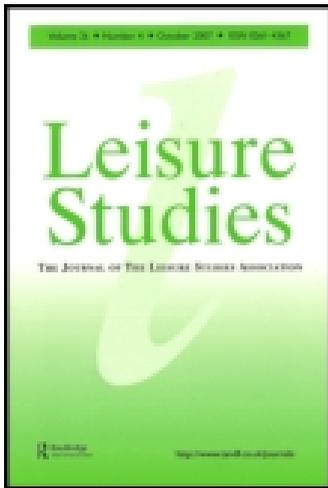


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Publisher: Routledge

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Leisure Studies

Publication details, including instructions for authors and subscription information:

<http://www.tandfonline.com/loi/rlst20>

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Published online: 13 Jan 2011.

To cite this article: Mahmoud Emira & David Thompson (2011) In the quest for their trust: the perceptions of families on accessing leisure services for disabled children, *Leisure Studies*, 30:1, 33-48, DOI: [10.1080/02614367.2010.506648](https://doi.org/10.1080/02614367.2010.506648)

To link to this article: <http://dx.doi.org/10.1080/02614367.2010.506648>

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In the quest for their trust: the perceptions of families on accessing leisure services for disabled children

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(Received 28 October 2009; final version received 3 July 2010)

This paper is based on the findings of a research project commissioned by a public body in the English Midlands, UK. Telephone surveys, focus groups and individual interviews were the data collection methods. It focuses on the perceptions of 44 families on the barriers to accessing leisure services for disabled children. Although there are numerous advantages for accessing such services, the findings showed that the families had very few successful experiences with the current provision due to a number of structural barriers. Trust was perceived as crucial to access these services.

Keywords: participation; leisure services; disabled children; barriers, trust

Introduction

Participation in leisure is unequal due to a number of constraints (which are described below). Although health/wellness could hinder access to participation, this depends on how disability is conceptualised in society. In the social creationist view of disability, which was developed mainly in the UK, the main attention is directed to the *disabling* barriers (Vehmas, 2004). These barriers may cause inequality in participation in leisure between those who are enabled and disabled (Carr, 2004; King, Petrenchik, Law, & Hurley, 2009; Reynolds, 2002). The literature shows that leisure services have *numerous* advantages for families and their disabled children alike (Herman & Marcenko, 1997; Preece & Jordan, 2007; Turner, 2003), regardless of the level of their disability. Therefore, the UK government invests heavily in improving outcomes for disabled children and their families (DfES & HM Treasury, 2007). However, research indicates that access to leisure services can be challenging (Preece & Jordan, 2007) and that barriers still exist. This paper focuses on the perceptions of 44 families of the barriers to accessing leisure services for disabled children. Previous research shows that trust is a *priority* for families to access leisure services (Cumbria Children's Services, 2009; Flynn, 2002). The authors of this paper argue that families' trust will be restored once all the underlying barriers, which they face when accessing these services, are addressed.

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Constraints to participation in leisure

Participation in leisure is unequal due to a number of constraints. Constraints may be defined as barriers that are 'assumed by researchers and perceived or experienced by individuals to limit the formation of leisure preferences and to inhibit or prohibit participation and enjoyment in leisure' (Jackson, 1997, p. 461). Leisure constraints were conceptualised as a mechanism for better understanding barriers to activity participation (Buchanan & Allen, 1985; Jackson & Searle, 1985). Samdahl and Jekubovich (1997) suggested that the constraints approach to understanding participation in leisure has dominated to a great extent the leisure research, despite having received some criticism (Kay & Jackson, 1991; Shaw, Bonen, & McCabe, 1991).

Nevertheless, to understand constraints to participation in leisure, a model (see Figure 1) will be used in this paper to help unpick the overlapping challenges for people with a disability. This is an adaptation of Raymore (2002), which is based on a model by Crawford and Godbey (1987) and a later version by Crawford, Jackson, and Godbey (1991). The model in Figure 1 consists of three types of constraints to participation in leisure: intrapersonal, interpersonal and structural.

