Family Reflections on the Foundations of Self–Determination in Early Childhood

10 authors, including:

Jean Ann Summers
University of Kansas
105 PUBLICATIONS **3,020** CITATIONS

SEE PROFILE

Mary Jane Brotherson
Iowa State University
35 PUBLICATIONS **663** CITATIONS

SEE PROFILE

Elizabeth Joy Erwin
Montclair State University
39 PUBLICATIONS **747** CITATIONS

SEE PROFILE

Susan P. Maude
26 PUBLICATIONS **116** CITATIONS

SEE PROFILE

Some of the authors of this publication are also working on these related projects:

Influences from EC Professional Organizations View project

Refugee Home Literacy and Family-School Partnership View project

Family Reflections on the Foundations of Self-Determination in Early Childhood

Jean Ann Summers, Mary Jane Brotherson, Elizabeth J. Erwin, Susan P. Maude, Susan B. Palmer, Shana J. Haines, Vera Stroup-Rentier, Hsiang-Yi Wu, Nancy Farstad Peck, and Yuzhu Z. Zheng

Abstract

This study investigated families' perspectives about and strategies used to develop foundational skills (i.e., choice-making, self-regulation, and engagement) leading to the development of the self-determination of their young children with disabilities. Two research questions guided the study: (1) What do families believe is important when working with practitioners in partnership to build foundational skills leading to self-determination at home and school? (2) What do families think about providing opportunities for developing these skills, and how do they provide such opportunities? Qualitative data were collected through in-depth interviews and an open-ended online survey. Families reported a variety of strategies used to develop choice-making, self-regulation, and engagement skills. Results can assist early education service providers to better understand how families conceptualize choice-making, self-regulation, and engagement for their children to successfully build partnerships and engage families.

Key Words: *self-determination; early childhood special education; families; practitioners; choice-making; self-regulation; engagement; disabilities*

There is growing interest in understanding how the foundational skills leading to the development of self-determination can support young children with disabilities (Brotherson, Cook, Erwin, & Weigel, 2008; Palmer et al., 2013; Shogren & Turnbull, 2006). Self-determination has been broadly understood as making or causing things to happen in one's life; as acting volitionally (Palmer & Wehmeyer, 2003). In early childhood we can focus on the foundational skills and behaviors leading to the development of self-determination. For children ages 3–5 years, the foundations to these skills include (a) having opportunity to make age-appropriate choices, (b) supporting and enhancing self-regulation skills, and (c) increasing levels of engagement with people and activities (Erwin et al., 2009; Palmer et al., 2013).

Young children are naturally inquisitive. The foundational skills leading to the development of self-determination play a natural role in how

preschoolers discover and interact with the environment, people, and objects they encounter. Erwin and Brown (2003) suggested that "as young children make choices, indicate preferences, problem solve, plan, and initiate, they are making sense of the world around them in a way that can ultimately produce feelings of competence, confidence, and empowerment" (p. 78). Since young children remain dependent upon others for caregiving and support, they are not developmentally ready to act in a self-determined manner, fundamentally due to a lack of maturity, experience, and overall capabilities. However, it is becoming increasingly clear that the antecedent skills leading to the emergence of self-determination in adolescence begin to emerge in early childhood (Palmer & Wehmeyer, 2003). Further, the adults in a young child's life are in a position to foster these *foundations* of self-determination by promoting a sense of autonomy and self-realization (Brotherson et al., 2008; Shogren & Turnbull,

2006) and by practicing and building children's capacity for choice-making, self-regulation, and engagement (Palmer et al., 2013).

Any discussion of the development of self-determination and early childhood must place families at the center because they play a key role in providing natural and multiple opportunities for their children to develop foundational skills leading to the development of self-determination (Brotherson et al., 2008). And yet, there is often limited understanding regarding what self-determination means to families and how practitioners can work in partnership with families to promote early foundational skills at home and school. Despite the support in the literature for the critical role of families in encouraging the precursors of self-determination in young children, there is little empirical literature to shed light on what families actually think and do about elements of self-determination.

As we investigate family perspectives, we must consider how culture impacts viewpoints. Although there is still much to learn about how self-determination is operationalized in culturally and linguistically diverse populations, there is a rapidly expanding body of knowledge that has begun to shape our understanding of what is known (Nota, Ferrari, Soresi, & Wehmeyer, 2007). Wehmeyer and colleagues (2011) suggest although self-determination as volitional action may be valued across cultures, the construct of self-determination may be operationalized uniquely across various cultural belief systems. The focus on cultural perspectives and self-determination is essential in strengthening an understanding of how to translate research into personally tailored practices for students with disabilities in the classroom and home environments. Although there is an established context for understanding culture and self-determination (Shogren, 2011), there remains a need to intentionally document family voices, practices, and beliefs, especially as they change over time.

Because families are the constant cultural variable in children's lives, it is particularly helpful to understand practices that underscore families' perspectives on promoting foundational skills that lead to the development of self-determination. Specific Anglo-European cultural values mistakenly understood as being associated with self-determination such as personal control, individualism, time dictates, informality, future and goal orientation, competition, materialism, and change (Turnbull & Turnbull, 2001) may be in contrast to views held by individuals from other cultures (Lynch & Hanson, 2011). Although values and beliefs related to self-determination have been studied from a diverse cultural lens, given the number of studies exploring divergent perspectives about self-determination in non-European cultures, we know very little about how families in the mainstream American culture think about building children's foundational skills to promote the development of self-determination and what strategies they use to do so. Equally, we lack understanding about what actions families may or may not take in support of building foundational skills in young children with disabilities leading to the development of self-determination.

The primary focus of this article is to understand what families think about building children's foundational skills and what strategies they use to do so in partnership with practitioners. This article builds on a conceptual model that describes the basic foundational skills for the development of self-determination (Palmer et al., 2013). The foundations model focuses on three encompassing early foundational skills that can lead to later self-determination: choice-making, self-regulation, and engagement. This research was part of the initial query of family perspectives to design the Foundations Intervention, as part of an Institute for Educational Sciences Goal Two Development Grant.

Method

This study was an initial exploration to determine family perspectives about building children's foundational skills to promote the development of self-determination and the strategies they use so as to develop an intervention to yield positive outcomes for the child within the framework of adult support. This study used a qualitative, constructivist design fusing two primary sources of information from families to explore answers to two research questions: (1) What do families believe is important when working with practitioners in partnership to build foundational skills at home and school leading to self-determination? (2) What do families think about providing opportunities for developing these skills, and how do they provide such opportunities? The use of multiple data sources in qualitative research is an approach supported by methodologists to

strengthen the dependability and overall trustworthiness of the research (Anfara, Brown, & Mangione, 2002; Creswell, 2012). The first data source was a series of in-depth individual qualitative interviews with 15 families. The second data source were the open-ended comments taken from an online survey of 216 families disseminated through national family support newsletters and list serves.

Researcher Background

Qualitative researchers are the instruments of their research and it is important to know their backgrounds to gain an understanding of the lens through which they collected and analyzed the data (Creswell, 2012). We conducted this study as a collaborative research team including principal investigators and graduate students working at one of three universities. The complete 12-member research team provided rich and broad perspectives in the analysis and interpretation of data during weekly conference calls and individual site weekly research team meetings. The research team represented the perspectives of researchers, practitioners, family members of children or young adults with disabilities, and graduate students. It included the disciplines of early childhood special education/inclusive education, human development and family studies, and elementary education. One White male and two Asian females joined nine White female researchers. Eight of the group members were also mothers. As a whole, the research team valued the wisdom of families when identifying child priorities within a culturally responsive, family-centered context.

Data Source One: In-Depth Qualitative Interviews

Participants. We asked early childhood administrators and practitioners in three states to send a recruitment flyer to parents who had a child 3–5 years of age with an individualized education program (IEP) in their inclusive programs to invite participation in this study. The flyer indicated that families would participate in an interview to give their thoughts about working with practitioners, and about their insights on offering their child choices, developing self-regulation, and supporting engagement. They were told they would receive an honorarium ($25) for participating. Fifteen mothers of 16 young children with various physical, sensory,

and cognitive disabilities responded and were interviewed for this study; one interview also included a father who joined his wife. Table 1 shows the participants were well-educated, White, and their children represented a range of disabilities including types and severity levels. Protection procedures for human subjects were followed via protocols at all three research sites.

