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It is entitled:
Identifying Engagement in Children with Autism in the Home Setting

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Identifying Engagement in Children with Autism in the Home Setting

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Abstract

This qualitative study examines perspectives of parents of children with autism related to engagement in the home environment. Increased engagement decreases the likelihood of less productive behaviors. Investigation of engagement in the home setting may provide insights into the development of interventions. Collaboration between parents and professionals is essential for success for children with autism. Using the photovoice method, interviews were conducted with 5 parents of children with autism from preschool through fourth grade. The parent participants were all female. Five questions guided this study: 1) What are indicators of engagement in the home? 2) In what kinds of activities are children with autism engaged in the home setting? 3) How do parents of children with autism identify engagement? 4) What are some things parents do to facilitate engagement? 5) What are some needs and goals of parents in terms of facilitating engagement in the home setting?

Findings suggest that children are engaged with objects such as toys, computers and musical instruments. Parents of children with autism identify engagement based on the duration of interactions, the focus of the child and the absence of undesirable behaviors. Parents use a variety of teaching strategies to engage children including physical activity, building on the interests of children, breaking tasks down into steps and facilitating sibling interactions. A major parent goal is independence with a need for consistency across settings and support in dealing with obstacles.
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Introduction

This study examines strategies used by parents in the home setting to engage children with autism. Using both photographs and interviews to determine parent goals, perspectives and educational techniques; we can garner additional information about how to support children with autism and their families. The first section describes the context and importance of this study. I begin with an overview of the role and value of engagement for children with autism. This section continues with a description of autism and the role of evidence based practices. Next there is a connection to my personal experiences and how they are related to the current exploration. This section concludes with an explanation of the value of collaboration between educators and caregivers.

Engagement and Autism

One way to facilitate positive interactions and successful learning both at school and at home is to keep children with autism interacting with the persons and things around them. Engagement is safe and productive interaction with people and materials (O’Reilly, Sigafoos, Giulio, Edrisinha, & Andrews, 2005). Effective educational programs and interventions for children with autism provide at least twenty five hours a week of engaged time (National Research Council [NRC], 2001). The importance of engagement extends beyond educational institutions. Parents and educators benefit when children attend to people and activities in order to successfully accomplish desired tasks. Effective programs for children with autism incorporate parent training and parent involvement (NRC, 2001; Ozonoff, Rogers, & Hendren, 2003). Parent involvement and collaboration is an integral component in successful interventions for children with autism (Iovannone, Dunlap, Huber, & Kincaid, 2003).
Autism is a developmental delay resulting from neurological impairment. Symptoms of autism include impairments in a variety of communication and social skills as well as repetitive behaviors and interests (American Psychiatric Association, [APA], 2000). The impairments of individuals with autism lie along various points on a spectrum and each person is unique (Autism Society of America, 2008). Individuals with autism differ in interests, skills, intellectual ability and disposition. No single behavior results in inclusion or exclusion from a diagnosis (NRC, 2001; Mesibov, Shea, & Schopler, 2004). There is variation in relationship to other disorders including mental retardation and epilepsy (NRC, 2001). There is great variation in both abilities and disabilities (Iovannone et al, 2003).

In response to this significant heterogeneity, individualization of services is a core component of effective educational practices for children with autism (Iovannone et al., 2003) Identification of strategies used in the home that are consistent with recommendations in the research literature as well as promising practices which have support in the research literature may facilitate utilization of evidence based practices. Evidence-based practices combine knowledge from research and experience. Outside of the school environment, a variety of factors are taken into account resulting in “integration of the best available research with out-of-school time expertise within the context of child, teen, family and community characteristics, culture and preferences” (Metz, Espiritu, & Moore, 2007, p. 1). Incorporating parent expertise with research based strategies, facilitated learning in my personal experiences as an educator.

Personal Experiences with Autism

As a teacher of children with autism for two years, I worked individually and in small groups to help children develop both functional communication skills and social skills. In my experience, parent involvement and consistency between the home and school settings facilitated
learning in both settings. In addition, as an early childhood educator in an inclusive preschool classroom, I worked with children with autism each year. Over the years I was challenged by and interested in ways to engage children with autism. The open ended nature of the preschool classroom required special structure and organization to meet the unique needs of children with autism. Adaptations such as inclusion of individualized visual schedules and clearly defined centers were developed after collaboration with parents and other professionals.

Individualization and implementation of Individualized Education Program (IEP) and Individualized Family Service Plan (IFSP) goals required collaboration with occupational therapists, physical therapists, speech therapists and parents. Parent suggestions for incorporating the interests of children into the classroom provided necessary insight for effectively facilitating IEP goals. For example, one parent suggested taking her son to the muscle room before working with him on his turn taking or having him sit down for group time. At home they found allowing him to jump on the trampoline before expecting him to sit and look at a book resulted in increased attending and fewer undesirable behaviors. The classroom teaching team incorporated this suggestion into the day, using gross motor activity as an antecedent to activity that required sitting still and attending. He would go to the muscle room before group time, lunch time or one-on-one skill development sessions including turn taking and speech therapy. We also observed increased attending and fewer behavioral outbursts. Utilization of antecedent physical activity in this case was based on parent knowledge and experience. The value of exercise prior to academic sessions is supported in the research literature. Effects of antecedent exercise include decreased self-stimulatory or stereotypic behaviors and increased engagement (Celiberti, Bobo, Kelly, Harris, & Handleman, 1997; Elliot, Dobbin, Rose, & Saper, 1994).
Another parent suggested sending home new activities such as story extensions or introducing group activities to her child individually before doing them as a large group at group time. These parents found having some time to explore materials in advance resulted in fewer undesirable behaviors. This is consistent with the concept of priming or advance exploration of classroom assignments which results in improved academic performance and decreased problem behavior (Koegel, Koegel, Frea, & Green-Hopkins, 2003). In another example, one child with autism continued to drive trains and cars out of the block area in spite of verbal direction and redirection. In order to maintain a safe environment, free of obstacles, the vehicles had to remain in the designated area. Placing a piece of colored tape on the floor and including stop signs, created a visual barrier that helped him keep the vehicle in the block area. At home, his family used stop signs as a visual cue. The utilization of visual cues is supported by the research literature. Visual cues help children with autism focus on salient features of an activity and make things more concrete (Mesibov et al., 2004). Parent suggestions, based on intimate knowledge of children’s strengths, interests and reactions, were often consistent with research-based practices. Discussion, communication and collaboration with parents allowed for successful engagement in the classroom setting. Parents are effective and reliable sources of information for professionals (CDC, 2006).

The value of collaboration

Examination of parental strategies and expertise can assist design of curriculum and interventions and can begin to create foundations of evidence in an attempt to connect research to practice. Determining that which is successful is an integral part of planning and utilizing new interventions. Research literature exploring strategies for engaging children with autism are presented from the perspective of educational and medical professionals. Parents have
knowledge about their children that is valuable and can facilitate engagement. Parent knowledge needs to be explored in a systematic way and added to the research literature in order to be differentiated from fads.

Educators can benefit from the perspective of parents by using what is successful in the home environment at school. Collaboration between home and school settings allows for consistency and facilitates generalization. Collecting information about engagement in the home environment can inform the educational environment resulting in evidence-based practices.

Engagement can be an indicator of effective practices. In order to have successful education and intervention through which children develop desired behaviors skills and knowledge, children must be engaged. In this research, the term engagement is defined as attending to tasks and interacting with them appropriately and with persistence. The environment plays a role in engagement. Parent roles in the home environment regarding engagement of their children with autism may provide insights applicable to the academic environment. Through communication with parents and examination of images from the home, attempts can be made to comprehend the nature of engagement within the context of the home environment. Exploration of what occurs in the home setting and why may facilitate collaboration and encourage engagement in a variety of settings.

Review of the Literature and Research Questions

The characteristics of autism provide a context for this study. Following this information, I will provide a definition of engagement and its importance. Next, there is an exploration of parents of children with autism including: of the role of parents, validity of parental report, use of interests to increase desired behaviors and communicative competence in the home. An overview of the origins of photovoice is provided to clarify the data collection method. The section
concludes by connecting the purpose of the study to the review of the literature and the research questions.

Characteristics of Autism

Autism is a pervasive developmental disorder characterized by deficits in social relations, social communication and stereotyped behaviors. Autism is a neurodevelopmental disorder (APA, 2000). Although individuals vary greatly in tested intellectual ability, skills and interests, there are some shared characteristics related to diagnosis that sometimes is referred to as the “culture of autism” (Mesibov et al., 2004, p. 21). Individuals with autism tend to have difficulty understanding the thinking of others. They also have difficulty generating meaning and creating relationships between activities and experiences. Other symptoms include distractibility, sensory issues, generalization difficulties, concrete thinking, visual learning, prompt dependence, limited social and play skills, difficulty determining which details are relevant and difficulty with initiation (Mesibov et al., 2004; National Research Council, 2001).

The Centers for Disease Control (CDC, 2007) report an increased prevalence of children diagnosed with autism in the United States from previous reports of 1 in 166 to an average of 1 in 150. The reason for this increase is unclear. More children may be diagnosed with autism because the number of cases has actually increased or because of changes in how children are identified and diagnosed. Regardless, with large numbers of children with autism entering the educational system, it is important to determine goals and develop interventions to meet those goals.

No one treatment, intervention or instructional strategy can be identified as best practice for all children with autism (Iovannone et al., 2003; Simpson, 2005). Programs use a variety of approaches including behavioral, developmental, adult directed, peer mediated, augmentative
alternative communication, individual instruction and group instruction. Behavioral approaches utilize antecedents and consequences to shape behavior. Developmental techniques focus on following the child’s lead. In an evaluation of 33 interventions for children with autism, Simpson (2005) differentiates among four different types of interventions.

The first group of interventions includes scientifically-based practices with significant supporting research. Only three programs fit into this category, 1) applied behavior analysis, 2) discrete trial teaching and 3) pivotal response training. All three utilize behavioral techniques. Next are promising practices with some demonstration of effectiveness, but the need for additional research. These include Picture Exchange Communication System, incidental teaching, structured teaching (such as TEACCH), augmentative alternative communication, assistive technology, joint action routines and social stories (Simpson, 2005). Third are practices that do not have very much information to support them, but have potential. Finally, there are those practices not recommended because of their potential to be harmful. With so many varied options it may be difficult to determine which path to take for each individual child, which can cause tension between parents and professionals.

One conflict among parents and researchers is that parents feel a sense of urgency and therefore may be vulnerable to fads (Ozonoff et al., 2003). Parents obtain information about interventions from other parents and the internet and implement treatments that lack empirical support (Green, 2007; Green, Pituch, Itchon, Choi, O’Reilly, & Sigafos, 2004). With collaboration, communication, mutual respect and mutual education, researchers could be more flexible in exploring new methods while parents develop an understanding for the need for scientific support. Parents can attend professional conferences while educators attend parent
groups (Ozonoff et al., 2003). One way to determine what works is to examine commonalities among efficacious practices that have empirical support.

Comprehensive programs vary in theoretical framework and instructional strategies, but in spite of their differences share key features. Similarities among effective programs include early intensive intervention, a minimum of 25 hours a week during which children are actively engaged, individualization for both children and families, systematic instruction with explicit curriculum, structured environments, inclusion of families, ongoing evaluation, addressing problem behaviors with a functional approach and low student teacher ratios. (Hume, Bellini, & Pratt, 2005; Iovannone et al., 2003; NRC, 2001). Goals for intervention and education ought to include enhancement of: language (verbal and non verbal), social skills, engagement, cognitive and academic development, motor skills (fine motor and gross motor), and desirable behaviors rather than those deemed as inappropriate (NRC, 2001). Finally, goals for intervention ought to include skills to be able to not only follow directions but also participate independently and successfully as a functioning member of society (Mesibov et al., 2004). Concerns about independent functioning of children with autism are a contributing factor to parental stress (Baker-Ericzen, Brookman-Frazee, & Stahmer, 2005; Koegel, Schreibman, Loos, Dirlich-Wilhelm, Dunlap, & Robbins, 1992).

Importance of Engagement

A primary goal of working with children with autism is to increase independence and encourage engagement (Bryan & Gast, 2000; Mesibov et al., 2004). Simply teaching children with autism to be compliant is not enough. Children with autism must develop skills and understanding to function without teachers and parents in order to succeed as adults in the larger culture (Mesibov et al., 2004). Educators and parents work toward fading away adult assistance
and facilitating independent functioning. Professionals must take into consideration functionality and generalization of interventions in order to work towards skills that will result in independence (Ozonoff et al., 2003). The level of independence acquired by a student with disabilities relates to success as an adult (Copeland & Hughes, 2000). Defining engagement and determining indicators of engagement in the home setting may help parents and educators to facilitate this independence by developing appropriate interventions.

The frequency and duration of active engagement is a significant factor in both the diagnosis of autism and in intervention (Dunlap, 1999). O’Reilly, Sigafoos, Giulio, Edrisinha, and Andrews (2005) define engagement as “being actively and appropriately involved with instructors or items” (p. 306). Ruble and Robson (2007) describe two types of engagement, compliant engagement and congruent engagement. Compliant engagement necessitates responding to adult directions and behaviors without opposition. Congruent engagement involves having behavior consistent with that of peers. Both compliant and congruent engagement are important for school settings. Children who are engaged are actively participating in behaviors deemed appropriate by adults. Therefore, they are not participating in undesirable behaviors. Engaged children are less likely to exhibit challenging behaviors, self-stimulatory behaviors and self-injurious behaviors (Mesibov et al., 2004; O’Reilly et al., 2005).

