

Running Head: Learning Adaptations Families Make

Physical and Social Adaptations of Families to Promote Learning in Everyday Experiences

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Abstract

The purpose of this study was to inform early intervention practice by exploring the various adaptations families make to promote their children's learning, the supports they perceive as helpful in creating adaptations, and the supports they perceive as still needed. Holistic case studies were developed of five families of infants and toddlers with disabilities or developmental delays. Resulting conclusions were that families (1) created adaptations according to their goals, their child's developmental characteristics, and environmental factors; (2) relied primarily on their own knowledge of their child; (3) most frequently used responsive caregiving strategies and adapting the requirements of, or instruction for, participation; and (4) applied intervention guidance in various ways. Resulting recommendations for early intervention practices are described.

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Recommended practices in early intervention advocate for supporting families as the primary facilitators of their child's development. These supports do not replace what the family is already doing, but enhance the family's existing strengths (Dunst, 2000). To achieve this aim, interventionists must understand the family's current approaches to promoting their child's development, as well as the kind of support they desire.

Facilitating child development through everyday experiences, or routine activities, is a natural part of the parenting process (Bornstein, 2002; Dunst, Trivette, Humphries, Raab, & Roper, 2001; National Research Council, 2000). These experiences are the contexts in which children develop in general, as well as learn about family cultural norms, perspectives, and functioning (Diamond & Kontos, 2004; National Research Council, 2000; Turnbull, Blue-Banning, Turbiville, & Park, 1999). Families of children who are typically developing create these learning opportunities by considering their child's individual characteristics, such as temperament, interaction and communication style, activity level, and interests. For families of children with disabilities, "the challenge ... is to figure disability into their knowledge of their child's personality, temperament, likes and dislikes (Gilkerson & Stott, 2000, p. 46)." While all families create learning opportunities for their children, families of children with disabilities may feel less competent in doing so, a support that can be provided by early intervention (Jackson & Turnbull, 2004).

Developmental Promotion in Ecocultural Theory

Ecocultural theory contends that all families organize their life to meet the needs of individual family members as well as the family as a whole (Bernheimer & Keogh, 1995; Gallimore, Weisner, Bernheimer, Guthrie, & Nihira, 1993; Gallimore, Weisner, Kaufman, & Bernheimer, 1989). The ways families purposely structure routine activities represent the cultural

context of their family – their values, beliefs, and, more concretely, economic and social resources. Parents are quite deliberate in establishing routines that (a) meet the functional aspects of daily life, (b) reflect their beliefs about their children, and (c) are aligned with their goals for their children (Bernheimer & Keogh, 1995; Gallimore, et al., 1989; Kellegrew, 2000).

One family task is designing routine activities to promote child development (Gallimore, et al., 1989). Survey and case study research investigated these routine activities and found an average of over 110 learning opportunities available in everyday life (Dunst, Hamby, Trivette, Raab, & Bruder, 2000). For families of children with disabilities, the construction of learning opportunities in routine activities may be more deliberate and require more effort as they consider their child's unique needs (Bernheimer & Keogh, 1995). Interventionists can support this process by collaborating with families to identify appropriate social and physical adaptations for learning.

Social and Physical Adaptations

Years of early intervention research have resulted in social and physical adaptations that promote child learning and development (Mulhearn Blasco, 2001). Adaptations are modifications to the social and physical environment attuned to the unique characteristics of the child to facilitate participation, exploration, and discovery.

Responsive caregiving, where an adult tailors her or his interactions by accurately reading and responding to the child's unique communicative cues, are social adaptations (Campbell, Milbourne, & Silverman, 2002; Trivette, 2003). Studies have found that responsive caregiving strategies are related to the cognitive, social-emotional, and emergent literacy development of children with disabilities and developmental delays (Dodici, Draper, & Peterson, 2003; Mahoney & Perales, 2003; Trivette, 2003). Three primary components of responsive

caregiving have been identified in the literature – (1) contingent responsiveness, where the adult response is dependent on the child’s initiation and intent; (2) sensitivity, where the adult is attuned to the child’s individual characteristics including temperament, mood, and regulatory needs; and (3) engagement, where the adult initiates and/or sustains the child’s active involvement in play and other routine activities (Dodici, et al., 2003; Kelly & Barnard, 2000; Kim & Mahoney, 2003; Trivette, 2003).

Physical adaptations can be made to the general environment, activity, materials, requirements of participation, and/or level of assistance (Campbell, 2004). Physical adaptations can facilitate independent exploration and play and decrease adult interference in the child’s self-discovery (Doctoroff, 2001).

The field of early intervention has the knowledge resources to facilitate child learning through social and physical adaptations. This knowledge can be helpful to families, provided that the recommendations are aligned with their parenting beliefs, values, and culture, and are individualized to their interaction style, childrearing knowledge, and ways they promote child development (Bernheimer & Keogh, 1995; Mahoney et al., 1999; Woods, Kashinath, & Goldstein, 2004). In order to create strengths-based interventions, practitioners need to understand the family’s current capacities and, more practically, what developmentally supportive approaches the family is already using. Very few studies have examined the specific adaptations families make to promote child learning in everyday life.

In the occupational therapy literature, two qualitative studies examined the physical adaptations families made for their young children. The studies were situated in the conceptual framework that supporting child learning is a family “occupation.” Kellegrew (2000) examined the self-care routines of six mothers and their toddlers (28 to 32 months) with disabilities. The

study found that the mothers adapted routines according to their personal childrearing style and consciously provided learning opportunities that addressed their current goals for their child, as well as the perceived competencies necessary in future environments. Adaptations were adjusted daily, depending on the child's varying strengths and needs of the day.

In a longitudinal study, Pierce (2000) explored the physical management of play space for 18 mothers and their typically developing infants over the first 18 months. Findings indicated diverse play space management techniques were used depending on the types of play objects available, level of parenting experience, access provided to different play objects (e.g., kitchen cupboards), child's age, and location of play space (e.g., inside versus outside). Commonalities across families included the conscious provision of play objects that, after one year of age, addressed specific learning opportunities, distinct adaptations that allowed for safe exploration but also maintained order, and placement of play objects depending on the child's mobility. All mothers responded to their child's developing competencies by adapting their management of space and objects.

