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Understanding Self-Determination and Families of Young Children with Disabilities in Home Environments

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This article is about emergent self-determination for young children with disabilities in their home environments. The purpose of this study was to better understand family and home characteristics and how they influence the ways in which families can support the development of self-determination for their children with disabilities. Thirty families of young children with disabilities were interviewed, and their homes were systematically observed. Using a grounded theory design, an emergent model was developed that examined family and home context and the influence of context on the strategies that families used to support self-determination. Future research and practice implications of this research for supporting families are discussed.

Keywords: *early childhood; families; disability; self-determination; home environments*

During the past decade, there has been a growing interest in understanding how the concept of self-determination relates to young children with disabilities (Brown & Cohen, 1996; Erwin & Brown, 2003; Palmer & Wehmeyer, 2003; Shogren & Turnbull, 2006). Self-determination has been defined as the abilities and skills that allow one to define personal and interpersonal goals in life and to take initiative in reaching those goals (Ward, 1988). It embodies the capacity to choose and to have one's choices be the determinants of one's actions and quality of life (Deci & Ryan, 1985). According to Turnbull and Turnbull (2001), self-determination is "the means for experiencing quality of life consistent with one's own values, preferences, strengths and needs" (p. 58). Self-determination emerges across an individual's life span and plays a significant role in an adult's life (Turnbull & Turnbull, 2006; Wehmeyer, Martin, & Sands, 2008). Yet it will not automatically emerge at adolescence or young adulthood if it is not nurtured and supported early in life (Brotherson, Cook, Cunconan-Lahr, & Wehmeyer, 1995; Wehmeyer, 1998). Families play a key role in nurturing and supporting the early development of self-determination (Erwin & Brown, 2003; Shogren & Turnbull, 2006).

A developing body of work on self-determination has emerged regarding young children in their family and home contexts (Brotherson, Cook, & Parette, 1996; Erwin & Brown, 2000, 2003; Weigel-Garrey, Cook, & Brotherson, 1998). Researchers have provided an

understanding of the fundamental foundations for self-determination early in life and early opportunities for engagement and choice (Lee, Palmer, Turnbull, & Wehmeyer, 2006; Palmer & Wehmeyer, 2003; Shogren & Turnbull, 2006; Wehmeyer & Palmer, 2000). Our review of literature presents a background for understanding self-determination issues for families and young children with disabilities and is organized into two areas: family and home context, and engagement and choice.

Family and Home Context

Any discussion on self-determination in early childhood should place families at its center. Families play a key role in providing, maintaining, and regulating children's options and choices for self-determination (Cook, Brotherson, Weigel-Garrey, & Mize, 1996; Weigel-Garrey et al., 1998). Parents and caregivers make decisions each day regarding the types of experiences and learning opportunities their children will have. Because families are the main decision makers for their children, they also play the primary role in interpreting their children's communications about preferences and choices, and this occurs within the context of families' cultural values, beliefs, and definitions of quality of life (Turnbull & Turnbull, 1996).

Self-determination as a social value may be more consistent with some cultures than with others. Self-determination is a "personally and culturally-determined value that is not necessarily considered important in the eyes of all families of children with disabilities" (Erwin & Brown, 2003, p. 79). Families exercise their personal beliefs in many different ways (Lynch & Hanson, 2004); thus, how self-determination is interpreted or considered by families can vary greatly. In addition, the weight that self-determination has within a family may vary as the dynamics and circumstances within a family change over time. The lack of research specifically on self-determination and families makes it difficult to understand self-determination within family culture and context (Frankland, Turnbull, Wehmeyer, & Blackmountain, 2004).

Just as the family is the primary influence in early childhood, the primary learning environment for most young children is the home (Dunst, Hamby, Trivette, Raab, & Bruder, 2000). Dunst et al. suggested that the home be thought of not as a place but, rather, as the setting that makes up everyday family activities. The home is an important place for helping young children to initiate and direct activities in their own lives. Naturally occurring opportunities in the home may help children learn to access the environment, make choices and decisions, and act on their own behalves (Cook et al., 1996). It is within the home environment that young children can begin to develop a sense of self-awareness and self-esteem. Self-esteem is a construct that emphasizes positive self-regard, judgments of self-worth, and perceptions of personal worthiness (Powers, Singer, & Sowers, 1996). Self-determination, self-esteem, and coping have been discussed as three interrelated components that lead to optimum well-being and self-competence for persons with disability (Powers et al., 1996). Some of the critical forms of behaviors described as building blocks of self-determination include (a) expressing preferences and choices, (b) participating in decision making, (c) exhibiting self-awareness, (d) displaying engagement and persistence, and (e) exercising increased appropriate control over the environment (Brown & Cohen, 1996; Doll, Sands, Wehmeyer, & Palmer, 1996; Wehmeyer et al., 2008).

Environmental design researchers have noted that fears of home hazards, cultural norms regarding the use of space, lack of knowledge about the barriers contained in the home, discomfort with noisy or messy activities, and attitudes of protection have in the past resulted in restricted home environments for children (e.g., Johnson, 1987; Lang & Sullivan, 1986; Lewis, 1986; Miller, 1986). This may be particularly true for young children with severe and multiple disabilities, as their opportunities to develop skills and attitudes of self-determination are often restricted by social as well as environmental barriers (Schloss, Alper, & Jayne, 1993).

Engagement and Choice

Erwin and Brown (2003) suggested that "supporting children's active and meaningful engagement in the world is perhaps one of the most important tasks related to the development of self-determination" (p. 80). Generally, *engagement* refers to a child's sustained attention to an activity or an interaction in a positive, age-appropriate way. Engagement has been identified as a critical outcome for young children with disabilities (cf. Odom & Bailey, 2000). The concept of engagement has been an area of interest in the literature for many years, yet much of the research on child engagement has focused on how adults (mostly teachers) engage children (cf. McWilliam, Scarborough, & Kim, 2003). Some engagement researchers have emphasized the levels of "directiveness" that adults engage in with children, with higher levels of directiveness negatively associated with children's initiations (e.g., Mahoney & Wheeden, 1999).