Children with autism also require social engagement. Enhancement of social skills is one of the recommended practices for children with autism (NRC, 2001). Unfortunately, development of social skills and interventions with children who are typically developing is an area that is lacking in early intervention and early childhood education (Hume et al., 2005). When socially engaged, children with autism are interacting with peers. Children with autism have fewer social interactions than peers who are typically developing. These interactions are
shorter and more superficial. Repetitive and self-injurious behaviors may interfere with social interactions. A variety of interventions have demonstrated some success in increasing social interaction of children with autism and neuro-typical peers (McConnell, 2002).

Social stories provide visual support and short sentences to summarize expected behaviors in social situations highlighting important features of specific social situations. The stories indicate how to decipher social cues as well as how to respond. Use of social stories increases the demonstration of desired behaviors in children with autism such as obtaining attention from other in appropriate ways, conversation skills and cooperative problem solving. Children demonstrate positive changes in behavior both during and after the intervention (Delano & Snell, 2006). Bellini, Akullian and Hopf (2007) found that video self modeling with preschool children observing videos of themselves engaging in behavior successfully increased social engagement. The increased interaction with peers continued after the end of the video self modeling intervention.

Strategies for increased socialization include ecological models where modifications are made to the environment or play groupings. Another method is training in collateral skills such as play and language. Child specific interventions that facilitate particular features of interactions such as initiations are also utilized. During peer mediated interventions, expected social behaviors are prompted and guided by neurotypical peers (McConnell, 2002). Comprehensive interventions that utilize a combination of the ecological models, collateral skills training, child specific interventions and peer mediated interventions are recommended. Socialization should occur in naturalistic settings throughout the day during a range of activities. Enhancing social interaction in a comprehensive manner involves making environmental adaptations, teaching
specific skills, fading interventions and observing impact of interventions over long periods of time (McConnell, 2002). Social interaction is one component of social engagement.

Social engagement, a priority for children with autism in terms of both characteristics and environmental demands, requires joint attention or attending to the same task at the same time with the same intent as another person. Joint attention is necessary for conversation, communication and perspective taking (Prizant, Wetherby, Rubin & Laurent, 2003). Joint attention describes a range of behaviors and skills involved in interacting with another person, which are deficient in children with autism (Naber et al., 2007). Joint attention is one of the central challenges of children with autism. It is a critical skill and important component of receptive language. Joint attention is impaired in children with autism who do not develop language by the age of five (Thurm, Lord, Lee, & Newschaffer, 2006).

Engagement is an integral factor in educational practices for children with autism (Ruble & Robson, 2007). In examination of engagement it is important to consider diagnosis, play skills and involvement of adults and peers (McWilliam & Bailey, 1995). Engagement involves participation, persistence and concentration and influences everything we do as educators (Fredricks, Blumenfeld, & Paris, 2004; Ruble & Robson, 2007). There is a connection between engagement and various environmental factors (Ruble & Robson, 2007). In the school setting environmental variables that influence the level of engagement in children with developmental delays include accessibility of materials, teacher responsiveness and incidental teaching (Maimskog & McDonnell, 1999). Incidental teaching involves encouraging elaborations of child initiated language in order to engage children and enhance language skills (Hart & Risley, 1978). Available literature on engagement in children with autism focuses on educational settings
School specific interventions and behaviors may not support the development of a child’s independent living skills. Parents’ perception of engagement relates to social validity. Social validity includes utilization of significant goals, acceptable procedures and satisfaction with results from the perspective of those using an intervention (Baer, Wolf, & Risley, 1987; Wolf, 1978). Parents must be willing to implement interventions and see that children are able to participate successfully. In other words, regardless of how effective a strategy may be, if an intervention is not something that families can realistically use, it is not helpful. In order to meet children’s needs, educators must view children outside of the school setting and take into account the various contexts which influence children’s lives (Bronfenbrenner, 2005).

Though emphasis has been on educational settings, family involvement is a necessary component in any intervention involving children with autism and assists with generalization of skills across settings (Dunlap, 1999; Mesibov et al., 2004). The research literature identifies family involvement as a consistent factor in programs for children with autism that are successful and evidence based (Hume et al., 2005; Iovannone et al., 2003; Simpson, 2005). Involvement and training of parents relates to positive outcomes for children (Brookman-Frazee, 2004; Hume et al., 2005). Parents experience reduced stress and increased confidence when working as partners with professionals as opposed to being directed by professionals (Brookman-Frazee). Identifying, defining and facilitating engagement is a significant factor in helping children with autism to be successful in both home and school settings.
The Role of Parents

Professionals once attributed a diagnosis of autism to cold and unemotional parents with poor parenting skills (Kanner, 1943). This history of blaming parents influenced parent perceptions of educators, psychologists and physicians. Parents of children with autism have historically felt mistrust when dealing with professionals and have expressed their voices have not been heard (Maurice, Mannion, Letso, & Perry, 2001; Stoner et al., 2005). Parents have often been disenfranchised and even viewed as hindrances (Stoner et al., 2005). Some parents feel that professionals may focus on disability and deficit rather than the individual child (Blue-Banning et al., 2004). Parents perceive a lack of collaboration and a struggle to obtain both diagnosis and interventions for their children (Blue-Banning et al., 2004; Maurice et al., 2001; Stoner et al., 2005). In the struggle for diagnosis, some parents may engage in a significant self-education phase and develop a strong knowledge base about special education laws, autism and interventions options (Stoner et al., 2005). Parents of children with autism report communication challenges between home and school (Blue-Banning et al., 2004). They express the need for constant negotiations of services, placements and support (Stoner & Angell, 2006).

Most parents of children with autism have the child’s best interest at the center. They know their children well and use this knowledge to help meet their needs. For example, transitions serve a particular challenge for children with autism. Whether moving from one task to another or one setting to another, transitions are a time of stress for both children with autism and those who work with them (Stoner, Angell, House, & Bock, 2007). Parents provide time for children to know there will be a transition and opportunities to examine their surroundings. Parents of children with autism would like professionals to get to know and understand their individual child and use that knowledge of their characteristics and reactions to ease transitions.
Getting to know children and this information about them is considered to be a necessary component of preparation by professionals interacting with their children (Stoner et al., 2007).

While parents have successful strategies and knowledge of their children, they also need support. Parents of children with autism struggle with stress, exhaustion and exasperation. Some parents have difficulty coping. In some families one parent serves as the primary caregiver, assuming responsibility for coordination of services. Simple outings such as going to the store can be a source of stress (Koegel et al., 1992). Obtaining information, interacting with professionals and acquiring services are additional sources of stress (Baker-Ericzen et al., 2005). Dealing with varied needs of children with autism and the impact on the family can be a daunting task. Negotiating and communicating with professionals may provide additional challenges.

Parents also perceive the need to monitor implementation. Although parents view educators as experts, parents of children with autism do not believe educational professionals have as much knowledge of autism intervention as parents do (Stoner & Angell, 2006). Educators may not be experts in the area of autism. It is imperative to create collaborative relationships with families that promote dialogue and address both strengths and needs of children and families (Hess, Molina, & Kozleski, 2006).

Parents of children with autism often recognize differences about their children early on (Coonrod & Stone, 2004; Schall, 2000). Pediatricians and other experts may assure parents everything is fine (Maurice et al., 2001). Professionals sometimes dismiss parents as unreliable (Schall, 2000). However, there is a growing body of literature that suggests that parental report of ongoing behavior is as accurate as test results (Goin & Myers, 2004; Ko, Wasserman, McReynolds, & Katz, 2004; Miller & Sedey, 1995; Oliver et al., 2002; Youngstrom et al., 2004).
Hawes and Dadds (2006) compared a self-report parenting questionnaire with an observation coding system and found research and parent self-ratings to be consistent. Parents know their children and engaging parents in collaborative research may provide them with the tools to create change (Ditrano & Silverstein, 2006).

**Validity of Parent Report**

The issue of the validity of parent reports challenges assumptions that parents are not an accurate source of information (R.R. Kretschmer, personal communication, February 27, 2006). Inconsistencies in parent report of skills and teachers’ observations often result in an assumption that parents are inaccurate. Professionals may even perceive parents as a hindrance to their child’s success (Corbett, Wilson, & Williams, 2002). Negative perceptions of parents may be due to lack of communication. Professionals may not understand the impact of the child’s autism on the family. Parents want educators to listen to them (Pruitt, Wandry, & Hollums, 1998). The lack of trust in parents is indicative of the deficit model. Educators create an atmosphere in which parents view them as experts doubting their own knowledge and deferring to teachers. Parents internalize that they lack knowledge, which teachers have constructed. This maintains domination through social practices (McLaren, 2003). The system is set up to “change the consciousness of the oppressed, not the situation that oppresses them (Freire, 1993, p.74).” In other words, the idea is to get the oppressed to share the goals of the oppressors, seeking to fulfill desires that maintain the status quo.

**Building On Children’s Interests to Increase Desired Behaviors**

The Premack principle (1959), referred to as “Grandma’s law,” states that high frequency behaviors can serve as reinforcers for low frequency behaviors. For example, if you eat all of your vegetables you can have your dessert (Heron, 1987). Parents and educators may use
knowledge of behaviors in which children with autism are already engaged to increase desired behaviors. By examining the activities in which children are engaged in the home setting, we can learn about their interests and incorporate these interests into interventions.

Engaging children in experiences that build on their interests provides opportunities to embed learning into social interaction in a natural way (Hancock & Kaiser, 2002). When children are motivated and interested, teaching is more effective. Using naturalistic speech interventions which incorporate child selected toys of high interest, results in more accurate, intelligible speech production and fewer behavior problems than analog teaching with isolated drilling of sounds (Koegel, Camarata, Koegel, Ben-Tall, & Smith, 1998). Building on the preferred objects and activities can motivate children with autism (Grandin, 1995). Incorporating thematic fixations of children with autism into play may increase interactions with siblings as well as decrease inappropriate behaviors associated with these fixations (Baker, 2000). Thematic fixations are also referred to as restricted interests or circumscribed interests and are part of the repetitive behaviors that are part of the diagnostic criteria of autism. When educators provide opportunities for children to make choices, the result is increased motivation and engagement and decreased problem behaviors (Reinhartsen, Garfinkle, & Wolery, 2002). When children are interested in materials, engagement is more likely. This leads to learning and then further interests (Odom & Wolery, 2003). Utilization of children’s interests can facilitate joint attention and parent child interaction (Schertz & Robb, 2006). One challenge may be how to differentiate between an interest and an obsession. There is a range of repetitive behaviors from repetitive actions to complex restricted repetitive behaviors which are thought to be more prevalent in individuals with high functioning autism (Boyd, Conroy, Mancil, Nakao, & Alter, 2007). Parents and educators need to determine if they can utilize an obsession to expand cognitive thinking and
extend interests or simply continue repetitive behavior. Parents may utilize obsessions for bonding purposes.

In special education, the focus is often on deficits and differences that are considered to be a weakness; this results in overlooking students’ strengths (Brantlinger, 2004; Corbett et al., 2002; Dudley-Marling, 2004). Student strengths ought to be incorporated into educational practices (Mesibov et al., 2004; Ozonoff et al., 2003). At times conflict between parents and educators may be due to inconsistencies between how parents and teachers view children. Parents sometimes fear that educators focus on goals without taking into account the interests of children or developing a complete picture of a child (Lake & Billingsley, 2000). Parent goals, needs and interests are also significant and are part of individualizing interventions (Iovannone et al., 2003).

Communicative Competence at Home

Problems with using conventional communication often result in undesirable behaviors (Bauer, Sapona, & Ventura, 1988). These behaviors may be an unconventional way of communicating. If children learn effective ways to communicate, aggression decreases (Carr et al., 1994). If behavior can act as a form of communication, we can learn from children’s behavior at home, how they may be communicating with parents. When children engage in undesirable behavior, educators perform functional behavior assessments to replace that behavior with what an appropriate behavior from the same response class.

Even without use of formal functional behavior assessments, parents use children’s behaviors to determine and meet children’s needs. For example, a child may reach for a glass of juice or point to the refrigerator resulting in obtaining juice. Parents use their assets and knowledge to meet children’s needs in the home setting and to keep children engaged.
Investigation of what this looks like in some instances may help build a home school connection as parent ideas are extended into the school setting to develop interventions that meet children’s needs.

*Photovoice*

Photovoice is a research method that pairs participant generated photographs with interviews. Photovoice as a method of examination and reflection for families of children with autism could provide a context for children’s behavior. The purpose of photovoice is to document strengths, needs and concerns in order to create change (Wang & Burris, 1994, 1997). The theoretical foundations of photovoice are Freire’s problem posing education and feminist theory (Wang & Burris, 1994, 1997). Problem posing education identifies students as creative critical thinkers rather than objects. Students engage in dialogue, reflection and action, not only illuminating but also transforming reality (Freire, 1993). Feminist theory emphasizes the notion that researchers engage in investigations with and by women rather than on women, identifying women’s issues and ideas and creating change (Wang & Burris, 1997). Utilization of the photovoice method is a part of the process of participatory action research. Participatory research allows “researchers and participants to co-construct knowledge unsettling power dynamics between outside experts and local community insiders (Ditrano & Silverstein, 2006, p.359).” Researchers place cameras in the hands of participants rather than outsiders in order to reflect the realities of their lives and enhance awareness and understanding of various issues.

Wang (1999) described the steps involved in the photovoice process. Researchers determine the intended audience with whom to share the evidence. In this case, educational professionals are the audience. The next step is to select participants and determine a theme for taking pictures. The theme of this investigation is engagement. Next, participants take
photographs over a predetermined period of time. Researchers and participants meet, discuss and analyze photos. Finally, participants share images and stories with the intended audience.

Researchers use photographs as evidence (Wang & Burris, 1997). Photovoice allows researchers to document settings to which they do not typically have access (Wang & Burris). Images provide opportunities for participants to communicate with researchers (Clark-Ibáñez, 2004). Photographs facilitate rapport building, focus and meaning that may be lost when simply interviewing participants (Clark-Ibáñez, 2004).