These studies illustrate the very conscious ways families support their children's development. This information, unique for each family, is critical to understanding the family culture and building on existing developmental promotion strategies. The purpose of this current study was to inform early intervention practice by exploring how families meet their parenting goal of fostering child development. This study examined the adaptations families make, how they figured out those adaptations, the supports they perceive as helpful in making them, and those they perceive as still needed. With this knowledge, interventionists can tailor their support by building on what the family is already doing and their perceived resource needs.

Methodology

Holistic, collective case studies were used for intrinsic and instrumental purposes. Stake (2003) identified intrinsic case studies as those used to understand the nuances of a single case, while instrumental case studies look across cases to understand a particular topic. The cases were examined for both purposes, to illustrate each family's individuality and their commonalities.

The following research questions guided this study:

1. How do families create adaptations to promote child development?
 - a. What types of routine activities do families identify as learning opportunities?
 - b. What kinds of adaptations do families make to support child development?
 - c. What supports do families identify as resources in creating adaptations?
2. What supports do families report as needed but not received?

Recruitment

An early intervention agency partnered with the researchers in recruitment. Agency leadership identified families who might be interested in participating and met the inclusion criteria. The family's service coordinator or interventionist informed the family about the project and, if the family was interested, obtained permission to provide the researchers with family contact information. The first author conducted a preliminary phone conversation with the family to describe the study, answer any questions, and secure verbal consent. Before the first observation, the first author reviewed participant rights and obtained written consent.

Sample

The sample consisted of five families who were eligible for early intervention due to their child's disability or developmental delay. Families eligible for early intervention due to risk factors, but whose child was not currently evidencing a delay, were excluded from participation.

One family from each of the following age ranges was purposely sampled: (1) 6-12 months, (2) 13-18 months, (3) 19-24 months, (4) 25-30 months, and (5) 31-36 months.

One family was identified as African-American; two families were identified as Hispanic/Latino. These three families were bilingual or trilingual, however fluent in English and participated in the study in English. Two families were identified as Caucasian. In four families, only the mother participated; in one family both the mother and father participated. Two of the children had identified disabilities (Down syndrome and visual impairment). Three children were identified with developmental delays; one with an unknown etiology, one with a significant medical history, and one who evidenced characteristics similar to PDD. Four of the children were boys; one participating child was a girl. In all families, the parents were the primary caregiver during the day; no child attended childcare at the time of the study. According to the most recent IFSP, the number of early intervention professionals involved with each family ranged from one to four disciplines, with the total amount of home based early intervention services ranging from 2 to 17 times per month ($M = 9.6$; $SD = 5.77$) for 45 to 75 minutes per visit. One family also received classroom-based early intervention support 7.5 hours per week from the public agency, and private therapy services 12 times per month by two therapists.

Data Collection

Data were collected through interviews, observations, and record reviews. During an initial phone call, families identified routine activities they perceived as times their child was learning, and what specifically their child was learning. These resulting routine activities were the context for observations.

Naturalistic observations of routine activities were conducted during their regularly scheduled time. Observations were used to increase the validity of identifying social and physical

adaptations. It was assumed families might not necessarily identify adaptations if asked directly, as these adaptations could be perceived as typical everyday parenting strategies. The researchers explained they would be “like a fly on the wall” and the family should go about their routine activities as they usually do. Observations were conducted in one to two visits totaling two to four hours. Extensive field notes were taken during the observations.

Physical adaptations were defined as any modifications to the environment, activity, materials, requirements, or assistance given. Responsive caregiving strategies were considered social adaptations when they were based on the unique characteristics of the child. A strategy might be generally used with young children, but was identified as an adaptation in this study if the family used the strategy to meet a specific need. The researchers identified all potential adaptations and allowed the family to determine whether it was indeed an adaptation during the interview.

After the observations, the researchers collaborated to identify all adaptations recorded and conducted a semi-structured, in-person, audio taped interview. For each routine activity observed, caregivers identified “goals” for their child. For each adaptation, the researchers explained the adaptation and asked the caregiver why the adaptation was used and how she “figured it out,” as well as any supports that assisted. These supports could be individuals, such as family members or interventionists, or an object or event, such as books or conferences. Families were also asked to describe any needed supports in helping their child learn.

The two researchers conducted the observations and interviews with three of the participating families. One researcher conducted the observations and interviews with one family. For the remaining family, both researchers conducted the observations and one researcher conducted the interview, but collaborated with the other to identify adaptations prior

to the discussion. Interviews were transcribed verbatim by the first author, with both researchers transcribing one interview where the audiotape was difficult to hear. Each family's early intervention records were reviewed for information pertaining to routine activities and adaptations listed on the IFSP or visit notes.

Data Analysis

Data were analyzed within each case and across cases (Merriam, 1998). For each case, data reduction began by categorizing units of data into routine activities, adaptations, caregiver goals, and identified supports. If a caregiver reported that a researcher-identified adaptation was not used for a specific purpose, that "adaptation" was removed from the analysis. Reciprocally, additional adaptations the researchers did not observe but emerged from the interview were included.

Adaptations were coded according to Campbell's hierarchy of adaptations (2004), with the modification of separate codes for motor adaptations and positioning adaptations (See Appendix). This hierarchy is organized from least to most intrusive adaptations. Adaptations codes were not mutually exclusive; more than one code could be used for each adaptation. Social adaptations were coded as responsive caregiving strategies, and further categorized as engagement, sensitivity, or contingent responsiveness. Codes for the supports used in figuring out the adaptations were researcher-derived prior to coding with additional codes added when a data unit did not fit an existing code. Each researcher separately coded the data, and then compared the coded data and came to consensus on any disagreements. Each researcher independently cross-referenced the coded data with the raw data to ensure there was evidence and that the codes were credible within the context of the raw data. The researchers came to consensus in adding any missing raw data to the tables and removing unsubstantiated units.

Case studies were created to capture the atmosphere and routine activities observed, developmental goals, specific adaptations used and the supports the family identified as useful, as well as needed supports for promoting child development in routine activities. Information not related to these aspects, such as needed transition supports, was excluded from the case studies.

