Journal of Child Health Care

Out-of-school lives of physically disabled children and young people in the United Kingdom: A qualitative literature review

Kate Helen Knight, Lorna Porcellato and Lyvonne Tume

Additional services and information for *Journal of Child Health Care* can be found at:

Email Alerts: http://chc.sagepub.com/cgi/alerts

Subscriptions: http://chc.sagepub.com/subscriptions

Reprints: http://www.sagepub.com/journalsReprints.nav

Permissions: http://www.sagepub.com/journalsPermissions.nav

>> OnlineFirst Version of Record - Jul 1, 2013

What is This?

Out-of-school lives of physically disabled children and young people in the United Kingdom: A qualitative literature review

Kate Helen Knight and Lorna Porcellato
Faculty of Health and Applied Social Sciences, Liverpool John Moores University, UK

Lyvonne Tume
University of Central Lancashire, UK

Abstract

Currently there appears to be few opportunities and little evidence of physically disabled children and young people (C&YP) participating in mainstream social activities. A qualitative review was undertaken to examine the factors affecting physically disabled C&YP (8–15 years) in the United Kingdom participating in out-of-school activities. Views and experiences were explored from the perspective of the service users and providers to assess current provision and to determine the need for future research into factors that may affect participation. Searches were conducted across eight databases, the references of the included studies were checked and the websites were searched. Studies that used a qualitative design that examined the views relating to out-of-school activities were included. Nine papers were identified, which included three peer-reviewed papers and six pieces of grey literature and pertinent government documents to include views and experiences of out-of-school activity provision. The main themes emerging from the review were the need for social inclusion, out-of-school activities run by volunteers and accessibility, with threads throughout, which require further research including parental influence, provision, training and attitudes. This review highlights the absence of the service user's voice and sheds light on the limited provision and barriers affecting participation in out-of-school activities.

Keywords

Children, young people, physical disability, disabled, participation, social activities and out-of-school activities

Corresponding author:
Kate Helen Knight, Faculty of Health and Applied Social Sciences, Liverpool John Moores University, 15-21 Webster Street, Liverpool, L3 2ET, UK.
Email: k.h.knight@ljmu.ac.uk

Introduction

Disability issues are high on the current political agenda, with the launch of the new cross-government Disability Strategy in September 2012 (Department of Work and Pensions, 2012), which aims to break down the barriers to social mobility and equal opportunities faced by disabled people in Britain (Department of Health (DOH), 2011). Disability is defined by The Equality Act (2010: 7) as a person who has a 'physical or mental impairment which has a substantial and long-term adverse effect on their ability to perform normal day-to-day activities'. There are over 10 million disabled people in Great Britain today. According to the estimates from the Family Resource Survey (HM Government: Office for Disability, 2011), disability prevalence in the North West of England is 1.5 million, higher than any other region in the United Kingdom (UK). Every Disabled Child Matters (2011) highlights that there are around 770,000 disabled children aged 0–16 years in the UK. This equates to one child in 20 being disabled. Terminology changes from time to time but 'the term considered to be best practice from the disabled people's movement is in fact the term ''disabled children''' (Kids Playwork Inclusion Project, 2011: 2).

In the UK, a 10-year National Service Framework highlighting the need for disabled C&YP to be supported to participate in family and community activities has been set (DOH, 2004). Whilst a range of specialised activity provision is available, there appears to be few opportunities and little evidence of participation in mainstream social activities. Given the known benefits of participating in social activities and the adverse effect the lack of social interaction can have on quality of life, understanding why disabled C&YP are excluded from or less likely to access clubs and activities out-of-school is warranted (Bennett, 2009; Beresford and Clarke, 2010). To elicit greater understanding of the reasons for the lack of engagement, it is vital to hear from the service users or potential service users of social out-of-school activities themselves. Service user research is increasingly becoming important within research and policy development (McLaughlin, 2010). It is only by listening to service user and provider views about factors that influence participation and inclusion in out-of-school activities that improvement can be promoted (Pelchat et al., 2009).