Interview protocol. We developed the interview protocol during weekly research discussions, centered on the following five grand tour questions with probes:

1. Tell me about your family.
2. What choices does your child make and how does he or she make those choices?
3. How does your child manage or regulate his or her emotions, behavior, or attention?
4. How does your child engage with the people and things around him or her?
5. How do you think the school can work most effectively with you and your family to promote these skills for your child?

Probe questions could also be asked depending on the question content and direction of the interview. For example, the question on choices might include the probes: How does your child let you know what she wants? How do you decide when to let her make choices? Or how, if at all, do you encourage choice-making?

Interviews. All members of the team received training on qualitative interviewing techniques, supplemented by reflections and feedback during the weekly face-to-face staff meetings at each site as well as full research team conference calls. The interviews averaged 45 mins in length and were arranged at the convenience of the families. Five families had a telephone interview; the other 10 interviews were conducted face-to-face. Immediately following each interview, the researcher completed an interview sheet to summarize the essence of the interview; this was disseminated to the full team prior to weekly debriefing meetings. The interview summary sheets encouraged interviewers to record analytic memos about initial codes or emergent patterns. All of the interviews were audio recorded and professionally transcribed.

Data analyses. In the weekly research conference calls, the team as a whole discussed the ongoing interviews, shared interview summaries and analytic memos, and discussed emerging categories. These calls were useful to coordinate interviews across researchers and to bring research-

Table 1
Demographic Information for Families Participating in Phone or Face-to-Face Interviews

Site	Gender	Age Range	ES	Race	Education Level	Location	Children	ATC	GTC	Primary Diagnosis
Iowa										
1	F	30–34	E	W	M	SC	4	4	M	Physical disability
2	F	30–34	E	W	CC	SC	1	5	M	Social and language delays
3	F	40–44	E	W	MD	U	2	4	M	ASD
4	F	45–49	E	W	AS	SC	2	5	F	Down syndrome
5	F	30–34	E	W	B	SC	2	4	M	Hearing loss
Kansas										
1	F	40–44	UE	W/NA	JD	U	3	4	F	CP, D/B, & multiple disabilities
2	F	40–44	E	W	B	SC	3	5	M	ASD
3	F	30–34	E	W	M	SC	3	4	M	CP, D/B
4	F	35–39	E	W	M	U	2	5	M	Sensory integration
5	F	24–29	E	W	HS	U	1	5	M	Epilepsy and ASD
New Jersey										
1	F	35–39	UE	W	M	U	3	3 & 5	M/F	3 = ASD & 5 = ADHD
2	Male & F	40–44	E	W	M	SC	3	5	M	DD
3	F	35–39	UE	W	B	SC	2	5	M	ASD
4	F	40–44	E	W	M	SC	1	5	M	DD
5	F	45–49	E	W	M	SC	1	4	M	ASD

Note. F = Female; W = White; NA = Native American; ES = Employment Status; E = Employed; UE = Unemployed; M = Master's degree; B = Bachelor's degree; CC = Community College; JD = Juris Doctorate; HS = High School Diploma; MD = Medical Degree; AS = Arts and Sciences Degree; SC = Small City (population between 2,500 and 50,000); U = Urban (population between 50,000 and 200,000); ATC = Age of Target Child; GTC = Gender of Target Child; ASD = Autism Spectrum Disorder; CP = Cerebral Palsy; D/B = Deaf/Blind; ADHD = Attention Deficit Hyperactivity Disorder; DD = Developmental Delay

ers together for initial data analysis simultaneously with data collection (Creswell, 2012). The team as a whole discussed the steps to guide phases of analysis and used interview summary sheets, transcripts, transcript summaries, and analytic memos throughout data analysis.

We conducted the analysis through three iterative cycles: open coding, pattern coding, and selective coding (Saldaña, 2013). In open coding, also called initial coding, the researchers examined discrete parts of the data and continuously examined them and compared them for similarities and differences (Saldaña, 2013). The goal of open coding was to remain open to all possible directions emerging from the data and to begin to label or code what was *seen* in the data. The open coding

process resulted in a number of initial codes (e.g., building trust with professionals, recognizing individual family concerns). In pattern coding, we reorganized and reconfigured the initial codes identified in open coding to develop a more select list of broader categories and themes (Saldaña, 2013). This second cycle of coding "…pull[ed] together a lot of material into a more meaningful and parsimonious unit of analysis" (Miles & Huberman, 1994, p. 69). Two members of the research team reviewed the raw data and came to agreement about the membership and definition of the codes and themes. In the third iterative cycle, selective coding, the researchers then arranged those categories and themes into a framework that made the most analytic and interpretive sense (Charmaz,

2006). The team reviewed and discussed this document during the weekly conference calls.

Data Source Two: Online Survey Open Ended Narrative Analysis

Participants. The purpose of the online survey was to inform the design of our Foundations Intervention project and provide input from a larger number of families than we could interview in-depth. We contacted family leaders in Parent Training and Information Centers and in state early childhood agencies from Illinois and New Jersey to publish a description of our study in their statewide newsletters or electronic family list serves; subsequently, agency and parent groups from New York and Vermont also requested permission to publish the article about our study in their newsletters as well. The description of the study contained a link to our online survey and invited responses from families of children with disabilities ages birth through 8 years. A limitation of this method of distribution is that we cannot compute response rates since we do not know how many people actually received the invitation to participate in the survey. The focus of the survey was to provide an additional source of information from families to inform our intervention development project about acceptable practices related to choice-making, self-regulation, engagement, and partnership. The widespread nature of the distribution resulted in 237 responses from families of which 216 were families of children between birth and age 8. Participants were primarily located in New York (34.7%), New Jersey (10.2%) and Illinois (9.7%), but we also received responses from people in at least 23 other states as the family groups tend to share such online opportunities. Table 2 provides a summary of the participants who completed the online survey. Disability labels represented in the sample included speech/language, developmental delay, autism, attention deficit disorder, visual and hearing impairments, and physical disabilities. Upon survey completion families received several children's books and a summary report of the tips and strategies we collected. Table 2 provides a summary of the participants who completed the online survey.

Survey protocol. The 25-item survey was created in an electronic, online survey format (http://www.surveymonkey.com). In addition to a demographic section about the child and the family respondent (11 items), the survey contained

Table 2

Demographic Information as Reported by Families Participating in Online Survey N = 216

Characteristic	N	%
Race		
White	155	71.80
Black	11	5.10
Latino	33	15.30
Asian/Pacific Islander	8	2.20
Native American	6	2.80
Other	3	2.80
Marital Status		
Married	175	81.00
Single	20	9.30
Not Reported	21	9.70
Highest Level of Education		
Some High School	2	.90
High School Graduate or GED	33	15.30
Associate Degree (AA, AS)	29	13.50
Bachelor's Degree (BA, BS)	65	30.10
Graduate Degree	56	25.90
Not Reported	31	14.30
Employment Status		
Full-time	80	37.00
Part-time	43	19.90
Unemployed	4	1.90
Not employed outside of home	65	30.10
Not Reported	24	11.10
Income		
Less than $19,000	15	6.90
Between $20,000 and $39,999	25	11.60
Between $40,000 and $59,999	39	18.10
Between $60,000 and $79,999	45	20.80
Over $80,000	70	32.40
Not Reported	22	10.20
Other Children at Home		
Three or Fewer	172	80.00
Four or More	26	12.00
Not Reported	18	8.00

open-ended questions related to (a) choice-making, (b) self-regulation, (c) engagement, and (d) family-practitioner partnerships. In the choice-making section, we asked respondents to describe types of choices they offered their child, their child's access to items, and limitations to the

family's ability to offer choices. For self-regulation, we asked families to identify situations or routines where their child had difficulty calming him or herself (e.g., mornings, transitions, and bedtime). Engagement included a request for respondents to describe situations or types of activities that their child liked to spend time doing, whether he or she was easily distracted, or, on the other hand, became over stimulated during certain activities. In these three sections, we asked respondents to share any tips or strategies related to choice-making, self-regulation, or engagement. In the fourth section, family-practitioner partnership, families shared information they wanted professionals to tell them about foundational skills.