Conclusions were drawn across cases through the constant comparative method (Merriam, 1998). Conclusions emerged during data collection and further refined in data analysis, triangulating the conclusions across the two researchers and the multiple data sources of observation, interview and record review (Merriam, 1998). As with the individual case analyses, the researchers independently cross-referenced the conclusions with the raw data to ensure sufficient evidence across cases.

Findings were validated by peer review and member checks (Merriam, 1998). An audit was conducted by a graduate student familiar with early intervention principles and adaptations, but not directly involved in the study. The auditor reviewed and cross-checked the conclusions and interpretations to the raw data. Member checks were solicited from each family. Three families agreed to participate, who reviewed their case study and the conclusions, and responded to five questions about whether confidentiality was maintained and the validity of the results.

Case Studies

Gregory, 35 months old

Gregory and his mother were observed in their home during afternoon play time, dinner, and the bath and bedtime routine. These routines appeared very structured and playful, with Gregory's mother leading the activities. She appeared to address her language and play goals for Gregory during this play routine. She asked questions related to the play (e.g., "What are we going to name the train?"), made suggestions to expand play (e.g., suggested making an airport),

modeled and verbally described new play schemes (e.g., “Mommy made a bridge.”), and integrated concepts into play (e.g., “Can he go backwards? He’s going forward.”). At the same time, Gregory’s mother was responsive to his initiations and reactions. For example, when she tried to move his lined up blocks, Gregory became upset. His mother allowed Gregory to line up the blocks again. When Gregory left the train play, his mother asked him, “Are we all done with the trains?” It was explained that his mother gives Gregory the choice to continue playing with one toy or clean up before moving on to maintain focus on one play activity at a time.

Multiple goals were consciously embedded throughout every activity. For example, Gregory’s mother identified that her goals during play time were to use verbal skills, engage in two-way play, play productively, learn concepts, self-regulate, build self-esteem, increase flexibility, and “do our homework for this week” suggested by the interventionists.

Twenty-seven adaptations were identified. More than half (n=15) were responsive caregiving strategies, such as modeling play scenarios and asking questions to create engagement, building on Gregory’s interests, providing choices, providing deep pressure for regulation, and praising language and productive play. Most of the remaining adaptations were adapting materials (n = 6) and adapting the requirements or instruction of the activity (n=7). Adapted materials included introducing straws for drinking, something not previously used, and using a transition chart with visual cues. An example of adapting the requirements of an activity was Gregory cutting his own food, an activity his mother would not normally expect a young child to do. This supervised activity with a butter knife was provided to give Gregory control over cutting because it is difficult for him to accept food and other objects in “parts” instead of whole. When Gregory’s mother used a plate with sections for different foods for the first time, she quickly figured out that Gregory was upset when one section was empty, and filled that

section with food [adapted materials] to make the plate “whole.” Adapted instruction for participation included providing verbal and gestural cues, modeling language concepts, verbally preparing for transitions, and consciously changing play and routines to facilitate acceptance of difference or novelty.

Gregory’s mother made adaptations based on her knowledge and understanding of Gregory. The transition from mealtime to bedtime, and the bedtime routine itself, exhibited the sophisticated understanding his mother had of Gregory’s unique learning characteristics. At a certain point during dinner, Gregory’s mother began the transition preparation by making sure all toys were picked up and out of view when Gregory moved from the kitchen to upstairs. This strategy was used to avoid Gregory returning to play and refusing to stop playing for bedtime:

And then I pull out the bed, get his pajamas ready; get everything ready on the bed. His hairbrush, his creams if I’m gonna put on his creams...set everything up. I dim the lights, the CD is ready, the curtains are down, the towel ...I bring the towels so that when he comes up the stairs it’s straight to either the bathroom, and we’ll do that, and then we’ll go straight to the room and everything is ready...I don’t want to give him an opportunity to sit down and start playing.

She explained how she would provide music for him at bedtime regardless of his disability, but had to adapt the type of CD used to calming sounds instead of music [adapted materials], as well as the type of CD player:

I picked the CD because he’s very good with music so if I put anything that’s a song he’ll hum it. He’ll memorize it. So, the CD’s on purpose where...it’s not concrete. He can’t really imitate it all that well. So it works and yet it doesn’t

contribute to the whole unproductive piece... I had to buy a new CD player because the other one you could see the CD rolling and he would watch it.

Many (n=18) of the adaptations observed were reported to be strategies suggested by the early intervention team and/or private therapists. Gregory's mother discussed how she critiqued intervention strategies and then generalized the strategies that were either meaningful to her or that she trusted logically. She explained why she used the strategy of giving Gregory fruit smoothies to drink [adapted materials]:

[OT] told me to get those straws...because it kind of helps work his mouth – oral motor or whatever it is – because he doesn't blow. He has issues here in terms of strength, so that's kind of working.

When asked if she saw how the use of the straw was related to his verbal communication:

No, just working oral – actually drinking from a straw is strengthening his whole mouth area. So it's an exercise within a routine. So now I'm trying to give him everything with a straw.

She related the benefit of straw drinking to her own goal:

He's not eating a lot of – he doesn't eat fruits and vegetables. But now I've realized he likes the smoothie ...I was trying a thicker liquid and he can get fresh fruit right there....

While Gregory's mother did not communicate a connection between straw drinking and oral motor development to her goals around Gregory's language development, she did see how this strategy met her goal of eating more fruits and vegetables. Gregory's mother explained why she used the interventionist's recommended strategy of putting two adjectives together:

I really don't always understand why the next steps, but I follow what they tell me...But I think if something makes sense to me and it's kind of a natural progression. I may not know it's a natural progression, cause I'm not a specialist, but I kind of follow it and it makes sense. If he was doing "big car," now we start working on "big red car." It kind of makes sense.

Gregory's mother described conflicted feelings between family life and intervention recommendations. She specifically discussed feeling like she has to constantly talk to Gregory to promote his language development:

...I tend to be -- in general, I'm not that talkative, communicating all the time. Whereas now I feel you have to be talking all the time and getting him engaged. And so it's hard. And in the car...I just want to listen to music. And we'll go to [the next town over] to see [the speech therapist] and I'll just listen to music. And then on my way back I'll feel guilty and I'll say, "Okay let's talk about the car in front, what is the color of the car in front of mommy's car or next to mommy's car?" So we started working on prepositions, you know that kind of stuff.

