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Developing a self-report measure of participatory experience, skill development and environmental influence and a measure of environment affordances for youth with intellectual disabilities: the participatory experience survey and the setting affordances survey

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DEVELOPING A SELF-REPORT MEASURE OF PARTICIPATORY EXPERIENCE, SKILL DEVELOPMENT AND ENVIRONMENTAL INFLUENCE AND A MEASURE OF ENVIRONMENT AFFORDANCES FOR YOUTH WITH INTELLECTUAL DISABILITIES: THE PARTICIPATORY EXPERIENCE SURVEY AND THE SETTING AFFORDANCES SURVEY

by

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DEDICATION

I dedicate this dissertation to any person, old or young, who has ever felt excluded because they were “different”. It is my sincere hope that the work this dissertation encompasses will lend itself to a more inclusive society for all.
ACKNOWLEDGMENTS

To my mother, Jennet Liljenquist, I say thank you. Thank you for loving me through every doubt I felt and each rejection I encountered. Thank you for celebrating my accomplishments and supporting my successes. But most of all, thank you for being you. Thank you for sharing your incredible perspective on humanity and life. Thank you for helping me to recognize the needs of others and how to work towards alleviating those needs. The understanding of the world you’ve helped me develop is in everything I do and I am forever grateful for your guidance.

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ABSTRACT

**Introduction.** Assessing the participation experiences of young people with *significant intellectual and developmental disabilities* (SIDD) in recreational activities is imperative to ensure these activities provide youth with optimal opportunities to develop skills needed for adulthood. Currently, no instrument accessible to youth with SIDD is available to assess these experiences. The Participatory Experience Survey (PES) and the Setting Affordances Survey (SAS) were developed to meet this need.

**Method.** The PES was developed with input from a panel of youth with SIDD while they were participating in a summer program. A draft was then presented to three groups of stakeholders: parents of youth with SIDD, service providers, and experts in intellectual disability and/or program planning. After making revisions based on stakeholder feedback, cognitive interviewing was conducted with eight youth ages 14 – 22 with SIDD. Next, to examine feasibility of the PES, the survey was given to 10 youth with
SIDD. After finalizing a draft of the PES based on youth feedback, questions for the SAS were written to align with topics on the PES. Finally, a program evaluation was conducted that provided an additional feasibility evaluation of the PES and SAS.

**Results.** Of the 24 initial questions on the PES, stakeholder groups identified 15 questions needing revision and suggested 7 additional questions. Youth feedback during cognitive interviewing identified 13 questions needing revisions and 4 needing removal. Changes were made to address three issues: word choice, understanding of concept, and questions relating to others. Administering the PES directly following an activity was found to be feasible, however, the length was shortened from 31 to 15 questions to provide an appropriate administration time (<5 minutes).

**Conclusion.** The PES and the SAS proved to be relevant, accessible and feasible ways to assess the individual experiences of youth with SIDD in recreational settings and the affordances, measured objectively, of those settings. Use of these two measures may help programs to include young people with SIDD during program evaluations, resulting in better-structured, more supportive programs.
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LIST OF ABBREVIATIONS

ICF ........................................... International Classification of Function, Disability and Health

ICF-CY ............................. International Classification of Function, Disability and Health –
Children and Youth

PAR ............................................................. Participatory Action Research

PES ............................................................... Participatory Experience Survey

PYD ............................................................ Positive Youth Development

SAS ............................................................ Setting Affordances Survey

SIDD ................................. Significant Intellectual and Developmental Disabilities
GLOSSARY

Accessible: Specifically refers to the Participatory Experience Survey items and administration format. Representative of youth being able to understand and respond appropriately to each item on the PES.

Activity Setting: A setting representative of a specific purpose (e.g. soccer practice, art class) where youth derive participatory experiences. (King, Rigby, Batorowicz, 2013)

Affordances: Perceptions of objects drive actions (e.g. a knob suggests one should pull). (Gibson, 1977)

Participatory Experience: Experience a young person derives from involvement in an activity setting (e.g. enjoyment, social networking). This experience is promoted and fostered by the setting affordances within an activity setting.

Setting Affordances: Opportunities presented to young people within an activity setting that foster many different experiences. Opportunities are derived from the organization of resources within a setting (human, physical and temporal)

Significant Intellectual and Developmental Disabilities: Characterized by the individual’s need for pervasive supports “to participate in activities linked with normative human functioning” (Thompson et al., 2009)
Background and Significance

Introduction

The World Health Organization introduced participation as an important construct in the International Classification of Functioning, Disability and Health (ICF) in 2001. The ICF defines participation as “involvement in a life situation” (WHO, 2001) and Dijkers (2010) further describes participation as a domain that is beyond impairment and performance of activities, but rather represents an individual fulfilling whatever societal roles they may choose. Mallinson and Hammel (2010) describe participation as occurring at the intersection of what the person can do, wants to do, has the opportunity or affordances to do, and is not prevented from doing by the world in which the person lives and seeks to participate. Unfortunately, for many young people with disabilities participation in meaningful life situations is limited, often due to factors within the social and physical environment (Tonkin, Ogilvie, Greenwood, Law and Anaby, 2013; Harding, Harding, Jamieson, Mullally, Politi, Wong-Sing,... & Petrenchik, 2009; Hilton, Crouch, & Israel, 2008; Buttimer & Tierney, 2005).

One particular area of more limited participation for youth with disabilities is recreational activities. In addition to the health benefits and enjoyment derived from recreational activities, these experiences also afford young people opportunities to develop skills needed for successful transition to adulthood (King, Gibson, Mistry, Pinto, Goh, et al., & Thompson, 2013; Duerden, Taniguchi, & Widmer, 2012; Carter and Hughes, 2005; Dworkin, Larson & Hansen, 2003).Thus, it is imperative that when youth with disabilities do access recreational activities, these activities provide a meaningful
experience with adequate opportunity to develop important skills. However, currently the field lacks adequate measures to evaluate whether the interaction between the individual and the supports provided in the activity setting result in this desired outcome.

The purpose of this dissertation research was to develop and evaluate two complementary instruments: a self-report measure of *participatory experience*, to be completed by young people with intellectual and developmental disabilities, and a measure of *setting affordances*, to be completed by an observer of recreational activity settings. The conceptualization of these two constructs is discussed in the next section.

**The Participatory Experience**

Many current measures of participation of young people with SIDD reflect the emphasis on ensuring access and support to access. Tools designed to capture this outcome examine the types of activities a young person participates in and what factors within the built and social environment either support or hinder access to these activities (Coster, Bedell, Law, Khetani, Teplicky, Liljenquist, Gleason, Kao, 2011; Bedell, 2009; King, Law, King, Hurley, Hanna, Kertoy, Rosenbaum, & Young, 2004). Research with these instruments has provided important information regarding the types of environmental factors that affect the ability of young people with varying needs to *access* a wide range of activities and opportunities. However, these instruments do not provide an understanding of what occurs once youth with SIDD are participating in these life situations. Therefore, this approach to measuring participation neglects the concept of *involvement* – the dynamic interaction between an individual and their environment.

With the exception of education, measurement of involvement has received
limited attention in disability related literature. However, one area that has stressed the importance of going beyond access is special and inclusive education. The Individuals with Disabilities Education Act (IDEA) legislation mandates the following: 1) Free and Appropriate Public Education (FAPE) resulting in access to “educational benefit” for students with disabilities, which has been further clarified to mean “meaningful progress”; and 2) Least Restrictive Environment (LRE), meaning students with disabilities are educated to the maximum extent possible with peers without disabilities and that removal only occurs after provision of supplementary aids and services (Individuals with Disabilities Education Act [IDEA], 2004). Research in special and inclusive education conducted after implementation of this legislation has demonstrated that interactions with general education peers may play a positive role in academic, functional, and social skill development, as well as contribute to increased social competence, attainment of educational goals, friendship development and enhanced quality of life for students with disabilities (Tonkin, Ogilvie, Greenwood, Law and Anaby, 2013; Rossetti, 2011; Carter and Hughes, 2005; Jorgensen, 2002). Hence, the literature and legislation reflects an understanding that simply accessing the school or classroom environment amongst peers is not enough for students with disabilities to reap the benefits. Instead, an active effort must be made to promote meaningful and dynamic engagement within an educational setting.

Research in Positive Youth Development (PYD), typically conducted with youth without disabilities, has shown that participation in out-of-school activities offers opportunities not always available in school to support development of skills and
competencies important for successful transition into adulthood (Larson, Hanson, Moneta, 2006; Dworkin, Larson and Hansen, 2003). Activities such as sports and community service programs offer opportunities to develop skills such as managing decision-making responsibilities, working together with others and development of autonomy, opportunities that may either not be present within the educational environment or not stressed as a focus of the activity. These findings suggest that ensuring meaningful involvement for youth SIDD in activities outside the typical school day should also be a focus of intervention. However, the relative lack of research in this area pertaining to youth with SIDD indicates a need for further examination to gain a greater understanding of how best to facilitate interactions that lead to the development of skills to support successful transition to adulthood.

In order to measure the transaction between the young person and their environment, it is necessary to have an accessible tool that measures youths’ own perceptions of their experiences (enjoyment, sense of belonging, supportive peers and adults) and opportunities to develop skills (independence, problem solving, working with others) within the context of an activity setting environment. Such a tool would enable examination of how various types of activities, and the environments these activities occur in, influence the development of certain skills from the perspective of youth themselves. However, in order to examine this person-environment transaction, we must also conceptualize the ways in which the young person interacts with their environmental settings; that is, what experiences and opportunities does a setting afford the young person?
**Setting Affordances**

The ICF highlights the influence of environment on participation, as well as the influence of individual characteristics of the person such as age, sex, culture and abilities. However, most research looking at the intersection of young people and their environments has focused on accessing the setting, not on the experience or outcomes gained once in the setting. Although many studies have documented the influence of the environment on participation in a variety of activities (Anaby, Law, Coster, Bedell, Kehtani, Avery and Teplicky, 2014; Bedell, Coster, Law, Liljenquist, Kao, Teplicky, & Anaby, 2012; Coster, Bedell, Law, Khetani, Teplicky, Liljenquist, Gleason, Kao, 2011), this influence has been measured very concretely. Much of this work appears to make the assumption that by identifying and subsequently reducing the number of environmental barriers in a particular setting, the person’s participation will increase. This approach to measurement is appropriate if one’s major concern is to increase access to participation opportunities, but overlooks the important question of the *purpose* of that participation. We also need to understand what opportunities are afforded to the individual once they have accessed the setting. Special education legislation highlights the importance of not just being present in educational settings, but also ensuring children are receiving many of the same benefits from schooling as their peers (Individuals with Disabilities Education Act [IDEA], 2004). The field of rehabilitation science would benefit from adopting this perspective when considering participation in other settings outside of the school day. In order to do so, we need a better understanding of the *match* between the individual and their environment.
Work in the field of Positive Youth Development recognizes that youth develop skills for adulthood when opportunities to develop those skills are offered as part of activities young people participate in. Furthermore, special education literature and legislation acknowledges that often support in some form (e.g. altered testing approaches, peer mentorship) is needed for youth with disabilities to participate in school related activities. Therefore, in order to assess and promote participation in recreational activities for young people with disabilities, it is important to understand the needs of the young person and to assess if the setting is meeting those needs through affordances as part of the activity and physical/social environment. Figure 1 illustrates this concept.

[Insert Figure 1 here]

The Person-Setting Match Framework was developed by the author and guides the foundation of the overall dissertation project. The framework highlights that successful participation involves not only that the person can access a particular setting, but also that there is an appropriate match between the desires, needs and abilities of the individual and the affordances of the setting. The International Classification of Functioning, Disability and Health – Children and Youth (ICF-CY; WHO, 2007) acknowledges there are many individual characteristics, referred to as Personal Factors, that, in conjunction with impairments related to pathology and features of the external environment, influence the ability of a young person to carry out specific activities or participate in life situations. Important individual characteristics to note include: demographics (age, race, gender), character style, behavioral patterns, and preferences. Additionally, The ICF-CY primarily focuses on qualifying the degree to which various
environmental factors (e.g. products and technology, attitudes of others) either hinder or facilitate access to participation opportunities. This framework seeks to further expand on the personal and environment components of the ICF-CY by shifting the focus from the objective assessment of concrete environmental resources to the relation between the individual and the perception of what is possible for that individual within a setting based on environmental *affordances* of that setting. The term *affordances* is drawn from Gibson’s work concerning the Theory of Affordances (Gibson, 1977) in which the environment is described as offering possibilities for actions (e.g. a button can be pushed, a handle can be pulled). Realization of these possibilities depends on the capacities of the person to see and execute the potential actions. The Person-Setting Match framework suggests that an activity setting needs to be structured in a way that supports the participants to perceive the relevant cues and to act accordingly in order to successfully be involved. Thus, one way to measure successful involvement of youth in recreational activities is to examine whether they report positive experiences associated with engaging in activities in a particular setting that support meaningful skill development (e.g. working with others).