“The immediacy of the visual image creates evidence and promotes a vivid participatory means of sharing expertise and knowledge” (Wang, 2003, p.181). According to Wang (1999), images have the power to both educate and impact. Three uses of photovoice are needs assessment, asset mapping and evaluation (Wang, 1999). Asset mapping documents strengths and resources. The current investigation focuses on mapping parents’ assets in the area of promoting engagement in order to educate professionals, create a home school connection and design interventions.

**Purpose**

The purpose of this study is to determine some of the strategies, needs and goals of parents in engaging children with autism in the home setting. Parents of children with disabilities are often marginalized (Massey & Rosenbaum, 2005). Attempting to provide one on one attention to meet the needs of one child can be exhausting. When there are siblings involved siblings can feel left out and neglected. The intensity, degree and duration of undesired behaviors and reactions of children with autism forces parents to intervene with intensity, frequency and duration, which makes these parents unique. Using photovoice, and working with parents has the potential to uncover challenges and interests and discuss parent ideas for possible solutions and
effective interventions. In discussing solutions with parents, it will be necessary to acknowledge what parents are currently doing at home that is successful. Parents have valuable experience and contributions to make. When parents of children with disabilities feel they can influence children’s education, they are more likely to be able to support children and work towards positive outcomes for both the child and the family (Bailey et al., 2006). Thus, this research study seeks to explore the following questions:

1. What are indicators of engagement in the home?
2. In what kinds of activities are children with autism engaged in the home setting?
3. How do parents of children with autism identify engagement?
4. What are some things parents do to facilitate engagement?
5. What are some needs and goals of parents in terms of facilitating engagement in the home setting?

In examination of the above questions, I aimed to determine not only parents’ perceptions of engagement but also what engagement looks like outside of the educational settings on which current literature focuses. I also examined how engagement in the home setting is related to the research literature and engagement in the school setting from the perspective of professionals. The study gathered evidence about which parent interventions are effective in the home setting in order to facilitate interventions in the school setting. The methods used in the current study may help facilitate communication and collaboration between parents and professionals and perhaps result in continuity and consistency between home and school settings.

Method

This study used qualitative research methods to explore engagement in autism in the home setting. Qualitative research is defined as “a systematic approach to understanding
Qualitative methods allow for the study of participants in a natural setting, from their viewpoint and over a period of time. Rather than beginning with a null hypothesis, to reject or accept, researchers analyze patterns in the data, allowing the data to speak (Altheide, 1996; Glesne, 2006; Strauss & Corbin, 1998). Selection of a methodology however begins not because one prefers qualitative over quantitative analysis.

Methodology begins with ontology or how we view reality and being. Ontology flows into epistemology or how we come to know what we know. From our epistemologies spring the theoretical perspectives or research paradigms, which explicate the assumptions upon which our research is based and therefore dictate the methods utilized. The methodology is the plan and design of the research followed by the methods or the recipe for collecting and analyzing data (Crotty, 1998; Hatch, 2002).

In order to describe the methods, I will begin by explaining the ontological, epistemological and theoretical foundations upon which the methods are built. There are actually two separate, yet not incommensurable paths that lead to the methods: constructivism and critical theory. The ontological basis of constructivism assumes that people and groups construct several realities. The participant and the researcher both construct knowledge. One obtains knowledge. The final product is a descriptive and interpretive construction. This paper is such a construction. The knowledge the participants construct and share in the interview process is synthesized with the knowledge the researcher constructs in the coding and analysis process. Constructivism is relevant to and underlies this investigation because there are multiple realities created by our varying perspectives (Wertsch, 1998). The camera serves a cultural tool which both facilitates and confines the interaction between the researcher and the participant. In providing a context for
the interview and a glimpse into the home, photographs serve an aid. They also provide only a
piece of reality, which is a limitation. The individuals involved, the tools utilized and the context
of the interaction, in this case the interview, result in a new construction or reality, which is an
attempt to connect perspectives rather than reducing one to another (Wertsch, 1998).

Critical theorists’ view of reality is that race, class and gender matter and influence
whose voices are heard, therefore what is valued as knowledge depends upon power and politics.
One obtains knowledge through reflection and dialogue. The end result in critical theory is to
create change (Crotty, 1998; Hatch, 2002). The photovoice images allow for application to
practice with the parents as active participants in the dialogue. The parents are critical thinkers
engaged in the action of taking the photographs and the reflection of the photovoice interview.

From the feminist perspective, it is essential that women have an opportunity to express
their way of knowing and address inequalities in a male centered society (Crotty, 1998). Women
are sharing their insights and strategies for survival in the home setting. It is interesting to note
that recruitment materials sought out parents of children with autism, without attention to gender,
yet all of those who chose to participate are women. The demands of daily care on the primary
caregiver, who is often the mother, may be a source of stress for parents of children with autism
(Baker-Ericzen et al., 2005). Examination of the role of mothers and their perspectives provides
an opportunity to hear the voices of women as valued contributors to the educational dialogue.

Ultimately, this is a photovoice interview study done within a constructivist paradigm.
The critical/feminist underpinnings cannot be ignored however as the participants are women
sharing their perspectives and voices with the ultimate goal of communicating with professionals
in order to both inform and transform current educational practices. Also, the development of the
photovoice process stems from a critical/feminist perspective.
The photovoice process illustrates the perspective of the parent. The parent participant captures the images based on a theme selected by the researcher; however, it is the parent who determines where and when to take the photographs as well as what fits the theme from their perspective. Structuring photos around a topic or theme rather than using candid photos allows for systematic exploration particularly if making comparisons across groups (Collier, 1967). When the participants take the photographs, they make decisions about what to leave in and what to leave out (Epstein, Stevens, McKeever, & Baruchel, 2006). Another term utilized in the research literature to describe image based interviews is the photo elicitation interview (PEI). Photographs assist with participant recall and creating a connection to and empathetic relationship with the researcher (Epstein et al., 2006).

Anthropologists have employed image-based research methodologies since the 1940s to create cultural inventories and explore various societies (Collier, 1967). The camera serves as an instrument to assist in illumination of what we perceive in the same way a microscope provides another level to observation (Collier, 1967). Photographs allow for a record of reality. They provide not only a view of reality but also an extension of reality and the senses, which enables us to have additional information (Collier, 1967). The photovoice interview provides an opportunity for each participant to explain the significance of the image to them and why they took the photo. The participants have some structure and a starting point from which to tell their stories. Each word selected reveals a window into the consciousness of the participants (Vygotsky, 1987). What is significant about photovoice is the connection to action. The photographs are a tool to facilitate reflection and include parent voice in the intervention process. They provide a glimpse into the home environment. The images speak for the participants laying
the foundation on which they can begin to share stories and values from their perspective (Kroeger et al., 2004).

Document analysis allows for organization, description and comparison of photographs. Document analysis alone fails to reveal the relevance, importance and context of the images (Leary, 1988). Document analysis of the photographs entails examination of the subject and uniqueness of each photograph (Leary, 1988). The researcher seeks to determine the commonalities among the photographs and how they might be different. Altheide (1996) describes qualitative document analysis as an iterative process, during which the researcher interacts with the materials, in this case, photographs, and there is continuous unearthing of meaning. The researcher creates a written description of each photograph including the contents of the photographs, types of activities and objects and appearance of materials in the images.

Research Questions

1. What are indicators of engagement in the home?
2. In what kinds of activities are children with autism engaged in the home setting?
3. How do parents of children with autism identify engagement?
4. What are some things parents do to facilitate engagement?
5. What are some needs and goals of parents in terms of facilitating engagement in the home setting?

Research Design

Subjectivity Statement

As an experienced early childhood special educator, I have worked with children and families with disabilities in both the home and school settings. Over the years, I have discussed parent goals and concerns at home visits, IEP meetings and parent-teacher conferences. As a
therapist at the New York Child Learning Institute, I used applied behavior analysis including discrete trial training creating environmental changes to work on skills. For example, a child might work on letter identification using discrete trials pointing to and saying letters and receiving verbal reinforcement. After that, we might focus on looking at letters in a book. We did not use aversives. Although often beginning with skills out of context we attempted to put them in context and focus on generalization. Another example is that one child might be working on requesting items. Throughout the day, teachers would be preferred items out of reach and only give them to the child after a verbal request such as “train please.” I also worked with toilet training and eating issues. I graphed progress for each skill, scoring the number of correct and incorrect responses or attempts. Working closely with parents and an educational coordinator, we set goals for learning as a team. We conducted monthly home visits to review progress and update goals.

In my inclusive preschool classroom, typically one of the sixteen students was identified as demonstrating autism. I worked on organizing the environment by creating clear boundaries using dividers and furniture as well as labeling classroom centers. I included visual schedules, picture sequencing for hand washing and labels. At snack-time and lunch-time, we worked on requesting items. I integrated interests into the classroom, attempting to motivate participation and expand on those interests, for example, having the children create a train for the dramatic play area. I paired children with autism with neurotypical peers sitting with them as they played classroom math games and prompting the child to say “My turn or your turn.” I would gradually remove myself from the situation attempting to encourage peer interaction. I frequently held conferences with families and worked with them to implement instruction and intervention.
I have extensive experience working with children identified along the autism spectrum and their families. I am a parent with training and education in typical and atypical child development. Utilizing this education and experience, I was able to build a rapport with families for this study. I met with families on their schedules in the home setting, just as I did as an educator. My experiences with children with autism and their families are part of my autobiography and therefore influence the lens through which I view my research. They caused me to question why parent expertise was not utilized more. My experiences influenced the interest in obtaining information about parent strategies and perspectives.

Context and Participants

Five parent participants and five children completed the study. Both mothers and fathers were welcome to participate, but only one parent would take the photographs and engage in the interview process. All parent participants were mothers and all children with autism were males in fourth grade or younger. Two of the children were present during the interview process. Initials will identify child participants. Table 1 shows demographic information for all participants.
**Table 1**

*Demographic Information*

<table>
<thead>
<tr>
<th>Child’s Initials</th>
<th>Child’s Age</th>
<th>Child’s Grade</th>
<th>Child’s Gender</th>
<th>Child’s Race</th>
<th>Siblings</th>
<th>Parent Marital Status</th>
<th>Mother’s Age</th>
<th>Approximate Annual Household Income</th>
</tr>
</thead>
<tbody>
<tr>
<td>WB</td>
<td>5</td>
<td>Preschool</td>
<td>Male</td>
<td>Caucasian</td>
<td>2 sisters (Ages 6 and 15)</td>
<td>Married</td>
<td>37</td>
<td>$50,000</td>
</tr>
<tr>
<td>FA</td>
<td>6</td>
<td>First</td>
<td>Male</td>
<td>Bi-racial</td>
<td>None</td>
<td>Married</td>
<td>38</td>
<td>$114,000</td>
</tr>
<tr>
<td>SW</td>
<td>8</td>
<td>Second</td>
<td>Male</td>
<td>Caucasian</td>
<td>2 sisters (Ages 3 and 5)</td>
<td>Married</td>
<td>35</td>
<td>$50,000</td>
</tr>
<tr>
<td>DC</td>
<td>9</td>
<td>Second or Third</td>
<td>Male</td>
<td>Caucasian</td>
<td>2 sisters (Ages 1 week old and 10 years old)</td>
<td>Married</td>
<td>37</td>
<td>$70,000</td>
</tr>
<tr>
<td>MG</td>
<td>10</td>
<td>Fourth</td>
<td>Male</td>
<td>Caucasian</td>
<td>2 sisters (Ages 8 and 12)</td>
<td>Married</td>
<td>39</td>
<td>$80,000</td>
</tr>
</tbody>
</table>

**WB** is a five-year-old male. He received a diagnosis at the age of two at a children’s hospital division of developmental disabilities. Some of his strengths include puzzles and learning routines. According to his mother, “He likes to do things over and over again. He likes routine. He gets mad if things are not done the same way. He does not like to change direction (if you are going somewhere and you forgot something and you have to go back.)” **WB’s** mother is concerned that he will not be able to communicate effectively with others, live on his own and have a job. He can feed himself, but cannot do other daily living skills without help.

**FA** is a six-year-old male. He is an only child. He currently attends a private elementary school. He received a diagnosis at the age of three at school during an early intervention program week. According to his mother, he has an excellent memory for people’s names and a sense of
humor. His mother explains that with ample preparation and when things are “going his way”, he integrates well into situations with children who are typically developing. Sometimes school staff, who do not have direct, consistent contact with him question whether he has autism. His diagnosis is high functioning autism and according to his mother has a “near genius” level IQ. One of her concerns includes how to help him cope with changes in the school day. Events such as fire drills, picture day and assemblies can ruin his entire day.

**SW** is an eight-year-old male. He received a diagnosis of autism at the age of three by a developmental pediatrician. Some of his strengths include reading, math and computer skills. He has two sisters, both of whom are on the autism spectrum as well. His mother describes him as a sweet, smart, loving, funny fairly high functioning child, who hates transitions. Her concern is that he may never be independent, drive, go to college or most of all be happy.

**DC** is a nine-year-old male. He attends an ungraded self-contained private applied behavior analysis school. He would be in the 2nd or 3rd grade in public school. He attended two years of kindergarten. **DC** received his diagnosis while receiving early intervention for significant delays at the local children’s hospital. His mother described his strengths as follows “[He is] loving, willing to keep trying and very happy. He loves to go and transitions easily.” Some of her concerns are the things that challenge him. He is non-verbal. His cognitive self-help skills are at 11-18 months. He is a runner. He has delayed fine motor skills and trouble with peer interactions. He sometimes pulls hair.