Gregory's mother identified washing Gregory's hair as a need. She tried using a cap that keeps the shampoo out of his eyes [adapted materials], but recognized that the issue was not shampoo in his eyes, but a sensory concern. At the time of the observation, she washed his hair twice a week as quickly as possible as a solution. However, this continued to be a struggle.

Isabel, 28 months old

Isabel and her family were observed in their home and backyard in the morning. Her mother stated that Isabel learns throughout the day and identified time spent with her siblings, playing, getting ready in the morning, and eating as learning opportunities. Isabel was observed

playing outside with her father; playing inside with family members using dolls, books, a mirror, and other toys; singing songs; and eating snack. There was no clear delineation among these activities, but instead the family moved casually back and forth among them. Both parents interacted with all the children at different times; sometimes altogether, sometimes with one child at a time. Sometimes, one parent played with the children while the other attended to daily routines such as preparing meals and helping the children get dressed. Even though the morning proceeded in a very relaxed atmosphere, Isabel's parents articulated very clear goals for Isabel in each activity. For example, the goal for playing with toys was stated:

That she will know the function of them. That she will know how to play with them. Learn how to relate to the toy, like how she could – let's say the kitchen – that she'll know it's a little kitchen and that's where you cook....

Other goals included walking, sliding down the slide, learning body parts, vocalizing more and understanding language, keeping focused, eating with a spoon and drinking independently, being aware of who she is and what's going on around her, feeling happy when successful, knowing textures, and stopping pinching, biting, and hitting others. At the same time, goals emerged from Isabel. Her mother described how learning opportunities arose at any time:

Like all of a sudden she'll do something new and we're like oh my gosh, let's work on this. You know she did this new thing and let's just work with that and teach her more... We wait for her so she's ready. She's doing a lot of things on her own and then we move from there. Like I just said, we move from there. We see what we could -- how could we make her do it better ...or learn to do something else with that.

Twenty-nine adaptations were identified. Ten were adaptations to the requirements or instruction for participating in activities and five were adaptations to materials. Examples of adapting the requirements included giving her a spoon to eat traditionally finger foods, giving her small amounts of liquid in an open cup in order to ask for more, and providing oral motor stimulation prior to eating. Adapting the instructions for participation included using verbal reminders, and giving and repeating directions on how to participate. Her parents identified repetition as an important learning strategy for Isabel, especially in learning new words:

I just – I always keep repeating it to her and she kept repeating it back to me.

Sometimes she would say it back to me and I'm like, okay, she can learn this way.

I'm just going to repeat it and repeat it and repeat it. And some days she would say it and some other days she won't...But I know she knows it. Somewhere in her brain those words are there.

Adapting materials included draping a towel around Isabel so she could drink independently from an open cup but not worry about spilling, using a large-handled spoon, using thick foods that stick to a spoon, and hanging a reflective paper on the wall so Isabel can see her mirror image. This last adaptation occurred when her parents noticed that Isabel was very interested in her reflection in mirrors. They believe the mirror promoted using sounds by watching her mouth in the mirror, and promoted independent standing because they hung the mirror so she has to stand to see in it. This also exemplified the several responsive caregiving strategies (n=14) the family used. Isabel's parents were responsive by "watching and waiting" to see what Isabel was interested in, and then joining in the activity by modeling ways to play, taking turns while playing and vocalizing sounds that Isabel initiated, and repeating engaging activities.

Isabel's mother stated that they take their cues from Isabel to figure out how best to help her learn. She explained in book reading:

Now she's putting her fingers on the letters. Like if she'll see a picture, she'll start pointing at it. She makes you think she's reading ... I [point things out to her in books] more now because now I see that she can retain more of her attention. As to before, it was just so difficult she would just like, she'll move on, because with her, her attention span is very short... To be honest with you, [her attention to sitting and reading] is something that she came up with; it's something that she evolved on her own. You know it's something that she's done on her own.

The family also drew from their experiences with Isabel's older siblings, written information about her disability, and early intervention. The family spoke about how they supported language development for each of their children:

We talk a lot with her. I mean, we've done that with all [the] girls. We talk to them because I understand that that's how language is formed. You don't talk to a child, then that child's not gonna talk back because she doesn't hear words – doesn't hear sounds so has no knowledge of it.

The family discussed how this strategy was adapted to Isabel by using simpler language than they used with their other children at this age [responsive caregiving and adapted instruction]. The family specifically read touch-and-feel books to Isabel so she could touch different textures. This strategy resulted from information obtained from books and their early interventionist about the need for sensory exploration. Other adaptations from early interventionists included the adapted spoon, oral motor exercises, and use of thick, sticky foods. Isabel's parents explained that the strategies provided by early interventionists need to make

sense for them to implement. For example, an interventionist told Isabel's parents to focus on standing and sitting down, and avoid walking until she shows more readiness for the skill. While they do use the strategies related to standing and sitting, they also encourage her to cruise or walk holding their hands. Since their goal is for Isabel to walk, they believe that she needs practice in order to learn how to walk.

Isabel's parents expressed areas of continued support to help Isabel learn. They specifically identified the need for strategies to decrease Isabel's tongue thrusting and teeth grinding. They also identified a need for materials, specifically a mirror that is clearer to see in, but safer than a glass mirror, to replace the cloudy, paper "mirror" they are currently using.

Will, 20 months adjusted age

Will was observed during dressing, eating, playing indoors, reading books, and playing outdoors. While Will's mother identified meal time and play time as important routine activities for learning, she stated that every routine activity was a learning opportunity. She explained that, since Will is "blind," the adults in his life, including his mother, father, and babysitters, constantly help him understand what is going on around him or with him. Will's mother or one of his babysitters facilitated each activity observed, either with Will alone or with one or more of his siblings. During the observation, the adults appeared deliberate in their caregiving and interactions with the children, however the activities and transitions between them seemed fluid and casual. The busy day progressed at an even pace, appearing to meet the needs of each child individually as well as the needs of the family as a whole.