While intrapersonal barriers relate to one's beliefs or characteristics which may direct individual's participation in a certain activity, interpersonal barriers are about the relationships with others, which may also impact on one's participation in leisure. To better understand the intrapersonal constraints, they should be viewed in relation to the interpersonal and structural constraints (Raymore, 2002). On the other hand, structural constraints, which are the most frequently cited type of constraint (Jackson & Scott, 1999), are barriers that hinder participation such as time and resources (Crawford et al., 1991). Beauvais (2001) lists a number of intrapersonal, interpersonal and structural constraints which prevent participation in leisure like age, gender, income, urban/rural living, ethnicity, time, parental influence, family type, peer influence and changing life styles. She goes on to say that there are 'infrastructural'

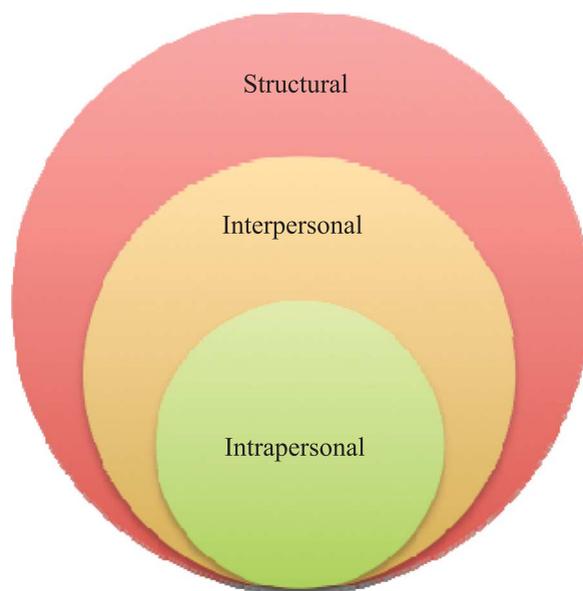


Figure 1. Types of constraints to participation in leisure.

barriers such as the quality of provision, failure to meet the needs of the users, lack of flexibility, lack of coordination among service providers and the lack of regards for their needs. Allison and Hibbler (2004) identified a collection of constraints related to the changing faces of the community, the changing faces of management and staff, deferred programme responsibility, language barriers, and negative attitudes and stereotypes held by some management and staff. Their findings suggested that *leisure providers*, often unwittingly or unknowingly, foster the above barriers.

Another example of structural constraints is health or wellness, and according to Raymore (2002), a main claim of the literature on inclusive leisure for disabled/chronically ill is that society is structured in a way that excludes these people (Dattilo, 1994; Hutchinson & McGill, 1992). Therefore, if we want to understand structural constraints, such as health or wellness, we will need to consider how they are conceptualised by society (Raymore, 2002).

Conceptualisation of disability

According to Vehmas (2004), approaches to conceptualising disability can be divided into two main categories: individualistic and social approaches. In the individualistic framework, disability is seen as an individual condition that results in a disadvantaged position regarding civic, economic and personal growth. On the other hand, in the social approaches disability is seen as a result of the oppressive material arrangements in existing societies. A criticism to the individualistic framework has been presented by theorists who take a social approach to defining disability and differentiate between social constructionist and social creationist (Oliver, 1990). Although both approaches shift away from the individualistic perspective, they differ in terms of locating where the disability is.¹ In the social creationist view of disability, which was developed mainly in the UK and became the model view that should be followed to become morally and politically correct, the main attention is directed to the disabling barriers (Vehmas, 2004). However, this view was criticised; it turned into a form of oppression by dictating a particular perspective and thus contradicting one of the fundamental principles of the social approach to disability, which called for respecting the different individual experiences (Vehmas, 2004).

Whether we agree/disagree with the social creationist model, the point is that participation in leisure is not equal between those who are enabled and disabled (Carr, 2004; King et al., 2009; Reynolds, 2002) and even within a particular group. Carr (2004) suggests that people with a disability find it difficult to do their own daily routines, which gets more difficult *depending on the level of their disability*, let alone organise their leisure time. Indeed, people with a disability may be doubly disadvantaged by their disability (Flynn, 2002). Therefore, this should be considered when engaging them in leisure services.

