

# Youth with disabilities' perspectives of the environment and participation: a qualitative meta-synthesis

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## Abstract

Meta-syntheses can enhance our knowledge regarding the impact of the environment on the participation of youth with disabilities and generate theoretical frameworks to inform policy and best practices. The purpose of this study was to describe school-aged youth with disabilities' perspectives regarding the impact of the environment and modifications on their participation. A meta-synthesis systematically integrates qualitative evidence from multiple studies. Six databases were searched and 1287 citations reviewed for inclusion by two independent raters; 15 qualitative articles were selected for inclusion. Two independent reviewers evaluated the quality of each study and coded the results section. Patterns between codes within and across articles were examined using a constant comparative approach. Environments may be more or less inclusive for youth with disabilities depending upon others' understanding of individual abilities and needs, youth involvement in decisions about accommodations, and quality of services and policies. Youth implemented strategies to negotiate environmental barriers and appraised the quality of their participation based on the extent to which they engaged alongside peers. This meta-synthesis generated a framework illustrating the relationship between the environment, modifications and participation, and provided a conceptualization of participation grounded in the lived experiences of youth with disabilities. Findings reveal gaps in current knowledge and highlight the importance of involving youth with disabilities in decision making.

## Keywords

disabled children, environment, participation, qualitative research

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## Introduction

A critical shift is taking place in how researchers and professionals understand the participation of youth<sup>1</sup> with disabilities in life situations such as education and community life. This shift has been influenced by institutions and disciplines that have proposed alternative conceptualizations of disability. The World Health Organization's (WHO) International Classification of Functioning, Disability and Health (ICF) recognizes that physical, social, political and cultural aspects of the environment

impact participation (WHO 2001). The social model of disability (Oliver 1996) depicts disability as a consequence of inaccessible environments. These conceptualizations have shifted research questions away from an exclusive focus on development and impairment to questions about environmental supports and barriers (Law & Dunn 1993; Rosenbaum 2007; Rosenbaum & Stewart 2007). As a result, a growing body of research demonstrates that environmental barriers such as inaccessible spaces, attitudes and beliefs about disability, and lack of information about resources limit the participation of youth with disabilities (Hammal *et al.* 2004; Mihaylov *et al.* 2004; Forsyth *et al.* 2007).

<sup>1</sup> The term youth is used in this paper to refer to children and adolescents with disabilities.

In addition to the increased attention on environmental factors that impact youth with disabilities, there is a growing recognition that young people, including youth with disabilities, can express their thoughts and feelings, make informed decisions, and exert influence (United Nations General Assembly 1989; James & Prout 1997; Garth & Aroni 2003; Sloper & Lightfoot 2003; Cavet & Sloper 2004; Mayall 2004; Tisdall & Davis 2004; Bearman *et al.* 2005; Lansdown & Karkara 2006). This shift in the conceptualization of children and childhood has been influenced by the UN Convention on the Rights of the Child and contemporary approaches to childhood sociology. The UN Convention on the Rights of the Child states all children, including children with disabilities, are entitled to be involved in matters and decisions concerning them (Garth & Aroni 2003; Sloper & Lightfoot 2003; Cavet & Sloper 2004; Tisdall & Davis 2004; Bearman *et al.* 2005; Lansdown & Karkara 2006). Contemporary sociological approaches recognize that children are social actors who demonstrate agency within the socially, culturally and politically created structures of childhood (James & Prout 1997; James *et al.* 1998; James & James 2004; Mayall 2004). Together, these perspectives recognize that children with disabilities influence their surroundings, have expert knowledge regarding their everyday lived experiences, and have the capacity to make decisions (United Nations General Assembly 1989; James & James 2004).

The intersection of these contemporary approaches has resulted in an influx of qualitative studies that feature the perspectives and experiences of youth with disabilities regarding their physical and social environments. While an individual qualitative study may provide an in-depth understanding about a particular phenomenon or client group (Barnes 1992), the nature of qualitative research design limits our ability to generalize those findings across broad practice contexts (Sandelowski *et al.* 1997; Kearney 2001). While several recent literature reviews have compiled qualitative studies on the topic of environment and participation (Imms 2008; Shikako-Thomas *et al.* 2008), interpretations arising from these literature reviews are limited to general comments regarding the similarities and differences in results across studies. Scholars in the health sciences have called for a more systematic approach to synthesizing qualitative studies to enhance the generalizability of findings, advance the state of knowledge about a particular topic, and identify implications for practice (Jensen & Allen 1996; Sandelowski *et al.* 1997; Booth 2001; Kane *et al.* 2007). One method, meta-synthesis, has the capacity to enhance our collective knowledge (Nelson 2002) regarding youth's perceptions of the impact of the environment on their participation. Meta-

synthesis reviews and merges an existing body of evidence to generate theoretical frameworks that can inform research, policy and service delivery.

The purpose of this study was to describe the impact of the environment and environmental modifications on school-aged youth with disabilities' participation in their school, home and community. The research question guiding the meta-synthesis was: What are school-aged youth with disabilities' perspectives regarding the impact of the environment on their participation at home, school and community?

## Methods

Meta-synthesis is an approach of systematically integrating qualitative evidence emerging from multiple studies (Jensen & Allen 1996; Sandelowski *et al.* 1997). The primary goal of all meta-synthesis is interpretative, not summative (Noblit & Hare 1988; Sandelowski *et al.* 1997; Dixon-Woods *et al.* 2005). In a meta-synthesis, data from multiple studies are continuously and iteratively compared and integrated to achieve a new understanding of an underlying phenomenon and construct overarching narratives or new theories (Jensen & Allen 1996; Sandelowski *et al.* 1997; Harden & Thomas 2005; Kane *et al.* 2007).