Special education investigators have focused on engagement through choices in the classroom. Some researchers have suggested that the lack of available choices for students may lead to negative forms of engagement, resulting in problem behaviors such as non-compliance, aggression, and self-injury (e.g., Ruef & Turnbull, 2002). For example, Reinhartsen, Garfinkle, and Wolery (2002) demonstrated that when children were given a choice in toy selection, as compared to teacher selection of toys, they were more engaged with the task and displayed fewer problematic behaviors. Hence, opportunities for choice and control at school are increasingly recognized as important for high-quality education. What is noticeably missing from the literature is how the home might be arranged to promote successful engagement and choice for children.

For example, the use of assistive technology may increase a young child's opportunities for engagement and choice, but the research base is relatively limited. Campbell, Milbourne, Dugan, and Wilcox (2006) reported in their recent review of assistive technology devices in early childhood that although the knowledge base has expanded over the past quarter century, there continues to be a lack of evidenced-based intervention practices in this area. This may be due, in part, to the limited use of assistive technology in early intervention (Dugan, Campbell, & Wilcox, 2006; Moore & Wilcox, 2006). With respect to the home, limited use of assistive technology to increase opportunities for engagement and choice may be due to several factors, including families abandoning the use of technology (Parette & Brotherson, 2004; Parette & McMahan, 2002), lack of professional or parent training (Parette & Murkick, 1998), and expense (Judge, 2002; Sullivan & Lewis, 2000). Whereas the research in this area has been expanding, very few researchers have examined assistive technology and its relationship to self-determination in the home.

Purpose of the Study

Many professionals have come to understand that if self-determination is valued, then it becomes especially important to promote self-determination early in a child's life. This may influence the quality of life for children with disabilities and their families in the home, school, and community (Brotherson et al., 1995). The purpose of this study was to understand family and home characteristics and how those characteristics influence the ways in which families supported and provided learning opportunities for the development of self-determination for young children with disabilities in the home. Whereas there is a substantial body of knowledge on self-determination with adults and youths with disabilities, much less is known about self-determination and young children with disabilities. Few investigators have examined the ways that families support self-determination and what influences that support. The questions guiding this research were (a) What are the family and home characteristics that influence family support of self-determination? and (b) How do those characteristics influence the ways in which families support the development of self-determination for their young children with disabilities in the home?

Method

In our study, we used a grounded theory method to understand the influence of family and home context on the strategies used by families to support self-determination (cf. Charmaz, 2006). We listened to families and observed their homes to understand the multiple perspectives by which they experienced disability and the concept of self-determination. We conducted this study through the lens of our past and present perspectives as researchers in early childhood education, early childhood special education, and housing and home environments. We came to this research with two primary assumptions: that the child's home provides many opportunities for development and that parents are the primary caregivers and decision makers for their children.

Participants

Thirty families of 31 children (ages 3-8) with physical and mental disabilities participated in the study. All but 3 of the families were European American; the others were 2 African American families and 1 Asian American family. Twenty-five of the families were married couples, and 5 were in other familial arrangements. Families reported income in broad categories, and the mean income for families was $30,000 and ranged from below $10,000 to above $40,000. Half of the families (15) had some high school or were high school graduates, and half of the families (15) had some college or were college graduates. Twenty-four of the families owned their homes, and 6 rented. They lived in a variety of types of homes, including 24 single-family homes, 2 mobile homes, and 4 apartments located in both small, rural towns and large metropolitan areas. The community contexts of the participating families represented varied neighborhoods. For example, some homes in rural towns were on the busiest streets, and some homes in rural towns were on farms. Likewise, some homes in large metropolitan areas were in quiet neighborhoods, others on busy streets.

Families were recruited for this study with the assistance of public schools in an area of the U.S. Midwest. District administrators provided access to early childhood special education teachers and physical therapists, who then contacted families. We subsequently contacted families who expressed interest to participate. A sample of convenience was used that was relatively variable with respect to four criteria for selecting families. These criteria included families who (a) represented a range of income and education levels, (b) had children who represented a wide variety of disabilities, (c) had children receiving early childhood special education services, and (d) had children between the ages of 3 and 8 years.

The 31 children (twins in one family) varied in age from 3 to 8 years, with a mean age of 5.7 years and a mode of 5 years. There were 20 girls and 11 boys. Twenty-three of the children had siblings, and 8 had no siblings. Of the 23 who had siblings, 15 shared a bedroom with a sibling. Using five questions, the parent was asked to rate the child's cognitive disability by severity as mild, moderate, or severe. The parent was also asked to rate the child's physical disability as mild, moderate, or severe, based on questions about the child's hearing and vision and use of hands or arms and legs or feet. For example, parents were asked, Does your child have limitations in the use of his/her legs (mild, moderate, or severe)? and Does your child have any limitations in vision (mild, moderate, or severe)? Parents self-reported a range of types of disabilities (e.g., cerebral palsy, Down syndrome, spina bifida, autism). Table 1 provides a summary of the children in the families interviewed (pseudonyms are used for children names).

Data Collection

Two or three researchers met with each participant family once and spent an average of 2 hours with each family in the home. Family members participated in semistructured interviews and responded to questions about the activities their children could do or were allowed to do at home and how and where their children did these activities. Interview questions were aimed at eliciting families' experiences related to self-determination, and questions were asked regarding opportunities for choice, access, independence, and control. Table 2 gives a representative sample of questions that were asked during the interviews. For 22 families, the interviews were solely with the mothers. The remaining interviews included 7 fathers and 1 grandmother. The interviews were taped and transcribed for analysis.

In each home, observations of the home were conducted, and photographs were taken (with parent permission) of children's rooms, family rooms, kitchens, bathrooms and backyards. Cook and colleagues (1996) provide a more detailed description of the observation measures. Field notes were recorded to document modifications and accommodations made by parents. Parents also described modifications they believed they needed or wanted for their children. The data were collected at the convenience of families, and each family was reimbursed $50 for participation. All Iowa State University Institutional Review Board procedures for protection of human subjects in research were followed.

