

9-1-2014

An integrated methods study of the experiences of youth with severe disabilities in leisure activity settings: The importance of belonging, fun, and control and choice

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Citation of this paper:

King, Gillian; Gibson, Barbara E.; Mistry, Bhavnita; Pinto, Madhu; Goh, Freda; Teachman, Gail; and Thompson, Laura, "An integrated methods study of the experiences of youth with severe disabilities in leisure activity settings: The importance of belonging, fun, and control and choice" (2014). *Paediatrics Publications*. 1553.

<https://ir.lib.uwo.ca/paedpub/1553>

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An Integrated Methods Study of the Experiences of Youth with Severe Disabilities in Leisure
Activity Settings: The Importance of Belonging, Fun, and Control and Choice

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Acknowledgements:

This work was supported by the CIHR Team in Optimal Environments for Severely Disabled Youth, funded by the Canadian Institutes of Health Research [TWC-95045]. We extend our thanks to other team members, including Beata Batorowicz, Yani Hamdani, Patty Rigby, Margot McMain-Klein, the youth and families who participated in the study, and the service providers and managers at participating children's treatment centres who assisted with study recruitment.

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Running Head: Youth Experiences of Activity Settings

Keywords: disability, activity setting, participation, experience, severe disability, leisure, recreation, youth, mixed methods

Implications for Rehabilitation

- The integration of multiple qualitative and quantitative methods throughout data collection and analysis provides a rigorous approach for understanding the activity setting experiences of disabled youth.
- In addition to the skill-based outcomes for youth with disabilities that are valued by the rehabilitation system, we suggest that consideration needs to be given to other types of outcomes that matter to youth.
- Service providers can lose sight of the importance of broader concepts of belonging, fun, and control and choice when providing interventions that focus on ‘participating’ in an ‘activity’ to build specific skills.
- It is important not to assume that youth with severe disabilities are not enjoying their participation or are not benefiting from their leisure experiences.

An Integrated Methods Study of the Experiences of Youth with Severe Disabilities in Leisure
Activity Settings: The Importance of Belonging, Fun, and Control and Choice

Abstract

Purpose: The aim was to examine the leisure activity setting experiences of two groups of youth with severe disabilities—those with complex continuing care (CCC) needs and those who have little functional speech and communicate using augmentative and alternative communication (AAC).

Method: Twelve youth took part in a mixed methods study, in which their experiences were ascertained using qualitative methods (observations, photo elicitation, and interviews) and the measure of Self-Reported Experiences of Activity Settings (SEAS). Data integration occurred using a “following a thread” technique and case-by-case analysis.

Results: The analysis revealed several highly valued aspects of leisure activity setting experiences for youth, including engagement with others, enjoying the moment, and control and choice in selection and participation in activity settings.

Conclusions: The findings provide preliminary insights into the nature of optimal activity settings for youth with severe disabilities, and the mediators of these experiences. Compared to other youth, the data illustrate both the commonalities of experiences and differences in the ways in which these experiences are attained. Implications for research concern the utility of mixed methods approaches in understanding the complex nature of participation experiences. Implications for clinical practice concern the importance of not assuming the nature of youths’ experiences.

Despite increasing research on the lived experiences of youth with disabilities, especially in school settings [1], little is known about how youth with severe disabilities experience leisure activity settings at home and in the community [2]. In the present article, the term 'severe disabilities' is used to denote high levels of both impairment and social exclusion.

The paucity of research on the leisure experiences of youth with severe disabilities is at least partly due to there being few measurement methods and research techniques for use with people who have significant physical and communication impairments. Since there are dangers in making assumptions about the experiences and preferences of these youth, measures and techniques are needed that provide a window into their worlds. Research that combines qualitative and quantitative methods has important advantages in helping us to understand the complex nature of participation experiences [3]. In the present study, we integrated multiple qualitative and quantitative methods to ascertain the experiences of youth with complex continuing care (CCC) needs and those who communicate using augmentative and alternative communication (AAC).

To set the stage for this study, we reviewed recent literature (January 2010 to December 2013) on the experiences of children/youth with a range of disabilities in leisure/recreation activities at home or in the community. Our search of CINAHL/MEDLINE, OVID, PsychINFO, and SCOPUS included terms such as youth, leisure, recreation, participation, environment, disab*, activit*, and experien*. We also examined the reference lists of retrieved articles. Of the 120 articles retrieved, we excluded those examining activity patterns, the intensity/frequency of participation, and parent reports, resulting in 15 relevant articles. The majority of these were qualitative studies involving 10 or fewer children/youth with disabilities, including studies of: the leisure experience perceptions of three children ages 8 to 11 years with spinal cord injury

[4]; the nature of 'engaging' leisure activities for youth/young adults who are blind [5]; and the social participation experiences and perceptions of adolescents with cerebral palsy [6]. Other than the study by Hynes et al. [4], a study of the perceptions of shopping activities involving four young adults with cerebral palsy who used AAC [7], and a study by Agnihotri et al. [8], described below, none of the studies involved participants with severe disabilities.