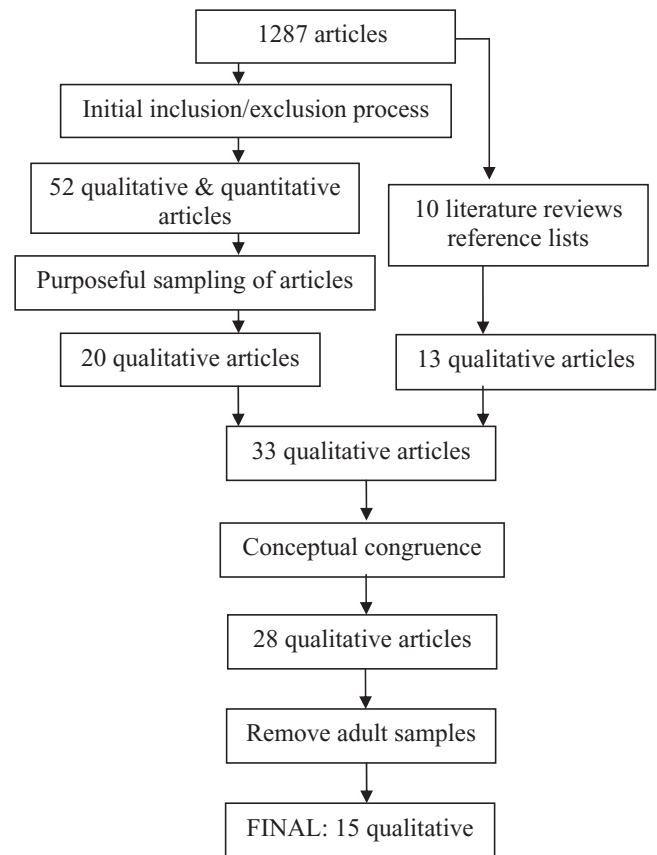
## Procedure

This research process lasted approximately 7 months. We searched six databases that included research related to youth with disabilities; search terms were based on four terms derived from the ICF model and modified to be database specific (Table 1). Our initial search attempted to be as broad as possible and included both qualitative and quantitative research articles. From this search, 1287 citations were found, not accounting for duplicates across databases.

Each abstract was reviewed by the first author and one graduate student using an inclusion/exclusion matrix. Inclusion criteria included: samples with youth ages 3–21 years and diagnosis of autism spectrum disorder, developmental disability (including physical disabilities), deafness or blindness, mental retardation/intellectual disability, and/or chronic illness; research completed in western countries; and studies that addressed participation in the home, school or community and at least one environmental component as defined by the ICF (WHO 2001). Exclusion criteria included: not written in English; not peer reviewed; sample of adults or youth with learning disabilities as primary disability; non-research articles; intervention studies; or other topics not relevant to the research question

**Table 1.** Databases and search terms

Search concepts	Terms used in each database
Children	CINHAL headings: child, adolescence ERIC headings: children, youth, adolescents ISI headings: child, youth, adolescent, young adult Medline limits: Preschool child: 2–5 years; child: 6–12 years; adolescent: 13–18 years; young adult: 19–24 years. PsychInfo headings/keyterms: child*, youth, adolescent, young adult Pubmed headings: child, preschool, adolescent, young adult
Disability	CINHAL headings: 'Developmental disabilities', 'Mental retardation', 'Child development disorders, pervasive', 'Chronic disease' ERIC headings: Disabilities ISI key terms: disab* Medline keyterms: disab*, chronic disease* PsychInfo headings/key terms: disab*, chronic disease Pubmed headings/key terms: disab*, chronic disease
Environment	CINHAL headings: 'attitude to disability', 'Social environment', 'Architectural accessibility', 'Access to information', 'Organizational policies' ERIC headings: environment, environment* ISI headings: environment Medline headings: environment* PsychInfo headings: environment* Pubmed headings: environment
Participation	CINHAL headings: Human activities ERIC: participat*, participation, activities ISI headings: participat* Medline headings/keyterms: participat*, human activit* PsychInfo keyterms: participat* Pubmed headings/keyterms: participat*, human activities

**Figure 1.** Meta-synthesis inclusion flowchart.

(e.g. experiences of healthcare utilization). If reviewers disagreed on inclusion or were undecided, articles were retrieved and independently reviewed in full. This resulted in an initial pool of 52 qualitative and quantitative articles. In addition, reference lists from 10 literature reviews and the included articles were reviewed using a 'citation snowballing' technique (Booth 2001). At this time, the authors identified that the published literature reviews primarily featured quantitative studies and did not represent the voice of children and youth with disabilities. To address this gap in the literature, the authors decided to proceed by conducting a qualitative meta-synthesis.

Next, a series of iterative questions were asked to identify those qualitative research studies that would best answer the research question, using a purposeful sampling technique (Booth 2001; Campbell *et al.* 2003; Thomas & Harden 2008). All qualitative studies were reviewed by at least two reviewers to identify those studies most relevant for inclusion and most likely to have 'conceptual congruence' (Jensen & Allen 1996).

Initially, we included qualitative studies with samples of youth and adults. However, during the analytical process, we were unable to verify if data referenced youth's or adult's perspectives; therefore, articles including adults (i.e. parents) were excluded. Our final sample was 15 articles (Fig. 1).

A worksheet was used to identify, extract and evaluate study design and content (revised from Classen *et al.* 2008). Two review teams extracted and evaluated the included manuscripts; each team consisted of the first author and one graduate student. The reviewers independently appraised components of each study using quality indicators (Thomas *et al.* 2003), and assigned an overall quality rating of 1 (poor) to 10 (excellent). Agreement in the overall quality rating for each review team as calculated by spearman's rho was 0.44 ( $P > 0.05$ ) and 0.84 ( $P < 0.01$ ). Reviewers met to discuss discrepancies in quality indicators and overall quality ratings until consensus was achieved. Studies were not excluded on the basis of quality. Reasons were twofold: one is the lack of clear guidelines with which to evaluate qualitative research quality (Sandelowski *et al.*

1997; Popay *et al.* 1998; Kearney 2001), and two is to ensure that a wide range of children's perspectives were represented in the analytical process.

