# Participation-Focused Strategy Use Among Caregivers of Children Receiving Early Intervention

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**Importance:** Evidence on common types of participation-focused caregiver strategies can help occupational therapy practitioners to take an evidence-based approach to designing participation-focused practice.

**Objective:** To identify and explore types of caregiver strategies to support young children's participation in valued occupations in the home and community.

**Design:** Qualitative study using a subset of data collected online with the Young Children's Participation and Environment Measure (YC–PEM). Narrative responses about strategy use were content coded to the family of Participation-Related Constructs (fPRC) framework using a deductive analytic approach to identify relevant types of participation-focused strategies used in the home and community. Responses were further analyzed within each relevant fPRC construct using an inductive analytic approach to identify the scope of strategies used for each construct.

#### Setting: Early intervention.

Participants: Caregivers (N = 106) of young children receiving early intervention.

**Outcomes and Measures:** Caregivers' strategies to support their child's home and community participation, provided by the YC-PEM.

**Results:** Caregivers most commonly adapted the child's environment or context to support their child's home and community participation (45.06%). The least common focus of caregiver strategies was the child's activity competencies (11.16%). Three or more types of caregiver strategies were identified for each participation-related construct.

**Conclusion and Relevance:** Results indicated that caregivers used a range of strategies related to each of the participation-related constructs to support their child's participation in home and community occupations, most commonly targeting the environment. Occupational therapy practitioners can select from this range of strategies when planning participation-focused early intervention with families.

What This Article Adds: This study yields new evidence on the scope of caregiver strategy use to support young children's participation in home and community occupations. Occupational therapy practitioners can apply this evidence to anticipate common areas of caregiver strategy use in participation-focused practice with families in early intervention.

O ccupational therapy practitioners are a central part of the interprofessional team that seeks to enact client-centered and participation-focused practice when working with families of young children (American Occupational Therapy Association, 2020). Although there is agreement on the importance of client-centered and participation-focused practice in early intervention, implementing the concepts in practice is complex (Ausderau et al., 2019; Jarvis et al., 2018; Killeen et al., 2019).

The family of Participation-Related Constructs (fPRC) framework is an evidence-based road map for coherently advancing knowledge about children's participation and applying it to practice (Imms et al., 2017). The fPRC framework provides conceptual clarity about children's participation as both attendance and involvement. The transactions among participation-related constructs, including intrinsic factors (i.e., the child's activity competence, sense of self,

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and preferences) and extrinsic factors (i.e., the environment or context), are seen as drivers of participation experiences and outcomes. Transactional exchanges are described using verbs. For example, the environment or context is hypothesized as "providing" and "regulating," whereas the child "responds" to and "influences" the environment or context; thus, a transactional exchange occurs, and each influences the other.

Participation measures such as the Young Children's Participation and Environment Measure (YC–PEM; Khetani, 2015; Khetani et al., 2015) that align with the fPRC framework (Adair et al., 2018) provide opportunities to facilitate clientcentered and participation-focused practice for young children. The YC–PEM is a parent proxy questionnaire that yields a comprehensive profile of a young child's current and desired participation as well as strategies to improve attendance and involvement in home, preschool or day care, and community occupations (Khetani, 2015; Khetani et al., 2015). Gathering information from families about their priorities for participation change and participation-focused strategy use may be a valuable method for identifying how occupational therapy practitioners can support clientcentered and participation-focused practice (Graham et al., 2013; Jarvis et al., 2019; Law et al., 2015).

Evidence on common types of participation-focused strategies used by caregivers can help occupational therapy practitioners take an evidence-based approach to designing participation-focused practice. Caregiver strategies to promote young children's home and preschool or day care participation have previously been mapped to developmental and disability frameworks, which include participation but do not primarily focus on it (Benjamin et al., 2017; Jarvis et al., 2018). Leveraging the fPRC as a framework that explicitly and primarily focuses on participation can extend current knowledge of the complexity in caregiver strategy use to promote children's participation (Adair et al., 2018).