The Person-Setting Match framework draws on several frameworks and theories for understanding youth development and how to measure settings that promote this development. Tseng and Seidman (2007) have proposed a framework for the ecological process of a social setting in which both the resources and the organization of resources facilitate social processes, defined as ongoing transactions between two or more people or groups in a setting. Resources and their organization are defined as human, physical,
economic and temporal. An important feature of this framework is its recognition that not only availability of resources, but also the organization of these resources influences the social process among people and groups. Although this framework offers a valuable ecological perspective on the environment, it does not suggest ways to measure these relationships. Therefore, in order to generate a way to measure these relational transactions, it is necessary to draw on concepts from ecometrics, the study of social settings.

Raudenbush and Sampson (1999) proposed that a unique way to evaluate ecometric assessments is needed. They have argued that “without comparable standards to evaluate ecological assessments, the search for individual and ecological effects may overemphasize the individual component simply because the well-studied psychometric properties are likely to be superior to the unstudied ecometric ones.” pp.3 In order to appropriately measure aspects of the environment, a method to aggregate findings from individual assessments of experience to create a representation of afforded experiences of an entire activity setting must be developed. In addition, Chan (1998) acknowledged that without a clear conceptualization of the constructs to be measured, a mismatch may occur between the level of measurement and the generalization of the findings. Therefore, unless the proper conceptualization has been made at the lower level (i.e. individual experience), it is inappropriate to relate it to higher level constructs (i.e. afforded experience in various activity settings).

Drawing on the frameworks set forth by Tseng and Seidman (2007) and the Person-Environment-Occupation Model (Law, Cooper, Strong, Stewart, Rigby, & Letts,
1996), it is possible to reshape the concept of the environment to *setting affordances*. This shift in emphasis creates a more holistic theory of what the environment offers in relation to promoting participation in a specific activity. Participation is measured at the level of the person, whereas environment is viewed as an ecological property. Functional relationships help define the connections between these two dimensions. Chan (1998) notes that composition frameworks must be developed to guide multilevel research (i.e., including lower and higher levels). If too much focus is placed on findings at the individual level (i.e., can a person do this activity?) and these findings are not related to higher levels (i.e. what in the setting promoted this person’s ability to do this activity?), we risk not capturing the entire picture. It is important to note that models of these higher levels must account for transactional processes and interfaces that only occur when multiple parts are present (i.e., the individual, the setting). In other words, the whole is greater than the sum of its parts.

**Measuring the Participatory Experience and Setting Affordances**

While efforts to increase participation are important, it is also crucial to determine if activities youth with intellectual disabilities do participate in are promoting the development of skills that may support positive transitions to adulthood and community living outcomes. In order to do so, it is necessary to have an accessible tool that measures both the participants’ own experiences within the activity setting and their perceptions of the development of such skills. A tool such as this would support efforts to gain a better understanding of which activities are most appropriate for providing certain experiences
and promoting the development of specific skills from the perspective of the youth themselves.

In addition to a youth self-report instrument, a tool designed to assess the affordances of a setting objectively is needed. This instrument would provide information about what types of experiences and opportunities are present within varying activity settings. The instrument would also make it possible to draw comparisons between the affordances offered in the setting and the affordances the youth report experiencing and utilizing. This combination would support an ecometric approach to measuring and understanding the activity setting. This information would be valuable for both program evaluation and larger scale research. For program evaluation, it would provide a better understanding of how young people are interacting with their environments and identify potential changes needed to ensure the affordances within a setting are matching the experiences young people report having. Researchers would benefit from having methods to assess the types of experiences and opportunities different activity settings offer. This knowledge may then contribute to service planning for youth with intellectual disabilities by helping to identify the activities that would be most appropriate for the young person to engage in based on experience and skill development needs.

Meyers and Andresen (2000) note that in order to develop appropriate research instruments, researchers must include people with disabilities in the design of the questions and in the focus groups, cognitive interviews, pre-tests, pilot studies, and other formal and informal processes that go into research instrument development. In the past decade, measurement developers have begun to actively seek the input of individuals
with disabilities through interviews, focus groups and cognitive testing. However, these methods may still be limiting to certain individuals who struggle with more abstract thinking or expressive language. As a result, other approaches and methodologies are needed to make the development of outcome measures more fully accessible and inclusive.

This dissertation describes the development of two measures designed to assess participation in recreational activities by youth with significant intellectual and developmental disabilities (SIDD) (Thompson et al., 2009). To ensure relevance and accessibility of the self-report measure, many different stakeholders were involved in the development work including the youth themselves, their families, educators, service providers and other researchers. Each group offered a unique perspective in terms of what information needs to be captured in a measure designed to aid in service planning. Therefore, utilization of both traditional and non-traditional methods of data collection was necessary to ensure all stakeholders were included. Employing new and unconventional strategies to collect stakeholder input supported construction of relevant and accessible measures of participatory experience and setting affordances.
References


Figure I

*Person – Setting Match Framework*

- **Personal Factors**
  - Demographics
  - Character Style
  - Behavioral Patterns
  - Preferences

- **Organization of Affordances**
  - Affordances
    - Human
    - Physical
    - Temporal
    - Economic

- **Setting Affordances**
Enabling Participation of Young People with Significant Disabilities in Measurement Development Research:

Photo Self-Representation and the SELFIE Procedure

Kendra Liljenquist

Zachary Rossetti

Wendy Coster

Jessica Kramer
Abstract

**Purpose.** Participation in recreational activities affords young people opportunities to develop important skills such as decision-making and interpersonal skills needed for success in adulthood. In order to evaluate whether young people with significant disabilities also experience these opportunities, it is necessary to have an appropriate instrument that captures their perspective using a method that is accessible.

**Method.** This paper describes the development and implementation of a new methodology, Photo Self-Representation and the SELFIE procedure, designed to enable the engagement of young people with significant disabilities in the instrument development process. Six youth (3 boys, 3 girls) aged 13 to 19 years old, all identified as having significant disabilities, participated in four recreational activities in the community. The youth then reviewed photos taken during the outings to identify important and meaningful experiences.

**Results.** Youth described their participation in 3 general categories: personal, social and environmental. 16 themes further describing youth’s experiences were then identified. Factors influencing positive experiences included autonomy and friendship. Factors relating to negative experiences included activity requirements and built structures.

**Conclusion.** Findings from this project guided the content development and format of a new self-report measure of participation experience and environmental influences – The Participatory Experience Survey.
The World Health Organization (WHO) defines “participation in life situations” as an ultimate outcome goal for young people living with disabilities (WHO, 2008; WHO, 2001). Recreational activities such as youth groups and sports have been shown to promote the development of skills such as independence and problem solving, skills needed for successful transition to adulthood (Larson, Hanson and Moneta, 2006; Carter and Hughes, 2005; Dworkin, Larson and Hansen, 2003). Unfortunately, many young people with disabilities do not participate in recreational and community activities at the same rate as their peers without disabilities and thus may not experience these opportunities to the same extent (Bedell, Coster, Law, Liljenquist, Kao, Teplicky, & Anaby, 2012; Coster, Bedell, Law, Khetani, Teplicky, Liljenquist, Gleason, Kao, 2011). Understanding the participation experiences of young people with disabilities is important to ensure youth are being afforded opportunities that foster healthy development, which requires availability of a suitable instrument. Such a measure must be relevant and accessible to the young people so that they can provide their own views directly.

It has become an expected principle of measurement development that the population for which an instrument is being designed should be included in the conception and development of the measure (Velozo, Seel, Magasi, Heinemann, Romero, 2012; Meyes & Andresen, 2000). However, despite the increasing application of this principle, many of the methods used to gain population input do not provide appropriate accommodation to be fully accessible to people with intellectual or developmental disabilities (IDD). Data collection strategies such as interviews, focus groups and
cognitive testing may still be limiting to certain individuals as these approaches depend on a degree of abstract thinking and memory and expressive language skills that may be beyond the capacity of people with cognitive impairments (Finlay & Lyons, 2002). Thus, there is a need for data collection strategies that increase accessibility to the instrument development process for individuals with IDD. This is particularly important for self-report measures where the individual experiences or perceptions of the person themselves are the focus of the instrument.

Approaches used in Participatory Action Research (PAR) suggest some possible strategies to include young people with IDD in the development of self-report measures. Two approaches in PAR, Photo-Voice and Photo-Elicitation, are methodologies that utilize visual supports through photos to encourage discussion and exchange of knowledge and ideas on varying topics of interest to individuals and communities (Wang, 2006; Harper, 2002; Wang & Burris, 1997). The use of photos provides an alternative to the traditional interview and focus group format for people who may struggle with these traditional methods to share their experiences (Jurkowski, 2008). Thus, application of a method derived from Photo-Voice and Photo-Elicitation may enable an inclusive research process and result in more accessible and relevant self-report instruments.

This paper presents a new approach designed to enable youth with significant intellectual and developmental disabilities (SIDD) to participate in the development of self-report instruments. SIDD is defined as an intellectual or developmental disability that is characterized by the individual’s need for pervasive supports “to participate in activities linked with normative human functioning” (Thompson et al., 2009).
Methods used in PAR such as Photo Voice (Wang & Burris, 1997) and Photo-Elicitation (Harper, 2002) were drawn on to generate a new, more accessible methodology to capture the perspectives of young people with SIDD: Photo Self-Representation and the SELFIE approach. This methodology was employed during the initial stage of the development of a new self-report measure, the Participatory Experience Survey, designed to capture the experiences of young people with SIDD during recreational activities. Input from youth from backgrounds not traditionally included in research was also incorporated as the perspectives of youth with disabilities from racial minority and/or lower economic groups have rarely been considered in the development and design of measurement tools (Flores, 2002).

The following research questions were addressed in this project:

1) Are youth able to share their experiences while out in the community utilizing the Photo Self-Representation and the SELFIE methodology?

2) What factors do youth with SIDD perceive to be influencing their experience when participating in community recreational activities?

Findings from this project were used to develop the content of the Participatory Experience Survey.
Method

Setting and Participants

A youth panel was developed in collaboration with a community-based organization serving families of youth with disabilities from underserved and immigrant populations. The stated mission of the organization was to empower and support parents of children with disabilities within the inner city to improve the lives of children at home, in school and in the community. Additionally, the organization sought to improve the availability of and access to culturally responsive, disability-related support, information, and training for culturally and linguistically diverse families who have children with disabilities, as well as young adults with disabilities.

Recruitment occurred through the director of the organization who acted as a liaison between families and the researcher. The liaison directly contacted families she thought might be interested in participating in the program. The program was advertised in the organization’s newsletter; parents were asked to call the organization’s office to get more information and be put in contact with the researcher if they had additional questions. The only exclusion criterion was the need of significant help with transfers and/or toileting due to staff limitation and safety concerns. Once six families had expressed interest in having their child participate in the project, an information night was held at the organization’s office. The researcher presented information on the focus of the project, as well as what the summer project would entail. Parents were then given an opportunity to ask additional questions and gain further clarification on the project. Two youth attended the meeting with their families, which gave the youth an opportunity to
share their opinions on participating in the project. At the end of the information session, parents were asked to provide consent.

Two families were unable to attend the information session so the researcher went to the families’ homes to provide information about the project and obtain consent and assent. For one family, the parents’ primary language was Spanish so a staff member from the organization came to the family’s home and translated as necessary to ensure the family understood the project. Youth were present during home visits. All research activities, including the recruitment process, were approved by the university’s Institutional Review Board.

All participating youth (n = 6) were between the ages of 13 and 19 and received special education services related to a significant disability. Individual descriptions, based on parent report, observations and interactions during the research activities, are below. All names are pseudonyms.