### Analysis

The results section of each article was read line by line. Several rules of thumb guided the identification of data for coding. First, only information contained in a well-marked results section was considered for coding. Second, all data contained in direct quotes were coded. Third, text in which researchers annotated a story told by one youth or summarized issues reported across multiple participants was considered for coding. Finally, we reviewed each methods section for indications that the original researchers used strategies to ground their interpretations in the voice of the youth. Researcher interpretations that did not appear to be grounded in reported data were not coded and instead tagged as a 'validity concern'. When salient, an article's original theme or subtheme name was used as the code and definition. An initial code list was generated by four reviewers who individually reviewed three common and nine unique articles.

A constant comparative approach was then used to code the remaining articles; new data were examined for instances in which prior codes could be used to explain data and new codes were added as needed to describe concepts not represented by the current code list. This approach to data analysis meant that translation of concepts from one study to another (Noblit & Hare 1988; Nelson 2002) was ongoing and iterative, and went beyond a static test of concepts (Arai *et al.* 2007). Two times during the research process, the research team met to discuss the relationship between codes, organize codes into a hierarchical structure (Thomas & Harden 2008) and identify emerging themes. As not every code applied to every article, the research team searched for patterns emerging between pairs of codes within each article, and then looked across articles to identify instances in which a code from one pair was linked to a code from another pair. This process enabled the team to go beyond pooling of the data and construct a framework that explained the influence of the environment on participation.

### Sample

The 15 included articles used interview-based data collection techniques (Table 2). Studies included youth aged 6–21 years. The most common disabilities were cerebral palsy and spina bifida. Very few studies included youth with cognitive or intel-

lectual disabilities. Most studies took place within a school context. The quality of most studies was moderate (Table 3).

## Results

Three factors emerged as most strongly influencing youth's participation: adult and peer understanding of individual abilities and needs; decisions about accommodations; and the quality of services and policies. Additionally, youth used strategies to enable their own participation. The data suggest that the interaction of these factors support higher or lower quality participation; across studies, youth appraised the quality of their participation based on the extent to which they had meaningful roles and engaged alongside peers. Table 4 illustrates the number of times data from each article contributed to a thematic category.

### Factors influencing participation

#### *Adult and peer understanding of individual abilities and needs*

Adult's and peer's understanding of the needs and abilities of individual youth with disabilities influenced the extent to which youth participated in activities. Understanding enabled adults and peers to provide the appropriate level of emotional, cognitive or physical support at the right time. The literature contained numerous examples of the positive support that stemmed from a well-rounded understanding of a youth's unique abilities and needs. For example:

One teacher kept driving me the whole way. Kind of 'put it in a context, fair enough you have a disability but . . . throw it away from you and continue on' like. . . . It was the best thing ever. (Shevlin *et al.*)<sup>2</sup>

Parents demonstrated understanding by providing physical assistance, resources such as transportation and money, and emotional encouragement to youth. Peers also provided physical and practical support, especially at school. Friends helped students with disabilities carry things, held doors and took notes. Occasionally, friends acted as a mediator and explained what the youth with disability could and could not do, or stood up to bullies to protect youth with disabilities. The support received from understanding family and friends was particularly vital for participation when youth were not able to secure high quality services that met their needs.

<sup>2</sup> Data sources are referenced using abbreviated author information. For full reference information see Table 2.

Table 2. Study details of included articles: sample and method

Sample information					
Author	n	Age (years)	Diagnosis (n)	Ethnicity/nationality	Method
Asbjornsløtt & Hemmingsson (2008)	14	13–18	Inclusion: physical disability (CP, spina bifida, juvenile rheumatoid arthritis)*	Norway	Focus group & individual interviews
Blinde & McCallister (1998)	20	10–17	CP (11), spina bifida (3), birth defect (2), muscular dystrophy (1), head injury (1), paraplegia (1), polysonic fibrous dysplasia (1)	100% Caucasian	Interview
Curtin & Clarke (2005)	9	10–13	Use manual or powered wheelchair*	England	Biographical interviews
Doubt & McColl (2003)	7	15–19	CP (3), spina bifida (4)	Canada	Semi-structured interview
Goodwin & Watkinson (2000)	9	10–12	Spina bifida (4), CP (4) – one was hard of hearing, Amputation (1)	Canada	Focus group interviews, field notes and participant drawings
Harding <i>et al.</i> (2009)	6	8–13	Cardiopulmonary (1), physical and motor impairments (3), emotional/behavioural developmental disabilities (2)	Canada, 100% Caucasian	Case-study: CAPE, photos of out-of-school-time activity settings, and semi-structured interviews
Hutzler <i>et al.</i> (2002)	10	9–15	Spastic diplegia (4), spastic hemiplegia (4), spinal muscle atrophy (1), limb-girdle muscular dystrophy (1)	Israel	In-depth interviews
Lightfoot <i>et al.</i> (1999)	33	11–16	Health condition for at least 1 year*	UK	Semi-structured interview
Pitt & Curtin (2004)	10	17–21	Congenital physical impairment*	UK	Group and individual interviews
Prelwitz & Tamm (2000)	10	7–12	Restricted mobility (CP, spina bifida, polio, muscular disorders)*	Sweden	Semi-structured interview
Shevlin <i>et al.</i> (2002)	16	Left primary school 2–3 years ago	CP, hearing impairment, dyslexia, other*	Ireland	Semi-structured, group interviews
Skär (2002)	8	6–11	CP (1), spina bifida (5), polyneuropati (1), polio (1)	Sweden	Interview
Tamm & Skär (2000)	10	6–12	Restricted mobility related to spina bifida, CP or polio syndrome*	Sweden	Interviews
Taub & Greer (2000)	21	10–17	CP (10), Muscular dystrophy (1), spina bifida (3), paraplegia (1), head injury (1), degenerative bone disease (1), congenital motor co-ordination impairment (2), cerebral hypoventilation syndrome (1), congenital muscular weakness (1) (no details provided)*	Midwestern United States, 100% Caucasian	In-depth interviews
Woolfson <i>et al.</i> (2007)	30	10–13, 16+		Scotland	Focus groups