The purpose of the review is twofold: to explore factors that may affect physically disabled C&YP accessing out-of-school activities and to define future areas for research in this field. A qualitative methodology was chosen, as it is the voices of the C&YP, their families and those involved in activities that are most important. The paucity of research is highlighted by Carpenter and McConkey (2012) and Stalker et al. (2012) who state the need to hear disabled children's voices about their lives but highlight that there is very little in general. Kay and Tisdall (2012) demonstrate the importance of hearing children's voices, but research needs to look beyond the direct quotes and focus on the various means of communication through non-verbal, play and observation, which unfortunately are lacking in UK studies.

Search strategy

The literature search was carried out by K.H.K. with clarification from a Research and Learner Support Officer to ensure all relevant databases were covered and to check search strategies. The results and themes were discussed with L.P. and L.T. The literature search was conducted between March and July 2012 to answer the following question: What are the factors affecting physically disabled C&YP (8–15 years) participating in out-of-school activities in the UK? The databases searched were Cinahl Plus with full text 2006–2012, Web of Science, Social Care Online, ASSIA, Community Care Inform, Medline, Google Scholar and British Education Index. The search terms

used were children, young people, participation, social activities, out-of-school activities and disability. In addition, Internet searches were conducted using the keywords 'Boolean logic' and 'snowball techniques'. This process was checked by RC for quality assurance. A hand search of reference lists of studies included in relevant papers was also done. Key national policy documents were checked for relevance. The search included published studies, relevant grey literature and government reports. As the focus was on UK provision of services, the review excluded non-UK papers that could potentially reflect a different cultural view of disability. Grey literature was sought using Google scholar, reference lists from the published literature and relevant websites relating to C&YP and disability. The grey literature is defined here as any information that has not been published in a peer-reviewed journal. This has been included as it provides relevant qualitative information that can add to the understanding of the needs of C&YP and their families and those providing out-of-school activities.

UK studies were only included if they meet the following inclusion criteria:

- Included views of services users: physically disabled C&YP aged 8–15 years and their families. The age range corresponds with much of the out-of-school provision of social activities.
- Included views of service providers running out-of-school activities.
- Included issues relating to participation, out-of-school, social leisure or community activities.
- Papers published after 2006, to critique the recent literature within the last 6 years due to the paucity of published literature and to include changes in policy and government drives.

This literature review is based on nine papers including both published and grey literature (summarised in Tables 1 and 2). Published studies that met all of the inclusion criteria were limited to three papers (Knight et al., 2009; Lawlor et al., 2006; Sloper et al., 2009). A further five reports (Bennett, 2009; Beresford and Clarke, 2010; Langer et al., 2010; Petrie et al., 2007; The Bevan Foundation, 2010) and one briefing paper (Kids Playwork Inclusion Project, 2011) were identified through relevant websites. Knight et al. (2009) and Petrie et al. (2007) present research results pertaining to the same study, which will be discussed together. All peer-reviewed papers that have met the inclusion criteria have been critiqued using the Critical Appraisal Skills Programme (CASP, 2012) tool for qualitative research by the lead author (K.H.K.). Eight were key government and charity documents, which were relevant to this literature search. Of these, four were key documents from the UK (DOH, 2004; Welsh Assembly, 2007; National Institute for Health and Clinical Excellence (NICE), 2009; HM Government: Office for Disability, 2011). These key documents were pertinent to this topic, and although the DOH National Service Framework was published in 2004, it is a 10-year plan so warranted review (a flowchart relating to the search is in Figure 1).

Results

Three main themes emerged from the review: the need for social inclusion, out-of-school activities run by volunteers and accessibility. Themes were identified through the aims of the study and from major overriding topics identified from the service user and service provider's comments found within the literature review, but there are points identified, which are threads across the themes that require further investigation, such as parental influence, provision, training and attitudes.