Importance of leisure services for people with a disability

Mencap (2006) defines leisure services such as short break or respite care as services which give people with a disability and their families a break from their daily routine. The UK government invests heavily in improving outcomes for disabled children and their families (DfES & HM Treasury, 2007). It was found that disabled children have poorer outcomes compared to their non-disabled counterparts. Therefore, the government is committed to campaigns such as Aiming High for Disabled Children and

Every Disabled Child Matters, which followed the Disability Discrimination Act, that would lead to improved outcomes (DfES & HM Treasury, 2007).

The literature shows that leisure services have *numerous* advantages for families and children alike, regardless of the level of children's health. Edgar and Uhl (1994) pointed out that participation in leisure might prevent likely situations where children can be abused. Leisure could also be a source of support. According to Turner (2003, p. 8), the majority of disabled children felt 'most comfortable' when attending leisure services. Furthermore, leisure was found to have an impact on their academic achievement (Barnard-Brak & Thomson, 2009).

In fact, not only do disabled children benefit from accessing these services, but also their families. Ambler and Kupper (1996) listed a number of benefits such as enabling families to cope with daily tasks, keeping the families intact, giving them the opportunity to engage in community services and take a necessary vacation and allowing the needs of other family members to be catered for. Families perceived that the availability of leisure services would improve overall quality of family life (Abelson, 1999; Herman & Marcenko, 1997; Preece & Jordan, 2007), which persists even after the leisure services have been accessed (Aldgate, 1998; Botuck & Winsberg, 1991). Leisure services have also been described as a major support for families with autistic children (Randall & Parker, 1999; Tarleton & Macaulay, 2003). This is because many parents of autistic children experience high levels of stress due to the challenges which they face when caring for children as such (Openden, Symon, Koegel, & Koegel, 2006; Preece & Jordan, 2007). However, research indicates that access to leisure services can be challenging (Preece & Jordan, 2007), and these challenges may be even greater if the service users are disabled (Flynn, 2002).

Barriers to leisure services for people with a disability

In addition to the constraints which might prevent participation in leisure in general, there are barriers which might hinder people with a disability to access leisure services. People who have learning difficulties or mental health problems are more likely to be excluded from participation in leisure activities (Barnes & Mercer, 2003). A number of barriers to leisure services were identified by service users and service providers alike. Providers of leisure services perceived the major barrier for people with a disability to participate in leisure to be the cost (Reynolds, 2002). On the other hand, service users identified barriers such as lack of friends, transportation, cost, people's attitude, including that of service providers (Carr, 2004). A more recent study by Radcliffe and Turk (2008) indicated that the majority of the children showed medium or high negative reactions when accessing leisure services. However, the fact that some children's views differed from those of their families implies that the barriers could be perceived differently by service users and also within the family.

One of the barriers which could be perceived by the *families* of service users is the feeling of distress. Stanzler (1982) described how families of disabled children found participation in leisure services hard because of the feelings of guilt, tension between motherhood and satisfying children's needs, a sense of punishment for having a disabled child and fear of separation from a closely monitored child. Rimmerman's (1989) study showed that although children who accessed leisure services improved their independent life skills, their families' stress levels increased. However, families' feeling of distress could be the result of *not meeting the needs* of their disabled family

member. Indeed, a study by Hare, Pratt, Burton, Bromley, and Emerson (2004) of families of 26 adults with Autistic Spectrum Disorder (ASD) indicated a strong relationship between their distress and unmet needs of their disabled family member. Therefore, they called for a more tailored intervention and support to suit the needs of adults with ASD. The authors of this paper argue that participation is likely to be even better when trust is established between service user and providers.