\*Authors did not specify diagnostic details.

CP, cerebral palsy; CAPE, Children's Assessment of Participation and Enjoyment.

**Table 3.** Quality appraisal of included articles

First author	Quality appraisal question														
	Overall quality rating*	A	B	C	D	E	F	G	H	I	J	K	L	M	N
Asbjornslett	6	Y	N	Y	Y	N	Y	Y	S	S	Y	Y	M	G	Y
Blinde	4	Y	N	Y	Y	N	Y	N	N	N	C	N	N	N	N
Curtin	6	Y	Y	Y	Y	P	Y	Y	S	G	P	N	M	M	N
Doubt	8	Y	Y	Y	Y	N	Y	Y	G	S	Y	Y	G	S	Y
Goodwin	7	Y	Y	Y	Y	N	Y	Y	S	S	Y	Y	S	G	Y
Harding	5	Y	Y	Y	Y	N	Y	Y	S	S	Y	Y	G	S	P
Hutzler	5	Y	Y	N	Y	N	Y	N	S	S	P	Y	S	S	N
Lightfoot	5	N	N	Y	Y	N	Y	Y	M	M	Y	Y	M	M	N
Pitt	6	Y	N	Y	Y	P	Y	Y	S	S	Y	Y	M	S	Y
Prellwitz	7	Y	Y	Y	Y	N	Y	Y	S	S	P	Y	S	S	Y
Shevlin	4	Y	Y	N	Y	N	Y	N	S	G	Y	N	N	N	N
Skar	4	Y	Y	Y	Y	N	Y	Y	N	M	P	Y	G	M	P
Tamm	7	Y	Y	Y	Y	N	N	Y	S	M	P	Y	G	G	Y
Taub	5	N	Y	Y	Y	N	Y	Y	M	M	N	Y	G	S	N
Woolfson	4	Y	N	Y	Y	N	Y	Y	S	S	Y	N	N	N	N

\*Overall quality rating: 1 = poor to 10 = excellent.

Key for quality appraisal questions:

A – Are the aims of the study clearly reported? N, no; Y, yes.

B – Are the objectives of the study clearly reported? N, no; Y, yes.

C – Is there an adequate description of how the sample was identified and recruited? N, no; Y, yes.

D – Is there an adequate description of the sample used in this study? N, no; Y, yes.

E – Were children actively involved in the design or conduct of this study? N, no; Y, yes; P, partially; C, can't tell.

F – Is the context of the study adequately described? N, no; Y, yes.

G – Is there an adequate description of the methods used in the study to collect data? N, no; Y, yes.

H – Have sufficient attempts been made to establish the reliability of data collection methods and tools? N, no; M, minimal; S, some; G, good.

I – Have sufficient attempts been made to establish the validity of data collection tools and methods? N, no; M, minimal; S, some; G, good.

J – Does this study use appropriate data collection methods for helping children to express their views? N, no; Y, yes; P, partially; C, can't tell.

K – Is there an adequate description of the methods of data analysis? N, no; Y, yes.

L – Have sufficient attempts been made to establish the reliability of data analysis? N, no; M, minimal; S, some; G, good.

M – Have sufficient attempts been made to establish the validity of data analysis? N, no; M, minimal; S, some; G, good.

N – Does this study use appropriate data analysis methods to ensure that study findings are grounded in the perspectives of children? N, no; P, partially; Y, yes.

In contrast, a poor understanding of the abilities of individual youth led adults and peers to over or underestimate youths' needs. When adults overestimated the needs of an individual youth with a disability, they restricted the youth's choices and opportunities for participation. For example:

One of Betty's few negative experiences came when she had a substitute teacher . . . the teacher singled her out as the only person who could not participate in an activity that she had previously played. (Blinde & McCallister)

In other instances, adults underestimated the needs of youth with disabilities and pushed them into activities that were uncomfortable or, at times, dangerous. As one young woman explained:

He had me walking, jogging, running and I said 'Sir I can't do this, I'm going to be sick', I was in such a state, I was blue . . . But they still made me do it. (Lightfoot *et al.*)

Peers could also misunderstand the abilities and needs of youth with disabilities. Many youth told stories in which peers believed that a physical disability always corresponded with a cognitive disability. A youth explained:

When they're talking, some people I found talk to you different because I guess they think there's something wrong with your mind too. (Doubt & McColl)

Peer misunderstandings such as this were often catalysts for bullying. Verbal or physical bullying from peers was mentioned by youth in eight of the included studies.