Will's mother articulated overarching goals with regard to Will's learning and development: "The goals for him are the same for any of our other kids really...We have high expectations for him and treat him like any other child in our family" and "I want him to be

aware that he has siblings and that there are other people in this house.” Specific goals articulated during the interview were functional to participating in everyday life, such as (1) independently dressing, eating, playing, and navigating his surroundings; (2) exploring the world by knowing what to do with toys, “hav[ing] a sense of what a book is,” and “be[ing] out and about;” and (3) being engaged and self-regulated. Will’s mother identified specific immediate goals as well, but they appeared to be steps to meeting these larger goals. The observed adaptations addressed meeting these goals, as well as the overarching priorities.

Twenty-seven adaptations were identified, most of which were responsive caregiving strategies (n=9), adapting the requirements or instruction of participation (n=6), environmental accommodations (n=6), or adult help (n=5). Since his babysitters partner with his mother in the everyday functioning of the house, and are aware of the family’s goals and related strategies, the adaptations applied by the babysitters were included in the analysis. The babysitter was observed to ask Will’s mother the specific strategies to use while Will was eating.

Responsive caregiving strategies included picking Will up to soothe him, constantly engaging him in activities to avoid self-stimulation, and verbally explaining and verbally preparing him for events going on around him or to him. For example, Will’s mother verbally explained that it was his sibling playing with a toy instrument, that he was sitting on the floor, and that his sibling was at the table alongside him. Will was verbally prepared for movement, something being given to him, and sounds he did not like, such as the nebulizer and vacuum. Verbal explanation and verbal preparation were used because:

It’s...been drilled into our heads by the therapists and the books and everything that the only way he’s going to learn about his environment and learn about

things is by people talking to him and showing him with his hands. At this point ... I don't even know I'm really doing it.

Will's mother has found these strategies to be effective:

It took a long time. Every time we would pick him up, we would lift his arms up and say, "We're gonna pick you up." So now if I say, "Will, Mommy's gonna pick you up" his arms go up.

Adaptations that modified the requirements of participation included having Will feel the bowl and food with his fingers before eating, smelling the food on the spoon, touching the spoon to his lips to initiate opening his mouth, and rubbing his hands over Braille letters while reading a book [also adult help]. As he felt the Braille letters, Will's mother asked him, "do you feel words?" or to "find the words." She explained this adaptation:

You know a lot of the books out there for little kids are very touchy feely books that have the texture in them or feel the fur of the animal or whatever. So, for him, you know it's just, it doesn't mean anything. It has no meaning to read these books. He can't see any of the pictures. He can't see, you know if I say "the elephants" – you know – what's an elephant? ...If I can -- while he's reading -- give him some sense that there is something on this page that he can be feeling that has a meaning for him, which clearly doesn't mean anything right now. It just feels like a bunch of dots. But it's getting his finger tips aware...

After reading each page, Will's mother paused as if to wait for Will to turn the page. She explained this responsive caregiving strategy:

If I read a book to [sibling] ... you sort of read the book and then you pause and let them look at the pictures ... Probably a little subconscious, but I'm also trying

to get that idea that, okay I'm done talking, now it's time to turn the page. He's not quite there yet so sometimes I'll just sort of wait and then I'll say turn the page and he'll turn it.

Putting his hands over the Braille letters and waiting before turning the page were used so Will could participate in reading the way other children his age do.

Environmental accommodations included bringing inside toys outside for engagement, sitting on the grass to balance on uneven surfaces, keeping the television off to reduce artificial noise that detracts from understanding the noise in his surroundings, and keeping everything in the same spot because “he does have a mental map of where everything is.” She described why the latter adaptation is important for Will based on his individual characteristics versus his disability:

If all of a sudden I were to put him at his table out in the middle of the floor, you know he sometimes will push on his table and it moves up against the wall. If it was in the middle of the floor he would push on it and it would keep moving. You know for now it's better for him to have sort of...a sense of space.

Adaptations where an adult provided assistance included hand over hand assistance when picking up Cheerios and puzzle pieces. The specificity of how hand over hand assistance was provided was clearly thought out. For example, during his first exposure to a puzzle, Will's mother used his current scheme of raking to grasp the knob and pull the pieces in and out of their forms rather than facilitate a pincer grasp as expected by the early interventionist. Will's mother explained that the pincer grasp will:

Come later. Right now it's just really trying to get him aware...and make him understand that he can do things. He's capable.

Will's mother attributed figuring out adaptations to parental instincts:

I think it's just us being able to read him as his parents ... So for us I think it's just being his parents and his caregivers and just being with him all day long and being able to read him – his cues from him.

and looking at how Will can achieve a goal or participate in routine activities according to his individual characteristics:

It's just always the only thing that's ever gone through my mind when I'm doing any of this stuff is getting him to do it himself. Getting him to understand that there is something in front of him...It's the same thing no matter what it is. Because he can't see it we have to help him to know that it's out there. And the way to do that is showing him with his hands.

Will's mother obtained information about Will's disability and his own learning characteristics from a variety of sources -- early interventionists, written resources, and conferences. She was aware of the "fairy godmother syndrome," sensory and self-stimulatory behaviors, and general intervention strategies common for children with visual impairments. She then used the information to tailor her own individualized adaptations for Will. For example, when an early interventionist recommended that Will experience raising and lowering his arms, Will's mother Velcroed a toy to a small stool [adapted material] so he would have to lift his arms to play with it. While Will's mother discussed the strategies and suggestions given to her, she did not use them if they did not "fit" her knowledge of Will as an individual. For example:

People will say you should never approach a blind person or a blind child from behind. But I, you know, we do it – it doesn't bother him... We don't see any difference if we're telling him we're picking him up whether we're picking him up

from behind or whether we're picking him up from the front. So, a lot of it I think, like any child, is part of their personality.

Will's mother figured out adaptations using her knowledge of Will, his interests, and information gathered from different sources. She reported no additional needs with regard to supporting Will's learning and participation in everyday life.

Kyle, 17 months old

Kyle and his family were observed in their home while Kyle was eating and playing in his highchair, and playing in the living room with his mother and sibling. Kyle played with different toys, read books with his mother, danced, and walked around the house and on the couch. His mother identified these routine activities as important learning opportunities. The atmosphere appeared casual and free-flowing. For example, while eating, Kyle's mother sang and talked to him, moved his highchair so he could watch his sibling dance [environmental accommodations], and gave him a toy to play with before redirecting back to eating.