Trust and participation in leisure

Flynn's (2002) study of leisure services for disabled children in England and Scotland highlighted four key principles in successful schemes such as the establishment of community relations and *building trust* between service providers and users. Flynn concluded that services should be provided by people who are *trusted* and credible and that should be a provider's *priority*. The establishment of trust between service providers and users was also noted by the Integration of Services for Disabled Children (2006). One of the suggested outcomes for the new service was that families should have *trust* and confidence in services which care for their children. Cumbria Children's Services (2009) stressed the need to promote a high degree of *trust* between professionals and the children and parents with whom they work. The above emphasis on the importance of trust seems to reflect the inadequate degree of trust (shown in the literature) between service users and service providers. Unless trust is well established, it might be argued that families are likely to abandon the services and possibly leading to alienation and social exclusion. This obviously counteracts the inclusion agenda (Every Child Matters and Every Disabled Child Matters) adopted by the UK government. Furthermore, a loss of trust may turn into mistrust/suspicion (Rai-Atkins et al., 2002). This may imply that participation in leisure is likely to deteriorate, if families' trust is not restored. When the voices of service users are heard, the suggestions they make are considered, they are more likely to trust the service provision and access those services again and again.

Research aim and importance

The authors of this paper, and other members of the Research Team, were commissioned by a public body² to study the perceptions of families of disabled children (who were diagnosed with ASD/attention deficit hyperactivity disorder [ADHD]) of the barriers which might hinder their participation in leisure. In order to achieve equality in participation, it was recommended that further research is required to examine the barriers that are perceived by people with a disability when accessing leisure services (Reynolds, 2002). It should be noted that the voices of families of disabled children are often marginalised within research. Indeed, a report by the formerly entitled Department for Children, Schools and Families (DCSF, 2009) indicated that only 8% of the respondents from one local authority said they were asked over the past 12 months about their opinions on the care and family support services they received for their disabled children. This shows the importance of this research. The authors of this paper argue that giving voice to the families of disabled children and addressing their concerns of access to leisure services will contribute to an increase in trust in both local policy-making and also leisure service providers.

Methodology and research sample

This research followed the interpretive paradigm. Interpretive research aims to find out about people's understanding (Mason, 2002). According to Raymore (2002, p. 47), perception is 'dependant on the individual and the interpersonal and structural influences on his or her life'. Interpretive research would give families the opportunity to express their views and allow the authors to give voice to their perceptions. Three methods of data collection were used. The aim of this three-stage approach was to triangulate the data from a range of methods. Triangulation or using more than one method 'contributes to the trustworthiness of the data' (Glesne & Peshkin, 1992, p. 24).

First, a telephone survey was designed and implemented. Forty-four respondents out of 150 contacts, listed on the database³ of families of children with ASD/ADHD, were available and agreed to participate in the telephone survey. Only 10% of the telephone respondents were other than 'White British'. It must be noted that ethnic background could not be determined from the database. None of the ethnic minority telephone respondents were available to participate in the focus groups. Secondly, five focus groups were held with a sub-sample drawn from the telephone respondents ($N = 30$, 24 females and six males). Most of the focus group participants (27 out of 30) were parents, only three participants were carers. Each focus group lasted approximately one hour. Thirdly, seven face-to-face individual interviews took place. Four interviewees were 'White British' and three had Asian heritage. Most of the participants' children were diagnosed with ASD, only three of them had ADHD. All the interviewees were parents of children with ASD. The age of the participants' children ranged from 8 to 17 years.

Ethics

The participants were informed about the reasons for undertaking this research, their rights of withdrawal at any stage during the research without giving reasons. They were also assured that their identities would be anonymous and not disclosed and that any information obtained would be strictly confidential and would be used for academic purposes and to inform the report for the commissioning local authority. Permission from the participants was obtained to record the focus groups and interviews. The commissioning body gave their permission to the authors to use the data for academic publication.