#### *Decisions about accommodations*

Decisions about accommodations were made in one of three ways: by the youth, by the professional, or collaboratively. Youth sometimes made decisions about the types of activities in which to engage. One young person reported: 'I suggest to the teacher

Table 4. Individual article contribution to meta-synthesis themes and subthemes

Theme	Absjornsett	Blinde	Curtin	Doubt	Goodwin	Harding	Hutzler	Lightfoot	Pitt	Prelwitz	Skar	Tamm	Taub	Shevlin	Woolfson
Adult and peer understanding of individual abilities & needs	8	1	13	9	10	2	6	35	12	9	7	8	7	16	9
Over/underestimation of needs	4	1	3	6	5	0	2	7	6	2	1	1	5	5	1
Understanding unique needs and abilities	4	0	10	3	5	2	4	28	6	7	6	7	2	11	8
Decisions about accommodations	8	0	9	1	0	2	5	8	3	6	1	1	1	6	10
Youth as decision maker	2	0	6	1	0	2	3	1	1	5	1	0	1	1	2
Collaborative decision making	2	0	0	0	0	0	1	0	0	0	0	0	0	0	3
Professional as decision maker	4	0	3	0	0	0	1	7	2	1	0	1	0	5	5
Quality of services and policies	1	4	14	6	6	0	6	11	10	6	2	0	0	13	6
Individualized services & policies	0	1	4	0	0	0	2	3	2	0	0	0	0	2	1
General services & resources	0	0	3	0	0	0	0	0	4	0	0	0	0	2	2
Inadequate accommodations/need not recognized	1	3	7	6	6	0	4	8	4	6	2	0	0	9	3
Strategies	1	0	7	13	1	2	8	8	0	3	2	2	4	4	1
Cognitive strategies	1	0	2	0	1	0	3	5	0	2	0	1	0	1	1
Interpersonal strategies	0	0	5	11	0	0	5	2	0	0	0	1	4	3	0
Physical & object strategies	0	0	0	2	0	2	0	1	0	1	2	0	0	0	0
Levels of participation	10	9	3	8	10	2	2	4	3	7	3	12	11	5	4
Doing what everyone else is doing	6	0	0	0	1	1	1	1	0	1	1	0	4	2	3
Fringe participation	0	2	0	7	2	0	0	0	0	0	2	6	0	0	0
Waiting or watching	0	6	0	0	2	1	0	0	0	0	0	2	1	3	0
Doing something different	4	1	3	1	5	0	1	3	3	6	0	4	6	0	1

which exercises I should do' (Hutzler *et al.*). Other times youth suggested alternative ways of completing activities or arranging support. For example:

[Riley] often missed his physical education lessons, using these periods as a time to see his physiotherapist or occupational therapist. He felt that this was a better use of his time, as he did not have to miss many of the so-called more academic lessons. (Curtin & Clarke)

These data illustrate that some youth made decisions about how and when they would engage in activities.

Collaborative decision making occurred when teachers and other professionals actively sought youth's perspectives, either during formal decision-making processes or informally during day-to-day operations. An example of collaboration was put forth in Woolfson:

Pupils are usually invited to attend review meetings about themselves, and to speak at them (but they usually do not want to): 'Teachers asked what I thought and how I was getting on.' (Woolfson *et al.*)

Meetings with professionals provided youth with disabilities the opportunity to collaborate in the decision-making process.

While the studies contained examples of collaborative and youth-driven decision making, it was also common for professionals to make decisions about accommodations without the input of youth with disabilities. Youth often attempted to suggest a more effective accommodation or explain to professionals why an accommodation would not be useful. However, in many of these instances, youth reported that their perspectives and suggestions were disregarded. For example:

He promised to ask and take into consideration what I could and could not do, but actually he did not accept any changes and nothing was done. (Asbjornslett & Hemmingsson)

When professionals made decisions about accommodations without collaborating with youth with disabilities, misunderstandings of the unique abilities and needs of an individual youth typically led to accommodations that did not support participation.

### *Quality of services and policies*

While the other factors describe youth's perception of the impact of individuals (primarily adults) on participation, this factor describes how services and systems impacted youth's participation. Youth described services as most helpful when they

were individualized to the unique needs and strengths of each youth. Flexibility was a defining characteristic of individualized services, whereby the rules as well as the amount and type of supports could be changed at any time. As one youth described:

[I was in] the A class for most subjects, though I studied [lower level] maths and Irish. I only did History and Geography [exams] at lower level but I was studying at honours level, it was kind of honours/pass for me. For homework I didn't do as much detail as people doing honours. (Shevlin *et al.*)

Adjusting the pace or timing was another way in which youth felt services were individualized to meet their needs. The Pitt article described: A slower pace of work and differentiated curriculum meant that they could work more independently and were less reliant on the support of an LSA (Pitt & Curtin). Thus, individualized services and policies were most likely to meet youth's needs and support participation.

Although individualized services were believed to be most helpful, youth occasionally benefited from general services and resources available to all youth. For example, a youth explained, 'I go to the homework club if the work is too difficult' (Woolfson *et al.*). While generic disability services were sometimes effective in meeting youth's needs, generalized policies were not ideal for all youth: Xanthe did not like the learning support system . . . because she had to share the learning support assistants (Curtin & Clarke). Across studies, general services and resources were most helpful when offered as a supplement to individualized services and policies.

Youth considered services inadequate when accommodations were not provided at the optimal place or time. These accommodations often led youth with disabilities to expend unnecessary time and energy and actually interfered with participation in more meaningful activities. For example: They [students] pointed out that there was a larger toilet, in some cases adapted for the disabled, but that it was further away or on another floor (Prellwitz & Tamm). In other instances, accommodations were provided in a place that was not conducive to the goal of the activity or lacked the necessary privacy:

A few teachers took me aside and went through things with me. But we had to work in the canteen, there was nowhere else. Classmates were astonished at me . . . spending time with a teacher! If they knew what [we] were talking about they'd know I needed the extra help. (Shevlin *et al.*)

Accommodations that required youth with disabilities to complete activities in alternative spaces or at alternative times did not support feelings of inclusion.