The purpose of this study was to extend knowledge about the types of strategies that caregivers use to promote their children's home and community participation. The two aims of this study were to (1) identify which of the fPRC framework's participation-related constructs (i.e., environment or context, sense of self, preferences, activity competence) were most commonly represented in caregiver strategies to promote home and community participation and (2) characterize ways that caregivers targeted each participation-related construct.

#### Method

This was a qualitative study of a subset of data collected in a pilot study to implement the YC–PEM in early intervention. Multi-institutional ethics approval was obtained before recruitment and data collection (from March 2017 to August 2018).

#### **Participants**

Eligible participants were 163 primary caregivers of children ages 0 to 3 yr who had received early intervention for at least 3 mo from a large, urban early intervention program. Included caregivers were at least 18 yr old; had internet access; and could read, write, and speak English or Spanish. Caregivers who completed a Spanish version of the YC–PEM (n = 10) or who were lost to follow-up (n = 14) were excluded, as were cases with no data on all strategies (n = 33), resulting in 106 participating caregivers with relevant data.

#### **Data Collection**

Consenting caregivers completed a demographic questionnaire about their gender, level of education, and annual income and their child's gender, age, race and ethnicity, and type of rehabilitation services received. Caregivers then completed the online YC–PEM to report on areas of desired change in participation across home and community occupations (by responding either yes or no). When caregivers indicated that change was desired in one or more occupations, an open-ended item asked them to describe up to three strategies they use to support their child's participation in that occupational category.

#### **Data Analysis**

For data analysis, two team members (Dianna L. Bosak and Vivian C. Villegas) independently screened all narrative responses and resolved discrepancies with a third team member (Vera C. Kaelin) about whether a response qualified as a strategy. Open-ended responses were excluded from the main analyses if the response described a type of therapy (e.g., "feeding therapy"), there was no identifiable action (e.g., "He likes Costco"), a need was described (e.g., "She needs to be walking first"), or the entry was a duplicate. When responses included multiple strategies (e.g., "repetitive routines, incorporate fun such as songs and games"), the strategies were decoupled and coded separately as needed.

Strategies were then content analyzed using a deductive and inductive approach according to the study aims, focusing on prevalence of strategies (Aim 1: deductive coding) and on exploration of strategies (Aim 2: inductive coding; Patton, 2015). For Aim 1, three team members (Bosak, Villegas, and Kaelin) coded content to the constructs in the fPRC framework as defined by Imms and colleagues (2017). Coders first established credibility by pilot coding the first 11% of strategies, which was followed by consultation with the lead author of the fPRC framework (Christine Imms) to clarify coding to select constructs.

Content coding was completed in three rounds (Figure 1). For each round, two coders (Bosak and Villegas) independently content coded the data by identifying the participation-related fPRC construct on the basis of their definitions and the hypothesized transactions (i.e., environment–context [regulating–providing], sense of self [engaging–perceiving], preferences [choosing–complying], and activity competence [acting–learning]; Imms et al., 2017) that best corresponded to the strategy described. The two coders met with a third coder (Kaelin) to settle coding discrepancies by majority rule, seeking feedback from a key informant (Mary A. Khetani) as needed. This coding process resulted in a matrix data display that was used to summarize the occurrence of fPRC constructs.

For Aim 2, strategies within each fPRC construct were content analyzed using an inductive analytic approach. First, and as a way of analytical triangulation (Patton, 2015), two coders (Bosak and Villegas) independently analyzed content for each construct, resulting in subcategories that were compared and discussed with a third coder (Kaelin), while going back and forth between data and coding. Each of these comparisons of similarities and differences in coding with subcategories led to a common coding scheme (Patton, 2015). Second, coders collapsed subcategories to create categories that were compared with the original data to ensure fit of data to category (Patton, 2015). To enhance interpretation, each coder independently fit the categories to the transaction terms (verbs) specific to each participation-related construct as outlined in the fPRC framework (Imms et al., 2017).

#### **Results**

#### Sample Characteristics

Most caregivers had graduate education (56.6%) and an annual family income exceeding \$100,001 (55.7%). More than half of the sampled children were White (75.5%), non-Latinx (78.3%), male (51.9%), and older than age 24 mo (55.7%; Table 1). On average, caregivers desired change in 31.21% of home occupations and 29.6% of community occupations.

