Factors affecting UK physically disabled children and young people participating in mainstream out-of-school activities: the children, young people and family perspective

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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 770,000 disabled children aged 0-16 in the UK.   This equates to one child in 20 being disabled (Every Disabled Child Matters, 2011)

➢ 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

References

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Methods

➢ Qualitative study using creative focus groups, focus groups and semi-structured interviews
➢ Ethical approval obtained from LJMU

Sample
• 10 disabled C&YP aged 7-15 years
• 11 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
• 10 Service providers
• 19 volunteers working in mainstream activities
• One County within the North West of England

Procedure
• Age and developmentally appropriate creative focus groups conducted within specialist disabled group settings
• Creative focus groups use activities and play
• Gatekeeper co-facilitated to ensure the C&YP felt comfortable with researcher
• Semi-structured interviews and focus groups with adults and children who chose to be interviewed as a family in a location of their choice
• Digitally recorded focus groups and interviews were transcribed and analysed thematically using Nvivo 10

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Provisional Findings

Choice of out of school activity was individualised and influenced by location, previous experience and friendships. Two C&YP did not access any activities at all, seven accessed specialised disabled groups and one accessed only mainstream.

➢ **Facilitators to Participation**
• **Social benefits**
Participation had perceived social benefits for everyone interviewed:

"I choose activities coz I enjoy them or I like the sport, I would also choose them as well if there are people that are disabled they can help you with it" (15 year old male)

" I enjoy the actually playing but also the social side as well meeting everyone, meeting new friends and seeing the friends that I have got" (15 years old male)

➢ **Barriers to participation**
• **Awareness**
Other people's awareness of the needs of disabled C&YP affected participation in all of the cases described by parents:

"I think it is about their lack of awareness and confidence" (Father talking about a mainstream youth group)

"When you ring up and explain they think you are from out-of-space and until they meet him they don't understand what he is about" (Mother of 8 year old male)

• **Access**
Access is an issue for the wheelchair users:

"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).

• **Personal care**
Three 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:

"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 years old male)

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

Implications

o C&YP and families must be listened to in relation to out-of-school provision
o Social interaction/inclusion has positive benefits on all C&YP and families
o Effective out-of-school provision can provide respite for families