**MG** is a ten-year-old male. He attends fourth grade at a small K-8 elementary school for children with special needs. He was identified at the age of two and a half. His parents met another parent at speech therapy whose child had been diagnosed with autism. This parent described her son’s play habits and **MG**’s parents recognized the similarites. He was diagnosed
officially six months later at the local children’s hospital. According to his mother, some of his strengths include his “memory, physical abilities and genuine caring personality.” She explains that he enjoys social situations particularly when there is a connection to one of his obsessions or restricted interests. One example is he likes to attend sporting events because he knows there will be an elevator. He enjoys seeing how things work and learning about weather related tragedies such as tornadoes and hurricanes. MG’s mother describes his as high functioning. She says that only people familiar with the disorder recognize that he has autism when they meet him. “After spending increased amounts of time with him, people begin to realize that something is ‘off’ and he is extremely smart.” He is delayed academically at least one year and emotionally probably two years. MG’s mother is concerned because her son is easily frustrated and extremely impulsive. According to her, “He is behind enough socially that peers see him as a ‘freak’. I worry that he will never find a true friend.”

Data Collection Method

Following approval from the University of Cincinnati Institutional Review Board, I conducted an extensive and exhaustive search for participants. I contacted teachers and program directors over the phone as well as visiting sites in person. I distributed recruitment letters and flyers in person and via electronic mail to two public school districts, three private schools, a children’s hospital, a local occupational therapy institute, a county center for educational services serving over 100,000 students and the Ohio Center for Autism and Low Incidence. In addition, I posted information in the Autism Society of Cincinnati newsletter and distributed on two autism listservs (autism speaks, familieswithASD@yahoogroups.com). Parents who participated in the pilot study provided referrals and posted flyers at their children’s schools. Parents had an opportunity to self-select based on their interest in participation. The goal was to recruit seven to
ten parents of children with a medical diagnosis of autism who are in preschool through fourth grade; however, ultimately five parents chose to be a part of the current research.

Three meetings occurred with each parent. During the first meeting, parents received an overview of the research and provided informed consent. Parent participants received two disposable cameras. One was for the purpose of the study. The other was extra in case a camera was lost or a child expressed interest in taking photographs for personal use. Using the photovoice process developed by Wang and Burris (1994; 1997), participants took photographs and then described what was happening in the photos related to the theme of engagement. Participants sharing stories in their own voices provides meaning and context for the images (Wang, Yi, Tao, & Carovano, 1998). Over the course of a week, parents photographed their children engaged in various activities. Parents delivered cameras to locations of their choosing convenient to them. Parents provided email notification upon delivering the cameras. Only parent participants (mothers) took the photographs used for the purpose of the study. I retrieved photographs so there would be no cost or inconvenience to the parents. During a second meeting, we met to interview the parents about the content of the photographs, why they took the photographs and how they related to engagement. I met with all participants individually, in order to discuss all of the photographs. Participants then had the option to select three or four of the photographs for participation in a group discussion with the other participants. Citing time constraints, none of the parents opted to participate in the group portion of the study. In our individual photovoice interviews, we considered the following questions about each photograph.

- How would you describe the photograph?
- What is happening in the photograph?
- Why did you take a picture of this?
• What does the photograph tell you about engagement?
• How can this provide information about how parents and teachers can encourage engagement?

Parent participants discussed how they knew when their child was engaged in something.

The interview and analysis of photographs lasted approximately one hour and were tape-recorded. Tapes were transcribed verbatim by a paid transcriptionist. Transcriptions were double-checked. First I listened to each recording and made corrections to typed transcripts. Then I sent copies to each participant to check and verify.

Data Analysis

Data sources included 118 of photographs and 71 pages of transcripts. I conducted a content analysis on transcriptions of interviews including an analysis by searching for “units of meaning” (Stringer, 2004, p.113) and documenting emerging themes. Using an open coding process (Strauss & Corbin, 1998), I identified conceptual labels for each sentence in the transcription. It is important to review and interrogate data revisiting it in terms of the research questions. The goal is examination of individual parts in order to combine them into something complete and significant (Hatch, 2002).

Data analysis consisted of multi-level analysis including microanalysis, inductive analysis and document analysis. After a thorough reading of the transcript, microanalysis included line by line coding of the photovoice interview transcripts. Microanalysis is detailed, exhaustive examination of words, phrases and sentences (Strauss & Corbin, 1998). It involves questioning and listing the possible meanings of words and phrases and then returning to the data to make comparisons and determine which is most accurate. Utilizing the technique referred to as open coding, each line of data is assigned a conceptual label determined by the language and
the context. The conceptual labels are grouped into categories and using axial coding, categories are related to one another (Strauss and Corbin, 1998). Inductive analysis helped to identify domains of interest in the data set (Hatch, 2002). Conceptual labels were grouped into domains that break down the meaning by looking for cover terms, included terms and semantic relationships (Spradley, 1979). The analysis is an iterative process, which entails reading and re-reading data to determine frames of analysis. The goal is to reduce the data, narrowing the analysis to determine what is important. There is a re-reading and fine-tuning of the data with the semantic relationships in mind (Hatch, 2002). I examined relationships both within and across domains with an attempt to use patterns and relationships to explain parents’ use of engagement and perspectives about engagement. All transcripts and codes were checked by two researchers with consensus on both the codes and the domains. An example of the analysis process follows. The codes stayed as close to the data as possible, often including many of the same words. The codes are indicated in bold and in brackets.

That is him eating his breakfast in the morning. [Eating breakfast]
That’s his hot chocolate, which he makes himself, using water from the sink, the hot water from the sink [making hot chocolate independently] and he got his own vitamin, which is laying on the napkin. [Gets vitamin independently] [vitamin accessible] The milk is down in a small container that he can handle [milk in container he can use] and the cheerios are on the lower shelf [cheerios accessible] so he can make that whole breakfast himself. [Makes breakfast independently]

Each code included the participant initials and line number of the transcript in order to allow for revisiting of the data. Using the strict inclusion semantic relationship ____ is a kind of_____, each code can be placed into a domain.

Eating breakfast is a kind of self help skill.
Making hot chocolate independently is a kind of self help skill
[Making the] vitamin accessible is a kind of parental teaching strategy
[Putting] milk in a container he can use is a kind of parental teaching strategy
Determining domains involved revisiting the data and looking at codes in a variety of ways, before deciding upon a category. Eating breakfast is a way to obtain nourishment. In the context of this data, eating breakfast is part of independent living skills and self-help skills towards which the parents were working. The line by line coding necessitated continually returning to the data for clarification.

I documented the frequency of instances in which each behavior in various domains occurred by recording the number of photographs indicative of each area. I recorded frequency both within and across participants. Photovoice allowed for illumination of the parents’ perspective. Additional analysis of the photos facilitated verification of data.

Using document analysis techniques for examination of archival data, I created a visual description of each photograph including the source, location and subject matter (Altheide, 1996; Leary, 1988). The analysis also involved making comparisons to determine similarities and differences among photographs. The analysis included who, what, why and where, what is pictured and what is missing in an effort to uncover perspective, themes and relationships (Altheide, 1996; Leary, 1988). In other words document analysis entails development of a protocol or strategy for questioning the documents. The protocol allows for examination of each photograph with the same questions as a guide. The protocol utilized for the current study can be viewed in Table 2. Once the protocols were completed for each photograph, emerging themes were documented and compared across participants for all of the photographs.
Table 2

Photograph Protocol

<table>
<thead>
<tr>
<th>Protocol for engagement in children with autism photographs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Who are people in the photo?</td>
</tr>
<tr>
<td>What are the people doing?</td>
</tr>
<tr>
<td>What objects are in the photo?</td>
</tr>
<tr>
<td>What might be the purpose of the objects?</td>
</tr>
<tr>
<td>How are the objects arranged?</td>
</tr>
<tr>
<td>What is the setting of the photo?</td>
</tr>
<tr>
<td>What, if anything, is missing from the photo?</td>
</tr>
</tbody>
</table>

Trustworthiness

There are several ways to augment the credibility and trustworthiness of a study. One technique is using different sources of data or data triangulation. Another way to demonstrate trustworthiness is methodological triangulation “The use of multiple methods to study a single problem” (Brantlinger, Klinger and Richardson, 2005 p. 116). An additional procedure to enhance trustworthiness is to conduct member checks, which entails the process of sharing results at various stages with participants in order to determine their perception of its accuracy. Finally, reflection and documentation of researcher bias and subjectivity increases trustworthiness (Glesne, 2006).

In order to ensure credibility and trustworthiness three measures were utilized: member checks, data triangulation and “clarification of researcher bias” (Glesne, 2006, p.37). In order to
ensure that participants view interpretations as valid as well as allow them to respond to the interpretations, member checks were conducted (Hatch, 2002). Two level member checks involve referring back to participants not only at the transcript level but also at the interpretation and analysis level (Brantlinger, Klinger and Richardson, 2005). I shared all results, including transcripts and codes, with participants with a request to respond to accuracy in the perception of the parents. Use of both photographs and interview transcripts as sources of data allowed for data triangulation. Dual coding of data by two researchers with complete consensus of codes and domains allowed for a measure of inter-rater reliability in terms of data analysis.

Maintenance of a journal throughout the research process by writing before and after photovoice interviews addressed preconceived notions and biases. Research journals are extensions of the concept of bracketing from the field of phenomenology, where the goal is to focus solely on the participants’ experiences and set aside researcher bias (Hatch, 2002). In analysis of the photos and transcripts, journal writing allowed not only for documentation of what I perceived, but also why I attended to it (Glesne, 2006). The reflective journal illuminated awareness of the impact of personal biases.

Limitations

Parents had the opportunity to self-select to be participants in the study based on posted flyers. The reason for this recruitment method was lack of current interaction with a convenient sample and attempts to avoid any coercion. In spite of extensive recruitment efforts and exposure to hundreds of potential participants, only five participants chose to engage in the study. The group photovoice interview was an optional portion which none of the parents selected. There are a range of possibilities for challenges in recruitment.
When compared with parents of children who are typically developing, there are higher levels of stress among parents of children with autism (Baker-Ericzen et al., 2005; Koegel et al., 1992). Stress may be related to concerns about long term outcomes, child characteristics, monetary strain and the time and effort required for determination and implementation of interventions (Baker-Ericzen et al.; Koegel et al.). Already stressed parents may have been reluctant to take on another activity or obligation. There is some lack of trust of professionals among parents of children with autism. Parents of children with autism are extremely busy. All of the participants except one had more than one child. One parent had three children, all of whom were on the autism spectrum. Two parents worked outside of the home. All of the parents were active participants in their child’s school as well as taking children to additional therapies outside of the home and school setting. Parents who took the time to choose to participate in this study are likely to be well organized.

Findings

This section describes the themes that emerged from analysis of the photos, the domains from the interview transcripts and how both relate back to the research questions. Table 3 includes the research questions and the related findings. Analysis of the picture reveals the materials and activities in which children were engaged and the categorization of those materials and activities. Analysis of the transcripts includes a deeper level of investigation providing insight into parent perspectives and motivations often illuminating how and why activities were selected.

I began by coding each line of the transcripts. I used the strict inclusion (X is a kind of Y) and means-end (X is a way to do Y) semantic relationships, in order to categorize the codes into thirty three domains. The hypothesized domains appear in Table 3.
Table 3

*A summary of the list of hypothesized domains*

Domain
1. Kinds of accomplishments
2. Ways to attend over time
3. Kinds of child escape/avoidance
4. Kinds of needs children have
5. Kinds of chores
6. Ways to collaborate
7. Kind of communication
8. Ways to be consistent
9. Kinds of educational activities
10. Kinds of entertainment
11. Kinds of exposure to different or unexpected things
12. Ways to facilitate communication
13. Ways to be flexible
14. Ways to help child fit in
15. Kinds of independence
16. Ways to work toward independence
17. Kinds of interest
18. Ways to build on interests
19. Ways to make connections
20. Kinds of motivator
21. Ways to use music
22. Kinds of obstacle, barrier or concern
23. Ways to use organization
24. Kinds of parent goals/wishes
25. Ways parents identify engagement
26. Kinds of parent knowledge of child
27. Kinds of parent reflection
28. Kinds of parental teaching strategies
29. Kinds of persistence
30. Kinds of physical activity/sensory input
31. Kinds of play (toys, computer, pretend)
32. Kinds of self help skills
33. Kinds of sibling interaction or knowledge

After determination of the domains, I connected them back to the research questions.

The summary of findings as they correspond to the research questions can be found in Table 4.

The activities in which children engage are consistent with the photo analysis.
<table>
<thead>
<tr>
<th>Research questions</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>What are indicators of engagement in the home?</strong></td>
<td>Accomplishment ( Appropriately engaging in task that has been worked on for years), Attending over time, Persisting at a task, Escape/avoidance (negative example)</td>
</tr>
<tr>
<td><strong>In what kinds of activities are children with autism engaged in the home setting?</strong></td>
<td>Chores, Communication, Educational activity, Entertainment, Play (with toys or games), Self help skills, Physical activity/sensory input, Play (computer game), Play (dress up/pretend play), Sibling interaction or knowledge, Music, Interests</td>
</tr>
<tr>
<td><strong>How do parents of children with autism identify engagement? (Photovoice question: Why did you take a picture of this?)</strong></td>
<td>Child makes connections; child is focused, Interacting with materials as a “typically developing” child would; absence of inappropriate behavior; persisting at something the child would not typically do (This involves using parent knowledge of children’s behavior and interests.)</td>
</tr>
<tr>
<td><strong>What are some things parents do to facilitate engagement?</strong></td>
<td>Use children’s interests, break tasks down into parts, use consistency (Ex: Same time and place for homework), encourage sibling modeling, provide a variety of materials, use of novelty, use visual supports</td>
</tr>
<tr>
<td><strong>What are some needs and goals of parents in terms of facilitating engagement in the home setting?</strong></td>
<td>Goals: Independence, facilitating communication, children’s happiness, helping children fit in, Needs: consistency across settings, support in dealing with obstacles and barriers</td>
</tr>
</tbody>
</table>

Children are predominantly engaged in interacting with objects such as toys, musical instruments and computer games. Next, children attempt to communicate with parents and siblings to meet their needs. Parents know children are engaged when they are focused and
engaging in activities in an appropriate manner. One parent illustrates this as she describes why she took a photo. “He’s sitting down and he’s not rocking. He’s actually sitting down and he’s focused.” Indicators of engagement include successful accomplishment of a task and attending over time. “He’s obviously engaged because he did it for a while.” Another indicator of engagement was active involvement “If he stops putting the marbles in, it won’t work anymore. That’s good because it’s not just something you can turn off and on and leave him with. He has to do it.”