#### Caregiver Strategies to Support Children's Home and Community Participation

A total of 523 eligible responses were available for coding, of which 137 (26.2%) were decoupled because the response included a description of multiple strategies. This resulted in a total of 708 strategies for analysis (490 for home and 218 for community). To support participation, caregivers most commonly adapted their child's environment or context (45.1%), followed by supporting their child's sense of self (26.0%). Caregivers described tapping into their child's preferences to support participation in 17.80% of cases, and 11.2% of all strategies focused on improving the child's activity competence (Figure 2).

#### Figure 1. Deductive coding process.



*Note.* fPRC = family of Participation-Related Constructs.

#### Caregiver Targeting of Participation-Related Constructs to Support Children's Participation

Three or more categories of strategies were identified for each participation-related construct (i.e., environment or context, sense of self, preferences, and activity competence). In the subsequent sections, these categories within each participation-related construct are listed in order from most commonly described by caregivers to least commonly described. In addition, related fPRC transaction terms were referenced for all participation-related constructs (see the Appendix).

#### Strategies Targeting Children's Environment or Context

Four categories of strategies were identified for modifying the child's environment or context. The first category was "Intentionally arrange or include items and/or people" (n = 126), which encompassed strategies to involve siblings,

## Table 1. Child and Family Characteristics (N = 106)

Characteristic	n (%)
Child sex, male <sup>a</sup>	55 (51.9)
Reason for EI services	
Diagnosis	26 (24.5)
Developmental delay (no diagnosis)	73 (68.9)
Risk for developmental delay (no diagnosis)	7 (6.6)
Child age, mo	
12–24	47 (44.3)
>24	59 (55.7)
Child race <sup>a, b</sup>	
White	80 (75.5)
Black	7 (6.6)
Latinx	23 (21.7)
American Indian/Alaska Native	2 (1.9)
Multiple races, other	15 (14.1)
Caregiver education level	
High school or some college	15 (14.2)
College degree	31 (29.2)
Graduate education	60 (56.6)
Family income, \$ <sup>a</sup>	
0–50,000	18 (17.0)
50,001-100,000	26 (24.5)
≥100,001	59 (55.7)
El services received <sup>a, b</sup>	
Occupational therapy	37 (34.9)
Physical therapy	52 (49.1)
Speech therapy	74 (69.8)
Developmental intervention	41 (38.7)
<i>Note.</i> EI = early intervention.	

<sup>a</sup>Missing data. <sup>b</sup>Respondents could select multiple responses.

caregivers, objects, or sound to support the child's participation. Examples include "involving his older sister as a . . . 'buddy' when there are friends over" and rearranging the items in the situation, such as "Put away plastic tableware in easily accessible cabinet." The second category, "Set the scene: Provide predictable environmental structure or routines" (n = 76), included strategies to create, maintain, and adapt routines as well as to inform the child about what will happen to make the environment predictable for the child (e.g., "talking about the activity in advance, looking at pictures"). The third category, "Model or provide cues" (n = 61), included strategies that make explicit reference to visual or auditory support in the child's social environment, such as "demonstrating brushing teeth." The fourth category, "Facilitate a physical change in location" (n = 56), was commonly described as a way of increasing the child's attendance in community classes and family trips.

#### Strategies Targeting Children's Sense of Self

Three categories of strategies targeted a child's sense of self. Most strategies were aimed at the first category, "Increase child's perceived comfort, confidence, or freedom" (n = 80). Caregivers described encouraging or positively reinforcing the child with the goal of ensuring the child's comfort to take part in an occupation (e.g., "ensure that he feels safe and secure at these events, so he knows we are there for him") and supporting the child's confidence by exposure and freedom to try new things unsupervised (e.g., "[providing] free time in the apartment courtyard with friends"). The second category, "Letting them experience a part" (n = 55), involved strategies that make explicit reference to engaging the child in part of an occupation with the caregiver to build confidence about capacity to contribute (e.g., "I often pull his shirt over his head, but he

pushes his arms through the sleeves"). The third category was "Give the child a set helper role in an advanced occupation" (n = 49), such as the child helping the caregiver with laundry or groceries (e.g., "ask her to help daddy take care of groceries when we get home").