Data Analysis

Our study builds on researchers' earlier analyses of the data, which examined how the home environment supported privacy for young children (Weigel-Garrey et al., 1998), and

Table 1
Child Demographics (31 children and 30 families)

Child	Age (in years)	Gender	Siblings	Disability as Described by Parents	Physical/Cognitive Limitations as Indicated by Parents
Carol	5	Female	0	Spina bifida	Moderate/mild
Lauren	7	Female	1	Cerebral palsy	Moderate/mild
Joe	7	Male	1	Short stature	Mild/mild
Jeff	7	Male	6	Cerebral palsy	Severe/mild
Megan	6	Female	0	Physical disability	Severe/none
Jillian	6	Female	0	Developmental delays	Mild/mild
Katelyn	8	Female	2	Physical/mental disabilities	Moderate/mild
Dylan	5	Male	3 (plus twin)	Cerebral palsy	Mild/mild
Devon	5	Male	3 (plus twin)	Cerebral palsy/visually impaired	Moderate/severe
Drew	5	Male	2	Cerebral palsy	Moderate/mild
Jenny	5	Female	1	Cerebral palsy	Severe/moderate
Jocelyn	8	Female	2	Physical, mental disabilities/visually impaired	Moderate/severe
Leah	5	Female	1	Spina bifida	Moderate/mild
Kylee	6	Female	0	Physical disability	Moderate/none
Jayden	3	Male	4	Hydrocephalus/visually impaired	Mild/moderate
Maggie	4	Female	1	Physical abnormalities	Moderate/none
Blain	8	Male	0	Cerebral Palsy/visually impaired	Moderate/moderate
Lacey	7	Female	2	Mental disability/seizure disorder/ADHD	Mild/moderate
Cora	4	Female	2	Down syndrome	None/moderate
Elena	7	Female	1	Physical, mental disabilities/visuall, hearing impaired	Severe/severe
Riley	5	Female	2	Spina bifida	Moderate/none
Sophie	3	Female	1	Cerebral palsy	Moderate/mild
Maya	5	Female	2	Mental disability/seizure disorder/ADHD	Mild/moderate
Jeffrey	4	Male	0	Cerebral palsy	Severe/mild
Lucy	7	Female	3	Down syndrome	Mild/moderate
Cole	5	Male	2	Cerebral palsy/visually impaired	Severe/severe
Jared	3	Male	2	Cerebral palsy	Moderate/mild
Hailey	4	Female	1	Autism/mental disability	None/moderate
Theodore	5	Male	0	Cerebral palsy	Moderate/mild
Kara	4	Female	1	Down syndrome	Mild/mild
Carmen	4	Female	0	Developmental delay/ADHD	None/mild

Note: Children's names are pseudonyms. ADHD = attention deficit hyperactivity disorder.

Table 2
Interview Protocol

Sample Questions From the Family Interviews

Tell me about your family and who is in your family.

Tell me more about *child.* (Follow-up probes on desires and hopes for the future.)

Can you describe the nature of *child's* disability and what you have been told about it? (Follow-up questions would probe for the use of special or adaptive equipment.)

Can you give me a sense of what *child's* typical day is like? (Follow-up probes on how much independence and access the child had in dressing, food, and toys.)

What choices or decisions does your child make about where to play?

Tell me about the toys *he/she* likes to play with and how *he/she* gets to those toys. (Follow-up probes on independent movement in home and control and access to toys or play spaces.)

Can you describe opportunities that *child* has to play outside and play with other children? Where would your child choose to play?

How does *child* get in and out of your house? (Follow-up probes on how independently and how much choice/access and control.)

Does *child* choose time to be alone? How would that happen? Does he/she have favorite places to be alone?

Are there modifications or adaptations you have made in the kitchen (each room would be addressed for opportunities for choice/access and control) for *child?*

What modifications do you wish you could make in the kitchen (each room would be addressed with focus on kitchen, child's bedroom, family/living room, bathroom, and indoor/outdoor play area)?

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a subset of the data was also analyzed to examine how the home environment supported friendships (Geisthardt, Brotherson, & Cook, 2002). Our analysis provides a broader perspective of the process by which families provided opportunities for self-determination in the home.

Coding process. The qualitative process of grounded theory data analysis involved ongoing data collection, coding, and memo writing. In reviewing the data, we separated, sorted, and synthesized the information using a constant comparative approach (Glaser & Strauss, 1967). Data coding and analyses may be thought of in three iterative phases that are not linear. In the initial open-coding phase, we used transcripts, field notes, observations, and photographs to identify salient categories of information. Some of the initial open categories included (a) location of home, (b) safety concerns, (c) family values, (d) variety of strategies, (e) parent frustrations, (f) toys, (g) clothes, (h) mirrors, (i) bed, (j) privacy, (k) places to play, and (l) visual access to outside. The photographs of each home promoted our understanding and personalizing of the experiences of each family and also provided visual permanent products of the modifications and strategies that each family used.

In the second phase of coding, we used a variation of axial coding (Strauss & Corbin, 1998). In axial coding, we used the initial codes that were reoccurring and viewed as significant to continue to sort and analyze data (Charmaz, 2000). Our axial coding was focused and required decisions about the initial codes that made the most "analytic sense" in categorizing the data. In axial coding, we systematically reviewed interviews and observations and compared family experiences. Using a constant comparative approach, new categories of the information were compared to previous categories until analysis produced no new categories (i.e., we were comfortable that categories were saturated) and the data were accounted for meaningfully in the emerging model. Short stories were then written for each family; these stories summarized the interview and observational data for the family, modifications wanted and needed, and strategies used in each home.

The central phenomenon is the central or core category about the phenomenon of study around which the emergent model develops and other categories are related (Strauss & Corbin, 1998). During the final coding phase, selective coding, one category was placed at the center of the emergent model as the central phenomenon. The central phenomenon we placed at the center was the diversity of strategies used by families, and other categories were related to this core category of the phenomenon.