Only two of the 15 studies used mixed methods [8,9], and both used case-study designs. In the study by Agnihotri et al. [8], two adolescents with severe childhood brain disorder completed pre-post quantitative data on an arts-based intervention and took part in a focus group; these focus group data were then analyzed qualitatively. In the study by Harding et al. [9], six children with various physical or developmental disabilities completed the CAPE, a measure of children's recreational and leisure activity participation [10], took photographs of their out-of-school-time activities, and took part in semi-structured interviews assessing their perceptions of activity participation and environments. In both studies, the qualitative and quantitative data were analyzed separately, with the quantitative data providing a context for the qualitative findings.

Since little is known about the recreation and leisure experiences (hereafter referred to as 'leisure') of youth with severe disabilities, we set out to assess their experiences using a mixed methods approach combining standardized questionnaires, qualitative methods, and physiological measures (the latter is not reported here). Integration of methods and data was built into our study from the start, which involved an interdisciplinary team consisting of occupational and physical therapists, a social psychologist, a geographer, and engineers. The team included members who had extensive experience in measure development and qualitative inquiry. The first objective of our research program (Phase 1) was to develop a series of

innovative research techniques and instruments to assess youths' experiences of home and community activity settings, as well as the environmental qualities of these settings. We then conducted a case study to investigate the feasibility of integrating the three methods (standardized questionnaires, qualitative methods, and physiological measures) to study disabled youth's experiences of activity settings [11]. This case study indicated that these diverse methods can be practically combined to study the leisure experiences of youth with severe disabilities.

In the present study (Phase 2 of our research program), we integrated data collected using a quantitative measure of youth experiences (SEAS; Self-Reported Experiences of Activity Settings) [12], with data collected using youth-friendly qualitative methods, including photo-elicitation, observations, electronic interviews, and face-to-face interviews. Our objective was to comprehensively describe the experiences of youth with severe disabilities in their most frequently experienced activity settings, using integrated quantitative and qualitative data. 'Activity settings' for youth refer to particular places in which they 'do things', including playing games, participating in physical activity, and watching television [13]. The study involved youth with complex continuing care needs (CCC group) and those who communicate using AAC (AAC group). The AAC group used a broad range of alternative communication, not just devices.

As indicated above, previous studies of the experiences of youth or children with disabilities have predominantly been qualitative in nature. Themes arising in these studies of leisure experiences, home and community participation, and inclusion include the importance of supportive environments [8] and the presence of challenges and barriers to leading an active and varied life [14]. Studies also indicate the importance of leisure activities that provide supportive relationships, a sense of identity, and experiences of power and control [5];

meaningful engagement with peers, and support and understanding [15]; a sense of autonomy [16]; and friendships [17]. Since these studies did not include youth with severe disabilities, we do not know if or how the reported study results are relevant to these youth. The combination of qualitative and quantitative approaches in our study provides greater understanding of the nature of inclusion for this group and the factors that contribute to its realization [17].

Mixed method research designs vary in the sequence of collecting quantitative and qualitative data, the weight given to each, and the stage at which integration occurs [18]. We adopted what Hanson et al. [19] describe as a ‘concurrent triangulation’ approach, in which quantitative and qualitative data were collected at the same time, with equal weight given to each. Unlike mixed methods designs that only integrate qualitative and quantitative findings post data collection and analysis, we engaged in integration throughout the research process [20], including at the level of the research design and during data collection, analysis, and interpretation. For example, data collection procedures were changed to ensure that questions for the final interview captured the emerging SEAS constructs, and the SEAS administration was changed to ensure youth understanding, based on qualitative observations. Of most relevance to this article, the data were combined and analyzed together during the data analysis stage, leading to the development of integrated themes.

It is important for researchers to explicitly state their rationale and theoretical approach to mixed methods research [21]. We took the view that the complexity of understanding youth’s participatory experiences requires multiple methods for fuller exploration [22]. To maintain epistemological congruency [23], we adopted a descriptive exploratory approach for the overarching study [24], which guided both qualitative and quantitative methodologies. Although the SEAS and qualitative data for each participant were collected simultaneously, the SEAS data

described the participant's experience at that specific time, while the qualitative data explored his/her experiences in greater detail, both in the activity setting and other activity settings in general.

Study Objective

The objective was to comprehensively describe the leisure activity setting experiences of youth with severe disabilities (at home and in the community) by integrating qualitative and quantitative data about their experiences at the level of analysis.

Methods

Participants

The participant inclusion criteria were (a) ages 12 to 22, (b) has a physical disability and uses AAC, or has a physical disability and CCC needs, (c) communicates in English (orally or using a communication system/device), (d) has a level of cognitive functioning and language comprehension at approximately a grade 3 level or higher (as determined in discussion with the youth, parent, and referring clinician), and (e) has a caregiver and/or service provider who agrees to support and/or enable their participation. The presence of CCC needs was based on having at least three hours of paid or unpaid care daily for activities of daily living. Youth were categorized in the AAC group if they used AAC and received AAC services at a treatment centre. Research Ethics Board approval was obtained from Holland Bloorview Kids Rehabilitation Hospital and Hamilton Health Sciences/McMaster University. Participating organizations (all in Ontario, Canada) were Holland Bloorview, ErinoakKids Centre for Treatment and Development, the Technology Assessment Clinic at Chedoke in Hamilton, and Niagara Peninsula Children's Centre. Participants were recruited using a variety of convenience sampling strategies.