Data analysis

The research design resulted in a large amount of qualitative data which provided reliable evidence relating to the experiences of families of disabled children. The interview findings were transcribed and coded into emerging themes (Glaser & Strauss, 1967). The data were analysed through a process of coding, sorting, constant comparison and analytic induction (Silverman, 2001) to move from the particular instances revealed in this research to the general themes discussed in this paper. It should be noted that the paper was not guided by the leisure constraints model. On the contrary, the model was used to interpret (Samdahl & Jekubovich, 1997) the experiences of the families of disabled children when accessing leisure services. Indeed, the constraints model was used *after* examining the themes generated by the grounded analysis. A meticulous comparison of the results from all the methods of data collection

undertaken contributed to the robustness and validity of the findings that could be replicated. In fact, through all three approaches the Research Team felt that a point of 'saturation' had been reached on a number of themes (Glaser & Strauss, 1967).

Findings

A number of themes have emerged. These were mainly about (1) the importance of establishing trust with service providers, (2) the barriers which they identified such as staff attitudes/lack of training, lack of availability, lack of flexibility, lack of information, cost, lack of support and distress, and (3) the need to address those barriers.

Lack of trust

The most significant issue for the families in accessing leisure services was the lack of trust. In the focus groups, the lack of trust was raised as a *significant* issue. Many parents were aware that service providers may perceive them as overprotective, and this may inhibit them from voicing concerns about provision. One could argue that this overprotection may be a reaction to the barriers which will be discussed in the next sections. The mother of Abdul (13 years old) strongly stated that it would be 'important' for her to be able to trust any potential Buddy or Befriender. In fact, parents had concerns about leaving their children with a stranger as the parents of a 10-year-old boy believed that 'if a relationship of trust were developed, [they] would consider short break provision'.

This shows that trust is a *priority* for families to access leisure services. This confirms the views of Flynn (2002) and Cumbria Children's Services (2009). The fear of leaving their children with a stranger was not their only concern. The mother of two boys, a 10-year-old boy with ASD and an 11-year-old with ADHD, had a negative experience with her younger child who was abused while being under the care of the service providers. This contradicts the findings of Edgar and Uhl (1994), which indicated that leisure services may create a safe environment from being abused. This negative experience had led to a lack of trust. She agrees with other parents in this research that the 'opportunity to get to know any support worker and develop a trusting relationship, based on knowledge of the child, is crucial'. The main argument in this paper is that the quest for families' trust will continue unless their perceived concerns are addressed and taken into account by the service providers. Families identified a number of *interrelated* barriers, which contributed to their lack of trust in the service provision, as discussed below.

Staff attitudes/lack of training

Parents in the focus groups perceived this point as one of the most significant barriers to access leisure services. One parent said: '[staff] lack of expertise [is] frequently a problem'. Other families referred to the training of staff and how this could prevent them from accessing the service provision: 'I think it comes down to a training issue. Unless you feel comfortable that you know people are trained ... then, it's no fun for you or your child, you worried watching them all the time'. Similar comment was made by a parent about accessing buildings: 'public buildings and everything – they've got to be accessible to disabled people, but the people who run the buildings don't have to have any training of any sort'.

Another comment by a parent: ‘I did send [Tim] to a specialist unit who knew all this and had training, was there for half an hour and was supposed to be there for a week. They couldn’t cope’. Another parent pointed to staff attitudes of ignoring parents’ knowledge and experience of their children:

The thing that irritates me the most and really gets my goat is professionals and staff who talk to me like I don’t know. I’m not an expert on Autism and I’m not an expert on my child but I know him and very often we’re spoken to like we’re stupid.

The mother of 13-year-old boy with ASD, therefore, believed that staff ‘attitudes have got to change’. However, it is not only the attitude of staff that could be problematic, families also expressed concerns about the minimal checking of staff once they have received some training and the use of staff whose level of fluency in English language may be low: ‘some of the agency staff can barely speak English; how can you expect them to understand challenging behaviour or anything; so how can you expect them to take care of your child who is extremely vulnerable’.

Families also stated that they wanted to be sure that their vulnerable children were cared for by qualified staff with whom they expect to build a relationship focused on the particular needs of the child. They indicated that staff needed more training, especially around emotional issues and challenging behaviour, and they did not want their children stigmatised for the disability. As one parent said:

You can’t just, like, treat them differently from everybody else. They’ve got to be treated the same – they wanted to be treated the same – that’s a training issue as well. It’s just a word of praise – you are doing that really good.