Memo writing was an important component of data analysis and occurred throughout coding phases (Charmaz, 2006). Memo writing was self-reflective and allowed researchers to capture ideas, comparisons, and relationships between categories. We wrote memos that explained categories, captured important quotes, identified questions for member checks, described strategies, and explored gaps and meanings in the data. The memos also facilitated our understanding of the characteristics of families and the ways in which family characteristics might have influenced the use of any strategies they employed.

Validation of analysis. Standards of validation refer to the mechanisms used during the process of research to contribute to the rigor of data collection, analyses, and interpretation (cf. Creswell, 2007). Charmaz (2005) discussed criteria for assessing grounded theory by asking ongoing questions during analysis. *Credibility:* Do the researchers provide links between the data and the analysis? *Originality:* Do the categories offer new insights and extend current concepts? *Resonance:* Do the categories portray the fullness of the studied experience? *Usefulness:* Does the analysis offer interpretations that people can use in their everyday lives? To address criteria for rigor, we performed several procedures throughout the research process. Multiple methods (e.g., observations, interviews, photographs) were used, progressive subjectivity was employed (i.e., continual reflection of our values and assumptions), and regular peer debriefings between interdisciplinary researchers were held to validate the "realities constructed" by the participants and the "realities represented" by the researchers and attributed to the participants (cf. Lincoln, 1995). In peer debriefings, we met regularly during data collection and analysis to review the research design and emerging categories and to record self-reflections and interpretations of the data. Insights and emerging categories were recorded in memos as the study progressed. Through ongoing member checks, family members were asked questions related to initial emerging categories during interviews (Creswell, 2007). Member checks with two mothers were conducted in person at the end of data collection to review and discuss our emerging model. The categories were discussed, and these mothers agreed with the model and both thought it offered new and useful information for families.

We sought reciprocity with families by providing honorariums and encouraging the opportunity to have families' voices heard (Lincoln, 1995). Sometimes research activities were interventions; certain questions that were asked of parents gave them ideas for home interventions. For example, when asked if their children had access to see themselves in a mirror, parents expressed, "I had not thought of that before" or "That is a good idea." One mother, when asked if her daughter had access to her clothes, stated, "I should get some shelves in her closet to put the clothes on so she could pick what she wants to wear. You got me thinking now."

Results

Families responded with multiple and diverse strategies to support their children's self-determination in the home. Our model was based on the hypothesis that if families choose to give their children more opportunities to develop self-determination at home, then greater self-determination will emerge across time. The model that emerged illustrates a dynamic process between family and home context and the self-determination strategies used by families (see Figure 1). To exemplify the emergent model, we start with two family examples from the study. The family examples emphasize similarities and contrasts in family and home contexts. Then, we describe the strategies the families used with a discussion of home and family characteristics related to those strategies.
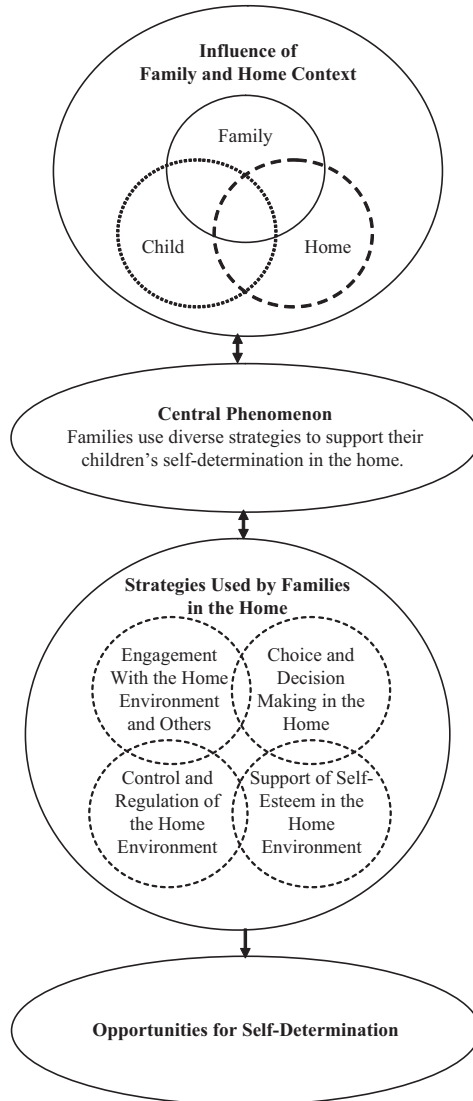
Two Family Examples

Comparisons between two families may help to understand how families use different strategies to support self-determination. The two families selected for comparisons were the Campbell family and the Anderson family (both names are pseudonyms). Each family had a 5-year-old child with a disability, and both children were described by their parents as having moderate physical disability and mild cognitive disability. Both families, who were European American, described themselves as having low to medium income (above $40,000) and worried about money and paying bills. The following are the characteristics we observed or discussed with the families. Table 3 provides a description of the strategies used in each family.

Characteristics of the Campbell family and home. The Campbell family lived in an older two-story home that the family owned. The family consisted of Carol, her mother and father, and an older half brother who stayed on some weekends. The home had steep stairs to the second floor that were not negotiable for Carol, but her parents had built an addition off the kitchen for her bedroom. There were no stools to the sink or cabinets in the kitchen, but Carol could reach the bathroom faucets. The front-door stairs were very steep, and the mother reported that Carol could only manage the one step off the back porch to play outside. Her mom stated, "If she could do anything it would be go outside and swing." Carol was born with spina bifida; she is ambulatory with a walker and leg braces, is catheterized, and has only limited use of her right arm. She was in half-day kindergarten and spent half days with an aunt.