#### Strategies Targeting Children's Preferences

Four categories of strategies targeted a child's preferences to support the child's participation. The first category, "Incorporate child's interests through fun games and/or things the child likes" (n = 64), involved strategies to support a child's participation (e.g., "We had breakfast at a bagel shop along the light rail route near our home, so we could pass the time and engage his interest anticipating and watching the trains go by"). The second category, "Communicating clear expectations" (n = 27), included strategies that helped the child comply with choices made by others, such as repeating requests. The third category, "Offering choices and letting the child choose" (n = 23), encompassed strategies such as "Provide variety in choices (swimming, music)." The fourth category, "Respond to actions with rewards or punishment to support or reinforce expectations" (n = 12), included strategies using negative reinforcement and bribery (e.g., "not allowing her to move on to the next toy").



#### Figure 2. Types of strategies to support children's home and community participation.

#### Strategies Targeting Children's Activity Competence

Three categories of strategies targeted a child's activity competence through supporting participation. The first was "Learning an occupation through caregiver assistance" (n = 43), which made explicit reference to the caregiver teaching the child how to perform an occupation when doing the occupation (e.g., "helping him learn how to feed himself"). The second category, "Practicing and repeating an occupation" (n = 22), involved the child working on an occupation (e.g., "practicing putting blocks in and out"). The third category, "Acting and learning through imitating" (n = 14), included the child imitating a caregiver, sibling, or peer (e.g., "my child will mimic my own teeth brushing motions and brush better than if I leave him to brush").

#### Discussion

This study extends current knowledge about the scope of participation-focused strategy use for young children receiving early intervention. Results provide further knowledge on core constructs and their interactions as depicted in the fPRC framework and support the use of this coherent conceptual framework by practitioners to design participationfocused practice with families.

#### **Unpacking Complexity to Design Participation-Focused Early Intervention**

Study results confirm that caregiver strategy use is complex (Ausderau et al., 2019; Jarvis et al., 2018). Nearly 20% of the responses consisted of two or more strategies targeting constructs in the fPRC framework. As analyzed, all four participation-related constructs of the fPRC framework were relevant to families when strategizing how to best support their young child's participation at home and in the community. In addition, each participation-related construct contained multiple categories describing how caregivers target the construct through strategies.

Although the overall strategy scope was broad, nearly half of caregiver strategies targeted the extrinsic participationrelated construct, that is, the child's environment or context. Similarly, the environment has been reported on as a primary focus in prior studies examining children's participation in an educational setting (Benjamin et al., 2017; Killeen et al., 2019) as well as among caregivers of children with physical disabilities or surviving critical illness (Jarvis et al., 2018; Killeen et al., 2019). Together, these findings reinforce the importance, and familiarity, of environmentally focused strategies to families when supporting a young child's participation across multiple settings and regardless of diagnosis.

Sense of self was the most commonly targeted intrinsic participation-related construct. The strategies used focused on increasing a child's perceived comfort, confidence, or sense of freedom and engaging the child in part of the occupation or as a helper to build a sense of self-worth. These results confirm prior literature on the importance of children feeling valued and valuable, competent, and autonomous to motivate their participation (Almqvist & Granlund, 2005; Imms et al., 2017; Ryan & Deci, 2000). Occupational therapy assessments such as the Pediatric Volitional Questionnaire (Basu et al., 2008) assess parts of a child's sense of self. Collecting information on caregiver strategy use to promote participation may naturally elicit similar information about a child's sense of self because this construct affects participation in occupation. Hence, this approach may allow occupational therapy practitioners to collect information on sense of self in relation to participation without administering additional assessments.