Data analysis. All demographic items were summarized using descriptive statistics. The open-ended comments were downloaded from the electronic databases into Word documents, one for each of the three constructs and a fourth for partnerships. As these were written comments, we treated this dataset as a modified content or narrative analysis (Saldaña, 2013). We coded each document (choice-making, self-regulation, engagement, and partnership) separately. We used an open, pattern, and selective coding process (Saldaña, 2013) similar to that described previously for the interview transcripts. The open coding process resulted in a large number of initial codes (e.g., providing age appropriate choice options, recruiting peers or siblings for engagement). Second, the pattern coding process consisted of clustering similar open codes into emergent themes. Two members of the research team reviewed the raw data and came to agreement about the membership and definition of the themes. The selective coding process assembled the themes, open codes, and example open-ended quotes into an analytical table and circulated to the full research team. The team reviewed this document and discussed areas of ambiguity or convergence during the weekly conference calls. Within the four constructs of the survey, the results included specific themes and strategies for each construct.

Synthesis of Results

Synthesis. To synthesize the data from the two sources (interviews and online surveys), we created an analytical matrix. On the left hand column of the matrix, we inserted the primary themes identified in the first data source (e.g., partnership preferences, intentional strategies, environmental access). Across the top row of the matrix, we placed headings for the four primary construct/topic areas for the second data source (i.e., partnership, choice making, engagement, and self-regulation). Each of the research team members independently assigned the Data Source Two themes into a relevant cell of the matrix (e.g., choice-making/intentional strategies). Following this process, we compared results across coders and discussed results to reach consensus on the appropriate placement of themes from Data Source Two as well as areas of ambiguity and convergence of themes in Data Source One. Table 3 depicts the analysis worksheet showing the results of the independent coding synthesis; the reader will also be able to see the initial structures and categories/themes from both data sources. The process resulted in some modifications of the overall framework with categories eliminated, merged, or expanded. At an in-person cross-site meeting of the research teams from all three states, the researchers developed the final conceptual framework in Figure 1.

Validation. Validation refers to the mechanisms or processes used during research that contribute to the rigor and trustworthiness of the data collection, analyses, and interpretation (Creswell, 2012). We asked several questions throughout the study to address rigor and trustworthiness (Charmaz, 2006), such as (a) Are there solid links between the data and the findings (credibility)? (b) Are categories offering new insights and extending current knowledge (originality)? (c) Do the categories portray the fullness of the studied experience (resonance)? and (d) Does the analysis offer interpretations and knowledge that can be used by programs and families in their everyday context (usefulness)? To address these questions of rigor, three validation processes were used: peer debriefing, triangulation, and member checking.

The research team communicated regularly during data collection and analysis to engage in peer debriefing and to record self-reflections and interpretations of data. Part of debriefing included a process of reflexivity, which involves continually examining our own biases in relationship to findings and interpretations (Kleinsasser, 2000). Although it can be difficult to bring together the thinking and perspectives of 12 researchers, the process of doing so enriched our understanding of the data and the credibility of the findings.

Triangulation is a process of examining the data and data analysis from several perspectives (Creswell, 2012). One form of triangulation used was multiple data sources–the use of both in-depth

Table 3
Analysis Worksheet for Synthesizing Data Source 1 and Source 2

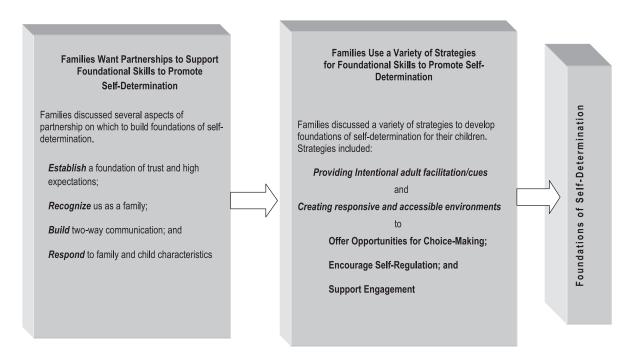| Themes/Categories From Family Interviews	Themes/Categories From Open-Ended Survey Comments			
	Partnership	Choice-Making	Self-Regulation	Engagement
Expectations for Partnerships: • Establish trust • Have expectations for the future • Recognize whole family • Build reciprocity • Adapt to family and child characteristics	• Be on the same page • Home-school consistency • Provide resources • Practitioners should understand family and child • Have two-way communication • Parents should be actively involved as advocates			
For all 3 Foundations constructs, strategies fell into: • Provide intentional adult cues • Modify the environment for access		(classify specific strategies as facilitation or modification)	(classify specific strategies)	(classify specific strategies)
Choice Making • Choice as means to end • Concerns about safety and age-appropriateness		• Limit choices • Celebrate and reward choice-making • Physically show choices • Maintain neutrality about which to choose		
Self-Regulation: • Sensory strategies • Behavioral strategies			• Yoga, relaxation, hugging, reducing noise and light • Reward systems, redirecting • Social stories • Prepare for transitions	
Engagement • Creative ideas • Autism special issues				• Positive rewards • Make activity FUN • Schedules and timers • Follow child's interests

Figure 1. What families are telling us about foundations of self-determination.

interviews and open-ended online surveys provided an opportunity to include a wide range of perspectives. We also utilized researcher triangulation. More specifically, 12 researchers on the team allowed for a subgroup of the researchers to conduct an audit trail; two researchers conducted an audit procedure to ensure that nothing was missed in both the interview and transcript summaries and that comparisons and connections in the data were noted. Multiple researchers also facilitated the production of a thick and rich description of the participants, settings, interviews and analysis as a way of making the research more credible and useful (Anfara et al., 2002).

Another validation process used was member checking. We sent a summary of findings to several study participants for feedback. Several parents not involved in the study were also asked to provide feedback on the usefulness of the study and their input enriched the understanding of the interpretations. Member checking was more than a single event such as verification of transcripts or early interpretations (Carlson, 2010).

Findings

We conducted this study to understand what families think about building the foundational skills leading to the development of self-determination and, in partnership with practitioners, what strategies they employ. More specifically, we asked two primary research questions: (1) What do families believe is important when working with practitioners in partnership to build foundational skills leading to self-determination at home and school? (2) What do families think about providing opportunities for developing these skills, and how do they provide such opportunities?

Families discussed their beliefs, desires, and priorities as well as describing a variety of strategies to develop the foundational skills leading to the development of self-determination. The strategies they identified fell into two types: (a) providing intentional adult facilitation and cues, and (b) creating responsive and accessible environments. The strategies they reported were influenced both by expectations and experiences for partnering with practitioners and their own family and child characteristics. Figure 1 depicts the two major themes of the findings and the categories within each: (a) families want partnerships to support foundational skills leading to the development of self-determination, and (b) families use a variety of strategies to promote foundational skills leading to the development of self-determination. Note that

in the examples below, the names are changed to preserve confidentiality.

Families Want Partnerships to Support Foundational Skills to Promote Self-Determination

The first of the two major themes highlighted the importance of partnerships. In early childhood special education, families often work on teams with a number of other practitioners such as their child's teacher, as well as a myriad of related service personnel (e.g., speech and language pathologists, occupational therapists, physical therapists). Families in this study identified wanting partnership support from practitioners that would establish a foundation of trust and high expectations, recognize them as a family, build two-way communication, and respond to their specific family and child characteristics.

Establish a foundation of trust and high expectations. Although we asked questions about partnership last in the personal interviews and as a fourth question in the open-ended survey, comments about partnership were interwoven throughout all topic areas. A pervasive theme was a desire for partnerships built on a solid foundation of trust. Families wanted to trust that they were "on the same page" as practitioners and that their hopes and dreams for the future were understood, recognized, and supported by practitioners. These participants discussed their hopes and dreams for their children, including friendships, dating, getting married, having jobs and careers, and obtaining the skills to live a happy and an independent life. Several parents spoke of wanting practitioners to respect their optimism and their dreams of normalcy for their children. As one parent shared, "Teacher expectations can give us hope." The family members interviewed did not want to abandon their dreams of normalcy. Families expressed that they wanted the outcome of trust and expectations to be consistency; as one mother put it, "I hope for consistency of strategies between home and school."