The above finding reiterates the results of Wertheimer (1989) who found that staff looked down on families of disabled children and they did not keep their promises to help. Professionals’ attitudes were perceived by parents as a barrier to their participation in planning (Contact a Family Wales, 2006). Wertheimer (1989) pointed out that parents valued situations when professionals can be trusted; when professionals acknowledged their experience and expertise, had the right skills and training and understood the difficulties the parents were going through. Although the findings of the present study highlighted far more negative experiences when accessing leisure services, some families, like the mother of an 11-year-old boy with ASD, had an excellent experience at a mainstream soft play centre:

They are willing to listen and willing to hear! ... I mentioned to them about having a sensory room or some kind of calming down space and they took that on and said ‘well actually we’ve got lots of children that will access this – what a good idea.

Just like their views in the focus groups, families in the interviews expanded on the issues of staff training and expertise and confirmed that these were essential to the establishment of trust between them and the service providers. In fact, both findings showed that the issue of trust in staff/experts and training/education seem to be *closely linked*. When staff are trained to support children with ASD/ADHD, then families develop trust that their child will be safe and will be cared for professionally. Unfortunately, in this study there were far more examples of poor practice than of good practice. These findings confirm those within the ADHD document (DfES & HM Treasury, 2007, p. 56) which specifically note that areas in which staff across all

services lack preparation and training include ‘communication and interpersonal skills ... (especially with Autistic Spectrum Disorder and challenging behaviour)’.

Lack of availability

The findings showed that the lack of availability of leisure services was raised as another barrier. This echoed the results of a large-scale survey which highlighted the unavailability and inaccessibility of these services regardless of the families’ demographic background, income level or level of disability (Abelson, 1999). Some families in the present study were even concerned about the availability and suitability of the services when their children grow up: ‘[I am] concerned about what will be available for [Harry] as he grows up, i.e. what is for teenagers?’

Lack of flexibility

The research findings revealed that families had concerns about the flexibility of the leisure provision. This point confirms the findings of a survey of 2800 parents of disabled children, which found that families were dissatisfied with the services’ lack of flexibility, illogical restrictions on use, inability to deal with crises and lack of parental voice in forming or reforming services (Knoll & Bedford, 1989a, 1989b). The lack of flexibility is found not only in the leisure services but also in the medical care provided for disabled children. There seems to be a rigid adherence to medical guidelines: ‘concerns over medication; common sense stuff for example, they only have prescription things, won’t use nappy rash cream from supermarket and it takes four attempts to get Dr to write the prescription’.

This inflexibility is likely to influence families’ trust in the service provision. Leisure services are supposed to provide them with peace of mind from their daily routine of looking after a disabled child, but with such inflexibility and the additional concerns, they are likely to think twice before accessing such provision.

Lack of information

Throughout the data collection process, the Research Team found that the families did not find it easy to access information about leisure services. For example, none of the interviewees had accessed the Buddy scheme (one of the current befriending services) and most were unaware of its existence or how to access it. In fact, they found it difficult to keep up-to-date with the changes in service provision, providers and policy. One of the families said: ‘we ain’t told this stuff, we have to find out for ourselves and through school’.

Also, Jordan’s mother described her own ‘difficulty’ in knowing what is ‘suitable’ for him. While some families had access to the Internet, it was not always easy to find the right provision when having to try different key search words, which is in itself a constraint. Therefore, they supported the idea of a directory of leisure services, together with an identifier which could demonstrate to families whether their children could be catered for.