#### Translating Findings to Optimize Family-Centered and Participation-Focused Interventions

Our findings about the complexity of caregiver strategies may help explain the challenges that practitioners experience when working with families to develop participation-focused strategies for goal attainment (Anaby et al., 2015). Findings may also provide clues for optimizing interventions under development. For example, the electronic application Participation and Environment Measure–Plus (PEM+) builds on the YC–PEM results, including results pertaining to caregiver strategy use, to support caregivers in prioritizing their child's specific participation needs, setting goals, and searching for strategies to attain their goals (Jarvis et al., 2019; Khetani et al., 2017). Although promising, PEM+ acceptability results highlight the need to optimize its strategy search functions (Jarvis et al., 2020). Our findings could be used to restructure this PEM+ feature before further testing to facilitate navigation through strategies across the four participation-related constructs when seeking ideas to support goal attainment.

## **Implications for Occupational Therapy Practice**

The challenge for both caregivers and occupational therapy practitioners in supporting home and community participation of children receiving early intervention is to use information learned through a detailed examination of caregiver strategy use, such as that presented by this research, and then identify and provide opportunities and supports for children and caregivers to learn together through participation-focused interventions. One of the advantages of highlighting where varying caregiver strategies fit into the fPRC framework is that it allows caregivers and practitioners to be purposeful about their intent during intervention. For example, to support participation for some children, or at some times, it may be necessary to focus on developing a child's strong sense of self rather than on building activity competence. Thus, strategy selection (or emphasis) can be tailored purposefully.

Occupational therapy practitioners can benefit from this study's evidence on caregiver strategy use to support children's home and community participation by anticipating common areas of caregiver expertise to elicit participation-

focused practice with families. There are three immediate implications of these study results for occupational therapy practice:

- Caregiver strategies may range across the four participation-related constructs, within a construct, or both.
- It is beneficial for practitioners to ask about caregiver strategies to modify the child's environment or context to support home and community participation because study findings show that these strategies are the most common types used by caregivers.
- Collecting participation-focused caregiver strategies may be a valuable way to gain information about participation-related constructs and to support targeted intervention planning in early intervention.

## **Limitations**

Study findings are constrained by the data collection methods used. Although the YC–PEM supported efficient data collection on strategy use across a broad range of occupations, the strategies described were brief compared with what may have been elicited in a semistructured interview, which is standard practice in early intervention (McWilliam, 2009). The brevity of the open-ended responses, coupled with the lack of opportunity to clarify with the caregiver, could have increased the number of strategies that were screened out or misinterpreted and additionally affected knowing whether strategies promoted involvement or attendance.

This study was conducted with a subset of data from a pilot implementation study with no information on children's specific disabilities. This information could have enhanced the interpretation of our results. In addition, it is possible that using the fPRC framework limited or narrowed the interpretation of the findings. However, all the reported strategies could be mapped to the fPRC constructs, and all constructs had at least one strategy mapped to them, suggesting that the fPRC provides a useful framework for exploring strategy use to support participation. The transactional verbs identified in the fPRC framework were also evident in our data, although it is acknowledged that other verbs may have been elicited if a more in-depth data collection method had been used.

#### Conclusion

This study extends prior knowledge on the complexity of caregiver strategy use to support young children's home and community participation. All participation-related constructs (i.e., environment or context, sense of self, preferences, and activity competence) were represented in the strategies described in three or more ways and were connected to the dual transaction terms associated with the constructs. This knowledge can help occupational therapy practitioners to better understand the range of strategies that families may use, support others to use strategies they may not have considered, and contribute to planning participation-focused early intervention. Future research is needed to examine the longitudinal transactional processes that support children's participation over their lifespan. Questions could relate to whether the number, the complexity, the focus of strategies in the fPRC framework, or the manner in which strategies are blended changes over time and to what effect.

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Appendix. fPRC Framework Constructs