One respondent gave this message to practitioners: "Have confidence in him and believe that he is capable of doing whatever he sets out to do….We see him as having completely unlimited potential….I think the sky is the limit." Another expressed that she understands her hopes and dreams for her son may be more difficult to reach than with her other children, but she wants and expects the same for all of her children. For some parents these dreams included the goal of inclusion. One participant declared, "When Clay is ready for Kindergarten he is not going to a special class. I will fight tooth and nail…."

The family survey responses were very consistent with the family interview responses. When asked about what they wanted in partnerships, survey respondents wanted to be "on the same page" as practitioners. Family members also indicated they wanted to know that the same values, expectations, or goals were understood by the practitioners working with their child. The need for everyone to be working on the same goals was illustrated by this parent: "Our daughter does well with verbal cues, and I've noticed that when everyone uses the same terms, for example, "fix your head" when she goes into ATNR [asymmetrical tonic neck reflex], then she know[s] what to do when it happens." The participating families in both the interviews and surveys were very well aware that positive outcomes for their child required consistency and trust between home and school environments.

Recognize us as a family. Participants discussed awareness or recognition of the family context as key to partnership. As one interviewee stated, "I want the therapist to understand the whole dynamic of our family. It's important. There is stress. It's exhausting. It's good for everyone to know what is going on!" For these families, understanding the "whole dynamic" of the family included involving siblings and grandparents; understanding care requirements, rural distances, and weekends; building on child and family routines; and understanding changes in routines. One survey participant explained that understanding the family context also meant that practitioners need to recognize that some parents live with "ambiguity and are still grieving."

Families who were interviewed particularly discussed wanting their family's strengths acknowledged and respected. Several of these families discussed the support they provided to their children and wanted their knowledge and competence recognized and valued. Some also wanted teachers to recognize the unique strengths of their children. One family member of a son with severe disabilities talked about being proud of her son's "stubbornness and ability to manipulate others" as characteristics of his unique strengths.

Build two-way communication. A third and a particularly large category within supporting partnerships was reciprocal communication. Families, both interviewed and surveyed, wanted partnerships with on-going, two-way communication to answer questions or to discuss needs related to their child as they arose. One interviewed family member wanted "lots of communication especially on a daily basis…about what happened at school so I can engage him in conversations at home." This was consistent with the responses from the survey respondents, whom also indicated the desire for consistency between home and school. One surveyed family member said, "I find it helpful when the teachers and therapists keep me informed of what tasks they are working on with him so that I know which specific things to focus on at home."

Several families wrote in the survey about wanting more strategies, resources, and information while others reported it was helpful to receive strategies from practitioners that promote foundational skills leading to the development of self-determination such as "providing limited choices" or "taking the time to find the activity that engages my child the most." Other families appreciated specific resources such as using the Picture Exchange Communication System (PECs) or choice-type switches to generate child responses to promote skills. These families discussed valuing the tools and information they received from practitioners about how to better understand and promote their child's foundational skills to promote self-determination.

Some interviewed families discussed being able to talk with teachers face-to-face during morning drop-offs; others used a daily notebook that went back and forth from home and school. Still others identified the importance of "even quick notes or e-mails on the day's activities." Surveyed families also discussed a variety of modes of communication (e.g., notebook, face-to-face, phone, e-mail). An important indicator of partnership was matching the communication modes with the individual preferences of families. For example, one surveyed family member stated, "A communication book is best because it is a running diary that we can reference and compare the entire year of days against each other." Yet another stated, "Face-to-face meetings are my FAVORITE. You gain much more personalized information and have the chance to offer information in return." Another said, "I prefer phone calls….I want to hear the joy when there are successes and the concern when there are worries." These differences in families highlight the need for practitioners to meet the individual communication preferences of families.

For some interviewed families, however, the communication between home and school was stifled. One participant indicated she was not sure how to communicate her hopes to teachers. Another participant discussed that communication was a delicate balance, not knowing how far she could go or what she could ask for from the school. She wanted to know "how the school accommodates my child without always having to ask."

Families not only discussed what they wanted from practitioners regarding communication but also what they expected of themselves. Several families expected to be their child's main advocate for helping their child learn the skills to take her or him into a successful future. They assumed the responsibility to explain their child's needs to the teacher and therapists. One participant said, "Don't be shy. Don't be afraid to be the mom who comes looking for people in the hallway at school." Another participant shared that at IEP meetings she wrote and copied a summary for all team members of "the main things we want for our daughter." She stated, "I want them to know that we're serious. That we are engaged and we're serious….We want to make sure that we're kind of overseeing, managing and that they know where we are wanting to go." Another participant was less assertive about advocating for her child. She said that she "didn't want to burden the teacher with communication." One participant stated, "I haven't connected with therapists since they did the evaluation….I've done nothing on my part." She also stated that if she had time it would "be very helpful to sometimes observe what different teachers do…get new ideas." Building partnerships with families takes two-way communication that respects and recognizes the differences of each family and their individual preferences and priorities.

Respond to specific family and child characteristics. Families wanted practitioners to respond to their individual challenges and recognize their personalized journeys of raising children with disabilities. This journey presented challenges to many parents, including having struggles in their marriages, making it difficult for caring for siblings, dealing with their children being exclud-

ed from birthday parties, not being able to read their children's cues, being anxious about their children's safety, and just being overwhelmed. In the midst of their journeys, families wanted practitioners to recognize that they have strengths and competence.

Families also expressed the need to have practitioners understand the uniqueness of their children, including the children's particular characteristics, interests, and preferences. Families simply wanted their child to be seen, acknowledged, and valued for who they were. In addition, the type and degree of disability of the child influenced the strategies families used and advocated. For example, a child who was identified as having multiple disabilities including deaf-blindness would be given different opportunities for choice-making and engagement than a child who had a hearing loss. Families who had a child with autism encountered their own unique set of issues; sometimes they needed to restrict their child's opportunities to make choices or engage with the environment. A child's disability is not the defining factor in identifying strategies or opportunities but rather the child's unique and individual qualities that shape who they are.

Each family's unique life experiences also shaped their expectations for their child. For example, one mother said:

> I look back in my life and I can see how one of the first times I had to make a big decision and it was really hard and it would have been nice to have more help in decision making when I was younger…because of that experience in my life, I would like to be able to pass on the ability to my children to be able to think through choices.

Families Use a Variety of Strategies to Promote Foundational Skills to Promote Self-Determination

For families of young children, fostering their children's foundational skills leading to the development of self-determination included (a) providing opportunities to make age-appropriate choices; (b) supporting and enhancing self-regulation skills; and (c) increasing levels of engagement with people, their environment, and activities. The families in this study discussed and reported using a variety of strategies which they believed would lead to developing choice opportunities, self-

regulation, or enhanced engagement. The strategies used primarily fell into two overarching and overlapping categories: (a) providing intentional adult facilitation and cues and (b) creating responsive and accessible environments (see Figure 1). Families gave examples of each of these two categories of strategies throughout their discussions of choice-making, self-regulation, and engagement. In the following section, we describe these two categories. Then, we describe how these overarching categories applied to the families' fostering of their children's skills within the specific foundational skill areas. Clearly, there is overlap between these two types of categories. For example, changing the environment by lowering the shelves for accessibility by their child or removing other barriers requires intentional adult facilitation. It is important to keep both in mind as we describe the strategies that families used to facilitate the three skill areas that were the focus of this study.

Providing intentional adult facilitation and cues. Overall, families expressed the belief that developing skills for young children requires adults both at home and school to be intentional in encouraging foundational skills to promote the development of self-determination. For children with disabilities, they also noted that they may need to be more purposeful in presenting children with deliberate and multiple opportunities to practice choice-making, self-regulation, and engagement skills. Families embedded intentional opportunities for choice-making, self-regulation, and engagement throughout the day. The differences in families' intention in developing foundation skills varied based on type and severity of their child's disability.