Twelve youth participated in the study. Table 1 provides aggregate information regarding

their age, gender, medical condition, Gross Motor Function Classification System (GMFCS) level [25], Manual Ability Classification System (MACS) level [26], and education. Participants ranged in age from 16 to 22 years and there were equal numbers of male and female youth. Seven participants used AAC to communicate and five had CCC needs. The majority (91.7%) had GMFCS levels of III or greater (i.e., 'unable to walk independently') and most (58.3%) were at level V of the MACS (i.e., 'had severely limited manual ability'). The majority of the participants (83.3%) were attending a regular neighborhood school; the rest were not attending school.

Procedure

Data were collected over four visits with each participant. In Visit 1, study consent was sought and a short interview was conducted to learn more about participants' daily activities, as well as their methods of and preferences for communicating. We used a consent guideline augmented with Picture Communication Symbols (PCS[®]) to provide study information and obtain consent for participants with little or no speech [27]. Youth completed the Children's Assessment of Participation and Enjoyment (CAPE) [10,28] to provide information about their leisure participation as a whole, and also to help youth identify two leisure activity settings for data collection in visits 2 and 3. In preparation for use of photo-elicitation in these visits (described below), an individualized camera set-up was completed (e.g., stable camera mounted on a participant's wheelchair, along with switch access to camera controls). Participants could also choose to direct the research assistant (RA) or another individual (e.g., parent) to take photos on their behalf.

In Visits 2 and 3, the youth participated in the two different activity settings, accompanied by two RAs, one primarily responsible for collecting the quantitative data and the other for the qualitative data. Each visit took between one-half to three hours, with the average

visit lasting two hours. The qualitative RA made observations and took field notes, engaged the youth in informal conversation, and assisted them to take photos/videos reflecting their experiences. When needed, the quantitative RA assisted youth in completing the SEAS questionnaire at the end of the activity setting, by providing instructions; partner-assisted scanning, eye gaze, reading, or scribing assistance; or an enlarged rating scale. As well, simplified examples, wording, and explanations were used, as needed, to ensure that participants understood the SEAS instructions and items.

After the on-site data collection, email questions were prepared for each participant, including generic questions (e.g., 'what would have made this activity perfect?'), setting-specific questions (e.g., 'what were the good things about shopping at the mall?'), and those related to the participant's SEAS responses (e.g., 'in your responses you indicated you felt included in the yoga class. What made you feel this way?').

Visit 4 was a semi-structured interview, conducted in each participant's preferred location, typically the youth's home (only one participant requested an interview at the rehabilitation centre). The interview guide was adapted for each participant based on observation of the activity settings and youths' responses to electronic questions. Selected video clips and/or photos were used to elicit the participants' reflection on the two activities and their settings. The average length of each interview was approximately 75 minutes.

Description of Methods and Measures

Self-Reported Experiences of Activity Settings (SEAS). The SEAS was developed to measure the situation-specific experiences of youth with or without physical impairments in leisure activity settings at home and in the community. The 22-item SEAS has five scales that capture the following experiences of youth with at least a grade 3 level of language

comprehension: Personal Growth, Psychological Engagement, Social Belonging, Meaningful Interactions, and Choice and Control. The SEAS has good to excellent internal consistency (Cronbach's alphas from 0.71 to 0.88) and moderate test-retest reliability (mean scale ICC= 0.68) as expected due to changes in activity settings over time [12]. As well, the SEAS is able to differentiate various types of activity settings and participation partners (i.e., relatives, friends, no one else). SEAS items are rated on a 7-point scale with two oppositely labeled endpoints (e.g., I was having fun vs. I wasn't having fun; I had a say in things vs. I didn't have a say in things), and options to Strongly Agree, Agree, or Agree a Little with either endpoint, or to indicate Neither. For purposes of analysis, scores are entered on a 7-point scale ranging from +3 (Strongly Agree) to -3 (Strongly Disagree).

Qualitative methods. These focused on in-depth exploration of activity experiences that could illuminate the broader environmental, social, physical, and technological mediators of experience beyond the delimited activity setting [19,29]. The methods included photo-elicitation, observations, electronic interviews, and face-to-face interviews. In photo-elicitation, participant-generated photographs are used to enrich discussions in individual qualitative interviews. This approach has been found to facilitate researcher-interviewee rapport and provide a point of focus to engage the interviewee [30,31]. Second, with respect to observations, RAs recorded details of the chosen activity settings, including youths' interactions with others and the sequence of unfolding events. These observations afforded the opportunity to ask questions while the participant was immersed in the activity setting, and provided a rich appreciation for the activity setting that could be probed within the interviews [32].

Third, we used electronic interviewing, which is increasingly used as part of a 'toolbox' of options for investigating participant perspectives [33]. In our study, written questions were

emailed to participants after the activity and their answers were returned prior to the interview, allowing us to probe their answers in greater depth within the interview [34]. This was particularly useful in helping to focus the interviews with our AAC-user participants, who often required significant time to compose an answer.

Fourth, semi-structured, face-to-face interviews were conducted, consisting of generic and specific questions constructed for each participant. Data collected during the activities (i.e., participant generated images, SEAS responses, email responses, and RA observations) were used as points of discussion and prompts. For both electronic and face-to-face interviews, participants were encouraged to respond using any of their preferred communication methods, including use of a communication assistant.

