, manual wheelchair

Parents' perceptions of risks associated with the outdoors were coupled with concerns that the teenagers were incapable of negotiating challenges – or at the extreme dangers - independently. The concept of risk and its impact on adult rulemaking for children and young people is not new (Pain, 2004); indeed Cloke and Jones (2005) note that adults' desires to represent children as innocent have the potential to limit the spaces that they use. Concerns of this kind are usually voiced in relation to the lifeworlds of young children; by the early teenage years parents often feel that their offspring are developing an awareness of the risks associated with spending time in public places (Gill, 2007).

Risk has also been cited as a reason that disabled adults may choose not to spend time in outdoor places, leading to arguments suggesting that risk in itself is used to exclude disabled people (Burns et al., 2013). The young people in this research did not discuss fears for their own safety in outdoor public spaces in the same way as their parents did, illustrating that perhaps they viewed the 'risk' associated with outdoor more seriously than those inherent in indoor public spaces. Parents, on the other hand, painted their offspring as innocents, and in need of protection in their accounts. They stressed the need for their constant supervision for their own safety and signalled the ways in which risky situations could be avoided. In most cases this restricted the use of outdoor spaces by the teenagers to times when adults were available to accompany them however for some young people this closed down opportunities for spending their leisure time in these spaces completely.

'Opening up' leisure: strategies, aspirations and negotiations

The multifaceted negotiations of the teenagers within their family units also reflected the importance of 'family' in opening up leisure opportunities. The families responded to the challenges inherent in accessing leisure in a range of different ways. As the needs of the teenagers changed, so too did the strategies that they and their parents employed to overcome barriers to leisure in both private and public spaces.

Some of the restricted elements of the teenagers' homes have already been discussed above, with the impacts of restricted home environments in terms of dependence, reducing confidence and enhanced levels of stress (Beresford and

Rhodes, 2008). A number of the families in this research had developed their own adaptations and strategies in their homes to enhance freedom of movement and access. In this way many of the teenagers had worked with their parents to increase their independent use of the home for leisure.

This is illustrated through Alec's experiences. He explained that his wheelchair would not fit through the doorways of his home, or manoeuvre in the small available space within his living room. To enable independent movement within his home, he and his parents had trialled several different types of chair for his use. Previous chairs had been uncomfortable during his prolonged use of them however the addition of a computer chair on wheels had both increased his comfort and his freedom of movement to move around independently. In Alec's case this addition also enabled him to move towards the television independently where he needed to view it from a closer position due to a visual impairment.

Mother: We have that chair that we can move.

Alec: Twenty quid off a car boot.

Mother: And it's good because we can scoot it, and he can scoot it.

Alec (15, manual chair) and his mother

James, another teenager, explained that he and his parents had changed the arrangement of his bedroom furniture to enable him to sit on his bed and play on his playstation (the use of his wheelchair for long periods was uncomfortable). Following this change, James had attempted to transfer himself from his chair onto his bed, using the table which housed the television and games console to bear his weight. The table had given way and James had fallen to the floor. His mother described her concern at this, alongside a reluctance to restrict James' attempts to move himself into and out of his chair. Instead the family adapted the layout of the room, using a sturdier table that James could use for transfers which had been adapted by his parents to include a raised element, bringing the screen up to his eye-level for gaming.

James: You should see my TV upstairs...I've got it one a, like a...

Mother: It was an old coffee table...my husband got this table and chairs and we got them remodelled.

James: Massive thing, massive.

Mother: It's a sturdy table, really sturdy.

James: And we got the TV up a bit.

Mother: ...it was a coffee table and we chopped it so, his TV sits on that, even more to bring it up to his eye level.

James (17, manual wheelchair) and his mother

These changes enabled James to be independent in these instances. Alongside this it had the double bearing of reassuring his parents over his safety in transferring between chair and bed. Rather than relying on the adaptations put into place by service providers which often met only the daily living or care needs of generic wheelchair users (Imrie, 2004; Milner and Madigan, 2004), these self-developed adaptations opened up leisure whilst offering these young people ways to exert independence in their homes.