Parents engage children in ways to facilitate independence, which is a major goal. Parent engagement of children includes teaching and use of independent living skills such as chores and self-help skills. “I guess we’re kind of big on self-help skills. Like I wanted to make sure that he can take care of himself and start learning certain things so when he becomes a teenager, certain things he just has. Washing your hands, making sure you have clean clothes, picking up your clothes and putting them in the dirty clothes, if you spill something clean it up.”

Using knowledge of their children’s interests, motivators and distracters, parents organize the environment to maximize learning needs of their children. Examples include orderly organization of materials and accessibility of engaging materials. Opportunities for physical activity and sensory input seemed to help. Clarification may be needed for use of the term sensory input. Parents did not use sensory integration, which involves one-on-one controlled experiences aimed at helping children with autism integrate information and does not have a conclusive research base (Green, 2007). Parents attended to sensory abnormalities by attempting to block out unexpected stimuli and providing materials with which children could have some control over sensory input such as textured balls one child played with.
Another area in which parents used knowledge of their children is following their cues. One parent describes how her son communicates by standing in front of an open cabinet and using eye gaze to show what food he wants. Only those with an awareness of his cues and ability to follow them would be able to meet his needs. Another example is his morning routine. DC likes to have about 15 minutes in his parents’ bed watching country music television each morning. It may seem simple, but his mother explains how important this time is.

I think that teaches parents and teachers that you need to follow their cues. If there is something they enjoy that makes the day go more smoothly it’s worth that 15 minutes. We get up 15 minutes earlier just so we’ve got that every morning. Then he’s ready to go and his day goes pretty smoothly.

Parents are not just thinking about one skill or one activity, they are thinking ahead to work towards having a successful day, week and month. Another component of this is communication with teachers. One parent uses a journal that goes back and forth each day to communicate any events that occurred that morning or the evening before that might influence his day. Another parent works to communicate with everyone who works with her son. In order to be clear and consistent they all use the same word when they want him to stop doing something, so he is able to understand what is being asked of him. She takes it a step further and communicates with those who do not necessarily work with her son, but are likely to interact with him including family, friends and school staff.

So I think clear communication around, among everybody is very important to make sure that everyone in your circle knows because otherwise it’s hard to reinforce the sign for eat, if only two people know that he can do that sign. It’s especially important in school because sometimes the people they want to communicate with are the people you don’t think about like the secretary and the janitor. Especially for… like [DC] loves janitors, any males in the building, the gym teacher whom you normally wouldn’t show signs to but I make sure they know what all those signs look like or what we’re working on. So that when [DC] goes up and grabs their hands they can engage him appropriately.
Parents are working on goals that will help children to be successful and function in society over time and in a variety of settings. The domain with the highest number of subsets and links to all of the other domains was “kinds of parental teaching strategies.” This domain is aligned with the research question about what parents do to facilitate engagement. The taxonomic analysis clarifies the manner in which parents facilitate engagement and identify engagement.

Tables 5-9 include brief descriptions of each photograph developed after utilization of the protocol. Most of the photos depict interactions with materials including the combined themes of play with toys, educational activities, computer games and entertainment. A number of photos depicted demonstration and practicing of independent living skills including both self-help skills and chores. The next key theme is communication. Communication includes initiating interactions, telling stories, explaining, pointing, signing and other communication attempts. Finally photos showed children interacting with siblings and parents. The low number of photographs of parent interaction are probably because the primary caregiver was the person taking the photographs.
### Table 5- FA Photographs

<table>
<thead>
<tr>
<th>Picture</th>
<th>FA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Picture #1</td>
<td>Taking a Bath</td>
</tr>
<tr>
<td>Picture #2</td>
<td>Eating breakfast</td>
</tr>
<tr>
<td>Picture #3</td>
<td>Reading a Book</td>
</tr>
<tr>
<td>Picture #4</td>
<td>Playing with marble Truck</td>
</tr>
<tr>
<td>Picture #5</td>
<td>Taking a juice box out of the refrigerator</td>
</tr>
<tr>
<td>Picture #6</td>
<td>Washing his hands</td>
</tr>
<tr>
<td>Picture #7</td>
<td>Putting boots on</td>
</tr>
<tr>
<td>Picture #8</td>
<td>Brushing the dog</td>
</tr>
<tr>
<td>Picture #9</td>
<td>Playing basketball</td>
</tr>
<tr>
<td>Picture #10</td>
<td>Playing with trains</td>
</tr>
<tr>
<td>Picture #11</td>
<td>Playing the drums</td>
</tr>
<tr>
<td>Picture #12</td>
<td>Playing the accordion</td>
</tr>
<tr>
<td>Picture #13</td>
<td>Playing a Dora game on the computer</td>
</tr>
<tr>
<td>Picture #14</td>
<td>Playing with Tickle me Elmo</td>
</tr>
<tr>
<td>Picture #15</td>
<td>Sleeping</td>
</tr>
<tr>
<td>Picture #16</td>
<td>Playing the Guitar</td>
</tr>
<tr>
<td>Picture #17</td>
<td>Doing Homework</td>
</tr>
<tr>
<td>Picture #18</td>
<td>Brushing his teeth</td>
</tr>
<tr>
<td>Picture #19</td>
<td>Brushing his hair in the mirror</td>
</tr>
<tr>
<td>Picture #20</td>
<td>Using a Lacing Board</td>
</tr>
<tr>
<td>Picture #21</td>
<td>Riding a Scooter</td>
</tr>
<tr>
<td>Picture #22</td>
<td>Driving a toy truck</td>
</tr>
<tr>
<td>Picture #23</td>
<td>Flying a toy helicopter</td>
</tr>
<tr>
<td>Picture #24</td>
<td>Putting Clothes in the Dryer</td>
</tr>
<tr>
<td>Picture #25</td>
<td>Dressing up like a pirate</td>
</tr>
<tr>
<td>Picture #26</td>
<td>Playing with a toy boat</td>
</tr>
<tr>
<td>Picture #27</td>
<td>Dressing up like a superhero</td>
</tr>
</tbody>
</table>

### Table 6- MG Photographs

<table>
<thead>
<tr>
<th>Picture</th>
<th>MG</th>
</tr>
</thead>
<tbody>
<tr>
<td>Picture #1</td>
<td>Playing A Board Game</td>
</tr>
<tr>
<td>Picture #2</td>
<td>Showing his mother an award</td>
</tr>
<tr>
<td>Picture #3</td>
<td>Telling his mother about what is on television</td>
</tr>
<tr>
<td>Picture #4</td>
<td>Eating breakfast</td>
</tr>
<tr>
<td>Picture #5</td>
<td>Wearing a boy scout uniform and talking about boy scouts</td>
</tr>
<tr>
<td>Picture #6</td>
<td>Giving a piece of a cookie to his sister</td>
</tr>
<tr>
<td>Picture #7</td>
<td>Playing table soccer with his sister</td>
</tr>
<tr>
<td>Picture #8</td>
<td>Counting and sorting money with his sister.</td>
</tr>
<tr>
<td>Picture #9</td>
<td>Talking to his grandmother</td>
</tr>
<tr>
<td>Picture #10</td>
<td>Showing his mom the wood for his pinewood derby car</td>
</tr>
<tr>
<td>Picture #11</td>
<td>Getting into the car independently</td>
</tr>
<tr>
<td>Picture #12</td>
<td>Helping take down the Christmas tree</td>
</tr>
<tr>
<td>Picture #13</td>
<td>Heating food in the microwave</td>
</tr>
<tr>
<td>Picture #14</td>
<td>Helping put away the Christmas ornaments</td>
</tr>
<tr>
<td>Picture #15</td>
<td>Doing homework worksheets</td>
</tr>
<tr>
<td>Picture #16</td>
<td>Writing a Letter</td>
</tr>
<tr>
<td>Picture #17</td>
<td>Reading a book for homework</td>
</tr>
<tr>
<td>Picture #18</td>
<td>Wrapping and packing a fragile nativity set</td>
</tr>
<tr>
<td>Picture #19</td>
<td>Writing and illustrating a book</td>
</tr>
<tr>
<td>Picture #20</td>
<td>Loading the dishwasher</td>
</tr>
<tr>
<td>Picture #21</td>
<td>Asking his sister to sign his cast</td>
</tr>
<tr>
<td>Picture #22</td>
<td>Wrestling with his sister</td>
</tr>
<tr>
<td>Picture #23</td>
<td>Talking to his sisters</td>
</tr>
<tr>
<td>Picture #24</td>
<td>Vacuuming</td>
</tr>
<tr>
<td>Picture #25</td>
<td>Showing and talking about his “UC” tattoo and the cross-town shootout</td>
</tr>
<tr>
<td>Picture #26</td>
<td>Making microwave popcorn</td>
</tr>
</tbody>
</table>

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Table 7- DC Photographs

<table>
<thead>
<tr>
<th>DC</th>
</tr>
</thead>
<tbody>
<tr>
<td>Picture #1</td>
</tr>
<tr>
<td>Sitting with his sister under a weighed blanket and playing with toys</td>
</tr>
<tr>
<td>Picture #2</td>
</tr>
<tr>
<td>Sister moving away from him as he is about to have a seizure</td>
</tr>
<tr>
<td>Picture #3</td>
</tr>
<tr>
<td>Signing for juice to his sister</td>
</tr>
<tr>
<td>Picture #4</td>
</tr>
<tr>
<td>Handing a toy car to an adult</td>
</tr>
<tr>
<td>Picture #5</td>
</tr>
<tr>
<td>Doing a sorting activity with assistance from his sister.</td>
</tr>
<tr>
<td>Picture #6</td>
</tr>
<tr>
<td>Doing a piggy bank sorter with assistance from his sister.</td>
</tr>
<tr>
<td>Picture #7</td>
</tr>
<tr>
<td>Ring sorter with sister prompting</td>
</tr>
<tr>
<td>Picture #8</td>
</tr>
<tr>
<td>Selecting preferred activity from toys</td>
</tr>
<tr>
<td>Picture #9</td>
</tr>
<tr>
<td>Lying in bed with father</td>
</tr>
<tr>
<td>Picture #10</td>
</tr>
<tr>
<td>Eating frosted flakes independently</td>
</tr>
<tr>
<td>Picture #11</td>
</tr>
<tr>
<td>Drinking soda independently</td>
</tr>
<tr>
<td>Picture #12</td>
</tr>
<tr>
<td>Making a selection from his work shelf</td>
</tr>
<tr>
<td>Picture #13</td>
</tr>
<tr>
<td>Pushing a ball to his sister</td>
</tr>
<tr>
<td>Picture #14</td>
</tr>
<tr>
<td>Reaching for his lunch box during a work session</td>
</tr>
<tr>
<td>Picture #15</td>
</tr>
<tr>
<td>Holding the remote control</td>
</tr>
<tr>
<td>Picture #16</td>
</tr>
<tr>
<td>Holding the telephone</td>
</tr>
<tr>
<td>Picture #17</td>
</tr>
<tr>
<td>Sitting on his bed</td>
</tr>
<tr>
<td>Picture #18</td>
</tr>
<tr>
<td>Doing the piggy bank sorter independently</td>
</tr>
<tr>
<td>Picture #19</td>
</tr>
<tr>
<td>Giving his dad a “high five”</td>
</tr>
<tr>
<td>Picture #20</td>
</tr>
<tr>
<td>Touching the vacuum cleaner</td>
</tr>
<tr>
<td>Picture #21</td>
</tr>
<tr>
<td>Selecting an item from his work shelf</td>
</tr>
<tr>
<td>Picture #22</td>
</tr>
<tr>
<td>Pushing buttons on a pop up toy</td>
</tr>
<tr>
<td>Picture #23</td>
</tr>
<tr>
<td>Lying down with his sister and a truck</td>
</tr>
<tr>
<td>Picture #24</td>
</tr>
<tr>
<td>Biting a pillow</td>
</tr>
<tr>
<td>Picture #25</td>
</tr>
<tr>
<td>Using “eye gaze” to get pizza rolls</td>
</tr>
</tbody>
</table>