**Winnie.** A 17 year-old Hispanic young woman, Winnie primarily spoke Spanish in the home although she also understood English. Winnie had a diagnosis of Down syndrome and was of smaller stature, which sometimes made it difficult for her to navigate certain structures within the built environment, such as climbing stairs or getting into vehicles. Winnie was quieter than her peers and preferred to use an iPad with a voice output communication aid although she would communicate verbally with her family both in person and on the phone.

**Niehla.** Niehla was a 17 year-old young woman who identified as Hispanic and African American and spoke English as her primary language. Niehla had moderate
difficulties in motor coordination and receptive and expressive language. She was very energetic and smiled a lot. Sometimes she struggled with transitions between tasks or activities, as evidenced by refusal or withdrawal behaviors.

**Sarah.** A 17 year-old Caucasian young woman, Sarah’s primary language was English. Sarah had difficulty with expressive language due to a developmental delay and was learning to use a voice output communication aid to communicate in response to verbal interactions. She was very enthusiastic and used both body movements and vocalized noises to communicate her feelings and needs more often than using her communication device. Sarah considered Niehla her friend and often sought to sit or stand close with her.

**Darren.** Darren was a 19 year-old African American man whose primary language was English. Darren had a learning disability for which he received special education services. Darren was the oldest of the group and often spoke up the most when the group was asked to share experiences or suggestions. He also was independent when undertaking many community activities such as attending local school basketball games and often would share stories of his afterschool and weekend experiences.

**Christopher.** Christopher was a 13 year-old African American boy whose primary language was English. Christopher’s primary diagnosis was Pervasive Developmental Disorder-Not Otherwise Specified. Christopher was the youngest of the group and took some time to warm up to the others. He looked up to another member of the youth panel, Darren, and shared that he enjoyed doing activities with Darren the most.
Kelechi. An 18 year-old man of Nigerian descent whose family had immigrated to America, Kelechi’s primary language was English. His primary diagnosis was Autism. He was verbally expressive, especially when discussing what he did and did not like. Both he and Christopher enjoyed dancing and showing their moves to the group.

Procedures

Youth Panel Activities. The youth participated in four community outings. The outings included going out to eat at a restaurant, going bowling, attending a pottery painting workshop, and a trip to the science museum. The first author sought outings representative of varying types of social and recreational experiences, however, the young people were given some choices between different types of recreational outings and input into where the outings should occur. During the first outing to the restaurant, the first author suggested a variety of recreational activities and sought feedback from both the group and director of the community based program, who also attended the lunch outing. For example, when discussing a possible bowling outing, one young man shared that he had never been to a bowling center in the area that had dimmer lighting, lounge-like seats and an extensive menu. It was then decided that the bowling outing would occur at this location. Additionally, going to the movies was a suggested outing, however, Niehla expressed she did not want to do this. The director of the organization agreed this would not be something she would enjoy as it involved needing to sit quietly rather than being more active. Thus, the group was encouraged to select another activity. While on the outings, the researcher took photos of the youth participating in the various activities. Photos of their environmental surroundings were also taken including people,
building structures, and other objects relevant to the activity (e.g., a bowling ball or a paint brush). A group discussion was then held on a separate day, one week after each outing to reflect on the outing.

**Photo self-representation.** The procedure used during the recreational outings combined two existing methods utilizing photography to prompt reflections on social participation. In PhotoVoice methodology (Wang & Burris, 1997), an individual takes the photo him or herself and then reflects on aspects of the photo as well as the experience of choosing to take a particular photo later through discussion with others. In Photo-elicitation (Harper, 2002), the individual is shown a photo to provide context to a particular experience he or she is reflecting on. This photo is not of the individual themselves nor from the actual context or environment the individual is being asked to reflect on, but rather offers support to give an example of what is being discussed. We combined these two approaches to develop a new approach that would be more accessible for individuals with significant disabilities. We named this methodology *Photo Self-Representation.* In this method, multiple photos are taken of the individual engaging in a particular recreational activity with peers, with a particular emphasis on having the individual direct what is photographed. Later the photos are shown to the individual to provide contextual support when reflecting on their experience. The post-outing reflection session is guided procedurally by a series of steps that is done in a group setting. However, individual support can be provided to any youth who needs it.

This method was devised after we found that the disposable cameras that had been purchased for the project were too difficult for the youth due to fine motor and
vision difficulties (e.g., pressing the small button on the camera, looking through the camera frame to view and choose the object of the photo). Additionally, the concept of taking a photo of something meaningful or important was abstract for some participants. Therefore, photos were taken by the researcher with the goal of capturing each youth engaging in at least three to four different tasks during the outing.

**Reflective group session.** After each recreational outing the youth participated in a reflective group session the following week. First, the youth were asked to identify pictures that were representative of “things they liked” and “things they did not like” while on the recreational outing. The youth created two scrapbook pages that included the photos they chose and descriptive or reflective statements they composed in response to the photos. One page consisted of photos that represented positive aspects of the outing; the other consisted of pictures that represented negative aspects. Each participant then gave a statement, either written by them, given verbally, or through assistive technology and then transcribed by the first author or the research assistant. A new approach, titled the SELFIE approach, was developed to guide the youth through the reflection process when looking at a photo (see Figure 1).

![Insert Figure 1 here]

Youth then shared their statements and photos with the other members of the group. The group reflection sessions were audio recorded and transcribed to provide further context and understanding during the coding process outlined below.

**Data collection.** The first author and a research assistant collected data during the four recreational outings in the community. To collect the data, a participant observer
approach was utilized (Watts, 2011). Methods of data collection included photography during the recreational outing, audio recording of group sessions reflecting on the photos, and reflective notes of the outings taken by the researchers. In total, the data collection approach generated 27 pictures per outing and 108 pictures over the duration of the project. Each young person chose 16 photos and made eight pages total for the four outings. Christopher only participated in three of the four outings as he left the program early to attend summer camp, thus he made six pages with 12 photos.

**Data Analysis.** Data was analyzed inductively to maintain a focus on the experiences and perceptions of the youth with significant disabilities who participated in this study. The youths’ statements about their photos were analyzed using a two-stage process of content coding and then thematic organization (Berg & Loon, 2014) based on findings and theories within rehabilitation literature concerning interactions between individuals and their environment. Initially, the first author and a trained research assistant marked data units with notable words and phrases to highlight and organize topics related to either positive or negative experiences, those that were frequently repeated, and those that suggested a unique participant perspective. While doing this, reflective field notes by the researchers and transcriptions of the group reflective sessions were used to provide additional context to the photos and statements chosen by the young people. These codes and emerging themes were then compared, discussed until consensus, and refined. The youths’ statements about their photos were then coded independently by a second trained research assistant. The first author and second research assistant then cross-checked their coding, which resulted in an intercoder
reliability score of 0.79. This score was calculated by dividing the number of agreements for each codable unit and specific code chosen by the total number of agreements and disagreements and multiplying by 100.

The codes were organized into three categories that identified key aspects of social participation and contained sub-codes within each denoting relevant characteristics of social participation within each category. After the fact, as a final reliability check, the second author utilized this existing framework to code each of the youth statements about their photos resulting in an intercoder reliability score of 0.80. It is important to note that neither of the independent scorers were present during the recreational outings and thus did not have personal experience to draw from when coding. The first author was present and therefore drew on observational data when coding. An example of differing codes where this difference in knowledge was apparent was for the statement “I did not like looking at the menu.” The first author coded this as activity requirement due to knowledge that Niehla was not able to read well, while the second author coded this as disinterest. This example highlights the importance of an active participant observer when utilizing Photo Self-Representation and the SELFIE methodology, as it is the exchange between the participant observer and the individual that yields valid findings vetted by the individuals themselves.

Results

The results will be presented in response to each of the two research questions of the study: evaluating the feasibility (appropriateness and accessibility) of the Photo Self-Representation and the SELFIE methodology and understanding the youths’ participatory
experience in varying community recreational activities.

**Feasibility of Photo Self-Representation and the SELFIE Methodology**

The SELFIE procedure appeared enjoyable and accessible to all six youth panel members. All young people were able to choose and reflect upon photos that represented experiences they liked and did not like. However, the amount of time the procedure took varied depending on the young person’s abilities to physically construct the pages and to express themselves in writing. Those who were able to both glue the photos to the page and write their own statements took about 15 to 20 minutes to complete their pages. The process took 30–40 minutes for the young people who needed additional help with gluing photos and who needed to dictate statements verbally or use augmentative communication devices for transcription. Additionally, these youth needed further prompting and questions to clarify why the photos had been chosen. For example, when asked to choose a picture of something she did not like, Winnie chose the picture of the escalator. Using knowledge of Winnie’s experience when she encountered the escalator, the researcher asked her yes/no questions — “did you not like the escalator” that she then constructed into a sentence. The final sentences, either written by the participant or dictated to a researcher, were then read back to the young people and they were asked if the sentence said what they meant. This was done as an additional accuracy check. Because only two researchers were working with the young people while making the pages, time and attention needed to be divided between the six youth panel members. This contributed to the amount of time taken to complete the scrapbook pages and led to some of the youth panel members expressing boredom once they had completed their
pages. We found that one effective response was to ask these youth to help the others glue their pictures while the first author and research assistant supported those who needed assistance with their statements.

**Factors Influencing Youth’s Participatory Experience**

The statements youth composed in response to the photos of their recreational outings in the community revealed three general categories of factors affecting the *participatory experience* by the youth: personal experience, social experience and environmental experience. Within each category there were several characteristics that were coded as being both positive and negative in relation to the participation experience. Other characteristics were either positive or negative. Table 1 includes the categories and characteristics that were identified by the youth panel along with example statements from the youth for each.

[Insert Table 1 here]

**Personal Experience.** The personal experience category included factors that were central to how the young person directly interacted with and perceived the activity within the setting. For many youth, factors resulting in positive perceptions included having autonomy and being successful. Factors resulting in both positive and negative perceptions included level of interest in the activity and the amount of opportunity for choice during the activity. For some, engaging in a new experience interested them in the activity. For others, a key element of the activity was uninteresting. For example, Kelechi considered one particular exhibit within the science museum to be boring. Related to the opportunity to make choices during the activity, some youth relished the chance to do so
while others were overwhelmed or otherwise did not enjoy it.

**Social Experience.** The social experience category consisted of factors that had to do with relating to and interacting with others in the activity setting. The characteristic in this category that yielded both positive and negative perceptions was interactions with others. Most youth cited interactions with others positively, especially as related to engaging in shared experiences during the activity. However, Darren cited it negatively in response to what he viewed as Christopher interacting with him too much, for example, by following him around during the activities and trying to do similar things while on the outings. Additional positive characteristics were interacting either with established friends or new people during the activities. For example, Sarah considered Niehla to be a friend, tried to interact with her as much as possible during the outings, and often described that she enjoyed being with Niehla during the activities.

**Environmental Experience.** The environmental experience category consisted of the salient qualities of the environment such as the built environment and the related sensory aspects and dynamics. Two key characteristics were coded as resulting in both positive and negative perceptions of participation in the activity. First, level of familiarity with the setting contributed to the youths’ perceptions. For example, the sign on the bathroom door at the pottery workshop had an outline of a person with the same haircut as Sarah. She was very drawn to this and sought to point it out. Second, the sensory qualities of the environment were cited as critical to the youths’ participation. Kelechi expressed dislike for the electricity theater at the science museum because of the noise and actually chose to exit the theater right after the start of the display. Additionally,
built environment structures affected the participatory experience for some youth. Winnie and Niehla, who both had motor coordination difficulties, found navigating the built environment more difficult and chose photos to represent this experience. Niehla did not want to get on top of a stuffed camel for a photo at the science museum, as did some of the other group members, and Winnie did not want to use the escalator and instead preferred the elevator.

**Discussion**

In this study, we both developed and explored the use of a new methodology designed to make participation in the development of self-report measures more accessible to young people with SIDD. The new methodology broadens the ways through which young people with significant disabilities can contribute to the development of outcome measures designed to understand their experiences and needs. Utilizing photos to facilitate recall of experiences proved successful in eliciting sharing from the youth. Photos supported memory recall of what the young person was doing in the photo, which enabled the young person to express whether this was a positive or negative experience and why. Our results suggest that Photo Self-Representation and the SELFIE approach facilitate youth with cognitive impairments and learning disabilities to articulate their experiences in meaningful and informative ways.