**Table 5.** Strategies used by youth with disabilities to negotiate environmental barriers

Strategy	Definition	Exemplar quotes
Cognitive strategies	Planning ahead, changing the organization of activities, or problem-solving to negotiate physical or social barriers. Includes seeking assistance from others to problem-solve.	I can choose to work on something that is easier or put it aside for a while. (Asbjornslett & Hemmingsson) Tell Mom. (Hutzler <i>et al.</i> ) We'd pair up, and my [school] partner used to do all the physical work. I just couldn't do it, I couldn't hold a glass of water. (Shelvin <i>et al.</i> ) One young man who had spent some time in a wheelchair talked about helping his friend with dyslexia: 'He helps me physically and I help him mentally, so we get on very well.' (Lightfoot <i>et al.</i> )
Interpersonal strategies	Changing the nature of interactions with others in order to change perceptions of disability. Includes explicit attempts to educate others about disability, emphasizing abilities and similarities over differences, and occasionally avoiding association with others with disabilities.	One girl in this study reported on writing a book in which she describes her own disability. (Hutzler <i>et al.</i> ) I feel like my body and their body are the same. They can do what I can do. I can do what they can do. Only thing is, I can't walk like they can. (Taub & Greer) I didn't like being on the table with the other disabled children. It was uncool . . . (Curtin & Clarke).
Physical & object strategies	Using one's body, surrounding space, or objects/technology in alternative ways to enable participation.	If you've ever seen a discus thrower they use the spin. And because my balance isn't perfect I use an altered spin. (Doubt & McColl). When she was swimming in the summer she needed her crutches to get into the water. In the water she had a problem when dropping the crutches, which she compensated for by attaching a float. (Skar)

Youth also shared stories in which service systems did not recognize that an accommodation was needed or followed rigid policies that did not allow for alternative ways of completing activities. System practices and policies that limited the participation of youth with disabilities often stemmed from professional over or underestimation of the needs of youth with disabilities. For example:

Pupils with continence difficulties were refused permission to go to the toilet by teachers who were unaware of their condition. (Lightfoot *et al.*)

These examples illustrate that without individualized services and policies, youth did not receive the high quality support needed to participate in a safe, comfortable and satisfying manner.

When services and policies did not meet the needs of youth with disabilities, youth used strategies to enable their own participation. Youth with disabilities initiated the use of cognitive, interpersonal, physical and object strategies (see Table 5) to negotiate environmental barriers and to compensate for inadequate accommodations.

### Levels of participation

When describing participation in home, school and the community, youth with disabilities commented on the extent to which they felt meaningfully engaged and authentically included. Their descriptions can be conceptualized as a con-

tinuum representing more to less inclusive participation that is determined by the interaction between the previously described factors.

#### *Doing what everyone else is doing*

Doing what everyone else is doing occurred when youth with disabilities engaged in tasks and activities alongside and along with everyone else. Sometimes the structure and content of activities were accessible to youth without additional modifications. In other instances, activities were modified so youth with disabilities could fully participate:

They were pleased when teachers adapted extracurricular activities, such as drama and music events, to enable them to take part and when they had the opportunity to go on school trips. (Lightfoot *et al.*)

These modifications provided youth with the opportunity to do the same things at the same time as their peers and resulted in the most authentic level of engagement and inclusion.

#### *Fringe participation*

Fringe participation occurred when youth could only participate in an activity in one particular way or were unable to access all facets of an activity. These restricted roles led to fewer opportunities for authentic interactions with others and did not engender a feeling of inclusion or acceptance. This was illustrated in one story:

Okay, we were going to do some line dancing on the stage for the whole school. Guess what, he [teacher] wouldn't let me do it. . . . Well, they could have just lifted me upon the stage and wheeled my chair up. I got to practice, but I didn't get to perform. [Interviewer: How did you feel?] Horrible, just horrible (Goodwin & Watkinson).

As a result, fringe participation was less meaningful or unfulfilling to youth with disabilities.

In some instances, youth accepted a fringe level of participation when it provided an opportunity to be included in activities with peers. One youth explained:

In physical education a lot of the times I'll be the last one to be picked . . . but when we play floor hockey I'll be the first one to get picked . . . Everybody else is reluctant to put on the pads because there's more glory in scoring. But I'll play net because I'm not as fast as the other kids so I just stay at home in the net. (Doubt & McColl)

Youth with disabilities felt that adopting these limited roles could provide entrée to an activity from which they would otherwise be excluded. While not ideal, participating on the fringe with peers was preferred over participating in activities alone or not at all.

#### *Waiting or watching*

Sometimes youth were left on their own to do nothing but wait or watch while their peers participated in activities. Spaces that were inaccessible to individual youth because of their particular disability were one cause of this level of participation:

I don't find it as accessible as the other places . . . there's actually a little bench sitting area in the park and on the slide area where that house is, so I'm just sitting there and sometimes my friends come up. (Harding *et al.*)

In other instances, youth were forced to watch when professionals refused to modify activities. One study conveyed a story in which a youth with a disability was not provided with accommodations to participate in physical education class, and instead sat and watched his classmates play (Blinde & McCallister). Across studies, youth reported feelings of frustration and exclusion when required to wait or watch others.