Table 1. Characteristics of the included published peer-reviewed literature.

Study	Aims	Location	Sampling		Data collection	Findings
			Sample	Details		
Knight et al. (2009)	To understand how provision for holidays and other out-of-school times may contribute to the social inclusion of families with a disabled child	Six local authorities in the UK	86 children and young people (C&YP) 90 parents 121 staff	7–19 years old; 38 girls/48 boys; represented; mixture of disabilities – included 17 physically disabled C&YP Higher number of White British represented Mostly middle/senior management – local authority social services, education, early years, special and mainstream schools, health services, play, youth services and voluntary organisations	Semi-structured interviews; case study approach	High levels of social isolation and exclusion during out-of-school periods and during school holidays in particular. The topic areas included rather than themes presented: • Experiences/perspectives of disabled young people of the school holidays • Holiday clubs/other leisure opportunities • Promoting social inclusion for disabled young people • Gaps in provision • Meeting disabled children's rights
Lawlor et al. (2006)	To ascertain from families of children with cerebral palsy the features of physical, social and attitudinal environments that facilitate or restrict participation	North East of England	Families of C&YP with cerebral palsy aged 5–17 years	Five mothers, three fathers, one grandmother, three both parents; only two children gave views; cerebral palsy with a variety of mobility (six walking and six non-walking)	In-depth interviews using a topic guide	The main themes presented were: • Importance of mobility • Transport • Support by and to parents • Attitudes of individuals and institutions towards children.
Sloper et al. (2009)	To explore how disabled children and their parents defined their desired outcomes for their own/their child's life	Three local authorities in the UK	Families of C&YP aged 1–18 years; 95 families took part representing 100 children; 90 mothers; 18 fathers; included seven bereaved parents of children with degenerative conditions; 27 'other informants' (person child choose to accompany); 29 C&YP participated directly	55 boys/45 girls; 27 minority ethnic group families; four groups of disabled children: • Autistic spectrum disorders • Complex health needs • Degenerative conditions • Children who do not use speech to communicate for physical or neurological reasons.	Semi-structured interviews	The themes presented were: Fundamental outcomes • Physical well-being • Communication • Staying Safe Higher level outcomes • Enjoying and achieving • Socialising and having friends and relationships • Activities and experiences • Education and learning • Self-care skills • Life skills Making a positive contribution; economic well-being

C&YP: children and young people.

4

Table 2. Characteristics of the included grey literature reports.

Study	Aims	Location	Sampling		Data collection	Findings
			Sample	Details		
Bennett (2009)	To ask families about their social emotional and practical experiences of raising a child with a disability	UK	615 families caring for a disabled child/young person aged 0–19 years	22% have child 0–5 years; 52% have child 6–12 years 26% have a child 13–19 years; range of disabilities and health conditions	Online survey with open/closed questions	Three clear themes were presented: Lack of services, attitudes towards disability, lack of support from professionals; 73% of respondents said their child's access to play/leisure specifically for disabled children is poor or unsatisfactory; Families want more play/leisure and choice
Beresford and Clarke (2010)	To describe what works in improving access to positive and inclusive activities for disabled C&YP (excludes literature where mental health problems were the disabled child's primary diagnosis)	UK	16 disabled C&YP; 19 parents of disabled C&YP; 170 service providers	10 C&YP Six young people (aged 14–25 years) 15 mothers; 4 fathers; range of disabilities Across seven regional workshops; including mainly local authority children's services	Two focus groups Interviews and questionnaires Interviews or email views Knowledge workshops	Key messages presented included: • Positive activities associated with positive outcomes in terms of health, experiences, enjoyment and community participation. • Existing services need to examine whether the services they believe to be inclusive are truly inclusive
Kids Playwork Inclusion Project (2011)	Briefing paper looking at myths based on inclusion of disabled children in play setting and services					
Langer et al. (2010)	To assess the impact of short break provision on the lives and well-being of disabled C&YP	North of England (mainly North West)	17 parents/carers; three disabled C&YP three siblings of disabled C&YP Four interviews with eight parent/carers Nine parent/carer responses		Semi-structured individual interviews using topic guides Group interviews Narrative tools (e.g. story space')	Some of the related major findings reported: • There was a wide range of short break provisions, parents use and value short breaks for different reasons. • Have positive impacts on children's lives, e.g. developing and maintaining social relationships and being able to enjoy fun activities. • Leaving the child could make parents feel vulnerable
Petrie et al. (2007)	Report of 'On holiday!' study, which is published by Knight et al.'s (2009) study	Wales	82 disabled C&YP	Aged 11–17 years	Short-questionnaire survey – open and closed questions; observation of activities with discussions with young people	
The Bevan Foundation (2010)	To explore views of disabled C&YP's experiences of play and leisure; to ascertain experiences of providers of leisure/play activities for C&YP		25 providers; 22 from voluntary/community organisations; three from local authorities		Survey and interviews	• The majority of disabled C&YP in the study participate in a limited number & range of activities and some feel there is 'nothing for them'. • They face barriers from lack of provision, lack of support, poor access to buildings and negative attitudes. 18 of 25 provided integrated provision; 1 of 25 did not involve any disabled C&YP 9 of 25 provided activities exclusively for disabled C&YP three provided both • Of the inclusive organisations, eight knew whether they had policies on inclusion of disabled C&YP • 10 provided disability awareness staff training