Characteristics of the Anderson family and home. The Anderson family owned a single-family ranch-style home. The family included Drew, his mother and father, and two siblings: a 9-year-old brother and a 10-month-old sister. There were three bedrooms, and Drew shared a bedroom with his older brother. There was a stool in the bathroom that Drew could use to brush his teeth or see his head in the mirror. Mom stated she really did not want Drew in the kitchen—"too messy." There was a special highchair for Drew to sit at the kitchen table. The only toys observed were toys for his younger sister. Drew developed cerebral palsy at 4 months of age due to illness and fever. His mother stated, "He is going to get better." He mostly crawled throughout the house. His walker was outside and the

Figure 1
Process by Which Families Provide Opportunities for
Self-Determination in the Home

Influence of
Family and Home Context

Family

Child   Home

Central Phenomenon
Families use diverse strategies to support their
children's self-determination in the home.

Strategies Used by Families
in the Home

Engagement
With the Home
Environment
and Others

Choice and
Decision
Making in the
Home

Control and
Regulation of
the Home
Environment

Support of Self-
Esteem in the
Home
Environment

Opportunities for Self-Determination

wheelchair was kept in the garage. Mom believed that both pieces of equipment cause dam-age to the walls in the house, and there was little space to store them.

Discussion of family examples. Both families stated they did not have opportunity to talk with other parents of children with disabilities nor had they talked with teachers about things they could do at home (other than some language activities in Drew's family). A

Table 3
Two Families: Opportunities for Self-Determination

| | Examples of Strategies Used by | |
Category	Families Campbell Family	Anderson Family
Engagement with the home environment	The living room had "kid space." There was a child-sized table and chairs in the living room that mother reported is where Carol and friend Ellie like to color/draw. Swing seats removed and a bench-style swing added for her to use.	Mom reported his favorite place to be was on the living room floor. "He likes to be seen-he likes people to see him do stuff." Mom states friends don't really come over because "they don't understand why he can't walk."
Choice and decision making in the home	Toys are located throughout the house on shelves and in cabinets that Carol can access without assistance. Her clothes drawers can be easily opened, and on weekends, her mother lets her choose what she wants to wear.	Parents moved the coffee table out of living room so there is more space for Drew to move around. Drew's toys were in a tall/deep inaccessible toy box in his bedroom. His clothes were difficult to reach in dresser drawers.
Control and regulation of the home environment	Parents lowered Carol's bed for easier access by removing the box spring. Light switches have been lowered for her control.	Drew could use his walker outside to get to backyard swing set. Drew likes to ride his adapted tricycle in the driveway with protective helmet. Mom said it gives him a sense of independence.
Support of self-esteem in the home environment	There was a full-length mirror in the bathroom where Carol could see herself. Photos of Carol and samples of her schoolwork were displayed on the walls and refrigerator.	Drew could see his head in the bathroom mirror. Photos of Drew and samples of his schoolwork were displayed on the walls and refrigerator.

greater influence on the use of strategies may be the family's expectations for the future. Drew's mother believed he was going to get better and walk: "We try to just think of him like he's a normal child and someday he will walk and he won't have to do all this." Carol's mother had known of her daughter's disability since birth and had modified their home for a child with a disability. This different view of what the future holds may have influenced the strategies used by the families. For example, Carol's family used many strategies that provided greater opportunities for engagement with the environment and choice and control in the home environment. In contrast, Drew's family used fewer strategies. In addition, Carol's family identified several additional strategies that the family wanted to use if more money and time were available, such as make the front door more accessible and lower kitchen cabinets and light switches so Carol could reach items without assistance. In contrast, Drew's family identified fewer additional strategies the family needed or wanted to put into place; the mother stated, "We don't have money to do that stuff." Drew's mother did, however, want to put up "chair rails" for "Drew to hold onto and walk."

The greater number of siblings in Drew's family may have been an increased economic burden on the family, but some strategies do not cost much money, for example, putting clothes in a bin on the floor or making toys accessible. The families appeared to differ in

their comfort level with messiness. Keeping toys out of the living room, the walker out of the house, or kids out of the kitchen was discussed in Drew's family. Carol's family did not mention issues related to messiness, but we recognize this may have been more of an issue with three children as compared to one.

Family and Home Context

In this section, we describe the first major component of the emergent model (Figure 1)—influence of family and home context. The potential interaction of three characteristics, family, child, and home, formed each unique family and home context, which may have influenced the self-determination strategies each family used. In the following subsections, we highlight this information for the 30 families who participated in our study: family characteristics, home characteristics, and child characteristics.

Family characteristics. As the two family examples began to demonstrate, family values and attitudes may have influenced family responses to self-determination. Concern for safety was one family attitude that appeared to influence the opportunities for self-determination that some families allowed. For example, one mother shared that when her child played outside, "I don't want to be hovering over her, but I realize at times she might not realize her limitations and . . . she could fall." Some of the safety concerns were related to the home's characteristics and its location (e.g., steep stairs, busy streets), but it was also related to the type of disability. As another example, three children had attention deficit hyperactivity disorder, and one child had autism. In the cases of these children, and particularly a 4-year-old with autism, doors and cabinets were locked and access limited because of a greater focus on safety.

Social stigma appeared to be a concern for some families; several families did not make home modifications that may have supported self-determination because they perceived them as stigmatizing. Whereas income was an issue that may have influenced parents' ability to make modifications—stigma sometimes appeared to weigh more than income. For example and most notably was the issue of building a ramp that for three families did not fit their definition of "home" and "advertised disability." One family had just built a big new deck on the back of the house and used only two precariously placed slats of wood resting against the deck to allow the child in a wheelchair access to the deck or backyard. The visible stigma of a ramp was an issue for this family.

Mothers also varied in their boundaries of space. For example, some mothers saw kitchen space as "mother's space," and the children with disabilities, and sometimes other family members, were allowed very limited independence in the kitchen. Likewise, mothers varied in their attitudes about separating "adult space" and "child space." For example, living rooms and parent bedrooms were off limits to children and their play, particularly for the children who were very active. In contrast, other mothers allowed their children to have toys and play in all areas of the home.

Parents' attitudes regarding gender roles also appeared related to self-determination opportunities for their children with disabilities. Mothers were the primary caregivers in most of the families. These mothers felt responsible to "clean up the mess" or remove furniture or alter floor coverings when rooms were inaccessible to their children in walkers.