Overview of Methods used in the Integration of Data

Integration at the level of analysis calls for the transformation of one kind of data into another kind, creating one overall data set [24]. We engaged in data transformation using two techniques: “following a thread” and the “mixed methods matrix” [35]. We engaged in these two techniques in a fluid manner, going back and forth over a series of meetings from a more macro approach (following a thread) to a more micro approach (mixed methods matrix). In “following a thread”, data are initially analyzed following the qualitative and quantitative lines of inquiry, and the overarching themes and questions that emerge are then incorporated into a secondary analysis to look at how the data interact [35,36]. In contrast, the “mixed methods matrix” approach provides a comprehensive picture of each individual’s experience in a particular activity setting, by examining both qualitative and quantitative data on a case-by-case basis. We were looking for evidence of big picture themes within individual case analyses, and also at how the individual case analyses informed the big picture themes. Thus, the combination

of both approaches provided a rich understanding of the data, both overall and individually.

Preparatory Analyses

The quantitative and qualitative data were analyzed separately, prior to the integrated data analysis process, as done by others including Kramer [37]. Separate quantitative and qualitative analysis reports of the overall study data were prepared [38], using data collected in both study phases. In these preparatory analyses, SEAS data for the full study ($n= 54$ activity settings; 26 participants with severe disabilities) were analyzed to determine mean scale scores and standard deviations. The overall SEAS data indicated that youth experienced relatively high levels of psychological engagement, social belonging, and control and choice in their selected activity settings (means > 2.0 , where 3= strongly agree and 2= agree). They experienced low levels of meaningful interactions and personal growth (means < 1 , where 1= agree a little, 0= neither agree nor disagree, and -1= disagree a little).

Analysis of the qualitative data also occurred separately to generate the dominant themes across all participants in both study phases ($n= 20$). These data were analyzed to answer the research questions using combined inductive and deductive analyses consistent with the research objectives and the study's descriptive exploratory framework. The analysis procedures drew on techniques described by Miles and Huberman [39] as follows. Each transcript was reviewed by team members to explore participants' experiences of activity settings, inclusion/exclusion, participation, interactions, and features of activity settings, and any new information emerging from the accounts. Detailed analytical notes were prepared for each case and cross case matrices were used to identify themes across the data. Data analyses proceeded concurrently with data collection and informed subsequent data collection. Multiple iterative analytic cycles of further levels of abstraction were used by the team to facilitate the

identification of patterns, recurring relationships, and conceptual congruence or incongruence. The results are described in more detail elsewhere (Authors forthcoming), but were organized according to a central theme of ‘activity/assemblages’, which consisted of networks of people, technologies, and places that could either enable or constrain participation in particular activity settings. The subthemes focused on what the assemblages enabled—thus explicating the nature of positive or negative activity setting experiences. These subthemes included in/dependence, competency, fun, social connections, risk and safety, and sensory experiences.

Integrated Data Analysis Procedures

The analyses involved information on two activity setting experiences for 12 participants, for a total of 24 cases (activity settings). Data from observations, interviews, e-questions, and the SEAS constituted the case data set.

The process of integrated data analysis is outlined in Figure 1. The top half of the figure shows the initial separate analyses of quantitative and qualitative data, with the findings subsequently used to identify ‘threads’ for the integrated analysis. As shown in the figure box labeled ‘integrated analysis’, we conducted a cross case analysis by following these threads, in which both the overall quantitative findings and overall qualitative themes were used to query the case-by-case data. The common themes that arose were reviewed for applicability to the individual cases.

We also conducted within case analyses, in which we used the mixed methods matrix approach to understand the individual experiences of each participant. This involved creating a mixed methods matrix for each case (each activity setting for each participant), containing SEAS scale scores (including individual items) and aspects of the qualitative data such as notes and quotes. Each cell of the matrix therefore contained data and group analysis notes related to a

specific SEAS domain. The last column of the matrix contained the common threads identified in both sets of data. The findings from these individual case reviews were examined for applicability to the overall themes. In an iterative and fluid manner, an integrated interpretation of the data was generated, in the form of integrated themes combining the richness and insights provided by the quantitative and qualitative data, considered together. Thus, the mixed methods matrix facilitated data analysis and allowed pattern recognition across cases [40].

Team analysis meetings considered how the qualitative and quantitative findings supported each other, and also where the two sets of data diverged. Multiple iterative analytic meetings were used to identify patterns, concepts, and recurring relationships.

Results

Selection of Activity Settings by Youth

Since experiences are intimately tied to social context, we examined the types of activity settings selected by youth. Table 2 shows the number of activity settings in the activity categories provided by the CAPE [10,28]. Youth primarily took part in recreational activities such as playing computer/video games or watching TV/movies (45.8%) and in self-improvement activities such as going to the public library or reading (24%), with low percentages of social, active physical, and skill-based activities. We also examined whether youth took part in the activity settings alone or with others. Of the 24 activity settings, 20 (83.3%) involved other people.

Integrated Themes

These reflected points of intersection between the qualitative and quantitative data—explication of what makes an activity setting a positive or negative experience. Figure 2 portrays the integrated themes, situated within the activity setting context, which is comprised of

environmental, social, physical, and technological mediators of experience. The integrated analyses revealed the clear importance of experiences providing a sense of belonging, fun, and control and choice. The themes were interrelated, in that aspects of one were pertinent to the others. For example, engagement with others was a means for youth to experience choice within activities, enjoyment of experiences led to the development of a sense of self and of competencies, and risky in-the-moment behaviors were not only associated with enjoyment, but also with being in control.