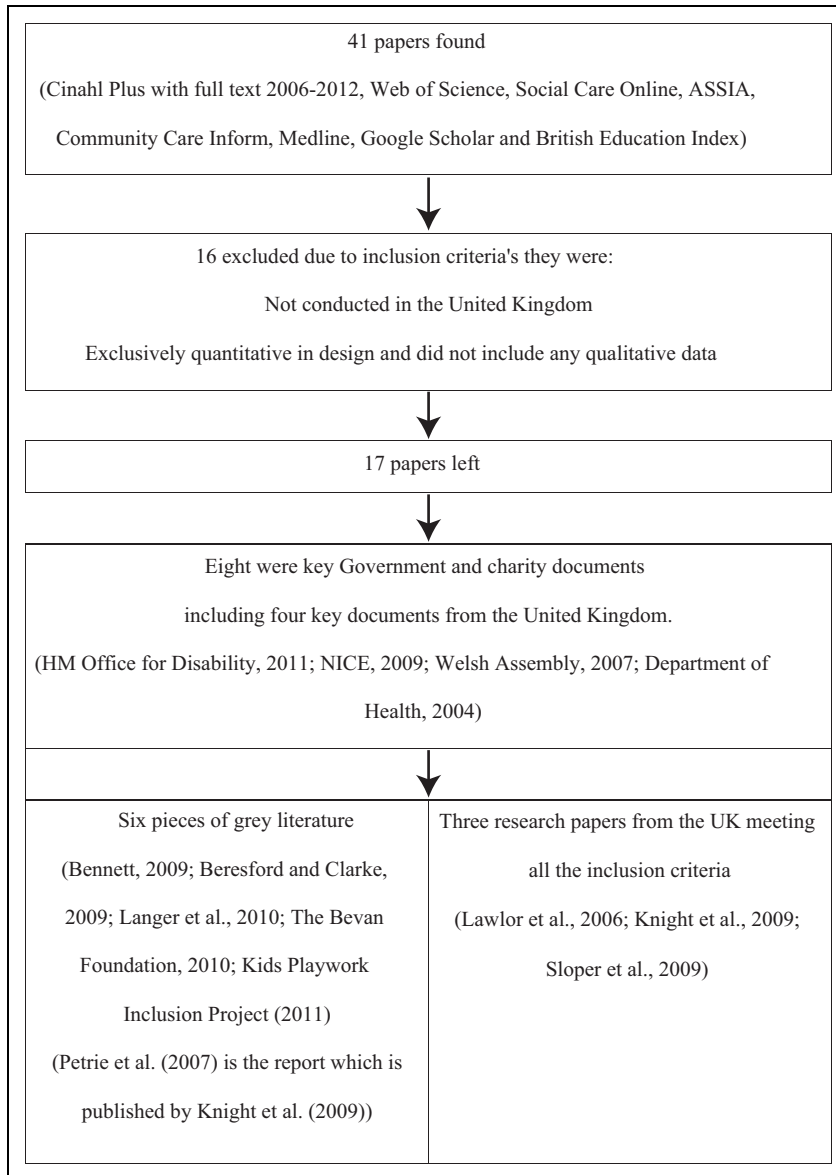C&YP: children and young people.

