THESIS

UTILITY OF THE PARTICIPATION AND ENVIRONMENT MEASURE FOR CHILDREN

AND YOUTH (PEM-CY) FOR PROGRAMMATIC ASSESSMENT AND INTERVENTION

PLANNING: A MIXED METHODS STUDY

Submitted by

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ABSTRACT

UTILITY OF THE PARTICIPATION AND ENVIRONMENT MEASURE FOR CHILDREN
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The purpose of this mixed methods sequential explanatory study was to examine the utility of the Participation and Environment Measure for Children and Youth (PEM-CY) for use by a community service agency, Adaptive Recreation Opportunities (ARO), for programmatic assessment and service planning to promote children's community participation. The study used two distinct, interactive phases, which included collection and analysis of quantitative data (Phase 1) and sequential collection and analysis of qualitative data (Phase 2) to determine if qualitative results could be used to further explain results from the quantitative phase. The first phase of the study (quan) included gathering PEM-CY data from 23 families who were receiving services from ARO to better understand patterns in children's community participation and environmental supports and barriers to participation in community activities. Results from Phase 1 were summarized into a report and used during Phase 2 (QUAL) to gather the perspectives of 7 ARO staff via semi-structured interviews. Phase two findings suggest that ARO staff perceived the PEM-CY to provide for a more comprehensive and detailed initial assessment process to identify individual and program-level needs. Providers were also able to delineate a core decisional process for leveraging PEM-CY results to develop an intervention plan with families. Future validation with parents and considerations for enabling collaborative and feasible uptake of the decisional process by parents and providers is discussed.

ACKNOWLEDGEMENTS

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Introduction

Importance of Children's Participation as a Health-Related Outcome

Children's participation in activities is an important indicator of their health and well-being (WHO, 2007). For children with and without disabilities, increased participation has been associated with enhanced quality of life (Bedell, Khetani, Cousins, Coster, & Law, 2011; Law, 2002), improved social competence (Khetani, Bedell, Coster, Cousins, & Law, 2012; Mahoney, Cairns & Farmer, 2003), development of self-identity (Bedell, 2012; King et al., 2003) and greater educational successes (Bedell, 2012; Brown & Gordon, 1987; Eccles, Barber, Stone, & Hunt, 2003; King et al., 2003; Simeonsson, Dawn, Huntington, McMillen, & Brent, 2001).

Occupational therapists are committed to building and applying knowledge about the participation of children and youth with disabilities to promote their health and well-being. As guided by the *Occupational Therapy Practice Framework* (2008), occupational therapists promote child health and well-being by optimizing children's participation in occupations that have meaning and relevance to their lives (Roley et al., 2008). Hence, one of the key professional tasks of occupational therapists is to understand what participation restriction means and the child, family, and environmental factors that support or challenge participation for children with diverse backgrounds and abilities (Bedell et al., 2011; Law, 2002; WHO, 2001, 2007). Detailed assessment of children's participation across a range of activities and settings is important so that occupational therapists can identify the specific settings and activities in which a parent needs and/or wants their child to participate and modifiable factors that impact the child's participation. Through inference, or clinical reasoning, occupational therapists, can then assemble this information to diagnose a problem related to participation and partner with clients to develop a therapeutic plan to promote children's participation (Abbott, 1988).

Defining Children's Participation

Despite its importance, there is still no single universal definition of children's participation. The World Health Organization developed the International Classification of Functioning (ICF; WHO, 2001) and the International Classification of Functioning for Children and Youth (ICF-CY; WHO, 2007) to provide a common language with which to classify the functional consequences of having a health-related condition. According to the ICF and ICF-CY (see Figure 1), participation is defined as "involvement in important life situations" (WHO, 2007, p. 129) and contextual factors have either positive ("facilitator") or negative ("barrier") influences on a child's participation (WHO, 2001, 2007).
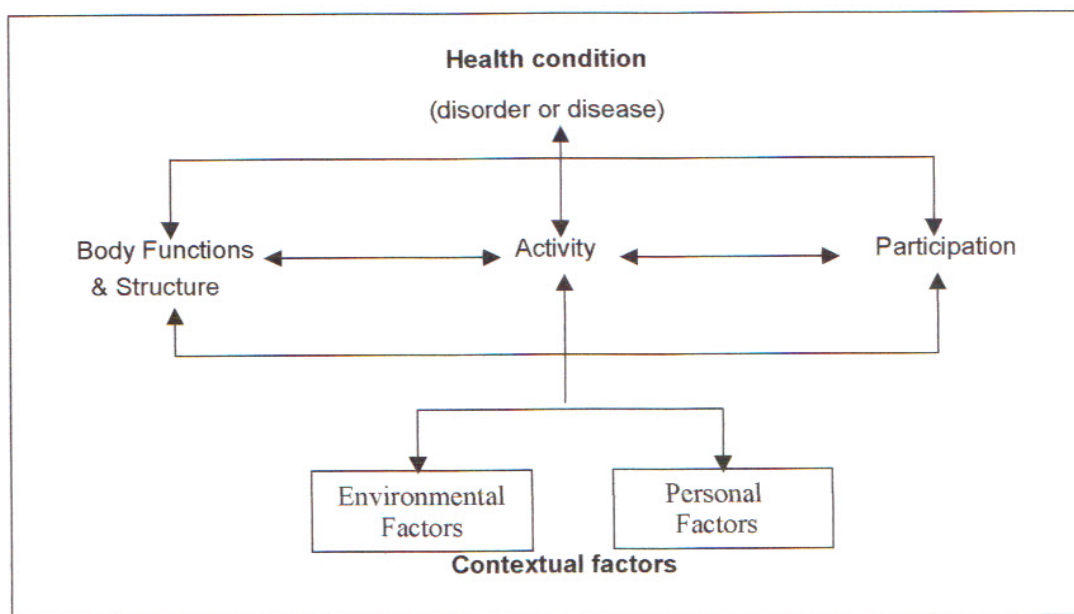
Figure 1: Participation according to the ICF-CY. Reprinted from (WHO, 2007).

The classification of contextual factors in the ICF and ICF-CY was a major step forward in helping researchers conceptualize the role of the environment on childhood disability (Whiteneck, 2006; WHO, 2007). Prior to the ICF and ICF-CY, the Nagi model (Whiteneck, 2006) looked at disability as a condition that was medically based, describing the negative

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consequences that stemmed from the health condition, and failed to recognize contextual factors (child factors and environmental factors) as having a strong influence on the disablement experience. The *International Classification of Impairments, Disabilities, and Handicaps* (ICIDH) model followed the Nagi model and used labels to describe three negative consequences of a health condition, which included impairments to describe the organ level, disability to describe the person level, and handicap to define the societal level. However, environmental factors were not explicitly incorporated into the ICIDH. This limitation of the ICIDH, coupled with increased advocacy by the Union of the Physically Impaired Against Segregation (UPIAS), drew awareness to the need for more systematic and detailed documentation of the physical, social, attitudinal, and institutional dimensions of the environment in contemporary models of disablement (UPIAS, 1976; Whiteneck, 2006). The ICF and ICF-CY models (see Figure 1) were developed to address this need for more detailed documentation (Whiteneck, 2006).

While the ICF and ICF-CY present a conceptual advance in the definition of disability, there is ambiguity with respect to the definition of participation in this model. Activity and participation are depicted as two separate categories. Activity is defined as "the execution of a task or action by an individual" (WHO, 2007, p. 129), whereas participation is defined as "involvement in a life situation" (WHO, 2007, p. 129). However, the ICF-CY combines activity and participation into one section using the same classification codes, thus implying that they are nearly synonymous and perhaps even inseparable (Coster & Khetani, 2008; Whiteneck, 2006; Whiteneck & Dijkers, 2009). Without differentiating activity and participation, the ICF and ICF-CY are limited in guiding the assessment of children's participation (Coster & Khetani, 2008).

Although the ICF and ICF-CY alone cannot conceptually guide assessment of children's participation, they are congruent with other theoretical models (see Table 1) of children's participation that have been developed within and outside of occupational therapy. Similar to the ICF and ICF-CY, a common theme in the two models reviewed to date is the idea that children's participation is affected by the child's strengths and interests and is closely linked to the social, cultural, physical, and temporal features of the environments (Bronfenbrenner, 1977) and the ways that activities themselves are organized to enable children to participate (Brown & Gordon, 1987; Law et al., 1996).

Table 1

Alternative Models Addressing Environmental Influences on Children's Participation

Model/Author	Target Population	Model's Link to Participation
Ecological Systems Model (WHO, 2007, p. 17)	social groups, families, and individuals	Through one's lifespan, individuals create meaning within their environments which include home, family, school, work, community and country
Person-Environment Occupation Model (Bronfenbrenner, 1977)	Individuals	Transaction and interdependence between the person, their specified occupation (or activity), and their participation in the environment in which they live, work and play

Note. Table adapted from Law et al. (1996), p. 12.

This close relationship between children's participation and their environment has been further echoed in the perspectives of parents and children with disabilities. For example, Kramer and Hammel (2011) used observations, semi-structured interviews with narrative elaboration (i.e., pictures were taken during the observation period and children used these pictures to elaborate on their activities during semi-structured interviews), and cognitive interviews with five children with cerebral palsy aged 6 to 17 years to identify 5 themes of occupational performance which included: 1) The environment (people, places, and objects) matching their own physical abilities;

2) their own strengths and limitations; 3) the quality of the activity (pleasurable activities); 4) abilities to practice and problem-solve through activities; and 5) actually doing activities and being able to do them correctly. Similarly, Heah, Case, McGuire, and Law (2007) interviewed eight parents and their children (5 boys and 3 girls, average age of 10.6 years), with autism, cerebral palsy, developmental delay, epilepsy, and spina bifida. Parents in this study described successful participation as dependent on the design of community activities, parent values and preferences, parent vigilance, social and physical supports (time, friends, family, and support workers), and personal barriers including fears of the "gap" (Heah, Case, McGuire, & Law, 2007, p. 44) that develop as children age and their abilities are less likely to match up to their peers.

Child and parent perspectives of participation have provided rich insights into the meaning of children's participation and the personal and environmental factors impacting participation. However, survey methodology may be more appropriate for more feasibly examining child, family, and environmental factors impacting the participation of larger groups of children (Coster & Khetani, 2008). For example, Law et al. (2006) used the Children's Assessment of Participation and Environment (CAPE) to examine predictors of community participation among 427 children who had physical disabilities (cerebral palsy, spina bifida, acquired brain injury, and musculoskeletal impairments) and their families. Differences in participation were related to activity preferences (more children preferred informal activities over formal activities), intensity of participation (participation intensity in formal activities was lower than informal activities), gender (females tended to participate in more social and skill-based activities whereas males tended to participate more frequently and with more intensity in active physical activities), age (children aged 12 years or older had significantly lower participation in informal and recreational activities), and family factors such as lower income,

single-parent households, and lower parent education were strong predictors of children's participation in out-of-school activities (Law et al., 2006; King et al., 2007). Both Law et al. (2006) and King et al. (2007) demonstrated the feasibility of using survey methodology to understand the participation of children with physical disabilities in recreational and leisure activities. However, these studies primarily examined children's participation in out-of-school activities, which comprise a subset of important and meaningful activities in a child's life. Another limitation of these studies is that there was limited opportunity for detailed assessment of environmental supports and barriers to children's participation.

Interviews and surveys have typically been employed to understand patterns and correlates of children's participation restriction. Neither method affords comprehensive, detailed, and feasible assessment of children's participation in all assessment contexts (Bedell & Coster, 2008). Currently available surveys of children's participation are more feasible for programmatic assessment and large-scale research but are also limited in that the information obtained may be setting-specific (e.g., SFA pertains to participation in the school setting) or specific to a subset of relevant activities (e.g., CAPE focuses exclusively on out-of-school activities), designed for use with a specific population (e.g., CASP and CASE were developed specifically for children and youth with acquired brain injury), and take a significant amount of time to administer (e.g., CAPE takes 30-45 minutes to administer which makes it less feasible for use in programmatic assessment or large-scale research).

Development of a Comprehensive Children's Participation and Environment Measure

There is need to document children's participation in ways that are comprehensive and feasible for use in intervention planning, programmatic assessment, and large-scale research. Building upon prior research, the ICF-CY framework, and contemporary theory about children's

participation, Coster and Khetani (2008) proposed a definition of children's participation to inform measure development in this area. They suggested that a child finds meaning through engagement in activities that are specific to a setting (home, school, and community) and goal-directed in terms of being oriented towards "sustenance and physical health, development of skills and capacities, or enjoyment and emotional well-being" (p. 643).

This working definition then guided the development of a new parent-report measure of children's participation and environment, called the Participation and Environment Measure for Children and Youth (PEM-CY; Coster et al. 2011) (see Appendix A). The PEM-CY was designed in response to parent input about the important facets of participation to evaluate (Bedell et al., 2011) and addresses the need in the rehabilitation field for a comprehensive and feasible measure to simultaneously assess children's participation and environment when carrying out large-scale population-level studies (Bedell et al., 2011). The PEM-CY has 25 items focused on participation in various types of activities listed under the broader categories of home (10 items), school (5 items), and community (10 items) settings (Coster et al., 2011). For each activity type listed, the parent identifies how often (from daily to never), how involved (from very to minimally), and whether or not the parent would like to see change (yes or no; if yes, then what type(s) of change is/are desired). Additionally, parents are asked to describe if certain features of the child's environment such as the physical layout make it easier or harder for their child to participate in activities within that setting (Coster et al., 2011). Finally, parents are asked to describe up to three strategies they have developed to promote their child's participation in each setting.

The PEM-CY joins a family of survey measures that have been recently developed to systematically evaluate the participation of children and youth with disabilities including the

Children's Assessment of Participation and Enjoyment (CAPE) (King et al., 2007), School

Function Assessment (SFA) (Coster, Deeney, Haltwanger, & Haley, 1998), Assessment of Life

Habits for Children (LIFE-H) (Noreau, Fougeyrollas, & Tremblay, 2005), Child and Adolescent

Scale of Participation (CASP; Bedell, 2009). In comparison to other measures, the PEM-CY

covers a broader range of activities pertinent to home, school, and community life, includes

assessment of multiple dimensions of participation, includes an assessment of environmental

supports and barriers to participation for the home, school, and community settings, includes

items about strategy use for each setting, and has been validated on a sample of children with and

without disabilities between 5-17 years of age and with a broader range of diagnostic conditions

and functional limitations, including: ability to pay attention, learning new information, reacting

to senses, managing emotions, seeing, hearing, etc. (Coster et al., 2011). In comparison to the

ICF-CY (WHO, 2007) and existing measures of children's environments such as the CHIEF-CP

(Craig Hospital, 2000) and CASE (Bedell, 2009), the PEM-CY also includes assessment of a

broader range of environmental factors, including appraisal of the physical, social, and cognitive

demands of activities as impacting children's participation in the home, school, and community

environments (Coster et al., 2011; Khetani et al., 2012).

Exploring Alternative Uses of the PEM-CY

The PEM-CY was initially designed for use in population-level research studies to

examine similarities and differences in participation across groups of children and youth in

environments that differ in geography, resources, or organization (Coster et al., 2011).

Additional analyses of data from the PEM-CY validation study suggest that the PEM-CY can

detect significant differences between children with and without disabilities for each setting in

terms of their participation frequency, extent of involvement, desire for change, and

environmental supportiveness at both the summary and item-level, even when controlling for age, gender, and/or income (Bedell et al., 2012; Coster et al., 2012; Law et al., 2013). There is still need to further validate the PEM-CY with larger and more diverse samples in terms of socioeconomic status, race/ethnicity, and geographic region.

Providers and parents have also expressed interest in the use of the PEM-CY within an intervention context. It is not well known if a community organization can use the PEM-CY to diagnose participation-related problems that children and youth within their program encounter to help inform program improvement and resource allocation and/or collaborative intervention planning with families. Program directors and service staff may be expected to benefit from use of the PEM-CY to diagnose and treat problems related to participation because they can 1) gather information about the specific activities in which their clients experience participation restriction, 2) identify contextual factors that impact their clients' participation, and 3) gather the expertise of parents who have developed strategies to promote participation in specific settings and activities. However, limited time, resources, and accessibility to tools like the PEM-CY are potential barriers to the uptake of information about children's participation to inform practice.