Photo Self-Representation and the SELFIE Approach offer an alternative approach to involve youth with significant disabilities in research and to gain an understanding of how youth conceptualize and understand their participation experience. To use this method most effectively, it is recommended that a participant-observer
approach (Watts, 2011) be used. This means that the same individuals who attend the activities and take the photos also work with the young people as they assess the photos and code the statements for themes. In this way, all individuals who will be involved in the data analysis have personal knowledge of the young people as well as first-hand knowledge of the experiences. To minimize bias, the young people themselves should verify each statement and all participant-observers should code the statements independently. Additionally, while group process can be effective, working individually to assess each photo with the SELFIE procedure is ideal for this target group as this allows for optimal support when working with the young person to understand their particular experience.

Using this methodology, we were able to identify important factors the youth perceived to influence their participatory experience in recreational activities. Many of these factors align with findings from other studies of individuals with disabilities: independence, opportunities for choice, feelings of success and being with others (Bedell, Khetani, Cousins, Coster, & Law, 2011; Carter, Swedeen, Moss, & Pesko, 2010; Heah, Case, McGuire, & Law, 2007; King, Law, King, Rosenbaum, Kertoy, & Young, 2003). The similarity across studies supports that the method was successful in eliciting meaningful information from the youth participants.

The findings in this study also suggest that a measure of participatory experience needs to be able to distinguish between different factors within a setting and the unique impact of those factors on an individual. This recommendation is consistent with influential theories such as Bronfenbrenner’s Ecological Systems Theory and Law’s
Person-Environment-Occupation Model that recognize the dynamic and unique interaction between an individual and their environment (Law, 1996; Bronfenbrenner, 1977). Participants often identified different factors within the environment that influenced their participation in the same activity. For example, Brandon enjoyed the bowling outing because he felt successful while Niehla and Julie enjoyed the outing because they spent time with one another. As this example illustrates, it is important not only to know whether an individual had a positive or negative participation experience but also what factors within the setting contributed to that positive or negative experience. This information is crucial when evaluating recreational settings as it identifies what factors and experiences are needed to provide a setting that can foster a positive experience for many different individuals.

**Limitations**

This study sought to develop and apply a new approach to include young people with significant disabilities in the development of self-report measures. While this study yielded important findings, some limitations should be noted. The project included a small number of young people (6) and was qualitative, which limits the generalizability of findings. In addition, although all participants had significant disabilities, as individuals they had very diverse profiles of strengths and limitations, which may have influenced the findings in unknown ways.

**Conclusion**

The Photo Self-Representation and SELFIE methodology was feasible and effective to elicit information from youth with significant intellectual and developmental
disabilities to guide instrument development. Factors identified through use of Photo Self-Representation and the SELFIE methodology will guide development of relevant and appropriate questions for the Participatory Experience Survey (PES). The PES is a self-report instrument designed to be accessible to youth with SIDD and assesses opportunities for positive experiences and skill development provided to youth within a recreational setting. Knowledge gleaned from the PES will provide programs serving youth with disabilities information concerning how best to structure activities and provide optimal support to participants.

Acknowledgements

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A conceptual model of the factors affecting the recreation and leisure


Figure 1

SELFIE Methodology

- **S** • Ask the young person to **See** and **Select** a photo representative of an experience

- **E** • Ask the young person to **Examine** the photo and describe why he or she chose the photo

- **L** • **Listen** to the young person explain why this photo was chosen

- **F** • **Fully** record through writing what the young person says and describes

- **I** • Ask the young person to **Indicate** if what has been recorded is correct

- **E** • **Evaluate** and **Extract** thematic data of the experience the young person described
Table 1

*Categories and characteristics affecting participation experience*

<table>
<thead>
<tr>
<th>Personal Experience</th>
<th></th>
<th>Negative</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Positive</strong></td>
<td><strong>Negative</strong></td>
<td></td>
</tr>
<tr>
<td>Interest in activity</td>
<td>“I like this picture because the thing never stops; it is something new.” –Kelechi (said in response to a pendulum)</td>
<td>Disinterest in activity</td>
</tr>
<tr>
<td>Opportunity for choice</td>
<td>“I liked being able to choose lots of different colors. Brown and pink colors!” -Niehla</td>
<td>Opportunity for choice</td>
</tr>
<tr>
<td>Autonomy</td>
<td>“I got to do the drink machine by myself.” -Niehla</td>
<td></td>
</tr>
<tr>
<td>Success</td>
<td>“This was important to me because I was winning.” -Darren</td>
<td>Dislike for activity requirements</td>
</tr>
</tbody>
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<table>
<thead>
<tr>
<th>Social Experience</th>
<th></th>
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</tr>
</thead>
<tbody>
<tr>
<td><strong>Positive</strong></td>
<td><strong>Negative</strong></td>
<td></td>
</tr>
<tr>
<td>Interactions with others</td>
<td>“We got to see the butterflies together.” - Sarah</td>
<td>Interactions with others</td>
</tr>
<tr>
<td>Friendship</td>
<td>“I like this picture because Niehla is in it. Niehla is my friend.” - Sarah</td>
<td></td>
</tr>
<tr>
<td>New people</td>
<td>“It is important to me because I met new people.” -Christopher</td>
<td></td>
</tr>
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<thead>
<tr>
<th>Environmental experience</th>
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<tbody>
<tr>
<td><strong>Positive</strong></td>
<td><strong>Negative</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Familiarity</td>
<td>“I like that the picture looked like me.” -Sarah</td>
<td>Lack of Familiarity</td>
<td>“I did not like this picture because they are looking at movie frames that did not come out.” –Kelechi (said in response to movie posters he had never seen before)</td>
</tr>
<tr>
<td>Sensory Qualities</td>
<td>“I like this picture because the area inside was very nice.” -Christopher</td>
<td>Sensory Qualities</td>
<td>“The electricity in the theater was too loud.” -Kelechi</td>
</tr>
<tr>
<td>Built Structure</td>
<td>“I did not like the escalator.” -Winnie</td>
<td></td>
<td></td>
</tr>
</tbody>
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Content Evaluation and Cognitive Interviewing of a New Self-Report of Participation and Environment for Youth with Significant Intellectual and Developmental Disabilities:

The Participatory Experience Survey

Kendra Liljenquist
Wendy Coster
Jessica Kramer
Zachary Rossetti
Abstract

**Purpose.** The purpose of this study was to obtain feedback on the Participatory Experience Survey (PES) from stakeholders, further evaluate accessibility of items through cognitive interviewing and determine initial feasibility of administering the survey within the desired context.

**Method.** Three groups of stakeholders, parents of youth with significant intellectual and developmental disabilities (SIDD) (Group 1), service providers (Group 2), and experts in intellectual disability and/or program planning (Group 3), reviewed the 24-item PES to provide feedback on the relevance and accessibility of the measure. After stakeholder feedback was incorporated, cognitive interviewing was conducted with eight young people between 14 and 22 with SIDD. Finally, initial feasibility of administration of the PES was assessed.

**Results.** Stakeholder groups 1 and 2 identified 15 questions as needing revisions. Seven additional questions were added based on suggestions from stakeholder group 3. Cognitive interviewing identified 13 questions needing revisions and 4 needing removal. Changes were made to address three issues: vocabulary, item meaning and response bias. Initial feasibility work indicated the PES needed to be shortened for use within desired contexts.

**Conclusion.** Feedback from stakeholders and cognitive interviewing results support the content validity of the revised PES as relevant to and understandable by the intended respondents.
**Introduction**

In the past decades, international and domestic policies have increased access to opportunities for children and youth with disabilities to participate in the same experiences available to their peers without disabilities (United Nations [UN], 2007; Individuals with Disabilities Education Act [IDEA], 2004; UN, 1989). Furthermore, research has shown that participation in *recreational* activities promotes positive developmental experiences (King, Gibson, Mistry, Pinto, Goh, et al., & Thompson, 2013; Duerden, Taniguchi, & Widmer, 2012; Dworkin, Larson and Hansen, 2003) ranging from facilitating development of interpersonal skills to fostering independence and problem solving (Larson, Hanson, Moneta, 2006; Hansen, Larson & Dworkin, 2003). Acquisition of these skills helps promote successful transitions to adulthood for youth with disabilities (King, Curran, & McPherson, 2012). However, we lack an accessible and reliable instrument to assess the experiences of youth with *significant intellectual and developmental disabilities* (SIDD), defined as an intellectual or developmental disability requiring the need for pervasive supports “to participate in activities linked with normative human functioning” (Thompson et al., 2009). Understanding the experiences of young people with SIDD is necessary to help direct recreational program efforts to appropriately support participation and ensure participants are developing skills needed for successful transitions into adulthood (Hoogsteens, & Woodgate, 2010).

Currently, only two self-report measures of participation have been developed to examine the experiences of young people with disabilities engaging in recreational activities. The Children’s Assessment of Participation and Enjoyment (CAPE) is a 55-
item survey that asks about activity preference, who an activity is done with, where it is done and whether it is enjoyable (King, Law, King, Hurley, Hanna, Kertoy, Rosenbaum, & Young, 2004). Although the content of the CAPE captures important aspects of participation, the instrument is very long, which is problematic for youth with cognitive processing difficulties and may not be feasible for use in situations where there is limited time. The Self-reported Experiences of Activity Settings (SEAS) is a 22-item self-report instrument that measures 5 constructs (Personal Growth, Psychological Engagement, Social Belonging, Meaningful Interactions, and Choice & Control) using a 7-point Likert response scale (King, Batorowicz, Rigby, McMain-Klein, Thompson & Pinto, 2014). However, Likert scales have been shown to be difficult for individuals with intellectual disabilities to use (Kramer, Smith & Kielhofner, 2009; Hartley & MacLean, 2006; Finlay & Lyons, 2001), highlighting an issue of accessibility. Furthermore, the SEAS requires a grade 3 reading level and youth with SIDD may not be able to read at this level. Thus, there is a need for a self-report measure designed specifically to assess the experiences of young people with SIDD while engaging in recreational activities. The Participatory Experience Survey (PES) was developed for this purpose.

The PES is designed to be completed by a young person with SIDD in reference to a particular recreational activity he or she has just participated in. It provides information about the young person’s experience while engaged in the activity, the skills they applied during this activity and their perception of the influence of features of the environment on their participatory experience. Items for the PES were generated based on findings from previous qualitative work with young people with SIDD that is reported
elsewhere (Liljenquist, Rossetti, Kramer & Coster, in preparation). Items are framed as yes/no questions and are presented during an interview to enable optimal accessibility. Some of the items include an option to provide additional open-ended responses, which are intended to gather additional information from the young person to help guide program evaluation and structuring.

Although intended respondents (youth with SIDD) were involved in the initial development of the PES, guidelines for sound instrument development call for additional input and evaluation by stakeholders prior to finalizing the instrument (Velozo, Seel, Magasi, Heinemann, Romero, 2012; Meyes & Andresen, 2000). This paper describes three further development activities:

1. Stakeholder Content Evaluation – To evaluate the appropriateness of the content of the PES through feedback from stakeholder review groups.

2. Cognitive Interviewing – To determine relevance and accessibility of the PES through cognitive interviewing with youth with intellectual disabilities.

3. Initial Feasibility – To determine if the PES can be administered effectively in the desired context (i.e., directly following a recreational activity)
Methods

Participants

Stakeholder Review

An initial draft of the PES was presented to three groups of stakeholders to obtain feedback. Members of each group represented a different role in relation to youth with SIDD. Participants in Group 1 were five parents/guardians of a young person who was between 14 and 22 years of age, had a diagnosed intellectual or developmental disability resulting in cognitive impairment, and was verbal. The average age of the youth Group 1 members were reporting about was 18.2 years of age. Participants in Group 2 were 10 service providers, including allied health and education providers. Each service provider had been practicing in his or her respective field for a minimum of three years. Participant details for these two groups are shown in Table 2.

[Insert Table 2 Here]

Group 3 included five experts on intellectual disability and program planning/evaluation. Each individual had either a clinical degree or a master’s degree or above. Two of the participants in Group 3 also had teenage children with intellectual disabilities.