Parents also supported teenagers in accessing different parts of their home by carrying them. Carrying served its purpose in relation to enabling parents to support the daily living needs of their child but it also helped them to open up the home to enjoyment. Where barriers in the design of homes stopped their child accessing particular places, participants often spoke of the ways that parents would support access by carrying.

My brother and sister's bedrooms are upstairs. I like going up there to see what they're doing but I can't unless someone carries me.

Sophie, 15, multiple chairs

...[At home] most of the time it's just as easy for me to pick him up and go places at the minute.

Father of David (17, manual chair)

Parents were therefore essential for many of the teenagers in opening up different areas of their homes. Assistance of this nature was practical, expedient and in general necessary, it resulted in increased dependence for the teenagers. In addition, the option to be carried markedly decreased with increasing age and size, illustrating the short-term usability of these strategies.

Whilst Parents often opened up leisure opportunities for their children by acting as chauffeur to places away from the home. The opportunity to be driven to places extended their mobility in this context, but in ways which were still restricted to a willingness or ability of parents to act in this role, and on the presence of a suitable vehicle for them to travel in.

...Because I use my electric chair all the time, I only can use my mum's car when I want to go places because [the electric chair] won't fit any others.

Jane, 14, electric wheelchair

[Mother] didn't use to work then so it would be OK to go [to local club] after school, but now she works on Thursdays and you can't get my wheelchair in Dad's car so I don't go anymore.

Vicky, 16, multiple wheelchairs

Positively therefore, the availability of private cars enabled the teenagers to access leisure that would otherwise have been closed down to them had they been solely reliant on public transport. The willingness of parents to drive them these places extended the opportunities that were open to them. Whilst the use of private transport extended their mobility in relation to leisure, they could also serve to restrict opportunities through a dependence on adult chauffeurs (further discussions on this issue are forthcoming elsewhere: see Pyer and Tucker, in press).

The teenagers and their parents shared examples of the range of ways that they, as family units, would seek to open up leisure opportunities away from the home. Opportunities for them to effect change in public places were, perhaps unsurprisingly, noticeably more restricted than in their own personal homes. In the private homes, families were able make tailored adaptations and parents could offer personal support in ways which were not possible in public environments. In these places, they applied a range of strategies to open up leisure opportunities. Where parents were concerned for the safety of their child, they would often accompany them on their leisure outing. The teenagers discussed the ways that parents would participate in leisure activities alongside them, for example by playing sports or visiting the cinema with them. In these ways they facilitated the leisure experiences of the young people through emotional support and participation.

When Mum takes me to the park we go on the roundabout – my whole [wheel]chair goes on. Dad has to run round [to turn it]. He says I’m a big lump.

Ben, 15, multiple wheelchairs

In this photo we was playing ball in the back garden (see Figure 4).

John, 15, manual wheelchair

Figure 4: Parents as participants in leisure

Parents also supported the teenagers in more subtle ways when they were in public places. This chapter has already touched on the social barriers inherent in the public spaces that the teenagers frequented. Parents discussed the ways in which they supported the teenagers in responding to instances where members of the public or staff in local businesses were unsupportive of the young peoples’ needs. James and his mother offered one example where, when James attempted to buy a new game from a store, a staff member had failed to assist him:

Mum: Actually that was one of the [shops] where...they sort of...like threw his change back to him like that [gestures]...

James: It went all over the floor. It says a hundred percent service – yeah right! Yeah, just threw my money at me...Lost a 20p in the store.

Mum: Yeah, we looked for a while and the lady didn't even seem to acknowledge that we were looking for it. I said well I guess that 20p's gone to the cleaner...that's why I did it...to make her think.

James, 17, manual wheelchair and his mother

Whilst a number of the discussions above intimated that parents' anxieties for their children could impact on their independence in leisure, some parents also spoke of how they were working to develop their autonomy together.