Engagement with others: who (not what) is important. A key theme was the primary importance of social connections as part of positively experienced activity settings. Youth reported high levels of social belonging or social connection in their chosen activity settings. They reported high scores on the SEAS social belonging scale, which contains items such as getting along with others, feeling a sense of belonging, being supported and encouraged by others, and being valued by others. Thus, optimal activity settings appear to be as much or more about *who* than *what*. Although particular activity settings offered different opportunities, *who* was there could not only provide a social experience, but could also have a strong influence on participants' abilities to realize other experiences, such as fun or a sense of choice. For certain participants, what they actually did in their leisure time appeared to matter less than who they were with. When asked 'what were the good things about doing this activity?', one youth replied "I got to hang out with my best friend."

Participants wanted opportunities to socialize and be in the world. Although they wanted opportunities to engage in activities that were 'fun' and worthwhile, socializing with significant others or just being around other people away from home (shopping at the mall, going for a walk in the neighborhood) was at least as important.

Experiences of social belonging were different from meaningful interactions or conversations with others in which youth share personal thoughts, feelings, or ideas. Meaningful experiences often arose when youth were the focal point or centre of attention in an activity. The differentiation of social belonging from meaningful experience is a novel finding arising from our integrated analysis.

Enjoying the moment: fun and freedom. Overall, youths' scores on the SEAS psychological engagement scale were high; this scale reflects experiencing positive emotions, including good mood, fun, and interest. These emotions were explained by the qualitative data, which suggested that enjoying the moment had many facets.

Clearly the element of fun was very important to youth in the study, but the meaning of fun differed. Some youth expressed their appreciation of sensory experiences, such as being outside in the garden or feeling the breeze on their face when going fast in their wheelchair. The accounts suggested that various sensory experiences contributed to participants' enjoyment or dislike of activities. Engaging the senses contributed to the meaningful enjoyment of the activity in tandem with other meaningful aspects including social interaction, inclusion, and a sense of accomplishment. Sensations contributed to overall inclusion in the activity (experiencing it as everyone else does), challenged the participant's body in some way (such as exercise), or provided relaxation for the body and mind. In all of these instances, participants experienced some sort of sensory stimulation in doing and being a part of the activity. For example, when a youth who went to the park was asked 'what makes the park a good or 'not so good' place to visit?', he responded "Well, I don't know about you but seeing big water calms me, plus I like freedom...it's pretty peaceful."

For some youth, engaging in more risky physical activities and feeling free were

paramount to their experience of fun; others preferred safe environments. Some of the (male) participants expressed strong desires to engage in more risky physical activities like ATV riding, bungee jumping, or sailing. Others were risk averse and reluctant or hesitant to try new activities outside of the home. One youth expressed feeling anxious when he was away from those who can communicate best with him and understand his needs.

Another facet of 'fun' was demonstrating competency. Some participants preferred activities where they were able to demonstrate some degree of success or achievement. Purposeful or goal oriented activities that were successfully achieved (or seen as achievable) were sources of pride and associated with 'fun'. The quantitative findings indicated low levels of experienced personal growth in the activity settings chosen for this study, whereas the qualitative findings indicated that youth enjoyed demonstrating *existing* competencies. Personal growth, as captured in the SEAS, reflects skill development, challenge, and trying new things.

Being in control: control and choice in selection and participation in activity settings.

Youth had a high mean score on the SEAS scale corresponding to this theme (Choice and Control), which contains items such as being free to choose what to do, being in control, having a say in things, and feeling free of pressure. Both control and choice have been linked to having a sense of personal autonomy (i.e., feeling free of pressure) and independence. In the study, having control over choices was linked to a sense of independence. When asked 'what would need to change for this activity to be perfect?', one youth said "I would like voice command to be able to do it on my own."

Youth wanted control over some choices but not over others, and there were differences in the levels or types of choice they desired. For example, one youth was happy to choose an ice cream flavor while another wanted to have more control over his day to day schedule and

activities.

Various factors affected their choice or selection of activities. Some youth appeared to choose their activity settings based on a desire to display their competence—their ability to do something well. They wanted to demonstrate and talk about excelling at a task ('this is what I am good at'). In addition to displaying competence, time and a weighing of pros and cons were important considerations for youth: It was as if they asked themselves "Is it worth it?" Youth with severe disabilities have less time for leisure in a day taken up with care routines, extra time for transport, and extra time to communicate. Some were also very aware of the limits on other people's time, for example not wanting to add to parents' burden. An appreciable amount of structure and planning were required for participation. The activities for CCC youth involved much planning in advance (e.g., arranging transportation) yet more spontaneity within; whereas activities for youth using AAC seemed to require planning, support, and structure in advance and throughout.

Discussion

Three major themes were generated from our integrated analysis of the experiences of youth with severe disabilities in their selected activity settings: 'engagement with others: who (not what) is important', 'enjoying the moment: fun and freedom', and 'being in control: control and choice in selection and participation in activity settings'. These integrated themes went beyond the initial qualitative and quantitative findings by consolidating these findings and providing a richer understanding of the role of environmental, social, physical, and technological mediators of experience. These mediators are important in determining a positive activity setting experience, as defined by the themes. The themes provide preliminary insights into the nature of optimal activity settings for youth with severe disabilities.

