

# Factors affecting physically disabled children and young people (C&YP) participating in out-of-school activities: Focus on Personal Care and Training

Kate Knight

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## Abstract

A recent qualitative literature review highlighted paucity of information in the out-of-school provision for disabled C&YP, families and providers in the UK (Knight et al., 2013). Along with limited participation, the review noted an absence of the service user's voice in the evidence base around social out-of-school activities and concluded that it was vital to hear from the service users or potential service users themselves, to elicit greater understanding of the reasons for the lack of engagement. To address this gap in the evidence base, a multi-method qualitative study was conducted examining the factors affecting physically disabled C&YP accessing mainstream out-of-school activities within one county in the North West of England from the perspective of both the service user and service provider. Focus groups, semi-structured interviews and creative focus groups were used across the study. A creative focus group is an age and developmentally appropriate activity and play-based tool that was specifically designed for use in this study.

Study findings have highlighted the need for activities with barriers including lack of information and awareness and access issues. This poster focuses specifically on personal care and training issues as these were deemed to be areas of specific relevance to conference delegates.

These areas can be influenced by health care providers, social support in the community and youth work. Most of the C&YP and families interviewed access ongoing support from health care providers therefore it was felt that it was important to disseminate to this field.

## Barriers to Participation - Personal care

In terms of the C&YP and families interviewed, personal care was discussed in relation to toileting, bathing and changing needs when at an out-of-school activity. Personal care was identified as an issue that caused additional stress for service users but is perceived to an area where health care professionals can offer some assistance, training or support in conjunction with youth and social care. Four mothers of C&YP needing personal care or assistance felt that groups did not always cater for their children's needs and as a consequence, the C&YP did not attend or required someone to accompany them:

*"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 an 8 year old male with complex needs).

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

## Suggestions for improved participation – Training

Participants in the study were asked for their opinions on service improvement. Training (or lack of training) was a dominant theme and a range of suggestions to address this issue were made.

*"We don't need to be treated differently but there are differences"* (Seventeen year old female who requires the use of a wheelchair).

For the parents this meant better provision of personal care support, a willingness of providers to give inclusion a try and a coordinated information centre. This could be a website coordinating a services from social care, activities and health: *"They are scared. They don't know how to deal with it and look on all the negative sides, how hard it is going to be for them rather than the positive side. At the youth club they were much more helpful, I mean he had to go with a one to one, there is no way he could go without that, that was one of his aids"* (Mother of 13 year old male).

*“His (medical) specialists concentrate on the medical side of things rather than passing on info that can help us in the community” (Mother of 9 year old male).*

For service providers this included disability awareness training and the issues surrounding this. There was many providers who wished for more training but either didn't know where to access or there were financial barriers or restrictions:

*“No, we do some child protection but not disability. One of our volunteers has family experience of disability so I would go to her for advice” (Youth provider).*

*“Yes, coaches have training. I would want training on specific disabilities as I wouldn't know what to do and how they react” (Sports volunteer).*

## Conclusion

This study provides new insight on the many barriers to participation faced by physically disabled C&YP such as how other people's lack of awareness and understanding affects participation, how access remains a constant battle, and how the need for personal care provides an additional challenge to families trying to access out-of-school activities. Whilst these findings echo those from the limited UK literature (Knight et al., 2013), it does highlight gaps in the evidence base which require further in depth investigation (for example; difficulty around personal care).

Health and social care professionals could drive forward a coordinated approach to information, training and support for volunteers in the communication via communication material and practical steps.

## Terminology

\*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).

### Author details

**Kate H Knight**

Senior Lecturer Children's Nursing

Liverpool John Moores University

K.H.Knight@ljmu.ac.uk

0151 231 4503

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