Most goals articulated were specific competencies, including walking, holding, and playing with toys, holding the bottle and spoon, eating with a spoon, and looking at pictures in books. Other goals were more general -- to do things on his own, talk, enjoy activities instead of cry, and pay attention.

Thirty-two different adaptations were identified, more than half (n=18) of which were responsive caregiving strategies, which were used to either support Kyle's learning or help him remain regulated. Kyle's mother imitated the sounds that Kyle produced and translated the sounds into functional words, such as his sibling's name and "da-da," to facilitate language development. She gained Kyle's attention by calling his name repeatedly using different tones of voice and intonation, and using auditory strategies such as snapping her fingers, and tapping the

table and two blocks. She encouraged further engagement by providing positive reinforcement, encouraging him to “do one more” and to “try again,” providing ample time to explore each toy on his own, and setting up toys so he could be successful before challenging him with a more difficult task. When attempting something challenging, Kyle’s mother would frequently use hand over hand assistance [adult help]. When Kyle would pull his hands away from his mother’s hands, she respected his resistance and waited before trying again. She recognized Kyle’s medical history and the amount of energy he expended when attempting challenges:

Kyle is scared. It’s like he don’t want to do nothing. He’s scared to do everything. It’s normal because [he] has a breathing problem. He tried to breathe – [it’s] too much for him and then he has to work for that...

There were 14 adaptations coded as modifying the requirements or instruction of an activity; many were also considered responsive caregiving strategies. Kyle’s mother adapted the requirements of activities by putting the spoon to the side of his mouth to chew, putting the spoon in his line of vision to help him attend, and playing on the couch since he is motivated by the light behind the couch and walk towards it. His mother primarily spoke English to him, chosen because of her experiences with her older child:

Because for [my older child] it was difficult to talk because I was speaking to her in my language, English and [another language] ...she was 1 year and 4 months and she was not talking at all because too much language. They told me “That’s not good, you have to use one language with kids.” With Kyle, just English.

Other notable adaptations were using a spoon that flashes a light [adapted materials] to focus his attention, and showing his sibling strategies to interact with him [another child help], such as dancing with him, giving a “High 5,” and holding his hands to support walking.

Kyle's mother attributed learning to Kyle himself; that he would develop at his own pace:

When [early intervention] comes again and she's gonna find Kyle did something new, but that did not come from her. It come from Kyle. ...It did not come from me. It come from Kyle.

When asked about the strategies she used in general, Kyle's mother stated that they came from Kyle as well. When asked about specific adaptations, she attributed one-quarter of the adaptations to reading and knowing Kyle; and one quarter from early intervention. It appeared that, based on her specific experiences with Kyle, she used her understanding of his interests and learning characteristics to facilitate Kyle's development, as well as knowledge gained from being a member of a large family, previous experience as a child care provider, being a mother of an older child, and working with early interventionists. She explained:

I used to work with the kids and I come from a big family ... you don't need to learn much because I grow up with a big family. You have a baby and you know.

Kyle's mother explained that intervention supports were most helpful when they model specific strategies and then provide an opportunity for her to try them out. Early intervention was less helpful when strategies were only described to her, or when the interventionist tried them out but without success. Kyle's mother was in the process of finding child care for Kyle as she felt he could learn best by being with other children.

Brian, 6 months old

Brian, his mother, and older sibling were observed while Brian was playing, eating, reading books, diapering, and being held. His mother explained there were no set times when Brian was learning. Instead, learning opportunities were times in the morning and afternoon when she and his older sibling get on the floor with him, when Brian is "hanging out on his

own,” when his sibling is napping, and when her husband comes home. Learning opportunities included learning how to communicate and progressing in his overall development.

Eating, more specifically taking a bottle, was a particular learning opportunity. Brian’s mother identified the long term and immediate goals around eating:

...how to suck and swallow food. So, right, just the eating and want[ing] different tastes and textures and learning to eat healthy food. And want healthy food. But then also the social part of it, which I think with [his sibling] around -- although he’s not eating with him yet. So a goal would be to sit there with us and learn how to eat with people. But that’s a little far away. So immediately would just be, I mean gosh just taking a bottle would be a huge thing.

She identified specific motor goals of reaching for things, rolling over, sitting up and being on his stomach. Brian’s mother articulated the importance of these goals from a motor standpoint, but also related them to play and other routine activities:

To be able to strengthen his arms and his shoulders and his neck...to be able to push up cause that’ll help him roll and sit up and all that stuff. And then just to be able to stay like that longer. Have a little bit more endurance...And then it’ll help him be able to play and entertain himself and things like that.

Thirty adaptations were identified. The most frequent adaptation type was responsive caregiving strategies (n=8), followed by adult help (n=7), adapting materials (n=6), positioning adaptations (n=5), and adapting the requirements or instruction of an activity (n=5).

The day appeared to be structured around responding to the children; activities occurred according to the communicative cues of one or both of the children. Responsive caregiving strategies included holding Brian when he became fussy, putting the spoon to his lips and

waiting for him to initiate, trying not to surprise him to maintain regulation, and talking to him about what he appeared to be looking at. Brian's mother explained why she talked to him throughout their activities:

I just do it without thinking about it. But, I think it's a good idea because of their language development and ... their brain, their communication ...help them learn to request their needs.

Adult assistance included motor support, such as helping Brian roll over, moving his legs in a reciprocal motion while on his back, and pulling him up to a sitting position, which occurred from an incline of two big pillows [adapted material]. While sitting, Brian's mother sometimes put her hand on his chest and one on his back and straightened him out as he was sitting up [positioning adaptation]. She explained she does this to show him:

How it feels to sit up straight...And he's so close to doing it. If he's kind of holding himself up but not all the way, then giving him that little bit of help cause then maybe he can hold himself up better.

Examples of adapting the requirements or instruction of an activity included putting objects on his chest or to the side of him so he could grasp them "even if it's accidental." To help with manipulating objects, Brian's mother placed plastic rings into his grasp [adult help] and sometimes looped the ring around his thumb. This was purposely done:

Just to keep it in his hand...because sometimes he doesn't grab so I'm just like, well if it's there and decides to check his hand, then he'll have it.

This strategy also frees Brian's mother to attend to other things around the house for a moment, as she knows the rings are available for Brian and will not fall out of reach.