5

Figure 1. Flowchart of the literature search.

The need for social inclusion

All of the literature discussed the issue of social inclusion. Social inclusion refers to C&YP joining in with activities of their choice and having the right to participate fully in their community (Barnardos, 2012). Barnardos (2012) believe that disabled C&YP must have the same choices, opportunities and experiences as other children, to make local friends and to access, play, leisure and recreational facilities. According to DOH (2004: 9), disabled children wish to 'have friends of

the same age or who share similar experiences and to do the same things as other C&YP of their age'. This suggests a desire for inclusion in mainstream activities. This is confirmed in The Bevan Foundation's (2010) cross-sectional mixed method study exploring disabled C&YP's experiences of play and leisure in Wales. A total of 82 disabled C&YP completed the questionnaire that included open questions (aged 8 years to young adults). The response rate was not stated. They found a number of activities were rarely undertaken, with 90% replying rarely or never attending a youth club such as Scouting or Brownies. More than half of the respondents rarely or never attended a disabled children's club because they did not know whether there was one in their area. Of those who did attend out-of-school activities, some preferred to be involved in 'disabled – only groups' as they felt more comfortable with others like themselves and felt that the adult leaders were very patient. Eight of the 82 children felt there was nothing for them, with one young person stating 'activities not available locally with people that can cater for my disability' The Bevan Foundation (2010: 25). This is an interesting starting point, but this study gave a limited voice to the disabled C&YP, as it did not provide them with the opportunity to elaborate on responses. The sample included C&YP aged 11–17 years; therefore, the findings need to be interpreted with caution as some of the issues raised may relate to adult provision or the transition into adult services, so the findings may not be representative of the child population.

The need for social inclusion also featured in Knight et al.'s (2009) qualitative holiday study with 86 disabled 7–19 year C&YP across the UK. Within this sample, only 17 C&YP were reported as having physical disabilities; so it is difficult to gain their views from the overall findings, which showed that disabled children wanted to mix with non-disabled young people but the experience was problematic. Often these children were worried what other C&YP might say about their disability. They found that when exploring social inclusion, most of the experiences were positive. There was some boredom reported, however, this issue would need to be compared to findings with their mainstream peers. They also highlighted that a major motivator for disabled children to join clubs is being with other young people and doing activities along with their peers. In this study, it was suggested that disabled C&YP value provision that is designed for all children regardless of their ability (Knight et al., 2009). Although useful to ascertain C&YP voices, including children who only used non-verbal communication, the study did not report piloting the interview questions. A further limitation is that the age group was broad (reported as 7–19 years), and it is unclear how many children were in each age group. If the average age in this sample was high, this may bias the findings due to issues around transition between child and adult services. In support of the need for social inclusion, Langer et al. (2010), through interviews and focus groups, explore short break provision with a total of 34 parents/carers and three disabled C&YP. They -portrayed the social benefits of this out-of-school provision, but only reported the type of activity the C&YP engaged in and the contact with friends rather than how the short breaks affect them individually. In order to evaluate out-of-school lives like in the previous two papers, the UK disabled children's charity, 'Contact a Family', commissioned an online survey, including open-ended questions, in which families were asked to describe their experiences (Bennett, 2009). The 615 families taking part in their survey had children with a range of disabilities. The C&YP represented were aged 0–19 years, which again makes it difficult to elicit findings specifically to those aged 8–15 years. However, 78% of their sample was over 6 years of age, information is of value to ascertain factors affecting the access to out-of-school activities. Seventy-three percent of the families said that the access to play and leisure specifically for disabled children was poor and unsatisfactory. A parent of a severely physically disabled child stated that her child 'has a very active social life which is due to the support networks I have fostered' with another describing