Mothers were most often the parent to give baths in a bathroom with very few modifications for disability or most likely to be available when a child needed to be carried upstairs to bed or downstairs to the basement playroom. The lack of home modifications often meant a greater physical care burden for mothers. As one mother expressed, "When you are in your 20s you can do anything. When you are in your 40s it's a lot harder to do it, getting down on your knees. I have days when my back is just tired!" The definition of *home* also may have influenced the type of home parents desired and the physical care burden for mothers. For example, in one family the father really wanted a two-story house. His wife shared, "I didn't really want a two-story, but my husband wanted something different—the apartment was flat. He said I will help you with getting her up and down. . . . She does pretty good crawling up—but when she's tired—Lauren says carry me up!"

Home characteristics. Families lived in a variety of homes, which appeared to have influenced the strategies that they used. Many smaller homes lacked sufficient space for a child who used a walker or wheelchair. For example, one child with severe cerebral palsy lived in a doublewide mobile home with both parents and six siblings. There was very limited living space for raising seven children, with few toys visible and very limited outdoor play space. For this family, as with other families, storage space for equipment appeared to be a significant issue. For example, Jeff's mother asked, "Where can we put it? . . . We are looking at getting a walker that would be beneficial for him . . . but where can we store it if we do get it?" Home location also appeared to have influenced accessibility and availability of outdoor play, including such things as whether the home was on a busy street or whether the neighborhood was safe. Four families reported that the lack of sidewalks was a barrier to outdoor play.

Children's characteristics. The type and the level of disability may have influenced the use of strategies by families. For example, if the child had a severe physical limitation, then supporting independent movement in the home may not be an issue for a family. Alternatively, if the child was blind, then providing mirrors may not be a needed strategy. Yet other strategies, such as making play spaces available in main living areas or offering options for privacy, were offered to children with a wide range of disabilities and levels of physical or cognitive limitations.

The age of the child appeared to be an obvious factor in the strategies that families used. However, the age of the child may have been less of an issue than the parents' attitudes and beliefs about what children should be allowed to do at different ages. For example, as one parent noted, "Should a child ever be allowed to climb on counters to reach food?" Or, as one mother expressed, "Should a 4-year-old really be expected to dress themselves?"

The type of and level of disability and the values of families appeared to have interacted to influence what families thought about the future and what they allowed or encouraged their children to do. Some parents were optimistic that they could "take on anything," so the future held promise and hope, and they used strategies to support independence. Other families focused less on the future and took things a day at a time. As Drew's mother conveyed, "I guess I keep hoping everything's going to be fine by the time he goes to [elementary school], but if they're not, I guess we'll have to live with it when we get there. I haven't really thought that far ahead yet." A few families appeared to have been given the

message "don't count on the future," as was the situation with Megan, who had a progressive motor disease.

Families had different background experiences with disability that may have influenced their plans and expectations. Some parents had never known anyone with a disability, whereas others knew or had other family members with disabilities. One family had a history of overcoming disability, which that appeared to have influenced their positive expectations about the future. This mother expressed, "My family had a lot of orthopedic problems as I was growing up so I was familiar with what that meant . . . so Katelyn has been one surprise after another. Just amazing." Some families were clear about what disabilities their children had, such as spina bifida or Down syndrome. Other families were unclear about the disabilities their children had, as communicated by this mother: "Nobody tells me anything. I've not really had a straight answer from anybody yet. They don't know why it happened; they don't know how it happened, it just happened." This may have contributed to a family's lack of future planning.

Strategies Families Used to Promote Self-Determination

At noted in the emergent model, the strategies used by families varied according to the individual family, child, and home characteristics. We summarize and discuss the strategies used by families in each of four categories: (a) engagement with the home and others, (b) choice and decision making in the home environment, (c) control and regulation of the home environment, and (d) support of self-esteem in the home environment.

Engagement with the home environment and others. Families appeared to be creative in the ways that they helped their children with disabilities to be engaged with others in their homes. For some families, it was a priority to locate play spaces in main living areas of the home. These were most often in the kitchen and family rooms so that children could play while in proximity to other family members. For example, Cal's mother wanted a "child's chair" in the living room instead of a wheelchair because she felt the wheelchair "separates him" from others. For other families, however, play spaces were only in children's bedrooms or often times in inaccessible basements. This may have been related to varying levels of parental tolerance for disorganization and messiness and comfort with toys left out and visible.

Many families created spaces inside and out in which their children had the opportunity to play with others. Inside, there were locations in the home that allowed the children to get toys and be "busy and noisy," and outside, play equipment was safe and accessible for playmates to play, including the child with a disability. Three families provided children motorized toy vehicles. Jared's mother shared that "this toy was a magnet for other children" wanting to ride with her son up and down the front yard sidewalk. For another family, drawing peers over to play did not appear to be planned but, rather, circumstantial. The family rented a ground-level apartment with a cement wheelchair ramp for their daughter. The cement ramp was also a "magnet" for children in the neighbor because it was the only paved area that children had access for play with cars, chalk, and balls. Families also increased opportunities for engagement by providing children with opportunities to see outside through windows and doors or by providing pets. One family with a child with severe physical disability had an accessible hamster cage on the floor in his bedroom (the mess was tolerated).

Choice and decision making in the home environment. Providing access to toys so that children might make choices and decisions was accomplished in several ways. Toys were located in bins, cardboard boxes, baskets, or lower shelves, which allowed children to choose what toys they wanted for play. Parents appeared to be creative in how they offered accessibility to toys. For example, Jillian's grandmother locked the front door and turned the front entryway into a play area because Jillian's mobility was limited due to use of an oxygen tube. As another example, Jenny's family created a "beanbag nest" in the family room and provided a choice of toys within her reach.