Table 8- WB Photographs

<table>
<thead>
<tr>
<th>WB</th>
</tr>
</thead>
<tbody>
<tr>
<td>Picture #1</td>
</tr>
<tr>
<td>Playing with an Eric Carle card game</td>
</tr>
<tr>
<td>Picture #2</td>
</tr>
<tr>
<td>Reading a book</td>
</tr>
<tr>
<td>Picture #3</td>
</tr>
<tr>
<td>Playing with a marble track with his dad</td>
</tr>
<tr>
<td>Picture #4</td>
</tr>
<tr>
<td>Playing with a marble track with his sister</td>
</tr>
<tr>
<td>Picture #5</td>
</tr>
<tr>
<td>Playing with color tactile dominoes</td>
</tr>
<tr>
<td>Picture #6</td>
</tr>
<tr>
<td>Doing a dinosaur puzzle</td>
</tr>
<tr>
<td>Picture #7</td>
</tr>
<tr>
<td>Playing with his sister on the therapy ball</td>
</tr>
<tr>
<td>Picture #8</td>
</tr>
<tr>
<td>Playing on the computer</td>
</tr>
<tr>
<td>Picture #9</td>
</tr>
<tr>
<td>Stacking blocks with his sister</td>
</tr>
<tr>
<td>Picture #10</td>
</tr>
<tr>
<td>Playing with crank tops with his father and sister</td>
</tr>
<tr>
<td>Picture #11</td>
</tr>
<tr>
<td>Playing with a light up volcano with his sister</td>
</tr>
<tr>
<td>Picture #12</td>
</tr>
<tr>
<td>Playing with toy with sister</td>
</tr>
<tr>
<td>Picture #13</td>
</tr>
<tr>
<td>Playing in the snow with his sister</td>
</tr>
<tr>
<td>Picture #14</td>
</tr>
<tr>
<td>Playing in the snow with his sister</td>
</tr>
<tr>
<td>Picture #15</td>
</tr>
<tr>
<td>Getting in the car independently</td>
</tr>
<tr>
<td>Picture #16</td>
</tr>
<tr>
<td>Getting groceries</td>
</tr>
<tr>
<td>Picture #17</td>
</tr>
<tr>
<td>Reading signs at the grocery store</td>
</tr>
<tr>
<td>Picture #18</td>
</tr>
<tr>
<td>Looking at fish at the pet store</td>
</tr>
<tr>
<td>Picture #19</td>
</tr>
<tr>
<td>Pointing to fish at the pet store</td>
</tr>
<tr>
<td>Picture #20</td>
</tr>
<tr>
<td>Requesting bubble tape at the grocery store</td>
</tr>
</tbody>
</table>
Table 9- SW Photographs

<table>
<thead>
<tr>
<th>Picture #1</th>
<th>Picture #2</th>
<th>Picture #3</th>
<th>Picture #4</th>
<th>Picture #5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Playing Video Games</td>
<td>Playing Operation</td>
<td>Watching Television</td>
<td>Playing with and sorting blocks</td>
<td>Putting on Socks</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Picture #6</th>
<th>Picture #7</th>
<th>Picture #8</th>
<th>Picture #9</th>
<th>Picture #10</th>
</tr>
</thead>
<tbody>
<tr>
<td>Playing in the snow</td>
<td>Eating Pizza</td>
<td>Taking a bath with siblings</td>
<td>Taking a bath</td>
<td>Playing with a laptop under the table</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Picture #11</th>
<th>Picture #12</th>
<th>Picture #13</th>
<th>Picture #14</th>
<th>Picture #15</th>
</tr>
</thead>
<tbody>
<tr>
<td>Playing the keyboard</td>
<td>Dancing while listening to music and looking at his reflection</td>
<td>Dancing</td>
<td>Watching Television</td>
<td>Jumping on the bed</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Picture #16</th>
<th>Picture #17</th>
<th>Picture #18</th>
<th>Picture #19</th>
<th>Picture #20</th>
</tr>
</thead>
<tbody>
<tr>
<td>Playing music on the keyboard while looking in the mirror</td>
<td>Playing music on the keyboard</td>
<td>Pointing to objects outside the window</td>
<td>Taking a photograph</td>
<td>Fast forwarding a video</td>
</tr>
</tbody>
</table>

The Percentage of photo themes across participant photographs (N=118) is as follows

Independent Living Skills: Self Help (17.8%); Play: Toys (16.1%); Communication (16.1%); Educational Activity (11.9%); Independent Living Skills: Chores (6.8%); Sibling Interaction (6.8%); Exercise (6.8%); Music (5.9%); Entertainment (4.2%); Computer (3.4%); Parent Interaction (2.5%) and Play: dress up (1.7%).

“Parental teaching strategies” is the domain with the most included terms. I selected this domain for a taxonomic analysis, dividing included terms into subsets (See Table 6).

Reexamination of the domains by questioning cover terms and included terms for verification revealed that some domains such as types of chores could be included under parental teaching strategies. Although the items are types of chores, the use of chores is a parental teaching strategy.
Table 10

**Taxonomic Analysis of Parental Teaching Strategies**

Cover Term: Parental teaching strategies (Related research question: What are some things parents do to facilitate engagement?)

<table>
<thead>
<tr>
<th>PROVIDING CHOICES</th>
<th>CHOICES FOR WORK/ ACADEMICS</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Have a variety of educational materials available</td>
</tr>
<tr>
<td></td>
<td>Allow child to self-select task</td>
</tr>
<tr>
<td></td>
<td>Allow child to choose activities and rewards</td>
</tr>
<tr>
<td>CHOICES FOR PLAY</td>
<td>Variety of books available</td>
</tr>
<tr>
<td></td>
<td>Variety of instruments available</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>MAKING THINGS ACCESSIBLE</th>
<th>CLOTHING</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Boots and gloves are accessible on a shelf</td>
</tr>
<tr>
<td></td>
<td>Boots are easy to put on</td>
</tr>
<tr>
<td></td>
<td>Cheerios placed on a lower shelf, so child can make his own breakfast</td>
</tr>
<tr>
<td></td>
<td>Lower sugar juice at bottom of fridge</td>
</tr>
<tr>
<td></td>
<td>Milk kept on low shelf in a smaller container that he can use</td>
</tr>
<tr>
<td></td>
<td>Open cabinet with several food choices, child selects using eye gaze</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>OPPORTUNITIES</th>
<th>Provide opportunities for sharing and conversation</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Provide time for no pressure reading not associate with homework</td>
</tr>
<tr>
<td></td>
<td>Provide time for interaction</td>
</tr>
<tr>
<td></td>
<td>Provide appropriate outlets</td>
</tr>
<tr>
<td></td>
<td>Provide time and space for a break</td>
</tr>
</tbody>
</table>

| TOYS                       | Using crank tops instead of regular tops because more accessible                             |

<table>
<thead>
<tr>
<th>BREAKING THINGS DOWN INTO STEPS</th>
<th>MODEL EACH STEP</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>USE PHOTOS OF EACH STEP</td>
</tr>
<tr>
<td>UTILIZATION OF CHORES TO TEACH SKILLS</td>
<td>BRUSHING THE DOG</td>
</tr>
<tr>
<td></td>
<td>VACUUMING</td>
</tr>
<tr>
<td></td>
<td>PUTTING CLOTHES IN DRYER</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>TAKING ADVANTAGE OF TEACHABLE MOMENTS</th>
<th>LEARNING THROUGH PLAY</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>USING BATH TIME TO TEACH</td>
</tr>
<tr>
<td>CHILD EXCITED ABOUT ITEM, MOM EXPLAINS RESPONSIBILITIES</td>
<td>READING SIGNS IN THE GROCERY STORE</td>
</tr>
<tr>
<td>--------------------------------------------------------</td>
<td>---------------------------------</td>
</tr>
<tr>
<td>MODELING APPROPRIATE BEHAVIORS</td>
<td>USE OF CAST TO REACH OUT SOCIALLY</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>USE OF KNOWLEDGE OF CHILD</th>
<th>PHYSICAL ACTIVITY/SENSORY INPUT</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mobile sensory equipment</td>
</tr>
<tr>
<td></td>
<td>Crash pad</td>
</tr>
<tr>
<td></td>
<td>Weighted Blanket</td>
</tr>
<tr>
<td></td>
<td>Therapy ball</td>
</tr>
<tr>
<td></td>
<td>Sits on while working</td>
</tr>
<tr>
<td></td>
<td>Bounces on</td>
</tr>
<tr>
<td></td>
<td>Likes sister to squash him onto</td>
</tr>
<tr>
<td></td>
<td>Playing in the snow</td>
</tr>
<tr>
<td></td>
<td>Water play</td>
</tr>
<tr>
<td></td>
<td>Child is tactiley defensive</td>
</tr>
<tr>
<td></td>
<td>Textures</td>
</tr>
<tr>
<td></td>
<td>Textured balls</td>
</tr>
<tr>
<td></td>
<td>Textured puzzle</td>
</tr>
<tr>
<td></td>
<td>Jumping (After jumping, attends well)</td>
</tr>
<tr>
<td></td>
<td>Bed</td>
</tr>
<tr>
<td></td>
<td>Trampoline</td>
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<table>
<thead>
<tr>
<th>USE OF INTERESTS</th>
<th>Access to interests</th>
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<tr>
<td></td>
<td>Computers</td>
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<td></td>
<td>Music</td>
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<td>Trains</td>
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<td>Elevators</td>
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<td>Books related to interests</td>
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<td></td>
<td>Real life interaction with interests</td>
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<td>Games related to interests</td>
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<tr>
<th>ACKNOWLEDGE FEELINGS AND LISTEN TO CHILDREN</th>
<th>FOLLOW CUES</th>
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<tbody>
<tr>
<td></td>
<td>Building trust/meeting children where they are</td>
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<tr>
<td></td>
<td>Being flexible</td>
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<tr>
<th>PROMPTING</th>
<th>VERBAL PROMPTS</th>
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<tr>
<td></td>
<td>Prompts for chores</td>
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<tr>
<td></td>
<td>Prompts for social interaction</td>
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<tr>
<td></td>
<td>Prompts to use language</td>
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<tr>
<td></td>
<td>Prompts for work</td>
</tr>
</tbody>
</table>
### CHORE CHART

**SHOWING PHOTOS TO HELP WITH TRANSITION**
- Photos of grocery store before going
- Photos of pet store before going
- Use of photo to remind him to keep pillowcase on pillow
- Use of sequenced photos to teach what to do when using the bathroom

**ORGANIZATION**
- Organized shelf with work
- Place for toys and place for work (separate)
- Quiet work environment
- 3 drawer system from academics to more preferred items

**SCHEDULES**
- Use of visual schedule
- Timer for play on computer

### SIBLING SUPPORT

**PAIR TASKS**

**ENCOURAGE SIBLING INTERACTION**

**STEP BACK AND ALLOW SIBLINGS TO HELP**

### REDIRECTION

**BITING PILLOW INSTEAD OF PEOPLE**

### NOVELTY AND EXPOSURE

**READ TO CHILD EVEN IF HE DOESN'T SIT AND LISTEN**

**EXPLORE NEW WEBSITES**

**FIND A WAY TO MAKE THINGS INTERESTING**

**TOYS**
- Table tennis
- Instruments
- Costumes

### CONSISTENCY

**KEEP ALL ADULTS ON SAME PAGE**
- Teach everyone signs
- Let everyone know what working on

**HOMEWORK IN THE SAME PLACE AT THE SAME TIME**

**FOLLOW THROUGH ON PROMISED REWARDS**

**CONSISTENT LANGUAGE**
- Use same word when want child to stop.

**CONSISTENT, CLEAR BODY LANGUAGE**

**MORNING ROUTINE**

**WEEKLY ROUTINE**
- Clean every Saturday
The taxonomy reveals the complexity of the role of the parents of children with autism. Within the range of teaching strategies utilized on a daily basis are connections to parental goals as well as children’s strengths and challenges. Parents struggle and work to make each moment a teaching moment and to keep children engaged. Parents find a role for children in daily tasks. One parent explains, “… it goes back to including him in what we needed to do that day.”

As parents attempt to facilitate engagement there is an interesting process that determines what methods will be utilized. Self help skills are important to parents in terms of helping children to be independent and successful. Figure 1 illustrates the process of facilitation of engagement in learning a new skill.

*Figure 1. How parents facilitate engagement when teaching new skills to children*
When a child demonstrated an unexpected interest in an activity or with a material, parents attempted to extend and build on that interest. A child might receive an item as a gift or begin using it at the home of a peer. Figure 2 illustrates the process of building on a new interest and exposing children to new things.

**Figure 2. Process for facilitating and extending engagement utilized by parents.**

- **Exposure:**
  - Child demonstrates unexpected interest to novel item, such as a gift
  - *Ex. Puts on costume; plays friend’s accordion*

- **Can parent make material accessible?**
  - **Yes**
  - **No**
    - **Provide variety of materials**
      - *Ex: Many costumes; variety of instruments*
    - **Attempt to find similar or related item**
    - **Facilitate learning with materials**
      - *Ex. Ask questions and provide models for costumes; provide video models for instruments*

“You think, ‘No he’s not going to like that. No he’s not going to be able to do that.’ And yeah he just went for it. It was really cool.” – NW (Describing her son playing an “operation” game.)

“… We just keep giving him stuff when we find a flicker of interest and we try to make sure to encourage that.” – OA

When children are engaged they are less likely to demonstrate repetitive and self-stimulatory behaviors. Parents recognized that those behaviors could sometimes be redirected into age appropriate activities. A child could watch something spinning, while interacting with
peers, manipulatives and toys. Parents found ways to make “abnormal” behaviors look “normal.”

(See figure 3.)

Figure 3. Redirecting restricted interests and repetitive behaviors by facilitating engagement in appropriate activities.

The final model (Figure 4) makes connections across various domains and research questions. Parents have goals and wishes for their children. They act on those goals to engage children in activities. Parents utilize a variety of teaching strategies. Children are engaged in a variety of ways.
Figure 4. How parent goals are translated into action.