Purpose

The purpose of this study is to examine the utility of the PEM-CY for use by a community service agency for programmatic assessment and intervention planning to promote children's community participation. To meet this objective, we engaged Adaptive Recreation Opportunities (ARO), a premier agency providing recreation and leisure services to community members with disabilities in Fort Collins, Colorado, a small town community comprised of approximately 143, 986 residents (City of Fort Collins, 2013; 2010 Census). ARO offers healthy and fun experiences for children and youth of all ages and abilities that include specialized programs (e.g. swim, art, sports) and provide individualized participation supports and transition services as needed. We employed a mixed methods explanatory sequential design (Creswell & Clark, 2011) (see Figure 2) because our research team believed that parent responses on the PEM-CY would be necessary but insufficient to fully understand the utility of the PEM-CY within an intervention context. Rather, two data collection phases were needed. Hence, in the first quantitative phase of the study (quan), we proposed to gather and summarize PEM-CY data on a subsample of families who were receiving ARO services to better understand patterns in children's community participation and environmental supports and barriers to children's community participation. In the second qualitative phase of the study (QUAL), PEM-CY results were shared with ARO staff (e.g. supervisors, coordinators, and class leaders) to determine if ARO staff could use this type of information to define therapeutic goals, reallocate resources and supports, and/or reorganize their services to promote children's community participation.
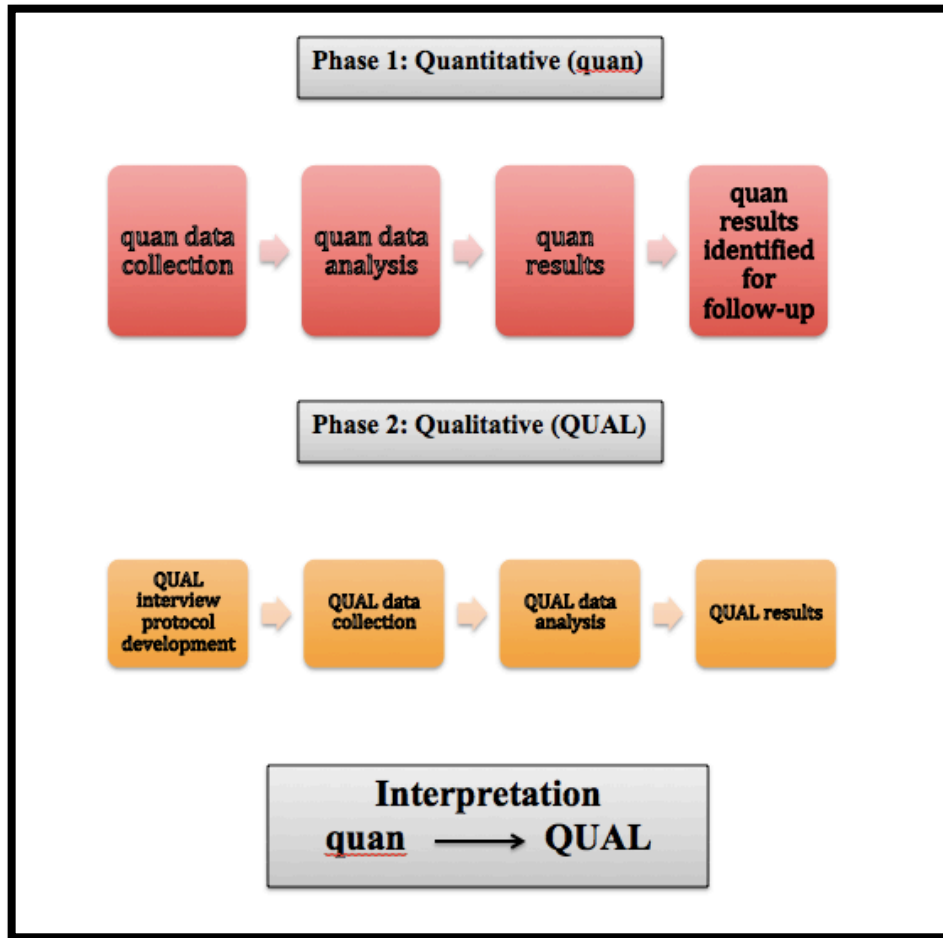
Figure 2: Mixed Methods Sequential Explanatory Design. Adapted from Creswell & Clark, 2011.

For this study, a mixed-methods explanatory sequential approach was employed to answer the following research questions:

Quantitative Research Questions (quan)

1) In what types of community activities do parents most often desire change in their children's participation?

2) Which features of the community environment do most parents perceive to support and challenge children's community participation?

Qualitative Research Questions (QUAL)

1) For children who are enrolled in Adaptive Recreation Opportunities (ARO) services, how can ARO staff use the PEM-CY summary report for programmatic assessment?

2) For children who are enrolled in Adaptive Recreation Opportunities (ARO) services, how can ARO staff use the PEM-CY case report for intervention planning?

Mixed Methods Question (quan > QUAL)

1) What do ARO staff perceive to be the key advantages and disadvantages of PEM-CY relative to their usual process of care?

Method

Study Design

This study involved collaboration between the Colorado State University (CSU)

Occupational Therapy (OT) Department, specifically the Children's Participation and

Environment Research Lab (CPERL; Director: Mary Khetani) and the Center for Community

Partnerships (CCP; Director: Cathy Schelly), and ARO, which is funded by the City of Fort

Collins (Director: Renee Lee). This study was funded by the Department of Occupational

Therapy at Colorado State University.

In the first, quantitative phase of the study (quan), PEM-CY data were collected from a

subsample of ARO clients (parents of children and youth with disabilities) to describe their

children's community participation. Specifically, PEM-CY data were gathered and summarized

to understand those community activities in which parents most often desired change, the types

of changes parents desired, and environmental supports and barriers to community participation.

In the second, qualitative phase of the study (QUAL), PEM-CY data summaries were used

during interviews with ARO staff to obtain their perspectives about how these data could be used

to strengthen their programmatic assessment and intervention planning efforts with clients.

Participants

IRB approval for Phase 1 (quan) was obtained and data collection occurred between

March 2012 and June 2012. To be eligible, participants had to 1) be able to read and write in

English, 2) identify as the parent or guardian of at least one child with a developmental delay or

disability, 3) have a child ages 5 to 17 years old, 4) reside in Fort Collins or the surrounding area,

and 5) have interacted with ARO to support their child's community participation.

An IRB amendment that included Phase 1 results was approved prior to undertaking

Phase 2 (QUAL) data collection. To be eligible, participants had to 1) be able to read and speak

English, and 2) be an active staff member at ARO (e.g., supervisor, coordinator). The ARO

director took the lead for Phase 2 recruitment between October 2012-February 2013.

Phase 1: Quantitative Data Collection and Analysis

Quantitative data collection. For Phase 1 (quan), purposeful sampling methods were

used to obtain the perspectives of a diverse sample according to the child's gender, age,

disability status, and number of functional limitations (Creswell, 2007). Recruitment of families

occurred at ARO special events, outreach activities, weekly classes (including swim and soccer

classes), and through electronic newsletters and mailings (see Figure 3).
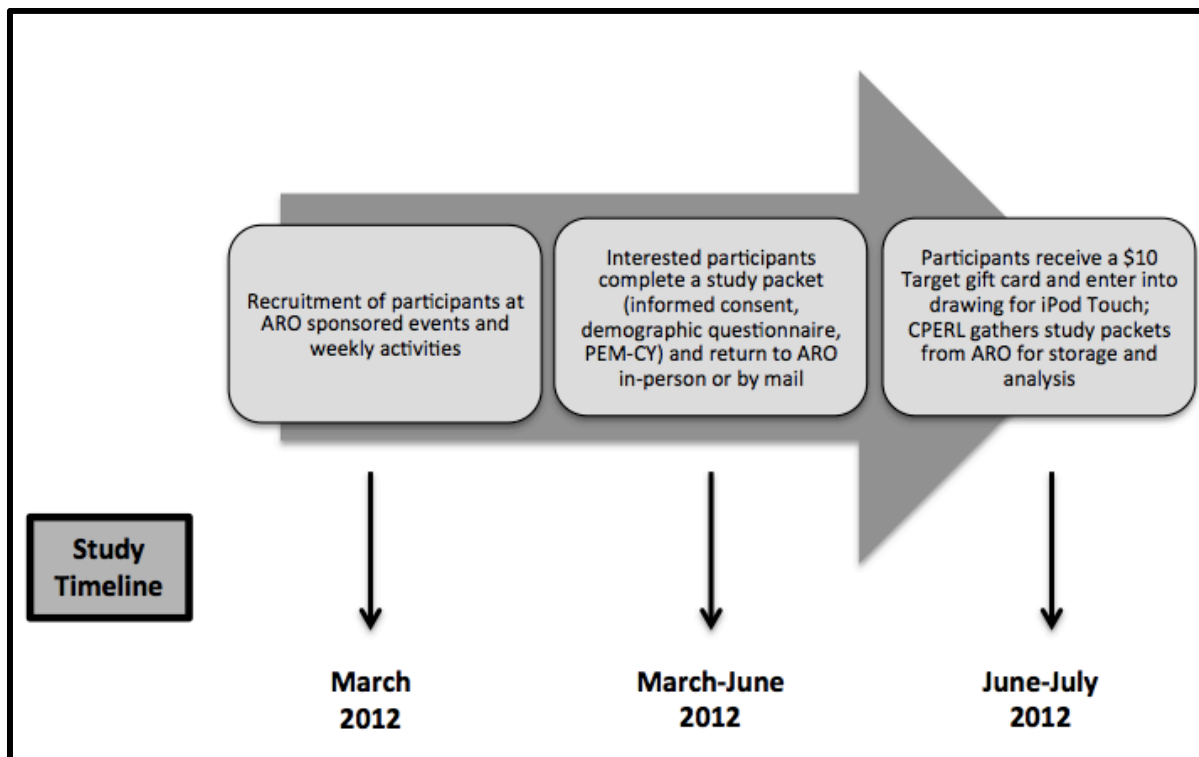
Figure 3. ARO Family Recruitment Process

Upon survey completion, families were provided with a $10 gift card and entered into a

drawing for a chance to win an iPod Touch. The following two surveys were administered to

families for Phase 1 (quan) data collection: 1) Demographic questionnaire, and 2) the

Participation and Environment Measure for Children and Youth (PEM-CY).

  Demographic Questionnaire. The demographic questionnaire took 5 minutes to

complete and consisted of items related to family-related factors (e.g., how long the family has

resided in Fort Collins or the surrounding community, marital status, income level, education

level, number of children in the home); child-related factors (e.g., child's disability, areas of

difficulty (e.g., paying attention, communicating, moving, etc.), use of adaptive equipment); and

3) items related to the participant's affiliation with ARO (e.g., how long they have been involved,

what types of adaptive opportunities they participate in, and their importance and satisfaction in

ARO-sponsored activities).

  Participation and Environment Measure for Children and Youth (PEM-CY). The

PEM-CY is a parent-report survey that gathers information about a child's participation in

activities within the home, school, and community settings and takes 20-30 minutes to complete.

Since ARO provides community-based programs and services, we anticipated that ARO staff

would be most interested in interpreting and applying data from the PEM-CY community section

(see Appendix A). However, per agency request we administered all three sections of the PEM-

CY during Phase 1 data collection. For each section of the PEM-CY, parents are asked to report

on their child's participation frequency (8-point scale from never (0) to daily (7)), extent of

involvement (5-point scale from minimally involved (1) to very involved (5)), and their desire

for their child's participation to change (yes or no; if yes, then what type(s) of change is/are

desired within frequency, involvement, and/or broader varieties). Parents are also asked to

answer 16 questions that describe the features of the environment that support or hinder their

child's participation, such as physical layout (e.g. elevator access), peer relationships, and access to personal or public transportation (e.g. family car or bus, respectively) (Coster et al., 2012).

The PEM-CY has been reported as having moderate to very good internal consistency with participation frequency (0.59 to 0.70), participation involvement (0.72 to 0.83), and Cronbach's alpha for environmental supportiveness (0.83 to 0.91) (Coster et al., 2011; Khetani et al., 2011). Test-retest reliability was shown to be moderate to very good for participation frequency (0.58 to 0.84), percent never participates (0.66 to 0.92), participation involvement (0.69 to 0.76), desire for change (0.76 to 0.89), and environmental supportiveness (0.85 to 0.95) (Coster et al., 2011; Khetani et al., 2011). Moderate to strong associations have also been found between the Craig Hospital Inventory of Environmental Factors (CHIEF-CP) total product score and the PEM-CY environmental supportiveness scores (r = -0.49 to -0.60, $p < 0.05$ to 0.01), PEM-CY total number of supports (r = -0.44, $p < 0.05$), and PEM-CY total number of barriers (r = 0.58, $p < 0.01$) (Khetani et al., under review). These estimates suggest that the PEM-CY could be used as a valid, reliable measure to understand the participation patterns and environmental supports and barriers to participation for children and youth with disabilities.

Quantitative analysis. Phase 1 (quan) data analysis was completed using IBM SPSS 20.0. Descriptive statistics were first used to summarize child and family characteristics for the entire study sample. Since ARO provides programs and services for children with disabilities in community activities, we anticipated that ARO staff would be most interested in interpreting and applying data about children's participation in the community and environmental supports and barriers to community participation. For this reason, I analyzed descriptively only those data obtained from the PEM-CY community section to answer Phase 1 (quan) research questions

about setting and activity-specific patterns in children's community participation and environmental supports and barriers to community participation.

For setting-specific patterns in children's community participation, the following summary scores were calculated: 1) average participation frequency (sum of the average participation frequency scores for each individual child, divided by the number of children in the sample), 2) average level of involvement (sum of the average involvement score for each individual child, divided by the number of children in the sample), 3) percentage of parents who desire change in community activities (sum of 'yes, desire change' responses for each individual child, divided by 10 community items, and multiplied by 100 to generate an individual percent change score, then calculate the average percent across all children sampled), and 4) the total number of environmental supports (total number of environmental ratings with "usually helps" or "usually, yes" responses) and total number of environmental barriers (total number of "usually makes harder" or "usually no" responses).

In order to consider feasible programmatic changes, we expected that ARO staff would also need to know about the activity-specific patterns in children's community participation. For this reason, we calculated the percentage of parents who reported a desire for change in their child's participation for each of ten community activities (sum of % yes, desire change responses for each item, divided by total number of parents sampled). We then rank ordered these responses (from highest to lowest percent) and identified five community activities in which at least two-thirds of the Phase 1 study sample desired change (69.6% or greater). We then generated a PEM-CY detailed summary that included the average frequency of participation, average level of involvement, and total number of environmental supports (usually helps/usually, yes) and barriers (usually makes harder/usually, no) for each of the five activities.

Development of Phase 2 Data Collection and Analysis

PEM-CY data were analyzed to generate an ARO Report that we used to facilitate Phase 2 data collection. This report consisted of PEM-CY aggregate and case reports that guided our interviews with ARO staff to obtain their feedback about the utility of the PEM-CY for programmatic assessment and intervention planning. This ARO Report was organized in two sections: 1) Section 1 included aggregate results of setting-specific and activity-specific patterns to support dialogue about the utility of the PEM-CY for programmatic assessment (see Appendix B), and 2) Section 2 contained 4 case reports to facilitate dialogue with ARO staff about the utility of the PEM-CY for intervention planning (see Appendix C).

ARO Aggregate Report (section 1). The aggregate report included a summary of child and family characteristics for the entire sample (n=23) and a summary of PEM-CY results for the setting-specific and activity-specific participation patterns within 10 community activities. Activity-specific patterns in children's community participation were displayed using several formats including charts, radar plots, and a bar graph for ease of interpretation by ARO staff in Phase 2 data collection (Mallinson & Hammel, 2010).

ARO Case Report (section 2). ARO staff report that they provide services to clientele of all ages, abilities, and participation-related problems. In order to examine the extent to which ARO staff can use the PEM-CY results to meet the most pressing needs of their commonly seen clients, we generated PEM-CY case reports that ARO staff would be likely to encounter if they used this measure in practice for intervention planning. These PEM-CY case reports reflect the most commonly reported functional limitations and areas of participation restriction for the entire study sample. Using the case selection function in SPSS 20.0, we identified four cases that met the following criteria: 1) their parent had reported a desire for change in at least four of the top

five community activities in which all parents who were sampled in Phase 1 had desired change (i.e., community events, organized physical activities, unstructured physical activities, and classes or lessons (not school sponsored)); 2) they were identified as having "big problems" with the top four functional abilities (paying attention or concentrating, remembering information, learning new information or new activities, and communicating with others) for the entire study sample; and 3) had complete data on the variables of interest.

These four cases differed according to the child's age (5-11, 12-17) and gender (male, female), which further enabled me to confirm and disconfirm Phase 2 study results. We made the decision to have case reports differ according to the child's age and gender because prior research has established that children's participation difficulty is associated with the child's age and gender (Jaffe, Humphry, & Case-Smith, 2010; King et al., 2003; Shikako-Thomas et al., 2008).