Participants for groups 1 and 2 were recruited via a flyer sent over various listservs of organizations across the United States serving youth with intellectual disabilities and their families. Interested individuals were asked to contact the investigator. Once the investigator had confirmed the participant met inclusion criteria described above, he or she was given a link to the Qualtrics website where they provided
consent. Participants were then able to access the PES and complete a survey to gather feedback about the measure. Participants in Group 3 were recruited through direct contact by the investigator. All individuals contacted to compose group 3 agreed to participate.

Cognitive Interviewing

Participants for cognitive interviews were recruited via a flyer sent home with youth who participated in specialized programs offered through a city parks and recreation department in the northwest region of the United States. A total of eight youth participated in the cognitive interviewing. Inclusion criteria included youth between the ages of 14 to 22 with a diagnosed intellectual or developmental disability resulting in cognitive impairment as reported by the parent and who were reported by their parents or guardians to be able to at least communicate wants and needs meaningfully (report based on a list of typical communication abilities). A male and a female each from four age categories (14–15, 16–17, 18–19, 20–22) were recruited for cognitive interviewing in order to have a range of ages and balance of gender. Demographics of the participants are presented in Table 3.

[Insert Table 3 Here]

Initial Feasibility

To determine the feasibility of administering the PES within the desired context, 10 youth completed the survey directly following participation in an after school program. The program was based in a large city in the northwest region of the United States. The program was open to any young people in the geographic area between the ages of 14 and 22 and identified as having a disability. The average age of youth who
participated was 17 and all youth qualified as having SIDD based on parent provided
information to program staff.

Procedure

Stakeholder Review

The initial version of the PES had 24 items and covered three content areas:
personal/social experience, skill development and environment. Table 4 shows examples
from each area. For each PES item, Group 1 was asked to indicate: 1) If this question
were read to your child, would she or he understand the question? and 2) Would your
child be able to answer this question meaningfully? For each PES item Group 2 was
asked to indicate: 1) Is this question relevant to the development of young people with
intellectual disabilities? and 2) Would an answer to this question provide meaningful
information you could utilize when working with young people with intellectual
disabilities? An additional question asking both groups 1 and 2 to offer any suggested
changes was included for each item. Suggestions from Groups 1 and 2 were then
presented to Group 3 for review. Suggestions were shared with Group 3 participants prior
to meeting with each one. An in-person or phone interview was conducted in which the
PI asked each participant in Group 3 to review each item and determine: 1) Did the
question capture an important piece of information relevant to the development of youth
with IDD?; and 2) Should any additional questions be added? Additionally, Group 3 was
asked to offer input regarding the accessibility of alternative wording for each item for a
young person with IDD. Final decisions on changes were based on several criteria
including whether multiple participants had made the same comment or suggestion, and
the consistency of the suggested change with the intent of the instrument.

Cognitive Interviewing

Once feedback from all stakeholder groups had been incorporated into the measure, cognitive interviewing (Velozo, Seel, Magasi, Heinemann, Romero, 2012) was undertaken to evaluate the accessibility of the PES. Accessibility was defined as respondents grasping the intended meaning of the item and giving an answer that was appropriate and “made sense” in the context of what was asked. Youth completed the PES during an interview directly following participation in a recreational activity such as swimming, an after-school club or community service. In order to evaluate their understanding of the item, youth were asked to give an example pertaining to the question asked in relation to the activity he or she had just participated in. Figure 2 illustrates this process.

[Insert Figure 2 Here]

After each interview any items that caused confusion were restructured to try to eliminate the problem and the revised form of the PES was then given to the next interviewee. This process iteratively revised the PES based on data from cognitive interviews and used further cognitive interviews to determine if revisions addressed the problem. Each interview was recorded and notes were taken to highlight any items that appeared to present difficulty to the youth.

Initial Feasibility

After cognitive interviewing, the PES included 31 items. This length proved acceptable for the context in which the measure was administered, i.e., one on one
cognitive interviews. However, it is important to acknowledge that the ultimate purpose of this measure is to obtain feedback from young people with cognitive limitations due to intellectual and/or developmental disability directly following participation in an activity. This may mean the measure will be administered under less than ideal circumstances (i.e., at the program site, during a short break etc.). Thus, further feasibility work was needed to determine if the length was appropriate or whether the survey needed to be shortened to match the needs of both programs serving young people with SIDD and the young people themselves.

Following cognitive interviewing, the PES was given to 10 youth with SIDD who participated in an after school program. The young people participated in the first half of the activity, an art project, and then were pulled aside during the second activity, swimming, to complete the PES. The PES was given in interview format to each young person by one of two program volunteers. Any statements made in regards to items or the survey administration process were documented, though no questions outside of the items were asked of the youth. The time to complete each interview was also documented.

Results

The frequency of “yes” and “no” responses to each question asked of Groups 1 and 2 were calculated. Of the 24 items on the PES, 15 items were identified with concerns, as indicated by a majority of respondents answering “no” to a question in the survey. The 15 items were then revised and presented to Group 3, who reviewed a total of 24 items. Group 3 then suggested an additional 7 items for a total of 31 items to be tested during cognitive interviewing. Of the 31 items, cognitive interviewing identified 13 items
that required changes and 4 that required removal. Table 4 gives example items representative of the types of issues encountered during the stakeholder review groups and cognitive interviewing and shows the process of revision. Revisions were primarily in response to three issues: vocabulary, intended item meaning, and response bias.

[Insert Table 4 Here]

Both the stakeholder groups and cognitive interview participants identified vocabulary issues in their feedback. One concept that received much attention was that of being “left-out” or “not a part of the group”. Parents and service providers indicated this wording may be difficult for the young people to understand and many were unsure how their child or client would answer. This item was included during cognitive interviewing to better understand how young people understand the concept. Many of the young people struggled to give an example of being “left-out” until one girl was able to share that “being left out means my friends are doing something and I can’t do it with them”. This explanation suggested a revision to capture the idea that being “left-out” meant not being able to interact with others whom the young person wanted to be with. In order to make the concept of interacting more concrete, the decision was made to focus on a primary form of interaction, talking. Thus, to make the item more accessible it was re-written as “was there anyone you wanted to talk to but didn’t?”

The second issue was the challenge to ensure the intended item meaning was understood. As an example, two items on the PES asked about exposure to new experiences: 1) learning something new and 2) doing something new. Often, the young people did not make a distinction between the two and saw these two questions as
repetitive. There was also a difference in what the young people considered a new experience. For some youth, if a new project had been presented during the activity (such as an art project) this was learning or doing something new. However, other youth, because they were at the same program they always attended, did not consider they had learned nor done something new, even if the activity during the program was new or different. This evidence of varying interpretations of the items suggested removal of the item might be appropriate. However, all stakeholder groups felt it was important to have an item that assessed new experiences. The item “learning something new” was then dropped and the item “doing something new” was retained.

A final issue regarding interpretation of the PES items was response bias, which is a situation where a person answers a certain way to fit a socially acceptable ideal (Schwartz, 1999). This issue was most evident with items that centered on the interactions the young person had with others. One question in particular highlighted the importance of ensuring items were not presented in such a way that the young person may feel judgments could be made on their character. Feedback from stakeholder groups expressed concern that the young people might respond positively to an item that asked about working with or helping someone even if this wasn’t the case because they may want to present themselves in a positive light. During cognitive interviewing one girl responded “yes” to having helped someone during the activity she had participated in. However, when asked to give an example of how she helped she responded, “Well, if someone would have needed help, of course I would have helped them because I’m a good person”. This highlighted the bias to respond positively to this question so as to
appear socially acceptable. Additionally, the desire to respond in a way that is seen as socially acceptable may be heightened because the PES is given in a face-to-face interview. Therefore, this item was rewritten as a two part question: 1) Did another kid need help today? and 2) Did you try to help that person? Asking the young person to first acknowledge whether someone had needed help helped to separate the socially desirable action of helping someone from the reality of someone actually needing help and acting on that reality. Thus, if the young person is first able to communicate they did not identify someone who needed help, he or she may be less likely to positively endorse the item concerned with helping someone.

During cognitive interviewing some youth were not able to give an example to demonstrate complete understanding of the item. When this happened, it was unclear whether they did not understand the question or simply did not have an example to share. However, youth had an example to share more often when responding positively to a question. This may indicate that if the young person did not have an experience to share, their experience was, in fact, negative in relation to the item.

The initial feasibility phase identified two issues, repetitiveness and length, that needed to be rectified before moving forward with further feasibility work. Over half of the youth stated they felt as though they had been asked the same question twice in relation to certain items. Based on this feedback, the investigator decided to cut five items that youth interpreted similarly. Length also proved to be problematic for many young people. Because the primary purpose of the PES is program evaluation, programs may need to administer the survey under less than ideal circumstances (i.e. pull aside from
another activity). Therefore, it was imperative to model this situation when assessing the feasibility of the PES.

Many young people lost focus after 15 questions, as demonstrated by asking “how much longer?” or attention drifting to other activities, highlighting the need for the instrument to be shortened. In order to shorten the survey, decisions to remove items were guided by feedback from stakeholder groups and cognitive interviewing. Eleven items were removed. Primary reasons for removing items related to content that was not stressed by all stakeholders and items whose interpretation by the youth was not unanimous (e.g. doing something new). Additionally, the stem of each item (When you were at (activity here)…) was dropped and instead “today” was added at the end of each it. For example, an item then read, “Did you get to pick or choose something today?” This was done to shorten administration time while still retaining the focus on the activity just completed. The final version of the PES included 15 yes/no items, 5 per content area (Built and Sensory Environment, Skill Development, and Personal and Social Experience). Some of these items have additional follow-up yes/no or open-ended questions.

Discussion

Feedback from many different stakeholders was sought and incorporated to produce an optimal measure of participatory experience for young people with SIDD (Liljenquist, Rossetti, Kramer, Coster, in preparation). The PES offers a way for programs to assess if youth are participating in positive situations that promote opportunities for growth and development of life skills. An important feature of this new
instrument is the extent to which stakeholders were involved in its development. Careful steps were taken to ensure service providers perceived the PES as able to provide relevant information concerning their clients’ experiences. In this way, we created a tool that can aid providers and programs in strategizing ways to offer optimal support of positive experiences for the young people they serve. Furthermore, families validated both the content and accessibility of the instrument. Parents and guardians were able to share examples of how their children talk about and understand various concepts, thus providing invaluable guidance for using appropriate vocabulary to communicate the intended item meaning.

Engaging youth with SIDD in the cognitive interviewing process enabled them to be meaningfully involved in the creation of an instrument designed to capture information about their lives. Including the young people followed best practice for instrument development (Velozo, Seel, Magasi, Heinemann, Romero, 2012) and demonstrated that, with a modified approach, youth with SIDD can participate effectively in cognitive interviewing. This modified approach was innovative in that it asked young people to reflect on their experience during a very recent event (e.g. “When you were at basketball, did you have fun?” “Why did you have fun?”), rather than respond to more general, abstract concepts (e.g. “what does it mean to have fun?”), which is more typical of cognitive interviewing. By asking the question in two parts, we were able to check the young person’s understanding of the item using their explanation of why they answered “yes” or “no”. If the response “made sense” (e.g. “Because my friends were there”), it provided evidence of whether or not the young person understood the question. However,
more work is needed to determine how best to distinguish lack of understanding from not having an example to share.

Initial feasibility work proved vital to further refine the PES. Factors such as requirements for administration training, time and scoring complexity often deter utilization of instruments in clinical and program settings (Greenhalgh, Long, Brettle & Grant, 1998). Thus, it was important to ensure the PES addressed these issues. The PES is given in interview format and requires no training to administer. Although the average time to administer the 31-item PES was nearly 10 minutes, shortening the PES to half the length should reduce the administration time as well, though further feasibility work is needed to determine by how much. Moreover, the “yes/no” response options on the PES make it easy to calculate a summary score.

Limitations

Because the PES was revised iteratively during cognitive interviewing, revisions were dependent on an individual response and thus it could not be determined if the issue was unique to the one person or was indicative of a general issue for this population. However, this was the most efficient and effective method for recognizing and addressing changes that needed to be made and is consistent with other approaches to measurement development (Irwin, Varni Yeatts, Dewalt, 2009; Kramer, 2009). Additionally, initial feasibility work was limited to a small number of respondents who answered about participation in one type of activity. Further feasibility work is needed to determine if the PES performs well in various types of recreational settings.
Conclusion

This project sought to evaluate the appropriateness of content and initial feasibility of a new self-report measure focused on the participatory experience and to determine the accessibility of this measure for youth with significant intellectual and developmental disabilities. In order to do so, stakeholders with various relationships to young people with SIDD were involved in the content evaluation of the PES, a new approach to cognitive interviewing was developed and implemented and an initial feasibility evaluation was conducted to ensure the PES could be utilized in the context it was designed for. The PES expands upon previous work to provide access and inclusion in evaluation efforts for individuals for whom other measures with a similar purpose may not be appropriate. This new instrument provides a means for programs serving youth with disabilities to assess the experiences of their participants and to use this feedback to better structure their programs and services.