Parent Goal

Independence

Parent action

Involving child in household tasks; engaging child in chores

Ex. Getting his own juice; microwaving lunch; loading dishwasher; vacuuming; brushing dog

Parent teaching strategies

Consistency
Breaking things down into steps
Prompting
Using chore chart
Using motivators

Continued teaching

High expectations
Consistency
Repetition
Persistence
Working on over time and for years

Accomplishments

Child demonstrates skill independently and practices regularly

Discussion

The results show convergence between practices for children with autism supported in the research literature and parent practices in the home setting. Peer modeling, building on the interests of children, schedules, use of visual supports; physical activity and making accommodations for sensory abnormalities are a few of the strategies consistent with the literature. See Table 7 for an overview.
### Table 11

**Evidence Based Practices for Children with Autism**

<table>
<thead>
<tr>
<th>Strategy</th>
<th>Research</th>
</tr>
</thead>
<tbody>
<tr>
<td>Peer modeling</td>
<td>Children with autism can effectively learn social skills and language skills from peer, sibling and adult models. (Garfinkle &amp; Schwartz, 2002; Jones &amp; Schwartz, 2004)</td>
</tr>
<tr>
<td>Use of children’s</td>
<td>Building on children’s interests, use of preferred activities and providing children with autism with choices provides a context for learning and increases attending and engagement with others (Baker, 2000; Grandin, 1995; Hancock &amp; Kaiser, 2002; Mesibov et al., 2004; Odom &amp; Wolery, 2003; Reinhartsen, Garfinkle, &amp; Wolery, 2002; Schertz &amp; Robb, 2006).</td>
</tr>
<tr>
<td>interests and</td>
<td></td>
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<tr>
<td>preferred activities</td>
<td></td>
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<tr>
<td>Use of schedules</td>
<td>Use of individualized schedules allows for predictability, less anxiety and self-injurious behavior and increased on task behavior (Bryan &amp; Gast, 2000; Massey &amp; Wheeler, 2000; Mesibov et al., 2004; Morrison, Sainato, Benchaaban, &amp; Endo, 2002; O’Reilly et al., 2005).</td>
</tr>
<tr>
<td>Visual supports</td>
<td>Visual supports, cues and schedules can help make expectations more clear and easier to understand (Dettmer, Simpson, Myles, &amp; Ganz, 2000; Grandin, 1995; Mesibov et al., 2004; Odom et al., 2003).</td>
</tr>
</tbody>
</table>
Physical Activity | Physical activity before or during engagement in academic behavior reduces stereotyped or self-stimulatory behaviors (Celiberti et al., 1997; Elliot et al., 1994; Schilling & Schwartz, 2004).

Making accommodations and adaptations for sensory abnormalities | Children with autism commonly have sensory abnormalities that can be distracting or may result in anxiety (Kern et al., 2007). When sensory needs are not met behavior is impacted (Myles, Grossman, Aspy, Henry & Coffin, 2007).

Parents combine these strategies with specific knowledge of their children, individual attention and use of children’s interests. The dedication, knowledge and diligence of professionals have a significant impact on the lives of children with autism and should not be ignored or minimized. The results of this study provide evidence that parents have expert knowledge as well as knowledge about their children. Parents of children with autism use a variety of strategies to keep children engaged in the home setting. Parent efforts underscore the well-documented recommendation for the importance of family involvement in children’s education and interventions.

The Ziggurat model (Aspy & Grossman, 2007) provides a model for creating comprehensive interventions for people with autism (See figure 5). The model rests on the assumption that it is important to attend to “underlying needs (Myles et al., 2007, p. 399).” According to the Ziggurat approach, there are five hierarchal levels which should be incorporated in comprehensive intervention plans. At the bottom of the pyramid is sensory...
differences and biological needs, next is reinforcement, followed by structure and visual/tactile supports, then comes task demands. Finally at the top are skills to teach. This is consistent with what parents are doing in the home setting. Before teaching discrete skills, parents meet their children’s needs, find motivators and organize the environment.

Figure 5. Ziggurat model (Aspy & Grossman, 2007)

For parents, everything is connected and each smaller skill is related to a more global desire. Keeping juice on a lower shelf in the refrigerator allows a child to meet his needs when he is thirsty, which is related to working towards independence. It also allows him to offer a drink to visitors, which is related to fitting in. Offering guests a drink is something most people would do. In the end fitting in and being happy are important and many efforts seem to work towards that end. Helping children to engage with materials and people as children who are typically developing is what Ruble and Robson (2007) refer to as congruent engagement. Functioning successfully in society requires some consistency with peers. Before helping children develop independent skills consistent with peers, parents deal with challenging behaviors. Helping children to follow directions without engaging in undesirable or self-injurious
behavior is compliant engagement (Ruble & Robson, 2007). Using knowledge of their children parents act as advocates, ensuring their needs are met and pushing them beyond current accomplishments. They meet children where they are and then help them to move beyond that point.

We always met him where he was, socially, emotionally, behaviorally … Not that he walked all over us because from a discipline standpoint we are pretty; well I don’t want to say we are strict but we are very stern. We are precise. When it comes to his interest and learning, particularly in learning; we went to where he was. We went to his level and then that facilitated the trust between us. That goes into, “okay I know she’s not going to make me do something that’s absolutely horrible. I know she’s listening to my fears. I know she knows my limitations.” We don’t lower our expectations because of limitations. He still has very high; well we have very high expectations for him. He’ll meet them if we keep them up. That was a big thing at school this year. He’s emotionally and behaviorally and socially doing great but his academics are getting further and further behind. We had to have a big discussion regarding; you know if we keep the bar low he’s always just going to go to the bar. When we raise the bar he’ll rise to that expectation. He’s not going to push the bar himself. That will never be in his makeup.

Another revelation from the data is that engagement is often difficult to identify and knowledge of the child assists with that task. One parent describes how she read near her child often when he was a toddler and he did not seem to be interested or paying attention, but now reads well and reads often. She continues to describe the challenges in identifying engagement.

So I guess this one would go back to, just because you think they might not be paying attention they are, so sometimes engagement is hard to see; because it’s not always crystal clear. It’s the same thing when they are disengaged. They might seem totally engaged and they are really just in their own world. And I have a thought here just to interject, that when he has conversations with people, [his father] and I can see when he’s leading them down the elevator path. [Elevators are a restricted interest for him.] So that’s not very engaging for him. I wouldn’t consider that an engaging thing because he’s going right back to his thing. But people, other people who don’t know him think, “oh my gosh, he’s got great conversation skills.” Yeah, but we’re going, you are falling right into his trap because three more questions and he’s going to ask you where you went to high school and if it had an elevator. So he’s totally on his own, in his own engagement, and it’s not with you.
There are complexities in both identifying and extending engagement. Both are important in helping to teach children with autism necessary skills. They are also important in helping children utilize those skills in order to participate and communicate as members of society in a variety of environments.

Limitations

Fewer participants self-selected for the study than the proposed 7-12. The group portion of the study did not occur due to lack of parent time and interest. I did not obtain information about the educational level of parents, which could possibly impact how they engage their children. Those who chose to volunteer for a research study in addition to a range of responsibilities and obligations are likely to be well organized and are not necessarily representative of the general population. All of these parents spoke of family, friends and therapists who worked with their children and helped the family. These various supports may have helped alleviate stress and allow for parents to encourage engagement. There are parents who have difficulty coping. They may lack the support systems that parents who chose to participate in this study had. Suppose the mother of a child with autism does not have any close family. They may live far away; they may be deceased. She also has a child who is typically developing. He is attending school and participating in extracurricular activities. She does not have anyone to help transport her child to activities or help him with his school work. Her husband works 13 hour days to pay for expenses and interventions. He is exhausted. She does not have respite care. She is not able to attend support groups due to lack of respite. Her child with autism does not sleep and sometimes leaves the house at night. She therefore does not get very much sleep. Her son jumps off of elevated surfaces such as furniture. Her focus is safety
and survival. Until those basic needs are met, she is unable to begin to use the strategies parents in this study demonstrated.

**Implications for further study**

Rather than using photovoice to encourage change in decision makers and those in power, the process can provide opportunities for participants to be agents of their own change (Carlson, Engebretson, & Chamberlain, 2006). The current study allowed parents to reflect on and examine their own practices. Wang and Burris (1994; 1997) provided opportunities for group discussion of photographs. One benefit of the photovoice process is learning from and collaborating with others (Wang et al., 1998). An attempt was made to incorporate a group module into the current study; however this was an optional component. Parents participants did not wish to participate in this feature of the study. In addition to lack of participant time and participant stress, one challenge may have been lack of rapport. The parents participating in the study did not know one another. They may have been reluctant to share pictures of their home, children and engagement strategies with a group of strangers. Utilizing photovoice with an existing parent group as a way to map assets, determine challenges, collaborate and communicate with one another is a possibility for a future study.

A logical next step is including children in the process. Due to previous interests of children in the cameras expressed by pilot study participants, all of the participants were provided with an extra camera for their children’s personal use. Placing the cameras in the hands of children with autism, Carnahan (2006) observed an increase in engagement in children with autism and an opportunity to develop relationships in the classroom. Children can reflect their interests, which educators can then incorporate into the classroom setting. Kroeger and colleagues (2004) conducted a photovoice study with six adolescents with behavior, social and
academic issues. The students took photographs that identified their experiences as learners. The students who were once isolated became socially engaged, interacting with one another and increasing participation in class. They developed a sense of community and demonstrated improved academic outcomes. Educators were able to determine student values, interests and concerns as well as the issues in the environment impacting their behavior.

Implications for practice

The focus of the current study was parent practices of engagement in the home setting; however, the results indicate a connection to educational settings. There are several implications of the above findings for educators and health care professionals working with children with autism.

1. Photovoice may be employed to identify strengths, goals, and facilitate engagement. Photovoice can be utilized concurrently in the home and school settings. These images may provide a shared context for communication and support clearer sharing of information between parents and professionals.

2. Sharing information between parents and teachers provides insights into identifying strengths, moods, and interests of children with autism. This information may then be used to generate more appropriate goals or objectives and developing IEPs. In some instances, abnormalities and obsessions can be utilized to engage children in appropriate behavior at home as well as at school.

3. Parents engage children with autism in the home setting in a variety of ways including use of interests, breaking tasks down into steps, involvement in daily activities and a variety of teaching strategies. Many of the strategies used are consistent with recommended practices. Educators may view them for potential
classroom use. This may facilitate consistency across settings and possibly generalization of skills.

4. Parents of children with autism have goals for their children that have an orientation towards the future as well as a focus on quality of life. Parents want their children to be happy, confident and independent. Connecting discrete skills learned in school to parents goals related to quality of life may alleviate conflict between parents and educators. Making fundamental needs the foundation and building towards teaching skills addresses congruent and compliant engagement facilitating success for children, parents and educators.

5. Parents suggest that educators ought to avoid making assumptions, keep an open mind and demonstrate the value of each individual child and his or her interests in order to develop a positive and productive relationship with parents. Meeting children where they are while also pushing them to move further is something parents do and would like educators to do as well.

6. Parents have unique knowledge of their children’s needs, strengths and interests that they can share with educators to facilitate learning in both the home and school settings. Photovoice allows parents to share their knowledge acting as experts about their own children. Knowledge of children’s cues and preferences are often necessary for communicating with children and meeting their needs. Communication with those who work with and interact with children allows for multiple opportunities to engage children appropriately. Exposure to novel materials and activities may spark an interest or enhance development of skills in a manner unexpected by adults. Parents expand on and extend interests at home.
7. Professionals may facilitate providing support, resources and referrals to parents in order to help meet basic needs. Parents who seem to lack a support system and have difficulty coping can be paired with parents who are able to engage children in the home setting to facilitate use of parental teaching strategies.


Behavioral Interventions, 16, 147-165.


APPENDIX A

INSTITUTIONAL REVIEW BOARD APPROVAL LETTERS

April 10, 2007
Helene A. Harte, M ED
Curriculum & Instruction
0105
9650 Lansford Dr.
Cincinnati, OH 45242

RE: IRB #: 06-03-06-05-E Using Photovoice to Identify Engagement in Children with Autism in the Home Setting

Dear Helene Harte,

The University of Cincinnati Institutional Review Board - Social and Behavioral Sciences (IRB-S) has reviewed and approved your Progress Report.


If your research requires signed consent, the approved consent version (with the IRB approval date and expiration date in the footer) is attached to this approval. This is the version that MUST be used with your participants.

The research MUST be conducted EXACTLY as approved. ANY modifications to the approved project must be reviewed and approved by the IRB-S BEFORE being implemented.

To continue your research beyond the expiration date shown above, you MUST submit a Progress Report to the IRB-S at least one month before the expiration date shown above. At the completion of your research, you MUST submit a final Progress Report to the IRB-S marked "completed."

Also attached to this approval are Investigator Responsibilities, which are expected of all human subjects researchers at the University of Cincinnati.

Sincerely,

Julie W. Gerlach, B.S.N., M.P.H., C.I.P.
Chair, UC IRB-S

JWG.cn

Co: Anne Lukas, E.D.D.
July 30, 2007

Helene Harte, M. Ed  
9650 Lansford Dr.  
Cincinnati, OH 45242

RE: IRB # 06-03-06-05E Using Photovoice to Identify Engagement in Children with Autism in the Home Setting

Dear Ms. Harte:

The University of Cincinnati Institutional Review Board - Social and Behavioral Sciences (IRB-S) has reviewed and approved your modification (Change exclusion criteria; Change Adult consent, Child assent & Parent permission forms, Add collecting demographic data, discuss photos as a group, increase enrollment from two to ten families: total 20 people, Change Autistic children age ranges preschool - fourth grade and their parents. Parents ages 25-60). This approval does NOT affect the expiration date of your study.

Approval is effective 7-27-07 and expires 4-10-08.

If this modification necessitates changes to the consent, the approved consent version (with the IRB approval date and expiration date in the footer) is attached to this approval. This is the version that MUST be used with your participants.

The research MUST be conducted EXACTLY as approved. ANY modifications to the approved project must be reviewed and approved by the IRB-S BEFORE being implemented.

To continue your research beyond the expiration date shown above, you MUST submit a Progress Report to the IRB-S at least one month before the expiration date shown above. At the completion of your research, you MUST submit a final Progress Report to the IRB-S marked "completed".

Also attached to this approval are Investigator Responsibilities, which are expected of all human subjects researchers at the University of Cincinnati.