Phase 2: Qualitative Data Collection and Analysis

Qualitative research design. For Phase 2 (QUAL), ARO staff were administered a Service Provider Questionnaire and an ARO Report that contained both the aggregate and case reports for their reference during the interviews.

Qualitative data collection. The goal of Phase 2 was to obtain ARO staff perspectives about how they might use information from the ARO Report to strengthen their programmatic assessment and intervention planning efforts with clients (Creswell et al., 2011). I piloted the interview guide with a member from my research team to ensure that my initial set of interview questions was clear. Additional interview questions and probes were further developed and refined during three rounds of transcript and interview guide review by my research advisor to increase the likelihood of reaching data saturation with respect to my Phase 2 research questions. This iterative review process resulted in a final interview guide after 5 out of 7 ARO staff had

been interviewed. All existing and new interview data were then recoded to the final interview guide to generate preliminary results (see Appendix D).

Qualitative analysis. All interviews were audiotaped and transcribed verbatim by a member of the research team. To establish trustworthiness for this study, we ensured credibility and dependability of our Phase 2 findings and used self-reflexivity to ensure authenticity (Creswell, 2011; Ivankova, Creswell, & Stick, 2005; Krefting, 1991; Lincoln & Guba, 1985; Patton, 2002).

Credibility. Credibility was ensured through triangulation of data, which occurred by using multiple sources of information including: a) audio recordings and transcripts for each interview, b) field notes to document clarification needed for subsequent interviews and interview protocols, and c) two researchers with different disciplinary backgrounds (occupational therapy, human development) to review and interpret data (Creswell, 2007). Furthermore, Phase 2 results were confirmed and disconfirmed via 30-40 minute follow-up interviews with ARO staff using additional case reports of ARO clientele to determine if staff could apply results to new case reports. This member-checking process was conducted either face-to-face or by telephone and was audiotaped, transcribed, and coded to ensure accuracy of findings. In addition, preliminary results for research question, QUAL 2, were also confirmed or disconfirmed by having 43 occupational therapy graduate students serve as key informants to this study. These graduate students participated in a 30-minute focus group as part of their regularly scheduled class time and were asked to confirm/disconfirm QUAL 2 results when applied to one of the four cases in the ARO Case Report. Key informants were selected because of their expertise and commitment to the topic of children's participation as a key outcome of their domain of practice.

Dependability. Dependability was ensured by having multiple reviewers of data. During the descriptive phase, each interview was coded separately by the primary researcher and a research assistant using analytical deductive coding in which codes were established prior to data analysis. Interviews were then transcribed and analyzed by searching for the presence of those codes. After two interviews, a coding comparison was used to check for inter-coder agreement using NVivo 9.0. We reached inter-coder agreement of 94.28% by the third interview and used the coding report to resolve coding differences. After interview 3, I proceeded to independently code the remaining two interviews and submitted 2 coding reports to my research advisor for feedback on topic development (e.g., match of topics to coded text) and to further refine interview questions in areas where I was not yet reaching data saturation with respect to my main research question(s).

Self-Reflexivity. Self-reflexivity in qualitative research includes an acknowledgement and reflection by the researcher on how their experiences and understandings impact the study, which in turn provides authenticity and trustworthiness to the findings (Creswell, 2007). Prior to graduate study, I was employed for six years as a special education teacher in school districts in Wisconsin and Colorado, in which I worked with young children and adolescents to support inclusion in the school setting. Hence, I already valued inclusion and prioritized having a detailed understanding of supports and barriers to children's school participation.

When working in the schools, however, I came to realize that it was difficult to effectively promote participation in daily school-based activities. Participation is a complex goal and I was not equipped with a systematic and feasible assessment process to diagnose a participation-related problem, which led to many "trial and error" approaches to intervention. Early on in my professional teaching career, I had some opportunity to promote participation

when I co-developed a Peer Partners Program at a high school to help youth with disabilities engage with typically developing peers to promote their social participation in the community setting. Although this program appeared to be effective, I was unable to systematically assess for each student's participation needs or document the outcomes of this intervention in terms of improved participation. Rather, I relied heavily on interviews with families, school staff, and students to obtain baseline information about the participation needs of my clients and to monitor their progress. I grew frustrated by my inability to effectively and efficiently track my students' progress and eventually experienced burnout as a special education teacher. Yet, I did not want to give up on promoting participation and felt that service providers, like myself, needed a more efficient step-by-step process to assess and intervene with children's participation. In this way, the topic of this study fills an unmet need that I had identified in practice.

As a graduate student in occupational therapy at CSU, I have been exposed to new ways of assessing and intervening to promote children's participation through coursework, fieldwork experiences, and my employment in the Assistive Technology Resource Center (ATRC) and the Children's Participation and Environment Research Laboratory (CPERL). My work in the ATRC and CPERL has given me unique opportunities to explore and learn about the development and/or application of more systematic assessment methods to inform environmentally focused interventions. These experiences have further heightened my sensitivity to the power of systematic assessment of environments when intervening to promote participation. In the ATRC, I have individually assessed for the learning needs of students with disabilities and have provided assistive technology that promotes their successful participation in academic life. My experiences in the ATRC made me curious about how technology could support children's participation in the community setting. I was seeing an increase in academic success using

assistive technology with students, and I wondered if assistive technology was being used or if it could be effectively used to promote community participation. This curiosity impacted my approach to data collection in this study, because I repeatedly asked families about their use of technology to support their children's community participation and tended to probe heavily for information about the use of AT by ARO staff during the qualitative phase of study. My tendency to probe about assistive technology was a familiar way for me to engage ARO staff in conversation about how environmental adaptations or supports can be used to promote children's participation. However, my tendency to probe about AT may have influenced my ability to fully examine how ARO staff incorporated information about the broader dimensions of a child's environment into their assessment-to-intervention planning process. In CPERL and for this study, I have been reminded that when using the PEM-CY there is opportunity to assess for a broader range of environmental supports and barriers to children's participation.

Results

Phase 1: Quantitative Findings

  Child and family characteristics. Twenty-three families (33.8% of the organization's Spring 2012 enrollment) completed the PEM-CY (see Appendix E). The majority of respondents were mothers (90.9%) and married (87.0%). More than half of the study sample (children) was male (69.8%) with an average age of 10.7 years (*SD*=3.42, range = 7-17 years). The four most commonly reported functional problems of their children were 1) paying attention or concentrating (60.9%), 2) remembering new information (e.g. directions; 56.5%), 3) learning new information (47.8%), and 4) communicating with others (47.8%) (Appendix F).

  Parental desire for change in child's community participation (quan 1). Approximately 58.3% of families who receive services at ARO desired some type of change in their child's participation in community activities. Setting-specific results are shown in Table 2 below. There were five activities in which at least two thirds of the study sample desired some type of change in their child's community participation. These activities included: community events (73.9%), organized physical activities (73.9%), unstructured physical activities (73.9%), classes or lessons (not school sponsored; 73.9%), and getting together with other children in the community (69.6%). On average, parents reported that their child participated in these five community activities once per month (range = 3.06-3.69) and were somewhat involved (range = 3.06-3.69).

Table 2.

PEM-CY Community Participation and Environment Summary Scores

PEM-CY Summary Scores (n=23 participants)	Community Setting		
	Range	Average	Standard Deviation
Participation Frequency	1.4-3.8	2.5	0.6
Level of Involvement	1.7-4.4	3.5	0.6
Parents who Desire change (%)	30.4-73.9	58.3	26.2
Number of Barriers	0-8	2.6	2.5
Number of Supports	0-9	4.0	2.3

Environmental supports and barriers to children's community participation (quan 2).

Among the 23 families, the most frequently reported supports to children's community

participation were 1) access to personal transportation (65.2%), 2) adequate family time (52.2%),

3) available equipment or supplies (e.g. sports equipment, craft supplies, etc.; 43.5%), and 4)

having enough family money (43.5%). The most frequently reported barriers were the 1) social

demands of an activity (47.8%), 2) cognitive demands of an activity (34.8%), and 3) peer

relationships (26.1%) (see Figure 4).
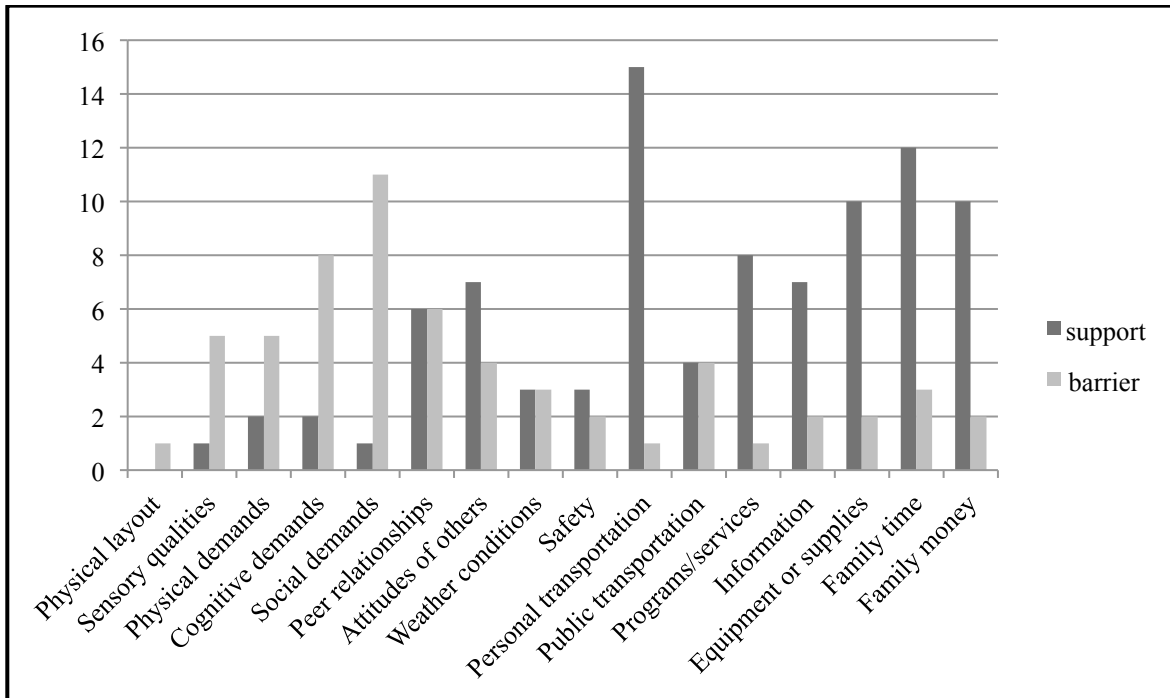
Figure 4. Parent Reported Supports and Barriers to Community Participation

Phase 2: Qualitative Findings

Study findings will be presented for two main qualitative research questions (QUAL 1 and QUAL 2) and the final mixed methods question (quan > QUAL). For each set of findings, I will present key topics that emerged from the data and exemplars that illustrate each topic (Creswell, 2007). All references to ARO staff participants use pseudonyms.

ARO staff characteristics. Seven ARO staff participated in this phase of study. A majority of these participants were female (85.7%) and aged 30 years or more (85.7%). As shown in Table 3 below, participants reported having a minimum of 2 years of direct experience working with children with disabilities, and had been affiliated with ARO for 2 or more years.

Table 3.

ARO Staff Participants

Name *	Job Title	Gender	Years employed at ARO	Years of Experience working with children with disabilities
Rachel	Supervisor	Female	14	> 15
Jaime	Coordinator	Female	5	> 5
Amanda	Coordinator	Female	3	> 5
Brandy	Coordinator	Female	5	> 15
Melissa	Leader	Female	2-5	< 5
Richard	Leader	Male	> 20	> 15
Natalie	Leader	Female	2-5	> 5

Utility of the PEM-CY for programmatic assessment (QUAL 1). The following three

topics best illustrate ARO staff perspectives' about the utility of the PEM-CY for programmatic

assessment: 1) PEM-CY reliably detects observed patterns of parental desire for change, 2)

Detailed information about types of change desired is perceived to be valuable, and 3) Proximal

environmental supports and barriers are perceived to be more relevant for establishing priorities

for programmatic change.

Topic 1. PEM-CY reliably detects observed patterns of parental desire for change.

Three out of seven ARO staff commented on how patterns in parental desire for change closely

aligned with what they observed and heard from parents whose children were actively enrolled in

their programs. For example, Rachel described that similar to what the PEM-CY results suggest,

many of their clients are observed or reported as having difficulty getting together with other

children in the community:

> This [getting together with other children in the community] seems like a big one
> that I've heard....It's like a high percentage, teens with disabilities, their parents
> want them to not only have friends that have disabilities, but they really want
> them to have like peer friends that don't have disabilities as well.

As shown by this exemplar, Rachel believed that PEM-CY results indicating that 69.6% of parents in the study sample would like to see their child's participation change in the activity of "getting together with other children in the community" matched staff perceptions of what they were already observing in ARO programs.

Topic 2. Detailed information about types of change desired is perceived to be valuable. Several ARO staff reported that making program changes is difficult and PEM-CY information needs to be detailed in order to inform decision-making about parent perceptions of need in promoting their child's community participation. Three out of seven ARO staff reported that they needed more detailed information from the parents about the type of change that they desired so that parent expectations of their child could be better understood. For example, Natalie said, "...sometimes the fact that the kids are just getting fresh air, getting some exercise, socializing with other kids is enough. So what do parents want more of?" In contrast, Brandy expressed that she would "…like to know specific changes that parents would like to see and how I could add that to my program" and Jaime emphasized that "it really needs to be specific (be)cause we're working with individuals… and every child that comes to our program has a different set of needs."

Topic 3. Proximal environmental supports and barriers are perceived to be more relevant for establishing priorities for programmatic change. ARO staff were asked about what supports and barriers stood out to them and if and how they would incorporate this information to assess their programs. It was interesting to find that staff repeatedly focused their attention on proximal environmental barriers that were less commonly reported by parents as limiting their child's community participation. The most commonly reported environmental barriers to community participation were both proximal factors (e.g., physical, social, and cognitive activity

demands, sensory qualities) and distal factors (e.g., peer relationships, public transportation).

However, four out of the seven staff focused exclusively on the utility of PEM-CY data related

to proximal factors as potential modifiable factors. For example, Rachel highlights this mismatch

between what parents report and what providers believe their role to be in intervening on the

environment to promote participation and states:

> …those supports and barriers, a lot of it is really the parents personal barriers of
> their time, their money, their transportation…maybe the highest kind of priority
> that they [parents] are trying to figure out right now rather than what we are kind
> of looking at like sensory or physical.

Utility of the PEM-CY for intervention planning (QUAL 2). ARO staff described a

series of decision-making points that resulted in up to five steps that providers could carry out in

order to systematically apply a client's PEM-CY results for intervention planning purposes.