The above findings confirm families’ experiences, which revealed that they had substantial problems working out the details of obtaining necessary support (Butler & Friesen, 1988; Knoll & Bedford, 1989a). The findings also reiterate the views of other parents and service providers (see Middleton, 1998) about the services for

disabled children. Middleton (1998) showed that they were confused about service provision and that they preferred a practical provision which could cater for their material and emotional needs. They also believed that emotional support could take different forms such as counselling, giving advice and listening to them. On the other hand, the views of social workers, in that study, who provided services for disabled children, revealed that they lacked confidence in their capabilities, lacked clarity in their role and were disappointed with the services which they provided. In a more recent study by Contact a Family Wales (2006), parents of disabled children shared some of the above-mentioned views of participation in planning. Based on the findings of the present study, service providers have a significant role to play in ensuring that families are aware of current services that may suit the needs of disabled children. If they do not do this, providers may convey a wrong message that they are unable to perform their role, which is likely to contribute to families' current lack of trust in their provision.

Cost

This was raised as a barrier too. Families in this study pointed to this barrier from a macro-level by referring to what staff say about the provision of some services: 'we haven't got the funding' or 'we haven't got the amount we need – we can't afford that'.

By addressing the issue of funding these services in general, they seemed to be aware of the financial restrictions imposed on service providers which might hinder the quality or continuity of certain provisions. However, the cost of accessing leisure services did not seem to have a significant impact on families. This may contradict parents' views in the above study by Contact a Family Wales (2006), who were concerned about the costs of travel and child care.

Lack of support

This point was noted by a number of families. One parent, for example, perceived a provider of such services for disabled children as uncaring by saying:

The problem with the buddy scheme and other specialist provision like that is you've actually got to get your social worker to 'fight your corner' to get you that provision and I wonder how many people round this table actually know who their social worker is?

In one of the five focus groups, which were conducted with the families, there was a general sense of being 'let down by the system'. One parent said:

It took me six months to get (daughter) into the youth club – Action 4 Children ... Six months it was and I kept chasing and chasing and the thing is, because you've got a disabled child, you haven't got the time or sometimes the energy to chase these things – you've got to fight for everything.

Families also spoke of the numerous play schemes 'out there' but noted that not all of the schemes were willing to 'take on children who have a problem'. This may suggest the need for a directory of provision which accepts children with special needs. The findings suggested that families needed adequate support. In the interviews, families spoke of their need for support and practical advice. A 'drop-in centre' for children with ASD was suggested by two families. Their need for support confirms the findings

of Douma, Dekker and Koot (2006), who found that most parents needed support, particularly someone to talk to. Their perception of being let down by service providers and the issue of lack of trust might inhibit them from accessing the services in the future.

Distress

The findings stressed that children with ASD/ADHD have specific needs for routine and consistency, which might not always be guaranteed when accessing leisure services. Abdul's mother identified a tension between keeping his life consistent, routine and structured, and allowing some natural deviation from this to help him cope with change. It is common among children with ASD to dislike strangers and crowds, which maybe something unavoidable when accessing such services. Another parent described the effect of the inflexibility of the service in terms of the rigidity of the medical care provided for the disabled children by saying: 'it causes no end of stress ... is it worth me sending him? It distracts from [its] value'.

It should be noted that parents of disabled children often experience high levels of parenting stress (Douma et al., 2006) and hence the need to provide them with leisure services that give them a break from their daily routine (Mencap, 2006). If these services do not alleviate their high levels of stress, then, at least, they should not worsen their situation. The deterioration of the well-being of families and/or their children is likely to deepen their lack of trust in the service providers.

Discussion

The main argument of this paper is that service providers of leisure services should address all the barriers perceived by families of disabled children, before they begin the quest for families' trust. A number of barriers to access leisure services were discussed from the perspectives of the families in this study. It is worth repeating here that the present study was not guided by the constraints model (Raymore, 2002). However, it might be interesting to note that most of the barriers identified in the findings could be described as structural barriers such as the lack of training, lack of availability, lack of flexibility, lack of information, cost and lack of support. These barriers might imply that it was *not* the disability that might hinder participation in leisure services, but, rather, it was the way these services were structured.