Sincerely,  

[Signature]

Julie W. Gerlach, B.S.N., M.P.H., C.I.P.  
Chair, UC IRB-S

CC: Anne Bauer, ED D

An affirmative action/equal opportunity institution
APPENDIX B

INFORMED CONSENT

Title of Study: Using photovoice to identify engagement in children with autism in the home setting.

Before agreeing to participate in this study, it is important that the following explanation of the proposed procedures be read and understood. It describes the purpose, procedures, risks, and benefits of the study. It also describes the right to withdraw from the study at any time. It is important to understand that no guarantee or assurance can be made as to the results of the study.

Purpose:
The purpose of this research study is to look at ways children with autism are engaged in meaningful activities in the home setting. To do this we need your permission to meet with you and analyze photographs that you will take of your child. There will be approximately 7-10 children with autism and one parent of each child taking part in this study, including yourself and your child.

Duration:
You will take photographs over the course of one week. We will have approximately two interviews that may be about one hour long each. Your participation in this study will last for approximately one month, depending on scheduling, during which we will meet with you three times.

Procedures:
1. We will meet, sign consent forms, go over the study and answer and questions you might have.
2. You will be given a disposable camera to photograph over the course of a week your child in typical activities around your home. Take photographs of your child engaged in any activity.
3. We will meet with you a second time and go over the photographs together discussing what is occurring in each one and whether or not your child is engaged. Engagement means participating in an activity in an appropriate way. We will meet individually and discuss all of the photographs.
4. In addition to meeting individually, you will have the option to select 3 or 4 of the photographs and engage in a group discussion with 7-10 other participants.
5. The interview during which we discuss the photographs will be audio taped.
6. The audiotape will be transcribed and analyzed for themes.
7. We will have a final interview to discuss what themes were found in the transcripts and what this means to you.

Risks/Discomforts:
1. You (the parent) are taking the photographs in order to keep the environment as natural and comfortable for your child as possible. If you or your child are upset and do not want to participate you can stop immediately and continue at another time or withdraw from the study at any time.
2. The interviews and meetings will be scheduled at your convenience.
3. Although every effort will be made to avoid risks or discomfort, there also may be discomforts and risks that are not yet known.

Benefits:
The benefits to you for participating in this study may be learning more about how and when your child is engaged in appropriate activities at home. However, you may receive no benefit from participating in this study.

Confidentiality:
Every effort will be made to maintain the confidentiality of any data. Your research data will be kept in a locked file cabinet in the investigator’s office. Only the investigator will have access to your data. After audiotapes of the interview have been transcribed the audiotapes will be erased. Research data will be stored in a locked file cabinet for three years after the end of this study and then will be destroyed by shredding. The data from the study may be published; however, you will not be identified by name.
If you have any questions about this study, you may call Helene Harte at 321-1291. The Chair of the Institutional Review Board – Social and Behavioral Sciences, may be contacted at 513-558-5784 for questions related to your rights as a participant in this research. I HAVE READ THE INFORMATION PROVIDED ABOVE. I VOLUNTARILY AGREE TO PARTICIPATE IN THIS STUDY. I WILL RECEIVE A COPY OF THIS CONSENT FORM FOR MY INFORMATION.

Name - Please Print ___________________________ Signature ___________________________ Date __________  

Signature of Person obtaining consent ___________________________ Date __________

The person obtaining consent will take a copy of this form. Please keep the other copy for your records.
Title of Study: Using photovoice to identify engagement in children with autism in the home setting.

Before agreeing to participate in this study, it is important that the following explanation of the proposed procedures be read and understood. It describes the purpose, procedures, risks, and benefits of the study. It also describes the right to withdraw from the study at any time. It is important to understand that no guarantee or assurance can be made as to the results of the study.

Purpose:
The purpose of this research study is to look at ways children with autism are engaged in meaningful activities in the home setting. To do this we need your permission to meet with you and analyze photographs that you will take of your child. There will be approximately 7-10 children with autism and one parent of each child taking part in this study, including yourself and your child.

Duration:
You will take photographs over the course of one week. We will have approximately two interviews that may be about one hour long each. Your participation in this study will last for approximately one month, depending on scheduling, during which we will meet with you three times.

Procedures:
1. We will meet, sign consent forms, go over the study and answer and questions you might have.
2. You will be given a disposable camera to photograph over the course of a week your child in typical activities around your home. Take photographs of your child engaged in any activity.
3. We will meet with you a second time and go over the photographs together discussing what is occurring in each one and whether or not your child is engaged. Engagement means participating in an activity in an appropriate way. We will meet individually and discuss all of the photographs.
4. In addition to meeting individually, you have the option to select 3 or 4 of the photographs and engage in a group discussion with 7-10 other participants.
5. The interview during which we discuss the photographs will be audiotaped.
6. The audiotape will be transcribed and analyzed for themes.
7. We will have a final interview to discuss what themes were found in the transcripts and what this means to you.

Risks/Discomforts:
1. You (the parent) are taking the photographs in order to keep the environment as natural and comfortable for your child as possible. If you or your child are upset and do not want to participate you can stop immediately and continue at another time or withdraw from the study at any time.
2. The interviews and meetings will be scheduled at your convenience.
3. Although every effort will be made to avoid risks or discomfort, there also may be discomforts and risks that are not yet known.

Benefits:
The benefits to you for participating in this study may be learning more about how and when your child is engaged in appropriate activities at home. However, you may receive no benefit from participating in this study.

Confidentiality:
Every effort will be made to maintain the confidentiality of any data. Your research data will be kept in a locked file cabinet in the investigator's office. Only the investigator will have access to your data. After audiotapes of the interview have been transcribed the audiotapes will be erased. Research data will be stored in a locked file cabinet for three years after the end of this study and then will be destroyed by shredding. The data from the study may be published; however, you will not be identified by name.
If you have any questions about this study, you may call Helene Harte at 321-1291. The Chair of the Institutional Review Board – Social and Behavioral Sciences, may be contacted at 513-558-5784 for questions related to your rights as a participant in this research. I HAVE READ THE INFORMATION PROVIDED ABOVE. I VOLUNTARILY AGREE TO PARTICIPATE IN THIS STUDY. I WILL RECEIVE A COPY OF THIS CONSENT FORM FOR MY INFORMATION.

Child's Name – Please Print

Parent/legal representative’s name – Please Print

Parent/Legal representative Signature

Date

Page 2 of 2
Helene Harte is a student at the University of Cincinnati. She wants to learn more about how she plays at home. My mom or dad _________ will take pictures of me doing things around the house. My mom or dad _________ will share the pictures with Helene Harte. They will talk about and write about the pictures. If I don't want to do it, I do not have to. Nobody else will look at the pictures. If I have any questions I can ask my mom or dad who will talk to Helene Harte. I understand and agree to do these things.

Name ___________________________  Date ___________________________

Signature of Person getting consent ___________________________  Role in study ___________________________  Date ___________________________

You can keep a copy of this piece of paper. Helene Harte will also keep a copy of this of paper

Harte #05-03-06-05E Child Assent v.4-21-06  IRB approved 4-10-07/ Expires 4-10-08
APPENDIX C

RECRUITMENT FLYER

Using photovoice to identify engagement in children with autism in the home setting. (Recruitment Flyer)

Participate in a research study.

Help us to learn more about autism!

The purpose of this research study is to look at ways children with autism are engaged in meaningful activities in the home setting. Engagement means participating in an activity in an appropriate way.

If you choose to participate in this study, you will be given a disposable camera to photograph over the course of a week your child in typical activities around your home. Take photographs of your child engaged in any activity. We will meet with you and go over the photographs together discussing what is occurring in each one and whether or not your child is engaged. You input is important to us and you will have a chance to share your expertise with us.

If you choose to participate, I will have you sign a consent form giving me permission to meet with you and analyze photographs that you will take of your child in the home setting. The consent form will also affirm that you understand the study I am proposing. If you wish to participate, please contact me at (513) 321-1291 or hartehe@ucmail.uc.edu. Thank you for your time and effort.
APPENDIX D
RECRUITMENT LETTER

Using photovoice to identify engagement in children with autism in the home setting.
Recruitment Letter

My name is Helene Harte. I am a doctoral student in special education at the University of Cincinnati. I am conducting a study to look at how children with autism are engaged in the home setting. Engagement means participating in an activity in an appropriate way.

If you or anyone you know would be interested please let me know. There is no obligation. Participation is completely optional and can be ended by you at any time. We hope to learn about how children with autism are engaged in the home setting and learn from the knowledge and expertise of parents.

If you choose to participate I will have you sign a consent form giving me permission to meet with you and analyze photographs that you will take of your child in the home setting. The consent form will also affirm that you understand the study I am proposing. If you wish to participate, please contact me at 513 321-1291 or hartehe@ucmail.uc.edu thank you for your time and effort.
APPENDIX E
DEMOGRAPHIC INFORMATION SURVEY

Demographic Information

(Feel free to use the back if necessary.)

Child’s Age:

Child’s Gender:

Child’s Race:

Current Educational Setting:

Family Constellation (Single parent, two parent etc.):

Ages and genders of siblings if applicable:

When and how was your child identified?

What are some of your child’s strengths?

What are some major characteristics of your child?

What are some of your concerns?
Describe the level of functioning of your child:

Parent’s Age:

Parent’s Race:

Approximate Household income:
Curriculum Vita

Personal Information

Helene A. Harte
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Educational Background
Currently pursing doctoral degree in special education, University of Cincinnati, Expected graduation date, June 2008.

Master of Education; June 2000; Early Childhood Education; University of Cincinnati, Cincinnati, OH.

Bachelor of Science; May 1995; Human Development and Family Studies; Cornell University, Ithaca, NY.

Professional Affiliations
- Council for Exceptional Children: DEC,
- National Association for the Education of Young Children
- American Educational Research Association
- Autism Society of Cincinnati

Professional Experience

Consultant, 4C, Cincinnati, OH September 2006 – present
Give presentations, workshops and interactive trainings with teachers and parents on early childhood and special education topics. Provide coaching for CDA students.

Give presentations, workshops and interactive trainings with teachers and parents on early childhood and special education topics. Consult in early childhood settings by conducting classroom observations and providing feedback about what seems to be successful and possible changes that could be made to the classroom environment, curriculum or teaching practices. Work in classrooms alongside teachers, modeling appropriate interactions with children and staff.
Term Adjunct Faculty, Early Childhood Learning Community, University of Cincinnati, September 2002- present. Student teaching and practice teaching seminar – online, Language arts and literacy II, Orientation to Professional practice Maintain regular communications with distance learning students through posted announcements, email and discussion board postings, maintain communication with ECLC academic director, coordinate textbook orders, syllabi and other course related activities with academic director, grade papers and provide feedback.


Term Adjunct Faculty, Early Childhood Care and Education, Associate Degree Program, University of Cincinnati, September 2002 - May 2004. Language arts and literacy I and II, Math and Science in Early Childhood, Integrated Curriculum I & II. Prepared course content and syllabi. Gave lectures and assessment. Used blackboard course management

Early Childhood Teacher Education Specialist/Academic Researcher, Arlitt Child and Family Research and Education Center, University of Cincinnati, June 1997 – August 2002. Prepared constructivist curricula and taught children ages 3-5 in both full day and half day preschool. Taught in an inclusive setting including children with English as a second language and children with disabilities. Conducted home visits with families discussing schedule, transition, goals, concerns and constructivism with parents. Taught one presentation a year. Maintained up to date paperwork including lesson plans, behavior intervention plans, anecdotal records, progress notes, progress checklists, child portfolios, and extensive Head Start paperwork. Supervised student teachers, reviewing and commenting on assignments, conducting weekly processing meetings, providing them with information on schedule, philosophy, constructivism and classroom management. Acted as parent involvement liaison for one year, attending center committee and parent policy meetings, planning family events and writing the newsletter. Served as a university mentor, grading papers and doing observations of student teachers doing their kindergarten practicum. Served as an academic researcher assisting with grant writing. Co-taught child development as part of a Hughes/UC partnership.


Publications

Book chapters:


Manuals:


Journals:

Paper:

Research projects:

Professional Presentations:
Harte, H.A. Identifying engagement in children with autism in the home setting. Third International Congress of Qualitative Inquiry, University of Illinois at Urbana-Champaign (May, 2007)


Postcards to Paulo. Second International Congress of Qualitative Inquiry, University of Illinois at Urbana-Champaign (Poster presentation) (May, 2006)

Harte, H.A. “Selecting Appropriate Multicultural Materials” Annual Ohio Association for the Education of Young Children Conference, Columbus, OH (April, 2005)

Local Presentations
Harte, H.A. “Early Childhood Social Studies” 4C (February 2008)

Harte, H.A. “Creating An Ant-Bias Curriculum” 4C (October 2007)

Harte, H.A. “Creating An Ant-Bias Curriculum” Harrison Early Learning Center (September 2007)

Harte, H.A. “Creating An Ant-Bias Curriculum” 4C (August 2007)

Harte, H.A. “Conducting an Effective Group Time” Victory Neighborhood Services (August 2007)

Harte, H.A. “Classroom Management” St. James Westwood Day Care Center (October, 2006)

Harte, H.A. “Aggressive Behavior in Young Children” St. James Westwood Day Care Center (October, 2006)

Harte, H.A. “Selecting Appropriate Children’s Books” Sharonville United Methodist Church Weekday Nursery (October, 2006)

Harte, H.A. “How to talk to young children: Meaningful Language” Sharonville United Methodist Church Weekday Nursery (October, 2006)

Harte, H.A. “Process Art vs. Modeled Art” (March, 2006)


Harte, H.A. “Developmentally Appropriate Curriculum” Arlitt Center, Parent Open House (October 2000)

Harte, H.A. “Math and Writing Suitcases” Arlitt Center, Parent Open House (October, 1999)