These five steps included: 1) Providers request that parents rank order community activities in

which they desire change in their child's community participation; 2) Providers ask that parents

incorporate their child's preferences and interests to generate a list of activities in which they

both desire change; 3) Providers clarify parent and child expectations for improved participation

in a specific activity; 4) Providers probe to identify a subset of environmental supports that can

be leveraged and barriers that need to be addressed to promote the child's participation in a

specific ranked activity; and 5) Providers and parents co-develop a detailed action plan to

address environmental factors to improve participation towards the parent's goal. We describe

each of these five steps as a separate topic and also show how these five steps come together in

sequence to form a decisional process for carrying out an intervention planning process using the

PEM-CY (see Figure 5).
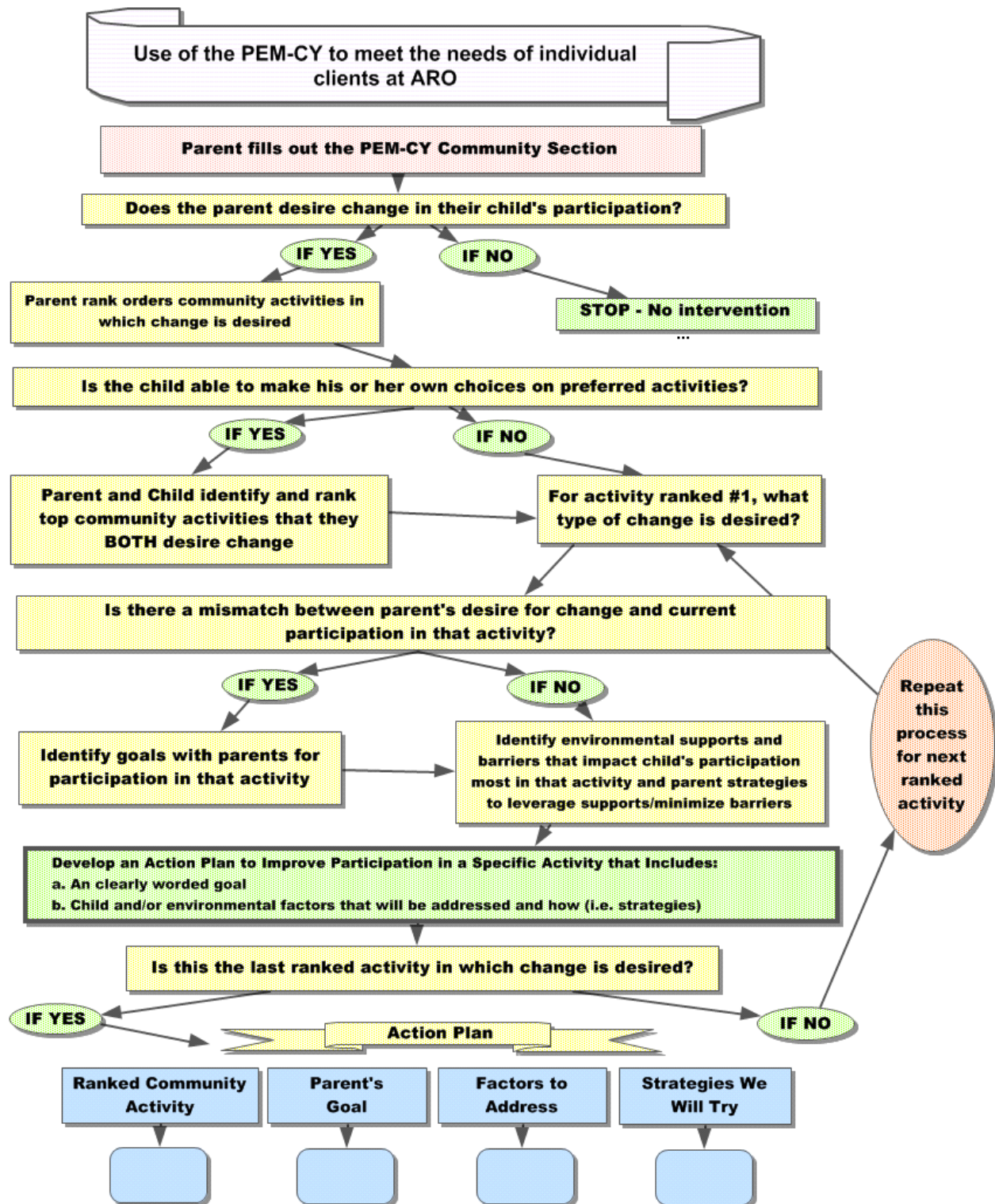
Figure 5: Core Decisional Process for Applying the PEM-CY for Intervention Planning

Topic 1. Parents rank order community activities in which they desire change in their child's community participation. Six out of seven ARO staff shared that they currently think to first ask parents about their activity preferences in order to prioritize which activity(ies) to target for intervention planning purposes. Hence, these staff identified the need to first draw upon the PEM-CY results about parental desire for change to help facilitate this first step in their intervention planning process. For example, Melissa stated that, "Rank ordering is something that you could see would be feasible to help a family figure out where to start in the process of getting some more participation." Rachel added:

> They could rank order based on the child's interests. They could rank order based on what's feasible and what fits into their schedules. They may choose what their therapists want, so related to a service goal. Or they might prioritize a certain activity, like getting kids moving more...

Several ARO staff also felt that it would be feasible to ask a parent to prioritize those activities in which they reportedly desired change in their child's participation. Rachel further shared that she believed if "they [parents] had to order [activities], if they had to think about what's really important, then it may help them" to figure out what directions to go with getting their child engaged in a particular community activity.

Topic 2. Parents incorporate their child's preferences and interests to generate a list of activities in which they both desire change. Six ARO staff indicated the importance of gathering both parent and child perspectives when providing client-centered interventions. Though the PEM-CY provides important information about the parent's perspective of participation-related problems, this information was perceived to be insufficient because the child's preferences and interests are not explicitly captured. Natalie stated, "I think it's always important regardless of what age they are, just to try and find out what they want to do and make them part of it rather than making it seem like you are just signing them up for stuff and making them do it." Staff did

not identify a specific age or skill-based cut-off for determining whether the child should be engaged in the intervention planning process. Rather, they recommended that the child be included if he or she was able to provide that information and that this might be more likely as children age. As Richard expressed:

> What is the interest of the child? Do they like overnight trips? Maybe he has like separation anxiety if he is away from an known, comfortable location... but as they get older, it would be nice to know kind of what the participant's interest is.

ARO Staff suggested that one way of incorporating the child's perspective was to have the parent consider the child's preferences and interests when generating a rank order of activities that they wanted to work on (most to least). For example, Natalie suggested that it would be good to "narrow it down to like three [activities] to start with." She suggested that older youth and young adults may be "able to make their own decisions and tell you what they want, so I would just ask them directly." Brandy reported that parents and ARO staff could promote a child's participation when she shared:

> Definitely rank ordering is something that is feasible to help a family figure out where to start in the process of getting some more participation ... I think that any kind of intervention should be client-centered, so I think involving the child in the decision is important because they're more likely to comply than if it's just he parents saying you're going to do this.

Topic 3. Provider clarifies parent and child expectations for improved participation in a specific activity. Five out of seven staff reported that they often perceived the need to clarify the parent's goals for their child and the child's goals for increasing participation in a specific ranked activity. This perceived need to clarify parental and child goals consistently arose from questions that staff had as they tried to assemble the three types of information from parents about their child's participation – 1) how frequently their child participated in the activity, 2)

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how involved their child was when participating in the activity, and 3) their desire for change in

their child's participation for that activity. For instance, Brandy said:

> … it was important to know...the short term goal and is that what you want to change…I would just ask more specifically, what exactly are specifics? Do you want him involved in seven days a week? Or for one hour, seven days a week and he's involved the entire hour...because if he's already involved and participating, then it's like how much more do you want?

Two of these providers, Melissa and Richard, paid particular attention clarifying client goals

when they identified a mismatch between the parents' desire for change in the child's

participation and the child's current participation (e.g., parent wants child to do an activity more

often, but child is reported as currently participating in that activity on a weekly basis). Melissa

and Richard provided their suggestions for how to obtain this type of information from the parent

about their goals for their child. For instance, Richard suggested the following:

> So maybe for like more often, why would you want to do this activity more often? Why do you feel your child needs this more often? Is it something they are missing out on? Is it a direction that you want to sort of drive your kids towards, like I want my kid to do be doing more creativity, artistic things? Yeah, it would be nice to sort of know why they wanted to push their child in a certain direction.

Similarly, Melissa said that she would inquire more about this type of mismatch and provided

some suggestions for how to ask parents for this type of clarification when she said:

> Well, it looks like he's doing this pretty frequently, but it sounds like you still
> have some concerns. What are your concerns? What do you think could be more
> optimal than what he's doing now? Do you want him to do it more frequently?
> Do you want him to ...interact with other participants more? ... like, okay, he's on
> the soccer team, what are you seeing that's not working right? Is he isolated from
> other kids? Does he not get to play frequently enough?

> As shown throughout the exemplars, ARO staff indicated that having specific

information from parents about their child's current frequency and involvement in

community activities was useful so that parent's goals for their child could be clarified.

By identifying the mismatches and then inquiring with parents for further explanation, ARO staff felt they could better set meaningful goals with families.

   Topic 4: Providers probe to identify a subset of environmental supports that can be leveraged and barriers that need to be addressed to promote the child's participation in a specific ranked activity. All seven ARO staff participants described the need to identify the subset of environmental supports, barriers and parent strategies that were impacting the child's participation in each ranked activity. Staff consistently disclosed that they would like to obtain specific examples from families because with more detailed information about the child's environment they could identify more concrete ways to intervene. Brandy expressed that it was important to identify relevant supports to participation in an activity, or "finding out what works so that you can maybe apply it to other areas" and that "any extra tips that a parent can give is huge." Melissa emphasized the need to explicitly probe for environmental barriers by asking, "what are you seeing that's not working right? …Is he isolated from the other kids? Does he not get to play frequently enough?" These examples illustrate that staff want to know more details about how to intervene and adapt the environment to support the child's needs.

   Topic 5: Developing a detailed action plan specific to family goals. Three ARO staff indicated that the decision-making tree would allow them to collaborate with a family to develop a detailed action plan that was specific to a child's participation goals. For example, Rachel felt that through this process she could determine if "there's a better way to offer that service so that parents will know we can find out their needs...we may need to provide a time where they can come in and look through their goals." This collaboration to develop a detailed action plan was further reiterated by Natalie when she said, "Any extra tips that parents can give is huge" and by Melissa who shared, "The families that get really involved often have pretty good knowledge and

are pretty good advocates for their kids...so that could lead to more specifics." The emphasis on collaboration with families to develop a detailed action plan that targets the family goals was evident in the ARO staff responses.

Advantages of the PEM-CY Relative to Standard Care (quan > QUAL). ARO staff reported that the PEM-CY had advantages relative to their current approach to client care and so would consider adding it to their current approach. In their current approach to client care, ARO families complete participant information forms in which they list information about their child (e.g. history, disability, medical information, likes and dislikes, etc.) and then they are further interviewed by ARO staff about their child's needs, class interests, accommodations, and/or environmental adaptations. Evaluations are also completed at final class sessions to further assess client satisfaction with their program offerings.

ARO staff expressed that they would consider the PEM-CY for use in combination with their current approach to identify the participation-related needs of their clients. Several staff reported that the PEM-CY aggregate report could provide the program with a detailed understanding of their clients' needs, and the PEM-CY case report, when combined with the decisional process, was easy to follow and would allow for a more comprehensive and detailed initial assessment process to identify individual needs. In fact, five out of seven ARO staff indicated that the PEM-CY could be a good starting point for consistently gathering comprehensive information from a parent for service planning. According to Rachel, the PEM-CY provides "a more well-rounded way of getting a better answer rather than having them list off a bunch of things" and that "it would be something that could easily roll into some of our first interactions with families." She provided a specific example of how it could be used by saying:

> ...maybe a new family...what would be their baseline or where they're starting
> from? Then you could start with some activities, view their progress over time,

and re-do their profile at the end of the year to what their progress has been and what their new goals are.

It is important to note that ARO staff consistently acknowledged that the PEM-CY report and decisional process were both needed to obtain relevant information to help the staff progress from assessment results to a focused intervention plan with individual clients. Melissa said:

I think it would help to get started, but then I think there would be more specifics I would want to talk to the family about. Like for instance, you know like the classes or less...so what classes and lesson is he involved in? ... and more specifics to each of the different types. And from there being able to make recommendations, if he really liked that, well maybe you could expand that interest by this program or that program...

Given the additional information that needs to be gathered, several staff acknowledged the associated costs in terms of additional staff time. In response, Melissa proposed that a portion of the PEM-CY (e.g., community section) could be administered to save time and money:

We could definitely use it as an option and say you know this gives us really good information… I think just looking at all the categories, even if a parent doesn't want to go through the process of filling out the whole thing, we can use it to kind of direct our assessment interview.

Alternatively, several key informants indicated that the decisional process would help to make it feasible for a service provider to efficiently intervene with a client using the PEM-CY. Jackie, for example, expressed that the process forces the service provider to "see the problem" and figure out tangible ways to intervene. For this reason, another key informant, Jordan, reported that the process of developing an intervention plan the decision making tree was "pretty intuitive." and Colleen shared that "I bet once you do it a few times, it becomes 'first nature' in how you intervene."

While most staff discussed the advantages of the PEM-CY relative to their usual process of care with individual clients, Rachel added that the PEM-CY results could be summarized for a group of clients to drive program changes and track client progress over time. She states, "What our activity management wants is to drive our services towards the needs of the people. We need to try to figure out how to get that and then go from there."

Discussion

The importance of children's participation in community activities to promote their health and well-being (WHO, 2007) and skill development (King et al., 2003; Law et al., 2007) is well established. Children with disabilities experience greater participation restriction than their peers without disabilities as they age (Barnett, 2012; King et al., 2013; Law et al, 2007; Verschuren, Wiart & Ketelaar, 2013), so meaningful community participation should be a major goal in service delivery to minimize health-related disparities (King et al., 2003). Service providers have a unique opportunity to assess and intervene on participation as an outcome, but their ability to do so effectively depends on 1) the availability of quality measures that reflect clearly defined constructs for each outcome of interest (Coster & Khetani, 2008), and 2) their ability to interpret and apply assessment results to formulate a relevant intervention plan to promote this type of outcome. Occupational therapists can play a lead role to gather and apply information about children's participation because it is one of their key professional tasks that defines their professional jurisdiction (Abbott, 1988).

For the outcome of children's participation, service providers have less often assessed for environmental influences that have been shown to be associated with participation restriction (Anaby et al., 2013; Khetani et al., 2012; Law et al., 2007; Mihaylov et al., 2004). However, environments may be as amenable to change as the child's performance capacities (Darrah et al., 2011; Law et al., 2011). This is the first study to investigate the utility of a newly developed and validated assessment of children's participation and environment, the PEM-CY, for use within an intervention context. By using a mixed-methods approach (see Appendix G), we revealed several ways that service providers could consistently interpret and apply PEM-CY results (quan) to define goals and organize an action plan when working with families. We also gained important

insights into the utility of the PEM-CY to support reallocation of programmatic resources to optimize children's community participation (QUAL).

Utility of the PEM-CY for Intervention Planning. We identified a core set of decision-making points to help a service provider assemble and further build on PEM-CY results to generate an action plan in partnership with their clients. One of the clearest decision-making points relates to when and how providers should integrate both parent and child perspectives when planning an intervention to promote the child's participation. Since the purpose of assessment guides the choice of which respondent to gather information, it is not surprising that participating staff recognized the need for parent and child perspectives to be engaged early on in the intervention planning process. This finding is congruent with current standards of best practice that emphasize collaborative approaches with multiple key stakeholders who are invested in promoting the child's participation (Adolfsson, 2012; Khetani et al., 2012; King, Teplicky, King, & Rosenbaum, 2004; McIntyre, Novak, & Cusick, 2010) and is also consistent with prior studies describing the importance of the child's perspective about meaningful participation for intervention planning (Kramer & Hammel, 2011; McConachie, Colver, Forsyth, Jarvis, & Parkinson, 2005). According to Mortier and colleagues (2011), children with disabilities in "many situations know very precisely what they need and what they do not need, what they like and what they do not like and why" (Mortier et al., 2011, p.217).

Despite its importance, prior studies have established that differences in parent and child perspectives about the child's participation and quality of life increase as children mature (Skivenes &Strandbu, 2006), and that there are challenges in how to best elicit and integrate the perspectives of children with and without disabilities with the perspectives of parents (Khetani et al., 2012; Skivenes & Strandbu, 2006). Staff in this study suggested several ways for capturing

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and integrating the child's perspective with parents' perspectives depending on their age and abilities. Their suggestions included conducting interviews with the child separately, asking the parent to think about the child's preferences and interests when they rank order, or having the child independently rank order those activities in which they desire change and then identifying matches in parent and child rankings. Some of these recommended approaches have been used in prior studies involving children and youth with disabilities. These include 1) semi-structured interviews with children and youth with disabilities (Harding et al., 2009); 2) youth self-report versions of participation measures such as the CAPE (Children's Assessment of Participation and Enjoyment) (Mortier, Desimpel, Schauwer, & Van Hove, 2011; Majnemer et al., 2008) or CASP (Child and Adolescent Scale of Participation) (Bedell, 2011); and 3) photographic methods (Kramer & Hammel, 2011; Obrusnikova & Cavalier, 2011; Marley, 2012). Future studies are needed to examine parent and provider perceptions of these options to determine which option(s) would most effectively and efficiently engage the child in the collaborative decision-making process of developing an intervention plan based on PEM-CY baseline results. Future work is also needed to further explicate the process of consensus-building around differences in perceived need that is likely to occur when multiple perspectives are gathered.