Families presented children with options to be independent or interdependent in dressing and personal care. This general strategy included such supports as step stools at the bathroom sink, accessible toothbrushes and hairbrushes, modifications to toilets and tubs. Leah's mother, who put a grab bar on the tub, said, "I put her in the tub and she can climb out of the tub. Sometimes I hear this crawl, crawl, crawl; she crawls into the toy room and grabs some toys . . . then she goes back into the tub." Some families provided their children with their own area for clothing, and closet doors, drawers, or clothes bins were made accessible with curtains, modified pull knobs, or lowered heights. For some of the children, personal care also involved getting their own snacks and greater independence in the kitchen. Parents provided stools to get to the kitchen sink, low drawers and cabinets with foods for their children to reach, and lower shelves in the refrigerator to reach foods. A few parents used simple devices that could support independence (e.g., toothpaste turners, adaptive eating utensils). One mother used jewelry clay on a spoon to assist eating; another taped wood on a handle to assist pulling a drawer.

Children appeared to have much greater access to people and things in their homes if they could move about the house. Families supported independent movement in the home by removing rugs, furniture, and doors and by creating pathways that allowed the movement of wheelchairs and walkers from room to room. For example, Theodore's mother stated, "I don't have rugs, even on the tile. It would be nice to have a throw rug there. But for him it would be a danger because he could slip on the rug and hit his head." Five of the eight children who used wheelchairs were allowed only limited use of them at home because of lack of clear pathways, possible damage to walls and windows, and lack of storage. Most of these children "belly crawled" to get around from room to room or downstairs to playrooms or backyards. One mother remarked, "Being that we have a two-story house, she's going to have to crawl."

Control and regulation of the home environment. The number of family members appeared to affect resources in the family for providing privacy or personal space per child. Some families with limited income, however, were very creative about providing personal space by setting up small partitions or using rugs to mark off space so that each child had privacy and territory and could control boundaries between self and others. Families employed several methods to establish personal spaces for their children. For example, a child's bedroom was located where he or she could get to it. As another example, some children's beds were lower or located on the floor so that the child could get into and out of bed independently. Three parents, however, raised their children's beds or placed the children with disabilities on top bunks in order to make the physical burden of their care easier for the parent, usually the mother. For some children, parents could offer privacy on the

toilet. Kylee's mother shared, "Upstairs I put her on then she hangs onto the counter or bathtub. Sometimes she wants me out when she goes potty. . . . If she has her walker she can get off herself."

The issue of personal safety related to privacy appeared to be very important to parents, and balancing the need for privacy and the need for safety was individual to each family. One mother commented, "I leave the door open so I can hear her in the case she could slip or fall. But Cora wants to wash by herself. . . . Most of her bath she spends in there alone now." In Jeff's family, they placed a "potty chair" in a closet nearby the bathroom so that their son could have privacy and still be safe.

Parents used several methods to allow their children to regulate and control space within the home. Children sometimes controlled a portion of a shared bedroom or out-of-the-way places such as storage areas, closets, play tents, or corners. In a variety of ways, families created personal spaces for their children to experience personal territory. For example, several children had access to sound and lighting regulations (e.g., touch lamps, lowered light switches) and were offered stereo or CD headphones for private listening. Some parents allowed children to close the bedroom door when they wanted privacy.

Support of self-esteem in the home environment. Healthy self-esteem may be a factor in the development of self-determination. The home may be a place where children can experience positive self-awareness and self-worth. Healthy self-esteem is composed of a number of factors and can be developed through responsive social interactions with parents, adults, and peers; however, in our investigation we focused on the physical aspects, rather than the social aspects, related to self-esteem. Whereas self-esteem is much more complex than a few physical changes, there were some physical strategies that parents used that may enhance self-esteem. In this study, some families provided opportunities for their children to see themselves, and they displayed the children's work, art, and awards in the home.

Access to a mirror is a physical strategy that may enhance a child's sense of self-esteem by providing the opportunity to look at himself or herself. Six of the 30 families had full-length mirrors available to their children. We observed 2 children admiring themselves in full-length mirrors. Six of the children who were not provided access to a mirror had limited visual abilities. Leah's mother put a full-length mirror horizontally alongside her bed so that she could see her body. Twelve children had no access to mirrors, and 9 others had only limited access to mirrors, usually viewing the top of their heads in the bathroom mirror. Displays of family photographs including the child with a disability were observed throughout most homes. Only in four homes were there no visible photographs. Refrigerators were the place most families displayed art, schoolwork, drawings, and other accomplishments of the children in the family. Twenty-two families displayed artwork or awards on refrigerators, kitchen walls, or in the children's bedrooms. Eight families displayed no children's artwork.

Missed or Realized Opportunities for Self-Determination

Our emergent model was based on the proposition that if families choose to give their children more opportunities to develop self-determination at home, then this can lead to greater

self-determination in the future. What we do know is that family knowledge about concepts of self-determination (engagement, choice, access, and independence) and self-determination strategies varied. Some families sought out information, tried new things, had hope for the future, and implemented strategies. Others were unsure or uninformed about what to do and lacked resources, knowledge, and desire to implement strategies. For some families, the struggles of getting through each day appeared to be a major effort, and they may have had limited energy to think about new strategies to try at home with their children.

But for all of these families, the identification and use of strategies in the home were most often left up to them. They gained knowledge about strategies in the home from their own search for information. After the children turned 3 years of age, parents reported that professionals did not come to their homes to offer support or suggestions for the development of their children with disabilities. A professional crossing the doorstep was rare; only one parent had experienced this past the child's age of 3. Suggestions for home strategies were rare, and if they were made, they were handed out in the context of school parent–teacher conferences or therapy sessions. One mother articulated her frustration with a lack of collaboration with professionals:

> When Jenny was 18 month they came to the house and . . . did in-home services. Then you can watch how they work with her and the things they use. But now she goes to school . . . frustrating for me to send her to school, the progress was real slow at school compared to the progress at home. . . . I am working on things at home and they are working on things at school and we are not working on the same things, so Jenny is not making progress.

Discussion

The purpose of this study was to understand family and home characteristics and how those characteristics might influence the ways in which families supported and provided learning opportunities for the development of self-determination for young children with disabilities in the home. Findings indicated that families used a variety of strategies that can potentially provide opportunities for self-determination, and the use of those diverse strategies depended on home, child, and family contexts. Children with cognitive disabilities may learn and generalize learning at a slower rate, and children with physical impairment may access and act on their environments at a slower or limited rate, but families of children with different disabilities used a variety of strategies for self-determination.