Acknowledgements

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References


### Table 2

*Demographics of Stakeholder Review Groups*

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<tr>
<td>Multiracial</td>
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<tr>
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<td>Intellectual Disability</td>
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<td><strong>Communication Level</strong></td>
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<td>Wide variety meaningfully</td>
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<td>Limited range meaningfully</td>
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Table 3  
*Demographics of Cognitive Interview Participants*

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<tr>
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<tr>
<td>Limited range of topics meaningfully</td>
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<td>Needs, wants and some ideas meaningfully</td>
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<td>-----------------------------------------------------------------------------------------------------------</td>
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<tr>
<td>Were you good at (activity here)?</td>
<td>Did you do a good job (activity here)?</td>
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<tr>
<td></td>
<td>Did it make you feel good (activity here)?</td>
</tr>
<tr>
<td></td>
<td>Did it make you feel happy inside (activity here)?</td>
</tr>
<tr>
<td>Did you feel left out when you were (activity here)?</td>
<td>Did you feel lonely at (activity here)?</td>
</tr>
<tr>
<td>Did you get to make choices when you were (activity here)?</td>
<td>Did you get to pick something at (activity here)?</td>
</tr>
<tr>
<td>Did you do something new when you were (activity here)?</td>
<td>Did you do something you had not done before at (activity here)?</td>
</tr>
<tr>
<td>Was it hard to move around in this place?</td>
<td>*Were you able to find all the places you needed to go (like the bathroom) when you were at (activity here)?</td>
</tr>
<tr>
<td></td>
<td>*Were you able to find the bathroom at (activity here)?</td>
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During cognitive interviewing, some youth were not able to give an example to demonstrate complete understanding of the item. Youth more often shared an example when responding positively to a question. This may indicate if young person did not have an experience to share, their experience was negative in relation to the item.
Feasibility of the Participatory Experience Survey and the Setting Affordances Survey for use in Evaluation of Programs Serving Youth with Intellectual and Developmental Disabilities

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Zachary Rossetti
Abstract

Purpose. Participation by youth with disabilities in recreational activities has been shown to promote the development of important skills needed for transition to adulthood. The Participatory Experience Survey (PES) and the Setting Affordances Survey (SAS) were developed for use by recreational programs serving youth with significant intellectual and developmental disabilities (SIDD) to assess participant experiences and ensure participants are afforded optimal opportunities to develop these skills. This paper presents a feasibility evaluation to determine the appropriateness of the PES and the SAS for use in a program evaluation context.

Method. The PES and the SAS were used to evaluate a program serving youth with SIDD in the greater northwest region of the United States. Three recreational activities were evaluated: an art project, trip to a zoo and a track practice. Program volunteers used the SAS to assess opportunities and affordances offered within each activity. The PES was then given to 10 young people in each activity to capture their experiences. It was hypothesized that each setting would afford different experiences and developmental opportunities due to the differing nature of the activities.

Results. The PES and SAS were found to be feasible for conducting a program evaluation. All three settings offered varying types of experiences and affordances. Notably, as measured by the SAS, opportunity for skill development was greater in more structured activities; the zoo had the fewest opportunities for skill development and the art project had the most skill development opportunities. Youth answered “no” most often to “asking for help” and “helping a kid”, suggesting changes to offer more
opportunities to develop these skills would be beneficial in all three activities.

**Conclusion.** These new instruments offer programs a means to more fully include young people with disabilities during program evaluations, leading to better-structured, more supportive programs.

Introduction

Participation in recreational activities by young people is an important contributor to healthy development into adulthood. Research has found that participation in a variety of out-of-school activities such as sports, art groups and organizations affords young people opportunities to develop essential skills necessary for success later in life, skills that may not be fostered within the general school day environment (King, Gibson, Mistry, Pinto, Goh, et al., & Thompson, 2013; Carter and Hughes, 2005; Dworkin, Larson and Hansen, 2003). These skills include autonomy, working with others, problem solving, time management and goal setting (Larson, Hanson, Moneta, 2006). Opportunities to develop these skills are equally important for youth with disabilities (King, Rigby, & Batorowicz, 2013; King, Curran, & McPherson, 2012). While many programs serving youth with disabilities are structured to offer developmental opportunities, it is important to obtain feedback from participants to ensure programs are achieving these goals. Self-report allows the perspectives of young people with disabilities to be shared as opposed to the interpretation of a proxy, such as a program staff member. Obtaining self-report responses from young people offers a unique perspective that can be of great value in promoting optimal health and development (Rebok 2001, Riley, 2004).

To determine whether recreational programs accomplish the goal of fostering the development of important life skills, it is important to have instruments that can obtain valid information concerning experiences from young people with significant intellectual and developmental disabilities (SIDD) while participating. SIDD is defined as an
intellectual or developmental disability requiring the need for pervasive supports “to participate in activities linked with normative human functioning” (Thompson et al., 2009). By assessing the experiences of young people with SIDD, we are able to determine if youth demonstrated certain skills such as working with others as well as what factors within the environment, such as noise level or attitudes of others, may have impacted this experience. Programs serving youth without disabilities can use a variety of methods to obtain this kind of information to use for program evaluation. However, traditional methods of obtaining participant feedback, such as pencil paper self-report instruments using Likert scales, are often not accessible for youth with disabilities, particularly those with cognitive and communication limitations (Kramer, Smith & Kielhofner, 2009; Hartley & MacLean, 2006). Thus, there is a need for tools designed to assess the experiences of youth with SIDD.

In addition to accessibility, these tools must be easy to use within the context they are designed for. Many self-report instruments are piloted under more rigid research conditions and then found not feasible for use in clinic or program settings due to constraints such as administration preparation and time (Greenhalgh, Long, Brettle & Grant, 1998). Therefore, before an instrument is made generally available, a feasibility study should be conducted within the context where the measure will be used. The purpose of the present project was to determine the feasibility of use of two new measures of participation and the environment, The Participatory Experience Survey (PES) and The Setting Affordances Survey (SAS) by conducting an evaluation of a recreational program serving youth ages 14 to 22 with SIDD.
The following feasibility and evaluation questions were examined:

Is the amount of time to complete the PES and SAS feasible for use in this context?

Do observers agree on the developmental opportunities, as measured by the SAS, offered within varying activities?

Are different developmental opportunities, as measured by both the PES and SAS, offered in varying activities?

Do participants report having experiences or demonstrating skills, as measured by the PES, that align with the developmental opportunities offered, as measured by the SAS, within differing activities?

**Methods**

The program evaluated offered recreational programs and activities to youth with disabilities ages 14 to 22 in a large city in the northwest region of the United States. Data collected for program evaluation purposes by the community program was used to address the feasibility and evaluation questions. Institutional Review Board (IRB) approval was sought, however upon further review, it was determined IRB approval was not needed since the primary purpose of data reported on here was for program evaluation purposes.

**Population**

Program activities were open to anyone in the geographic area between the ages of 14 and 22 and identified as having a disability. The average age of youth who participated in this program evaluation was 17. All youth who participated in the
program evaluation were reported to fall under the SIDD definition as determined by program staff based on parent reported documentation. Example primary diagnoses of participants included Autism, Down Syndrome and Intellectual Disability.

**Instruments**

The Participatory Experience Survey (PES) is designed to capture the experience of a young person with SIDD while participating in a recreational activity. The PES has three subscales: Environment, Skill Development and Experience, with each scale having 5 yes/no questions, with some follow-up yes/no and open-ended questions. Table 1 shows example questions from each section and a sample two-part question. The PES is given in interview format to avoid the need for respondents to be able to read. Further details regarding conception and development of the survey are reported elsewhere (Liljenquist, Coster, Kramer, Rossetti, in preparation; Liljenquist, Rossetti, Kramer and Coster, in preparation).

The Setting Affordances Survey (SAS) is designed to provide an objective measure of the types of experiences offered during a recreational activity. The SAS has three subscales: Environment, Skill Development and Experience, each with 5 items for a total of 15 items. Each item has three response options: “not at all”, “a little”, and “quite a bit”. Many of the items on the SAS were written to parallel items on the PES and draw comparisons between youth reported experiences (e.g. Was anyone not nice to you today?) and settings observations (e.g. People are respectful towards each other). Other items were developed to expand on information provided by the PES. These items were designed to address content that the young people themselves had difficulty reporting.
For example, the item “opportunity to learn new skill(s)” was included on the SAS but “did you learn something new” was not included on the PES because, during cognitive testing, it proved too confusing to the young people. Additionally, some self-report questions, such as “Did you like being at (activity here) today?” were not appropriate for an objective measurement as the question pertained to an experience the young people would need to evaluate themselves. Table 5 shows example items on both the PES and SAS.

[Insert Table 5 Here]

Procedure

The PES and the SAS were used to evaluate three distinct recreational activities: an art project, a community outing to the zoo, and a track and field sports practice. The art project was part of an after school activity club that met once every other week. Participants did an art project for the first hour of the program and the second hour was spent in free swim. The community outing, a trip to the zoo, gave youth the opportunity to see and learn about different animals. Track and Field practice took place once a week and provided opportunities to learn and practice different events to compete against other teams at meets.

During each activity, two program volunteers assessed the setting and completed the SAS after at least 30 minutes of observing the activity. This time limit was set to allow for an extended evaluation of what the program offered should it be needed. For example, a more structured activity where the setting remains generally the same, such as the art project, may only need to be evaluated for 30 minutes whereas a less structured
activity, such as the zoo outing, may need to be observed longer to evaluate the range of experiences and opportunities afforded during the activity. Time spent observing an activity is best decided upon by the program. No specific training to complete the SAS was given. Rather program volunteers assessed the setting utilizing descriptions offered as part of the response options. Examples of these response options are shown in Table 5.

Ten youth from each activity then completed the PES at the end of the activity. Some youth participated in two or three of the activities being evaluated and thus those youth completed the PES multiple times, once for each activity. The PES was given in short interview to each young person by one of the two program volunteers. The time to complete each survey interview was also documented.

**Data Analysis**

On the SAS, a response of “not at all” was scored as 0, “a little” as 1, and “quite a bit” as 2. The mean for each section (*Environment*, *Experience* and *Skill Development*) was calculated by adding up the scores of the items in each section and dividing by the number of items (5). Inter-rater reliability of each section on the SAS within each setting was then determined using percent agreement. Following standards used to evaluate a measure of similar purpose (King, Batorowicz, Rigby, McMain-Klein, Thompson & Pinto, 2014) agreement greater than 0.75 were considered excellent, 0.60 to 0.74 good, 0.40 to 0.59 moderate and less than 0.40 poor. If the percent agreement was at least 0.60 for each of the three sections, an aggregate score was created by adding the summary scores of a section and dividing by 2 (the number of observer reports). This was done to generate a *consensus* score rather choose one report or the other.
On the PES, a response indicating a positive experience was scored as 2 and a response indicating a negative experience was scored as 0. For example, a *yes* response to “Did you like the people you were with today?” was scored as 2 and a *yes* response to the question “Was anyone mean to you today?” was scored as 0. The mean for each section *(Environment, Experience and Skill Development)* was then calculated by adding the responses in each section and dividing by the number of items (5). A group average for each section was calculated by summing the individual section scores then dividing by the total number of surveys (i.e., 10). Radar plots were constructed to illustrate and compare the responses by the young people regarding each type of recreational activity.

The scoring procedures for the PES and the SAS were constructed so that the responses could be compared. While it was important to make the PES as accessible as possible by having a dichotomous response option, it was preferable to distinguish to what extent a program offered certain opportunities rather than simple presence or absence of the feature. Thus, a negative answer on the PES and “not at all” on the SAS both were scored as 0 and a positive answer on the PES and “yes, definitely” on the SAS were both scored as 2, while a response of “a little” on the SAS was scored as 1. Radar plots were constructed for each setting to examine correspondence between the youth reports of their experiences and the SAS ratings of the opportunities available.