Another key decision-making point revolved around reconciling the fairly frequent mismatch between the types of change desired by the parent and what the child was already doing. For example, ARO staff were unsure about how to proceed when they encountered a parent who had indicated wanting more frequency and involvement in classes or lessons (not school sponsored) (e.g. music, art, languages, computers), yet the child was reported to be participating in that type of activity daily and being very involved. In these instances, we found it interesting that ARO staff described how this mismatch prompted them to clarify parental

expectations of the child's participation as a way of tapping into the meaning of participation in a specific type of activity. Staff perspectives about the need to clarify the meaning of a child's participation in an activity is similar to how occupational therapists are called to assess for the fit between an individual's occupational patterns and their desired occupations in order to understand how to promote lifestyle balance, satisfaction, and well-being (King, 2004; Matuska & Christiansen, 2011; Park & Folkman, 1997; Stein, Foran, & Cermak, 2011). Given how often staff identified these mismatches in the PEM-CY case reports, it is possible that providers are aware that parental expectations of their child's engagement in activities change over time and need to be reframed due to individual differences, life situations and experiences, cultural and social factors, or environmental factors (King, 2004; Park & Folkman, 1997). Continual reevaluation and clarification of parent and child occupational goals should be considered to ensure meaningful participation in community activities.

Intervention planning through family centered care has been shown to support a child's development (King, 2004; Majnemer, 2012). Common methods that are used to clarify client preferences include observations, dialogue, and interview (King, 2004). These methods allow service providers to build therapeutic rapport during the intervention-planning phase and further support family centered services (King, 2004; Majnemer, 2012). Research has shown that individuals may experience adversity with participation and through a detailed understanding of client preferences, an individual may be able to develop resiliency skills that can be used to strengthen intervention planning (King, Brown, & Smith, 2003). Examination of positive protective factors that may reduce child adversity (e.g. positive self-esteem) and negative risk factors (e.g. socioeconomic disadvantage, negative parental relationships, etc.) can be used to understand a child's resiliency to cope with risk factors in new activities (King, Brown, & Smith,

2003; Case-Smith, 2010).   Further research should use holistic strategies to collaborate with families on systematic assessment techniques that gather information about a child's preferences, protective factors, and risk factors that relate to meaningful activities with family centered intervention planning.

PEM-CY for Programmatic Assessment. ARO staff in this study had fewer insights about how to apply PEM-CY aggregate results to inform programmatic changes. Our Phase 1 (quan) response rate was lower than expected (33.8%) which may have been insufficient data for use by ARO staff in this decision-making context. Alternatively, ARO staff may have been less familiar with how to interpret and apply information about the broader range of environmental supports and barriers to children's community participation as displayed on the PEM-CY aggregate report. It is possible that the information about environmental supports and barriers extended beyond the proximal supports and barriers that ARO staff had been more accustomed to assessing for in their current process of program assessment. Despite their familiarity with these factors, prior studies have shown that children's participation can be affected by a variety of factors in a child's environment beyond just proximal environmental factors, such as peer relationships, lack of support from staff and service providers, and environmental restrictions such as accessible transportation, policies, lack of programs or services, or program costs (Anaby et al., 2013; King et al., 2003; Law et al., 2007). Law and colleagues (2007) suggest that service providers cannot always change child-related factors but they can enhance participation by making changes to the environment. Hence, additional knowledge about the effect of the broader environment on the child can support the design of environmentally-focused interventions to improve the participation of multiple clients. Some modifiable environmental supports may include social support from family and friends, geographic location, and parent involvement and support

(Anaby et al., 2012; Khetani et al., 2012). Similarly, modifiable barriers may include negative

attitudes, accessibility to the physical environment (e.g. adapted ramps, aids, public

transportation etc.), services and policies, and lack of support from staff and service providers

(Anaby et al., 2012). For this reason, the specificity of the PEM-CY could be leveraged to help

ARO staff identify environmental factors warranting intervention.

Advantages and Disadvantages of PEM-CY. Taken together, we found that ARO staff

perceived the PEM-CY to afford "a more well-rounded way" to consistently evaluate the

participation needs of their clients (Rachel, personal communication, March 19, 2013) and that

PEM-CY case results could be built on to support systematic and consistent intervention

planning with individual families. To mitigate their concerns regarding feasibility of using the

PEM-CY in both decision-making contexts, future work should explore the use of accessible

mainstream mobile technology (e.g. iPhone, tablets, etc.) for making the PEM-CY accessible for

use in intervention planning and by a program or agency for broader assessment of the

participation needs of a group of clients. Studies have shown that technological advances with

software and hardware development can be prominent components of change and allow for more

accessible interaction for those with and without disabilities (Wilson, 2013). Furthermore,

accessible mobile technology has the potential to provide greater "mobile" access for children

with disabilities, their families, and the greater community (Ellis & Kent, 2011). The core

decisional process may be programmed into a new mobile health app that empowers parents to

independently complete the PEM-CY and actively collaborate with their provider to interpret and

apply their PEM-CY results for action planning purposes. Mobile technology with the PEM-CY

could enable a parent to actively plan and manage their child's activity participation in ways that

best integrate into their lifestyles. The decisional process should be validated with parents of

youth with disabilities to ensure that the process is perceived by parents to be accessible, feasible, and responsive to their needs to manage their efforts in promoting their child's participation.

Results of this study should be considered in light of several limitations, some of which are opportunities for future study. First, all analyses and results for this study pertain solely to data from the PEM-CY community section. We made this decision because ARO provides programs and services to promote children's community participation and so we anticipated that they would be most interested in interpreting and applying this subset of data to inform their current approach to practice. Future studies should confirm and disconfirm the transferability of our findings by having providers apply the decisional process to PEM-CY data from the home and school sections. Another study limitation is that our main study results reflect the providers' perspective about how to interpret and apply PEM-CY data. Providers are one key stakeholder in the intervention planning process, but the decisional process employed has to be clear and accessible to parents as well in order to support collaborative intervention planning in accordance with current standards for client-centered practice (Khetani et al., 2012; King et al., 2004). Hence, future studies are needed to gather the parent perspective directly in order to ascertain if the PEM-CY decisional process is viable for use in intervention planning when carried out using a client-centered practice approach. These studies may benefit from including multiple parental perspectives (mother, father) to examine differences according to respondent type (Thompson, Hiebert-Murphy, & Trute, 2013; Jaffe et al., 2010).

Other study limitations include our use of convenience sampling methods for both phases of the study that may have limited the transferability of our results. Since ARO staff took lead with participant recruitment for both phases of this study, we likely obtained the perspectives of more current, active, and satisfied clients and ARO staff. Finally, despite our attempts to confirm

our study results using a diverse set of cases according to child's age and gender, all study subjects resided in a non-urban community with direct access to services to promote their child's community participation. We cannot yet determine whether our study results would have differed according to the geographic locale of the study sample but is worth further exploration given differences in access to information, time, and money that may impact community participation (Anaby et al., 2012; Jaffe et al., 2010). Lastly, we mistakenly presented the ARO Aggregate Report (section 1) based on PEM-CY data for a subsample of study subjects (n=18). Fortunately, we found only minor percent changes in Phase 1 results for environmental supports and barriers after repeating our descriptive analyses using the full study sample (e.g., 65.2% of the full study sample and 66.7% of the subsample reported on personal transportation as the top-ranked support to their child's participation).

Conclusion

Despite its limitations, this mixed-methods study contributes to a growing body of literature about how to assess and intervene directly on participation as outcome for children with disabilities (Coster et al., 2011; Darrah et al., 2011; Palisano et al., 2012). In this study, we have built new knowledge about the utility of the PEM-CY for intervention planning and programmatic assessment within a local community organization serving non-urban families of children with disabilities. We discovered that ARO staff were able to use a core decisional process to interpret summarized PEM-CY data from their clients and then create individualized intervention plans to support their client's community participation and environment. We are now continuing to validate the decisional process with parents directly and compare it to their current approach to developing a meaningful action plan for their child. With these additional results, we will have sufficient knowledge to determine if there is a core decisional process that is meaningful to program through mobile technology for use by providers and parents in a clinical context.

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Appendix A: Community Section of the PEM-CY

Participation and Environment Measure – Children and Youth©

Wendy Coster, Mary Law, Gary Bedell

SURVEY INSTRUCTIONS

Participation refers to a child's involvement in important everyday activities at home, in school, and in the community. The meaning of participation includes both <u>how often</u> a child does activities AND <u>how involved</u> he or she is when doing these activities.

The survey asks a set of questions about your child's participation in 25 types of activities that take place in three environments: home, school, and community. We give a few examples to illustrate each type of activity. However, you should think about <u>all</u> of the activities that belong to the category when answering these questions.

For each type of activity we ask:

1. **how often** your child has participated <u>over the last 4 months</u>
2. **how involved** your child is when participating in <u>1 or 2</u> activities of this type that he or she does most often
3. whether or not you would like your child's participation **to change**, and if so, how you would like it to change

IMPORTANT

This survey is not asking about your child's level of independence when participating in activities. "Involvement" refers to how engaged your child is in an activity, using whatever supports, assistance, adaptations, or methods he or she routinely uses or has available.

When selecting your response, please think about your child's level of attention, concentration, emotional engagement, or satisfaction (using whatever supports or assistance are usually available).

> **<u>Very involved</u> =** In general, child is engaged throughout the activity. He or she shows a lot of initiative and/or interest in and attention to what he or she and others are doing during the activity.

> **<u>Somewhat involved</u> =** Child is engaged in the activity some of the time. He or she shows some initiative and/or interest in and attention to what he or she and others are doing during the activity.

> **<u>Minimally involved</u> =** Child is engaged in a small part of the activity. He or she only shows a little initiative and/or interest in and attention to what he or she and others are doing during the activity.

If there are things that help or make your child's participation more difficult, such as equipment or support from others, you can tell us about their impact in the home environment, school environment, and community environment sections of this survey.

COMMUNITY Participation

A) Typically, <u>how often</u> does your child participate in <u>1 or more activities</u> of this type?

CHECK ONE RESPONSE ☑

B) Think about <u>1 or 2 activities of this type</u> that your child participates in most often. Typically, <u>how involved</u> is your child when doing these activities?

CHECK ONE RESPONSE ☑

C) Would you like your child's participation <u>to change</u> in this type of activity?

IF YES, CHECK ALL THAT APPLY ☑

	Daily	Few times a week	Once a week	Few times a month	Once a month	Few times in last four months	Once in last four months	Never (Skip to Question C)	5 Very involved	4	3 Somewhat involved	2	1 Minimally involved	No change desired	Yes, do more often	Yes, do less often	Yes, be more involved	Yes, be less involved	Yes, be involved in a broader variety of activities
1) Neighborhood outings (e.g., shopping at the store/mall, going to a movie, eating out at a restaurant, visiting the local library/bookstore)																			
2) Community events (e.g., attending a play, concert, sports game, parade)																			
3) Organized physical activities (e.g., sports teams or classes such as baseball, hockey, martial arts, dance, horseback riding, swimming, gymnastics)																			
4) Unstructured physical activities (e.g., nature trail walks, bicycle riding, rollerblading, skateboarding, playing hide-and-seek or chase, playing pick-up games like basketball)																			
5) Classes and lessons (not school-sponsored) (e.g., music, art, languages, computers)																			

COMMUNITY Participation

A) Typically, <u>how often</u> does your child participate in <u>1 or more activities</u> of this type?

CHECK ONE RESPONSE ☑

B) Think about <u>1 or 2 activities of this type</u> that your child participates in most often. Typically, <u>how involved</u> is your child when doing these activities?

CHECK ONE RESPONSE ☑

C) Would you like your child's participation <u>to change</u> in this type of activity?

IF YES, CHECK ALL THAT APPLY ☑

	Daily	Few times a week	Once a week	Few times a month	Once a month	Few times in last four months	Once in last four months	Never (skip to Question C)	5 Very involved	4	3 Somewhat involved	2	1 Minimally involved	No change desired	Yes, do more often	Yes, do less often	Yes, be more involved	Yes, be less involved	Yes, be involved in a broader variety of activities
6) Organizations, groups, clubs, and volunteer or leadership activities (e.g., Boy Scouts, Brownies/Girl Guides, youth groups, public speaking)																			
7) Religious or spiritual gatherings and activities (e.g., attending places of worship, religion classes, groups)																			
8) Getting together with other children in the community (e.g., hanging out, informal gatherings outside of the home or school)																			
9) Working for pay (e.g., babysitting, paper route, working in a store, doing chores or running errands for pay)																			
10) Overnight visits or trips (e.g., sleepovers, vacations, camp)																			

COMMUNITY Environment

Do the following things <u>help or make it harder</u> for your child to participate in activities in the community? CHECK ONE RESPONSE ☑	Not an issue	Usually helps	Sometimes helps; sometimes makes harder	Usually makes harder
1. The physical layout or amount of space outside and inside buildings (e.g., distances to stores, presence of sidewalks, availability of ramps or elevators)				
2. The sensory qualities of community settings (e.g., noise, crowds, lighting)				
3. The physical demands of typical activities (e.g., strength, endurance, coordination)				
4. The cognitive demands of typical activities (e.g., concentration, attention, problem-solving)				
5. The social demands of typical activities (e.g., communication, interacting with others)				
6. Your child's relationships with peers				
7. The attitudes and actions of other members of the community towards your child (e.g., shopkeepers, instructors, coaches, other families)				
8. Outside weather conditions (e.g., temperature, climate)				
9. The safety of the community (e.g., traffic, crime, violence)				

Are the following available and/or adequate to support your child's participation in the community? CHECK ONE RESPONSE ☑	Not needed	Usually, yes	Sometimes yes; sometimes no	Usually, no
10. Access to personal transportation to access community activities (e.g., family car, bicycle)				
11. Access to public transportation to access community activities (e.g., bus, train, subway)				
12. Programs and services (e.g., inclusive sports programs, personal support worker)				

COMMUNITY Environment

Are the following available and/or adequate to support your child's participation in the community? CHECK ONE RESPONSE ☑	Usually, yes	Sometimes yes; sometimes no	Usually, no
13. Information (e.g., about activities, services, programs)			
14. Equipment or supplies (e.g., sports equipment, craft supplies, reading materials, assistive devices or technology)			
15. Do you (and your family) have enough time to support your child's participation in the community?			
16. Do you (and your family) have enough money to support your child's participation in the community?			

What are some things that you or other family members do that help your child participate successfully in activities in the community? PLEASE LIST UP TO 3 STRATEGIES
1.
2.
3.

PEM-CY Community Section - 4 of 4

ARO Parents' Perspectives of their Child's Community Participation

Project Summary

for

Adaptive Recreation Opportunities (ARO)
City of Fort Collins

Prepared by

Anna Martin, B.S.

Project Overview

This project is a partnership between the Children's Participation and Environment Research Lab (CPERL), the Center for Community Partnerships (CCP), and Adaptive Recreation Opportunities (ARO) and the City of Fort Collins that was funded by the CSU Department of Occupational Therapy. The goal of this project is to better understand parent perspectives of the needs and resources of children and youth with disabilities who are seeking formal support through Adaptive Recreation Opportunities (ARO). I coordinated this project and am completing my master's thesis based on your feedback of the results that we obtained from parents who participated in this project.

As shown in Figure 6 below, we recruited parents whose children were actively enrolled in ARO during the Spring 2012 season. Once we were approved by CSU to begin collecting information from parents in March, I worked with Renee Lee and Jenna Moriarty to distribute flyers to parents at ARO sponsored events and weekly activities. Parents who were interested in participating in our project provided their written consent and then completed a demographic questionnaire and survey about their child's participation in activities within the home, school, and community environments. Each parent received a $10.00 Target gift card and was entered into a drawing to win an iPod Touch that we issued in June. I began to summarize the information we received from parents beginning in August and have prepared this report for your feedback. I am interested in hearing your thoughts about how this information might support you in your current and future work with clients.
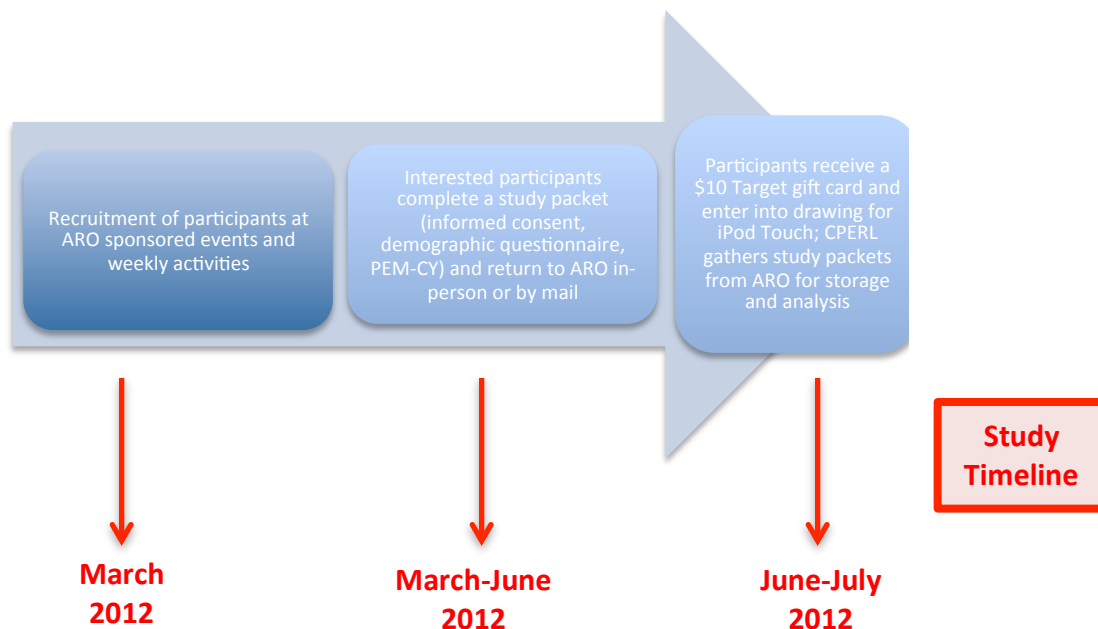
Figure 6. Recruitment Process

Child and Parent Characteristics

We were fortunate to have 23 parents take part in our project! On the next few pages, we summarize information about these parents and their children. We provide complete details in Appendices at the end of this document.