#### *Doing something different*

Doing something different described instances in which youth with disabilities participated in an activity, but not the activity that others were doing. Rather than adapt inaccessible activities,

professionals directed youth with disabilities to alternative activities as an accommodation. However, doing something different perpetuated feelings of exclusion as it removed youth from activities and the spaces and schedule in which their peers without disabilities engaged:

This year I helped the librarian pack our books . . . Because . . . the grass needs to be cut and I can't push through it. . . . I was really ticked off 'cause they had someone cutting some of the grass and I think they should have cut all the grass. (Goodwin & Watkinson)

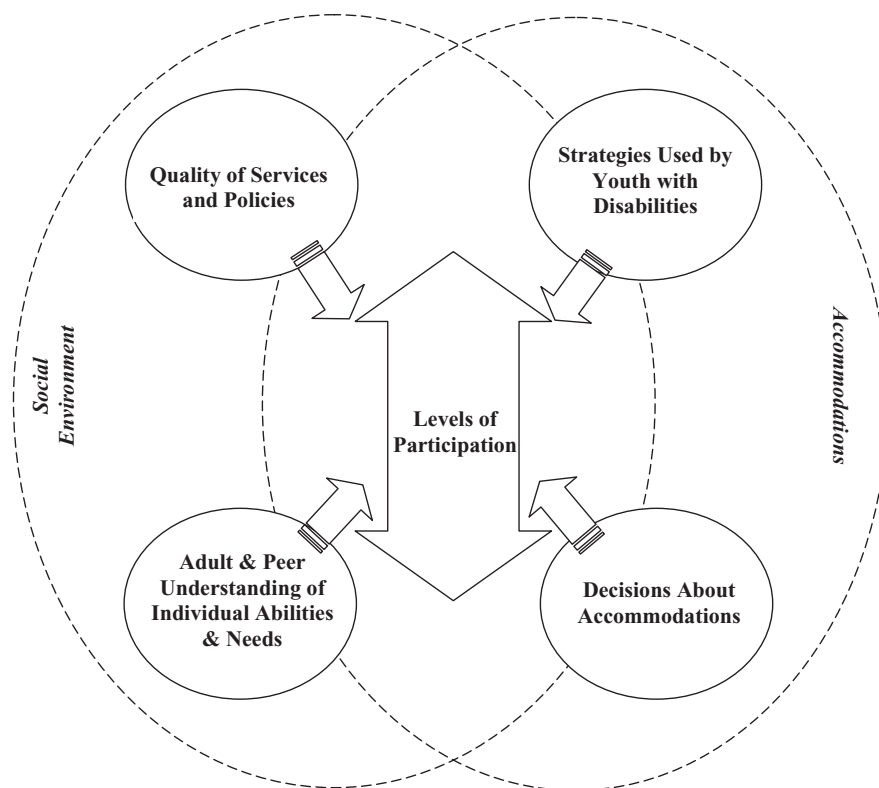
One child (#5) reported using an individualized worksheet and practicing alone, while other classmates did another activity. (Hutzler *et al.*)

These examples also reveal that the alternative activities frequently did not have the same goal or accomplish the same purpose as the original activity, further limiting the experiences of youth with disabilities. Ultimately, youth desired to feel like a part of the group even if participation was limited or if only able to watch.

## **Discussion**

This meta-synthesis revealed the youth's perspective that the social environment emerged as the factor most likely to influence youth's participation, resonating with findings from quantitative studies exploring barriers to participation (Hammal *et al.* 2004; Forsyth *et al.* 2007). The three main factors emerging from this meta-synthesis are all aspects of the social environment as defined by the ICF (WHO 2001) as seen from the perspectives of the youth themselves: (1) adult and peer support of an individual's unique abilities and needs; (2) the quality of services and policies; and (3) professionals' attitudes about involving youth in decisions about accommodations. These factors dynamically interact to detract or support youth's perceived level of participation, as illustrated Fig. 2. Additionally, youth with disabilities actively use strategies in an attempt to further accommodate environments and support meaningful participation. These findings are in keeping with a social model of disability in which the environment (Oliver 1996), rather than youth's impairment level, influences the extent to which youth participate in meaningful ways at home, school and the community.

The first factor that influences youth's perceived level of participation is adult and peer understanding of the abilities and needs of individual youth with disabilities. Across studies, youth were more likely to describe their engagement in activities as



**Figure 2.** Relationship between the environment, accommodations and levels of participation.

meaningful when adults and peers were responsive to both their capacities and limitations. Youth welcomed the support provided by understanding adults and peers, in contrast to the frustration expressed when professionals over or underestimated their needs or abilities. The data suggest that there is a dynamic interaction between adults' and peers' understanding of the unique needs and abilities of youth with disabilities and the other factors identified in the meta-synthesis. For example, professionals who engaged in collaborative or youth-directed decision making about accommodations were often more attuned to the abilities and needs of individual youth with disabilities. Similarly, professionals with a comprehensive understanding of a youth's unique abilities and needs were better able to provide high quality, individualized services. In contrast, inadequate accommodations often stemmed from professionals who did not understand the needs or abilities of youth, and who unilaterally made decisions about the accommodations provided to youth with disabilities. Professionals may increase their understanding of both the capacities and needs of youth with disabilities by asking youth to share their expertise about themselves and their everyday lived experiences (James *et al.* 1998; Mayall 2004).

The second factor that influences youth's perceived level of participation is the extent to which youth are involved in deci-

sions about accommodations. This meta-synthesis showcases the ability of youth with disabilities to articulate aspects of their environment that impact their participation. Youth expressed a desire to direct the decisions made regarding accommodations and supports, and their stories suggest that youth's knowledge about their own preferences, needs, and strengths were more likely to generate solutions that facilitated their inclusion in activities. Across studies, youth's stories revealed that they actively used a variety of strategies to negotiate environmental barriers, the third factor found to influence youth's perceived level of participation. In fact, as shown in the frequency counts of strategy categories in Table 4, youth most frequently used cognitive and interpersonal strategies that did not require extensive physical changes or resources. These types of cognitive and interpersonal strategies could be easily implemented in a variety of contexts. This finding highlights the unique expertise youth with disabilities contribute via their lived experiences as proposed by contemporary approaches to childhood sociology (James & James 2004; Mayall 2004).