Creating responsive and accessible environments. The families in this study described the importance of arranging the physical world to enable children to access it independently. Families discussed numerous strategies that focused on physical arrangements or accommodations of the environment to provide opportunities for choice-making, encourage self-regulation, and support engagement. The following section will highlight these responses.

Opportunities for choice-making. The majority of the participants agreed that providing children with choice opportunities and helping them learn how to make appropriate choices would help them learn and grow. Families helped their children to both make and regulate choices. Both

interviewed and surveyed families thought it was important to encourage their child to make choices for a variety of reasons. Some families thought it was important to help their child establish a sense of accomplishing some volitional action in their life. As one parent said, "I really try to give him as much control over his world as is safely possible...since there's so much that he doesn't control." Another parent noted:

> I have always allowed him as much freedom through trial and error as possible. This may mean a messy area but . . . "NO" is not something I use. There will always be times when options are limited and it's important for him to know the difference between when he has options and when he doesn't.

Other families offered choice opportunities as a teaching tool, especially for children who need practice with their language, socialization, or gross motor skills, such as requiring the child to "use their words" or reach for the preferred toy to help the child gain these skills. They also offered choice options as a way to help regulate behavior, as they observed their child was much calmer or less oppositional when he or she was given a choice about a food or an activity. In short, families valued the ability to make choices as a means to an end, for better communication, motor skills, and positive, prosocial behavior.

Families who shared strategies were well aware of the need to be intentional about teaching choice-making and/or decision-making to their child with a disability. Strategies included (a) using verbal or physical prompts to offer choice opportunities, (b) maintaining neutrality regarding child's choice, (c) providing space and time for the child to process and make choices, (d) beginning with limited or simple choice options, (e) celebrating/rewarding choices, (f) structuring the environment to place choices within reach, and (g) using a picture communication board or other assistive technology.

Verbal or physical prompts were often used, such as letting the child know what various options are available. One parent suggested, "I physically show him the choices. I get eye contact before we go over the choices." Another strategy was maintaining neutrality. Families tried to avoid showing a preference for one choice option or the other so as to ensure the child was really making a choice and not following the parent's cue. To promote independent choice-making, one parent commented, "I try not to say what they are since my daughter will normally answer with the last option. I just say, 'Which one do you want?'"

Another strategy that families discussed was taking extra time. The respondents pointed out the benefits for the parent to be patient and to encourage the child to take his or her time and not feel rushed. This seemed particularly important in remembering that young children often need to think about choice options and "process" their decisions. Parents pointed out that in a busy day this was not always possible, but they emphasized that taking the time to pause and wait for the child to respond was very important.

Families also identified limiting the number of choices as another useful strategy in promoting foundational skills leading to the development of self-determination. Keeping the options to a few, such as "do you want the red shirt or the orange shirt?" was a way to avoid overwhelming the child with too much information. One parent reported, "I try to limit the choices to two things because it seems that if he has more than that he gets confused and won't answer." Also, families noted that limiting choice options to those they found acceptable was the way to keep choice-making within age-appropriate boundaries (e.g., choosing between two healthy snacks). One family shared their experience with gradually adding more choice options:

> At first when we were teaching him to make a choice he only had one option and had to indicate or sign a request for whatever the item was (snack, milk, toy, etc.). Then we gave him two options. Next we will offer three [choices] and so on.

Families discussed the importance of celebrating and rewarding choices that resulted in more beneficial outcomes. For example, parents talked about providing incentives and rewards for choosing healthy snacks or choosing to pick up toys from the floor. Parents also talked about letting the child experience the consequences of making choices that did not include beneficial outcomes. One mother described an incident where her child threw a toy out the window of their moving car. She did not go back for the toy; rather, she talked with her child about why she did not have the toy anymore because of her choice to throw the toy out the window.

Families also discussed the value of structuring the environment by placing materials or toys the child can choose to reach in an accessible manner. "You may have a special place in each room where the child has ready access to materials or toys." Parents described putting drink choices on a lower shelf of the refrigerator, putting toys on low shelves and in a toy box the child could reach, and so on. One parent supported her child's choice-making by making his preferred foods accessible to him:

> [The] "I want" phrase is good for my son with autism. When he initiates or replies, I say, "Go get it" renaming what it is that he chose. This has alerted me to put foods that he likes in the freezer on the bottom shelf. If I know he can't reach something, sometimes, I wait to see if he will come ask for assistance. Then, we high-five each other when he brings the item he requested.

Families also discussed creating an accessible environment through the use of assistive technology. Families described using low-tech, assistive technology to help their children make choices about what foods they want using a variety of visual aids such as placing magnets with pictures of food items on the refrigerator door or using visual icons or picture labels to encourage their child to make choices. Families also discussed using picture sequences, such as pictures of different foods or activities, enabling them to guide their child's choice-making. One parent with a child with visual impairments used a high background contrast on which to present choice options to her son.

These families also described some of the challenges they encounter or think about when offering choice opportunities. One mother discussed the need to balance nonnegotiable choices options (such as taking a bath) with negotiable ones (such as choice of a bath toy). Another mother indicated that providing choice opportunities can be overwhelming to the child at times – she noted that too many choice options "can backfire, be confusing, and complicates thing[s]." This mother talked of providing the right amount of choice opportunities as "delicate." A mother of a son with autism described her son's difficulties letting them know what he wants:

> Like this morning he was trying to point to something in the cabinet that he wanted for breakfast and it's kind of a guessing game sometimes because he doesn't know how to say "yes" or "no" appropriately for what he wants. Usually I'll say, "Look at me," …. I'll have the item next to my face, and I'll say, "Do you want this?"

Other challenges of choice-making discussed by families included balancing safety and choice options; more specifically, they discussed balancing how much freedom to give or how directive to be. One mother was not sure how to give choice opportunities and she struggled with giving too many choices leading to tantrums. Several families discussed "giving natural consequences of choices." Another mother talked about her need to read her son's signals so she was aware when her son needed help making choices. If he was overwhelmed she would give him smaller or fewer choice options. Several families in the survey wrote of regulating choice opportunities by offering small or limited choice options at first. As one mother noted, "…not free reign or he might feel too overwhelmed." Families of children with significant disabilities did not offer a variety of choice opportunities beyond basic self-care or play such as choice options for clothes, food, or toys. For example, one mother with a daughter with significant intellectual and physical disabilities gave the options to take baby food off of a spoon or from a bottle.

Encourage self-regulation. The ability of a child to self-regulate his or her emotions and behaviors is a cornerstone of early development. This was an area of challenge, however, for several families. Both interviewed and surveyed families use of strategies to help their children with self-regulation primarily fell into three areas: sensory integration, behavior management, and communication.

Some children have difficulties sorting out sensory information. Families in this study described using sensory strategies to help their children self-regulate themselves when faced with an overload of sensory information. Sensory integration refers to the ability of the brain to organize sensory information as it comes in through the senses (Dunn, 2011). Some children, particularly, perhaps, children with autism, may have trouble "filtering out" sensory information and may be overwhelmed with bright lights, background noise, or sudden changes in routine. Some families discussed strategies such as massage, hugging, yoga, shoulder pressure, bouncing, deep

breathing, holding their child in a blanket to make them feel secure, platform swing in the basement, brushing techniques, hand presses, back rubs, equine therapy, getting into nature, or reducing outside distractions to help their child to self-regulate. Although research on the efficacy of these sensory integration strategies is still ongoing, both interview and survey families in this study recommended sensory integration strategies and believed that they worked well for their children.

Some families interpreted children's difficulties with self-regulation as a behavioral issue, and thus their suggestions focused on behavioral techniques. Successful behavioral techniques identified included (a) ignoring ("I use 'active ignoring' to avoid reinforcing outbursts"), (b) reward systems (stickers or other prizes for good behavior), or (c) positive praise for quiet behavior or following through on a request. Others reported strategies that combined sensory and behavioral techniques, such as (a) limiting triggers (sugary foods, TV, fast pace), (b) using visual cues and calendars for self-regulation, or (c) providing quiet spaces. Another mother discussed using a "time away box." She stated:

> It helps him calm down….He gets a little overwhelmed sometimes…there's too much going on and he starts making bad choices by kicking friends or getting into their spaces, then we need the break box. And that helps him… it has a few books or some manipulatives that he can choose from…just to calm him down.