Caregiver Characteristics:
Most caregivers who participated in the project were mothers (90.9%) and 87% were married. 72.7% of parents were between 40-49 years old. 52% of families reported that their annual household income was under $60,000.

Characteristics of Children and Youth:
Most of the children who were reported on in this project were Caucasian (77.3%) and male (69.8%). The average age of the child was 10.7 years (range= 7-17 years).

Parents also reported on their child's functional limitations. At least one- third of the parents reported that their child had big problems paying attention or concentrating (60.9%), remembering information (e.g. directions) (56.5%), learning new information or new activities (47.8%), and communicating with others (47.8%). In contrast, areas where parents reported children having little difficulty included moving around (60.9%), seeing (65.2%), hearing (78.3%), and using his or her hands to do activities (47.8%).

We found that 60.9% of children were enrolled in both a regular and special education classroom, 17.4% were enrolled in a regular classroom, 13% attend a special education classroom, and 8.7% attend other classrooms.

In Figure 7 below, we show the percentage of children who use and do not use assistive technology (e.g. iPads, Dynavox, or other devices).
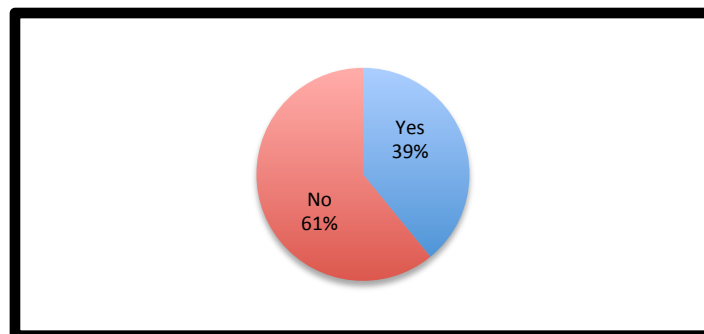
Figure 7. Parent Report on Child's Use of Assistive Technology (e.g. iPad, computer, etc.)

Parent Perceptions of ARO Services

In Figures 8-10 below, we provide information about children's participation in ARO services. Parents indicated how often their child participated, the importance of their participation, and how satisfied they were with ARO services.
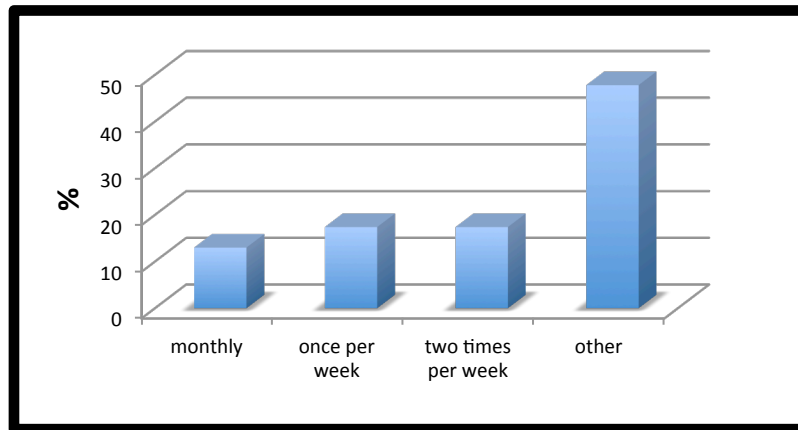
Figure 8. How often Do Children Participate in ARO Services
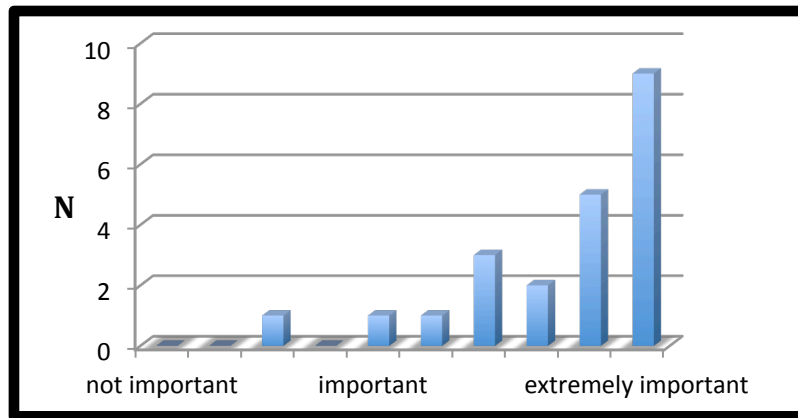
Importance of participation was rated on a scale of 0-10
(0=not important, 10=extremely important)

Figure 9. How Important is Participation in ARO Services
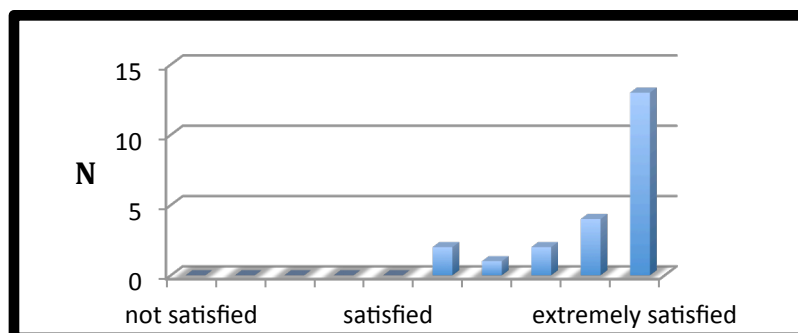
Satisfaction with participation was rated on a scale of 0-10 (0=not satisfied, 10=extremely satisfied)

Figure 10. How Satisfied are Parents with ARO Services

In this next section, we summarize parents' responses on the Participation and Environment Measure for Children and Youth (PEM-CY). We first describe the PEM-CY to you and then report on what we found out from parents about their child's participation in the community in both general and specific ways.

Overview of PEM-CY

The Participation and Environment Measures for Children and Youth (PEM-CY) is a caregiver-report survey that examines children's participation and environment in different settings. In this report, the community setting was examined. Within the community setting, participation is examined with respect to specific types of activities that typically take place in the community such as plays, concerts, dance, etc. Parents report on their child's participation in each activity area in terms of 1) how often their child participates, 2) their child's level of involvement, and 3) whether or not a parent desires change, and if so, of what type. For the community environment section, parents rate the extent to which things make it easier or harder for a child to participate (e.g. activity demands, environmental factors, etc.) and what resources are available/adequate to meet their needs.

General Survey Results

In Table 4 below, we summarize information for all 23 parents based on their responses on the PEM-CY community section. For frequency of participation in all community activities, children participated on average a few times within the last four months to once a month. The average level of involvement was 3.5, which means that children are somewhat involved in community activities. Additionally, 58.3% of families desired some type of change in their child's participation in community activities.

Table 4.
Community Participation and Environment Summary Scores

PEM-CY Summary Scores (n=23 participants)	Community Setting	
	Range	**Average**
Participation Frequency	1.4-3.8	2.5
Level of Involvement	1.7-4.4	3.5
Parents who Desire change (%)	30.4-73.9	58.3
Number of Barriers	0-8	2.6
Number of Supports	0-9	4

Frequency of participation was rated on a scale of 0 to 8
Level of Involvement was rated on a scale of 1 to 5 (1=Minimally to 5=Very Involved)
Parents who Desire Change was calculated by the percentage of "yes" response

Specific Survey Results

We rank ordered the top five community activities that parents would like to see change in their child's participation (see Table 5 below). For Figures 11-13, we show you the breakdown in terms of how frequently their children participated in these 5 activities, the child's average involvement in those activities, and parent perceptions of environmental supports and barriers to their child's participation in the community.

Table 5.

Top 5 Community Activities in which Parents Desire Change (n=18)

ACTIVITY:	% desire change
Community events	73.9
Organized physical activities	73.9
Unstructured physical activities	73.9
Classes or lessons (not school sponsored)	73.9
Getting together with other children in the community	69.6
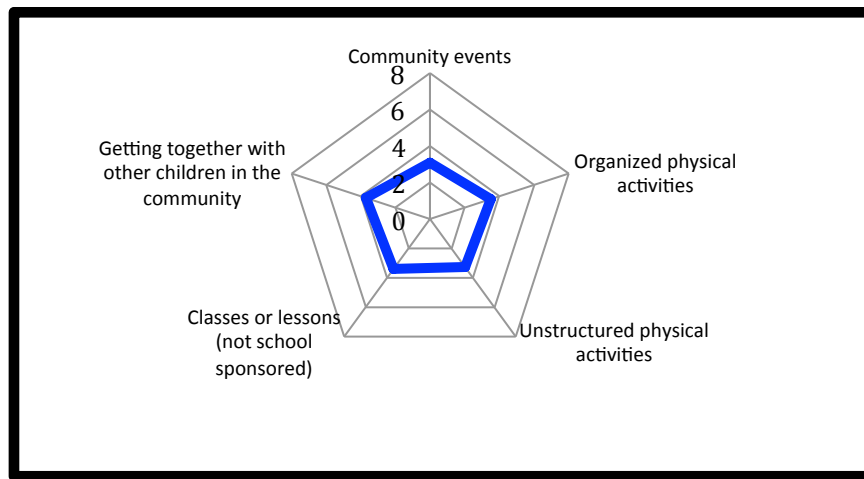
Frequency of participation was rated on a scale of 0 to 8
(0=Never, 2=few times in last 4 months, 6=few times a week, 8=Daily)

Figure 11. Average Frequency of Child's Participation (n=18)

Figure 11 shows on average how often children participated in those activities. On average many of the children were participating no more than a few times a month in these five activities.

Level of Involvement was rated on a scale of 1 to 5
(1=Minimally Involved, 3=somewhat involved, 5=Very Involved)
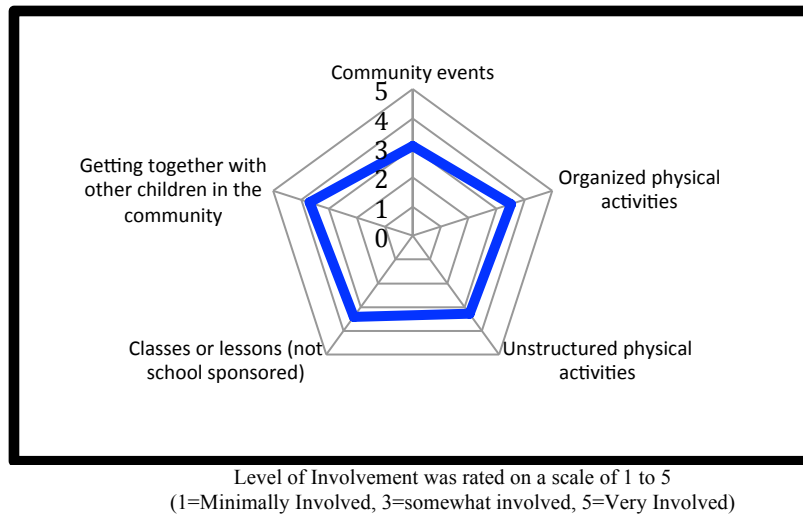
Figure 12. Average Involvement of Child's Participation (n=18)

Figure 12 shows the average child involvement in the top five community activities that parents identified as desiring change. Of the children that do participate in these 5 activities, their average level of involvement ranged from 3.0 (community events) to 3.7 (getting together with other children in the community) to indicate that they were at least somewhat involved.

Environmental features were rated on a scale of 0 to 4
(0=Not an issue/not needed, 1= usually helps/usually, yes, 2=sometimes helps; sometimes makes harder, and 3=usually makes harder/usually, no)
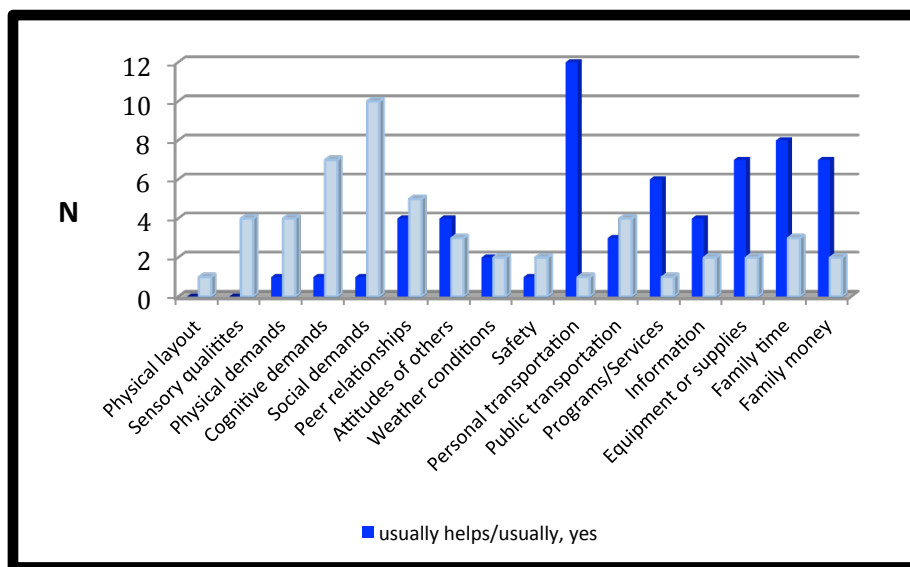
Figure 13. Environmental Supports and Barriers to Community Participation (n=18)

Figure 13 above tells us that the most frequently reported supports were personal transportation, adequate time, available and adequate equipment and supplies, and adequate family money. The most frequently reported barriers were related to the demands of activities, especially the social and cognitive demands, and peer relationships.

Take a moment to reflect on this information and answer the following questions:

1. What about this report is unclear? Please describe.

2. Do any of these results surprise you? If so, please describe.

3. What pieces of information in this section seem relevant to you? Why?

Case #1: John

John's Profile: John is a 9-year-old, Caucasian boy who has lived in Fort Collins his entire life. John's mother indicates that he has health problems or disabilities, which include a developmental delay, intellectual disability, hearing impairment, speech and language impairment, and health impairment. John's mother also noted that he experiences "big problems" or difficulties in the following areas: paying attention or concentrating, remembering information, (e.g. directions), learning new information or new activities, and communicating with others. At school, John attends a special education classroom. He does not currently use any assistive technology.

John's Family profile: John lives with his mother who is in her 40s and her mother's partner. They earn between $50,000-60,000 a year. John's mother has completed some college/university training.

John's Involvement in ARO Services: John just recently began accessing services at ARO and at the time of filling out this survey, his mother indicated this was his first sports class. John's mother said that participation in ARO services was a 6 out of 10, meaning they were important to her and Jonathan (0=not important to 10=extremely important). John's mother also indicated they were an 8 out of 10 with satisfaction meaning she was very satisfied with Jonathan's participation in ARO services (0=not satisfied to 10=extremely satisfied).

John's Participation Profile: Here we show you those community activities John's mother wants his participation to change and what type of change.

	Do more often	Do less often	Be more involved	Be less involved	Be involved in a broader variety of activities
Neighborhood outings	✔				
Community events	✔				
Organized physical activities	✔		✔		
Unstructured physical activities	✔		✔		
Classes or lessons (not school-sponsored)			✔		
Religious or spiritual gatherings & activities	✔				
Getting together with other children	✔		✔		
Overnight visits or trips	✔		✔		

Here we show you how often John actually participates in the 8 activities that his mother wants to see change.