The themes were interrelated, indicating how different components of the activity setting were important for different youth, and at different times. This contextual and temporal view was provided by the qualitative data, whereas the quantitative data provided an understanding of the relative extent to which youth had various situation-specific experiences. A given youth's experiences typically reflected more than one of the themes, showing changes in his/her focal point throughout an activity setting experience. For example, the focus of attention could change from physical enjoyment, to social connections, then to control over expressing identity.

The findings help us to more fully understand the leisure social context of youth with severe disabilities. There are similarities to the findings of other studies on leisure experiences, home and community participation, and inclusion involving youth with significant impairments (i.e., brain disorders, blindness, and spinal cord injury), which also point to the importance of supportive relationships and environments, and experiences of control and autonomy [5,8,16]. In contrast to research that has examined general barriers and supports to participation, we targeted specific activity settings. Unlike previous studies, we found more consideration of the element of fun and little evidence of reported meaningful engagement or friendships with peers, most likely due to opportunities afforded by activity settings. We also noted the importance of supportive environments that accommodated the presence of caregivers such as parents and personal attendants, which is likely due to the intense care and communication needs of youth in the present study.

On a general level, our results reflect the needs and interests of many youth in Western societies. Youth with severe disabilities, like most youth, want to belong, have fun, and have choices. Deci and Ryan [41] have proposed a theory of motivation that encompasses three

innate psychological needs—interpersonal relatedness, competence, and autonomy (i.e., needs for social belonging, personal development, and choice and control). Similarly, Maslow [42] discussed three basic human needs—the needs for affiliation, achievement, and self-actualization. It is noteworthy that we did not find a major theme concerning the personal growth and skill development aspects of competence in the present data, although some youth preferred activities where they could demonstrate existing competency. Control and choice were more dominant aspects of competency, in comparison to personal growth and skill development, which were mentioned infrequently and received low scores on the SEAS. Again, this could be due to our focus on in-the-moment experiences, where choice and control can be seen to be determinants of longer-term competencies [43].

The findings help to illuminate what participation in youth-chosen activity settings meant for these youth. They highlight the complex nature of the meaning of participation and provide detailed information about how needs for social belonging, personal development, and choice and control played out in the experiences of a select group of youth with severe disabilities in a limited set of selected activity settings. Despite common participation needs reflected in the themes, the data show that the mediators of participation for youth in this study were appreciably different to those of non-disabled youth. Specifically, the differences were the amount of support and planning youth required to enable participation; the choices they needed to make regarding whether engaging in a leisure activity setting was worth the effort and time involved; and how others in their worlds provided opportunities for choice and control within limits dictated by youths' impairments and the environmental qualities of their activity settings. Furthermore, the number of places they accessed (e.g., the mall, the home, the school, the community centre) were limited.

Although youth with severe disabilities seemed to want/enjoy the same types of overall experiences as other youth, there were clear differences in how these were realized. We cannot, however, be sure of the generalizability of this finding, since youths' activity selections were constrained by the study itself to at least some extent. Thus, the data illustrate both the commonalities of youths' leisure experiences and differences in the ways in which these experiences are attained—specifically the complex array of mediators involved in enabling these experiences.

Youths' choices of activity settings are revealing in and of themselves. The majority of their activities (46%) were 'passive' recreational; only 17% were active physical or skill-based; and only 13% were formally 'social', in the sense of occurring for the express purpose of social interaction. Social interaction with friends was noticeably absent, and these youth were with adults (parents and caregivers) in the majority of the activity settings included in this study. The usually prevalent, influential teen peer group activity settings are mostly absent in our data. Although few activities were formally 'active physical', we observed that the participation of some youth was physically effortful in recreational activities typically classified as 'passive' (e.g., playing video games). These findings illustrate the importance of the qualitative data in helping us to more fully understand youths' participation. Since 'traditional' classifications of activities do not always reflect the experiences of youth with severe disabilities (e.g., 'passive' activities may be physically effortful for these youth), one implication is that the data from the present study could be used to develop a more realistic taxonomy or portrayal of what youth with severe disabilities do [38], along with the skills, effort, and 'assemblages' that enable 'participation' (Authors forthcoming).

Another nuanced appreciation provided by the integration of data concerned the nature

of control and choice. Other researchers have discussed various factors affecting choice of activity, including making trade-offs [6], apprehension related to activity performance and participation [16], issues of gaining entry [17], and the gaining competency by engaging in fun and important activities [1]. Youth in our study explicitly mentioned trade-offs, wanting to engage in fun activities, and apprehension or worry about factors such as transportation. By focusing on experience in activity settings, we also captured choice making *within* activities. The distinction between control (i.e., ‘exercise direction over’) and choice (i.e., ‘having options’) is an important one. Although youth may have been constrained in their activity selection, people participating with them were observed to offer numerous opportunities for smaller choices, and youth reported high levels of control and choice *within* their selected activity settings.

Combining qualitative and quantitative perspectives provided various enrichments, including different contextual viewpoints by which to interpret the findings. The quantitative data provided a youth-centric view of present experiences relative to past experiences, preferences, and desires, whereas the qualitative data additionally provided a unique, larger contextual perspective in which to situate the findings of particular activity settings. Each perspective raised questions about the data collected using the other approach. For example, the integrated analysis suggested that particular youth may not have interpreted the SEAS correctly or were not comfortable to report more negative aspects. At times, the SEAS data indicated more positive experiences than what the qualitative data led one to expect, raising the possibility that being involved in some activity is relatively more positive than not being involved at all. At other times, SEAS scores were lower than what was verbally expressed—this may be because past experiences, expectations, relative judgments, and preferences are implicated in the judgments youth make on the SEAS.