Other behavioral techniques families shared included redirecting attention from the upsetting situation to something else, modeling calm behavior, setting clear rules ahead of time, avoiding situations where the child would feel challenged, and applying consequences consistently. Pre-planning an activity, especially outside the home, was reported as a strategy families of children with autism used to help their children enter a new or unique environment. These types of strategies focused on helping the child to anticipate a change such as preparing the child ahead of time for transitions and providing advance organizers such as visual schedules or other advance warnings about an upcoming change. One parent indicated that "explaining what is going to be happening goes a long way in preparing her for situations that are potentially trouble."

In addition to the need to communicate to children about changes, families also noted that difficulties in self-regulation arose when children felt frustrated in their own attempts to communicate. These parents noted that their children with language delays or other communication challenges had trouble negotiating their frustration when they could not make themselves understood or when they did not know what to expect. Strategies recommended included teaching the child to "use your words" or asking the child to verbalize how he or she is feeling. One parent indicated that she often talked to her son to help him understand his emotions and how his actions affected others, whereas another helped by labeling the child's emotions or drawing a picture to help him understand the emotion. Families also discussed other effective strategies, including the use of verbal cues (e.g., "How is your engine?"–a cue to explain whether he or she is sad or angry). Similarly, the use of scripted stories for social situations–talking through different ways to respond to situations that may be overstimulating – was another technique that families shared.

Many of these families also described some of the challenges they encountered when helping their son or daughter with self-regulation. One parent shared, "It is a struggle for me – recognizing when there will be a meltdown….I feel like I am always late in figuring out those small strategies to get him to think about himself internally and how he is feeling." A couple of families indicated they did not know how the teacher helped their children calm down at school – but it was a big job for them. Some families expressed frustration about their inability to solve this puzzle of "what works." "I wish I knew," said one survey respondent, and another said, "I often feel helpless." The challenge of teaching self-regulation can be a serious problem because of self-injurious behaviors. One family member said, "We need help on the head banging. We don't know what to do besides put her in her crib…but then she bangs her head on the wall."

In short, these comments illustrate that helping a child develop self-regulation skills was a very challenging experience for the families. Strategies worked for some children but not for others, and further, strategies that worked sometimes or in particular situations did not work in others for the same child. Families emphasized

remaining clear, calm, and trying a wide variety of strategies to reduce sensory overload and enhance communication.

Support engagement. Engagement is the third component of foundational skills promoting the development of self-determination. Children who self-regulate can be more engaged with people and their environment. Furthermore, opportunities for choice-making can help a child be more engaged and self-regulating (Palmer et al., 2013). The majority of the participants had thought about engagement and as one parent noted, "This is still his [son's] biggest area of challenge."

There was a range of family ingenuity in encouraging their children to engage with activities or materials for longer periods of time and in different ways. Some of the intentional strategies families used to increase engagement included (a) pacing activities, (b) using humor to help engage, (c) making up songs to go with activities, (d) encouraging peers and siblings to play, (e) teaching appropriate social responses, and (f) reading their child's cues. These families also focused on increasing social interactions through play dates and other planned interactions (e.g., swim class, dance class). Families described encouraging engagement by giving access to preferred activities and materials and "following the child's lead."

Family members tried to make activities look and sound fun with a variety of strategies, including (a) creating excitement, (b) playing with the child themselves, or (c) getting other children to play with the child. One mother said, "Sometimes I send him out to the sandbox with a story starter in his head. I tell a story about how Bob the Builder is going to build a town on the beach and I wonder what that will look like... He will stay in the sand for an hour if I let him!" Another parent shared:

> For my son I have to make the activity super exciting, using big facial gestures and tone of voice. I then "direct" him to the activity and once he's seen it or touched it, I make a big deal about it and get him laughing. If I do, then he's willing to stay with the activity for a whole 3 minutes. [Sigh].

For many families there was a connection between allowing opportunities to make choices and their child's sustained engagement. "You need to do something they like to do," as one family member put it. Another family member agreed, "When I

introduce new toys or activities I allow him to explore and foster his own interpretation of the item. I then go ahead and sit down and play with him." Other families also talked about ways to create a sense of novelty through new toys or finding new ways to play with old toys. For some children, especially in families with a child with autism, family members thought it was important for their child to engage in a variety of activities. "We make a conscious effort to make sure our son doesn't spend all his time staring/playing with only a limited number of toys." Even when this was not the issue, some families described giving multiple items so that the child could have choices.

Families also reported that some children engaged more appropriately for longer periods when they reduced potential distractions, such as the TV or number of people. Strategies varied across children. One family member described the need to reduce sounds and distractions while two others noted that quiet background music seemed to help their children be more active and engaged. A couple of parents also noted that limiting the selection of items, such as toys and activities, that were offered helped their child to maintain engagement.

Many of the respondents used strategies to gradually increase the amount of time their child would engage with an activity or material. Their strategies involved presenting a new activity for a short period and then going back to the previous activity, or setting timers for their child for a brief period (e.g., 3 min) and asking him or her to stick with an activity until the timer went off. Others gave a "count down" to be done with the activity such as "one more turn each" or "one more minute till play time is all done." Parents also spoke of the value of using visual schedules to foster their child's engagement.

Families also described challenges they encountered when supporting engagement of their son or daughter. They reported wide variation in the issues they faced regarding encouraging engagement for their child. Some families discussed issues such as how to balance change with predictability. A couple of families discussed how their child's fatigue hindered his or her ability to engage. Other families indicated they had no problem with encouraging engagement. In fact, for those with a child who had autism, the problem was sometimes quite the opposite. As one family member put it, "Our difficulty is

in stopping activities." Another family member said, "When he gets a new toy or even new shoes he will sleep with it and become obsessed with that item for quite a while." For these particular family members, the problem is in helping their child *dis*engage with an activity when it is time for a transition.

To summarize, some of the tips on promoting engagement seem contradictory: providing a wide range of choice options versus limiting choice options, reducing distractions versus providing background sound, and making activities novel versus taking it slow with new things. However, given the individual qualities of each child and the unique circumstances of each family, the range in strategies makes sense. It appears that families use trial and error to adapt to the unique characteristics of their child. Given the diverse pool of strategies parents used, perhaps the common bond they shared was to carefully notice and then intentionally respond to their children's behavior. As one family member said, "Being in tune is the key."

Discussion

The family members in this study expressed a variety of expectations for effective partnerships with practitioners that they believed to be important in helping them meet their children's needs in developing the foundational skills leading to the development of self-determination. These included the need for practitioners to (a) recognize them as a family, (b) build two-way communication, (c) establish a foundation of trust and high expectations, and (d) respond to their unique family and child characteristics. None of these findings would come as a surprise to the Turnbulls. Their work in advocating for true partnerships between families and practitioners dates back to some of their earliest publications. *Parents Speak Out: Views From the Other Side of the Two-Way Mirror,* first published in 1978, was one of the earliest attempts to shed light on the family perspective (Turnbull & Turnbull, 1978). Their textbook, *Families, Professionals, and Exceptionality: Positive Outcomes Through Partnerships and Trust,* now in its Seventh Edition (Turnbull, Turnbull, Erwin, Soodak, & Shogren, 2015), is the most widely adopted textbook on relationships between families of children with disabilities and professionals in special education in the United States.

Its purpose is to foster understanding between families and practitioners. The use of "trust" in the title is itself indicative of the Turnbulls' agreement with the families in this study. High expectations for the child with a disability is also a persistent theme for the Turnbulls; in numerous presentations and conversations, they consistently raised the bar of expectations for people with significant disabilities, including achieving a "rich life" (Turnbull & Turnbull, 2000) and even more: "an enviable life" (e.g.,Turnbull, 2009). Finally, throughout their careers, they have articulated a persistent theme about the importance of *listening* to families. In summary, the nuances of high quality partnerships advocated by the Turnbulls is a theme carried on in this article, both in the findings we report here about partnership, and in the methodology we chose – (i.e., listening to what families have to say about building foundational skills leading to the development of self-determination).