How often John Participates in Activities in which his Mother Wants Change

Frequency of participation was rated on a scale of 0 to 7
(0=Never, 2=few times in last 4 months, 3=once a month, 6=few times a week, 7=Daily)

Lastly, we show you what John's involvement looks like in the 8 activities that his mother wants to see change.

John's Involvement in Activities in which his Mother Wants Change

Level of Involvement was rated on a scale of 1 to 5
(1=Minimally Involved, 3=somewhat involved, 5=Very Involved)

Supports and Barriers to John's Participation:

Here we show what John's mother perceives to be supports and barriers to his participation in community-based activities.

	Not an issue/ not needed	Usually helps/ usually, yes	Sometimes helps; sometimes makes harder/sometimes no	Usually makes harder/ usually, no
Physical layout	✔			
Sensory qualities	✔			
Physical demands	✔			
Cognitive demands	✔			
Social demands	✔			
Peer relationships			✔	
Attitudes of others	✔			
Weather conditions			✔	
Safety	✔			
Personal transportation	✔			
Public transportation	✔			
Programs/services		✔		
Information		✔		
Equipment or supplies		✔		
Family time		✔		
Family money		✔		

Additional strategies that Jon's mother uses to support community participation:
none listed

Tim's Profile: Tim is a 12-year-old, Caucasian boy who has lived in Fort Collins for 2 years and Colorado his entire life. Tim's mother indicates that he has health problems or disabilities, which include orthopedic impairment/movement impairment (mild hypotonic) and autism spectrum disorder. Tim's mother also noted that he experiences "big problems" or difficulties in the following areas: paying attention or concentrating, remembering information, (e.g. directions), learning new information or new activities, communicating with others, reacting to sensations, managing emotions (e.g. anxiety), and controlling behavior or activity level. At school, Tim attends both a regular and special education classroom. He currently uses assistive technology, which his mother does not know the name, but stated it is a "computer with a program on it."

Tim's Family profile: Tim lives with his mother who is in her 40s and his father. They earn more than $100,000 a year. Tim's mother has completed some college/university training.
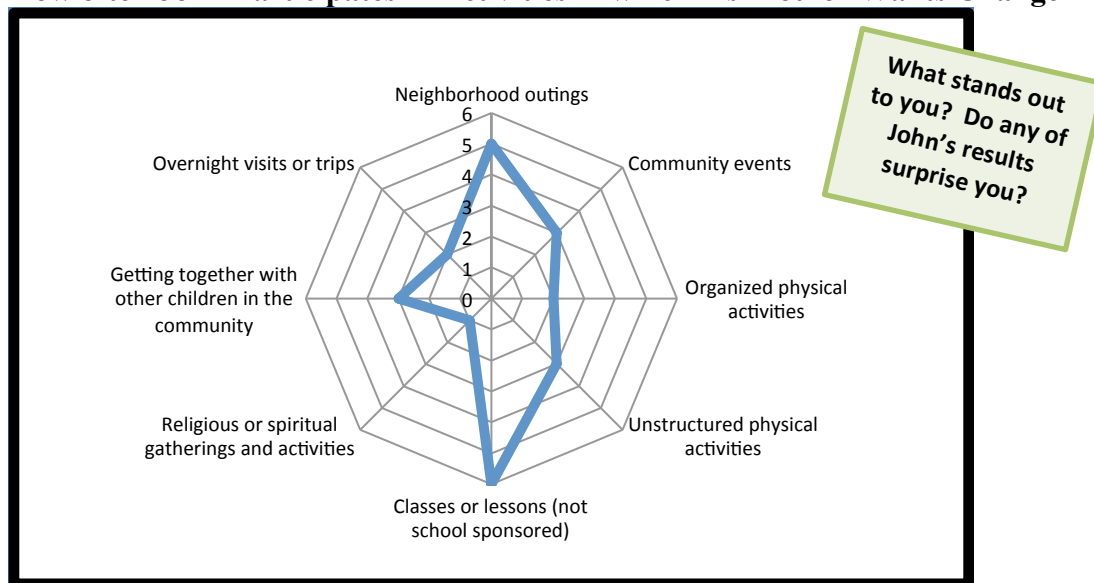
Tim's Involvement in ARO Services: Tim began accessing services at ARO about 2 months ago and participates in services about 1 time per week. He participates in aquatics, swim, and aqua fitness. Tim's mother said that participation in ARO services was a 10 out of 10, meaning they were extremely important to her and Tim. Tim's mother also indicated they were 10 out of 10 with satisfaction meaning she was extremely satisfied with Tim's participation in ARO services.

Tim's Participation Profile: Here we show you those community activities Tim's mother wants his participation to change and what type of change.

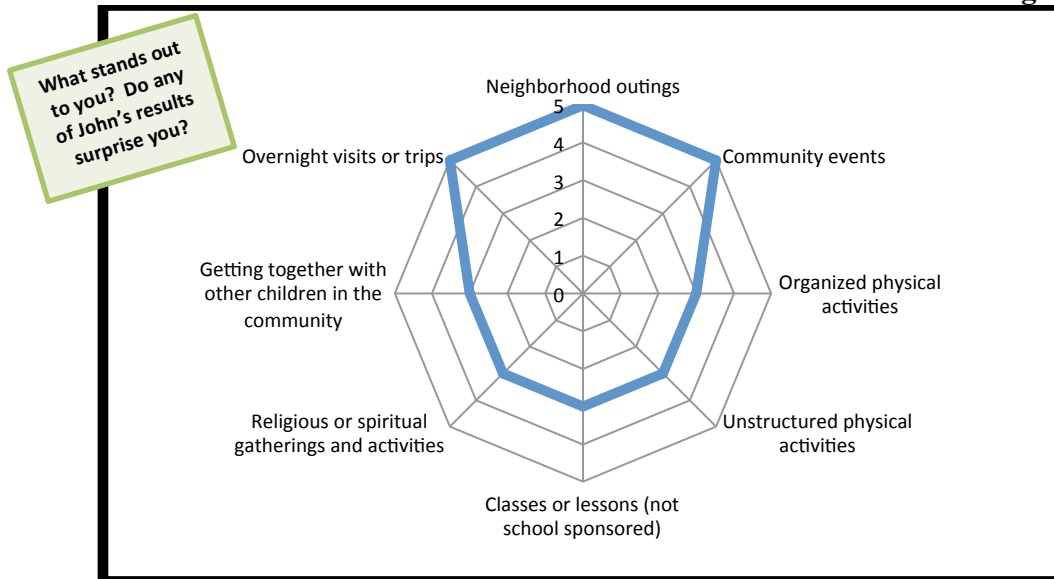|	Do more often	Do less often	Be more involved	Be less involved	Be involved in a broader variety of activities
Neighborhood outings	✔		✔		✔
Community events	✔		✔		
Organized physical activities	✔		✔		
Unstructured physical activities	✔		✔		
Classes or lessons (not school-sponsored)	✔		✔		
Organizations, groups, clubs, and volunteer or leadership activities	✔		✔		✔
Getting together with other children	✔		✔		
Working for pay	✔		✔		

Here we show you how often Tim actually participates in the 8 activities that his mother wants to see change.

How often Tim Participates in Activities in which his Mother Wants Change
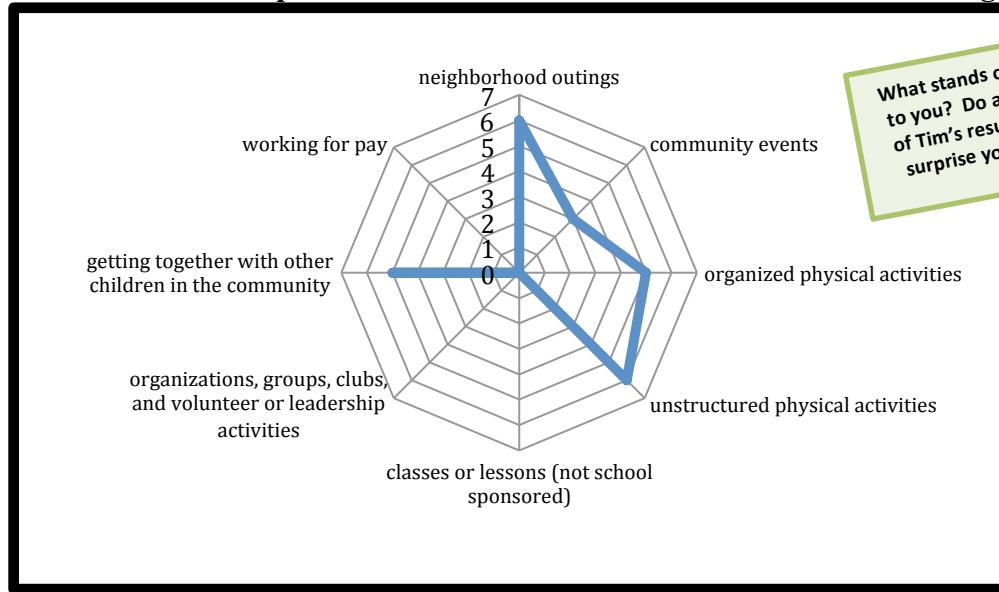
neighborhood outings

community events

organized physical activities

unstructured physical activities

classes or lessons (not school sponsored)

organizations, groups, clubs, and volunteer or leadership activities

getting together with other children in the community

working for pay

What stands out to you? Do any of Tim's results surprise you?

Frequency of participation was rated on a scale of 0 to 7
(0=Never, 2=few times in last 4 months, 3=once a month, 6=few times a week, 7=Daily)

Lastly, we show you what Tim's involvement looks like in the 8 activities that his mother wants to see change.

Tim's Involvement in Activities in which his Mother Wants Change

What stands out to you? Do any of Tim's results surprise you?

neighborhood outings

community events

organized physical activities

unstructured physical activities

classes or lessons (not school sponsored)

organizations, groups, clubs, and volunteer or leadership activities

getting together with other children in the community

working for pay

Level of Involvement was rated on a scale of 1 to 5
(1=Minimally Involved, 3=somewhat involved, 5=Very Involved)

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Supports and Barriers to Tim's Participation:

Here we show what Tim's mother perceives to be supports and barriers to his participation in community-based activities.

	Not an issue/ not needed	Usually helps/ usually, yes	Sometimes helps; sometimes makes harder/sometimes no	Usually makes harder/ usually, no
Physical layout			✔	
Sensory qualities				✔
Physical demands			✔	
Cognitive demands				✔
Social demands				✔
Peer relationships			✔	
Attitudes of others			✔	
Weather conditions			✔	
Safety			✔	
Personal transportation		✔		
Public transportation	✔			
Programs/services			✔	
Information			✔	
Equipment or supplies		✔		
Family time		✔		
Family money		✔		

Additional strategies that Tim's mother uses to support community participation:

1. Talk about what to expect
2. Adapt activities as needed
3. Coach others on our needs

Case #3: Tracy

Tracy's Profile: Tracy is a 7-year-old girl who is Asian who has lived in Fort Collins her entire life. At home, Tracy also speaks Chinese. Tracy's mother indicates that she has health problems or disabilities, which include developmental delay, intellectual disability, speech or language impairment, and multiple disabilities. Tracy's mother also noted that she experiences "big problems" or difficulties in the following areas: paying attention or concentrating, remembering information, (e.g. directions), learning new information or new activities, communicating with others, reacting to sensations (e.g. noises), and using her hands to do activities. At school, Tracy attends both a regular and special education classroom. She currently does not use any assistive technology.

Tracy's Family profile: Tracy lives with his mother who is in her 40s and her father. They earn more than $100,000 a year. Tracy's mother has completed her graduate degree.

Tracy's Involvement in ARO Services: Tracy began accessing services at ARO about 4 years ago and participates about 3 times a week depending on the season. At the time of filling out this survey, her mother indicated she was participating in aquatics, swim, or aqua fitness, dance, movement, gymnastics, summer day camps, ice-skating, and farm. Tracy's mother said that participation in ARO services was a 10 out of 10, meaning they were extremely important to her and Tracy. Tracy's mother also indicated they were 10 out of 10 with satisfaction meaning she was extremely satisfied with Tracy's participation in ARO services.

Tracy's Participation Profile: Here we show you those community activities Tracy's mother wants her participation to change and what type of change.

	Do more often	Do less often	Be more involved	Be less involved	Be involved in a broader variety of activities
Community events	✔		✔		
Organized physical activities	✔		✔		
Unstructured physical activities	✔		✔		
Classes or lessons (not school-sponsored)	✔		✔		
Organizations, groups, clubs, and volunteer or leadership activities	✔		✔		
Getting together with other children	✔		✔		
Overnight visits or trips	✔		✔		

Here we show you how often Tracy actually participates in the 7 activities that her mother wants to see change.
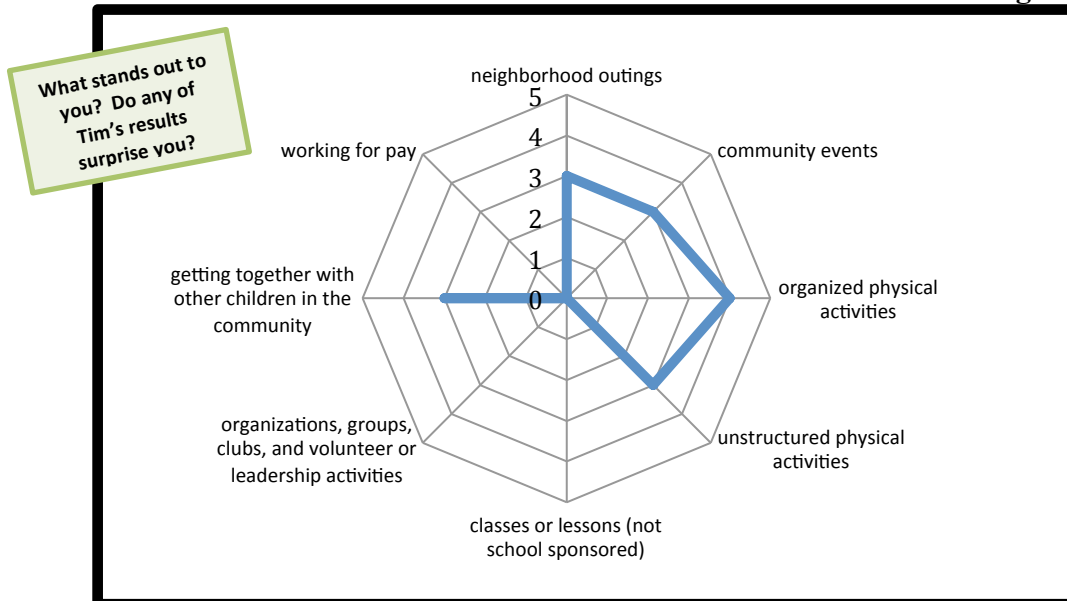
How often Tracy Participates in Activities in which her Mother Wants Change
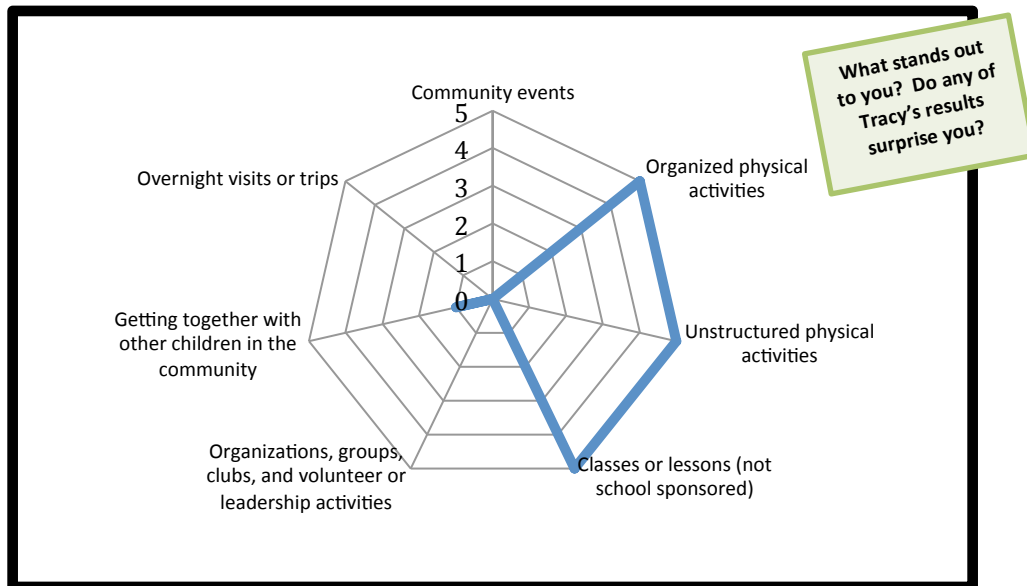
Frequency of participation was rated on a scale of 0 to 7
(0=Never, 2=few times in last 4 months, 3=once a month, 6=few times a week, 7=Daily)

Lastly, we show you what Tracy's involvement looks like in the 7 activities that her mother wants to see change.