The average time to complete the PES within each setting was calculated to evaluate feasibility of using the PES in a typical recreational program context.
Results

The average time to complete the PES within each setting was 3 minutes, indicating that giving this survey to multiple young people directly following participation in an activity was feasible. Percent agreement was determined to be above 0.60 for each section between the two surveys. Agreement on setting affordances (SAS scores) was also above 0.60: Art Project was 0.73, Zoo was 0.73 and Track was 0.80. These scores indicate that independent observers were able to agree on the affordances within each setting.

Results of SAS analyses indicated that different activities offered varying experiences and opportunities for development. The zoo had a lower environment score than the other two activities. Opportunity for skill development was greater in more structured activities: the zoo had the fewest opportunities for skill development and the art project program had the most. Responses on the PES indicated that youth found all activity environments to be highly supportive. Types of experiences varied somewhat, with respondents to the zoo outing indicating the least positive experiences, whereas the art project and track practice, more structured activities, had more consistently rated positive experiences by respondents. Finally, youth reports were similar for all three activities regarding skill development. However, it is important to note the average response score for each section was 1.2, thus indicating there is room to improve on the number of youth reporting having demonstrated a skill. Table 6 shows these findings.

[Insert Table 6 Here]

In addition to obtaining overall scores for the content areas (environment, skill
development and social), an average response score for each item was calculated. To illustrate differences by items, Figure 3 shows average response scores for each item by content area for each activity. All item scores are reflected in the positive (i.e. score displayed is representative of youth who responded “no” to “Was something too hard today?”).

[Insert Figure 3 Here]

As shown in Figure 3, most youth in all activities reported demonstrating the skills of being independent, making a choice and interacting with others. However, it is also apparent that during all three activities, asking for help and helping others did not occur as readily. Regarding the art project, youth reported asking for help more than helping others, while at the zoo more youth reported having helped others than having asked for help. Additionally, the types of experiences young people reported having differed by activity. The item asking about wanting to talk with other kids is designed to identify if youth felt excluded and felt limited in interacting with their peers. All youth who participated in the art project responded “no” to wanting to talk with another program participant. However, in a less structured activity, such as the zoo, some youth indicated wanting to talk to others yet not being able to.

One final use of the PES and the SAS for program evaluation was to compare the reported experiences of the young people and the opportunities and experiences observed in the setting. To illustrate this method, the aggregate scores for each section on both the PES and SAS were mapped onto a radar plot by activity. Figure 4 shows each activity comparison.
Analysis of the art project activity revealed a discrepancy between youth reported experiences and opportunities afforded for a positive experience within the setting and an even greater discrepancy between skills demonstrated by the youth and opportunities to execute those skills. The zoo also showed differences between youth self-report and observer reported affordances. Youth reported having a less positive experience than what observes reported on the SAS, indicating youth did not or were unable to take full advantage of all opportunities afforded within the setting. Additionally, while at the zoo, youth reported greater environmental supportiveness than what was observed utilizing the SAS. Finally, the comparison for track and field showed similar results for both youth reported experience and observer reported affordances. The only slight difference was between youth reports of a positive experience and setting observed opportunities and affordance for a positive experience, though both reports were still high.

Discussion

The assessment combination of the PES and the SAS proved to be a feasible way to conduct a program evaluation centered on better understanding the experiences and needs of participants. The PES and the SAS allowed the program to examine the types of affordances each setting offered as well as draw comparisons between youth reported experiences and setting affordances. For results of a program evaluation to be meaningful to all stakeholders, it is important they are presented in a way that helps identify patterns within the program evaluation data. Radar plots were used as one method to help illustrate patterns in the data for this group to discuss. This information
provided a way to identify specific issues within the program design, as well as generate targeted interventions. For example, although the Skill Development summary scores were nearly identical for each setting on the PES, by generating a radar plot with each item under Skill Development, we were able to see that differences did exist within each setting when youth were asked about “helping others” and “asking for help”. Identifying these differences by setting can help programs facilitate restructuring activities so that youth are given better support, such as additional staff interaction, to acquire these skills. Furthermore, identifying variations in affordances by setting allows programs to determine which activities may be most appropriate for promoting certain skills, contributing to the service planning of young people with SIDD.

When utilizing the SAS, one important issue was identified: programs must decide whether they want to account for scaffolding provided by staff in their ratings of environmental affordances. To illustrate, the difference between the PES and SAS scores in the reported supportiveness of the environment within the zoo setting was hypothesized to reflect differences in what was considered by the respective respondents. The observers completing the SAS evaluated the affordances of the environment without taking into account the scaffolding provided by the staff, whereas the youth reports of their experience of the environment included the staff support. Thus, the observer rated access to the bathroom in the zoo as moderate (1), however, all youth reported being able to find the bathroom (2). Their response may reflect the fact that the staff directed the youth to the bathroom rather than having the young people navigate the zoo themselves. Thus, when assessing the affordances of a setting, programs must make a decision
regarding which perspective they want to adopt, that is, whether to include staff support as part of the affordance rating or not.

**Limitations**

This paper reports information gathered during a program evaluation and participant demographic information was therefore limited. Additionally, information concerning differences in activity experiences and affordances was limited to a specific program. Before findings about the types of opportunities offered in varying activities can be generalized, it will be important to use the PES and SAS in many different settings with diverse groups of youth with SIDD.

**Conclusion**

Information from the PES and the SAS can provide an important additional source of information for evaluation of recreational programs designed to serve youth with significant intellectual and developmental disabilities. As the field continues to build understanding of participation and its effects, it will be important not only to measure access to opportunities, but also ensure those opportunities are meaningful and of value to the young person who seeks to participate.

**Acknowledgements**

This research was funded by a Dudley Allen Sargent Grant from Sargent College at Boston University
References


Liljenquist, K., Coster, W., Kramer, K., & Rossetti, Z. Development of the Participatory Experience Survey Content Evaluation by Stakeholders and Youth with Intellectual and Developmental Disabilities. *In preparation*


Table 5: PES and SAS Example Items

<table>
<thead>
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<th>The Participatory Experience Survey (PES)</th>
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<tr>
<td><strong>Environment</strong></td>
</tr>
<tr>
<td>Did you like being at __________ today?  Yes/No</td>
</tr>
<tr>
<td>Was it hard to move around at __________ today? Yes/No</td>
</tr>
<tr>
<td><strong>Skill Development</strong></td>
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<tr>
<td>Did you get to pick or choose something today? Yes/No</td>
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<tr>
<td>Did another (kid, teen, student) need help today? Yes/No</td>
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<td><strong>Experience</strong></td>
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<tr>
<td>Was anyone not nice to you today? Yes/No</td>
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<td>Was anything too hard today? Yes/No</td>
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</tr>
<tr>
<td>Free of physical obstacles and barriers</td>
</tr>
<tr>
<td>Not at all – setting never free of physical obstacles and barriers</td>
</tr>
<tr>
<td>A little – setting occasionally free of physical obstacles and barriers</td>
</tr>
<tr>
<td>Quite a bit – setting often free of physical obstacles and barriers</td>
</tr>
<tr>
<td><strong>Skill Development</strong></td>
</tr>
<tr>
<td>Opportunity to make choices</td>
</tr>
<tr>
<td>Not at all – youth never given opportunity to make choices during activity</td>
</tr>
<tr>
<td>A little – youth occasionally given opportunity to make choices during activity</td>
</tr>
<tr>
<td>Quite a bit – youth often given opportunity to make choices throughout most of activity</td>
</tr>
<tr>
<td><strong>Experience</strong></td>
</tr>
<tr>
<td>People are respectful towards each other</td>
</tr>
<tr>
<td>Not at all – people are never respectful towards each other during activity</td>
</tr>
<tr>
<td>A little – people are occasionally respectful towards each other during activity</td>
</tr>
<tr>
<td>Quite a bit – people are often respectful towards each other during activity</td>
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Table 6

*PES and SAS Scores*

**Participatory Experience Survey (PES)**

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<tr>
<td>Art Project</td>
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<td>1.2</td>
<td>1.7</td>
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<tr>
<td>Zoo</td>
<td>1.7</td>
<td>1.2</td>
<td>1.5</td>
</tr>
<tr>
<td>Track</td>
<td>1.8</td>
<td>1.2</td>
<td>1.7</td>
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**Setting Affordances Survey (SAS)**

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<td>Art Project</td>
<td>1.8</td>
<td>1.7</td>
<td>1.9</td>
</tr>
<tr>
<td>Zoo</td>
<td>1.2</td>
<td>1.1</td>
<td>2</td>
</tr>
<tr>
<td>Track</td>
<td>1.8</td>
<td>1.2</td>
<td>1.9</td>
</tr>
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</table>
Figure 3

*Item Scores by Content Area*

**Environment**

- Like Activity
- Too Loud
- Find Bathroom
- Hard to Move
- Everything Needed

**Skill Development**

- Pick or Choose
- Be Independent
- Help Another Kid
- Talk to Kids
- Ask for Help

**Experience**

- Like People
- Too Hard
- Want Talk Kids
- Did Not Like
- Not Nice
Figure 4

Comparison of PES and SAS Scores
Discussion

This dissertation included a series of three studies designed to inform the development of two new measurement tools – The Participatory Experience Survey (PES) and the Setting Affordances Survey (SAS). The PES is a self-report survey for youth with SIDD between the ages of 14 and 22. The PES is designed to capture the experience a young person has when participating in a recreational activity, such as soccer practice or volunteer work. The SAS is an objective instrument designed to evaluate to what extent a setting affords young people a positive experience and opportunities to develop essential skills for adulthood, including autonomy and working together with peers. Both instruments cover three content areas – Environment, Skill Development and Personal/Social Experience.

In Study 1, new methodologies – Photo Self-Representation and the SELFIE Procedure – were applied to identify content area for the PES. Six youth with disabilities selected photos to exemplify “things they liked” and “things they did not like” while participating in four community outings. Item topics from Study 1 findings were synthesized with literature concerning factors influencing the participation of young people with disabilities in a variety of settings to develop an initial set of items. The focus of study 2 was to conduct content evaluation work and cognitive interviewing to ensure the PES was both relevant and accessible to the population for which it was designed. Additionally, an initial feasibility trial was done to determine if the measure was appropriate for use directly following an activity. Issues such as administration time and response burden were addressed. Study 3 further assessed the feasibility of administering
the PES for program evaluation by giving it to youth who participated in three distinct recreational activities – an art project, a trip to the zoo and a track practice. Additionally, the SAS was used to evaluate affordances of each activity setting objectively. Percent agreement on the SAS was determined between two raters evaluating the three activities. Finally, data from the PES and SAS was examined to obtain a description of each activity regarding types of experiences and opportunities to develop skills afforded in each setting.

The work described above completed the first phase of development of two relevant and accessible measures designed to aid in the evaluation of programs serving young people with SIDD. Moving forward, it will be important to apply the PES and SAS to evaluate many different program and activity types. This additional work will provide further evidence of the validity of the instruments as well as enhanced knowledge concerning what types of activities afford particular experiences and opportunities for skill development. The remainder of this discussion will address two topics: 1) Indications and plans for further validation work and 2) Research to further conceptualize and understand setting affordances and the person-environment transaction.

**Further Validation Work**

This dissertation work established a foundation of initial support for the validity of the PES and the SAS. However, several aspects of the validity of both measures still need to be examined. Future work will focus on these tasks. First, it will be important to use the two complementary measures to assess a wider range of activity types across many different demographic populations such as varying socio-economic status and rural
vs. urban locations. This work is crucial for further evaluation of the feasibility and functionality of both measures in many settings for programs with differing structures and goals. Second, use of the PES and SAS in diverse settings by various programs will contribute to continuous refinement of items. While all items on the current measures were drawn from original research or peer-reviewed literature, it is important to continue to evaluate and expand on these items utilizing feedback from programs serving youth in assorted settings. Finally, it is imperative to further evaluate for whom the PES is best suited. For example, all youth in the current studies possessed at least moderate verbal communication abilities. Going forward, it will be important to utilize this instrument with populations who may be minimally verbal or use augmentative communication devices. Additional validation work will offer insight regarding how best to make the PES accessible to a young people with diverse disabilities.