how their daughter 'gets fed up being around her family and enjoys the company of others' (Bennett, 2009: 10–11). It is helpful to have the parent's views, where the C&YP were unable to communicate verbally due to their disability, but it is important to listen to C&YP also. This section gives a strong message that social inclusion is vital for all C&YP, the preferences of the service users and factors affecting access needs now be explored.

Out-of-school activities run by volunteers

The National Institute for Health and Clinical Excellence (NICE, 2009) promotes accessible physical activity for all C&YP and the voluntary sector plays a significant role in promoting opportunities for disabled C&YP and their families. When approaching an activity group, first impressions can be vital, and it is the individuals running them who are the first point of contact. Due to the nature of volunteering, there may be a mix of expertise, training and understanding of disabilities. There is a dearth of research on the views of staff that plan and run mainstream activities for all C&YP regardless of whether this is inclusive mainstream or specialist provision. Knight et al. (2009) claims it is important to explore the attitudes of those individuals carrying out the activities as this may determine if someone joins or not. In Knight et al.'s study, 121 staff from across health, education, youth and the voluntary sector were interviewed about holiday provision for disabled C&YP. Most were middle or senior management rather than individuals who have face-to-face contact with children and families. Study findings highlighted areas that the C&YP and families felt were inadequate even though the staff highlighted the steps to promote greater social inclusion. It is vital that all staff running community activities, including volunteers, have the skills to support individual C&YP. They also need to have a positive attitude, making the C&YP feel welcome and encourage each child as an individual (The Bevan Foundation, 2010). When 16 disabled C&YP were interviewed, they felt afraid of being bullied and made to feel different, with an example from a young person who stated 'just because you talk funny, people think you are thick' (Beresford and Clarke, 2010: 15). Therefore, an environment where C&YP feel safe is paramount (Beresford and Clarke, 2010). In order to explore how this could be reduced both Beresford and Clarke (2010) and the Bevan Foundation (2010) looked at staff disability awareness in terms of confidence, funding and understanding. The Bevan Foundation (2010) highlighted that the relationship between the volunteers and the parents can affect the participation. However, this study did not obtain the parents views in order to compare. Although this work does indicate the need to look at factors that may affect participation, such as staff training and attitudes, neither of these studies have been published in peer-reviewed journals. Bennett (2009) found that half of the families expressed dissatisfaction with mainstream play and leisure facilities due to the lack of accessibility, travel and lack of disability training amongst staff. Therefore, there appears to be a generalised dissatisfaction in these areas so any best practice found when this is researched needs to be shared. This is supported by The Bevan Foundation's work on providers of out-of-school activities, which found that the attitudes of staff can affect the participation experiences of C&YP and their families. They compared this to the findings from interviews and observations of play workers, some of whom were from the voluntary sector, where the staff acknowledged that in the past, children may have not felt welcome because of staff attitude as they were afraid about not being able to cope. On arrival, parents and C&YP experience these negative attitudes from staff, and this will naturally cause a barrier to participation. Such a premise needs further exploration as service providers could identify negative attitudes within their teams and more importantly consider ways of ensuring that staff are adequately skilled and resourced to include