Tracy's Involvement in Activities in which her Mother Wants Change
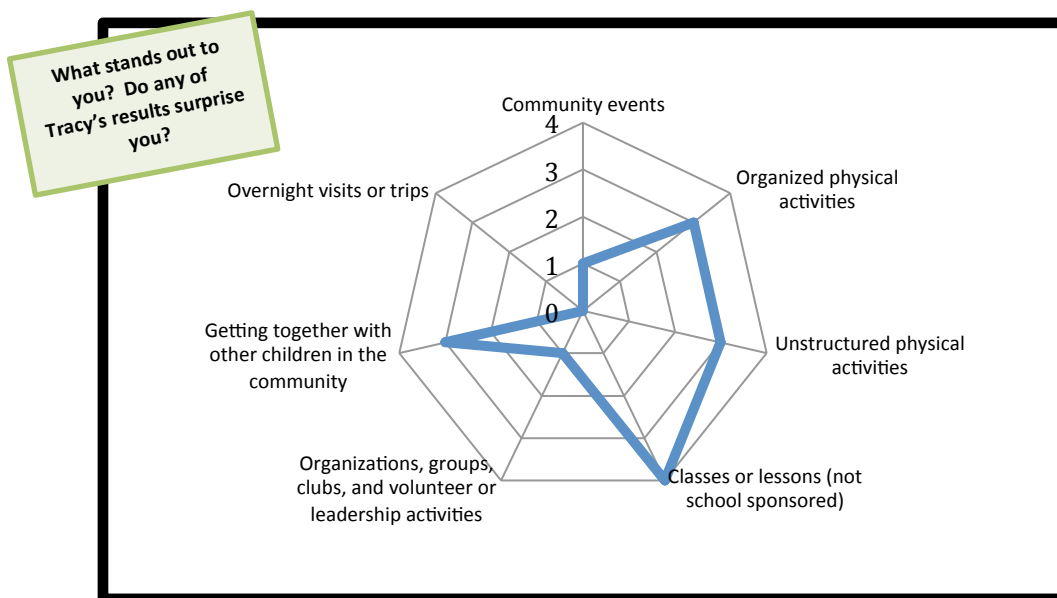
Level of Involvement was rated on a scale of 1 to 5
(1=Minimally Involved, 3=somewhat involved, 5=Very Involved)

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Supports and Barriers to Tracy's Participation:

Here we show what Tracy's mother perceives to be supports and barriers to his participation in community-based activities.

	Not an issue/ not needed	Usually helps/ usually, yes	Sometimes helps; sometimes makes harder/sometimes no	Usually makes harder/ usually, no
Physical layout	✔			
Sensory qualities	✔			
Physical demands	✔			
Cognitive demands	✔			
Social demands	✔			
Peer relationships		✔		
Attitudes of others		✔		
Weather conditions		✔		
Safety		✔		
Personal transportation		✔		
Public transportation				✔
Programs/services			✔	
Information			✔	
Equipment or supplies			✔	
Family time				✔
Family money			✔	

Additional strategies that Tracy's mother uses to support community participation: none listed

Case #4: Jessica

Jessica's Profile: Jessica is a 15-year-old Caucasian girl, who has lived in Fort Collins for 8 years. Jessica's mother indicates that she has health problems or disabilities, which include an intellectual disability, speech or language impairment, and autism spectrum disorder. Jessica's mother also noted that she experiences "big problems" or difficulties in the following areas: remembering information, (e.g. directions) and learning new information or new activities. At school, Jessica attends both a regular and special education classroom. She currently does not use any assistive technology.

Jessica's Family profile: Jessica lives with his mother who is in her 40s and her father. They earn between $50,000-$60,000 a year. Jessica's mother has completed a college degree.

Jessica's Involvement in ARO Services: Tracy began accessing services at ARO about 4 years ago and participates in services during the basketball season only. At the time of filling out this survey, her mother indicated she was participating in sports programs. Jessica's mother said that participation in ARO services was a 9 out of 10, meaning they were extremely important to her and Jessica. Jessica's mother also indicated they were 9 out of 10 with satisfaction meaning she was extremely satisfied with Jessica's participation in ARO services.

Jessica's Participation Profile: Here we show you those community activities Jessica's mother wants her participation to change and what type of change.

	Do more often	Do less often	Be more involved	Be less involved	Be involved in a broader variety of activities
Neighborhood outings	✔		✔		✔
Community events			✔		
Organized physical activities			✔		
Unstructured physical activities					✔
Classes or lessons (not school-sponsored)	✔				
Religious or spiritual gatherings			✔		
Getting together with other children			✔		
Working for pay	✔				

Here we show you how often Jessica actually participates in the 8 activities that her mother wants to see change.

How often Jessica Participates in Activities in which her Mother Wants Change
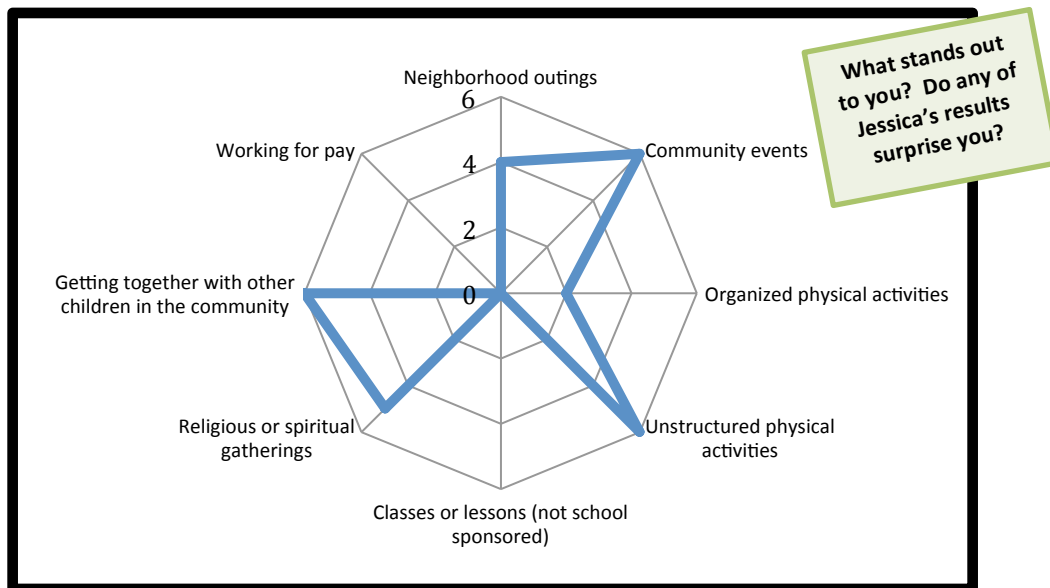
Frequency of participation was rated on a scale of 0 to 7
(0=Never, 2=few times in last 4 months, 3=once a month, 6=few times a week, 7=Daily)

Lastly, we show you what Jessica's involvement looks like in the 8 activities that her mother wants to see change.

Jessica's Involvement in Activities in which her Mother Wants Change
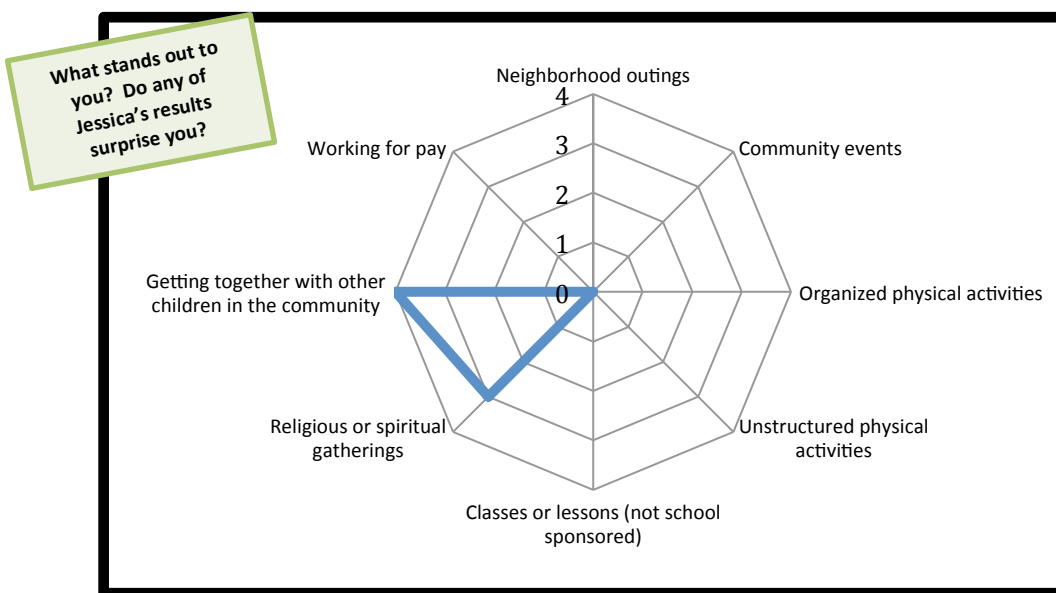
Level of Involvement was rated on a scale of 1 to 5
(1=Minimally Involved, 3=somewhat involved, 5=Very Involved)

Supports and Barriers to Jessica's Participation:

Here we show what Jessica's mother perceives to be supports and barriers to his participation in community-based activities.

	Not an issue/ not needed	Usually helps/ usually, yes	Sometimes helps; sometimes makes harder/sometimes no	Usually makes harder/ usually, no
Physical layout	✔			
Sensory qualities	✔			
Physical demands			✔	
Cognitive demands			✔	
Social demands				✔
Peer relationships			✔	
Attitudes of others			✔	
Weather conditions			✔	
Safety	✔			
Personal transportation		✔		
Public transportation				✔
Programs/services			✔	
Information			✔	
Equipment or supplies		✔		
Family time		✔		
Family money			✔	

Additional strategies that Jessica's mother uses to support community participation:
1. Special Olympics events/sports so she can do it at her level with rewards/praise.
2. Have her help make lists for shopping and errands then check off items at the store.

Appendix D: Phase 2 (QUAL) Final Interview Guide

Research Question 1

1. What do you make of the information about areas where change is most desired? Are these results what you anticipated? If not, please explain. Does this information make you think differently about the types of programs you currently offer, or the way in which they are offered? What aspects of your programs and services would you want to revisit based on this information, and why?

2. Does information about the types of change that parents desire help you with planning or making changes to your programs? Does it enhance your decision-making process in any way? If so, please explain. If not, why not?

3. Does information about the supports and barriers in the community environment make you think differently about how your programs are organized? Are there any environmental factors that you would want to know more about from the parent? If so, which ones and why? What do you want to know? What would you do with this information? Do you anticipate that any program changes that could be made as a result of knowing this information? If so, please explain.

Research Question 2

1. First we give you a snapshot of the areas where change is most desired. When you look at this table, in which activities does this parent want change?

2. Select activities on this table that you currently have programming for. For each activity:

   a. What types of change does this parent want for their child?
      i. **Probe:** Is it clear to you what more often and more involvement mean when desired? If not, how could you get this information?
      ii. **Probe:** Some of your peers have noticed that there are sometimes mismatches between the frequency and involvement in the radar plots. Does this make sense to you that there would be a mismatch? If so, how do you explain it? If not, how could you get a better understanding of this from the parent?

   b. Do you think that it is helpful to know about the specific types of change that parents want for their child? If so, please explain.

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c. What types of things do you think are associated with reduced participation in this activity?

      i. **Probe:** There is one chart that lists features of the environment that are supports and barriers for this child. Is this information helpful to how you would support a child in your classes?

      ii. Probe: Do you use the diagnosis of a child or the disability to help inform what programs and services the child may need or want?

Research Question 3

1. What is your current process for supporting families of children with disabilities in your classes and programs (e.g. phone conversations, paperwork from families, participant forms, etc.)?

2. After reviewing the general summary and the individual case studies, what do you see as the advantages and disadvantages of using the PEM-CY?

      Probe 1: Do you think the general information would be helpful to use?
      a. Is the general summary enough information to work with to make program level changes? If so, how so? If not, why not or what is it and what more do you want to know?

      Probe 2: Do you think you could use it with an individual family?
      a. Let's say this child is new to your class and the parent filled out the PEM-CY. How does this fit into your current process? Is it similar, different, and how?

Table 6

Parent Reported Demographic Information

Group Statistics (N=23)	N (%)
Child gender	
Male	16 (69.6)
Female	7(30.4)
Child age (years)	Mean= 10.7 yrs. (SD = 3.42)
Child's race/ethnicity	
Caucasian	17(77.3)
African-American	1 (4.5)
Asian or Pacific Islander	1 (4.5)
Multiracial	2 (9.1)
Hispanic	1 (4.5)
Respondent relationship to child	
Mother	20 (90.9)
Father	1 (4.5)
Female legal guardian	1 (4.5)
Respondent's marital status	
Married	20 (87)
Divorced	1 (4.3)
Separated	1 (4.3)
Domestic Partner	1 (4.3)
Respondent age (years)	
30-39	4 (18.2)
40-49	16 (72.7)
50-59	2 (9.1)
Respondent education	
High school or less	3 (13)
Some college/ university or technical training	4 (17.4)
Graduated college/university	9 (39.1)
Graduate degree	7 930.4)
Annual household income	
Less than $10,000	2 (8.7)
30-39,999	1 (4.3)
40-49,999	3 (13.0)
50-59,000	6 (26.1)
90-99,999	4 (17.4)
Greater than $100,000	7 (30.4)
Child's school placement	
Regular classroom	4 (17.4)
Regular and Special Education Class	14 (60.9)
Special Education Class	3 (13.0)
Other	2 (8.7)

Table 7

Parent Reported Functional Limitation of Sampled Children

Functional Ability	Not a Problem N (%)	Little Problem N (%)	Big Problem N (%)
Paying attention or concentrating	1 (4.3)	8 (34.8)	14 (60.9)
Remembering information (e.g. directions)	2 (8.7)	8 (34.8)	13 (56.5)
Learning new information or new activities	3 (13.0)	9 (39.1)	11 (47.8)
Communicating with others	1 (4.3)	11 (47.8)	11 (47.8)
Reacting to sensations (e.g. noise, crowds)	4 (17.4)	12 (52.2)	7 (30.4)
Moving around*	14 (60.9)	8 (34.8)	0 (0)
Using his or her hands to do activities	11 (47.8)	8 (34.8)	4 (17.4)
Managing emotions (e.g. anxiety; depression)	6 (26.1)	12 (52.2)	5 (21.7)
Controlling behavior or activity level	4 (17.4)	12 (52.2)	7 (30.4)
Seeing	15 (65.2)	6 (26.1)	1 (4.3)
Hearing*	18 (78.3)	4 (17.4)	0 (0)

*One participant value missing from these functional ability categories.

Appendix G: Visual Model of Mixed-Methods Explanatory Sequential Design

Visual Model of Mixed-Methods Explanatory Sequential Design Procedures		
Phase	**Procedure**	**Product**
Phase 1: Quantitative Data Collection	- Demographic Questionnaire - PEM-CY survey with ARO families (n=23) at ARO events	Numeric Data
Phase 1: Quantitative Data Analysis	- SPSS 20.0 - summary statistics - frequencies	- descriptive statistics of ARO family sample (n=23)
Connecting Quantitative and Qualitative Phases	- purposeful case selection of children with diverse demographics (n=4) - developing interview questions - developing ARO summary report	- Development of ARO Report with 2 sections: 1) aggregate results 2) 4 case reports - Interview Protocol
Phase 2: QUALITATIVE Data Collection	- individual or dyadic interviews with 7 ARO staff (n=7) - meetings to review interview guide	- Text data (interview transcripts, field notes) - audio data of interviews - development of final interview protocol and probes
Phase 2: QUALITATIVE Data Analysis	- NVivo 9.0 - analytic deductive coding after each interview - Phone and in-person member checking interviews	- themes/topics developed from searching text data and coding to final interview guide - visual model (decision-making tree) for intervention planning
Integration of the Quantitative and Qualitative Results	- interpretation and explanation of quantitative and qualitative results	- Discussion - Implications - Future Research

Note: Adapted from Ivankova et al., 2006, p. 16.