The participation of disabled youth was illuminated by the different approaches. The integrated analysis indicated the confluence of factors needed for youth with severe disabilities to have 'optimal' or good experiences, along with the nature of these experiences. The data indicated how social belonging, enjoying the moment, and control and choice play out as important experiences for these youth, and how youth make choices regarding participation, based on considerations such as the nature of the effort and planning involved, the need for accompaniment, and wanting to display competence and other strengths.

Study Strengths and Weaknesses

Strengths include the relatively large sample size ($n= 12$ participants; 24 activity setting cases) for a mixed and multiple methods study of the participatory experiences of children/youth with disabilities; the focus on youth with severe disabilities who are often excluded from research as "hard to study"; the use of integrated methods throughout the design, implementation, analysis, and interpretation; and the prolonged engagement over four visits using multiple qualitative methods.

The major study limitation is that conclusions are limited to the actual activity settings selected by the youth: we cannot be sure of the extent to which the findings might be different if different activity settings had been chosen. Youth typically wanted to choose an activity they enjoyed, which likely led to their high enjoyment scores, while at the same time indicating the nature of optimal experiences. In addition, it had to be practical for team members to be present. For example, there was a two-hour travel limit for visits, certain activity settings (such as those taking place in swimming pools) could not be chosen due to the camera equipment, and activity settings were limited to those that could be accessed within the study timeframe and with caregiver support (given parents' schedules). There may have been implicit demands

for youth to present themselves (and their activities) in certain ways. For example, youth who use AAC are encouraged to continuously work on communication and social interaction skills, so they may have selected social activities for this reason. We were committed, however, to allow self-selection of activity settings for various methodological and ethical reasons.

Research Implications

Our use of a mixed methods approach to examine the participation of youth with disabilities may be useful to others, since there are few existing examples. We are aware of no other studies of this population integrating the two approaches in study design, analysis, and interpretation. Studies of child/youth participation and inclusion most often take a purely qualitative or quantitative approach. Furthermore, since there are few studies of the participation and inclusion experiences of youth with severe disabilities [3], the methods and techniques we employed may be of particular interest to others.

Our study indicates that quantitative tools can help to situate qualitative data, while qualitative approaches can ‘animate’ quantitative data (i.e., help to interpret, provide broader perspectives, and illuminate assumptions). The combined use of both methods can generate specific, novel, and in-depth knowledge about a topic of inquiry, as shown in the present findings. We obtained a deeper understanding of the results, which assisted in identifying questions for further research [40].

Important directions for future research include further examination of the meaning of participation to youth, and the need to query the assumptions underlying the taxonomies of activity, participation, and environment that we use. If we had not used the SEAS and just examined participation using a measure of what is done (and with what frequency), then we would have gained a less rich, and somewhat misleading, view of the participation of youth with

severe disabilities. Participation measures typically focus on what children/youth are doing in life situations and the frequency and intensity of their participation [3]. These measures of 'doing' can be misleading, as youth may participate in a wider range of activities but not enjoy their participation, or may participate in few activities with high levels of enjoyment and meaning. In addition, knowledge of mediators of participation and environmental qualities of chosen activity settings is required to fully understand experiences.

Another direction of interest, highlighted by our awareness that participation is intimately tied to context [3] and our concerns about the meaning of our findings, is the selection of leisure activity settings. Research studies, including ours, have focused on how the environment affects child/youth opportunities and experiences, but little work, other than that by Stewart et al. [6] on trade-offs, has examined this relationship in the other direction. Work on psychological selection has linked the selection of activities to the 'anticipation' of experience and optimal experience [1,44].

Clinical and Service Implications

A clinical implication is the benefit of adopting a holistic orientation when looking at the participation and inclusion of youth with disabilities. Service providers can lose sight of the importance of broader concepts of belonging, fun, and control and choice when providing interventions that focus on 'participating' in an 'activity' to build specific skills (e.g., language or motor skills). It is important for service providers to remember that there are many contributors to meaningful experiences that may differ from person to person or even from situation to situation for a given youth. The rehabilitation system values skill-based outcomes; we suggest that consideration needs to be given to other types of outcomes that matter to youth.

Similarly, it is important not to assume that youth with severe disabilities are not

enjoying their participation or are not benefiting from their leisure experiences. As shown in the present study, belonging, enjoyment, and control and choice can be high in chosen activity settings. The clinical question of interest is: What would constitute an optimal leisure experience for this particular youth?

In conclusion, this integrated methods study has provided preliminary insights into the optimal leisure experiences and the mediators of experience for youth with severe disabilities. This is an important area of endeavor, since little is known about how these youth experience leisure. The findings advance our understanding of key aspects of experience and how they play out in the lives of a group of youth with CCC needs and youth who communicate using AAC.

Declaration of Interest

The authors report no conflicts of interest.