all children in the activity. This study was conducted in Wales (mid and south Wales); so this needs to be extended across the UK as there may be regional funding or training differences. It is recommended that volunteers working in activities, local leisure and recreation facilities as well as the providers should be trained in disability awareness (Beresford and Clarke, 2010). It is unclear how many volunteers are trained as there is no national database, thus training is an area for improvement. In the study by Sloper et al. (2009), the need for staff to be trained was important for all the 95 families with disabled children (100 children represented), which were identified through semi-structured interviews. Of the children, 29 directly participated. This large sample included C&YP with a range of disabilities and many with complex health needs. The findings showed the importance of everyone in regular contact with the child to have appropriate knowledge and skills to understand the child's means of communication. They highlighted the importance of socialising, having friends and relationships, for example, 'when she is not at school, she wants to go places where other young people go' (Sloper et al., 2009: 271). Whilst some conclusions might be drawn from this study, it needs to be with caution. There may be some additional difficulties in this group of children related to their communication needs that may not reflect the needs of all physically disabled children. This study included families with children aged 0–18 years, therefore, like previous studies discussed, this limits the information specifically in school children aged 8–15 years. This theme highlights the need to understand the provision, training and attitudes within the out-of-school activities in order to have an understanding of a gap between service providers and service users.

Accessibility

Knight et al. (2009) found that the accessibility and location of the out-of-school activities were factors affecting participation. This can lead to a lack of contact with school friends' out-of-school times, which can affect friendship and participation. Children who attended special schools away from their local area were found to have reduced social community-based activities (Knight et al., 2009; Petrie et al., 2007; Sloper et al., 2009). The Equality Act (2010) requires reasonable adjustments to be made to remove physical access as a barrier and, therefore, should not be a factor affecting participation. However, children interviewed by the Bevan Foundation (2010) stated that many of the leisure centres they had visited were good but access was more difficult in clubs, such as community groups. This was also found in Knight et al.'s study (2009), where a 12-year-old girl could not access a youth club due to physical access barriers. This limits their choice, which links back to the importance of the C&YP having a preference to any activity. Petrie et al. (2007) also found that the requirement in some cases was for parents to accompany the disabled child/young person to holiday activities, which may not be what they want. In addition, Lawlor et al. (2006) reported problems in accessing social and leisure provision in their study in the North East of England. Twelve parents/grandparents of 5- to 17-year-old children with cerebral palsy outlined lack of access to public transport and to buildings, making participation difficult. This study did not solely focus on the leisure activities but addressed it as one area of difficulty within their aim looking at activities of daily living. It does, however, give good insight into the factors affecting participation in out-of-school activities. It would have been beneficial to hear from more of the C&YP themselves in this study as only two children gave their views. This problem with access is echoed by another parent in the study by Bennett (2009: 10), who states that 'there is no suitable swimming or parks nearby with accessible equipment'.

Multiple issues within this overarching theme such as activity timing, location and physical access need to be specifically compared from a service user and service provider view in order to fully understand the challenges faced by disabled C&YP.

Limitations of the review

Due to the limited published work in this area, this review is based predominately on the grey literature, which is not peer reviewed and can potentially introduce bias into the results. To overcome this, all work was critically appraised. The weak evidence base demonstrates the lack of robust evidence about the out-of-school lives of disabled C&YP and their families in the UK.

Conclusion

This review of the qualitative literature highlights the absence of the service user's voice in relation to out-of-school activities in the UK. The evidence suggests that disabled C&YP wish to access and participate in out-of-school activities but encounter barriers. The need for social inclusion is clear, but the mitigating factors include the need for training and addressing accessibility issues. There are threads throughout, which require further research such as parental influence, provision, training and attitudes within the out-of-school activities. Further research is required to investigate the factors affecting physically disabled C&YP's participation of out-of-school activities from the viewpoint of both the service users and service providers.

References

Barnardos (2012) Disability, special needs and inclusion. Available at: http://www.barnardos.org.uk/what_we_do/our_projects/disability.htm (accessed 28 March 2012).

Bennett E (2009) What makes my family stronger? Report, London, Contact a Family, May.