**Setting Affordances and the Person-Environment Exchange**

This dissertation represents an initial effort to determine how to conceptualize and measure how young people with significant disabilities achieve *involvement* in recreational activities. The focus on recreational activities is of specific importance as these activities expose young people to different opportunities to develop skills needed for adult life (Duerden, Taniguchi, & Widmer, 2012; Hoogsteen, & Woodgate, 2010) than are available in school. For youth with disabilities participation in such activities has typically been approached from a rights perspective (i.e. the young person has the right to access these settings) or from a more limited perspective of development, with an emphasis on social skills or physical activity (Murphy, Carbone & Council on Children
with Disabilities, 2008; Orsmond, Kraus, Seltzer, 2004). However, more recent work shows that youth with disabilities derive many of the same benefits as their peers without disabilities who participate in recreational activities (King, Gibson, Mistry, Pinto, Goh, et al., & Thompson, 2013). These benefits not only include development of social skills but autonomy, decision-making and networking with peers and adults (Larson, Hanson, Moneta, 2006; Dworkin, Larson & Hansen, 2003), all skills needed for successful transitions to independent community living (King, Curran, & McPherson, 2012; Hoogsteen, & Woodgate, 2010). Thus, as young people with disabilities continue to have increased access to recreational activities, it will be imperative to better understand the exchanges that occur between young people and the opportunities for development afforded through those activity settings. As such, developing innovative ways to assess these environments will be critical to building this field of knowledge.

While the concept of “ecometrics” is somewhat novel, methodologies put forth within this field to assess settings will be useful to build knowledge regarding promotion of skill development in recreational activity settings. One possible approach is to film young people as they encounter and move through various settings. The video can then be used to promote discussion about the choices the young people made during the activity and their reasons for acting in a particular way. This approach would allow many different perspectives of the same setting to be captured. The information would generate a more holistic picture of how different young people come to understand and make use of the same setting components as affordances for their own participatory experience.
References


Conclusion

With the introduction of the social model of disability, a paradigm shift occurred in which disability was no longer seen as an inherent problem of the individual to be fixed, but rather the result of a mismatch between the individual’s abilities and the demands of the environment. When it relates to physical disabilities and access to locations, this mismatch is more readily solved through modifications to the physical environment (e.g. ramps, elevators etc.). However, as evidenced by the literature in the fifteen years since the introduction of the ICF, conceptualizing and promoting participation is a highly complex undertaking. It has also become evident that understanding and addressing the mismatch between the individual and their environment is particularly complex when factors affecting participation are not as concrete as barriers to physical access. This dissertation sought to conceptualize and develop measures that could be used to study this complex interaction as it pertains to young people with significant intellectual and developmental disabilities in order to foster meaningful participation in recreational activities.
APPENDIX A

The Participatory Experience Survey

Activity done: ________________________________________________

_Built and Sensory Environment_

1) Did you like being at _______________________ today? Yes / No

2) Did you have everything you needed during __________________ today? Yes / No
   _If no:_ What did you need? ______________________________________

3) Was it hard to move around at_______________________ today? Yes / No

4) Were you able to find the bathroom at _________________________ today? Yes / No

5) Was it too loud at________________________________ today? Yes / No

_Skill Development_

6) Did you get to pick or choose something today? Yes / No
   _If yes:_ What did you pick or choose? ________________________________

7) Did you talk with other (kids, teens, students) today? Yes / No

8) Did you need help today? Yes / No
   _If yes:_ Did you ask for help today? Yes / No
   _If yes:_ Did you ask an adult for help? Yes / No
   _If yes:_ Did you ask another (kid, teen student) for help? Yes / No
9) Did another (kid, teen, student) need help today? Yes / No
   If yes: Did you try to help that person? Yes / No

10) Did you do something by yourself today? Yes / No
    If yes: What did you do? ________________________________

**Personal Experience/ Social Interactions**

11) Did you like the people you were with today? Yes / No

12) Was there anyone you wanted to talk to but didn’t? Yes / No
    If yes: Why did you not talk to that person? _______________________

13) Was anyone not nice to you today? Yes / No
    If yes: How was that person not nice to you? _______________________

14) Was there anything you did not like today? Yes / No
    If yes: What did you not like? ________________________________

15) Was anything too hard today? Yes / No
    If yes: What was too hard? ________________________________
APPENDIX B

Setting Affordances Survey
Pilot Survey

**Built and Sensory Environment**

- Comfortable noise level
  - *Not at all* – noise level never comfortable for demands of activity
  - *A little* – noise level occasionally comfortable for demands of activity
  - *Quite a bit* – noise level often comfortable for demands of activity

- Appropriate lighting
  - *Not at all* – lighting never comfortable for demands of activity
  - *A little* – lighting occasionally comfortable for demands of activity
  - *Quite a bit* – lighting often comfortable for demands of activity

- Free of physical obstacles and barriers
  - *Not at all* – setting never free of physical obstacles and barriers
  - *A little* – setting occasionally free of physical obstacles and barriers
  - *Quite a bit* – setting often free of physical obstacles and barriers

- A place where objects and materials for the activity are easily accessible
  - *Not at all* – objects and materials never easily accessible
  - *A little* – objects and materials occasionally easily accessible
  - *Quite a bit* – objects and materials often easily accessible

- Easy to find the bathroom or other places (exit etc.)
  - *Not at all* – bathroom and other places never easy to find
  - *A little* – bathroom and other places occasionally easy to find
  - *Quite a bit* – bathroom and other places often easy to find

**Skill Development**

- Opportunity to learn new skill(s)
  - *Not at all* – no skill introduced during the activity
  - *A little* – new skill introduced with minimal feedback
  - *Quite a bit* – new skill introduced with substantial feedback

- Opportunity to be independent
  - *Not at all* – youth never given opportunity to do activity without help
  - *A little* – youth occasionally given opportunity to do activity without help
  - *Quite a bit* – youth often given opportunity to do activity without help
Opportunity to make choice(s)
- **Not at all** – youth never given opportunity to make choice(s) during activity
- **A little** – youth occasionally given opportunity to make choice(s) during activity
- **Quite a bit** – youth often given opportunity to make choices throughout most of activity

Opportunity to help other people
- **Not at all** – youth never given opportunity to help others during activity
- **A little** – youth occasionally given opportunity help others during activity
- **Quite a bit** – youth often given opportunity to help others throughout most of activity

Opportunity to work together with peers
- **Not at all** – youth never given opportunity to work with peers during activity
- **A little** – youth occasionally given opportunity to work with peers during activity
- **Quite a bit** – youth often given opportunity to work with peers throughout most of activity

**Personal Experience/ Social Interactions**

Opportunity to share ideas, thoughts and feelings with peers
- **Not at all** – youth never given opportunities share ideas, thoughts and feelings with peers during activity
- **A little** – youth occasionally given opportunities to share ideas, thoughts and feelings with peers during activity
- **Quite a bit** – youth often given opportunities to share ideas, thoughts and feelings with peers throughout most of activity

Opportunity to share ideas, thoughts and feelings with adults
- **Not at all** – youth never given opportunities to share ideas, thoughts and feelings with adults during activity
- **A little** – youth occasionally given opportunities to share ideas, thoughts and feelings with adults during activity
- **Quite a bit** – youth often given opportunities to share ideas, thoughts and feelings with adults throughout most of activity

People are helpful towards each other
- **Not at all** – people are never helpful towards each other during activity
- **A little** – people are occasionally helpful towards each other during activity
- **Quite a bit** – people are often helpful towards each other during activity
People are respectful towards each other
  o **Not at all** – people are never respectful towards each other during activity
  o **A little** – people are occasionally respectful towards each other during activity
  o **Quite a bit** – people are often respectful towards each other during activity

Opportunity to participate in activity
  o **Not at all** – not all youth encouraged to participate during activity
  o **A little** – all youth occasionally encouraged to participate during activity
  o **Quite a bit** – all youth often encouraged to participate during activity
BIBLIOGRAPHY


**Practice for Persons with Severe Disabilities**, 36, 23–33. doi: 10.2511/rpsd.36.1-2.23


CURRICULUM VITAE

Kendra Suzanne Liljenquist
1521 29th Ave. Seattle, WA 98122
Phone (206) 595-0642 Email: kendra.liljenquist@gmail.com

Purpose Statement
My long-term career goal is to direct a program or center that emphasizes collaboration with young people facing chronic health conditions and disability, their families and other service providers. Research conducted will focus on ensuring all stakeholders are involved in projects from the conceptualization of an idea through the dissemination of findings to enacting services or policy changes based on those findings. A specific focus will be on developing new and potentially unconventional ways of assessing needs and delivering services among populations that face the most restriction in access to health care and related services and resources both domestic and internationally.

Education

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<tr>
<td>Boston University</td>
<td>Boston, MA</td>
<td>2016</td>
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| PhD in Rehabilitation Sciences
  Emphasis in Activity, Participation and the Environment; Measurement Theory and Development |
| University of San Francisco | San Francisco, CA | 2010 |
| Bachelors of Science in Exercise and Sport Science
  Minor in Neuroscience |

Research Experience

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<tr>
<td>Boston, MA/ Seattle, WA</td>
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| Development of a Self-Report Measure of Participatory Experience, Skill Development and Environmental Influence and a Measure of Environmental Affordances for Youth with Intellectual Disabilities
  - The Participatory Experience Survey and The Setting Affordances Survey
    • Development of partnerships with community based organizations
    • Qualitative analysis of photographic and written material
    • Cognitive interviewing to determine accessibility of self-report component
    • Piloting and analysis to assess measure performance |
Research Specialist  
University of Wisconsin – Madison  
Waisman Center – Lifespan Family Research – Director Jan Greenberg, PhD.  
Quality of life of adults with an autism spectrum disorder  
• Field research – conduct in person interviews with participants living in Massachusetts  
• Collection of saliva sample for analysis  
Boston, MA  
2013 – 2014

Research Assistant/ Facilitator  
Youth and Young Adults Empowerment and Learning Lab (YELL) - Director Jessica Kramer, PhD  
Giving youth a voice: A collaborative evaluation of the effectiveness and feasibility of a novel environmental modification training for youth with disabilities.  
• Intervention implementation  
• Baseline and outcome assessment and measurement  
• Data analysis  
• Manuscript development and formation  
Boston, MA  
2011 – 2012

Research Assistant  
Kids in Context Lab - Director Wendy Coster, PhD  
Development of measures of participation and environment with children with disabilities  
• Data analysis; psychometric properties of PEM-CY instrument, secondary analyses  
• Manuscript development and formulation  
Boston, MA  
2010 – 2014

Research Assistant  
Kids in Context Lab - Director Wendy Coster, PhD  
Computer Adaptive Testing of Children and Youth with Autism  
• Participant recruitment  
• Data collection/ analysis  
• Manuscript development and formulation  
Boston, MA  
2010 – 2014

Grants, Awards and Fellowships

Dean’s Fellowship Award  
Sargent College: Boston University  
2011 – 2015

Dudley Allen Sargent Research Fund  
Sargent College: Boston University  
April, 2015

Received $500 to support dissertation research
Leadership and Education in Neurodevelopmental and Related Disabilities  
(LEND fellowship)  
University of Washington – Center on Human Development and Disability

Dudley Allen Sargent Research Fund  
Sargent College: Boston University  
April, 2012

Received $3,450 to support dissertation research

Leadership and Education in Neurodevelopmental and Related Disabilities  
(LEND fellowship)  
Boston Children’s Hospital/ Harvard/ Institute for Community Inclusion

Peer-Reviewed Publications


**Manuscripts In Progress**

Liljenquist, K., Coster, W., Kramer, K., & Rossetti, Z. [submitted] Using the participatory experience survey and the setting affordances survey in program evaluation for youth with intellectual and developmental disabilities.

Liljenquist, K., Coster, W., Kramer, K., & Rossetti, Z. [submitted] Development of the participatory experience survey: Content evaluation by stakeholders and youth with intellectual and developmental disabilities.


**Book Chapters**

Presentations

Peer-Reviewed Conference Presentations


Peer-Reviewed Poster Presentations


Bedell, G Coster, W., Law, M., Liljenquist, K., Kao, Y.C., Teplicky, R., Anaby, D., & Khetani, M. (April, 2013)
Community participation, supports and barriers of school-age children with and without disabilities. Presented at the 93rd Annual Conference for the American Occupational Therapy Association, San Diego, CA.


Service and Appointments

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