Brian's mother primarily used trial and error to determine adaptations, based on her hypotheses of Brian's needs or intervention recommendations. To facilitate drinking from a bottle, Brian's mother tried various bottles [adapted materials] to find one he might latch onto. She pumped fresh milk into bottles [adapted materials], hoping to motivate him. She used a sippy cup [adapted materials] with some success, and positioned him in different seating options, hoping he would be comfortable in one [adapted requirements]. She found that Brian ate best when she held him. In fact, "he pretty much does better when I'm holding him for everything." Brian's mother also tried different pacifiers to see which one he would keep in his mouth best [adapted materials]. She described her rationale for using a pacifier [adapted activity]:

My whole thing with the pacifier is -- cause I don't think he needs it so much to sleep or anything like that -- but just I figure if he can put that in his mouth, and that's different than me, then maybe he'll drink a bottle. You know to have some other something in his mouth. And so, help him with food and a pacifier, the more different things he has in his mouth, I'm hoping he'll take a bottle.

While the routine activity of sucking on a pacifier is not important itself, Brian's mother used this activity to address other goals. Hypothesized trial and error problem solving was also observed in play. Brian's mother bought a plastic mat that is filled with water with objects floating in it [adapted material]. She described her thought process:

I thought it might interest him a little. He might look at the colors ...and maybe he'd like it and maybe stay [on his stomach] longer. So that was the whole idea behind it...I just saw it in [a store] and thought, "Hmm, that's something different. It's on the floor. He's supposed to be on the floor." So I just thought I would try it.

Brian's mother explained that she identified adaptations with the help of early intervention services and a friend with children with developmental delays. However, she and her husband primarily figured out adaptations on their own. Sometimes, early intervention recommendations were modified. For example, in previous home visits, the interventionist propped Brian on a pillow to spend time on his stomach and demonstrated how to use a rolled towel under his stomach to see if it would aid Brian in forward movement. Brian's mother combined these strategies by putting the towel under his shoulders to prop him up on his stomach [positioning adaptation and adapted material], which was somewhat successful.

Brian's mother felt that she and her husband had figured out how to facilitate Brian's learning and development in routine activities. One identified area of support was knowledge of developmentally enhancing materials.

Conclusions

Analysis of the case studies resulted in the following conclusions:

Where/When do parents help their child learn?

Families clearly perceived their child to be learning throughout the day but did not specify every time during the day where learning occurred. During the pre-observation interview, families commented that there were no set times or specific routine activities for learning, but that their child was learning throughout the day. For almost every family, routine activities not identified in the pre-observation interview were observed. For these routine activities, as well as those previously identified, learning adaptations were observed and families reported clear goals and priorities for these routine activities.

Family goals and subsequent adaptations were used and integrated across routine activities. While families identified goals for each routine activity, some goals recurred in

different activities and some goals were unique to one routine activity. Goals that spanned routine activities were related to language/communication, mobility, learning about the world, regulation, play skills and social interaction. Families appeared to make adaptations according to the goals they had for their children within and across activities. Unique goals were specified for the routine activity of eating. The process families undertook to determine how to help their child learn appeared to be iterative rather than linear, with families addressing their goals by making adaptations within the context of the activity. The process of making adaptations did not seem to be driven by the routine activity or the goal alone, but by both the goal and the activity.

What do parents do to help to their child learn?

Families consciously used a variety of adaptations to support their child's learning and development and address their specific goals. The participating families made 27 to 32 learning adaptations within the two to four hour observation period. Regardless of the child's age and type of disability, families made multiple adaptations for each routine activity.

Responsive caregiving strategies, specifically sensitivity and engagement, were most frequently used to support child development. Contingent responsiveness was less frequently used. The second most frequently used adaptation was modifying an activity's requirements or instruction. Families appeared to use their knowledge of their child, their goals for their child, and the characteristics of the activity to make these adaptations. While some goals had multiple adaptations, there were other goals in which no adaptations were observed or the adaptations were unsuccessful.

The frequency of using adapted activities or materials, adult or child help, or environmental accommodations, varied. Positioning and mobility adaptations also varied, but

could not be attributed to the child's current mobility competencies. No family made adaptations by having the child do something different or do something outside the activity.

Families clearly read and responded to their child's individual learning characteristics when figuring out adaptations. Families frequently cited their own knowledge of their child in determining adaptations. Based on their knowledge of their child, families appeared to observe and hypothesize potential adaptations to promote development, try out different strategies, and then evaluate their effectiveness.

Families discontinued using adaptations when they were no longer necessary due to their child's development. For example, Gregory's mother stopped using a visual transition board when Gregory was able to transition with verbal reminders only. Will's mother stopped covering the play area with colorful, interlocking foam pads when Will was able to sit up without falling over. There were incidences where new adaptations were added between the observation and interview visits. The children's developing competencies seemed to dictate both the specific adaptations made and when certain adaptations were no longer used.

Public and private early intervention professionals were valued as resources for creating adaptations. Each family used the information provided differently. Some families used specific strategies from early intervention for the specific activities where demonstrated. Others generalized those strategies to other activities or their own goals. Some families used materials recommended by interventionists and tailored it to their family life. Some families took information about their child's disability or specific developmental needs and created their own strategies and materials based on that information. While families also created adaptations based on their general knowledge of child development and their experiences with other children, these sources were less frequently used. Some, but not all, routine activities, goals, and adaptations

observed were documented in early intervention records. Reciprocally, some routine activities, goals, and adaptations in the early intervention records were identified in the study as being used by the families.

The adaptations created and used were perceived by the families to be naturally occurring and common to parenting. When the researchers identified adaptations observed, families frequently commented that they did not know they were making such adaptations. Families did not think of their strategies as specifically individualized for their child. However, once identified, families had very conscious reasons behind the adaptations they choose.

What helped parents help their child to learn? (Supports)

Families primarily relied on themselves and child development professionals to make learning adaptations. Families attributed the majority of created adaptations to themselves, by knowing their child and/or other knowledge and experiences. All families also attributed particular adaptations to their public or private early interventionists. Three families obtained information from written resources and conferences that were specific to their child's disability. With the exception of one family, other formal supports, such as their doctors and outside therapists, were very rarely identified as sources of support in creating adaptations.