**Transaction** Regulating Regulating Perceiving Providing Providing Engaging Engaging I've shown her how to use two hands to lift dishes out I have him carry a few pieces of laundry and place them Follow routines suggested by [occupational therapist]. and movements that he finds entertaining. He has this same role every time and now understands how to do it Swim lessons: Mom and dad still participate in these We've tried giving her smaller portions at a time, as well also give him wet wipes and point to the area on my For feeding, I give him his own spoon and I have a I will wipe down his high chair after he eats, then give into the washing machine. He'll help press the buttons, have used a lot of bringing him along in the process. him the washcloth to wipe down the high chair himself. then we watch the laundry start to make the sounds Constantly search for affordable classes and activities showing him what comes next. This has been super Talking to him about what to expect. And then also Trying to make her feel comfortable in the situation as arranging her food and place setting in different We try to continuously encourage our daughter to We frequently visit a number of neighborhood Giving him his own seat at the movie theater. face that he needs to wipe on his own face. second spoon I actually use to feed him. Singing songs while putting away toys. interact more in community events Example classes in the water with him. nelpful at bedtime. of the dishwasher. playgrounds. Table A.1. Caregiver Responses: Categories, Subcategories, Examples, and Transactions for Each fPRC Framework Construct ways. Improve confidence through exposure to new things or giving Make a physical change in location to increase attendance (53) Child helps the caregiver with an advanced occupation (21) Bring items (tangible objects, songs) into the environment (68) occupation or before caregiver will do the occupation (16) Caregivers, siblings, or other children are modeling (52) Engage child in the occupation after caregiver does the Provide encouragement and positive reinforcement to Explain/show the child what is going to happen (30) Arrange space/time to support participation (24) Organize or plan physical change in location (3) Engage child in part of the occupation (39) Create, maintain, or adapt routines (46) Bring people into the environment (34) Provide cues in social environment (9) Subcategory (n) more freedom to the child (12) Get the child comfortable (24) the child (44) Intentionally arrange or include items and/or people (126) Set the scene: Provide predictable environmental Increase child's perceived comfort, confidence, Give the child a set helper role in an advanced Facilitate a physical change in location (56) Letting them experience a part (55) Category (n) Model or provide cues (61) structures or routines (76) or freedom (80) occupation (49) **fPRC** Construct Environment/ Sense of self Context

# Research Article

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Continued)

Asking [child] to help move the wet clothes into the

Ask the child to do something to enable contribution (28)

without prompting.

dryer and taking the dry clothes to the bedroom.

(Cont.)
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Examples
Subcategories,
Categories,
Responses:
l. Caregiver
Table A.1

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<b>fPRC</b> Construct	Category (n)	Subcategory (n)	Example	Transaction
Preferences	Incorporate child's interests through fun games and/or things the child likes (64)	Involve the child's likes or clear interests (40)	He really enjoys playing with water, so when I need him to wash his hands, I let him stand on the step stool at the sink and play with water in a bowl.	Choosing
		Make participation fun or make the activity a game (24)	Making it a countdown game: how fast can he pick up toys by the time I count to 100.	
	Communicating clear expectations (27)	Repeat requests (3) Talk about or show what is expected of the child (14)	Repeating requests: "find your shoes." We discuss that all members in the family must	Complying
			contribute to the functioning of the family. We have age-appropriate expectations of her just as [we do of] her brother. As she gets older, we will expect more.	
		Insist the child participates (10)	Having him stand up while getting dressed so that he has to lift his feet, etc., and doesn't have the option to just lay still.	
	Offering choices and letting the child choose (23)	Give choices and provide options to the child (9)	Giving a choice for diaper changing—laying down or standing up.	Choosing
		Let the child decide or choose (14)	I put out costumes and allow her to choose to wear one if she wants.	
	Respond to actions with rewards or punishment to support or reinforce expectations (12)	Clear, extrinsic tangible rewards (6)	Using rewards for good participation.	Complying
		Negative reinforcement (3) Bribing (3)	Not picking her up. Most of these are all bribery.	
Activity Competence	Learning an occupation through caregiver assistance (43)	Learning while doing through caregiver assistance (43)	Hand-over-hand brushing of teeth and washing of hands.	Learning
	Practicing and repeating an occupation (22)	Practicing or working on an occupation (17)	Have her practice certain "moves" at home during the week so she hears about them.	Acting
		Repetition (5)	We practice with a knife and fork whenever we can, as far as eating.	
	Acting and learning through imitating (14)	Child is imitating or copying caregiver, siblings, or peers (14)	Just letting him do and see what I am doing.	Acting
<i>Note</i> . Examples al Constructs.	re quotes from caregivers. Transactions are described usi	ng the verbs contained in the fPRC that indicate the transactional	exchanges among constructs. fPRC = family of Participal	tion-Related