Factors affecting UK physically disabled children and young people participating in mainstream out-of-school activities:
Focus on personal care and training

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Background

➢ Disability issues are high on the current political agenda, with the cross-government Disability Strategy in September 2012 (DWP, 2012)

➢ There are around 800,000 disabled children aged 0-16 in the UK. This equates to one child in 20 being disabled (Every Disabled Child Matters, 2014).

➢ Disabled children and young people (C&YP) wish to "have friends of the same age or who share similar experiences and to do the same things as others their age." This suggests a desire for inclusion in mainstream activities (DH, 2004).

➢ Research supports the need for social inclusion, (Lawlor et al., 2006; Knight et al., 2009; Sloper et al., 2009) however there is a paucity of UK peer-reviewed evidence (Knight et al., 2013).

➢ As service users of social out-of-school activities, it is vital to hear the voices of disabled C&YP and their families. To date, little is known locally about their views (Knight et al., 2013).

Aims

➢ To ascertain what out-of-school activities C&YP currently engage in

➢ To determine the facilitators and barriers to participation

Methods

Sample

• 14 disabled C&YP aged 7-17 years
• 13 mothers of disabled C&YP aged 7-15 years
• 3 fathers of disabled C&YP aged 13-15 years
• 1 sibling aged 13 years
• 10 Gatekeepers
• 11 Service providers
• 19 volunteers working in mainstream activities
• One County within the North West of England

Procedure

➢ Qualitative study using creative focus groups, focus groups and semi-structured interviews
➢ Ethical approval obtained from LJMU
➢ Digitally recorded focus groups and interviews were transcribed and analysed thematically using Nvivo 10

Provisional Findings

Facilitators to Participation
➢ Social Benefits
Barriers to Participation
➢ Information, Advertising and Networking
➢ Lack of Knowledge and Awareness
➢ Access
➢ **Personal Care**
Suggestions for improved participation
➢ **Training and Staffing**
Choice of out of school activity was individualised and influenced by location, previous experience and friendships. Two of the C&YP did not access any activities at all.

Designed by Georgina (16 years)

Highlighted Findings

Personal care - Which refers to a C&YP requiring assistance to use the toilet.
Four mothers of C&YP needing personal care or assistance felt that groups did not always cater for their children's needs and this meant they did not attend or required someone to accompany them. This impacts on social interaction and increases the need for parental respite:

"They are not prepared to assist with personal care, to take him to the toilet. We were met with quite a closed door on that. So we have now agreed that, if he needs to toilet they will phone me. I will drive to where they are and take him He can hold himself for that period of time" (Mother of 7 year old male)

"The (outdoor sports club) club has no wheelchair access to their toilet" (15 year old male)

"His dad did help him, if I was on my own , I would have really struggled with that, because I can't lift him anymore, so he was luckily that he had his dad to take him and actually go on the trips, so there is not much confidence in the group to take him on his own" (Mother talking about a mainstream youth group).

"James * can take me swimming but because of the changing rooms Jane* cant take me so its limited" (13 year old male) (*Names changed)

Highlighted findings

Personal care:

"The ones who are missing out are the ones who have the toileting issues" (Mother of 13 year old male)

"There are clubs they say oh we do all inclusive sports but actually they don't because they don't do personal care or one-to-one to me it should allow parents a little bit of respite for an hour" (Mother of 8 year old male)

Training and Staffing needs – which refers to suggestions for improvement.
All adult service users and service providers discussed the need for training, specifically awareness training.
Many of the gatekeepers interviewed provided free local training but providers and volunteers were unaware of this.

"If I look at the fantastically wide training available to our volunteers, I don't think there is a single bit in there that covers this sort of field. I don't think there is anything at all on this wider inclusion" (Youth service provider)

"As a coach I want to find out more about disability to try and engage. Previous training was free by the council child development service but it's not there now" (Sports and youth service provider)

Implications

➢ A joined up approach between providers of out-of-school activities, health providers, commissioners and local training providers is required.
➢ Personal care provision needs attention.
➢ Disability awareness training is required across sports and youth provision.

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