With respect to the second research question in this study, "What do families think about providing opportunities for developing these skills, and how do they provide such opportunities?" we learned that families found it important to (a) offer opportunities for choice-making opportunities to their children and to teach them how to make choices, (b) find ways to help their children's self-regulation, and (c) encourage and expand their children's ability to engage appropriately with materials or others. The strategies they employed and recommended involve a combination of providing intentional adult facilitation and cues, and creating responsive and accessible environments for their children. In all three of these areas, they also encountered stressors and/or challenges. The families shared a wide variety of strategies they used with their children to develop choice-making, self-regulation, and engagement skills. These strategies (a) provided intentional adult facilitation and cues, and (b) created responsive and accessible environments. Brotherson et al. (2008) found that a family's characteristics influenced how it supports and provides opportunities for young children with disabilities to develop the foundational skills leading to the development of self-determination. This was true in this study as well. Many participants were intentional in their support of foundational skills for their children and had the time and resources to do so.

The findings for this second research question illustrate another important belief the Turnbulls hold firmly: that families have a great deal of wisdom to share. This belief also has roots from the earliest days of their careers, when they advocated for parents as critical and best advocates for their children in the context of ensuring the "appropriate" part of Free and Appropriate Public Education, shortly after the initial passage of the Individuals With Disabilities Education Act (e.g., Goldstein, Strickland, Turnbull, & Curry, 1980; Turnbull & Learnard, 1981; Turnbull, Strickland, & Goldstein, 1978). Over the years they have consistently gathered family perspectives and advocated for practitioners to listen to the wisdom of parents on topics that include (a) mainstreaming (Turnbull & Winton, 1983), (b) early intervention family service plans (Summers et al. 1990), (c) educational outcomes (Turnbull & Vohs, 1994), (d) behavior (Turnbull & Ruef, 1996), and (e) advocacy (Wang, Mannan, Poston, Turnbull, & Summers, 2004). Certainly this article, which gives the perspectives of families about what works and does not work with their children with respect to building three foundational skills leading to the development of self-determination, is a product of that same line of work.

Even more, this work is an example of "family wisdom" (see, e.g., Turnbull et al., 2009), in which the Turnbulls make the case for the validity of the knowledge and wisdom families have to offer. Ann Turnbull came across the idea in the work of Buysse & Wesley (2006) who defined evidence-based practice in early childhood as "a decision-making process that integrates the best available research evidence with family and professional wisdom and values" (p. 12). The idea that research alone is not the only yardstick of evidence-based practice is not new; the inclusion of professional judgment and wisdom in applying practices to individual needs, along with a recognition of patient preferences and values, has been a part of the medical community for some time (see, e.g., Melnyk & Fineout-Overholt, 2011). But the idea that *families* also have wisdom to contribute to the body of evidence-based practice, is still a little difficult for many professionals to swallow. Yet the Turnbulls persevered in advocating for the possibility that families may have as much to say about what works as practitioners, and even (gasp!) researchers. For example, parents in this study described using evidence-based strategies such as (a) prompting and fading (Barton & Pavilanis,

2012; Barton, Reichow, Wolery, & Chen, 2011; Chambers & Horn, 2010; Schwartz, Billingsley, & McBride, 1998), and (b) advance cues and scripted stories (Broek et al., 1994; Ganz & Flores, 2010; Grey, 1994, 1995; Hemmeter, Ostrosky, & Corso, 2012; Whalon, Hanline, & Woods, 2007). We recognize that this sample, consisting as it does of middle and upper-middle income families, may be more well-read or involved than others. Nevertheless, it is clear that these families do have a good understanding of what they need to do to meet their child's needs.

Several limitations are to be noted in this study. In the interviews, credibility would have been enhanced with prolonged engagement; ideally researchers could have spent more time over several occasions with each of the parents interviewed. A second limitation was the use of convenience sampling for both studies, which resulted in a sample of volunteer participants who were not randomly selected and not representative of the diverse population in the United States. A more purposive sampling grid and intentional recruitment would have yielded a more diverse and random sample. We did conduct subsequent and separate studies focusing exclusively on participants who are underrepresented and from more diverse income brackets (Haines et al., 2012; Zheng et al., in press).

Summary

Tapping into the knowledge and wisdom that parents have has the potential to strengthen partnerships between families and service providers because of the nature of the exchange of information. It may lead to equalize the balance of power between families and practitioners so there is an equal and respected exchange of ideas. The consistency of seeking out and incorporating family knowledge and wisdom into instructional planning and implementation may strengthen communication and partnership between adults from the home and school. For example, the results of this study provided input into the design of our Foundations for Self-Determination intervention, in that it provided guideposts for what families might find both acceptable and useful within the context of their family lives. Both professional knowledge and wisdom and family knowledge and wisdom needs to be understood and blended (Buysse, Wesley, Snyder, & Winton,

2006). By tapping into the knowledge and wisdom of both families and practitioners, we can develop successful and effective partnerships to help children develop foundational skills to promote the development of self-determination.

Sharing information may be quite valuable to practitioners in establishing individualized and effective practices to facilitate skills that lead to the development of self-determination across a variety of contexts at school (e.g., playground, classroom, and stairwell). Thus, practitioners do not have to start from scratch but can gain critical insights about what has been successful (or unsuccessful) at home and then translate and embed that information into the school environment. This may have an immediate benefit for the child because the probability that mastery and generalization of skills can occur is maximized when strategies are consistent across environments. In summary, the knowledge and wisdom shared by families can provide a unique and lasting contribution to the growing knowledge base in the field and may also have immediate and personalized benefits for practitioners and the families and children they are ultimately working to serve. Practitioners need to focus on the family and build partnership – an idea espoused by the Turnbulls over 30 years ago, but which still bears repeating today.

References

Anfara, V. A., Brown, K. M., & Mangione, T. L. (2002). Qualitative analysis on stage: Making the research process more public. *Educational Researcher*, October, 28–38. doi: 10.3102/0013189X031007028

Barton, E. E., & Pavilanis, R. (2012). Teaching pretend play to young children with autism. *Young Exceptional Children, 15*(1), 5–17.

Barton, E. E., Reichow, B., Wolery, M., & Chen, C-I. (2011). We can all participate! Adapting circle time for children with autism. *Young Exceptional Children, 14*(2), 2–21.

Broek, E., Cain, S. L., Dutkiewicz, M., Fleck, C., Gray, B., Gray, C.,. . . Moore, L. (Eds.). (1994). *The original social story book*. Arlington, TX: Future Education. www.thegraycenter.org

Brotherson, M. J., Cook, C. C., Erwin, E. J., & Weigel, C. J. (2008). Understanding self-determination and families of young children with disabilities in home environments. *Journal of Early Intervention, 31*, 22–43. doi: 10.1177/1053815108324445

Buysse, V., & Wesley, P. (2006). How did it emerge. In V. Buysse & P. W. Wesley (Eds.), *Evidence-based practice in the early childhood field* (pp. 1–34). Washington, D.C.: Zero to Three.

Carlson, J. (2010). Avoiding traps in member checking. *The Qualitative Report, 15*(5), 1102–1113.

Chambers, C. R., & Horn, E. M. (2010). Strategies for family facilitation of play dates. *Young Exceptional Children, 13*(3), 2–14.

Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. Thousand Oaks, CA: Sage.

Creswell, J. (2012). *Qualitative inquiry and research design: Choosing among five traditions* (3rd ed.). Thousand Oaks, CA: Sage.

Dunn, W. (2011). Sensory processing: Tools for supporting young children in everyday life. In C. J. Groark, (Series Ed.) & S. P. Maude (Vol. Ed.), *Early childhood intervention: Shaping the future for children with special needs and their families, Vol. 2. Proven and promising practices in EI/ECSE* (pp.137–165). Santa Barbara, CA: ABC-CLIO/Praeger.