These findings provide additional evidence for the value of involving youth in planning their services and supports (King *et al.* 2005; Powers *et al.* 2007; Rosenbaum & Stewart 2007) and further stress the importance of involving youth in decisions that pertain to them in a variety of settings, including school,

the community, and in the development of local and national policies (United Nations General Assembly 1989). Findings suggest that youth are more likely to achieve their desired level of participation when professionals and youth collaborate to generate solutions to environmental barriers. However, not all youth may have the skills needed to identify barriers and solutions, particularly those with limited experience advocating for themselves or making decisions (Wehmeyer 1998). Youth may benefit from skills training teaching a systematic approach to identifying environmental barriers and potential solutions. The strategies identified in this meta-synthesis could be used as a model to teach youth with disabilities how to self-initiate modification strategies. Additionally, professional reflexivity regarding the limits of professional knowledge and the value of youth self-knowledge may also facilitate a sharing of power when making decisions about accommodations (Davis 1998; Mayall 2004; Kramer *et al.* 2012).

The fourth factor that influences youth's perceived level of participation is the quality of services and policies provided to youth with disabilities. Flexibility was a common factor underlying youths' descriptions of quality supports. This finding calls on both professionals and institutions to adapt procedures and policies to best meet individual needs and to avoid a 'one size fits all' approach to designing services and supports (Beresford 2004; Evans *et al.* 2006; Gan *et al.* 2008).

This meta-synthesis provides a more nuanced understanding of participation that is grounded in the lived experiences of youth with disabilities. Rather than conceptualizing participation as a dichotomous outcome (i.e. engaged vs. not engaged), this meta-synthesis suggests that participation occurs along a continuum of inclusion influenced by the interaction between the factors identified in Fig. 2. The description of participation in the subtheme 'doing what everyone else is doing' most closely resembles idealized conceptualizations of participation put forth in the literature, such as the ICF (WHO 2001). However, findings suggest that not all levels of participation are created equal, as suggested by the stories told regarding 'fringe participation' or 'doing something different'. In these instances, youth with disabilities performed activities and carried out tasks. However, completing an activity independently or the frequency of engagement in an activity were not the primary determinants of authentic and meaningful engagement (Ehrmann *et al.* 1995; King *et al.* 2006; Fauconnier *et al.* 2009). Rather, inclusive participation occurred when youth with disabilities had the opportunity to engage in a flexible, dynamic and meaningful way in activities alongside their peers (Kramer & Hammel 2011). This alternative understanding of participation can be used to inform practices and guide policies

pertaining to youth with disabilities to help ensure youth achieve meaningful outcomes.

The meta-synthesis approach enabled us to identify gaps in the literature and our understanding of the relationship between the environment and participation. One, most of the articles included in this meta-synthesis investigated educational settings. Future studies should engage youth with disabilities in identifying the barriers to participation in community activities. Two, articles lacked representation from youth with cognitive disabilities and youth of minority status. It is imperative that youth with cognitive disabilities are asked for their perspectives regarding the relationship between the environment and participation, as the barriers they encounter and their experiences with professionals and peers may be different from youth with physical disabilities. Similarly, youth with disabilities from other cultural backgrounds may have different values and perspectives regarding participation, supports and relationships with adult professionals (Patterson *et al.* 2000). Additional research is needed in these areas.

### Limitations

There are several limitations associated with this study. The studies included were of moderate quality. Most studies had minimal methodological rigor, and most result sections provided descriptive categories and lacked explanatory models (Kearney 2001). However, in an attempt to include as many voices as possible, we chose to include all eligible studies. As a result, the meta-synthesis themes identified in this article are limited by and subject to the rigor and quality of the original articles (Jensen & Allen 1996; Sandelowski *et al.* 1997). However, during analysis we noted that studies of minimal quality still contained data that contributed to our understanding of youth's experiences.

Other limitations are associated with analysing secondary data as part of a meta-synthesis (Jensen & Allen 1996; Sandelowski *et al.* 1997). One limitation is that to increase the amount of data available for coding, we coded direct quotes as well as text written by the researcher. Another limitation is that studies did not contribute equally to each theme and subtheme. Rather, this research team used inference to identify relationships between codes across studies. Therefore, the results and implications put forth in this manuscript may only reflect the assumptions and perspectives of this research team, which are further influenced by the perspectives of the original researchers. However, this study's use of multiple coders provided an opportunity for multiple interpretations to emerge from the data. Credence was lent to those concepts that were indepen-

dently identified by all team members, and the team considered these concepts to be highly salient and firmly grounded in the data.

## Conclusion

Meta-synthesis is an underutilized method in health scholarship. This meta-synthesis of the perspectives of youth with disabilities regarding the impact of the environment on their participation has generated a new framework for understanding the relationship between the environment, modifications and inclusive participation. The participation of youth with disabilities is more inclusive and meaningful when others understand their abilities and needs, when youth are involved in making decisions about accommodations, and when services and policies are individualized to the unique needs of youth. The synthesis of data across multiple studies provides a nuanced conceptualization of participation that is grounded in the lived experiences of youth with disabilities, and illustrates the active role that youth take negotiating environmental barriers through the use of modification strategies.

### Key messages

- When describing quality participation in home, school and the community, youth with disabilities consider the extent to which they felt meaningfully engaged and authentically included.
- Youth with disabilities are more likely to describe their engagement in activities as meaningful when adults and peers were responsive to both their capacities and limitations.
- Youth with disabilities described services and policies as most helpful when they were individualized to the unique needs and strengths of each youth.
- Youth with disabilities expressed a desire to direct the decisions made regarding accommodations and supports, and youth's knowledge about their own preferences, needs and strengths were more likely to generate solutions that facilitated their inclusion in activities.

## Declaration of interest

The authors report no conflicts of interest.

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