For young children with disabilities, the home may well be the first and most influential environment for developing self-determination. When a family increases a child's engagement with the home environment, provides choices and decision making for the child in the home, establishes opportunities for the child to exercise control and regulation, and encourages the development of a healthy self-esteem for the child, the family may enhance the prospects for developing self-determination during the early childhood years. Many parents in our study gave their children opportunities to access, initiate, choose, decide, and direct activities within the home, which appears to have provided a solid foundation for future self-determination.

Limitations of the Study

We acknowledge several limitations to our study. First, families were not directly asked about self-determination. Instead, we asked the family questions that we believed were related to self-determination—questions about opportunities for choice, access, independence, and engagement in the home. It will be important to address self-determination directly in future research to better assess and determine what families know about self-determination. Hence, our study focused on learning what families were doing with children that could support self-determination in their homes; it did not measure self-determination in the parents or children.

The emerging model developed in this study is based on the assumption that if families choose to provide their children more opportunities to develop self-determination at home then this can lead to greater self-determination in the future. Testing this basic assumption is the next logical step of our research. We do not know if more opportunities lead to greater self-determination. Second, the sample of participant families, families who were interested in collaborating with researchers, cannot provide the universe of possible strategies that families could use. In our observations, we envisioned strategies that could have been used in addition to those that we observed or discussed with families. Third, our investigation, albeit intensive in data collection, was restricted to one interview per family and mostly with mothers. Given the qualitative research process, prolonged engagement with families across longer periods might promote a better understanding of the complex issues related to self-determination. Fourth, with respect to sampling, our final group of families was relatively restricted in cultural, racial, and ethnic diversity.

Implications for Research

If children are given adequate supports, opportunities to experience control by having their preferences honored, chances to learn to make choices, and reasonable accommodations, it is possible for them to become self-determined individuals. Children need to learn they are the active causal agents in their own lives. As children get older, self-determination skills may increase their meaningful participation in school and community settings (Agran, Cavin, Wehmeyer, & Palmer, 2006; Wehmeyer et al., 2008) and their participation at home in such activities as identifying barriers, modifications, or changes in the home environment. Careful and sustained longitudinal research is needed to inform us of the outcomes of early self-determination strategies that are used in the home. This research presented an emergent model of the strategies families used, but the difference these strategies make in the development of self-determination over time needs further research.

Home and family provide a context for early learning to occur. Because of the diversity of family, child, and home characteristics, understanding of the ecological and cultural perspectives of each family is critical (Bronfenbrenner, 1979). In one of the few studies examining cultural influences on families' involvement in promoting self-determination, Zhang (2005) discovered that families with children with and without disabilities who were European American involved their children in personal independence activities more often than did families from Asian or African American backgrounds. Additional research is needed that focuses on understanding the cultural issues surrounding self-determination for families.

Implications for Practice

Self-determination occurs across the life span and can be nurtured from an early age, but for some families of very young children the focus on self-determination may emerge only later in life. If parents value self-determination, professionals can provide support in promoting it early in the context of their own homes and daily routines. Supports should be as normal, nonstigmatizing, and unobtrusive as possible, suggesting that the "support should ensure [that] the child participates fully like any other child [or family member] would . . . without draw[ing] unnecessary or negative attention to achieve this result" (Erwin & Schreiber, 1999, p. 168).

A critical role for educators may be determining the value, if any, a family places on self-determination in the child's life (Erwin & Brown, 2003; Shogren & Turnbull, 2006; Turnbull, Turnbull, Erwin, & Soodak, 2006). Practitioners need to be responsive and flexible when determining *with* families if self-determination is an important family value and concern. Only then should the nature and implementation of opportunities for self-determination to occur in the home be identified. Specifically, the following considerations could be addressed: (a) when (in what routines could self-determination be addressed), (b) where (what spaces in the home could be changed to promote self-determination), and (c) how (strategies matched to the family's style and interest to support self-determination). Shogren and Turnbull suggested several strategies that families and professionals can use to advance self-determination in young children, such as arranging the home environment and creating specific accommodations and supports. Nevertheless, to date, the specific interventions that professionals may use to support parents in creating home environments that develop self-determination for young children with disabilities have been limited.

Emphasis on Family Wisdom

Research should reflect the collective wisdom and voices of families who will eventually benefit from the research. During the 1980s, families' voices began to be consistently represented in the professional literature, and the perspectives of families from diverse backgrounds were subsequently acknowledged in the 1990s (Erwin & Soodak, 2008). Given recent attention to evidenced-based practice (EBP), it has become imperative that families' wisdom is integrated into this evidence. Systematic efforts in which data are collected, reflected on, and reported to understand the voice and wisdom of parents is critical (cf. Buysse & Wesley, 2006). Winton (2006) cautioned that families "are critical partners in decisions about learning and teaching, and their role in the EBP movement has not been addressed" (p. 99). As emphasis on evidence-based practices in the early childhood field continues to grow, collecting family wisdom related to self-determination is important so that family voices are part of the research.

In summary, a set of recommendations that could be shared with families and with practitioners might include the following:

- Professionals across disciplines need to be more aware of the home as a critical environment for nurturing self-determination.
- Many families want options and ideas to use in their homes, but the decision to address self-determination rests with the family.

- In collaboration with professionals, families can be supported to make and carry out decisions and changes in their home environments.
- Financial issues may inhibit some parents from making adaptations and modifications to the home, although many inexpensive modifications can be explored.
- Families and professionals can collaborate to identify ways to use assistive technology to increase self-determination in the home.
- To the extent possible, families may want to encourage their children's early advocacy skills through participation in identifying opportunities for self-determination in home, school, and community environments.

The key to promoting self-determination during the early childhood years may well rest in the partnership between families and professionals. Practitioners and families should work together to provide opportunities for and foster the development of self-determination that young children with disabilities may ultimately need for enjoying a better quality of life.

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