Erwin, E., Brotherson, M., Palmer, S., Cook, C., Weigel, C., & Summers, J. (2009). How to promote self-determination for young children with disabilities. *Young Exceptional Children, 12*, 27–37. doi: 10.1177/1096250608329611

Erwin, E., & Brown, F. (2003). From theory to practice: A contextual framework for understanding self-determination in early childhood environments. *Infants and Young Children, 16*(1), 77–87. doi: 10.1097/00001163-200301000-00008

Ganz, J. B., & Flores, M. M. (2010). Supporting the play of preschoolers with autism spectrum disorders: Implementation of visual scripts. *Young Exceptional Children, 13*(2), 58–70. doi: 10.1177/1096250609351795

Goldstein, S., Strickland, B., Turnbull, A. P., & Curry, L. (1980). An observational analysis of the conference. *Exceptional Children, 46*, 278–286.

Grey, C. (1994). The social story kit. In C. Gray (Ed.), *The new social story book* (pp. 215–224). Arlington, TX: Future Horizons.

Grey, C. (1995).Teaching children with autism to "read" social situations. In K. A. Quill (Ed.), *Teaching children with autism strategies to enhance communication and socialization* (pp. 219–241). Albany, NY: Delmar.

Haines, S. J., Summers, J. A., Palmer, S. P., Stroup-Rentier, V. L., Wu, H. Y., Szu, S.Y., & Turnbull, A. P. (2012). Immigrant parents' perceptions of fostering foundational skills for self-determination. Manuscript in preparation.

Hemmeter, M. L., Ostrosky, M. M., & Corso, R. M. (2012). Preventing and addressing challenging behavior: Common questions and practical strategies. *Young Exceptional Children 15*(2), 32–46. doi: 10.1177/1096250611427350

Kleinsasser, A. M. (2000). Researchers, reflexivity, and good data. *Theory Into Practice, 39,*155–162.

Lynch, E. W., & Hanson, M. J. (Eds.). (2011). *Developing cross-cultural competence: A guide for working with children and their families* (4th ed.). Baltimore, MD: Paul H. Brookes.

Melnyk, B. M., & Fineout-Overholt, E. (2011). *Evidence-based practice in nursing & healthcare: A guide to best practice* (2nd ed.). Philadelphia, PA: Lippincott Williams & Wilkins.

Miles, M. B., & Huberman. M. (1994). *An expanded sourcebook of qualitative data analysis* (2nd ed.). Thousand Oaks, CA: Sage.

Nota, L., Ferrari, L., Soresi, S., & Wehmeyer, M. L. (2007). Self-determination, social abilities, and the quality of life of people with intellectual disabilities. *Journal of Intellectual Disability Research, 51*, 850–865. doi: 10.1111/j.1365–2788.2006.00939.x

Palmer, S., Summers, J. A., Brotherson, M. J., Erwin, E., Maude, S., Stroup-Rentier, V., ... Haines, S. (2013). Building a foundation for self-determination in early childhood: An inclusive model for children with disabilities. *Topics in Early Childhood Special Education, 33*(1), 38–47. doi: 10.1177/0271121412445288

Palmer, S., & Wehmeyer, M. L. (2003). Promoting self-determination in early elementary school: Teaching self-regulated problem-solving and goal setting skills. *Remedial and Special Education, 24*, 115–126. doi: 10.1177/07419325030240020601

Saldaña, J. (2013). *The coding manual for qualitative researchers*. (2nd ed.). Thousand Oaks, CA: Sage.

Schwartz, I. S., Billingsley, F. F., & McBride, B. M. (1998). Including children with autism in inclusive preschools: Strategies that work. *Young Exceptional Children, 1*(2), 19–26.

Shogren, K. A. (2011). Culture and self-determination: A synthesis of the literature and directions for future research and practice. *Career Development for Exceptional Individuals, 34,* 115–127. doi: 10.1177/0885728811398271

Shogren, K. A., & Turnbull, A. P. (2006). Promoting self-determination in young children with disabilities: The critical role of families. *Infants and Young Children*, *19*(4), 338–352.

Summers, J. A., Dell'Oliver, C., Turnbull, A. P., Benson, H. A., Santelli, B., ... Siegel-Causey, E. (1990). Examining individualized family service plan process: What are family and practitioner preferences. *Topics in Early Childhood Special Education, 10*(1), 78–99.

Turnbull, A. P. (2009, July). Summer School on Inclusion Through Education, Research, and Advocacy, Dublin, Ireland: Presentation entitled "Transitioning to Enviable Lives: From Evidence-based Practice to Wisdom-based Action."

Turnbull, A. P., & Leonard, J. (1981). Parent involvement in special education: Emerging advocacy roles. *School Psychology Review, 10*(11), 37–44.

Turnbull, A. P., & Ruef, M. (1996). Family perspectives on problem behavior. *Mental Retardation, 34*(5), 280–293.

Turnbull, A. P., Strickland, B., & Goldstein, S. (1978). Training professionals and parents in developing and implementing the IEP. *Education and Training of the Mentally Retarded, 13*, 414–426.

Turnbull, A. P., Summers, J. A., Gotto, G., Stowe, M., Beauchamp, D., Klein, ... Zuna, N. (2009). Fostering wisdom-based action through web 2.0 communities of practice: An example of the early childhood family support community of practice. *Infants & Young Children, 22*, 54–62.

Turnbull, A. P., & Turnbull, H. R. (Eds.). (1978). *Parents speak out: Views from the other side of the two-way mirror*. Columbus, OH: Charles E. Merrill.

Turnbull, A. P., & Turnbull, H. R. (2000). Achieving "rich" lifestyles. *Journal of Positive Behavior Interventions, 2*(3), 190–192.

Turnbull, A. P., & Turnbull, H. R. (2001). Self-determination for individuals with significant cognitive disabilities and their families. *Journal of the Association for Persons with Severe Handicaps, 26*(1), 56–62.

Turnbull, A. P., Turnbull, H. R., Erwin, E., Soodak, L., & Shogren, K. (2015). *Families, professionals, and exceptionality: Positive outcomes through partnerships and trust* (7th ed.). Boston, MA: Merrill/Prentice Hall.

Turnbull, A. P., & Vohs, J. R. (1994). Parental perspectives on educational outcomes. *Special Services in the Schools, 9*(2), 185–192.

Turnbull, A. P., & Winton, P. J. (1983). A comparison of specialized and mainstreamed preschools from the perspectives of parents of handicapped children. *Journal of Pediatric Psychology, 8*(1), 57–71.

Wang, M., Mannan, H., Poston, D., Turnbull, A. P., Summers, J. A. (2004). Parents' perceptions of advocacy activities and their impact on family quality of life. *Research and Practice for Persons with Severe Disabilities, 29*(2), 144–155

Wehmeyer, M. L., Abery, B., Zhang, D., Ward, K., Willis, D., Palmer, S., & Walker, H. (2011). Personal self-determination and moderating variables that impact efforts to promote self-determination. *Exceptionality, 19*, 19–30. doi: 10.1080/09362835.2011.537225

Whalon, K., Hanline, M. F., & Woods, J. (2007). Using interactive storybook reading to increase language and literacy skills of children with Autism Spectrum Disorder. *Young Exceptional Children, 11*(1), 16.

Zheng, Y., Maude, S. P., Brotherson, M. J., Summers, J. A., Palmer, S. B., & Erwin, E. (in press). Foundations for self-determination perceived and promoted by families of young children with disabilities in the People's Republic of China. *Education and Training in Autism and Developmental Disabilities.*

Authors:

Jean Ann Summers, University of Kansas; **Mary Jane Brotherson**, Iowa State University; **Elizabeth J. Erwin**, Montclair State University, NJ; **Susan P. Maude**, Iowa State University; **Susan B. Palmer**, University of Kansas; **Shana J. Haines**, University of Vermont; **Vera Stroup-Rentier and Hsiang-Yi Wu**, University of Kansas; **Nancy Farstad Peck**, Keene State College, NH; and **Yuzhu Z. Zheng**, Iowa State University.

Correspondence concerning this article should be addressed to Jean Ann Summers, Beach Center on Disability, University of Kansas, 1200 Sunnyside, Room 3144, Lawrence, Kansas 66045, (e-mail: jsummers@ku.edu).