Families seemed to be unable to trust the service providers. They wanted their disabled children to be safe and to be cared for by responsible trained trustworthy staff. According to Morris (1994, p. 4), trust is built by being 'responsive' to families' needs and involving them in the 'formation and the implementation' of the services. Based on the research findings of this study, service providers are likely to be responsive to families' needs by:

Creating a balance between professionalism and establishment of trust

Cramer and Carlin (2008) stressed the importance of acknowledging staff professionalism, but that should not be done at the expense of establishing trust in their relationships with the families who use their services. Creating this balance is important; when a 'professional view is challenged, then the very basis of the professional identity is at stake. It is very easy in such a situation for conflict to arise' (Murray, 2000,

p. 692). Goodey (1991, p. 108) described a situation when parents did not trust professionals who offered services for their disabled children: 'they distrusted my word, they didn't believe me, so then I started distrusting them. That was when it really all started'.

Families sometimes might have more knowledge than professionals who offer services for their disabled children. Kirk and Glendinning (2004) noted that parents appreciated professionals' attitudes who acknowledged their limited knowledge, and this formed the basis for the establishment of trust. Establishing a continuous mutual relationship between families and professionals is crucial for the development of trust and respect for their knowledge/expertise, respectively (Kirk and Glendinning, 2004).

Giving staff necessary training

This was perhaps one of the families' priorities; they called for a specialist trained staff. Training is an indispensable element in the provision of any leisure services such as respite care (Access to Respite Care & Help, 1992). Without such training, families are not likely to trust staff to supervise their children. Families, therefore, should be involved in this process as they know the needs of their children. Engaging families in the training process is likely to assure them that the services will meet the needs of their children.

Making information accessible

One of the suggestions which families made to improve their access to leisure services was that information should be freely available in various formats. Indeed, families need to be informed about where and how they can obtain what kind of support (Contact a Family Wales, 2006; Douma et al., 2006). They need to have access to goods and adequate information from a wide range of sources about the available leisure services, which should be ensured by local authorities (Mahadevan, 2009).

Maintaining flexible services

Effective leisure provision should be flexible to meet the needs of disabled children. Leisure services for disabled children will improve when they are flexible (General Accounting Office, 1990). One of the characteristics of successful leisure services is that families should be given the choice, whenever possible, about the services in terms of the available providers, type of services, duration, etc. (Morris, 1994). By maintaining the availability of flexible provision, families are more likely to get support when they need it.

Conclusion

Participation in leisure is not equal between those who are enabled and disabled (Carr, 2004; King et al., 2009; Reynolds, 2002). Although the UK government invests heavily in improving outcomes for disabled children and their families (DfES & HM Treasury, 2007), constraints to participation in leisure still exist. Families' perceptions highlighted a number of barriers that affected their participation in leisure services. These barriers might imply that it was not the disability that hindered their participation, but, rather, it was the way these services were structured.

Leisure services can be a major support to families and their disabled children, but the findings suggested that the services might be falling short of offering them the support they need. In spite of the very few examples of effective leisure services, which were referred to by the families in this study, the number of examples of ineffective provision was far greater. Families' successful experiences in accessing leisure services were mainly due to their determination *and* the commitment and understanding of the very few exceptional members of staff. This does highlight the role of staff in creating a positive experience for these families. However, this role might be reliant on the establishment of trust in their relationship with the families. Unless families perceive staff as understanding, well trained and have the necessary experience to deal with disabled children, they are unlikely to trust them. The quest for families' trust necessitates that service providers become responsive to families' needs. Service providers, therefore, should address these issues in order to improve their provision and ultimately gain families' trust. Without taking action to address the concerns of these families, the quest for their trust will continue.

Acknowledgements

The Research Team would like to acknowledge the kind assistance of colleagues from the commissioning body, NHS local Community health, the School of Education and the Centre for Developmental and Applied Research in Education at the University of Wolverhampton and other organisations and individuals who have kindly contributed to this research.

Notes

1. Social constructionist views disability as located within the minds of non-disabled individuals or groups in terms of their attitudes or policies. The social constructionist locates disability within the practices of society in general (Oliver, 1990).
2. This public body is serving an urban location in the English Midlands, UK. This organisation has a responsibility to provide leisure services such as short breaks and respite care for children with ASD and ADHD within one Borough.
3. This database was provided by the commissioning organisation.

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