Mum: ...that's something we're still working on, is him being independent...

Mother of Chris, 17 year old, manual wheelchair

Mum:...last year, last August, I said to [father], 'I think the time's come, we'll take her down, try a wheelchair, powerchair, and just see how she gets on. If she's frightened, if it frightens her, we'll know it's...she's not ready'. She was down the shop, got the doors open.

Mother of Becca, 15 year old, multiple wheelchairs

Discussions on these issues were always predicated on a basis of concern for the young peoples' safety. The teenagers, for their part, sometimes discussed their attempts to extend their independence, negotiating the extension of their autonomy. Two examples of this are illustrated below. First, Sarah explains that she was actively 'working' on her parents to give her permission to spend time away from her home without them. Jessica's example is drawn from a video tour completed with her and her mother. In this instance, Jessica attempted to extend her independence to move to another room within a bowling alley, outwardly attempting to negotiate this with her mother (see Figure 5).

Sarah: I'm not allowed to go out on my own...*at the moment* [laughs]...I'm working on them. [At the moment]...it has to be with an adult.

Sarah, 15, electric wheelchair

Jessica: Mum! I wanna go...

Mum: There's no rush.

Jessica: I can go on my own.

Mum: You can't go on your own, can you?

Jessica (15, multiple wheelchairs) and her mother

Figure 5: Negotiating independence

The experiences presented here begin to show the complex relationships through which the families negotiated leisure. They illustrate parents as key actors in opening up these opportunities. Whilst in the context of familial homes and in the use of transport parents and young people reported similar viewpoints on the ways that this could be done; their views often differed in relation to accessing public environments. The role of parents often changed between that of facilitator and restrictor to their child's leisure experience. The complexity of these renegotiations often meant that the extent to which they would fulfil a facilitation role changes according to different contexts, events or anxieties.

Conclusion

Whilst young disabled people are spending increasing amounts of time at home in comparison to their non-disabled peers (Beresford and Rhodes, 2008), restrictions in their homes have implications for their leisure time. In attempting to access different leisure opportunities, young wheelchair users are 'positioned' in two groups which are often considered in need of care and at risk: i) young and ii) disabled people. Whilst the physical barriers inherent in different places pose realised challenges to accessing leisure, the social positioning of young wheelchair users further impacts on their treatment in private and public places, restricting or closing down leisure opportunities to them.

This chapter has highlighted the importance of situating the leisure-related experiences of teenage wheelchair users in the context of the family, including the changing nature of the teenagers' relationships with their parents, who often fulfilled a number of roles to meet the leisure-related needs of the young people.

The decision making of adults in the placement of adaptations for everyday living, or the location of gaming or other leisure related equipment inadvertently increased the challenges associated with undertaking leisure in the home. In addition, the anxieties of parents outside the home environment served to minimise the use of these services or closed them down altogether at age where research has shown non-disabled young people enjoy increasing mobility (Hopkins, 2010).

The importance of the familial context is also important in considering the strategies that were open to the young people, enabling leisure to take place where it might otherwise have been closed down because of physical access issues. Whilst their anxieties and decision making could serve to close down access to leisure, parents were also instrumental in opening up leisure-related opportunities.

A number of recommendations for future research arise from the discussions presented in this chapter. There is a need for studies which focus on the intrinsic enjoyment of "play", "recreation" or "leisure" for a range of groups who have

remained marginalised in research. In this way geographers are afforded a unique opportunity to further our understandings of these terms, and how they are differentially experienced by people in diverse contexts and places. Further, explorations of this kind will give us opportunities to unpack the complex and often intertwining challenges which compound to limit access to certain places and therefore recreational opportunities. Considerations of the diverse needs of particular marginalised groups, interspersed with spatial, social and environmental challenges are key to offering a more rounded understanding of recreational experience.

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Keywords

Young people, leisure, wheelchair, disability, homespace, commercial spaces, outdoor