Beresford B and Clarke S (2010) *Improving the Wellbeing of Disabled Children and Young People Through Improving Access to Positive and Inclusive Services. Disability Knowledge Review 2*. London, UK: Centre for Excellence and Outcomes in Children and Young People's Services.

Carpenter J and McConkey R (2012) Disabled children's voices: the nature and role of future empirical enquiry. *Children and Society* 26: 251–261.

CASP (2012) Critical Appraisal Skills Programme, making sense of evidence. Available at: http://www.casp-uk.net/ (accessed 3 March 2012).

Department of Health (DOH) (2004) *National Service Framework for Children, Young People and Maternity Services: Disabled Child (Standard 8)*. London, UK: DOH.

Department of Health (2011) *Governance Arrangements for Research Ethics Committees: A Harmonised Edition*. London, UK: DOH.

Department of Work and Pensions (2012) *Fulfilling potential, the discussion so far*. Report, September, London, DWP.

Every Disabled Child Matters (2011) Welfare Reform Bill, second reading briefing on welfare reform for disabled children.Available at: http://www.ncb.org.uk/media/474664/edcm_second_reading_briefing.pdf (accessed on 14 July 2012).

HM Government: Office for Disability Issues (2011) Disability prevalence estimates 2009/10. Available at: http://odi.dwp.gov.uk/docs/res/factsheets/disability-prevalence.pdf (accessed on 16 March 2012).

Kay E and Tisdall M (2012) The challenge and challenging of childhood studies? Learning from disability studies and research with disabled children. *Children and Society* 26: 181–191.

Kids Playwork Inclusion Project (2011) Myth busting, busting the myths of inclusion. London Kidds NDD. Available at: www.kids.org.uk (accessed 14 July 2011).

Knight A, Petrie P, Zuurmond M and Potts P (2009) Mingling together: promoting the social inclusion of disabled children and young people during the school holidays. *Child and Family Social Work* 14: 15–24.

Langer S, Collins M, Welch V, Wells E, Hatton C, Robertson J, et al. (2010) *A Report on Themes Emerging from Qualitative Research into the Impact of Short Break Provision on Families with Disabled Children*. London, UK: Department of Children, Schools and Families.

Lawlor K, Mihaylov S, Welsh B, Jarvis S and Cover A (2006) A qualitative study of the physical, social and attitudinal environments influencing the participation of children with cerebral palsy in Northeast England. *Pediatric Rehabilitation* 9(3): 219–228.

McLaughlin H (2010) Keeping service user involvement in research honest. *British Journal of Social Work* Vol 40, 1591–1608.

National Institute for Health and Clinical Excellence (NICE) (2009) *Promoting Physical Activity for Children and Young People*. London, UK: NICE.

Pelchat D, Levert MJ and Bourgeois-Guerin V (2009) How do mothers and fathers who have a child with a disability describe their adaptaion/transformation process? *Journal of Child Health* 13: 239–259.

Petrie P, Knight A, Zuurmond M and Potts P (2007) On Holiday! Policy and provision for disabled children and their families. Thomas Coram Research Unit, University of London. Report for DfES.

Sloper P, Beresford B and Rabiee P (2009) Every Child Matters Outcomes: What Do They mean for disabled children and young people? *Children in Society* 23: 265–278.

Stalker Kon behalf of guest editorial team Abbott D, Beresford B, Carpenter J, McConkey R, et al. (2012) Researching the lives of disabled children and young people. *Children and Society* 26: 173–180.

The Bevan Foundation (2010) *Fair Play for Disabled Children and Young People in Wales*. Wales, UK: The Bevan Foundation.

The Equality Act (2010) Available at: http://www.direct.gov.uk/en/DisabledPeople/RightsAndObligations/DisabilityRights/DG_4001068 (accessed 15 July 2012).

Welsh Assembly Government (2007) Local participation strategies 0-25 guidance. Welsh Assembly government Circular. Available at: http://wales.gov.uk/publications/circular/2007/participationstrategies/?lang=en (accessed 27 March 2012).