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Table 1

Study Participants

Variable	Categories	Total Sample (n= 12) n (%)
Age ^a	16 to 17 years	5 (41.7%)
	18 to 19 years	4 (33.3%)
	20 to 22 years	3 (25.0%)
Gender	Male	6 (50.0%)
	Female	6 (50.0%)
Medical Condition	AAC	7 (58.3%)
	CCC	5 (41.7%)
GMFCS Level	I	0 (0%)
	II	1 (8.3%)
	III	2 (16.7%)
	IV	3 (25.0%)
	V	6 (50.0%)
MACS Level	I	1 (8.3%)
	II	4 (33.3%)
	III	0 (0%)
	IV	0 (0%)
	V	7 (58.3%)
Current School Setting	No school	2 (16.7%)
	Regular school	6 (50.0%)
	Regular school, special program	4 (33.3%)

^a Age calculated as of date consent form signed by participant

Table 2

Numbers (Percents) and Examples of Types of Activity Settings Chosen by Youth According to CAPE Categories*

Active Physical	Recreational	Social	Skill-Based	Self-Improvement
2 (8.3%)	11 (45.8%)	3 (12.5%)	2 (8.3%)	6 (24%)
working out fitness class	playing video games watching TV watching a movie playing cards going for a walk	hanging out	fixing cars attending a teen group	going to the library reading shopping presenting in a panel

* Children’s Assessment of Participation and Enjoyment

Figure 1

Process of Integrated Data Analysis

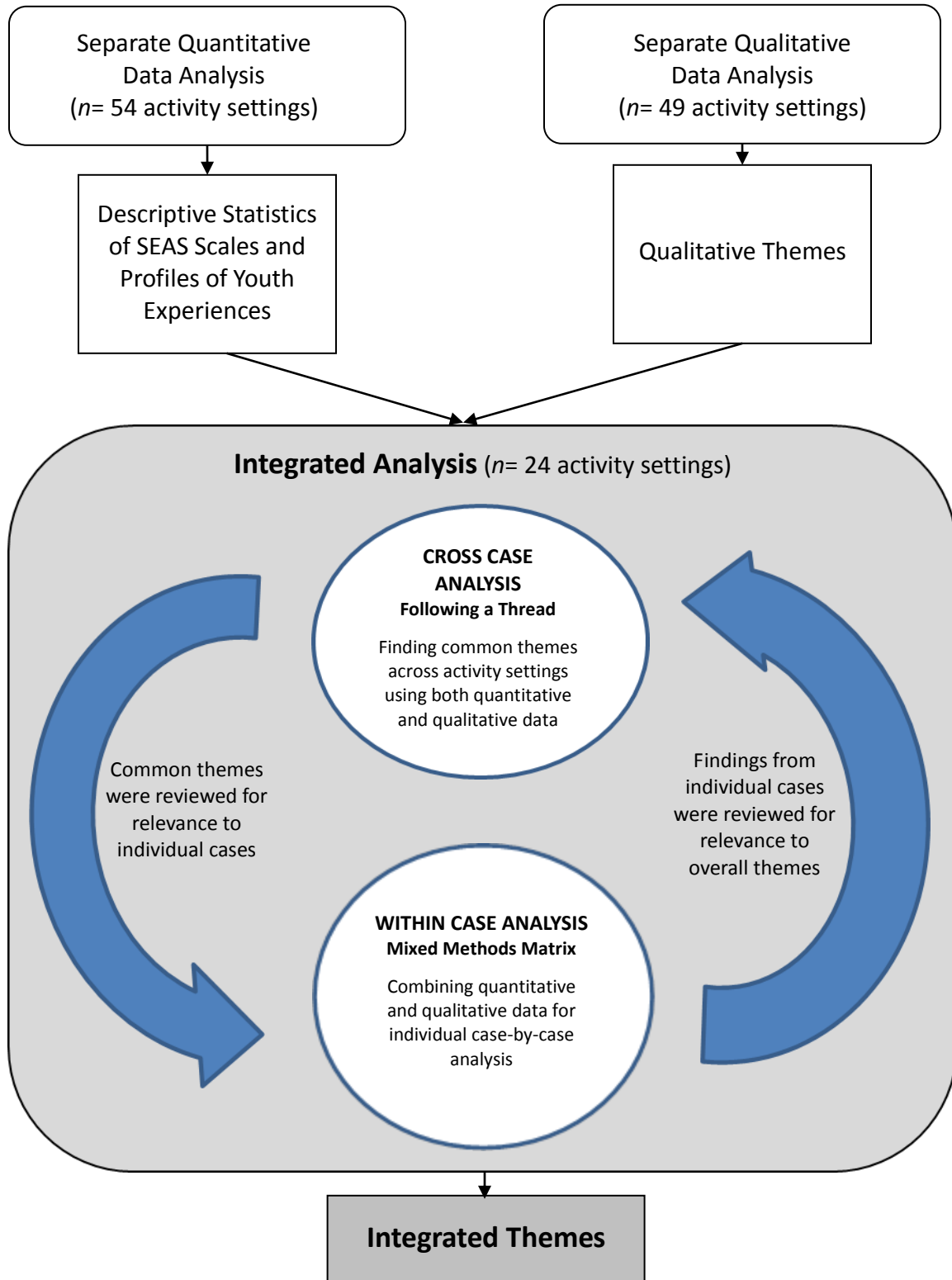


Figure 2

Integrated Themes Concerning Youth Experiences