Informal social supports were infrequently used. Friends and extended family members were not identified in creating adaptations, with one exception. This finding does not mean however, that friends and extended family are not used for other kinds of support, such as general caregiving advice and coping strategies.

What else is needed?

All families identified additional needs. Socialization and transition needs were most frequently reported. While additional needs around promoting child development were

identified, such as materials, resources, family support, and specific strategies, most families felt they were meeting their child's learning needs.

Two areas of need across families were transitions to programs and socialization. Four families talked about transitions, specifically finding and paying for appropriate child care, losing early intervention supports at home, and obtaining an inclusive preschool placement. Families identified the supports they expected to have during and after transition, including friends of children with similar disabilities, early intervention, and continued private therapy.

Three families discussed the need for more socialization, such as using child care to learn from other children, finding time and another parent to go on nature walks and to the local kid's gym, and having more play dates at home. While families felt they were able to make adaptations to support their child's learning needs, transition and socialization were clearly in the minds of these families. It is unknown how much their early interventionists were aware and supportive of meeting these family needs.

Discussion

This study explored the everyday lives of five families with young children with disabilities to understand how they facilitated their children's development through social and physical adaptations. The types of adaptations used, why they used these adaptations and how they were figured out, and what supports helped them in figuring out the adaptations were examined. The discussion focuses on the findings in relation to early intervention practices that support each family's already existing strengths and strategies in helping their child learn.

Families intentionally and actively supported their child's learning across many routine activities. Families identified some of these routine activities as important learning opportunities when asked; they did not identify other routine activities, but identified specific goals for these

routine activities after they were observed. Most goals spanned different routine activities. This finding suggests that assessment and program planning should occur across different routine activities versus focusing on one or two specific routine activities or scheduling intervention visits at a set time every visit. Even though certain routine activities may come to mind for families, which should continue to be targeted, varying the time of intervention visits to functionally assess and provide recommendations for different routine activities can target other learning opportunities that families are using to enhance their child's development.

Families are confident about and clearly articulate their knowledge of their child's interests, strengths, needs, and unique learning characteristics. They use this information to determine individualized adaptations for engagement in their routine activities. Interventionists should be cautious of negating this knowledge and proficiency. This can only occur with a clear understanding of what the individual family is already doing to support their child's learning. To do this, early interventionists can focus on the goals for which families have not already identified adaptations, as well as complement the adaptations families are already using with others they may not have considered. For example, while many adaptations observed were responsive caregiving strategies, the most frequently coded of these strategies were engagement and sensitivity. Contingent responsiveness was rarely observed. There is an evidence base for using contingent responsiveness in promoting the development of young children (Dunst, 2003; Kelly & Barnard, 2000). Interventionists can focus on contingent responsiveness to enhance families' responsive caregiving, in addition to engagement and sensitivity.

Another frequently used adaptation was modifying the requirements or instruction of an activity. While families were resourceful in identifying these adaptations, this type of adaptation is fairly intrusive according to Campbell's (2004) hierarchy of least to most intrusive

adaptations. Interventionists can collaborate with families to determine if a less intrusive adaptation can be substituted. In contrast, no family used the intrusive adaptations of having the child do something different or do something outside the activity. This suggests that families have either found a way to include their child in the family's everyday activities or have already modified family life to avoid excluding their child from family routine activities.

All families identified early intervention professionals as important sources of support, but used them in very different ways. Congruence between how early interventionists support families and how families expect to use early intervention information may further enhance early intervention effectiveness. Early interventionists can develop strategies to identify how families expect to use intervention recommendations and provide supports accordingly. However, making this determination will most likely be a more complex process than commonly practiced.

The process used to obtain the study results centers on a comprehensive, iterative method of authentic assessment for program planning through family-professional collaboration. A preliminary interview resulted in an initial set of goals and important routine activities. Naturalistic observations were used to gain a picture of child functioning and the learning created through social and physical adaptations in different routine activities, those previously identified and not. Finally, a follow-up interview with families was used to uncover their thought processes around creating learning opportunities and their learning style. While many interventionists focus on the initial interview process and subsequent observations, engaging in conversation with families around why they do what they do and how they came to figure it out provides substantial information from which to design supports around individual caregiver learning characteristics and the kinds of support (e.g., specific strategies, general strategies, information) that would most benefit them. The families who completed the member checks commented how

much this process could help interventionists learn about their child and their family. It is uncertain if any component of this process could be eliminated and still result in such a comprehensive picture. Future research investigating the use of this process as a program planning model could identify its practical utility.

This study illustrated how five families made adaptations to support their child's learning in routine activities. Two limitations of this research are acknowledged. First, this study relied primarily on family perception and recall of the supports used in figuring out specific adaptations. Second, the families included in this study were already receiving early intervention supports. It is uncertain the previous role early intervention played in facilitating family confidence and competence in knowing their child's learning characteristics and creating subsequent adaptations. Early intervention may have already provided support so families could make certain adaptations without the need for continued assistance. Future research with families not yet or newly enrolled in early intervention could provide additional insight into such a role.

The early intervention evidence base around how to design early intervention supports so families can facilitate learning and development in their young child with disabilities or developmental delays within family-identified contexts of everyday life continues to emerge. Knowing what families are already doing to support their child's learning can help interventionists consider how best to support, rather than supplant, family efforts. This study contributes to such an evidence base.

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Appendix:*Adaptations Hierarchy Coding Schema (Least to Most Intrusive)*

- **Environmental Accommodations**
 - Adapt room set up
 - Selection of equipment
 - *Positioning Adaptations:* The child is positioned and stabilized so that s/he can see, participate in face to face interaction, manipulate objects, and use his/her hand.
 - *Mobility Adaptations:* Assist the child to move around.
- **Adapt Schedule**
- **Select or Adapt Activity**
- **Adapt Materials**
- **Adapt Requirements or Instructions**
- **Have Another Child Help**
- **Have an Individual Child Do Something Different**
- **Have an Adult Help Child Do the Activity**
- **Have Child Do Something Outside the Activity**

Adapted from: Campbell, P. (2004). Participation-based services: Promoting children's participation in natural settings. *Young Exceptional Children*, 8(1) pp. 20-29.